The Experiences Of Young Adult Cancer Survivors Resuming An Occupation

by

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Table Of Contents

List Of Tables

Abstract

Young adulthood is generally a time when an individual completes a post-secondary education, decides on a career, and enters the workforce. When individuals are diagnosed with cancer during this stage in life, they often take time away from school or work to undergo treatment. The aim of this study was to collect data to get a richer understanding of the experiences of young adult cancer survivors who resumed an occupation of school or work following cancer treatment. Ten young adult cancer survivors were interviewed. An interpretative phenomenological approach allowed for the study of individuals' lived experiences. An account of participants' experiences is presented, organized by 4 master themes, "making the decision", "actively adapting to changed lives", "receiving support", and "renewed sense of health and wellness". These findings may be informative for cancer patients and survivors, as well as stakeholders, as they often have access to limited resources.

Chapter One: Introduction

Young adults are often faced with making choices in love, friendship, values, lifestyle, and occupation (Levinson, 1978). Young adulthood is typically the time when an individual completes a post-secondary education, decides on a career, and enters the workforce (Wheaton & Gotlib, 1997). Thus, education and work can be seen as key developmental milestones in an individual's life, as education is an essential step towards employment. However, life does not necessarily follow a straight path; individuals may be thrown off course by sudden turning points. Although rare, the onset of a chronic condition, such as cancer, could be a significant life-altering turning point during young adulthood (Grinyer, 2007).

The Public Health Agency of Canada (2006), in its report on young adult cancer, estimates that over 10,000 young adult Canadians are diagnosed with cancer each year, and more than 150,000 young adult Canadians have survived cancer in the past 30 years. While the number of adults surviving cancer has been increasing, the number of young adults surviving cancer is remaining constant (Bleyer, 2002). However, the incidence of many preventable types of cancer that occur during young adulthood is decreasing (Public Health Agency of Canada, 2006).

When young adults are diagnosed with cancer, many of their typical activities and responsibilities are interrupted so that they can undergo cancer treatment (Grinyer, 2007). When they have completed treatment, many will attempt to resume the activities and responsibilities they had prior to their diagnoses. For many, this will mean returning to an occupation of school or work. This can be a very difficult experience for an individual of any age, as occupations often give individuals satisfaction and meaning in everyday

1

life (Rasmussen & Elverdam, 2008). Additionally, people may have different methods of coping and different degrees of access to support (Boman & Bodegard, 2004; Cella & Tross, 1986; De Boer, Verbeek, & van Dijk, 2006; Langeveld et al., 2003; Rasmussen & Elverdam, 2007, 2008; Spelten, Sprangers, & Verbeek, 2002; Stone, 1974). Past research has found that the percentage of cancer survivors who resume work after treatment varies, depending on the cancer site (Peteet, 2000). Rasmussen and Elverdam (2008) note that the number of cancer survivors able to resume work following treatment is increasing each year. It appears no statistics have been compiled to determine the percentage of cancer survivors who return to school following treatment.

The experience of returning to school or work may be even more difficult for young adults than adults, as young adults are often already faced with the developmental tasks characteristic of this period of life, such as making important lifestyle choices and developing an identity (Hudson & Findlay, 2006). Additionally, there are many psychosocial and physical challenges related to recovering from cancer during young adulthood (Christ, Lane, & Marcove, 1995; Daiter, Larson, Weddington, & Ultmann, 1988; Deasy-Spinetta, 1993; Elad, Yagil, Cohen, & Meller, 2003; Enskar & von Essen, 2007; Glasson, 1995; Jones, 2008; Miedema, Hamilton, & Easley, 2007; Zebrack, Chesler, & Penn, 2007). Some of these challenges faced by young adult cancer survivors include experiencing feelings of stigmatization, difficulties coping with stress, anxiety, life disruptions, problems adapting to new life circumstances, attempting to achieve "normalcy", feelings of isolation, and struggling to maintain social networks.

Although many of these challenges are also experienced by residents of countries similar to Canada in their psychosocial maturation processes (Jones, 2008), Canada has a

different medical system, school system, and employment insurance policies than the United States and other countries, which may result in Canadian young adults having different experiences when resuming occupations compared to others (Atlas, 2009). It was therefore important that this study focus on a Canadian population.

Key Definitions

There is little consistency among many of the terms used to describe the young adult cancer experience. Therefore, a description of many of the terms referred to throughout this thesis is necessary.

Young Adult. For the purposes of this study, a young adult refers to an individual between the ages of 18 and 35 years. After careful analysis of literature, the most representative age range has been selected to be inclusive of the period during which transitions in college, university, or work may take place. Most Canadians graduate from high school at approximately 18 years of age and attend undergraduate university programs or college programs between 18 and 24 years of age (Cole, Cole, & Lightfoot, 2001). Also, the majority of North American university graduate students are between the ages of 24 and 34 (Office of Institutional Research and Assessment, 2010). Therefore, it seems most young adults would be attending school or joining the workforce between the ages of 18 and 35. Adding to this assumption, Miedema et al. (2007) note that individuals in their 20s and early 30s are typically seeking stable employment.

Other age ranges used by researchers when defining young adults were considered. While Arnett (2000) classified young adults as individuals ranging in age from 18 to 39 years, Levinson (1978) classified young adults as 17 to 33-year-olds, and

Erikson (1950) classified them as 20 to 44-year-olds. The United Nations classifies

young adults as those 20 to 24 years of age (Youth and the United Nations, 2009), while

the Public Health Agency of Canada (2006), in its report on cancer in young adults, used

an age range of 20 to 44 years. Young Adult Cancer Canada (2008) includes 15 to 39

years of age in the young adult range. Taking each of these perspectives into

consideration, an age range inclusive of late teenage years and early 30s seemed most

appropriate for this study.

Cancer Survivor. The term cancer survivor is a debated and evolving term

(Marcus, 2004). Marcus (2004) notes that, in the past, "cancer survivor" has been used to

describe anyone who is no longer undergoing treatment, anyone who has ever been

diagnosed with cancer, or even a friend, family member, or caregiver of someone with

cancer. For the purposes of this study, a cancer survivor refers to someone who has been

diagnosed with cancer and completed a primary treatment, such as radiation,

conventional chemotherapy, or surgery. Participants who were still undergoing

maintenance chemotherapy while resuming occupations classified themselves as

survivors, as maintenance chemotherapy is not a primary treatment (Chemocare, 2005).

Occupation. There are many definitions of the term "occupation". Occupations

are commonly defined as the ordinary and familiar things that people do everyday; an

occupation often includes all daily living tasks that are part of an individual's lifestyle

(Hasselkus, 2002). Kielhofner (2002) defines a human occupation as the doing of work

(both paid and unpaid), play (the earliest occupation of an individual), or any other

activity of daily living. Others define occupation more narrowly. In their article

describing transitions from school to work within different cultures, Shavit, Muller, and

Tame (1998) refer to occupations simply as school and work, as work is typically the source of an individual's livelihood, and school is typically an institution of instruction enabling an individual to gain the knowledge and skills necessary to earn a living. Similarly, in this study an occupation is defined as school or work; these are two of the most common activities in which young adult engage (Wheaton & Gotlib, 1997). School and work may also be a source of identity for young adults (Grinyer, 2007). Although leisure, recreational activities, and unpaid work (such as volunteering) are also daily living tasks of young adults that contribute to shaping their identities, this study will include only school and work in order to focus on activities that require adaptation to conditions largely set by others. Furthermore, education and employment are two of the most important social determinants of health, as they contribute to income and social status. Thus, throughout this thesis an occupation refers to school (which may include college or university) and paid work.

Therefore, the phrases "young adult cancer survivors" and "returning to an occupation" refer to individuals between the ages of 18 and 35 who have been diagnosed with cancer, have completed a primary treatment, and have returned to school or work, but may still be undergoing maintenance chemotherapy or having regular check-ups.

Summary

Young adult cancer survivors face challenges in returning to occupations in the context of the psychosocial and physical challenges of dealing with cancer and the challenges of making the transition to adulthood. Given that no researchers have specifically studied this experience for this population, this study should allow for an understanding of this actual experience. In order to promote the well-being of this

population, health practitioners need to understand resuming school or work from survivors' perspectives. Therefore, it is important to answer the following research questions in order to support young adults with making this crucial transition.

Research Questions

1. How do young adults experience resuming an occupation after treatment for cancer?

Subsidiary questions that were addressed included:

1. What types of strategies and supports do they find helpful?

2. How do they negotiate their return to occupations?

3. What does it mean to them to have resumed occupations?

Chapter Two: Literature Review

Young Adulthood

Young adulthood may be one of the most difficult periods of an individual's life. A young adult may be faced with building and maintaining relationships, completing a post-secondary education, deciding on a career and entering the workforce, starting a family, and managing an income, all while developing an identity (Cole et al., 2001). The shift from childhood and adolescence to adulthood can result in stress, confusion, and doubt (Sawyer, Drew, & Duncan, 2007). Although individuals are considered legal adults after 18 or 19 years of age in Canada depending on the province (Office of the Legislative Counsel, 1998), this does not necessarily result in a young adult's capacity for responsibility and self-management to suddenly become evident.

As mentioned in Chapter One, there seems to be no general consensus among researchers about the term "young adult". Keniston (1971) attempted to theorize about youth as a distinct period in life. However, his theory was never widely accepted due to the ambiguity of the term youth (Arnett, 2000). The United Nations defines youth as a population between 15 and 24 years of age, but divides this population into teenagers and young adults (Youth and the United Nations, 2009). It identifies young adults as those 20 to 24 years old, as it says this group faces unique sociological, psychological, and health issues. It also must be noted that classifications of young adulthood may differ from country to country, depending on socio-cultural, institutional, economic, and political factors (Arnett, 2000; Miedema et al., 2007; Youth and the United Nations, 2009).

Erikson (1950), who theorized about the stages of human development, broadly classified a young adult as a person between 18 and 39 years of age. His theories of early

adulthood mainly centered on individuals finding intimate life partners or facing

loneliness and isolation. Other psychologists and scholars have described their theories

of young adulthood in greater detail (Arnett, 2000; Levinson, 1978; Newton, 1994;

Wheaton & Gotlib, 1997).

Theories Of Young Adulthood And Life Trajectories

Arnett (2000) proposed one of the most recent theories of development from the

late teenage years through the early 20s, with a focus on ages 18 to 25 years. He named

this developmental stage "emerging adulthood". He argued that emerging adulthood is a

period of significant change for individuals, as they are obtaining the levels of education

and training that will provide them with the foundations for their incomes and vocational

achievements for their adult lives. Individuals will not necessarily progress through this

period linearly; periods of education or work are often punctuated by each other or non-

attendance. He went on to state that emerging adults might explore an array of potential

life directions in love, occupation, and worldviews, with little about the future decided for

certain. Arnett also suggested that young adulthood actually begins in the late 20s and

extends into the 30s, since the term implies that full adult status has been reached.

Prior to Arnett (2000), psychologist Levinson (1978) proposed a theory specific to

young adulthood. Levinson was one of the first to suggest that growth and development

continue long after childhood. Levinson's theory of adult development consisted of six

stages, with stages one and two corresponding to young adulthood. Stage one, "early

adult transition", takes place between 17 and 22 years of age. During this stage,

adolescents typically make preliminary choices for adult life. Stage two, "entering the

adult world", takes place from ages 22 to 33 years. During this stage, individuals may make initial choices in love, occupation, friendship, values, and lifestyle.

Levinson's (1978) theory, which had an underlying component of life structure, was subject to some additions by Newton (1994). Levinson believed life structure to be influenced by the social and physical environments, family, and work. Levinson asserted that life structure is defined by two key periods, a stable period and a transitional period. The stable period occurs when a person is making crucial choices in life. The transitional period occurs when one stage is ending and another beginning. Newton added that transitions between stages are affected by concrete occurrences in an individual's life, such as getting married or completing an education.

Similarly, Wheaton and Gotlib (1997) theorized about individuals' life trajectories and concrete occurrences that have the potential to alter the life path, called "turning points". They suggested that the essential characteristic of a turning point is that it changes the direction of a trajectory. Wheaton and Gotlib noted that because young adulthood is a period of life with a high degree of structural change, it is more likely to contain a higher number of turning point experiences. Such turning points may include graduating from high school, getting a first job, getting married, having a child, or buying a first house. The onset of a chronic illness is an example of a negative turning point that may happen during young adulthood.

Cancer As A Chronic Illness In Young Adulthood

Chronic Illness During Young Adulthood. Chronic illness, coupled with the typical challenges of young adulthood, is one of the toughest burdens with which young adults may have to cope. A chronic illness is an illness of long duration that has a

9

biological, psychological, or cognitive basis, and has lasted for at least one year (Markman, 2006; Stein, Bauman, Westbrook, Coupey, & Ireys, 1993). While chronic illnesses in adulthood, such as diabetes or heart disease, can often be prevented through healthy diets, physical activity, and other health promoting behaviours, most chronic illnesses of childhood, adolescence, and young adulthood are not as preventable by such health promoting behaviours or lifestyle changes (Sawyer, Drew, Yeo, & Britto, 2007). Over 12% of adolescents and young adults worldwide live with a chronic disease, such as type one diabetes or cystic fibrosis, and this percentage is increasing (Sawyer, Drew, Yeo, et al., 2007). Fortunately, recent research has suggested that recurrence of chronic illness during young adulthood is rare (Walker, 2010). In adolescents and young adults, chronic illness may limit physical, cognitive, emotional, and social development (Stein et al., 1993). Stress over initial diagnosis, social disruption, and changes in expectations of the future are just a few of the issues an adolescent or young adult with a chronic illness may face (Blum, 1995; Grinyer, 2007; Sawyer, Drew, Yeo, et al., 2007).

Stam, Hartman, Deurloo, Groothoff, and Grootenhuis (2006) conducted a study to assess the course of life of young adults, aged 18 to 30, who had a chronic illness. They administered a course-of-life questionnaire, which retrospectively assessed the achievement of developmental milestones, to 508 young adults with a chronic illness and 650 members of a control group. Chronic illnesses included anorectal malformations, Hirschspung's Disease, oesophageal atresia, renal disease, and cancer, diagnosed in childhood, adolescence, or young adulthood. All participants were aged 18 to 31 years. When comparing results between groups, Stam et al. found that the group with chronic illness had achieved fewer milestones than the control group in all course-of-life

10

domains. These domains included autonomy development, paid jobs, secondary school,

psychosexual development, first girl/boyfriend, first time falling in love, first sexual

intimacy, and first sexual intercourse.

Similarly, Blair, Cull, and Freeman (1994) assessed the psychosocial functioning

of 29 young adults with cystic fibrosis aged 14 to 24 years, by the use of questionnaires

and interviews. Participants were compared with a control group absent of chronic

illness, as well of a group of participants with anorexia nervosa. Blair et al. discovered

that the participants with cystic fibrosis were much less likely to be employed or be

attending school than either of the other two groups under investigation. They mainly

attributed this to a lack of available manageable part-time employment. However, they

may have been limitations in Blair et al.'s and Stam et al.'s (2006) studies, as they were

assessing participants retrospectively.

Gerhardt et al. (2008) also used self-report methods when assessing the

occupational and educational achievement of young adults with juvenile idiopathic

arthritis. Forty-five young adults diagnosed with juvenile idiopathic arthritis between

eight and 14 years of age and a control group of 46 participants free of chronic illness

were given questionnaires following their 18th birthdays. Gerhardt et al. found that

groups were similar in educational achievement, occupational achievement, as well as

occupational self-concept. These results, which conflict with the results of earlier

studies, may be due to Gerhardt et al.'s participants being diagnosed during childhood,

rather than young adulthood.

More recently, Walker (2010) conducted a two-year longitudinal study of 31

adolescents and young adults who had experienced a chronic illness while attending

11

grade school (not college or university). The types of chronic illnesses participants had

were not specified. Participants were between the ages of 10 and their mid-20s when the

study commenced. Participant interviews revealed that the adolescents and young adults

did not wish to be identified as people with chronic conditions, but as "normal young

people". They reported difficulties associated with school, such as maintaining social

connections, noticing a lack of awareness on the part of the school, and feeling isolated

and vulnerable. They also noted schoolwork setbacks, due to medical procedures,

depression, fatigue, and family disruptions. The results of this study, as well as the results

of Stam et al. (2006) and Blair et al. (2004), are consistent with Ewing's (2003) belief

that transitions and challenges inherent to normal maturation throughout young adulthood

are magnified by chronic illness.

While research has generally found that chronic illness has a negative impact in

young adulthood (Blair et al., 2004; Stam et al., 2006; Walker, 2010), it is important to

understand it from within the perspective of individual illness. One life-threatening

chronic illness that can occur during young adulthood is cancer. Cancer is a life-

threatening illness, that researchers in chronic illness increasingly include it in their

studies.

Cancer During Young Adulthood. Cancer occurs when a group of cells

displays uncontrolled growth and intrudes on and destroys adjacent body tissues (Public

Health Agency of Canada, 2006). It was estimated in 2009 that 171,000 new cases of

cancer would occur in Canada (Public Health Agency of Canada, 2006). Of these, it was

estimated that over 6500 cases would be in the young adult population. While cancer in

the young adult age group is relatively rare, it is among the most common causes of non-

accidental death for this age group (Grinyer, 2007). Nonetheless, it is increasingly seen as a chronic illness as survival rates go up (Stam et al., 2006).

The range of cancers that can occur during young adulthood, as identified by the Public Health Agency of Canada (2006), include Non-Hodgkin lymphoma, Hodgkin lymphoma, melanoma, sarcoma, Kaposi sarcoma, testis, brain, Leukemia, breast, thyroid, cervix, colon, rectum, lung, ovary, kidney, lip, oral cavity, pharynx, bladder, and uterus. The most common types of cancer to affect young adults include breast, testicular, and melanoma. The most common cancer in young adult females is breast cancer, while the most common in males is testicular. About two-thirds of young adults diagnosed with cancer are females.

The number of studies that focuses on young adult cancer survivors and their lives following treatment has been growing over the past decade (Langeveld et al., 2003). Past studies have reported physical challenges, such as losing hair, coping with baldness and scarring, experiencing weight loss or gain, feeling too ill to attend school, persistently feeling fatigued, physical fitness levels decreasing, as well as coping with sores that will not heal, pain, and other new sensations (Drew, 2007; Elad et al., 2003; Grinyer, 2007; Rasmussen & Elverdam, 2008). There are also psychological, emotional, and social challenges, experienced by young adults as feelings of stigmatization, having to cope with great stress, anxiety, and life disruptions, adapting to new life circumstances, attempting to achieve "normalcy", feeling isolated, and struggling to maintain social networks (Christ et al., 1995; Daiter et al., 1988; Deasy-Spinetta, 1993; Elad et al., 2003; Enskar & von Essen, 2007; Glasson, 1995; Jones, 2008; Miedema et al., 2007; Zebrack et

al., 2007). While a number of challenges may be the same for all those with cancer, there is a growing awareness that the cancer experience is different for young adults.

Comparing Young Adults With Cancer To Children And Adults With Cancer. Grinyer (2007) aimed to answer the question of why the adolescent and young adult age group with cancer differs from any other age group. Her study was qualitative, using in-depth interviews and brief written narratives from adolescents and young adults with cancer between 15 and 25 years of age. Participants had a range of cancer types, including testicular, osteosarcoma, leukaemia, Hodgkin's lymphoma, bowel, and ovarian. She found that young people's life trajectories are altered at a crucial moment, which seems to have lasting effects on all aspects of their lives. These effects included practical life implications as well as psychosocial and physical effects. As noted by Adams (2003), the impact of a life disruption such as cancer is magnified by the period of life during which it occurs. Because adolescence and young adulthood are periods of such great life changes, a cancer diagnosis may affect young adults more adversely than it would other age groups. Grinyer's adolescent and young adult participants reported a longing for "normalcy" in their lives. A longing for "normalcy" seems to be more pronounced in young adults with cancer than in children or adults. Miedema, Easley, and Hamilton (2006) also found that young adult participants longed to return to a "normal" life after treatment. Along with a longing for "normalcy", they often have unique medical, physical, financial, decision-making, and psychosocial issues.

Young adults often have medical issues to contend with that are different than those in other life stages. Thomas, Seymour, O'Brien, Sawyer, and Ashley (2006) note that cancer biology and tolerance for chemotherapy may alter unfavourably during young

14

adulthood, decreasing the ability to deliver effective treatment. Examples of such

biological changes are increasingly aggressive tumors and different rates of metabolizing

drugs than adults (Eaton, 2007). However, researchers still have much to learn about

how young adults with cancer differ biologically from children and adults with cancer, as

young adults are rarely included in clinical trials and research (Schmidt, 2006). Defining

adolescents and young adults as those aged 14 to 40, Schmidt (2006) found that only 1%

to 2% of adolescents and young adults with cancer participate in clinical trials. About

40% of cancer patients under 14 years of age and 10% of cancer patients over 40 years of

age participate.

Young adults with cancer also face unique physical challenges (Cole et al., 2001).

This period of life frequently involves experimental and risk-taking behaviours, such as

smoking, drug use, inactivity, poor nutrition, and non-compliance with medical regimes

(Hudson & Findlay, 2006). While many cancer patients face trying to maintain healthy

lifestyles (Björklund & Fridlund, 2001), only young adults are at the stage in life when an

individual is most likely to take these risks. Young adults' lack of motivation to practice

healthy lifestyles may also be complicated by inherent feelings of invulnerability

(Hudson & Findlay, 2006). Young adults frequently perceive themselves as invincible,

especially those in their late teens or early 20s (Drew, 2007). It is also an age where

health habits become more ingrained and young adults become more responsible for

maintaining overall health (Taylor, 2006). Consequently, health professionals working

with young adults may be challenged to promote healthy behaviours to improve cancer

treatment outcomes and promote a general healthy lifestyle during young adulthood.

Hudson and Findlay (2006) state that health professionals must attempt to promote health

by educating young adults with cancer about the factors that are increasing their vulnerability to health problems.

Another difference is financial concerns. When young adults are diagnosed with cancer, Adams (2003) believes that they often find themselves in difficult financial situations, especially if they are living on their own and paying their own bills. They may have to take time away from jobs while also having to be concerned about debts and loans (Larouche & Chin-Peuckert, 2006). Children with cancer typically do not have financial concerns, as their parents normally take care of their finances for them.

Similarily, children also usually have parents who communicate with doctors and health professionals and make decisions for them, whereas young adults may feel overprotected by parents and opt to make their own decisions, resulting in great stress (Larouche & Chin-Peuckert, 2006). Adults typically have more experience than young adults making such decisions and dealing with such stressors (Blum, 1995; Rosen, 1993). Young adults may comply poorly with treatment, especially in the absence of parents encouraging compliance (Blum, 1995), while adults may be more likely to follow medical regimes (Albritton & Bleyer, 2003). Young adults also have different perceptions of cancer than children or adults. Children may not understand the impact cancer may have on their lives as well as young adults would, while adults are often more comfortable than young adults being faced with the awareness of mortality.

Therefore, medical decision-making approaches can differentiate young adults from children and adults with cancer (Adams, 2003). Young adults may contribute to a delayed diagnosis by not visiting a doctor concerning symptoms as quickly as an adult or child, due to having a general unawareness of bodily symptoms, being embarrassed about

symptoms, or disbelief about having an illness (Adams, 2003; Miedema et al., 2007). Additionally, for children and adults there are many cancer services which provide counseling, resources, and psychosocial interventions that may not be age-appropriate for young adults (Drew, 2007). Thomas et al. (2006) explored how the Australian medical system manages young adult cancer. They found that some hospitals and institutions were unable to meet the expense of the specialized infrastructure needed for young adult psychosocial support. Consequently, there were often gaps in young adult cancer services.

Most studies in the last couple of decades have found that having cancer is associated with poor psychosocial functioning, especially when the cancer occurs during young adulthood. Poor psychosocial functioning may involve feeling stress and anxiety, experiencing life disruptions, and struggling to maintain social networks (Christ et al., 1995; Daiter et al., 1988; Elad et al., 2003; Enskar & von Essen, 2007; Glasson, 1995; Jones, 2008; Miedema et al., 2007; Zebrack et al., 2007). Several researchers have found that one of the most pronounced difficulties when a young adult is dealing with cancer and aiming to reintegrate into his or her "normal" life after treatment is the return to school or work (Amir, Neay, & Luker 2008; Christ et al., 1995; Glasson, 1995). This may be largely due to the fact that young adults' occupations are an important source of their identities (De Boer et al., 2006). While an occupation is typically a significant source of identity for any individual, De Boer et al. (2006) believe that a young adult cancer survivor's self-image and sense of competence are even more dependent on their occupational experiences and successes than an adult's.

Occupation As A Source Of Identity For Young Adult Cancer Survivors

Cole et al. (2001) believe that access to adult jobs and adult status is attained only after a long period of preparation during which young people learn the meaning of work and then acquire the skills that particular jobs require. Young adulthood is typically a period when individuals progress through high school, college, or university in preparation for establishing a career. Yeager and Bundick (2009) explored the meaning of schoolwork and paid work for adolescents and young adults, by conducting semi-structured interviews with 148 sixth-grade, ninth-grade, and high school senior students. They found that the most frequently named personal goals during adolescence and young adulthood were those regarding school and work; having such goals appeared to be a core part of developing an adult identity. Yeager and Bundick further identified that those with purposeful school or work goals, compared to those with lesser or no goals, reported a higher sense of purpose in life.

Other researchers have also found that young adults' identities begin to be defined by what type of work they do (Arnett, 2000; Levinson, 1978). Levinson (1978) theorized that to contribute to the economy through labor is an essential step for young adults, as it satisfies individuals' need to contribute to society. Obtaining employment appropriate to one's education and interests is an important life goal for anyone, but may be especially important for cancer survivors, as their sense of competency may be more closely related to daily work experiences than those without cancer (De Boer et al., 2006; Peteet, 2000). Amir et al. (2008) assert that returning to paid work after cancer treatment is a significant milestone in the transition from patient to survivor. As cancer treatments improve and cancer survival rates increase, it is becoming common for cancer survivors to return to

school and work shortly after treatment (Drew, 2007). Returning also allows young adult

cancer survivors to maintain their identities (Peteet, 2000).

Spelten et al. (2002) surveyed the literature from 1985 to 1999 to determine the

factors related to cancer survivors' return to paid work, as well as their rate of return to

work. They found that the mean rate of return to paid work for cancer survivors, ranging

in age from 15 to 84, was 62%. The main factor associated with a successful return to

paid work was a supportive work environment. Having to perform manual labor was

negatively associated with a return to work, because of physical limitations. Education,

income, gender, and marital status were not found to be associated with a return to work.

They concluded that being able to return to work was beneficial to both the cancer

survivor and society at large, but did not attempt to explain why resuming work may be

beneficial.

Rasmussen and Elverdam (2007) attempted to explain why resuming paid work

after treatment for cancer may be beneficial to the survivor. They interviewed 23 cancer

survivors, aged 28 to 67, to discover how they talk about, experience, and manage their

time. Participants' cancer types included leukemia, breast, testis, condrosarcoma, uterus,

ovary, colon, lung, pharynx, bladder, kidney, rectum, tonsil, and lymphoma. Because

cancer survivors generally have a new appreciation for time, there was a consensus

among participants that they would like to spend less time on work. If people had jobs

that they did not enjoy, they especially thought it was a waste to invest too much time

into these jobs. Rasmussen and Elverdam (2008) published a second paper from their

exploratory interviews, which primarily focused on the meaning of work and working life

to these survivors. Their paper centred on the idea that, because people live in a world in

which work is typically a natural part of everyday life, it is only when an individual is not able to work that the meaning of work becomes visible. For most people, work structures the day. When this structure is broken, the obvious order of everyday life is upset. Rasmussen and Elverdam (2007, 2008) found that participants equated having a job with having a normal life. Work gave participants satisfaction and meaning in everyday life. When questioned about working only part-time hours, participants stated their ultimate goal was to resume full-time work. Many participants considered retiring later than originally planned. The results of Rasmussen and Elverdam's (2007, 2008) studies seem to show that participants wanted to be capable of working full time, yet wished they could spend less time at work and more time doing alternative activities they enjoyed.

Main, Nowels, Cavender, Etschmaier, and Steiner (2005) found similar results in their qualitative study of cancer survivors aged 21 to 66 years, with participant cancer types including gastrointestinal, brain, leukemia, lymphoma, lung, thyroid, breast, bladder, testes, melanoma, and uterus. Through interviews they found that most survivors returned to paid work for economic reasons (regardless of socioeconomic status) and because of the great support they received from co-workers. They also typically desired to have reduced work hours, due to nausea, fatigue, paralysis, and reduced control of bodily functions. Neither Main et al. nor Rasmussen and Elverdam (2007, 2008) made comparisons among age groups.

Work As An Occupation For Young Adult Cancer Survivors. More recently, cancer researchers are beginning to differentiate among age groups. Many quantitative studies have demonstrated that young adult cancer survivors experience psychosocial and physical difficulties, as well as feelings of uncertainty when resuming paid work after

20

treatment (De Boer et al., 2006; Felder-Puig et al., 1998; Lansky, List, & Ritter-Sterr, 1986; Novakovic, Fears, Horowitz, Tucker, & Wexler, 1997). Felder-Puig et al. (1998) found that 18% of young adults who had been treated for cancer between the ages of 15 and 30 had to give up their jobs (including secretarial, government, health care, tradesmen, and retail positions) as a consequence of their treatment. Novakovic et al. (1997) compared survivors of cancer diagnosed between four and 34 years of age with their siblings, who were free of cancer, and found that the survivors were less likely to have obtained full-time employment later in life. De Boer et al. (2006) completed a comprehensive meta-analysis to assess the risk of unemployment of survivors of childhood cancer compared to a healthy control group by searching literature published between 1966 and 2006, with an average survivor age of 18 years. They discovered that survivors of childhood cancer are nearly twice as likely to be unemployed later in life as healthy controls. Over two decades ago, Lansky et al. (1986) found that 38% of young adult cancer survivors who had completed treatment, aged 16 to 33 years, had reported a negative shift in career goals as a result of their disease; many were not aiming to achieve previous goals or have high standards for themselves at occupations.

Yet, a more recent quantitative study of adult survivors of adolescent cancer in Germany had results which conflict with many of these findings. Dieluweit et al. (2010) distributed self-report questionnaires to collect socioeconomic data from 1922 survivors who had been diagnosed with cancer between the ages of 15 and 18 years, and were diagnosed at least five years prior to the study beginning. In comparison to a control group of general population survivors, the adolescent survivors were more likely to be employed than the control group later in life.

Qualitative studies have found that young adult cancer survivors often experience difficulties when resuming paid work. Several researchers have used semi-structured interviews to gain an in-depth understanding of young adult cancer survivors' situations and experiences when resuming occupations (Amir et al., 2008; Christ et al., 1995). Amir et al. (2008) interviewed 41 cancer survivors, aged 18 to 55 years, in the United Kingdom by telephone, thus including some young adults. Participants had a range of cancer types, including breast, lung, colon, prostate, testis, melanoma, brain, uterus, rectum, leukemia, thyroid, lymphoma, and ovary. They were asked to describe their experience of returning to work following cancer diagnosis and treatment, since Amir et al. recognized that each individual's experience would be subjective and unique. An interview guide led the researchers in exploring people's experiences from pre-diagnosis through diagnosis, time away from work, and returning to work, during the one-hour interview. Because participants were responding to open-ended inquiry, they were able to highlight the processes, context, and meanings attached to their experiences.

Amir et al. (2008) discovered that survivors most greatly valued social support from co-workers; they referred to it as therapeutic. Many participants remained in contact with co-workers when they were away from their jobs, during their treatment. Additionally, paid work provided participants with structure in their lives; returning to work soon after treatment was the main goal for the majority. Work helped keep participants from thinking about cancer, as it kept them busy. Only a small number of participants altered the trajectory of their working lives by switching jobs. Participants also returned to paid work because it was a financial necessity, as many people had accumulated significant debts and had to make a living. It must be noted that very few

22

participants received helpful advice from their physicians about the appropriate time to return to work. Some people thought they returned to work too early. About one-third of participants experienced cognitive difficulties upon returning. Many also reported experiencing severe fatigue. However, since Amir et al. did not make any comparisons among age groups, their results may not be generalizable to a young adult population.

Christ et al. (1995) also used interviews, along with standardized psychological measures, to assess the psychosocial adaptation of 45 young adult bone sarcoma cancer survivors aged 17 to 34 years. Participants had been diagnosed with cancer between the ages of 11 and 24, and had completed treatment at least one year previously. Participants were divided into two groups; one group contained all patients who underwent a limb salvage procedure, while the other group consisted of the individuals who had undergone a limb amputation. Two-hour interviews were taped with permission from participants. Most of the participants were in their early 20s, and were in the process of establishing a career at the time of the interview.

In relation to occupational achievement, Christ et al. (1995) found that three quarters of participants were working (or attending school) full-time or part-time. The only major occupation-related difference between groups was that the amputees perceived themselves as not being employed at a level appropriate to their skills and training and they thought they were subjected to more job "discrimination" than their co-workers, while the other group did not feel stigmatized at work. This study has limited applicability to those of other cancer types, including the most common ones, but does help us understand the role that noticeable disfigurement may play in returning to work,

as well as provides insight into the nature of the experience of returning to work for young adults.

While we know there are a number of challenges associated with returning to work, very little is known about how young adults themselves experience these challenges. Unlike older adults, young adults are also often engaged in school when they are diagnosed with cancer and therefore this is also crucial to study.

School As An Occupation For Young Adult Cancer Survivors. Young adult cancer patients and survivors are often regarded as being at risk for educational deficits (Stam, Grootenhuis, Caron, & Last, 2006). Langeveld et al. (2003) administered questionnaires to 500 young adult survivors of childhood cancer, including leukemia, lymphoma, osteosarcoma, and Hodgkin's Disease, and 1092 young adult participants with no history of cancer, aged 15 to 49 years. They compared levels of psychological, physical, and social functioning, with respect to educational achievement, between the two groups. Results indicated that the cancer survivors were less likely than the control group in young adulthood to finish high school or earn a degree. These results suggest that some survivors can experience problems that may affect their daily lives for years after their treatment. The researchers concluded that such problems may be due to physical or mental impairments, cancer treatments, long hospital stays and absenteeism from school, parents' lack of attention to their children's educational needs, or teachers believing that academic success is of less importance than physical health.

Boman and Bodegard (2004) used questionnaires to compare the educational status of 30 young adult survivors of childhood cancer, including lymphoma, leukemia, brain cancer, and sarcoma, with a control group with no history of chronic illness. All

participants were aged 18 to 29 years. Unlike Langeveld et al. (2003), Boman and Bodegard concluded that the educational status of the survivors was similar to that of the controls. However, only a very small proportion of the cancer survivors expressed concrete plans for future vocational or educational achievement compared to the control group. Dieluweit et al.'s (2010) recent quantitative study of adult survivors of adolescent cancer in Germany found that adolescent cancer survivors aged 15 to 18 years were more likely to achieve higher education levels than a control group of general population survivors.

However, without conducting in-depth interviews, neither Boman and Bodegard (2004), Langeveld et al. (2003), nor Dieluweit et al. (2010) could fully explore underlying psychosocial issues that may have contributed to young adult cancer survivors' ability to return to work or school or to fully explore what that experience is like for them. Interviews are an important means of obtaining a full understanding of cancer survivors' experiences (Smith, Jarman, & Osborn, 1999).

Christ et al. (1995), who did use interviews in addition to quantitative measures, found that young adult cancer survivors aged 17 to 34 years reported missing at least one year of their schooling, but did not think that their cancer had any long-term effects on their education. About one-fifth of participants believed that they had achieved more in school as a result of their illness because they now took their studies more seriously. However, others reported realizing that there was more to life than just school (or work). While Christ et al. did use interviews, quantitative methods were used to analyze the interview transcripts, resulting in many quantifiable facts, yet not allowing the

25

researchers to gain an in-depth understanding of the psychosocial issues facing the participants.

Glasson (1995) used tape-recorded semi-structured interviews to explore the process of school re-entrance for five adolescent cancer survivors in a pilot study. Participants, aged 12 to 16 (cancer sites not specified), were questioned about problems encountered on return to school and the reaction of teachers, peers, and pupils. Revealed through grounded theory analysis, emerging themes were disruption, adaptation, and normalcy. Glasson found that four of the five adolescents were behind in their schoolwork, and found it difficult to readapt to their school lives. She also discovered that adolescents longed to feel normal, but this was prevented as a result of overprotective teachers and peer reactions to hair loss.

In summary, while it seems that survivors of childhood and adolescent cancer are more likely than others to not complete a post-secondary education and face challenges while trying to do so, very little is known about the experience of returning to school for those diagnosed with cancer during young adulthood. It appears that no qualitative studies have been conducted to explore what this experience is like for young adult cancer survivors who are college or university students. In order to fully comprehend the meaning young adults attach to their experiences, it is necessary to understand the importance of occupation in society.

The Importance Of Occupation In Canadian Society

Canadians typically seek rewarding occupational experiences; obtaining careers that allow them to feel useful and productive in society is important to Canadians, as it reinforces the value North American culture places on having an occupation (Cole et al.,

2001). Past research has found that having an occupation often represents life significance, successfulness, and satisfaction for individuals (Dries, Peperman, & De, 2008).

Obtaining employment appropriate to one's education and interests is of greater importance to Canadians than to residents of lesser developed countries (Elizur, Kantor, Yaniv, & Sagie, 2008). Furthermore, young adult Canadians are beginning to seek occupations that are meaningful and fulfilling to them more often than young adult Canadians of past generations (Ng, Schweitzer, & Lyons, 2010). Ng et al. (2010) explored the occupational expectations and priorities of young adults (born in 1980 or later) across Canada. They collected data from a national survey completed by 23, 413 undergraduate university students. They found that young adults had high career and career advancement expectations, and desired support from co-workers within a nurturing work environment.

Therefore, in order to understand Canadian young adult cancer survivors' experiences resuming occupations, their lived experiences and the meanings they attach to these experiences must be explored and interpreted within the context of Canadian society's occupational ideals and expectations.

Conclusion

From this literature review, it is evident that research pertaining to young adult cancer survivors and the psychosocial and physical challenges they face is a relatively recent area of study, in which there is room for more exploration. While there are many studies focusing on adult cancer survivors (Rasmussen & Elverdam, 2007, 2008), survivors of childhood cancer (Langeveld et al., 2003), and young adults with other

chronic illnesses resuming occupations after treatment (Blair et al., 1994; Gerhardt et al., 2008), the literature focusing specifically on cancer survivors who were diagnosed and treated during young adulthood seems to be limited. It appears no studies have focused on both school and work as occupations in young adulthood, with a wide range of cancer diagnoses. Definitions of young adulthood are quite inconsistent from study to study, as age ranges differ significantly. In addition, no studies of returning to occupations for young adult cancer survivors have been carried out on a Canadian population. It is important to understand the Canadian experience, since not only are the health care and educational systems different in Canada (Atlas, 2009), but so are employment conditions and even rules of employment and education (Arnett, 2000).   Therefore, this study is focused on Canadian survivors of cancer between the ages of 18 and 35 years resuming an occupation of school or work.

Moreover, the majority of studies that do examine the return to an occupation for young adult cancer survivors use quantitative methods (Boman & Bodegard, 2004; De Boer et al., 2006; Felder-Puig et al., 1998; Langeveld et al., 2003; Lansky et al., 1986; Novakovic et al., 1997). One of the few studies that uses interviews with young adult cancer survivors does not use a qualitative analysis (Christ et al., 1995). Conducting qualitative interviews rather than using quantitative methods may provide a clearer picture of the lived experiences of young adult cancer survivors returning to occupations.

Chapter Three: Methods

Approach

Traditionally, the scientific method has been the principal approach for conducting research in the social sciences (Cohen & Crabtree, 2008). The scientific method involves hypothesis testing through controlled experimentation. In the late 1900s, social science researchers realized that there are different ways of looking at the world, and observations and interviews could lead to a more naturalistic understanding of that experience. In the late 1960s and early 1970s, qualitative research became more widely accepted and expanded in the social sciences and health care field (Cohen & Crabtree, 2008).

Britten, Jones, Murphy, and Stacy (1995) note that qualitative research can be used when researching a poorly understood topic for which a quantitative hypothesis cannot be constructed; qualitative research can be used to discover new information on the nature of a topic under investigation. This new information may later be used to construct a hypothesis or develop a theory. In qualitative research, the generation of a hypothesis replaces the testing of a hypothesis, explanation replaces measurement, and understanding replaces generalizability (Jones, 1995). Qualitative research begins with an acceptance by the researcher that there are a range of different ways of making sense of an event, which is often followed by an attempt to interpret such an event in terms of the meanings that people bring to it.

The qualitative tradition of inquiry this study used was phenomenology, which is underpinned by evolving philosophical traditions (Lopez & Willis, 2004). Within phenomenology, there is an interpretative tradition. This study took an interpretative

approach, which like all phenomenological approaches, has its foundations in Husserl's (1913/1970) phenomenology.

In the late 1800s, Husserl (1913/1970) introduced the basic concept of phenomenology as an attempt to create a universal foundation for philosophy and science. He developed the concept of the "life world". The "life world" represented the world as experienced by the individual, in contrast to natural scientists' world, which is experienced separate from the individual. This "life world" helped Husserl understand human experience in a way that challenged natural science. Husserl recognized that experiences in the "life world" were the ultimate meaning of knowledge (Smith, Flowers, & Larkin, 2009). Therefore, he argued that re-examining people's lived experiences could bring understanding to human experience. He believed this subjective information was important because people's actions are influenced by what they perceive to be real (Smith et al., 2009). He also believed that there are features of any lived experience that are common to all people who have had such an experience, called universal essences. To identify universal essences, he believed that one must set aside preconceived beliefs about the world. By exploring universal essences, a generalized description of an experience can be constructed. Husserl's approach later served as the basis for Smith's (1996) qualitative analytical technique, the interpretative phenomenological analysis (IPA). However, Smith et al. (2009) have incorporated a more interpretative approach into the more descriptive approach prescribed by Husserl.

It must be noted that Smith et al.'s IPA is only one variation of Husserlian phenomenology; there are many types involving different approaches. Variations include hermeneutic phenomenology, which focuses on the essence of lived experiences (van

Manen, 1990), hetreophenomenology, which focuses on consciousness (Dennett, 1992), and more recently, neurophenomenology, which focuses on introspection (Varela, 1996). Yet, research results always depend on which type of approach is taken, and in order to better understand the meanings individuals attach to their experiences with illness, an interpretative phenomenological approach seemed most useful for this study (Smith, Flowers, & Osburn, 1997).

The popularity of this method of analysis is growing amongst psychologists, especially health psychologists (Smith & Osborn, 2004). Smith et al. (1999) note that IPA is useful in health psychology because a health psychologist usually assumes that there is a connection among people's verbal responses, cognitions, and physical ailments. Interpretative phenomenological analyses have also been used to study cancer-related experiences in several health promotion-related studies in recent years in the United Kingdom (Earle, Davies, Greenfield, Ross, & Eiser, 2005; Reynolds & Prior, 2006). Smith et al.'s (1997) IPA was particularly useful for this study, since it was developed for exploring people's experiences of illness. Also, Smith and Osborn (2004) state that IPA is ideal for under-researched areas because of its inductive processes. As noted in Chapter Two, it is evident that young adult cancer is a relatively under-researched area, especially in reference to young adult cancer survivors resuming occupations. Therefore, using IPA seemed most appropriate for this study, as this study explored an under-researched aspect of individuals' experiences of illness (Smith & Osborn, 2004).

Analytical Technique

Lopez and Willis (2004) note that when using phenomenology, a researcher must choose an approach to knowledge development that will best answer the proposed

research question and most effectively address objectives, while adding substance to what is already known about the phenomenon under investigation. The present study used IPA to provide a better understanding of young adult cancer survivors' experiences when resuming an occupation (Smith, 1996). While phenomenology as a qualitative tradition of inquiry is largely dependent on theory and is rooted in philosophy (Koch, 1995), IPA is more inductive than theory-driven, and has many of its origins in psychology (Smith & Osborn, 2004). The approach is phenomenological in that it is concerned with individual's personal perceptions of an event or experience, as opposed to objective statements about an event itself (Smith et al., 1997). The approach is interpretative, as it is related to symbolic interactionism, which involves exploring the meaning individuals attach to events through a process of interpretation (Smith, 1996). Finally, Smith's (1996) interpretative approach is also rooted in the hermeneutic approach, which emphasizes the need to involve the researcher in understanding participants' reports (van Manen, 1990).

Smith (1996) developed IPA specifically for psychology out of the recognition that different people experience the world in different ways, dependent on their own set of priorities, prior life experiences, and motivations. Following the interpretative tradition of phenomenology, Smith realized that gaining a rich understanding of an experience from a participant's perspective cannot be achieved without the interpretative work of a researcher. A researcher cannot directly or completely understand how participants themselves make sense of their experiences; a researcher's understanding is dependent on his or her own conceptions through a process of interpretative activity (Smith & Osborn, 2004). Smith and Osborn (2004) refer to this as "the double hermeneutic", the process of the researcher attempting to understand the process

participants trying to understand their world. As Larkin, Watts, and Clifton (2006) point out, all qualitative research requires some position between simply presenting participants' experiences and interpreting them. IPA emphasizes the researcher's understanding of what it means for participants to have concerns within a particular context.

The analytical focus of IPA shifts between analyzing the experiences of participants and the researcher's interpretations of their experiences (Smith & Osborn, 2004). The study's results balance phenomenological descriptions and the researcher's insightful interpretations. Participants do not simply hold information; they assist in constructing new knowledge through collaboration with the interviewer. IPA is based on exploring the cognitions of participants. IPA does not view reported thoughts of participants as completely representative of inner experience, nor does it view cognitions as simply behaviours in response to the external context, such as the interview questions (Smith, 1996). IPA is an attempt, using the researcher's own conceptions, to interpret what an experience is like for a participant.

Participants

In order to obtain a portrayal of individual experience for careful analysis, the aim was to have between eight and 10 participants take part in this study. IPA rarely include more than 15 participants, while qualitative studies can use a wide variety of sample types (Smith & Osborn, 2004). IPA is concerned with issues of quality, not quantity, and benefits from a small number of participants, as human experiences are quite complex (Smith et al., 2009). Smith and Osborn (2004) note that IPA samples are generally purposive and homogeneous. A purposive sample is one in which participants are chosen based on some characteristic(s) (Furlong, Lovelace, & Lovelace, 2000). A homogeneous

sample is one in which participants are purposively similar in most characteristics (Jordan, Eccleston & Osborn, 2007). This type of sample is typically used when describing a group in depth. In this case, the experience of cancer shared by the young adult survivors represents the homogeneity; the participants offered a multitude of perspectives on a shared experience.

Inclusion And Exclusion Criteria. Inclusion criteria for participation were: being a young adult between 18 and 35, having been diagnosed with cancer between 18 and 35 (as this is the period noted by Miedema et al. (2007), during which individuals are typically making life transitions by seeking financial independence and stable employment), having completed a primary treatment between 18 and 35, having resumed an occupation in the last five years (so as to be able to recollect experiences with minimal difficulty), being able to provide consent, being English speaking, being a Canadian resident, having access to a telephone.

Exclusion criteria for participation were: having continued school or work throughout cancer treatment rather than resuming an occupation following cancer treatment (excluding maintenance chemotherapy), as some researchers have suggested that individuals who continue to work throughout the duration of their cancer treatment experience different psychosocial complications than those who decide to resume work once their treatment is complete (Hansen, Feurstein, Calvio, & Olsen, 2008; Miedema et al., 2008). Participants were permitted to be undergoing or have undergone maintenance chemotherapy when resuming their occupations, as long as they had stopped attending occupations to undergo primary treatment.

Maintenance chemotherapy is the administration of a chemotherapeutic regimen on an ongoing basis after managing cancer in a traditional manner, such as surgery, radiation, or conventional chemotherapy (McGraw-Hill Concise Dictionary of Modern Medicine, 2002). It is given in lower doses than other types of chemotherapy, to assist in prolonging a remission (Chemocare.com, 2005). It is most commonly used for leukemias, and it typically continues for two or three years following conventional chemotherapy (Nachman et al., 2009). According to recent research, as well as participant reports, maintenance chemotherapy does not result in fatigue, nausea, or other physical side-effects to the same extent as conventional chemotherapy (Maurer et al., 2006; Nachman et al., 2009). Therefore, three participants who were undergoing maintenance chemotherapy while resuming occupations were permitted to participate, as two stated on their screening forms that their "main treatment" was complete, and the third did not even mention maintenance chemotherapy on the screening form (it surfaced in the interview).

Recruitment. Participants were recruited throughout Canada by various methods, as young adult cancer is relatively rare (Public Health Agency of Canada, 2006). Advertisements (see Appendix A) were circulated via email by Dr. Lynne Robinson, to an informal group of researchers and practitioners interested in young adult cancer. Advertisements were posted on Young Adult Cancer Canada's website (youngadultcancer.ca, 2009), a website that strives to offer inspiration, support, and current information to young adult cancer survivors throughout Canada. Advertisements were posted on free online advertisement networks, including Kijiji (kijiji.ca, 2009), Craig's List (craigslits.org, 2009), Canet Ads (canetads.com, 2009), and Montreal Q

(montreallisting.ca, 2009). Advertisements were posted in classified sections of the websites for The Coast (thecoast.ca, 2009), a young-adult oriented news website, and Facebook (facebook.com, 2009), a social-networking website. Advertisements were also posted on webpages linked to Facebook, including webpages titled Young Adult Cancer Survivors (2009), Canadian Young Adult Cancer Survivors (2009), and Cancer and Careers (2009). Participants were also recruited through snowballing (existing participants recruiting potential participants from among their acquaintances (Furlong et al., 2000)). Finally, participants were recruited by snowballing through a Halifax, Nova Scotia based photographer, Shari Tucker, who photographs annual collections of cancer survivors, with a focus on young adults.

For those who were interested in participation, an email address and a phone number were listed. The email address was created especially for this study and used exclusively for the purposes of recruiting and communicating with participants. Once contact was established, consent was obtained via email (see Appendix B). In the case that a participant might not have had an email address, the consent form would have been sent through the mail, and able to be returned with postage provided. Participants also had the option to print the emailed consent form, provide their signature in writing, and return it through the mail, with postage provided.

After consent was obtained, each potential participant was sent an email containing a brief description of the purpose of the study, the types of questions they would be asked, the potential risks associated with participation (see Appendix C), as well as screening questions to determine if he or she was an appropriate candidate for the study (see Appendix D). The screening questions were used to assess inclusion and

36

exclusion criteria. Individuals who fit the criteria were offered the opportunity to participate in the study. The email also informed the participants that they may ask any questions about the study and that participation was voluntary. This consent could also have been made over the telephone. Recruiting continued for 10 weeks, until 10 individuals had participated.

Procedure

  Data Collection. Data were collected by conducting semi-structured telephone interviews. Nunkoosing (2005) emphasized that interviews are the best method of learning about the lived experiences of a person who has experienced a health-related issue because they allow for the unification of a person's cognitions, emotions, and behaviours, rather than having each of these parts researched separately. Fontana and Frey (1994) believe that semi-structured interviews are an effective means of gathering data, as they do not limit the field of inquiry.

  When compared with alternate means of gathering qualitative data, such as focus groups, participants should feel less pressure during interviews, without other participants present; there should be less of an observer bias (Whorton, 2009). It is typically easy to schedule interviews, as only the interviewer's and participant's schedules have to be coordinated, rather than many individuals' schedules, as in the case with focus groups. It is also generally simple to reschedule interviews if required. Finally, participants generally have more time to talk in a one-on-one interview, compared to a focus group, where participants only have about 10 minutes of a 90 minute meeting to speak, or compared to writing answers and experiences down, where participants may become too fatigued to write long and detailed answers (Whorton, 2009). On the other hand, Smith et

al. (2009) note that interviews can be challenging to conduct the first time, as the interviewer has to remember what issues to probe, has to remain focused and attentive, and has to avoid becoming "over excited" and accidentally leading the participant. It also may be easier for participants to get "off track" in one-on-one interviews, and often more difficult to establish rapport in comparison to focus groups. While IPA researchers do use focus groups for data collection (Larkin et al., 2006), they are not generally used in phenomenological studies (Smith et al., 2009).

The interviews in this study were conducted by telephone, which has advantages and disadvantages when compared to in-person interviews. Advantages of telephone interviews, when compared with face-to-face interviews, are that they are cost-effective, allow participants to speak at their convenience, and ensure confidentiality, as no others are typically present (Thomas, 2006; Whorton, 2009). Jordan, Marcus, and Reeder (1980) reported several disadvantages of telephone interviews; they are faster paced than face-to-face interviews, participants may answer questions too quickly, without taking time to properly think through their responses, and it may also make transcription more challenging when using a tape-recorder. In this study, there was no evidence that the participants answered too quickly, partly because they had received the interview questions prior to the interview. Since the advent of cell phones and cordless phones, several researchers have noted that sound quality is often poor, making transcription challenging (Whorton, 2009), yet sound quality was fine in this study. However, the main disadvantage of telephone interviews is not being able to analyze the participants' body language, as the interviewer cannot see the participant (Whorton, 2009). To ameliorate this difficulty, notes were taken about anything thought to be relevant during

interviews, in order to remember the manner in which the participant was responding.

These notes were analyzed in combination with transcripts (Earle et al., 2005). Interview

questions were pilot tested and recorded over the phone with a colleague prior to

conducting participant interviews, to further ensure telephone interviews were

appropriate for data collection in this study.

Telephone conversations began by reminding participants of the premise and

purpose of the study, providing them with an opportunity to ask any questions, and

ensuring that they still consented to the use of their verbatim quotations. Participants

were asked to choose pseudonyms for themselves, which were used to refer to

participants' quotations throughout the results. If participants had not provided consent

for their verbatim quotations to be used, they would not have been included. All

participants provided consent. If participants did not wish to choose a pseudonym,

pseudonyms were assigned to them and they were informed of what these pseudonyms

were. Several participants opted not to choose their own pseudonyms. Participants also

had the option to create pseudonyms to refer to others about whom they spoke in their

interviews.

The Interview Guide. The interviews lasted an average of 35 minutes each,

consisting of open-ended questions and subsidiary prompts pertaining to the experiences

of resuming an occupation following cancer treatment (see Appendix E). The questions

in the interview guide were developed to fill gaps in our understanding of how young

adult cancer survivors return to occupations. As suggested by Smith et al. (2009), the

questions focused on individuals' understanding of their experiences; they were

exploratory, rather than explanatory, reflecting process, rather than outcome, and focused

on meaning rather than consequences. They were designed to elicit in-depth, thoughtful engagement of young adults with their own experiences, within the specific context. They were also intended to be most helpful in guiding health promotion efforts and interventions. Finally, the questions were designed to be flexible, wide-ranging, and employed open-ended non-directive inquiry. The order of questions was not relevant, as this allowed great flexibility in probing any interesting topics that emerged (Smith & Osborn, 2004). It has been suggested that interview schedules should only be used as a guide to content (Ayling & Mewse, 2009); in this study, the participants were often leading the interview.

While phenomenological studies often involve two interviews, only one interview was conducted in the present study, as guided by the interpretative phenomenological approach of Smith (Smith & Osborn, 2004). Smith (1996) does not believe that more than one interview is usually necessary for a participant to tell his or her story about an experience, or for a researcher to gain a full understanding of a participant's experience.

Because the aim of the interviews was to gain understanding of a sensitive topic, extra attention was paid to establishing rapport with participants (Fontana & Frey, 1994). Fontana and Frey (1994) believe that close rapport opens the door to informed research. Yet, they also note that interviewers should avoid delving into "real" conversations, as they may lead to the interviewer voicing his or her opinion. Ideally there should be a balance between having empathetic understanding and refraining from expressing opinion. Smith et al. (1997) note that some participants will require more encouragement and facilitating than others to open up and share experiences. Ultimately, the aim was for participants to have honest interactions with the researcher, in order to uncover a realistic

portrait of their experience. The researcher attempted to maintain a curious and

facilitative stance, rather than a challenging or interrogative one, as this allows

participants to feel at ease and provide personally salient accounts and descriptions

(Smith & Osborn, 2004). As expected, participants discussed matters that were not

predicted (Nunkoosing, 2005). This information was enlightening to the original

research question (Smith & Osborn, 2004). Smith and Osborn (2004) note that when a

participant has not been specifically prompted to reveal particular information but

chooses to reveal it, it is most likely of great importance to him or her. Throughout the

study, ethical issues were also taken into consideration.

    Ethical Considerations. Conducting ethically sound research involves carrying

out the research in a way that is respectful, humane, honest, and embodies the values of

empathy, collaboration, and service (Cohen & Crabtree, 2008). Before the study began,

it was reviewed and approved by Dalhousie University's Research Ethics Board.

    It must be noted that original inclusion criteria stated that participants must have

resumed occupations in the last year. However, after a few weeks of recruiting, an ethics

amendment was submitted and approved to alter this particular criterion to be inclusive of

those interested in participating who had resumed an occupation in the last five years.

    The main reason for proposing this change was that limiting potential participants

to those who had resumed their occupations in the last year appeared to be an ethical

problem; several individuals expressed interest in participating who initially had to be

turned away because each of them had resumed an occupation in the past two to five

years. As these individuals had requested to take part in the study even though they

realized they did not fit all criteria, it seemed ethically wrong to exclude them. Although

41

the original reasoning for having the "in the last year" criterion was to ensure that participants remembered their experience as clearly as possible, all individuals who requested to participate fit all other inclusion criteria, and insisted they did remember their experiences well enough to speak about them, because they were traumatic, memorable, or left them with a great sense of pride. Without any prompting, these potential participants provided information about their experience in emails, and provided references to their blogs and webpages. Each also requested to know if the study's criteria did change in the future, so they could participate. Therefore, participants who resumed occupation within the last five years were included.

Guided by Tri-Council ethical guidelines (The Office of Research Ethics Administration, 2007), participants were informed of what the study was about and what was expected of them (Smith & Osborn, 2004). Participants were informed that they could stop the interview at any point, and did not have to complete the interview if they did not wish, as all participation was voluntary. Confidentiality was explained; any identifying information was removed from the transcripts, with the exception of pseudonyms. Only the researchers listened to the audio recordings and viewed the transcripts. Participants were also assured that the recording was solely for purposes of convenience.

While the interviews were planned to avoid any great distress by not probing about overly sensitive topics, it was a possibility that participants may have inadvertently become distressed. Any participants perceived as experiencing great distress or depression would have been referred to clinical psychologist Dr. Lynne Robinson. However, no participants appeared to express great distress. All participants were

provided with contact phone numbers for the researchers, should they have required additional assistance or had questions about the interview once it was completed. Additionally, all participants were emailed a list of relevant resources, including websites and national services. No honorarium was paid to participants, as the study did not receive any funding. Participation was simply honoured by any benefits for participants or others that may have arisen from the research. Indirect benefits of this study may have included contributing to new knowledge, observing how research is conducted, and potentially experiencing stress relief by talking about distressing events. Nunkoosing (2005) asserts that although a research interview should not be considered therapy, it may have a therapeutic effect for participants. A further indirect benefit of the study was that it may assist in providing improved supports and services for young adult cancer patients and survivors.

To conduct all interviews, a home telephone was used, located in a private room with a locked door, during times when the researcher was the only occupant home. The participants used telephones in any location that was convenient for them and allowed them to feel comfortable. Participants were asked if the call would be of any cost to them, as cell phones often charge for incoming calls, but all had access to landlines. The researcher paid for all calls, as all were long-distance.

Following each interview, participants were asked if they would like to receive a copy of the final written report once it is complete. Such information and documents will be emailed. Participants were informed by email when this research was presented at conferences and seminars, at least one month in advance. Participants will also be

informed via email if this research is to be presented at additional conferences or seminars, if it is to be published, or of any other knowledge translation efforts.

Interviews were audio-recorded by linking an audio-recorder to the telephone, with participants' permission. The researchers transcribed all interviews verbatim, excluding any non-meaningful distracters (such as "umms" or "ahhs"), as recent research has noted that individuals have better comprehension of sentences that are absent of non-meaningful distracters (Kemper, McDowd, Metcaf, & Liu, 2008). This suggests that participant quotations may be easier to read and understand when they do not contain "umms", "ahhs", or other non-meaningful expressions. There were no gaps in transcription, as phrases that were initially difficult to decipher were replayed until they were able to be clearly understood. Interviews were also replayed once transcribing was complete to ensure that all transcription was accurate. Each interview took an average of two days to transcribe, and transcription began either immediately after each interview was completed, or the following day in the case that an interview took place during the evening. Braun and Clarke (2006) note that a researcher will gain a greater in-depth understanding of data by transcribing it himself or herself, as it familiarizes the researcher with the participants' reports at an early stage. Bird (2005) also argues that transcription is a key phase in analyzing data when performing qualitative interpretative analyses.

In addition to transcribing the audio-recorded interviews, data collection also involved taking field notes while interviewing. This entailed composing short-hand written notes about the topics being discussed. The research also carried out reflexive journaling following each interview, which included writing a reflection on the perceived emotions and cognitions conveyed by the participant. Cohen and Crabtree (2008) note

that a hallmark of informed research involves understanding and reporting relevant conceptions, by means of reflexive journal keeping.

Data Management. All transcripts were typed and saved into Microsoft Word on a password protected computer. All data were backed-up on a flash drive that was stored in a locked drawer, to which only the researcher had access. The audio-recorder, notes, journals, and any printed transcripts were also stored in this locked drawer. The only person allowed access to this information was the research supervisor.

To manage the data once the final written report is complete, all documents, including the reflexive journal, field notes, coding schemes, flash drives, and transcripts will be safely stored in a locked filing cabinet in Dr. Robinson's office, to which only she will have access. According to Dalhousie University policies (The Office of Research Ethics Administration, 2007), data will be stored for five years after publication, and then destroyed. All data stored on the researcher's computer will be deleted after the final written report is complete. Also, all saved emails, as well as the email account, will be deleted when the final thesis is complete.

Data Analysis. IPA involves understanding the subjective experiences of individuals and the emotions and cognitions underlying their views, with an analytic focus shifting back and forth between the key claims of the participants and the researcher's interpretations (Smith et al., 1999). This form of analysis is unique in that the researcher must attempt to put him or herself "into the participants' shoes" to bring meaning to experience. The role of the researcher is important to note in IPA, as the analysis centers around the researcher's interpretations. In this thesis, the researcher came into the study knowing little about young adult cancer survivors resuming

occupations, eager to explore each participant's experience. However, the researcher did

have some preconceived notions and expectations about the participants' experiences, as

she was a young adult, with an occupation (university student). The researcher did inform

all participants that she was a young adult herself, although not a cancer survivor.

Therefore, the researcher attempted to use any experiences of her own that were similar or

relevant to help understand participants' experiences and "connect" with them, while still

being alert to the ways in which their experiences differed.

When compared to a thematic analysis or grounded theory analysis, IPA does not

appear to greatly differ in its application, as it follows a general inductive approach

(Smith et al., 1999). Thematic analysis essentially describes a basic process that can and

is applied in a number of different methodologies, or can be used as a stand-alone

approach. The main difference is that IPA more closely examines cognitions and

perceptions, and relies on the interpretative skills of the researcher. The aim of a

grounded theory study is to develop a more general theory that is 'grounded' in the

reports from the participants. This is not expected from IPA. Moreover, phenomenology

is derived from an entire philosophical movement, again unlike grounded theory.

"Grounded theory is expected to help the researcher explain a process, while IPA is

intended to help the researcher understand an experience." (L. Robinson, personal

communication, December 12, 2010).

No software was used for any data analysis, as I believed that I could better read,

comprehend, and interpret the data on paper than on a computer screen. When a similar

thesis project was undertaken with 10 participants, Joblin (2008) discovered that the

amount of data collected was easily manageable without the assistance of a computer

software program. Additionally, as this was the researcher's first attempt at performing a

qualitative analysis, it seemed using paper to analyze would help enlighten and develop understanding of the process.

An initial coding was carried out with each transcript as soon as the interview was recorded and transcribed. The first interview transcript was studied by reading it several times (Earle et al., 2005; Reynolds & Prior, 2006; Smith & Osborn, 2004). After taking notes about connections and summaries in the left margin of the transcript page, the transcript was coded through a systematic search to allow emerging themes to be established. Emerging themes were ideas or points of interest and significance that were introduced into conversation by the participant without suggestion of them by the interviewer (Smith, 1996). These were written in the right margin in the form of key words or phrases that captured something that could be identified about the concept being discussed. At this time, the researcher's notes and journaling were consulted to ensure that the researcher fully understood the content of the transcript. Connections among emergent themes were determined and these themes were grouped and labelled. These labels became master themes; sub-themes of each master theme were also noted (Smith et al., 1999).

The same analytic procedure was undertaken for each of the other interview transcripts (Smith et al., 1999; Smith & Osborn, 2004). An idiographic approach was taken to analyze each individual case as an end in itself, before moving on to a similarly detailed analysis of the next case (Smith, 1995). Each interview was transcribed and initially coded for analysis before subsequent interviews took place, as all interviews occurred at least a few days apart. Therefore, there was little time between the recording, transcription, and initial coding of each interview. As each transcript was analysed, the

themes from it and from previously analysed transcripts were applied to the next

transcript being analysed. As the researcher gained understanding of a given theme in the

process of analysis, that theme evolved to some extent and was checked again against the

transcripts in which it appeared. However, after consulting with the research supervisor

after all interviews were completed, all interviews were re-analyzed many more times.

The average time to code an interview was approximately one day, while the average

time to fully analyze an interview was several days.

Patterns between or among participant interview cases were determined by

searching for similar emerging themes, master themes, and sub-themes (Smith et al.,

1999). From establishing connections among these themes, master themes and sub-

themes for the group of participants as a whole were named.

A concept map also assisted in the development of master themes for the group

(Braun & Clarke, 2006). Constructing concept maps began with noting emergent themes,

findings connections between or among themes, and drawing these connections with

lines. Connected themes were grouped together as sub-themes, and then assigned a label,

the master theme. Each master theme was connected to its corresponding group of sub-

themes with a line. Concept maps are typically used when performing thematic analysis

(Braun & Clarke, 2006), not IPA, yet Dr. Robinson believed constructing such maps

would be a useful way to understand how to group themes, as this was the researcher's

first time performing qualitative analysis.

The master themes with sub-themes were arranged in a table, with the themes

arranged in an order that made sense by answering the research questions, while telling a

story. Verbatim quotations from participants to illustrate and support themes were

included in the table. In writing up the results, the table of themes and transcript

quotations was translated into an account that introduced each theme in turn, described

each theme in rich and thick detail, and provided supporting evidence from participant

extracts.

For purposes of validation, Dr. Robinson read all transcripts and checked that

themes were grounded in the data, representative, and constructed in a way that made

intuitive sense. Another verification strategy used was being certain that the research

question matched the method and the analytical technique (Morse, Barrett, Mayan, Olsen,

& Spiers, 2002). Also, the principles of trustworthiness were used to verify the analysis.

Trustworthiness

The principles of trustworthiness are outlined by Lincoln and Guba (1985) as

credibility, dependability, transferability, and confirmability. Lincoln and Guba define

the credibility of a study as the extent to which it answers the research question it was

designed to answer. Having two researchers involved in each level of the analysis, as

well as support from a thesis advisory committee, assisted in improving the study's

credibility. Credibility also deals with establishing that the results reflect the participants'

experiences (Lincoln & Guba, 1985). Nunkoosing (2005) states that participants' stories

will not necessarily be true, yet will be authentic. Therefore, to ensure credibility,

summary sheets (see Appendix F) of the interview transcripts were provided to

participants out of respect, to allow them to read through the information they provided in

the interview. These were emailed to each participant no later than one month after his or

her interview had taken place. A few participants replied to these emails by stating some

comments they wished to have added to their transcripts. Such comments were added to

participants' transcripts and analyzed. This contributed to ensuring that the participants'

experiences were reflected in the final results.

Lincoln and Guba (1985) define dependability as the consistency in the

measurement process; the dependability is the ability for outside researchers to be able to

follow and replicate the decision trail of the original researcher. Yet, Smith et al. (1999)

suggest that the dependability of an interpretative phenomenological analysis is

extremely dependent on the interpretative skills of the researcher attempting to replicate a

study's analysis, regardless of how systematically a qualitative method is presented.

Therefore, the researcher of this study carefully read each of Smith's publications

describing how to interpret data when doing IPA, in order to gain the interpretative skills

to increase the dependability.

Lincoln and Guba (1985) define transferability as the ability of research findings

to be transferred into contexts outside of the study scenario. Transferability is typically

questioned when the number of participants is small, as in the present study (Smith et al.,

1997). However, when there is very little research on a particular topic, even a single

case study can be useful in portraying an experience. Guest, Bunce, and Johnson (2006)

conducted a study to determine the number of interviews it takes to reach saturation,

defined as the point at which no new information or themes are observed in qualitative

data. They conducted 60 interviews and coded them. They found that after the first 12

interviews, new themes emerged infrequently; a saturation point had been reached. More

specifically, in the first 12 interviews 92% of the total number of codes developed from

the first 30 interviews and 88% of the total number of codes developed from all 60

interviews had emerged. Smith and Osborn (2004) do not specify a minimal number of

participants to be used in interpretative phenomenological research. Therefore, taking each these perspectives into consideration, it was estimated that having 10 participants in this study would be sufficient. A saturation point was reached because the same themes were emerging in all participant transcripts. In fact, no new themes emerged in the final transcript coded. If a saturation point had not been reached using these 10 participants, additional participants would have been recruited, to further increase the transferability. The transferability of the study was also increased by using thick and rich descriptions, as well as presenting raw data in the form of verbatim participant quotations.

The final concept of trustworthiness, confirmability, has been defined by Lincoln and Guba (1985) as the degree to which the study results are objective and unbiased. Having two researchers interpreting the data enhanced the confirmability. Also, memoranda were taken to document how the analysis of the data was approached.

Conclusion

In this chapter, the qualitative approach that was used in this thesis was outlined and the rationale for using an interpretative phenomenological analysis was given. IPA allows for the collection of open-ended data to gain an increased understanding of individuals' lived experiences of illness and the meanings they attach to these experiences. This understanding is achieved through a process of interpretation by both the participants and the researcher. The inclusion and exclusion criterion, recruitment methods, as well as data collection and management procedures were explained. Steps in data analysis were discussed, and the principles of trustworthiness and ethical considerations were outlined.

Chapter Four: Results

Participants

Ten individuals participated in the study. Five participants were recruited through the Young Adult Cancer Canada website (youngadultcancer.ca, 2009), one through Facebook (facebook.com, 2009), and four through snowballing (three through Shari Tucker, one through another participant). Participants ranged in age from 21 to 35 years, with a mean age of 29 years. There were four males and six females, diagnosed with a range of types of cancer between one and seven years ago. In total, five had resumed school and five had resumed work, all within the past five years. All were Canadian, residing in the provinces of British Columbia, Alberta, Ontario, Quebec, New Brunswick, and Nova Scotia.

Table 1 summarizes the number of participants in each age range at key time points.

Table 1

Number Of Participants In Each Age Range At Diagnosis, Return, And Interview

Participant age range	At diagnosis	At return to occupation	At time of interview
21-25 years	6	6	3
26-30 years	2	2	3
31-35 years	2	2	4

Introducing The Young Adult Cancer Survivors. All participants' names have been changed to pseudonyms to protect their identities.

Bret. Bret is a 28-year-old survivor of acute b-cell lymphocytic leukemia. He was diagnosed and began treatment at the age of 22. While undergoing treatment, Bret withdrew from university studies for about a year. He completed his primary treatment and resumed school at the age of 23. Bret was undergoing maintenance chemotherapy while attending school. Since completing university, Bret has began working, married, purchased a house, and is trying to have children. He has noticed that cancer is no longer the "biggest" thing that has happened in his life; his cancer experience now seems very long ago.

Chloe. Chloe is a 21-year-old survivor of acute lymphoblastic leukemia. She was diagnosed and began treatment at the age of 20. Chloe was traveling and working abroad at the time of diagnosis and was not employed for approximately a year, while she returned to Canada and underwent treatment. She completed the first course of her treatment at 20 years of age. Chloe decided to return to school at the age of 21, as her physicians advised her not to return to work or travel abroad at that point. Chloe is undergoing maintenance chemotherapy while attending school. She looks forward to finishing school and her maintenance chemotherapy, in order to resume traveling and living abroad. She also aspires to help other cancer patients identify as survivors.

Erica. Erica is a 28-year-old survivor of acute promyelocytic leukemia who shows no qualms about sharing her cancer experiences, as "cancer is her life". She was diagnosed and began treatment at the age of 25. During treatment, Erica withdrew from employment for a couple of months. She returned to work, at the age of 25. A year later,

at 26, Erica relapsed and withdrew for another few months. She returned again for a few weeks, until getting a bone marrow transplant, at age 26. Before Erica could attempt to return again, she was "let go" by her employer. She has not worked since, other than at small odd jobs that she enjoys. Work is no longer a large focus for Erica; she realizes there are other important aspects to life.

Greg. Greg is a 30-year-old survivor of acute osteosarcoma of the sphenoid sinus, brain stem, and pituitary gland. He played hockey for his university and, he believes, was on the cusp of becoming a professional player when diagnosed at 24 years of age. He began treatment right away and withdrew from university studies for one year. He completed treatment and resumed school at the age of 25. Greg described the resumption of his studies as a welcoming and empowering experience.

James. James is a 35-year-old survivor of testicular cancer. He was diagnosed and began treatment at the age of 28. While undergoing treatment, he withdrew from employment for about six months. James completed this treatment and resumed work at the age of 29. At the age of 30, he relapsed, and withdrew from work for another five months. He completed another treatment and resumed work for a second time at the age of 30. James showed a nonchalant attitude toward being away from his occupation, as to him "work is just work"; other aspects of life hold greater significance.

Jess. Jess is a 32-year-old survivor of ovarian cancer. She was diagnosed and began treatment at the age of 29. While undergoing treatment, Jess withdrew from employment for almost two years. She completed her treatment at the age of 29 and resumed part-time work at the age of 30 and full-time work at the age of 31. Jess has always appreciated the simple things in life and understands that patience is an important

trait for cancer survivors. She also believes that others need to learn how to be patient

with cancer survivors while they are on their road to recovery.

Kate. Kate is a 32-year-old survivor of non-Hodgkin's lymphoma. She was

diagnosed and began treatment at the age of 31. While undergoing treatment, Kate

withdrew from employment for about a year. She completed her treatment at the age of

31 and resumed full-time work at the age of 32. Kate did a small amount of part-time

work after finishing treatment, prior to resuming working full-time. She sees herself as a

strong advocate for young adult cancer awareness. She believes more people need to

understand the impact of cancer during young adulthood on individual lives.

Kevin. Kevin is a 25-year-old survivor of melanoma, diagnosed at the age of 20.

The cancer spread to his lymph nodes at 22 years of age and at that time Kevin began his

first treatment, which was completed when he was 23. He withdrew from his studies for

one semester of university to undergo this treatment and resumed studies the following

September, at 23 years of age. Kevin believes his experience with cancer was a "blessing

in disguise" which allowed him to become a better and stronger individual, especially at

his occupation.

Lisa. Lisa is a 22-year-old survivor of acute b-cell lymphoma/leukemia. She was

diagnosed and began treatment at the age of 21. While undergoing treatment, Lisa

withdrew from her studies for about a year. She completed her primary treatment and

resumed school at the age of 22. Lisa is undergoing maintenance chemotherapy while

attending school.

Sarah. Sarah is a mother and 35-year-old survivor of Hodgkin's lymphoma. She

was diagnosed and began treatment at the age of 33. While undergoing treatment, Sarah

ceased working for slightly more than a year. She completed her treatment at the age of 34 and resumed work at the age of 35. Sarah thinks her cancer experience has resulted in her feeling more in control of her life.

Findings

To add clarity throughout the results, the term "almost all" refers to nine out of 10 participants, "most" refers to eight, seven, or six out of 10 participants, and "some" refers to five, four, or three out of 10 participants.

Overall, participants' experience of resuming an occupation following cancer treatment was a positive one, yet, they dealt with a range of issues and had many needs. After careful analysis of participant transcripts, four master themes emerged from the data. The first master theme was "making the decision". Almost all participants felt "pushed" to make the decision to return to their occupations, "pushed" to stay home for a longer period of time before resuming their occupations, or "pushed" to do both, from different sources. The second master theme was "actively adapting to changed lives". Participants understood that to successfully resume their occupations, they would have to actively adapt to being back at school or work. They described the strategies that they used to adapt to being back and to make a smoother transition from being away. However, almost all participants also noted barriers to actively adapting. The third master theme was "receiving support". All participants described types of support they received while attempting to resume occupations, whether that support was viewed as helpful or unhelpful. Additionally, participants discussed support needs, although some participants noted that they did not need any additional support as they made the transition back to an occupation. The fourth master theme was "renewed sense of health

and wellness". Many participants spoke about the new experience of the value of being well. They believed being back at school or work signified a return to "normal", while at the same time they strived to achieve more balance in life; they focused less on school and work and more on the value of living life as they thought it ought to be lived.

These master themes and sub-themes are outlined in Table 2 and discussed in greater detail throughout the remainder of the chapter.

Table 2

Outline Of Master Themes And Sub-Themes

Master Themes	Sub-Themes
1. Making the decision	Pushed by external forces
	Pushed by internal forces
2. Actively adapting to changed lives	Strategies to actively adapt
	Barriers to actively adapting
3. Receiving support	Being able to share and be accepted
	Occupational security
4. Renewed sense of health and wellness	Resuming normalcy
	New and stronger sense of the value of life

Theme One: Making The Decision

Participants' experience of resuming an occupation following cancer treatment typically began with them making the decision to return to an occupation or not. The process of making this decision surfaced as a prominent theme in the data, as all

57

participants discussed deliberating and weighing "pushes" they felt from external and internal forces. External "pushes" left them weighing the opinions of others against their own self-perceptions. Internal "pushes" left them carefully considering their own circumstances.

      Sub-Theme: Pushed By External Forces. Most participants felt external pressure from various sources to return to school or work as soon as possible following their primary cancer treatment.

      Financial Circumstances. Financial circumstances were one source of pressure causing participants to feel "pushed" to return to school or work. Participants' everyday stressors while away from occupations were often compounded by a lack of funds, resulting in cancer survivors feeling pressured to resume occupations to earn money and make up for lost wages. When explaining how financial stress weighed on her after spending a year away from work, Sarah stated,

> *I had run out of funds during treatment and we* [*family*] *just couldn't afford for*
>
> *me to be off anymore . . . I didn't want to come out of having had cancer*
>
> *treatment, you know, 20, 30, 40 thousand dollars in debt. I didn't want to have*
>
> *that stress. That was it. I think that was the biggest issue . . . You don't have a*
>
> *choice as someone young. It's not like when, you know, you're close to*
>
> *retirement and you have the luxury of having saved money. I had no money*
>
> *saved. Well I did, and then it all went the year that I didn't really work.*

Sarah resumed work mainly due to this pressure, even though she did not perceive herself as being physically ready to return at the time. On the other hand, Kate did know that she had recovered physically and emotionally, yet was still not initially motivated enough to

begin seeking work. However, when she realized she was in need of an income, she began job-searching. As she said,

> *I just needed money and I needed to be doing something . . . so I started applying*
> *for jobs.*

The need for money was not the only external "push" for these survivors.

Medical Plan Providers. Several participants felt a significant "push" to return to school or work from their medical plan providers. Jess explained that her provider wanted her to go back to work a few short months after treatment. She described her struggle when contemplating resuming work,

> *Obviously* [my *medical plan provider*] *wanted me to go back to work. And I think*
> *they were almost kind of in a way forcing me to go and that felt a little*
> *pushed . . . It was difficult for people to understand.*

She noted not feeling able to return to work as soon as her provider expected her to; those expectations weighed heavily on her mind because she was not living up to them. Jess did not return to work until almost a year after the date her provider had originally anticipated. Kevin had a similar experience with his medical plan provider, but related to returning to school. He believed he really had no choice but to go back to school, as the medication he was taking was quite expensive and therefore was difficult to afford for him unless he was insured by his parents' medical plan. However, to be insured by this plan, he was required by the medical plan provider to be attending school. Kevin thought he was lucky that he felt he was ready to return to university anyway, since he did not think he had any choice in the matter.

Family. On the other end of the spectrum, some participants felt "pushed" to stay at home by external sources who strongly encouraged them to take more time away from occupations, to ensure they were absolutely ready to return. The majority of these individuals felt this pressure from their families. Parents were especially worried and fearful about their children returning to occupations. For instance, Sarah's mother worried about a relapse each time her daughter showed symptoms of an illness. Sarah commented,

> *My mother tried to convince me to take more time off . . . because I think she*
> *didn't want to see me get sick again . . . So when I started going back to work and*
> *I started getting things, it just started worrying her, and she tried to convince me*
> *to stay home.*

Sarah understood that her mother simply did not want to witness her daughter going through being sick at work again. Most participants feeling "pushed" to stay home reported realizing that their parents and families had the best intentions and were simply attempting to look out for their well-being. While parents expressed various concerns, physicians also sometimes encouraged their patients to avoid occupations for a longer period of time. Such concerns could also sometimes include statements about the reduced capacity of the young adult. Greg's family and physician attempted to convince him to spend more time at home, as a return to school would involve a return to the ice to pursue his passion for hockey. He recollected,

> *The doctor was terribly concerned that I was going to play hockey again. And I*
> *was a goal tender, you know, I could get a puck in the head. And having a brain*
> *tumour, that's probably not a positive thing. You know, very concerned, and*

obviously, "You're never going to play hockey again." And, you know, "Don't

jump right back into the books, because, you know, you probably lost some of

your capacity." . . . My Mom and my Dad, I didn't tell them I was going back on

the ice.

These concerns weighed heavily on Greg's mind when he was making the decision to
return to school and the hockey team.

Employers. One participant felt "pushed" by her employer to not return to work;
Erica believed her employer perceived her as a "drain on the company financially", since
she had left work to undergo treatments and recover several times. The company
representative attempted to terminate her employment. Erica believed they thought, "it
would be easier if she just didn't work here". Erica went on to say that experiencing this
"push" away from her occupation made her feel horrendous.

Sub-Theme: Pushed By Internal Forces. Participants also put a significant
amount of pressure on themselves to resume occupations; most of them felt driven to
move forward with their occupational lives. Erica talked about how she "pushed" herself
to return to work following her first time away,

It was mostly me putting pressure on myself and all that stuff, like "Oh my gosh,

I'm totally useless. I have to go back to work." . . . "Life has to get back together

and go on here, so [I] have to go back to work."

Erica remembered thinking that the only way to move on with life was to return to her
occupation. Similarly, Chloe felt proud of the way she always planned ahead for the
future and that this trait "pushed" her to go back to school.

Ease Of Decision-Making. All participants knew they wanted to resume occupations at some point, but they did differ in how easy it was to make this decision and most talked about how they made it. Regardless of the extent to which participants felt "pushed" to return to occupations or stay home, this "push" did not seem to affect how easy it was to make this decision.

Some participants did not find it simple or straightforward to make the decision; they thought they were not ready to go back. Some wondered why anyone would ever want to give up being unoccupied by either school or work. For James, an initial decision that he was ready to return to his work was followed by second-guessing his decision. He recalled,

> *But right when I went back to work, like, about a week in, I said, "You know*
> *what? What the heck was I thinking? . . I don't know why I'd want to come back*
> *here, when I could have stayed at home and just, I don't know, healed more*
> *mentally I guess" . . . I just regret the time that I didn't spend after treatment*
> *staying at home . . . if I could take another two months off, why wouldn't I do*
> *that?*

On the other hand, some participants felt they were ready to return to their occupations as soon as they were finished their primary treatment; not returning was never an option for them. As Lisa explained, she never considered not going back to school, even though she would still be undergoing maintenance chemotherapy while attending university,

> *I was happy to go back to school, cause in my head I never wanted to stop . . . So*
> *it was not really a question for me.*

Greg had a similar outlook on making the decision to return to school,

That [returning to school] was the goal from the onset . . . The year came full

circle and I just knew that was the next thing I had to do whether I liked it or

not . . . if you're not ready to do something relatively easy and enjoyable like

school after a year of challenges like that, then I don't know if you'll ever be

ready.

Participants remembered the decision to resume school or work becoming easier when they felt mentally and emotionally recovered. Some suggested that retreats to ensure this healing and relieve pressure would be useful. Readiness to resume occupations seemed to come for most of them from psychological healing, and not necessarily when others told them they should be ready.

Participants also believed feeling less "pushed" to return would allow for a smoother transition when the time to resume an occupation came, relieving pressure to quickly resume occupational duties and responsibilities and succeed before they themselves felt ready. Some desired a means of easing back into occupations, so they could return when they felt ready and capable. Erica explained,

[I would have liked] some sort of better system or something there so you didn't

feel as pressured to get back to work . . . Cross-sharing. Like, you know, if I

didn't want to return or couldn't be returning to the specific job I had, what other

options are there out there? Like, what is, you know a good employer that would

be a little more sensitive?

Participants did not always feel comfortable or capable of resuming previous occupations and suggested that having access to information about situations that might be more adaptable to their needs would be helpful.

Theme Two: Actively Adapting To Changed Lives

Once participants had made the decision to resume occupations, they had to actively adapt to an altered life at school or work. While participants generally managed this, they found that getting back to their normal lives and routines at school and work was not as straightforward a process as they initially expected. Almost all of them discussed the challenges associated with attempting to reclaim parts of their former lives, while integrating parts of themselves that had changed during the cancer experience. Erica, who attempted to resume work three separate times, summed this up by saying,

You don't get everything and it's not all the same as it's gonna be, but now you've a new life and you get to carry through whatever pieces from what you called your life before.

Participants seemed to realize that they needed to readjust and adapt to their altered work and school lives while still maintaining as much as they could of the identities they once had. To do this, they used a variety of strategies, but also perceived a number of barriers to adapting.

Sub-Theme: Strategies To Actively Adapt. Almost all participants used a variety of strategies to assist them in adapting to their altered occupational lives, often through finding ways to break tasks into more manageable elements. These strategies helped them feel capable to take on previous duties and responsibilities so they could complete school or work tasks once again.

Lighter Course Load/Reduced Work Hours. One of the most common of these strategies was taking on a lighter course load at school or working reduced hours at a job. This compensated for energy loss and a general decreased capacity. Most participants reported actively managing how much work they took on. Bret, who had the challenge of balancing university and maintenance chemotherapy, elaborated on this,

> *Instead of doing two semesters of six, I did three semesters of four. And that really, it didn't make it super easy, but it really let me focus what energy I had on my classes.*

Lisa's rehabilitation group recommended this strategy for her, which she found helpful for managing her time when resuming school while also undergoing maintenance chemotherapy. In a work setting, Erica requested shortened shifts when she initially resumed her employment.

Sharing/Dividing Work Tasks. Another strategy to create a more manageable workload, which some participants used, was sharing and dividing work tasks with colleagues. Cancer survivors often found it helped to have a good understanding of their co-workers' strengths and abilities, and to use this knowledge to their own advantage. Erica shared work by assigning tasks to the employees she managed in such a way as to reward and complement their abilities and strengths. Besides lightening her own work load, this strategy allowed her to feel more relaxed and at ease upon returning. Similarly, Sarah described how she shared work with her colleagues,

> *I would share work. I used to be more of the type to do my own thing at work, and want to be a perfectionist. So I think I would share resources with colleagues more. That way I didn't have to do the planning myself, all of it. Easier on time.*

Several participants reported receiving help with housework from family and friends while adapting to being back at an occupation. Parents of survivors often assisted by looking after children, arranging transportation, or cooking meals. When the survivors were able to share work or home tasks with others, it reduced the new workload to manageable proportions.

Progressing Step-By-Step. A related strategy participants elaborated on was taking things step-by-step, typically by pre-planning and breaking tasks down into manageable pieces. Kate explained how she used this strategy when first returning to work,

> *Really focus on the achievements I made today, or each hour, or whatever it was.*
>
> *Which is actually kind of similar to getting through cancer treatment.*

This strategy helped Kate adapt to her new job, which involved increased responsibility and recognition in comparison with the job she held prior to her cancer diagnosis.

Time Management. Similarly, managing time was also essential for many, as participants reported having busy schedules. They used different methods to time-manage; some found routines were helpful, while others preferred having flexibility in their days. Getting back into a routine was useful to regain their cognitive activity. The routine also gave them something to be committed to, which was useful. This was a strategy that proved effective for Kevin when re-entering school, as it kept him committed to his studies,

> *Once I kind of got into the swing of things, and kind of realized what my schedule*
>
> *was like and what I had to do, it was fine.*

Some participants found that having a flexible schedule at school or having the benefit of working flexible hours was an excellent strategy, as it kept them from feeling guilty about calling in sick when they did not feel well and allowed them to sleep when they felt it was necessary. Sarah realized that the flexible schedule of her occupation assisted her in adapting,

> *It was good that I was* [occupation] *because it was flexible. So if I was feeling too tired I just didn't work.*

Some participants struggled to manage an occupation and cancer, as they were still undergoing maintenance chemotherapy. Lisa, who continued to get maintenance chemotherapy after she returned to university, elaborated,

> *I have to manage those two things together: school and treatment. So that was a little anxious . . . it's complicated to manage your appointments and your homework and stuff . . . I wanted to take more* [classes]*. But I don't know if I would be able, cause, like I say, it's really a lot to manage.*

Therefore, time management and learning how to create balance appeared to be a particularly important skill when dealing with follow-up treatments and appointments on top of school or work schedules.

Taking On New Occupational Tasks. Finally, several participants found that using some occupational tasks and duties, such as redesigning work spaces, reorganizing, and revising resources, was an excellent tool for relearning and adapting. Jess, who was away from her occupation for nearly two years, explained,

It was like completely relearning everything. So when I came back I gave myself

the task to re-create a manual I'd already created before I left . . . and that was

an excellent tool for me to relearn everything.

Furthermore, policies and procedures had often changed while participants were away, resulting in the requirement to relearn. As Sarah recalled,

Things had changed while I was off . . . So, it was weird to have all of a sudden

this new technology . . . I felt like I had catching-up to do . . . I had left a lot of my

stuff behind and somehow it had gotten shuffled and taken by others . . . So I had

to start from scratch a bit too.

Having these new work tasks to learn and complete proved to be an excellent strategy for Sarah to adapt to being back at her occupation. While participants identified a number of strategies they had found to help them reduce the burden of the workload they had taken on again, and some found ways to get "up to speed" at their occupations, there were also many barriers.

Sub-Theme: Barriers To Actively Adapting. The perception of themselves as less able to manage some aspects of their mental and/or physical capacities was common to almost all participants when they returned to school or work. Almost all of them noticed a decrease in their physical capacity, including bodily changes, fatigue, lack of energy, and decreased fitness levels. This affected those returning to school as well as those returning to work and was seen as the consequence of both not being actively engaged in an occupation and of the treatment. Chloe was one of many participants to talk about lacking the energy to function at a capacity she once had. Kate mentioned the changes in her body, as well as a changed experience of her body. She said,

68

So much about me had changed during treatment. And so much has, just the way

that my body works and the things that I took for granted before, I can't

necessarily do anymore . . . The cancer ravages your body, then the chemo

ravages your body. I [*was*] *just a mess.*

Participants also noticed weakened immune systems, physical side-effects of

chemotherapy, and altered hormones decreasing their physical functioning. Such

changes in physical functioning often made it hard for them to actively adapt to being

back at their occupations. For example, Jess reported having a difficult time maintaining

her emotional equilibrium, as her body was going through a period of menopause

resulting from hormonal changes (due to chemotherapy). She explained,

I went through about eight months of menopause after my chemo. And being 29,

30ish and having pretty full-on hormones, and having them shut, like, completely

off . . . I was a mess. You know, one minute I'm, like, happy-go-lucky, and the

next minute I'm, like, screaming at something, you know, completely angry. Or

bawling my eyes out, like, at the drop of a hat. It was just ridiculous.

Jess found it hard to cope with these changes while also trying to adapt to being back at

work, with renewed work duties and responsibilities.

Other participants also noticed a decrease in their mental capacity upon returning.

Most often they reported lacking focus and concentration, as well as memory loss and

emotional stress. For example, Kevin, who described the return to school as having gone

fairly well, noted that decreased mental functioning was a side-effect of his medication

and presented a slight challenge for him,

Another side-effect from the medication was that I wasn't able to concentrate as
well as I used to. So that was a bit of a challenge. Especially cause the program
itself was a lot harder than anything I did in undergrad. So it was kind of a
challenge trying to stay focused on what I was supposed to do.

Jess also noted that it is not always simple to remember how to complete work tasks. She
had a decreased mental capacity upon returning to her occupation and struggled to
remember how to perform work duties, including using a computer. She noted that she
suffered from "chemo-brain". This meant her focus and concentration were severely
lacking, to the point where she could not remember the names of simple things, such as
"apple" or "fork". She described,

When I was thinking about going back to work, I'm like, "How am I going to
remember people's names? Cause that's a big part of my job." . . . I have to
remember how to work . . . I'm like, "How the hell am I supposed to go to work
like this when I can't keep myself together at all?"

Other participants reported being afraid and worried that they could no longer
cope with emotional stress, physical demands, and mental responsibilities, resulting from
their decreased capacities. Bret knew that being back on campus meant that he would be
surrounded by crowds of peers with germ and viruses. He explained,

I was scared. I'm not gonna lie. I was terrified to go back. I didn't know if
things would be a lot harder, if I would have the energy . . . just being afraid of
getting sick again; just feeling that let-down of being ripped away from my life
again.

Several participants stated that despite their attempts to actively adapt, they are still not where they want to be in terms of feeling comfortable again in their occupations. For example, Chloe, who is attempting to resume school after being away from it for some time, said,

I feel like I'm still working my way into it [school].

Yet Chloe is hopeful for her future and believes she will fully adapt to being back in school and eventually the workforce. Unhelpful support also may have contributed to hindering participants from actively adapting, as they found they received many forms of support when resuming school and work.

Theme Three: Receiving Support

All participants described support in some form, as it assisted them in making the decision to return and adapting to altered occupational lives. They described constructive support (being able to share and be accepted and having occupational security as the most significant types), as well as unhelpful support. They also noted gaps in support and support needs.

Sub-Theme: Being Able To Share And Be Accepted. Most participants discussed a positive type of support as being able to share their experiences with work colleagues and school peers and be accepted by them.

Accepting Peers. Some attributed this positive support to co-workers and fellow students acting welcoming and accepting. Erica mentioned how comforting it was to return to work following her first diagnosis and discover that her co-workers welcomed her back. She said,

That [*having co-workers*] *was good and reassuring, like you know, they still want*

me to come back and, "I'm going to go back. They still need me." So you know, it

was a boost that way.

Regaining Social Networks. Some also valued regaining the social aspect of their lives, by being surrounded by peers. Chloe and Greg each found that being back at school made them happy, as being around people always left them in high spirits.

Peer Survivor Support. Closely related to regaining social networks, it appeared that the greatest source of social support was having peer survivors' support; participants appreciated having someone to talk to who could relate to the young adult cancer experience and having to put an occupation on hold. Kate thought that talking to others who were slightly ahead of her in their cancer journeys was an excellent means of support; she met other survivors through young adult-specific support groups. Those who attended support groups noticed that most young adult cancer survivors have similar issues when resuming occupations. Chloe valued living in an area where she had the opportunity to attend a support group on a regular basis. She noted,

[*The young adult cancer support group helped me*] *to realize that there's a whole*

bunch of other people that are feeling the same thing . . . It feels good to be able

to be there for someone and actually say that you've experienced it the same as

they have.

Besides gaining helpful support, Chloe was sharing her strategies with other young adult cancer survivors.

Supportive College/University Professors. Closely related to supportive peers, some reported professors showing support by welcoming them back to school. Bret and

Kevin each appreciated the empathetic understanding their professors appeared to convey. Bret said,

The profs were excellent to deal with. They said, "If you're ever experiencing a problem, all you need to do is tell us beforehand." . . . and it wasn't sympathy, which I really appreciated.

Kevin appreciated a university advisor who had been through a similar life-altering experience and could relate to his situation; professors who displayed a genuine understanding were most appreciated.

Encouragement From Health Care Teams. In addition to peers and professors, some discussed positive helpful support they received from health care teams, including physicians and rehabilitation groups, when attempting to resume occupations. Rehabilitation groups typically consisted of psychologists, social workers, nurses, occupational therapists, physiotherapists, and oncologists. Health care teams seem to be most supportive through the encouragement they provided young adult cancer survivors. Sarah remembered the advice she received from her physician when she mentioned the possibility of returning to work,

My doctor encouraged me. She said, "It's probably better to go back to work, because otherwise you get stuck in the cancer phase of your life. Not that it's not part of your life always; they always remember it. But you need to have something, like, on the other side of it." But she was right.

Sarah found her physician's words heartening as well as truthful. While most reported, peers, professors, and health care teams as being helpful and accepting, they did not report employers conveying any empathy.

Uncertainty In Employers. Some participants believed their employers seemed

uncertain about how to react to them having cancer and perceived that employers may

have held the misconception that working contributes to cancer diagnoses and relapses.

James described a reaction from his new employer when he revealed that he was a cancer

survivor,

> *I'll give you something interesting that was said to me by my manager. And I said*
>
> [to *my manager*]*, "Oh, you know, I've got to take a day off because I*
>
> *have . . . I'm a cancer survivor; it might be a relapse kind of thing." And then he*
>
> *says to me, I kid you not, he says, "How did you get past the medical to work*
>
> *here?"*

James' experience was of being marginalized and misunderstood.

Other participants felt marginalized or stigmatized by their employers for having

cancer. Erica hoped to return to her occupation, after having withdrawn twice previously

for treatment. She sensed her employer now viewed her as a liability to the company and

was attempting to terminate her employment. She said,

> [My *employer was*] *citing performance issues and stuff that weren't really there,*
>
> *you know, at least from my point of view . . . Very obviously they were looking for*
>
> *reason to discontinue my employment with them . . . When I didn't die after*
>
> *having my bone marrow transplant and I thought to return the third time, I just*
>
> *got a thing in the mail saying, you know, I got my record of employment. And it*
>
> *just said I was no longer working with them.*

Sarah also talked about feeling stigmatized by her employer when attempting to re-enter the workforce. Those who returned to school did not report feeling marginalized or stigmatized by professors, but did report negative peer support.

Negative Peer Support. Even though many spoke positively about support from peers, almost all participants reflected on some unhelpful support from them as well. Most spoke about the cancer experience being awkward to share with others at their schools, while others reported similar difficulties sharing with colleagues at work. Peers were seen sometimes as reacting with shock, awkwardness, or in a "stand-offish" manner. Kevin, who resumed school by attending a new university and consequently having many new peers surrounding him, explained,

> *The weirdest part about going back* [to *school*] *. . . was telling people* [*fellow students*] *about it . . . It would be kind of awkward for them mostly, more so than me . . . I have no problem talking about it . . . it kind of makes other people uncomfortable sometimes.*

Others sometimes felt uncomfortable themselves when speaking about their experiences with cancer.

Support Needs. Accordingly, one of the greatest social support needs mentioned was an increased understanding and awareness from those who have not experienced young adult cancer. Bret explained how he initially found it difficult to discuss his experience with others at school, as young adult cancer is quite rare, and he thought no one would understand what he was going through. He said,

I never really talked to anybody else who was sick or who had gone through

something similar . . . it would have made things a lot easier and to have someone

to talk to who actually knew the experience.

Besides this increased understanding, many desired more young adult cancer support groups. Erica believed such groups could potentially result in improved means of "easing back into" occupations. She stated,

[*When resuming my occupation, I would have liked*] *More ability or option to fill*

my time within a group of younger people who had cancer, were cancer

survivors. Just so it would be a bigger availability of people within the same age

range or to have the same concerns and stuff.

Most felt that addressing these gaps in support could help young adults to feel better able to be accepted and feel comfortable sharing with others. The second type of support participants discussed was occupational security.

Sub-Theme: Occupational Security.

Having Occupations To Resume. Some reported appreciating having job security and occupations to return to following cancer treatment. Erica was appreciative of her occupation the first time she returned. However, after relapsing and attempting to return subsequent times, she perceived that the employer "pushed" for her termination and she did not experience support. Jess was also happy to have an occupation to return to, as she believed searching for a new occupation would likely heighten the stress she was already experiencing. She said,

Realizing I have this job to turn to and thank God I have this job to turn to

[*helped when resuming work*].

Bret was equally happy to know he had a university to return to, and if university was too stressful, he had the initial option to have his tuition returned.

Funding For School. One of the greatest needs participants found was the need for financial assistance, whether for education to ready themselves for school or work, funds to pay tuition and other school costs, or funds to make up for wages lost from being away from work or working only part-time. Some students did not have the time to work even part-time hours, some were not eligible for unemployment insurance or school bursaries due to living with parents, and some reported they were ordered by their physicians not to work. Chloe expanded on her dilemma,

> *I wasn't allowed to work last year, and my family doesn't exactly have money to pay for my school . . . . Definitely some sort of, like, bursaries, or some sort of, like, funding* [*is needed*].

Lisa also struggled with the costs associated with returning to university. Lisa and others did not want to rely on their parents' money or see their parents make sacrifices on their behalf. They also reported issues with obtaining student loans while being away from school and having their credit affected by loans.

No Need For Additional Support. Although each participant discussed support that could have helped him or her, some believed they had sufficient support to make a successful return to school or work. Lisa mentioned that she did not need any additional support, as she was living with her family throughout her cancer experience, who were readily available to assist her. Greg mentioned that although he did not need support, "it was certainly there if I needed it". Kevin also noted that he could not think of anything that could have been a helpful support that he did not have access to. He stated,

I don't feel like I need it [*support*] *a whole lot. But I think that anything, if I did*

need it, would have been available to me . . . there's nothing that I can think of

that I wish I'd had or wish that was available to me.

Although these participants did not think additional support was necessary for them when

resuming occupations, they noted that it may be helpful for others.

Theme Four: Renewed Sense Of Health And Wellness

For most participants, successfully returning to school or work signified that they

had recovered and defeated cancer; resuming an occupation represented a new experience

of the value of being well. When asked what it meant to her to have resumed her

occupation, Sarah, who had been back at work for over a year, summarized her thoughts

by saying,

It means to me that I'm healthy.

For most, a renewed sense of wellness and health signified having resumed a state of

"normalcy". For others, this renewed sense also involved a new and stronger sense of the

value of their own lives.

Sub-Theme: Resuming Normalcy. For most, being back to "normal", especially

at school and work, meant they were no longer constantly thinking about cancer and felt

like regular students and employees again. James discussed how resuming work meant

that he felt "normal" again,

I wanted to go back to work almost immediately . . . But I did it just for the

reasons to bring some normalcy back to my life . . . Going back to work to me was

normal. Staying at home wasn't . . . I went back to work early even if I didn't

need the money. Well, they'd [*some people*] *probably think I was a little bit crazy.*

It was just for more normalcy in my life . . . If there is such a thing after having

cancer.

Resuming normalcy by returning to an occupation involved being productive and moving

back into adulthood.

Being Productive. Some participants believed that feeling productive and

industrious again meant to them that they were "normal". Being in the hospital while

being absent from work or studies, a common occurrence, left participants feeling

especially unproductive. Others mentioned returning to the professions and positions

they had previously occupied helped them to feel productive. Erica, who was able to

easily return to her previous occupation following her first cancer treatment, noted the

comfort in returning to an occupation at which she felt she could be productive. Sarah

also noted that being able to be productive at work helped her regain a feeling of

"normalcy",

I felt really good about myself that I was able to have survived this and gone back

to work and I was able to function like everyone else.

Moving Back Into Adulthood. Several participants also felt they were beginning

to move back into adulthood, as "normal adults" have occupations and are productive

people. Sarah explained,

It [being back at work] meant that I was an adult again. I had regressed that

year. And that's the other reason I went back to work too. It's because I didn't

want to feel dependent. My parents did offer to continue supporting me. But I felt

that I was just too old to do it. I couldn't feel like a little kid anymore.

Although Sarah is a mother in her mid-30s, other participants also emphasized the desire

to no longer have to rely on their parents' care. Kate, who did not report having any

children and was in her early 30s, emphasized being proud of her sense of independence,

> *It's a tremendous source of pride to be independent, to be doing something that is*
>
> *meaningful to me, to be contributing to an organization, to causes that matter to*
>
> *me.*

Sub-Theme: New And Stronger Sense Of The Value Of Life. While resuming

"normalcy" and moving back into adulthood both represent a return to what life was like

before cancer, a stronger sense of the value of life represents new aspects of participants'

lives after the return to an occupation. These new aspects include participants realizing

they are able to achieve a balance between school or work and the other priorities in their

lives, as well as participants noticing they are achieving more at occupations.

Achieving Balance. Some participants reported having gained a better

perspective on life, especially school and working life. They realized that a balance

between school and life or work and life is crucial to feel well. To achieve this balance,

participants reported working more efficiently, spending less time at work, yet enough

time to still succeed in their endeavours, prioritizing their personal health and families

before work, and being content with doing well at work without feeling the need to

overachieve. Kate, who reflected on how she is better able to manage at her occupation

compared to before her diagnosis, said,

> *I think I have more respect for myself and more respect for my limits . . . Since*
>
> *I've been sick I've realized that I'm not going to be working more than 35 hours*
>
> *or 37 hours a week. In the past I have consistently worked more than that, and*

I'm just not going to do that any more because first of all, I can't, and second, I

don't want to.

Having an increased sense of confidence in work abilities and a decreased level of stress also contributed to having a good school or work and life balance. Erica, who realized that returning to work did not have to be the ultimate accomplishment following cancer, stated,

And you put so much into that [*occupation*] *as your identity that you, you know,*

forget or overlook other things that you might be interested in life . . . your

education, you get a job, you get a career, and little other pieces of your interests

just fall away from there . . . I'm trying to figure what those were . . . it definitely

changed a lot of stuff there and work isn't such a focus for me anymore.

Erica gained perspective by realizing that life does not have to be defined by what work one does. James also had a changed perspective after attempting to return to work. Like Erica, he realized there are worse things than not working. When reflecting on how cancer allowed him to gain this perspective, he said,

What's the worst thing that could happen to me at work? Maybe I get fired.

Well, at the end of the day, that's not a big thing, considering what I've been

through . . . once I reach a certain amount of money I will probably stop

working . . . Time is limited . . . I was planning my own funeral at 28, cause they

told me probably that things weren't going to happen. But, I mean, here I am.

I'm still going into work . . . Mentally have I changed? Probably a little bit.

Remembering the potentially fatal effects of cancer seemed to substantially change the way participants perceived what is important in life. Greg noted that getting through

cancer is an accomplishment in itself, but to beat cancer and actually come out in a better place, feeling better about himself, is something he will always have to remember and take pride in.

Achieving More. Finally, some reported doing better in school or obtaining better jobs upon returning to occupations and having a sense of value of their own lives. Bret, who looks back on his experience resuming school as a very positive one and takes pride in all he has achieved in life, remembered,

> *I got on the Dean's List for the last three semesters, which I hadn't done*
>
> *before . . . By then school was easier; it felt easier than before.*

Greg, who also looked back on his experience as a positive one, summed up the feeling of enjoying school more upon returning in September when he said,

> *It was sweeter than most Septembers.*

The majority of these participants felt their occupational lives were greatly improved due to their cancer experience, Kevin going as far as saying he was "glad the entire experience happened", as it allowed him to achieve more in school and in the occupation he obtained once completing school. Although some participants discussed their actual attempts of resuming occupations as difficult, stressful, and negative, even participants with difficult returns also noted many positive aspects of their experience as a whole and did appear to be achieving more at occupations.

Conclusion

By carrying out IPA, four master themes emerged from the data: making the decision, actively adapting to changed lives, receiving support, feeling healthy. Participants emphasized the internal and external "pushes" they felt when it came time to

make the decision to return, and the support they received during the course of making the decision and making the transition back into an occupation. Most talked about using various strategies to actively adapt to their changed occupational lives, and were eager to share the strategies they found helpful and unhelpful; it became evident that there are many barriers to overcome when adapting. They also highlighted that being able to be accepted and have occupational security were the greatest facilitators for resuming school or work. Once they returned, they felt healthy again, as they had defeated cancer, resumed normalcy, and had a new value for life. Ultimately, despite facing an array of challenges and expressing many needs, the experience of resuming an occupation following cancer treatment was interpreted as positive by all.

Chapter Five: Discussion

Overview

The main research question that guided this study was, "How do young adults experience resuming an occupation after treatment for cancer?" Subsidiary questions that assisted in guiding the study included, "What types of strategies and supports do they find helpful?", "How do they negotiate their return to occupations?", and "What does it mean to them to have resumed occupations?" Interviewing 10 young adult cancer survivors who had resumed school or work within the past five years provided insight into each of these questions.

These 10 young adults proved to be part of a unique population, as they discussed facing many challenges in returning to occupations in the context of the psychosocial and physical challenges of dealing with cancer and the challenges of making the transition to adulthood. Such age-specific challenges for participants included having to resume careers that they had only recently begun, having to complete university, having difficult financial circumstances due to student loan debts, not knowing many others in similar situations to theirs, having difficulty obtaining information and resources about young adult cancer, and experiencing feelings of digression from adulthood. Survivors felt "pushed" to make a decision to return to occupations. They described numerous strategies to adapt and it appeared that the most helpful support was feeling accepted by others at school or work, as this made them feel healthy and well again. In this chapter, how these findings build on and add to existing literature is discussed. Also, limitations and research challenges, accompanied by suggestions for future research, are noted.

Experiences Common To School And Work

One of the most important findings was that almost all participants felt "pushed" in one way or another to make a decision about returning to their occupations. This was an experience that has not been reported to date, although some researchers have identified elements of this experience (Amir et al., 2008; Main et al., 2005). One significant source of pressure was financial circumstances. Participants needed to return to work, as lost wages were causing them to feel stress. This was consistent with Amir et al.'s (2008) study, which found cancer survivors of all ages returned to work shortly after treatment because it was a financial necessity. Main et al. (2005), with their older sample, also noted their participants resumed work for financial reasons. This finding has not been specifically reported for a young adult population to date. Additionally, no researchers have reported that young adults feel "pushed" by their medical plan providers to resume occupations. Yet, this result is not entirely surprising in this population, as young adults are often in a constant state of transition between their parents' medical plans and their own (Soliman & Agresta, 2008). Medical plan providers may be "pushing" young adults to resume occupations more than they "push" older survivors because they may see young adults as generally healthier than older adults, and therefore more capable of working. Providers make a profit from those who pay into their plans, but who do not usually require any assistance; the majority of these clients are young adults (Pope, Fernandes, Bouthillette, & Etherington, 2000). Therefore, providers may want young adults to resume their occupations as quickly as possible following treatment, in order to continue making a profit from them. It would be useful for future research to determine if older cancer survivors feel any "push" from providers, to determine if

feeling this pressure is actually unique to young adults, as providers may emphasize the return to work equally for older and younger survivors, but young adults may simply experience it more strongly.

Reports of feeling pressure from families, physicians, and employers also add to what we know about feeling "pushed" when returning to an occupation. It can be speculated that young adults may feel this pressure more than older adults, as they may perceive themselves and others may perceive them as being a more active, healthy, and resilient population, who should be able to resume occupations readily. Again, it would be useful for future research to determine if these "pushes" are more commonly experienced by young adults.

Participants also discussed how they coped with these "pushes". This study has provided additional support for the value of reduced work hours and scheduling for this age group, and has additionally identified several other useful strategies found to be helpful by survivors and which have not been reported to date. Although several of the strategies outlined by participants have been reported in past studies of cancer survivors resuming work, such studies have not been specific to young adults, nor have they included a return to school (Amir et al., 2008; Main et al., 2005). For example, Main et al. (2005) reported that having reduced work hours assisted cancer survivors aged 21 to 66 years when returning to work. Additionally, Amir et al. (2008) noted that cancer survivors aged 18 to 55 years found creating schedules to provide structure in their lives assisted them in adapting when resuming work. Therefore, most of these strategies are likely not unique to the young adult population; they may also be useful for older adults, with the possible exception of sharing housework, as young adults may be more likely to

have parents to assist them compared to older adults. Future research on these strategies is essential in order to determine which may be young adult specific.

In addition to these strategies, several types of support were identified as useful by both those returning to school and those returning to work. The occupational security from knowing there was a school program or job to return to after treatment was useful. This is important to note, as it has not been mentioned in past studies of cancer survivors. Those resuming work tended to be more concerned with occupational security than those resuming school. This may have been because students can typically return to university as long as they can maintain grades and pay tuition, while employers are not required to hold positions for employees, nor may it be feasible for them to do so. While resuming school did involve significant financial concerns, such concerns may be stronger for those resuming work, as these individuals are usually older with greater financial responsibilities, such as children and mortgages (Cole et al., 2001). This study also confirms that financial assistance when away from school or work is one of the greatest support needs for young adult cancer survivors, as this need surfaced many times in participants' reports and in past studies and articles (Adams, 2003; Main et al., 2005).

Another important survivorship need seems to be the ability to effectively communicate with health care teams. Some participants reported feeling they were not receiving adequate answers and advice from their health care providers about when to resume occupations. Similarly, Amir et al. (2008) reported that very few of the cancer survivors they interviewed received helpful advice from their physicians about the appropriate time to return to work. Main et al. (2005) also reported participants receiving little encouragement from their physicians when returning to work. Receiving

encouragement from health care teams is also a form of useful support, as it may allow young adults to feel empowered to take control of their own health (Smith & Bashmore, 2006). Therefore, it seems receiving encouragement through adequate communication with health care teams is not a survivorship issues unique to young adults. However, older adults may require less direction and assistance with decision making processes from health care teams, than younger adults who may be inexperienced in making important life decisions. Furthermore, young adults may simply expect more from health care providers or services.

Another useful type of support for returning to school and work was being able to share and be accepted. Welcoming co-workers acting as a significant source of support is consistent with many past studies of cancer survivors of all ages resuming work (Amir et al., 2008; Main et al., 2005; Spelten et al., 2002). Having welcoming peers at school was also a great source of support, yet this result has not been reported in any past studies (specific to young adult cancer survivors or others). This may be because returning to school is less of an issue outside the young adult age group. Perhaps future studies should determine if this support need is actually specific to a young adult demographic or even how such support could be facilitated.

It is also interesting to note that the majority of participants who reported not needing support when resuming occupations were males. This was the only instance of an obvious gender difference within the results. Past studies have commonly found that males, in comparison with females, perceive themselves as needing less support, especially social support (Rueger, Malecki, & Demanary, 2008). Rueger et al. (2008)

note that this is especially evident in adolescent and young adult populations, and this study adds further support to that.

Another finding common to both those returning to school and work was that returning meant that participants had recovered, and were feeling healthy and "normal" again. The desire to reclaim normalcy has been found in many studies of young adult cancer survivors (Christ et al., 1995; Glasson, 1995; Grinyer, 2007; Manuel, 2010; Miedema et al., 2006). Most participants discussed feeling healthy, as their work styles were now better than they had been before diagnoses. Several aspects of sense of healthier work style parallel Christ et al.'s (1995) study of the occupational achievement of young adult cancer survivors, while other aspects have not been reported to date. Christ et al. found that some of their participants were achieving more in school because they now took their studies more seriously. On the other hand, they reported that participants realized that there was more to life than just school or work. Smith and Bashmore (2006) conducted a quantitative study of 60 young adult cancer survivors aged 16 to 33 years, and reported that adolescent and young adult cancer survivors were as optimistic about their current health as a control group who had not had cancer, and they had a positive outlook for the future. As in Smith and Bashmore's study, most participants in this study were also optimistic about their health and had positive outlooks for their futures. These consistencies in results demonstrate the need to highlight the positive aspects of the resumption of occupations after treatment; such knowledge may provide hope and encouragement for young adults.

This study also found additional positive outcomes that derived specifically from returning to an occupation after cancer, such as achieving balance at occupations. These

findings have not been reported to date, and should also be highlighted to encourage hope. Another new finding that may encourage young adults with cancer to resume occupations was having a renewed sense of health upon returning. Although past studies have noted survivors feeling better when resuming occupations following treatment, they have not emphasized valuing the feeling of health as a new experience. The feeling of moving back into adulthood after returning was also a novel finding; resuming an "adult status" by resuming school or work was extremely meaningful to participants. Therefore, although this study does not permit a determination of whether others would consider the survivors to be doing better, evidence from this study suggests that young adults are often positive about their futures and their health, despite barriers to returning to occupations.

Barriers to returning were reported by almost all participants, particularly those resuming work. Some of the earliest research about cancer survivors resuming paid work reported barriers to returning and adapting, as having cancer can lead to diminished work capacity (Cella & Tross, 1986). Spelton et al. (2002) noted that having to perform manual labour is negatively associated with a return to work, due to decreased physical capacities; some types of work may be easier or harder to return to than others. Having decreased mental functioning when resuming work has also commonly been reported in past research (Amir et al., 2008; Jones, 2008). Although Amir et al.'s (2008) study of resuming work following cancer treatment did not focus on the young adult population, their study did discover that one-third of the participants interviewed experienced decreased mental functioning upon returning to paid work. Increased stress was also a common negative aspect of returning to work. As Jones (2008) mentions, young adult cancer survivors have an increasingly difficult time dealing with stress and anxiety upon

90

resuming work compared to young adults absent of a chronic illness who may be beginning new occupations. Furthermore, several studies have reported young adult cancer survivors feeling worried and uncertain when returning to occupations (De Boer et al., 2006; Elad et al., 2003; Felder-Puig et al., 1998; Lansky et al., 1986; Novakovic et al., 1997). This thesis adds support to the growing awareness of decreased work capacities as a survivorship issue of importance for all employable cancer survivors.

In summary, young adults feel pressured to return to both school and work and face many barriers, but do use active strategies to adapt, and experience positive outcomes. These experiences are similar to those found in other cancer survivors, but pressure to return seems to be experienced more by young adults. While these experiences were common to both those returning to school and those returning to work, other experiences were more specific to those returning to school.

Returning To School

One experience specific to those returning to school was receiving support from a superior, as several participants discussed very supportive professors when resuming college or university, while they tended to portray their employers as not supportive. Therefore, this study expands on the current understanding of support, as it demonstrates that support from university professors may be essential to young adult cancer survivors when they resume school. This may be due to professors having a greater familiarity with young adults, as most university students are in their 20s (Office of Institutional Research and Assessment, 2010), while employers usually work with individuals of various ages. University professors may be more "in touch" with the challenges of young adulthood and, therefore, convey a greater empathetic understanding, while employers

91

may be mainly concerned about their employees from a business point of view (Hasselkus, 2002). Also, providing psychosocial support seems to be more a part of the job description of a professor, than it is of an employer.

As noted, peer support was useful to most survivors, but those returning to school tended to report awkwardness in sharing experiences with peers. This may be due to participants having been younger overall when resuming school (at an average age of 23 years) than when resuming work (at an average age of 30 years). Younger participants may have lacked the self-confidence and conversational skills to deal with the awkward subject that older participants may have acquired over the years (Cole et al., 2001). Furthermore, the nature of a work setting may persuade young adults to provide more explanation to colleagues about the cancer experience than a school setting, where students do not necessarily have to spend a lot of time in each other's company.

Finally, it is interesting to note that those resuming school appeared more eager and confident about returning than those resuming work. This is likely because most participants had resumed work more recently than school and, therefore, those who had resumed school appeared to be looking back on their experiences more fondly, as they occurred longer ago. Additionally, for some, school may be more enjoyable and be accompanied by less responsibility than work, even for those without cancer or a chronic condition, as students can often work at their own pace or request permission for extended deadlines. School may also be easier to withdraw from if necessary, as it is not a means of earning a living, unlike employment.

Overall, it seems that young adults experience some positive as well as unhelpful types of support when returning to school. Despite any unhelpful support, young adults

are eager to resume studies and enjoy returning. While these experiences were specific to those resuming school, other experiences discussed by participants appeared more specific to retuning to work.

Returning To Work

One significant difference in the experience of resuming work compared to school, was the unhelpful support from employers, as some felt marginalized by them. In their study of young adult survivors of childhood cancer, Langeveld et al. (2003) found that many of those who were working reported experiencing "job discrimination", while hiring processes also seemed unfair. Employers may not expect their younger employees to get cancer, and likely know less about it. Employers may have known their older employees for a longer period of time and, therefore, be more concerned about them on a personal level than their younger, newer employees (Hasselkus, 2002). However, in Main et al.'s (2005) qualitative study of cancer survivors aged 21 to 66 years resuming work, most participants reported having supportive employers who assisted them in returning to work after treatment. The difference with these studies may be that this study focused more specifically on young adult's perceptions of their relationships with employers, rather than employers' perceptions, thus underscoring the need to understand this transition more deeply from the participants' perspectives and experiences.

Those returning to work also experienced decreased mental capacities differently than those resuming school, as students did not find decreased mental capacities as problematic as workers. This may be due to the presumption that students can often work at their own pace at university, with more flexible schedules. Those who resumed work also experienced stress and anxiety more than those resuming school, possibly due to

resuming work being experienced as more urgent than resuming school, as participants

needed to earn a living again. Therefore, those resuming work often felt more

marginalized, in addition to feeling decreased mental functioning and anxiety more than

those resuming school.

Implications For Health Promotion

Determinants Of Health. Findings from this study have many implications for

health promotion. The World Health Organization (2010) notes that health promotion

moves beyond a focus on individual behaviour and concentrates on the health of a

population as a whole. Health promoters aim at ensuring equal opportunities and

resources for all and reducing inequities. Therefore, the field of health promotion focuses

on enabling people to increase control over the determinants of their health in order to

improve their health (World Health Organization, 1998). These determinants are the

"conditions in which people are born, grow, live, work, and age" (World Health

Organization, 2008). As outlined by Health Canada (1999), the 12 determinants of health

include income and social status, employment, education, social environments, physical

environments, healthy child development, personal health practices and coping skills,

health services, social support networks, biology and genetic endowment, gender, and

culture.

Although each of the determinants of health may be related to the inequities and

issues faced by this study's participants in some manner, four determinants seem to be

most responsible for the issues identified by the participants and are also the most

amenable to improvement using key health promotion strategies. These determinants

include employment, education, coping skills, and social support networks.

94

Employment And Education. Employment and education are two of the most important social determinants of health in general and they comprise the two occupations studied in this thesis. These determinants are important because they contribute to income and social status, as well as being important determinants in their own right. Moreover, they are the activities in which young adults engage in on a daily basis, and play a large role in shaping their identities. Therefore, it is crucial that young adults are supported in each of these occupations. In order to ensure equal opportunities for all, it is important to ensure this population is able to make a successful transition by providing comprehensive resources and sufficient information to make the decision to return and successfully adapt to it.

One form of presenting this information, as suggested by participants, could be employment or school retraining. Participants discussed many barriers keeping them from actively adapting at occupations, and so perhaps employers and school administrators could be encouraged to offer simple refresher courses for employees and students following cancer treatment, or other serious illness. Employees may require very basic job retraining; students may benefit from very basic refreshers about computers or writing skills. If formal training does not seem feasible due to high costs, employers or administrators could simply organize similar informal training from fellow co-workers or classmates willing to assist. Employers could further encourage coworkers to share work. Considering the low probability of young adult cancer (Public Health Agency of Canada, 2006), it may be easier for such retraining to be offered through rehabilitation services, although such training would likely not be as practical as actual "on-the-job" training.

The stakeholders involved in young adult cancer survivors' return to occupations (described by participants as employers, company management, co-workers, professors, school administrators, and student peers) also need to be aware of survivors' needs in order to enable them to make healthy transitions. "Enabling" involves allowing all people to achieve their fullest health potential and is a fundamental health promotion strategy (World Health Organization, Health and Welfare Canada, & Canadian Public Health Association, 1986). Since flexibility in scheduling was appreciated by participants, school advisors could help returning students to maximize their use of flexibility in the system, as universities and colleges are generally fairly flexible and permit students to choose from different course options and course loads. While post-secondary institutions are experienced as welcoming environments, such institutions may still benefit from a summary of the findings of this study as a way to help peers and professors tailor support to cancer survivors.

Promoting a general awareness of young adult cancer and the issues around returning to school for those with chronic illness also may result in greater understanding from peers and professors. It may also result in more understanding from the general public, especially when coming into contact with young adults who are dealing with cancer. Participants described their cancer experience as awkward to discuss and therefore promoting awareness of the issues they face could lessen the awkwardness of situations. It should make employers and co-workers more comfortable with employees who are cancer survivors and who are readjusting to their post-treatment occupational lives. It seems most crucial to promote this awareness among universities and young

adult populations, as student participants reported feeling most awkward sharing with their peers, and greatly desired an increased understanding.

Coping Skills. Another social determinant of health that may have contributed to the challenges experienced by participants is coping skills, as some participants believed that they received little information regarding these. They believed they were not receiving the answers they needed to questions about best health practices from physicians and health care teams. A way to combat this may be a better understanding from health care teams of the issues young adults with cancer are facing. If health care teams have a better understanding of the informational needs of survivors, they might be better able to support them. This could potentially be accomplished with more training, workshops, and seminars for health care providers.

Social Support Networks. Participants found social support to be important and this is also an important determinant of health. They noted having different degrees of access to support as well as various support needs and different degrees of success in meeting those needs. Support networks could include groups that meet in person, groups that meet online, families, peers, and co-workers. As an important new finding of this study was that peer support at school greatly facilitated returning, it seems encouraging peer support networks is an important health promotion strategy. Such networks could potentially be developed at universities and colleges by holding cancer awareness days and establishing young adult cancer awareness groups and societies.

Similarly, as there are a limited number of young adult specific cancer support groups throughout Canada, there is a need to establish an increased number of these groups. Individuals in rural areas especially need access to such support. However, this

may present a challenge as there are relatively few young survivors in Canada and they are spread out across a large geopolitical area (Public Health Agency of Canada, 2006). If creating a group that can meet in person is not possible, more online support groups and discussion boards are necessary, and in fact are starting to appear (Schiffman, Csongradi, & Suzuki, 2008; Young Adult Cancer Canada, 2009). Furthermore, judging by the present study, some participants prefer to discuss experiences through written communication rather than discussing them verbally and may be more comfortable remaining anonymous and getting support from an online group rather than in person, at least initially.

Since young adults feel "pushed" when making the decision to return to an occupation, perhaps support groups and networks could decrease feeling this pressure by providing credible resources and information about making the decision. Besides providing resources, information, and comfort, such networks could also contribute to promoting an awareness of young adult cancer, and the issues faced by survivors when attempting to resume occupations.

Health care teams working directly with young adults need to provide cancer patients and survivors with encouragement, as this was described by participants as a very useful type of support when resuming an occupation. Physicians should be knowledgeable about returning to school or work, or be able to refer young adults to an individual who is knowledgeable on the subject, such as a rehabilitation specialist. To help facilitate the return to normalcy, past research has suggested that physicians should fully understand what it is like to achieve adult status while dealing with a chronic condition (Grinyer, 2007) and should be at ease communicating with young adult cancer

survivors, as young adult patients often depend on oncologists and health care teams to assist with solving their problems (Drew, 2007). In this study, participants also wished for greater understanding from physicians about the psychosocial and physical issues they faced. Additionally, as participants' occupational challenges seemed to be related to their support from others, it seems health care teams should have a complete understanding of peer support and the social aspects of young adulthood and "growing up", as suggested by Sawyer, Drew, Yeo, et al. (2007). Above all, it seems physicians should communicate optimism and support to their patients, in order for patients to have confidence in their physicians' abilities.

Strategies For Health Promotion.

Coordinated Action Of Providers. Coordinated action among health care teams, government sectors, and community-based organizations may also be a useful means of supporting young adult cancer survivors, since health is most effectively promoted when the health seeker works with other health seekers (World Health Organization et al., 1986). Coordinated action involves collaborating and mediating among different interests in society to pursue best health care practices. Mediation is a fundamental health promotion strategy, as stated in the Ottawa Charter for Health Promotion (World Health Organization et al., 1986). Coordinated action may also be the best way to ensure compiling of and effective distribution of appropriate information concerning best health care practices for young adults with cancer, to help manage the stress of returning to an occupation.

Creation Of Resources. Creating resources is an important form of knowledge translation. Knowledge translation efforts need to be undertaken by health care teams

working with young adults with cancer. Knowledge translation is defined by the

Canadian Institute of Health Research (2009) as the process of practically disseminating,

exchanging, and applying information to promote health by providing more effective

health care services. Employers, school administrators, and professors appear to be

primary influences in young adult cancer survivors' lives when they are attempting to

resume occupations. Therefore, these stakeholders have the potential to ease and

simplify the transition of resuming school or work after cancer treatment and could

potentially be more helpful with some guidance. Such messages could be conveyed to

stakeholders through simple resource guides, created by health care teams or health

promoters.

Guides could also highlight examples and stories of young adult cancer survivors

who have become better employees and students by learning excellent work strategies,

gaining greater appreciation for their occupations, working more efficiently, becoming

more assertive, and experiencing less stress at occupations. By outlining the ways young

adult cancer survivors feel better able to manage themselves and achieve personal growth

at occupations, professors and employers may realize how valuable such students and

employees can be. This may further convince employers to secure young adult cancer

survivors' jobs.

Guides could be distributed by human resource personnel at the workplace and by

the students with cancer themselves (by email) at colleges and universities. Such guides

could be provided to cancer survivors to distribute appropriately as part of their

rehabilitation services. However, given the low probability of young adult cancer (Public

Health Agency of Canada, 2006), guides may have to be designed to address the common needs and concerns of young adults with any serious illnesses resuming school or work.

Just as health care teams could create resource guides for employers and school administrators, they could also translate knowledge by creating similar resource guides for families of young adult cancer survivors. Such guides may to help families understand what their loved ones are going through. According to participants in this study, such guides should explain how to be supportive without causing young adults to feel "pushed" to either resume or avoid occupations.

Creation Of A Comprehensive Website. Health care teams could also concentrate their efforts on creating a comprehensive resource for young adult cancer survivors who are resuming or contemplating resuming occupations. As suggested by Elad et al. (2003), interventions and initiatives suited specifically for their age group seem to be most effective when promoting the health of young adult cancer survivors. A website seems to be the most age-appropriate type of resource, as it can be easier to access and navigate through for most young adults (Schiffman et al., 2008). Schiffman et al. (2008) conducted a study of young adult cancer survivors' internet use and found that young adults are unsure of where to find appropriate and credible information, but do look primarily to the internet for the information they desire. A manager of a comprehensive website could network with medical plan providers, employers, universities, and other programs and resources that are suitable for and empathetic toward young adult cancer survivors. Resource guides could also be available to download from such a website. It could also include chat rooms and discussion boards, to discuss issues specific to resuming occupations, including ways to deal with decreased physical

capacities at school or work. It might be particularly useful to invite employers and

university professors to describe their suggestions, as this might be more difficult for

survivors to obtain than the opinion or experiences of others like them. As support

groups are scarce throughout Canada, it seems a comprehensive, easy-to-navigate website

or section of an existing website, specific to young adult cancer survivors resuming

occupations, could fill in many gaps in survivors' needs. While there are websites

designed specifically for Canadian young adult cancer survivors, such as Young Adult

Cancer Canada (youngadultcancer.ca, 2009), there do not appear to be any websites

specific to resuming school or work, although it is likely there are subdivisions of

existing websites specific to this.

Prevention. Health promotion strategies also emphasize prevention of the

development of health issues, as opposed to treating them once they have developed

(World Health Organization, 2010). This strategy reduces future health care costs and

results in healthier populations overall. If health promoters could encourage methods to

reduce the effects of many of the health problems that are a consequence of cancer, and

which accompany the return to school or work after treatment (such as decreases in

mental and physical capacities), perhaps young adult cancer survivors would not be faced

with as many barriers when resuming occupations. For example, health care teams could

provide informational guides or other resources that outline potential methods to reduce

fatigue, emotional stress, or mental exhaustion. Potential methods could include healing

retreats (as suggested by participants) and strategies to maintain healthy diets, physical

fitness, and mental faculties.

Advocacy For Improved Policies. Advocacy is the third fundamental health promotion strategy outlined by the Ottawa Charter for Heath Promotion (World Health Organization et al., 1986) and is essential so that the general public can gain a greater understanding of young adult cancer and a greater responsiveness to the issues faced by them. Advocacy would likely also result in young adult cancer survivors experiencing fewer "pushes". Improved polices may include developing funding and job security policies.

Policies concerning funding for young adult cancer survivors away from school or work seem necessary, as most participants reported having financial difficulties while taking time away from occupations. As young adults striving to gain independence prefer not to reply on their parents for money, improved employment insurance policies could be helpful. As well, students reported finding it difficult to pay tuition when returning to college and university, mostly due to not being able to work during summers. Additional school bursaries could be created specifically for young adult survivors of cancer and other illnesses which require them to take time away from their studies. Fortunately, awareness and availability of such resources are increasing, as Young Adult Cancer Canada has identified several bursaries, scholarships, and university programs available to young adult cancer survivors returning to post-secondary education (Chalifour, 2009).

An important new finding of this study is that young adult cancer survivors greatly value occupations they know they can return to after undergoing treatment, as having this security typically decreases the stress of finding new employment. Therefore, job security policies at the workplace could be quite useful in facilitating the transition

103

back to work. If possible, employers could sit down with young adults with cancer prior to them leaving their jobs to undergo treatment to discuss the status of their positions. This would allow young adults and their employers to have a mutual understanding about the status of their occupations. Actually securing jobs may not be feasible from a business perspective for most occupations, as certain jobs may have to be filled by permanent employees while the young adult is being treated for cancer. Many other difficulties may also arise, such as employers being more reluctant to hold a job for a younger employer than an older employee. Older survivors may have held the same position for many years, may have established excellent track records within a company, and may have accumulated more benefits than younger, newer employees. Furthermore, employers may be more uncertain of younger employers staying committed to a position, as young adults have more of a tendency to go from job to job than older adults. Past studies have determined that there is a great deal of job instability in young adults, due to changing values and "student to worker" transitions (Johnson, 2001). However, employers could attempt to offer the next available job opportunity within the company or business to the young adult when he or she is ready to return. Another option for young adults could be to continue working, at least part-time, throughout the course of their treatment. The psychosocial and physical implications of doing so should be explored in depth in future studies.

Finally, improved medical insurance policies seem necessary. At least one participant noted not having a choice of whether to return to school or not, as he required medication and could only gain coverage for it from an insurance provider under the condition that he was a full-time student. As the results of this study have demonstrated,

one of the best methods of actively adapting to resuming school is to do so gradually, as a part-time student, taking on a lighter course load. Not being able to have this option if they wish to have medical plan coverage puts cancer survivors in less than optimal situations, often being forced to make difficult decisions. Therefore, improved medical plan policies for young adults with chronic illness could be quite helpful in allowing them to attend school part-time, while still having the financial security of medical coverage.

While a number of these strategies address the issues identified by participants in this study, implementation of such strategies must be tempered by acknowledging the limitations in this research.

Limitations And Research Challenges

There are a few limitations in interpreting the data. First, as the scope of the study was to gain a greater understanding of the experience of resuming an occupation, only young adult cancer survivors who had resumed an occupation in the past five years were recruited. Although some participants had left occupations after returning to them, the experience of those who have been less successful in resuming occupations was not fully explored and, therefore, needs to be undertaken in future studies. Future studies could also recruit survivors who have completed treatment within similar timeframes, but who have not yet reintegrated themselves into occupations, to compare and contrast participants in terms of occupational progress.

Secondly, limiting the definition of "occupation" to describe school and work was a study limitation. "Occupation" can be defined much more broadly than it was in this study; it often includes leisure and recreational activities (Hasselkus, 2002; Kielhofner, 2002). Future researchers could use expanded definitions of occupation, or have

participants define what an occupation means to them, to get a broader idea of the challenges that young adult cancer survivors often face when attempting to resume "normalcy".

Another caution is that this was a first attempt at performing IPA, as well as qualitatively analyzing data. This may have limited the interpretation, as although Smith's (1996) analytic approach was followed, not having practice performing such an analysis may have resulted in some incorrect interpretations. However, Dr. Robinson checked that all codes and themes were grounded in the data and made sense. Nonetheless, having a larger team with more experience in IPA assisting in analyzing the data could have altered the study's results. Although IPA seemed to fit the goals of this study, it is a somewhat recent form of qualitative research and analysis and a limited number of studies have applied it (Smith, 2009). Therefore, information regarding the credibility of this approach is still somewhat inconclusive. Future studies employing IPA are necessary to better understand the credibility of this analytical technique.

Finally, conducting telephone interviews limited the interpretation, as I could not read body language cues. Nonetheless, I gained a sense of participants' emotions by listening to their tones of voice, as well as writing in a reflexive journal the emotions they seemed to be conveying. This helped me to have a more in-depth approach to the transcripts.

As telephone interviews made it impossible to "read" body language and note facial expressions, face-to-face interviews or focus groups may be a more suitable means of data collection for future studies. Then again, this would be costly, as well as limit recruitment to a smaller area and, therefore, possibly limit the number of participants. A

face-to-face interview may allow a researcher to "get to know" participants on a more personal level and interpret their experiences more accurately than telephone interviews would. Focus groups could allow participants to bounce thoughts and ideas off each other, stimulating conversation, as well as help them feel comforted by the presence of others who have had experiences similar to their own. However, focus groups are generally not considered appropriate for phenomenological studies (Smith & Osborn, 2004), and it would likely be challenging to recruit enough participants from one region to conduct one. New technologies, such as Skype (Skype.com, 2010) may help overcome these challenges.

On the other hand, simply emailing participants questions or creating an online survey with open-ended questions may also be an effective means of gathering data. Many of the participants interviewed for the present study emailed me days or weeks after their interviews to reflect on experiences they forgot to speak about, or did not feel comfortable speaking about over the telephone. Email communication would provide a sense of privacy, while allowing the participants to think through their answers and take their time to complete interview questions without feeling pressured or forgetting any important information. It would appear ideal to combine emailing questions to participants with telephone or Skype (Skype.com, 2010) communication. Using more than one means of gathering data is commonly done as part of phenomenological studies in general, as is conducting a second interview (van Manen, 1990). This would allow the interviewer to analyze the first interview transcript and develop questions with which to further probe on points of interest or topics that could be discussed at greater length.

However, neither of these techniques is particularly advocated by proponents of Smith's IPA (Smith & Osborn, 2004).

In addition to the outlined limitations in interpreting the data, this research project posed some research challenges, mainly with recruiting a young adult population. As young adult cancer is relatively rare (Public Health Agency of Canada, 2006), recruiting 10 participants required a considerable effort searching for appropriate places to post advertisements and determining the most suitable individuals to use for snowballing. The original inclusion criteria were altered to include those who had resumed an occupation within the last five years, rather than within one year. Therefore, many of those who had been initially rejected for participation were recruited. Had this criterion not been altered, recruitment may have been an even greater challenge, as fewer than half of the participants fit the original criteria. While altering this criterion resulted in recruitment being a lesser challenge, perhaps recruitment would have been even more effective and efficient if these criteria had been clearly stated on the recruitment poster initially. It is likely that individuals who read the initial recruitment poster and deemed themselves not eligible to participate did not re-check the advertisement to note if criteria had been altered at any point. It is difficult to know a priori how to establish criteria when studying a process with no clear end point. The process of adapting to going back to an occupation appeared longer than originally anticipated by the researcher. Being able to alter the process of data collection while it is ongoing is one of the advantages of qualitative research (Smith et al., 2009). Future researchers may want to consider allowing survivors to self-select into studies based on whether survivors believe their adaptation to occupations is complete.

To improve recruitment procedures for future studies, researchers could define the population broadly enough to be inclusive of all who might be able to contribute to the study, with as few exclusion criteria as possible, depending on the focus and scope of the study. Future research on any specific demographic group should include participants from the largest geopolitical region possible. However, this may lead to geopolitical differences among participants, which would need to be explored. While this study focused on a Canadian population from various geopolitical regions, all participants resided in or very nearby urban areas during their treatment and return to occupations. Future studies on this topic may have different results, depending on the geopolitical region under investigation, as different provinces, states, and countries have different levels of support for education and employment for young adults (Ewing, 2003).

 It may also be worthwhile to pay for advertisements, as well as submit applications to hospital research ethics boards in order to be able to recruit in hospital cancer clinics, although this can be cumbersome and costly. Recruiting by poster advertisements in hospitals would be more efficient and effective if hospitals Canada-wide could develop a common ethics application process.

Another research challenge involved defining the study's population. While the age range chosen seemed logical for this study, extending the range to include those up to 39 years of age may have allowed others in this unique young adult population to participate. Several recent reports in Canada and the United States have extended their age limits, to include those over 35 years of age. For example, the Public Health Agency of Canada (2006) estimated that more than 10,000 Canadians aged 20-44 receive a cancer diagnosis each year and that there are over 150,000 survivors of cancer diagnosed in that age range. Another report from the United States recommended developing and

evaluating supports to meet the psychosocial survivorship needs of those diagnosed with cancer between ages of 15 and 39 years (National Cancer Institute, 2006). Additionally, many participants in this study who were 35 years old mentioned having peers going through similar experiences who were only a few years older. Also, while many participants had resumed school up to five years prior to the study, most participants who had resumed work had only done so in the past year. Including older participants who had resumed their jobs a few years prior to the study may have added to the depth of the study, as such individuals may have looked back on their experiences with a different perspective. As well, this may have increased the speed and ease of recruitment, as many participants were 35 years old and had peers going through similar experiences who may have been only a few years older.

Future Studies. Similarly, future studies could draw comparisons among those who have resumed occupations recently, those who have resumed a few years ago, and those who have resumed many years ago. Alternatively, longitudinal studies following the same group of cancer survivors over the years by interviewing them at certain intervals may also be effective in determining the optimal time to successfully resume an occupation and cast further light on successful strategies. Jörngården, Mattsson, and von Essen (2007) conducted research that supports the usefulness of this method of collecting data. They collected information concerning adolescent and young adult cancer survivors' health-related quality of life at six month intervals for a year and a half and noticed a steady increase in psychological well-being from the time of diagnosis onwards. Pearce (2009) notes that longitudinal studies are necessary to understand young adult cancer along an illness trajectory. Understanding experiences of young adult cancer

survivors over time may also assist in determining the best timing for health promotion interventions.

Future studies could also either focus on those who have resumed school, those who have resumed work, or those who have resumed other occupations. In a larger, more in-depth study, greater differences between the groups might be noted than in this study and each experience might be more thoroughly understood, with only five participants in each group.

Finally, it may be interesting for future researchers to interview the stakeholders who play significant roles in young adult cancer survivors' experiences with resuming occupations. For example, employers, company leaders, professors, school administrators, or health care workers such as occupational therapists could be interviewed. They could be questioned about their knowledge and understanding of the challenges associated with young adult cancer when returning to school or work, as well as their particular concerns about having a survivor return. Such interviews also may assist in promoting awareness, informing, and educating stakeholders. Medical plan provider company representatives and any others with an involvement in the transition back to an occupation could also be interviewed. This could provide insight into how to encourage stakeholders to support young adult cancer survivors who are resuming occupations. It may also be helpful to collect information about how well employers find young adults with similar health histories adapt to work, as it may be difficult to justify research with employers since young adult cancer is rare.

Dissemination

The findings and implications of the present study have been disseminated in

many forms and will continue to be distributed. This study was presented at Dalhousie University's annual Meeting at the Crossroads: Student Research in Health. It was also presented at a graduate seminar organized by Dalhousie University's School of Health and Human Performance, and as a poster on the 12th World Congress of Psycho-Oncology.

This study will be submitted for publication to a journal relevant to psychosocial oncology. The complete thesis will be bound and submitted to Dalhousie University's library, with print and online access for students and faculty. A summmary of the results will also be distributed to interested stakeholders, such as Young Adult Cancer Canada and young adult cancer advocate Shari Tucker.

Conclusion

The purpose of this thesis project was to gain a richer, thicker, and more in-depth understanding of the experiences of young adult cancer survivors resuming occupations of school or work following cancer treatment. Conducting a literature review of studies and papers relevant to young adult cancer made it evident that research pertaining to young adult cancer survivors and the psychosocial issues they face is a relatively recent area of study, with opportunities for much further exploration. Reviewing this literature also made it clear that qualitative research concerning young adults with cancer is limited, especially research on the return to an occupation following treatment.

The young adult cancer survivors who participated in this study have each demonstrated great strength and resilience in attempting to resume school or work after their cancer treatment, while simultaneously dealing with the psychosocial and physical concerns that accompany cancer and its treatment, and the inherent challenges of being a

young adult. Young adult cancer survivors had to weigh "pushes" to make a decision to resume their occupations, had to actively adapt to their previous school and work duties and responsibilities, and discover the types of support that could be helpful and the types of support that could hinder their progress in resuming occupations. Despite these challenges, returning to occupations left participants contented and happy to have resumed a more normal life and state of health.

It is the researchers' hope that the participants' encouraging words will contribute to easing the transition of returning to an occupation for future young adult survivors of cancer. Information from this research should contribute to facilitating them on their journey as they resume occupations, by helping to make the transition as smooth and effortless as possible. Although cancer in young adults is still relatively rare, health professionals and the general population need to be aware of the issues these survivors are facing and work to improve their quality of life. While the number of survivors of young adult cancer is gradually climbing (Jones, 2008), researchers are only beginning to understand the needs of this population. Therefore, as they come of age and the needs and issues they face change over time, health promotion research with young adult cancer survivors resuming occupations should continue to progress to enable them and their communities to meet the survivors' needs so they can have productive and healthy lives.

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PARTICIPANTS NEEDED FOR RESEARCH IN YOUNG ADULT CANCER

Health Promotion
School of Health and Human Performance
Dalhousie University

We are looking for volunteers to take part in a study of young adult cancer survivors' experiences resuming school or work after treatment

To participate in this study you must:

· **Be between 18 and 35 years of age,**
have had first diagnosis of cancer between 18 and 35, and have completed first treatment between 18 and 35
· **Have stopped attending school and/or work while undergoing this treatment**
· **Have returned to school and/or work *in the last 5 years* (after having completed this treatment)**
·**Be a resident of Canada**

Your participation would involve taking part a telephone interview that will be audio-recorded that will last about one hour (total participation time should not exceed 2 hours). This research is part of Elizabeth Sharpe's Masters program.

For more information about this study, or to volunteer to participate in this study, please contact:
Elizabeth Sharpe (MA candidate)
902-363-2258 (collect calls are acceptable)
youngadultcancer@gmail.com

This study has been reviewed by the Research Ethics Board of Dalhousie University

Consent Form

DALHOUSIE
UNIVERSITY
Inspiring Minds

Consent Form
The Experiences of Young Adult Cancer Survivors Resuming an Occupation

Primary Investigators

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Introduction

I invite you to take part in a research study being done by myself, Elizabeth Sharpe, who is a graduate student at Dalhousie University, as part of my Master's in Health Promotion. Your participation in this study is voluntary and you may withdraw from the study at any time. The quality of your health care will not be affected by whether or not you participate. The study is described below. This description tells you about the risks, inconvenience, or discomfort that you might experience. Participation in this study might not benefit you, but I might learn things that will benefit others. You should discuss any questions you have about this study with me, Elizabeth Sharpe.

Purpose of the Study

When young adult cancer survivors have finished treatment, they usually try to pick up their lives from the place they left off before being diagnosed. This often includes resuming school or work. The purpose of this study is to gain a better understanding of how young adults who have undergone treatment for cancer think about going back to school and/or work. I would like to know how you decided to start back to school and/or work, the good and bad things about being back at school and/or work, and what it really means to you to have resumed school and/or work. I would like to make a summary of this new information from you and others available to cancer patients and health professionals, to help others going through a similar experience.

Study Design

The study will use interviews to gather information from you and about eight others like you. I hope to understand the experience of going back to school and/or work from your point of view.

Who can Participate in the Study

You may take part in this study if you:

- are between 18 and 35 years of age
- were first diagnosed with cancer between 18 and 35 years of age
- completed your primary treatment between 18 and 35 years of age
- stopped going to school and/or work while having treatment
- returned to school or work in the past 5 years (now that you've finished your treatment)
- are a Canadian resident
- have access to a telephone

You may not participate in this study if you:

- continued going to school or work during your cancer treatment

Who will be Conducting the Research

I will be conducting the research, with the help of Dr. Lynne Robinson, my thesis supervisor. I am a graduate student in Health Promotion.

What you will be asked to do

You will be interviewed by telephone for about one hour. The interview will be audio-recorded. If you wish to speak for less than one hour or more than one hour, that is fine. I will be using my home telephone, in a locked room in my home when no one else is at home. You may use a telephone wherever you feel private and comfortable. Before

the interview begins you will have the chance to ask any questions and create a fake name for yourself to protect your identity. You will be asked general questions about what it was like to resume school and/or work after your cancer treatment. You may decide to stop taking part or decide to have your data removed from the study at any time (up until the final thesis write-up is finished). If you decide to stop taking part, your data will be destroyed. When you have finished the interview you may ask any other questions. You will also be given contact names and phone numbers if you have any other thoughts or concerns. About a month after your interview, a summary of what you said (in my words) will be given to you, so you can read through what you have said in the interview. Once the final write-up for my study is complete, you can be emailed or mailed a copy of it. In total, your taking part in this study should take no more than two hours of your time.

Possible Risks and Discomforts

The risks of taking part in this study are small. The interview is planned to avoid any great distress by not asking about overly sensitive topics, keeping the conversation casual, and letting you feel at ease. You will be treated with great respect. Yet, it is possible that you may become distressed. If I think you are experiencing distress or if you feel upset, you will be able to talk to my thesis supervisor, Dr. Lynne Robinson, who will help you find support. You will also be provided with contact phone numbers if you have any questions or concerns about the interview once it is completed.

Possible Benefits

There are no direct personal benefits to taking part in this study, yet other benefits of this study may include adding to new knowledge, seeing how research is done, and possibly getting rid of stress by talking about your experience.

Compensation / Reimbursement

You will not be compensated for your participation.

Confidentiality & Anonymity

You will not be able to remain anonymous, as I will know your name and telephone number. However, you will be able to choose a fake name for yourself, which will be used in the final write-up of the study to refer to anything you said, with your permission. Therefore, you will never be identified in any reports or publications.
Everything you and others say will be kept confidential. Everything you say will be audio recorded (because this makes it easy for me to remember what you said) and then typed and saved into Microsoft Word on the my password protected computer. All data will be backed-up on a flash drive that will be stored in a locked drawer in my home, to which only I have access. Tapes and any notes taken will also be stored in this locked drawer. The only person allowed access to this information will be my thesis supervisor, Dr. Lynne Robinson. The data will be coded, by looking for things in common among

what you said and what other participants said. A list of themes will be made, supported by direct quotes from you and other participants. This will be turned into a final write-up about the experience of resuming an occupation after cancer treatment, as told by you and other participants, filtered through my understanding of all participants' interviews. After the study is finished, all records will be safely stored in a locked filing cabinet in Dr. Lynne Robinson's office, to which only she will have access. All records will be stored for five years after publication, and then destroyed (as required by Dalhousie University regulations). All information stored on my computer will be deleted, including emails.

Questions

If you have any questions about the study, do not hesitate to contact myself, Elizabeth Sharpe, at 902-363-2258, or Dr. Lynne Robinson, at 902-494-1157. After the interview, you will be given a list of contact names, phone numbers, and websites of young adult cancer organizations. You will be provided with any new information that may affect your decision to participate in the study. You will be asked if you would like to receive a copy of the final write-up or a copy of the interview questions.

Problems or Concerns

If you have any difficulties with, or wish to voice concern about, any aspect of your participation in this study, you may contact Patricia Lindley, Director of Dalhousie University's Office of Human Research Ethics Administration, for assistance by calling (902) 494-1462 or emailing patricia.lindley@dal.ca.

<u>The Experiences of Young Adult Cancer Survivors Resuming an Occupation</u>

I have read the explanation about this study. I have been given the chance to talk about it and my questions have been answered to my satisfaction. I agree to take part in this study. However I realize that my participation is voluntary and that I am free to withdraw from the study at any time.

_____

Signature

_____

Date

I agree to be audio-recoded in this study. However I realize that my participation is voluntary and that I am free to withdraw from being audio-recorded at any time.

_____

Signature

_____

Date

I agree to the researcher referring to my direct quotations, by using my chosen pseudonym (fake name). However I realize that my participation is voluntary and that I am free to withdraw from having my quotations used at any time.

_____

Signature

_____

Date

_____

_____

Researcher Signature (Elizabeth Sharpe: 902-363-2258)

_____

Date

Appendix C

Response Email To Potential Participants

Hi (participant name),

Thank you for your interest in this study! I really appreciate you taking the time to want to share your experience.

This study is part of my research for my Masters thesis in Health Promotion through Dalhousie University. In brief, I hope to gain an understanding of the experience of returning to school or work after having undergone treatment for cancer in young adulthood. Your participation would involve doing a telephone interview with me that should last about one hour. The interview is very casual with open-ended questions, such as, "Can you tell me about your experience going back to work after your treatment?". There are no real risks involved in taking part and all participation is voluntary; you may decide to stop taking part at any time.

Before we arrange a convenient time for an interview, you will need to read through the attached consent form, sign it, and return it to me. You may do so either by electronically singing the form (typing your name on it) and emailing it back to me, or you may print the form off and return it to the following address by mail (if you require postage to be provided, please let me know and I will send a self-addressed stamped envelope):

Elizabeth Sharpe
PO Box 281
Middleton, NS
B0S 1P0

If you have any questions before or after completing the consent form, feel free to call (902-363-2258) or email me. Once I have received the completed form, I will be in contact to set up a time for an interview.

Thanks again for your interest and I really look forward to speaking with you,

Elizabeth

Appendix D

Screening Form

1. Are you an English-speaking resident of Canada? (Yes/No)

2. What is you birth date?

3. What sex are you?

4. What type of cancer were you first diagnosed with?

5. In what town/city and province do you currently reside?

6. When were you first diagnosed with cancer? (age/approximate date)

7. When did you begin your first treatment? (age/approximate date)

8. When did you complete your first treatment? (age/approximate date)

9. Did you stop going to school and/or stop working while undergoing this
    treatment? (Yes/No)

    a. If so, for how long did you stop attending?

10. Have you made an attempt to resume school and/or work after your treatment?
    (Yes/No)

    a. If so, when did you return to school and/or work? (age/approximate date)

    b. Also if so, do you think your attempt was successful?

11. Do you have access to a landline telephone (or cell phone that does not charge for
    incoming calls) in a private, comfortable place?

12. How did you hear about this study?

Appendix E

Interview Schedule

Introduction:

Hello, as you know I'm Liz and I'm the principal researcher for this study. I'm doing this research for my thesis for my Masters in Health Promotion. And although I'm not a cancer survivor myself, like most people, I have many close friends and family members who have had cancer, and I am dedicated to improving the lives of those touched by the disease. Also, I am a young adult – I'm 25 – so I understand how challenging young adulthood can be, and I realize how it may become even more challenging for a cancer survivor.

So before we get started, I just want to make sure you're still ok with being audio-recorded. It's just so I don't have to try to write down everything you say while you say it. And the only other person who may listen to the recording is my thesis supervisor. And are you still ok with me referring to some of the things you say in the final write-up of my thesis? Of course, like you've probably read in the consent form, you can pick a name – just a first name – that I'll use in my write-up to refer to anything you've said, so your identity is protected. So do you have a name in mind you'd like to use? And I just want to remind you that your participation is completely voluntary, so you may decide to stop the interview or drop out of the study at any time.

So do you have any questions before we get started? Ok, well then I would like to sincerely thank you for agreeing to participate. I really appreciate it, and I look forward to hearing you share your story.

Questions:

1. I'd like you to tell me what it was like for you starting back to school or work after you completed your cancer treatment.

    a. Please tell me about any easy or pleasant experiences.

    b. Please tell me about any difficult or unpleasant experiences.

2. I'd like you to tell me about any strategies or supports you used when resuming [school/work].

    a. Please tell me if there were any other types of support you would have liked to have had access to.

3. I'd like you to tell me how you decided that you wanted to start back to [school/work].

    a. Please tell me if you think anything had an effect on your decision, such as other people or aspects of you as a person.

4. Now that you are back to [school/work], I'd like you to tell me what it means to you to have resumed [work/school].

    a. Thinking back to before you were diagnosed with cancer, is there anything different now about how you think about [school/work] or how you want to spend your time?

    b. Do any words or images come to mind?

Appendix F

Summary Sheet Example

October 17, 2009

I: Interviewer (Elizabeth)

J: Jess

I: I'd like you to tell me what it was like for you starting back to work after you finished your treatment.

J:

- Terrifying, even thought of going back

- Chemo-brain (focus, concentration, and memory lacking)

- Tired

- Much re-learning; re-created manual

- Rehabilitation not offered

- Financial issues

I: Did you have any easy or pleasant experiences when you went back? Or did you just find you had a lot of barriers to face?

J:

- High expectations, so everything a barrier

- Co-workers welcoming

- Sun-Life had different expectations of appropriate time to return to work

I: What kind of support did you have when you were returning or did you use any specific strategies when you got back to get you through it?

J:

- Created routine
- Played many brain games
- All support self-taught; nothing offered through medical plan or work

I: Are there any types of support you would have liked to have had access to that you didn't (you think might help others in your position)?

J:

- Education
- Financial assistance
- Retreats to recover physically and emotionally
- Better access to information
- Resource package for all patients

I: Can you tell me how you decided you were ready to start back at work?

J:

- Interactions with people and comfort level to be able to answer questions about experiences
- Had confidence back
- Ability within self to know
- Not an easy decision; huge psychological aspect

I: Were there people that influenced your decision?

J:

- Doctors

- Sun-Life

- Boyfriend

- Everyone had different point view; difficult situation for others to grasp

I: And how did that make you feel, that it was so difficult for everyone else to grasp?

J:

- Hopeless

- Felt never going to change

I: So now that you're back at work, can you tell me what it really means to you to have resumed your job?

- Overcame a challenge

- Created balance; knows what's important

- Appreciative (now that back for awhile especially)

- Seeing opportunity

I: If you think back to before you were diagnosed, is there anything different now about how you think about work in general? Or does work really have the same meaning for you as it did before?

J:

- Different meaning

- Appreciating life for what it is

- Balance

- Still desire to succeed and move forward

- Health, family, and life more important than job

- Realization of the importance of work contribution, but also importance of volunteer work, pets, friends, activity, etc.

- Realized was previously getting burned out

I: Is there different about how you want to spend your time now, compared to before you were diagnosed?

J:

- More with people, as well as time on own

- Always appreciated simple things in life

I: Is there anything else about your entire experience of having cancer, and then treatment, and then stopping work, then going back to work, that you want to add?

J:

- Eight months of menopause after chemo

- Many emotions

- Frustrating; no support for it

I: What was your coping strategy for getting through that?

J:

- Psychiatrist

- Drugs (anti-depressants, marijuana to relax and gain appetite)

- Used counselling support for employees

- Alternative therapy (acupuncture, homeopathy, naturopathy, massage, yoga)

- Physiotherapy

- Unexpected immune responses to deal with

I: So how is it that you knew you were ready to switch from part-time to full-time?

J:

- Gradual shift

- Support from doctors, supervisor, co-workers

- Getting a feel for new body

- Figuring out what could be handled and was manageable

- Ability to advocate for oneself (need to make your own decisions)

- Found self through this journey

- Gained deeper confidence

I: Are there any other words that come to mind to describe yourself now that you feel you're changed?

J:

- Hopeful

- Balanced

- Love (for self and others)

I: Is there anything else at all that stands out in your mind that you wanted to share?

J:

- Supportive best friend

- Supportive mother

- Patience is important (in self and others)

- Others should be patient with cancer patients