The Psychosocial Impact of Surviving Childhood Cancer and Reassimilating Back Into Society in Young Adults

By

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A Thesis submitted to the School of Graduate and Postdoctoral Studies in partial fulfillments of the Requirements for the Degree of

Master of Health Sciences in Community, Public and Population Health

The Faculty of Health Sciences/ Ontario Tech University/ Health Sciences

University of Ontario Institute of Technology (Ontario Tech University)

Oshawa, Ontario Canada

May 2023

THESIS EXAMINATION INFORMATION

Submitted by: **Shanelle Racine**

Master's in Health Sciences, Community Health

Thesis title: The Psychosocial Impact of Surviving Childhood Cancer and Reassimilating Back Into Society in Young Adults

An oral defense of this thesis took place on April 4th 2023 in front of the following examining committee:

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The above committee determined that the thesis is acceptable in form and content and that a satisfactory knowledge of the field covered by the thesis was demonstrated by the candidate during an oral examination. A signed copy of the Certificate of Approval is available from the School of Graduate and Postdoctoral Studies.

ABSTRACT

Approximately 82% of children with childhood cancer survive at least 5 years after their diagnosis. Survivors are faced with a new reality and are faced with having to navigate that reality based on their own perspectives. While many facets encompassing survivorship have been explored in the literature, holistic approaches that evaluate the psychosocial impacts of surviving childhood cancer and how these impacts interact collectively are relatively few. The purpose of this study is to explore the psychosocial impact of surviving childhood cancer and reassimilation back into society in young adult survivors of childhood cancer utilizing qualitative methodology. A total of 4 participants participated in this study and shared their experience with childhood cancer, with 2 participants participating in the focus group discussion. The implication of this study makes an important contribution for survivors, healthcare providers, policymakers, and educators involved in survivorship and long-term care for survivors.

Keywords: childhood cancer; survivorship; reassimilating; psychosocial impact; young adult

AUTHOR’S DECLARATION

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Shanelle Racine

STATEMENT OF CONTRIBUTIONS

I hereby certify that I am the sole author of this thesis and that no part of this thesis has been published or submitted for publication. I have used standard referencing practices to acknowledge ideas, research techniques, or other materials that belong to others. Furthermore, I hereby certify that I am the sole source of the creative works and/or inventive knowledge described in this thesis.

ACKNOWLEDGMENTS

This thesis is dedicated to my grandmother Norcelia Vagéry Racine who died at the age of 101 on November 17th, 2021.

To start, I would like to thank my supervisor Dr. Otto Sanchez for his unwavering support and mentorship. Otto, I am extremely grateful for your words of encouragement and belief in my abilities when imposter syndrome would settle in. Thank you for reminding me to take care of myself and for inspiring me to pursue my passions. You've enriched this experience, and for that, I am truly honoured to have worked with and learn from you. You are not only a mentor, but a dear friend.

Next, I would like to thank my committee members Dr. Michael Taccone and Dr. Manon Lemonde. With the both of you on my team, you've challenged and pushed me to constantly improve. I am exceedingly grateful for your belief in this project. Manon, I am so thankful for your guidance and for being a great listener and advisor when I needed one. Michael, thank you so much for helping me shape my ideas and thoughts into something tangible and for educating me on survivorship. Moreover, I would like to thank my parents, Mona and Jean Racine. Mom, Dad, thank you for giving me a life full of opportunity and unconditional support. I've only made it this far because of you and your prayers. I'd also like to thank my sisters, Jamilah and Julia for keeping me sane and for cheering me on all the way through.

Most of all, I'd like to thank God for being an anchor, keeping me grounded, and for being my calm during a storm. I pray You continue to use me as a tool for Your glory. Thank You for blessing me. "*For I know the plans I have for you, declares the Lord, plans for welfare and not for evil, to give you a future and a hope." Jeremiah 29:11.*

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LIST OF ABBREVIATIONS

ALL	Acute lymphoblastic leukemia
AML	Acute myeloid leukemia
CNS	Central nervous system (Brain and Spinal cord tumors)
LICs	Low income countries
LMICs	Low middle income countries
UMICs	Upper middle income countries
HICs	High income countries
HL	Hodgkin lymphoma
NHL	Non-Hodgkin lymphoma
RMS	Rhabdomyosarcoma
ERMS	Embryonal rhabdomyosarcoma
ARMS	Alveolar rhabdomyosarcoma
PTSD	Post traumatic stress disorder
CCS(s)	Childhood cancer survivor(s)
CVD	Cardiovascular disease
GI	Gastrointestinal
PTSS	Post traumatic stress symptoms
CRT	Cranial radiation therapy
LTFU	long term follow up
CCSC	Childhood Cancer Survivor Canada
FGD	Focus group discussion
AYA	Adolescent & young adult
HCPs	Healthcare professionals

CHAPTER ONE: INTRODUCTION

The remnants of a momentary experience can make monumental changes in someone's life. Full circle moments: to have experienced the same phenomenon as before. This could be easily interpreted as a déjà vu, however, with full circle moments, there is a distinct change or complete reversal in the position, or a series of events tracing back to the original situation. In saying this, my experience impacted by those with cancer has been a full-circle moment.

Hearing from my mother on a random afternoon that a classmate from high school not only remembers me fondly but thought highly of me was jarring. I had not even realized he had remembered me, nonetheless, had great things to say about myself to my mother, who gleamed with pride. When he landed back in the hospital due to his ongoing battle with cancer, he often exclaimed to the other nurses and doctors who cared for him that my mother was one of the reasons he made it to see Christmas. A cascade of events led to a full circle for my classmate.

I am not entirely sure when he was diagnosed, but I distinctly remember him progressively missing first a few days, then a few weeks, from school. I had grown accustomed to our banter and daily greetings whenever we approached our locker area. He was always smiling, until he wasn't. Always had a witty comeback, until he seemed in a state of constant fatigue. While he kept to himself, he was well-liked in high school. I don't recall him ever completely making a full return to school. I became intently focused on my studies, so much so that I quit sports my last year, as I wanted to avoid any distractions and unnecessary obstacles to my university acceptances. Fast forward to the last year of my undergraduate degree, and hearing of his relapse made me wonder what his life was like when he was in remission. I had also begun to wonder if life would ever be the same for him. What does life after having survived childhood cancer look like? Herein began my journey into exploring the experiences childhood cancer survivors faced not only during their cancer journey, but into their survivorship. My full-circle moment.

This chapter defines childhood cancer, what is known and understood about it, including survivorship and the challenges associated with surviving childhood cancer. This chapter also highlights a perspective of childhood cancer and survivorship within the Canadian context and covers the study's purpose, aims, and describes a qualitative approach to exploring survivorship.

1.1 Background

Childhood cancers, also referred to as pediatric cancers, occur between the ages of 0-14 and are considered rare. These differ from adult cancers in the way they grow and metastasize, that is spread to other areas of the body, as well as vary in treatment and patient response to treatment [1]. According to the American Cancer Society, the most common types of childhood cancers are leukemias, brain and spinal cord tumours, neuroblastomas, Wilms tumours, lymphomas (both Hodgkin and non-Hodgkin), rhabdomyosarcomas, retinoblastomas, and bone cancers (both osteosarcoma and Ewing sarcoma) [2].

Leukemias are cancers originating in the bone marrow and blood impacting the normal development of white blood cells and are the most common cancers inflicting children, accounting for approximately 28% of all cancers among those aged 0-14 years and are the leading cause of death in children [2, 3]. Generally speaking, there are two main groups of leukemias; acute lymphocytic leukemia (ALL) and acute myeloid leukemia (AML). All leukemias can cause bone and joint pain, weakness, fatigue, pallor, bleeding as well as other symptoms such as frequent or severe infections, swollen lymph nodes and an enlarged liver or spleen. Acute leukemias undergo rapid growth and require immediate treatment such as chemotherapy as soon as they are detected

[2]. In some instances, as in higher risk leukemia, radiation therapy to the brain and spine is used to eliminate leukemic cells from these important areas. ALL is more prevalent in Hispanic and White children than in African American and Asian American children, it is also more common in males than females, whereas AML occurs equally among males and females of all races [4]. The 5-year survival rate for ALL is approximately 90%, whereas AML has a survival rate of 65-70% [5]. The highest incidence of leukemia among children is in Asia, with the lowest incidence being in Oceania [3]. The disparity in incidence could in part be attributed to the differences in detection and in the accessibility of facilities within health care systems in various parts of the world [3].

Following leukemias, brain and spinal cord tumours (CNS) are the second most common cancers in children, making up nearly 26% of cancers in children [2]. There are several types of brain and spinal cord tumours, thus the treatments used for each may vary but typically include surgery, radiation therapy, chemotherapy, corticosteroids and antiseizure medication, stem cell transplants and active surveillance [6]. Occurrences of spinal cord tumours are less common in both children and adults [2]. However, most cerebral tumours in children originate in lower parts of the brain such as the cerebellum or brain stem, causing headaches, nausea, vomiting, and symptoms impacting the central nervous system [6]. The incidence rate has not changed much in recent years however, it ranges from 1.8 per 100,000 in Melanesia to 36.0 in North America [7, 8]. Brain and spinal cord malignancies are slightly more prevalent in males, while non-malignant tumours are slightly more prevalent in females [7]. Survival rates for CNS tumours range from as low as 20% for glioblastomas and 95% for pilocytic astrocytoma [9].

Neuroblastomas are the third most common cancer type, and originate in the developing embryo or fetus, affecting developing nerve cells of the sympathetic nervous system, with most beginning but not limited to the abdomen either in the adrenal gland or sympathetic chain of neurons, near the spine, chest, neck, or pelvis [2,10]. This cancer rarely arises in children older than the age of 10 and accounts for 6% of childhood cancers [2,10]. The average age of children when diagnosed is between 1-2 years, with 9 out of 10 neuroblastomas being diagnosed by age 5. The survival rate for low-risk children is 95%, whereas children considered high risk have a survival rate of 50% [11]. Treatment typically includes chemotherapy, surgery, radiation therapy, stem cell transplants, retinoids, targeted drugs, immunotherapy, anti-GD2 monoclonal antibodies, vaccines, and CAR T-cell therapy [11,12]. The highest percentage of countries that did not have reported incidences of neuroblastoma were from low-income countries (LICs), followed by low-middle-income countries (LMICs) upper-middle- income countries (UMICs) and high-income countries (HICs). The reason for low incidence among LICs is likely related to underreporting [13].

Following neuroblastomas are Wilms tumours. Wilms tumours can originate in one kidney and in rare cases, both kidneys [2]. It is often present in young children, typically of ages 3 to 4 and is uncommon in older children and adults [2]. Symptoms of Wilms tumour can be subtle. The abdomen may swell, or a lump may appear below the ribcage. Occasionally other symptoms such as fever, pain, nausea, or poor appetite may be present. This tumour accounts for approximately 5% of childhood cancers, in fact, 9 out of 10 kidney cancers in children are Wilms tumours [2,14]. There are two types of Wilms tumour; favorable, where the cancer cells are less dysplastic but the chance of curing this type is very good, and anaplastic, where the cancer cells vary widely in appearance making it harder to treat, however, most tumours are detected before they have metastasized [14]. Unlike most cancers, the survival rate for Wilms tumour is based on a 4-year survival, depending on tumour stage and the degree of anaplasia, survival can range from as low as 30% -45% to as high as 95%-100% [15]. The incidence of Wilms tumour is highest in low-income countries whose survival rates are the lowest, ranging between 25%-35% [16]. Treatment options for Wilms tumour includes surgery, chemotherapy, and radiation therapy [14].

Subsequently, lymphomas are cancers arising in lymphocytes; cells of the immune system, typically present in lymph nodes or in other tissues such as the tonsils or the thymus [2]. These differ from leukemias in that they typically originate outside of the bone marrow. The range of symptoms for lymphoma are dependent on the site of origin, but commonly include weight loss, unexplained fever, night sweats, and lumps in the neck, armpit or groin can be present. There are two main types of lymphomas: Hodgkin and non-Hodgkin. Hodgkin lymphomas (HL) account for almost 3% of childhood cancers, however, it is more common in people in their 20s and in those older than 55. This cancer is very similar in children and adults, including the types of treatments that work most effectively [2]. Non-Hodgkin lymphoma (NHL) is most likely to occur in younger children and makes up approximately 5% of childhood cancers, although, it is quite rare in children younger than 3 years of age.

Treatment types for lymphomas include chemotherapy, stem cell transplant, radiation, surgery, and immunotherapy [17,18]**.** Lymphomas grow quickly and require intensive treatment, but lymphomas in children respond better to treatment than most NHLs in adults [2]. As there are a variety of NHLs, the survival rates for this cancer type vary, ranging from as low as 60%-75% to as high as 90% [19]. Survival rates for HL depend on the extent of metastasis. Combining all stages, the survival rate is 88%, but can be as high as 94% if diagnosed in the regional stage and as low as 82% if discovered in the distant stage [20]. Incidence rates for NHL are highest in southern Europe, whereas HL is highest in European regions and Oceania [21].

After lymphomas are rhabdomyosarcomas (RMS). RMS originates as corrupted cells that were meant to differentiate into skeletal muscle. Therefore, this type of cancer can start in any place in the body where skeletal muscle is found, including the head, neck, groin, abdomen, pelvis, or an appendage such as an arm or leg. This is the most common type of tissue sarcoma in children making up nearly 3% of childhood cancers [2]. There are two main types of RMS: embryonal rhabdomyosarcoma (ERMS), occurring in the first 5 years of life, originating in the head, neck, bladder, vagina or in and around the prostate, and, alveolar rhabdomyosarcoma (ARMS), affecting all age groups equally, occurring in large muscles such as the abdomen, arms, and legs. ARMS typically grows faster than ERMS and requires intensive treatment which usually includes radiation [22]. However, doctors are looking for ways to limit doses as much as possible, giving rise to new radiation techniques such as stereotactic body radiation therapy, proton beam radiation, newer drugs, and immunotherapy [22]. RMS is more common in males than in females, impacting individuals of all races and ethnic groups relatively equally. Children aged 1-9 tend to have a better prognosis than infants, older children, or adults, however, depending on whether the child is a lowrisk or high-risk, survival ranges from 20-30% to as high as 70% to over 90% [22,23]. The incidence of RMS is highest in Europe and is least prevalent in Asia [24].

Second to last most common childhood cancers are retinoblastomas. Retinoblastomas are malignancies of the eye, specifically the retina. This disease affects 2% of children with childhood cancer, usually occurring in children at age 2, seldom presenting in children older than 6 [2]. It occurs equally in males and females and among different races and ethnicities, occurring equally in the right or left eye [1]. This cancer starts in the retina, the inner layer of cells in the back of the eye [25]. If left untreated it could grow and consume much of the eyeball, and metastasis to other areas of the eye could raise the pressure within the eyeball, causing glaucoma and leading to pain and loss of vision in the affected eye. Metastasis to areas outside the eyeball may occur in nearby tissues such as the lymph nodes and bone marrow [25]. In a healthy eye, when light is shone, the pupil looks red due to the blood vessels in the back of the eye, however in an eye consumed by retinoblastoma,

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[1] . Most of the world’s cases are present in LMICs, however, HICs have much higher rates of

the pupil usually looks white or pink [2]. Treatment methods vary from radiation therapy, and include focal treatments such as enucleation, laser therapy, or chemotherapy and oncolytic virus therapy diagnosis confined to one eye whereas the rates of diagnosis from one eye to other parts of the body as seen in LMICs, are associated with a poor prognosis [26] . The survival rate for retinoblastoma is 96%, with those who succumb to the disease being due to the aggressiveness of the cancer (late stage), rather than complications [27].

Lastly, bone cancers are malignancies primarily affecting bone and occur most often in older children and adolescents. However, they can develop at any age and account for approximately 3% of childhood cancers [2]. There are two main types of bone cancers in children. Osteosarcomas are most common in teens and develop where bone growth is rapid such as near the ends of the leg or arm bones. However, most tumours develop in bones around the knee, the distal femur, that is, the thigh bone or the proximal tibia, which is the upper part of the shinbone [28]. The upper arm bone close to the shoulder (proximal humerus) can also be affected. Bone pain due to osteosarcomas gets worse at night or with activity, swelling can also occur in the area around the bone [2]. Ewing sarcoma is a less common type of bone cancer and is most often present in young teens [2]. The most common areas affected by Ewing sarcoma are the hip bone, the chest wall or in the middle of the leg bones [29]. Bone pain and swelling are symptoms that are typically present in individuals with this type of cancer. The main types of Ewing tumours include Ewing sarcoma of bone, extraosseous Ewing tumour and peripheral primitive neuroectodermal tumour occurring more in males than in females [29]. Treatment options for bone cancers include surgery, radiation therapy, chemotherapy, targeted therapy drugs and immune therapy [28,29]. Osteosarcoma is more prevalent in Nigeria, whereas Ewing sarcoma is more widespread in Saudi Arabia [24].

Childhood cancers are not limited to these 8 types. Depending on the cancer type, the trajectory of survivorship may vary. Despite the varying survivorship odds for each of these cancers, surviving childhood cancer is highly probable.

1.2 Survivorship

1.2.1 What is survivorship?

In the 1900s, the term "cancer survivor" was created by physicians and researchers when comparing clinical trial outcomes to each other to assess advancements in research and cancer treatment [30]. At the time, childhood cancer deaths were alarmingly high, however, medicine and oncology treatments have made significant progress since then [30]**.** If children could make it at least 5 years after their initial diagnosis, then they were considered survivors. They completed the hardest feat possible: They survived cancer! Although more children are surviving cancer by virtue of treatment, survival comes at a cost [31]. The "cancer survivor" milestone includes children in remission, children and adolescents who are still receiving treatment, and those who are dying of an untreatable cancer beyond the 5 years since their diagnosis [30,32]. After treatment, challenges continue for survivors that do not end at the 5-year benchmark, rather, they extend into the rest of their lives [30].

Survivors of leukemia for example, are at a higher risk of developing other types of cancers later in life, along with heart and lung problems, learning difficulties, growth and development interruptions, fertility issues and bone problems [31,33,34, 35,36]. Children who survive brain and spinal cord tumours are at risk of similar difficulties, however main concerns include learning problems, delayed growth and development, hormonal issues, vision and hearing problems, as well as paralysis and other aspects of nervous system function such as seizures or impact to physical coordination [37]. Children who survived Wilms tumour face reduced kidney function, slowed or delayed development, changes in reproductive ability, especially in females, as well as the increased risk of developing a second cancer although it only occurs in rare cases [38].

The latent effects of lymphoma vary, for instance survivors of NHL experience complications such as bone damage or early-onset osteoporosis, and may experience changes in intellectual function, delayed growth and sexual development, however the long-term effects of HL treatment include infections, thyroid problems, heart disease and stroke, breast cancer among women who received chest radiation before 30, thyroid cancer and lung cancer [39,40]. Complications due to RMS can include scarring, cataracts, and decreased sexual functioning, to name a few [41]. The effects associated with retinoblastoma include deformities in bone surrounding the eye, especially after surgery or radiation, as well as reduction or loss of vision in the eye consumed by cancer [42]. Survivors of osteosarcoma and Ewing sarcoma are prone to heart or lung problems, learning problems, developing a second cancer as well as other latent effects [43,44]. Yet, there are a host of other unrelated-health obstacles faced by survivors due to their early cancer experience.

Apart from physical late effects to survivorship, there are also latent psychosocial effects that survivors face. In fact, they are more susceptible to depression, anxiety disorders, posttraumatic stress disorder (PTSD), high rates of psychosocial stress, lower educational attainment, being unemployed, lower household income, risky health behaviours such as increase smoking and alcohol use, and poor health outcomes such as fatigue and sleep disturbances [45].

1.2.2 Impact of survivorship

Nearly two-thirds of childhood cancer survivors (CCS) have a chronic or long-term side effect because of harsh cancer treatments [31]. Survivors of childhood cancer are predisposed to suffering latent effects due to cancer therapy, in fact, there is an increased risk of cardiovascular disease (CVD) and other diseases/complications including hypothyroidism, hyperthyroidism, neurocognitive dysfunction, glaucoma, hearing loss, pulmonary dysfunction, gastrointestinal (GI) complications and infections, renal disease, infertility, obesity, growth impairment, bone ailments, and secondary cancers due to exposure to cancer treatments at varying degrees at a young age [31,33, 34,38]. In recent years, as most children with cancer survive into adulthood, the health of adult survivors of childhood cancer has become a major focus of medical and scientific interest [46].

Depending on cancer type and treatment exposure, life after cancer often poses challenges for this population of Canadians.

1.2.3 A Canadian perspective of Childhood Cancer & Survivorship

The probability of Canadians developing cancer in their lifetime is approximately 1 in 2 compared to 161 new cases of childhood cancer per million children, per year [6,47]. The rate of new cases of pediatric cancers in Ontario has increased over the past three decades [31]. While cancer mostly affects Canadians aged 50 years and older, it can occur at any age [6]. Childhood cancer is the second leading cause of death in Canadian children after accidents [6,31]. Cancers in children are typically more aggressive in comparison to adult cancers, can grow at a quicker rate and are more likely to metastasize. Unlike adult cancers, preventing childhood cancer is to date limited, being that the causes of cancer in children are essentially unknown [31]. In Canada, 84% of children with childhood cancer survive at least 5 years after their diagnosis [31]. Beyond 5 years, the probability of surviving another 5 years exceeds 95% across most cancer diagnoses [48]. Therefore, the vast majority of children diagnosed with cancer will go on to join the rapidly growing population of childhood cancer survivors. This survival however comes with a cost. In one population based study it was found that approximately 41% of survivors compared to 17% of the general population was hospitalized due to late onset morbidity, suggesting that survivors are at an increased risk of age-matched morbidity [49].

With many of the survival rates of childhood cancers being as high as 90%, the more it is suspected that survivors are likely to land in the hospital because of the long-term affects of their childhood cancers. The Canadian healthcare system is based on a traditional hospital-focused and physician-focused model, it is often criticized for its inability to meet the growing demand of home-based, community-based, and institutional long-term care, specifically for those with chronic conditions [50]. In fact, in 2012 alone, almost half a million Canadians 15 years old or older reported that were unable to receive home care for a chronic health condition despite qualifying for that level of care [49]. Given that medical needs only form a fraction of the needs of childhood cancer survivors, this concerning data poses the question, are the needs of childhood cancer survivors in Canada being met?

1.2.4 Defining Reassimilation

According to the Merriam-Webster dictionary, assimilation is described as "the process of receiving new facts or of responding to new situations in conformity with what is already available to consciousness" (n.d.) [51]. This definition befits the lens used in exploring the survivorship experience. Survivors are faced with a new reality (receiving new facts or responding to a new situation), and are faced with having to navigate that reality based on their own perspectives (what is already available to consciousness). This study adds another layer to this definition where survivors also explore how their perspectives may change due to internal and external influences (their outlook on cancer, coping and reassimilating). In this study, reassimilating back into society is described as the return to life post-treatment, which includes navigating school, work and social relationships post-cancer.

1.3 Study Purpose

The purpose of this research is to understand the psychosocial aspects associated with reassimilating back into society as a childhood cancer survivor , to understand how intricately these aspects may be associated with each other, as well as to provide a comprehensive account of the contribution these themes make to the survivor experience. Through retelling these human experiences from their perspective, this work seeks to shed light on the burdens of cancer, its survival, and hopes to create an authentic testimony that leaves an impact on both the survivorship community and growing body of childhood cancer survivorship research. In utilizing a qualitative approach, the goal of this work is to acquire a richness of experiences and demonstrate how influential this singular event is to the psychosocial experience of CCS within society after cancer.

1.3.1 Study aims

Whether the process of reassimilating back into society is an active element to the transition from cancer patient to adult care, is unclear. It is also uncertain that the psychosocial experiences that have been documented among survivors interact with each other when exploring the ability to reassimilate back into society. For example, in relationships the evidence presented has been isolated to fertility status and the ability of family members to cope with their child's health status [52,53,54]. However, other relevant facets to relationships such as the impact reassimilation may have on the ability to foster friendships or manage changes to family dynamics, lack research. Furthermore, although social and psychological implications have been considered, it remains to be determined whether patient-oriented solutions have considered the pressures and burdens associated with reassimilating back into society have on managing the psychosocial consequences of surviving childhood cancer. In essence, there is a dire need to bring focus to the psychosocial aspects of surviving childhood cancer but in the context of reassimilating back into society and evaluating how these themes interact in this context.

The purpose of this study is to focus on evaluating the trajectory of survivorship in the context of reassimilating back into society through observing survivors outlook on their experience regarding their mental health, relationships, success in their environment (social, educational and/or professional) and their perspectives on their journey through life. The aims of this study are to explore the psychosocial impacts of surviving childhood cancer, how intricately these impacts are associated to each other and the internalization of these impacts. Therefore, the research questions is, how do the psychosocial impacts of surviving childhood cancer interact collectively throughout the survivor experience, and what is the lasting impact of these interactions in young adults?

1.4 A Qualitative scope

A common approach used in qualitative research methodology which explores survivorship is descriptive phenomenology that mainly assesses participant coping strategies for living a normal life, long term effects and consequences of cancer, and the prevalence of fear for cancer recurrence among CCS [55, 56, 57, 58, 59, 60]. There are few studies that explore survivorship favoring an interpretive phenomenological approach.

1.4.1 Interpretive Phenomenology

Interpretive phenomenology focuses on interpretation and deciphers the concept of being in the world [61]. This qualitative approach relies on reality, how we understand what exists and what we are experiencing. With this perspective, participants are involved in the research process as much as possible. Essentially, research is being done with participants, and not on participants.

This approach is not only necessary in further understanding CCS's life circumstances but allows their voices to be at the forefront of this research and puts an emphasis on meaning. Using interpretive phenomenology for this study is unique in that this approach has yet to be applied in the context of understanding the transition from cancer patient to survivor, reassimilation back into society and the psychosocial impact of surviving childhood cancer collectively.

There are few documented approaches that evaluate the psychosocial burdens of surviving childhood cancer, and how they interact collectively throughout the CCS experience. Particularly, it is not well understood within the context of transitioning from cancer patient to survivor, and how reassimilation impacts other aspects of life. In comparison to descriptive phenomenological approaches, the concept of being in the phenomenon versus knowing the phenomenon are different lenses to addressing what may be the same concept, however, interpretive phenomenology goes beyond description, instead seeking out the meanings imbedded in everyday occurrences [57]. Interpretive and descriptive phenomenology are distinctly different in that descriptive describes how individuals experience their lived experience, whereas interpretive describes how individuals interpret the contexts of their lived experience.

This qualitative approach will enable the exploration of the psychosocial impacts of survivorship, the meaning these impacts had, and the influence the meaning of these impacts had on their survivorship and reassimilation back into society.

CHAPTER TWO: LITERATURE REVIEW

This chapter covers the process of identifying, analyzing, and reviewing articles in support of this study. The purpose of this literature review is to explore the recent findings of the phenomenon under study and to assess the research lenses used by researchers. The search and selection criteria are discussed, and a comprehensive account of the findings is provided. This chapter also outlines the gaps that are present in research.

2.1 Search and Selection Criteria

The articles evaluated in this literature review were retrieved from PubMed due to it being widely accessible and having a large breadth of information available. Inclusion criteria included articles that were no more than 10 years old as this ensured that the information referenced and utilized regarding the topic of childhood cancer survivorship was current. Keywords used were "childhood cancer", "survivorship", "impact", "implication", "youth", "Psychosocial", "Reassimilate" and "young adult". Articles included in the review were originally in English or translated to English. Exclusion criteria included articles that were over 10 years old and articles that could not be accessed via PubMed. Articles considered grey literature were not included as there were none found in relevance to the research focus. Qualitative articles were reviewed and the themes of survivorship that were explored include psychosocial impacts, transition from cancer patient to survivor and reassimilation; return to normalcy. There are 12 qualitative studies discussed in this literature review exploring the realm of survivorship including transition and reassimilation into social settings and relationships.

2.2 History and Current Research

There are countless findings regarding the health of CCS [31,34,37,38]. The realm of cancer survivorship has been well studied with extensive quantitative and qualitative studies done with cancer survivors especially within the United States and Europe [30,36,50,51,56,58,62,62,63,64]. Despite differences in healthcare between Europe and the United States, there are a few consistencies that are present across countries or regions. One of a few findings to note, include that cancer has the potential to impact all aspects of an individual's life, this includes physical, psychological, social, financial and the spiritual [65, 66]. Furthermore, survivors require specific and comprehensive followup that encompasses any challenge they may face associated with the type of treatment received, cancer type, as well as psychosocial needs [63,64]. Life after cancer has become a growing focus in cancer research, and its focus only continues to expand in the lives of cancer survivors.

2.2.1 Qualitative Perspectives of Survivorship

The benefits provided by quantitative research is evident, however in emerging research, it is increasingly apparent that there is a need and benefit to implementing qualitative research when exploring cancer. It was found that meshing a qualitative approach to a quantitatively based study, provides context, increases effectiveness in developing new insights and enhances generalizability [56]. Not only does it support findings present in quantitative reviews exploring the management of advanced cancer pain for example, but it illuminates and puts an emphasis on individualized approaches to care.

However, the concern in quantitative studies is that the perspective of participants is diluted [59]. Perhaps, something to look forward to would be approaches implementing qualitative techniques being used more frequently in the clinical realm of cancer research. While the combination of a quantitative and qualitative approaches seems promising, the use of qualitative methods helps to understand the patient experience [59]. Qualitative studies focus on exploring concepts and experiences as they pertain to survivorship outcomes. Among qualitative studies, the themes explored include "life and relationships", "long-term psychosocial impacts", and "perspective and mindset". These themes will be discussed as they pertain to what survivors experience post-cancer.

2.2.2.1 Psychosocial Impacts to Life & Relationships

A cancer diagnosis in childhood, its treatment and late medical effects, alters the psychosocial trajectory of survivors across the course of their lives [67,68]. The prevalence of psychosocial impairment when compared to their sibling counter parts or population control groups is notable and significant [69,70,71,72,73].

A literature review depicting mental health, achievement of social milestones, socioeconomic attainment, and risky health behaviors in survivors of childhood cancer depict the psychosocial realities faced by childhood cancer survivors. Although survivors of childhood cancer are at risk for psychological impairments, 75%-80% in most studies do not experience significant psychological impairment [57]**.** However, as a whole, survivors are at risk for adverse psychological outcomes. Children and adolescent survivors are significantly more likely to have symptoms of anxiety and depression, inattention, antisocial behaviour, and impaired social competence compared with siblings [57]. There is also an increased prevalence of depression and anxiety symptoms among adult survivors of childhood cancer many years after completion of therapy, including post-traumatic stress symptoms (PTSS) and suicidal ideation.

There are several factors associated with adverse psychological symptoms in survivors, including low income, lower education, female sex, disability status, and unmarried status.

However, the directions of effects is unclear as these factors may contribute to or be the result of mental health problems [57]. Poor physical health has been shown to be consistently associated with poor mental health outcomes in survivors. With mental health being strongly linked to CCS physical health, it is not shocking that cancer treatments associated with medical late effects are associated with psychological adjustment. CNS-focused therapies, intensive chemotherapy and surgical therapies are associated with psychosocial symptoms and problems. Interestingly, little research has focused on implementing and evaluation interventions targeting psychological symptoms in CCS[57].

As for social outcomes, survivors are at risk for social difficulties marked by poor peer acceptance, isolation, and reduced leadership roles [57]. Social difficulties are not exclusive to survivors of CNS tumors and CNS-focused therapies, however, are most commonly present among these types of survivors. Essential tasks for survivors include the development of social relationships and establishing autonomy, specifically independence, from caregivers. Survivors are twice as likely to live dependently compared to their siblings, the ability to live independently and achieve autonomy serves as an important indicator to survivors of adult autonomy. Posing a challenge for many survivors of childhood cancer. Achieving these essential tasks may pose certain challenged for survivors due to treatment history, and/or the emergence of late effects.

In fact, regarding navigating social relationships, survivors typically have lower rates of marriage or cohabitation. Survivors also experience psychosexual impacts such as delayed achievement of psychosexual milestones such as dating, masturbation and sexual intercourse has been reported among survivors [57]. In fact, in terms of psychosexual outcomes are seen as important social outcomes for survivors of childhood cancer. The majority of intervention research in the realm of social functioning has involved social skills training among child and adolescent survivors of CNS tumors. This is an important focus in research as there is heightened risk of social functioning among survivors of CNS tumors, and immense importance is placed in early intervention to offset harmful social outcomes.

As a result of cancer and treatment, school aged cancer patients may miss significant educational opportunities, resulting in survivors requiring additional educational support or grade retention. Neurocognitive deficits contribute considerably to educational difficulties experienced by survivors. Among survivors there is a greater risk of not graduating high school, interestingly the reasons underlying poor attainment have not been fully elucidated, however it may be due to response to cancer-directed treatment, treatment-related late effects, or changes in teacher and peer behaviour after school re-entry. Educational attainment is an important aspect to survivorship that may set the precedent for employment opportunities in life.

In fact, survivors from the United States and Canada appear to be at greater risk of unemployment than survivors in Europe or Asia. Risk factors include diagnosis of a CNS tumor, younger age at diagnosis, treatment with cranial radiation therapy (CRT), cancer-related late effects and female sex [57]. Despite employment outcomes and associated financial consequences, interventions targeting this facet of survivorship have yet to be documented, however, the few young adult survivors of childhood cancer enrolled in state or federal rehabilitation programs have received job search assistance and on-the-job support were four times more likely to be employed after receiving services.

Unfortunately, the combination of psychological symptoms and poor socioeconomic outcomes place survivors at risk for engagement in risky health behaviours. Engaging in risky behaviours exacerbate existing health vulnerabilities, placing survivors at risk for adverse health outcomes [57]. In light of risks, survivors of childhood cancer generally will either engage in risky health behaviours at rates similar or only slightly lower than siblings and peers. Modifying risky behaviours may reduce the risk of second cancers in survivors. Health behaviours are modifiable and behavioural counselling and/or psychoeducation can encourage desired behaviour change. Risky behaviours among survivors of childhood cancer include the use of tobacco, cannabis and illicit drugs, alcohol, insufficient diet, nutrition and physical activity, lack of protection from sun exposure and risky sexual behaviours [57]. Overall this review emphasized that timely identification of psychosocial issues is crucial to offset potential harmful effects across the life course of survivors and in their development.

It is unclear how many articles are included in this review and the processes involved in synthesizing the findings, however, it is clear that the implementation of psychosocial interventions and programs should be a priority in pediatric oncology and survivorship care and settings, such as the promotion of prosocial development and mental health outcomes across cancer care, especially survivorship.

Additional psychosocial findings have focused on other facets of life that contribute to the survivorship experience, such as the return to daily life and how this impacts the family unit. A sub study of a larger study (Physical Activity and Function in Childhood Cancer Survivors) explored how 15 young survivors and their parents managed treatment related late effects in daily life post treatment, using a phenomenological-hermeneutic approach [74]. Survivors were aged 1118 years. Semi-structured interviews were conducted to assess everyday life post treatment, and to observe changes to everyday life, physical activity, and friendships. A significant finding of this study is that CCS and their parents had different perceptions as to how late effects impacted daily life, which led to different management strategies [74]. Rather than ignoring the latent effect of treatment, CCS adapted by accepting them. The dilemma for parents resided in negotiating balance between activities and rest and in accepting survivors' own management strategies [74]. The process of negotiation between survivors and their parents is the result of their differing experiences with late effects in the context of transitioning to daily life post-treatment.

There are changes to other aspects of life as well, namely work life, family life, partner relationships, and social life in the perspective of parents [75]. Observational longitudinal mixed methods were used, with the second part of the study having a naturalistic inquiry qualitative design and sampled 49 parents. During treatment, 70% of parents reported that they encountered difficulties reconciling paid work, household and family responsibilities and caring for their child. Couples spent little time with each other and approximately 25% reported disputes and burden [75]. Many parents also reported not having enough energy for pursuing any hobbies during treatment.

Longer term however, facing disease also led to strengthened relationships, new priorities, improved communication, increase in mutual trust and greater appreciation for daily life [75]. Supportive social networks such as friends and family, a strong partner relationship prior to diagnosis and the use of psychosocial services such as family-oriented rehab had a positive effect [75]. Most families adapted well to life after treatment, however reintegration is a difficult process and took time. Unfortunately, parents lack the energy required to continue life as they did before the diagnosis. This study illuminates the challenges faced by parents and that these challenges do not end upon the completion of cancer treatment.

A study analyzing how parents of CCS utilize social and cultural capital in an educational setting was conducted in 3 phases using a grounded theory approach. Ten parents participated in the interview and 222 participated in a survey where 1/3 answered an open-ended question. Parents of children from a variety of age ranges and education level were recruited for study participation. The first phase – the foundation of the study – involved recruiting parents of CCS in Baltimore and DC treatment centers. Social capital contains two main characteristics, the first involves relationships and networks that offer benefits for individuals interrupting social inequality. The second, concerns the active maintenance of those relationships with the aim of achieving mutual benefit [76]. There are 3 different forms of cultural capital, however institutionalized cultural capital is of focus in this study. Cultural capital is an individual's authority awarded to them based on credentials or qualifications, for instance, this can include a college degree, job title or professional credentials [76].

Results suggest that most parents made use of their social capital for their own benefit in seeking educational support for their children, and were hopeful that other individuals, including teachers, would benefit from their actions [76]. The desire for others to benefit includes concerns with navigating the school system, teachers, and the methods of special education available to children with disabilities. The desire to help other families affected by pediatric cancer was described as an act of social justice with the desire to distribute knowledge in a way that others can benefit, and as an attempt to diminish the structural barriers to educational supports [76]. The use of institutionalized cultural capital helped parents navigate change to improve the quality of life of their children. Parents used what they know, either with credentials they already had or were obtaining, to address the challenges that they and their children experienced [76]. Unfortunately, not all people will have the same ability to mobilize social and cultural capital.

The mentioned studies depict how impactful the survivorship experience is on the family dynamic and in what ways parents and caregivers as well as survivors manage in the face of treatment and in their transition into survivorship. This emphasizes that return to normalcy is not really a return, as things are no longer as they were, however, require adaptation in order to navigate a different set of circumstances post cancer. This aspect of survivorship is crucial, as it may be influential to survivor's ability to reassimilate and how they navigate their environment based on familial support, understanding and relationship.

Progressing toward additional long-term psychosocial impacts survivors face, a study conducted a semi-structured focus group and phone interviews consisting of open-ended questions with survivors from the Northern Region Young Persons' Malignant Disease Registry. This descriptive study contained a sample of 12 survivors diagnosed with CNS tumours, other solid tumours and blood malignancies before 18 years of age and who had survived 5 or more years from treatment. Survivors provided their views on how cancer has impacted their life including relationships, education, careers, and health [77]. There were differing views as to the extent to which cancer impacted CCS's present lives and it was not related to age at diagnosis or their diagnosis.

The most prominent theme was that survivors perceived their experience to have influenced their overall outlook in life [77]. This was voiced positively, with survivors articulating that their experience gave them a greater appreciation for life and of others, as it gave them an awareness that life is uncertain and can be short. Survivors expressed that they learned to make the most of their lives, express greater empathy, feel different to their peers in terms of physical appearance, and became acutely aware of their strengths and limitations. There was also a lasting impact on family, where their parents and friends were a source of support [77]. The data from this study will be used to provide insight to developing a questionnaire for a larger sample of CCS regarding the impact that cancer had on their lives. This is to provide a holistic and explanatory approach by providing insight into the many ways cancer can impact the life of a young person years after treatment.

Utilizing a descriptive phenomenological approach, a study was conducted to holistically assess any difficulties faced by survivors of childhood cancer. Fifteen South Korean participants aged 15-28 were recruited via an outpatient department. Survivors were asked semi-structured open-ended questions and revealed three essential themes in this study. First, survivors showed some degree of physical impairment including musculoskeletal impairments, limited functional mobility, and range of motion. Secondly, survivors experienced social desolation, its effects, and their ability to rebound from it. The third essential theme was related to emotional aspects such as distress and withdrawal. In addition, they experienced, changes in appearance, sexual problems such as menstrual irregularity, impaired ovary function and fear of infertility. Survivors also experienced social awkwardness, difficulty adapting due to interruption to schooling, family issues, social prejudices or discrimination and psychological distress [78]. This study was the first to analyze struggles of long-term CCS from their own perspectives in Korea.

These mentioned studies take into account the psychosocial variability that is experienced throughout survivorship in not only how survivors perceive themselves but how they perceive their experiences as a result of their childhood cancer. This emphasizes the lasting impact surviving cancer has in their lives in a psychosocial context.

A phenomenological study was conducted with 29 adolescent and young adult childhood cancer survivors exploring the metrics of success for transitional care practices in childhood cancer survivorship [79] . Survivors ages 18-29 were recruited from the Childhood Cancer Survivor Program at the University of Minnesota from both pediatric and adult settings. There were 18 participants from pediatric care settings while 11 had already transferred to adult care settings. Phone interviews were conducted for approximately 15-30 minutes where participants were encouraged to speak on the systems or support features that promote successful transition in care settings from their perspectives. Thematic analysis provided 4 major themes; transition practices should be flexible and individually tailored, effective communication is critical to a successful transition, survivors desire continuity during their transition, and comprehensive care that also addresses psychosocial well-being.

From the survivor perspective, there is no designated age or set or milestones that determine when a patient is ready to transfer care to adult care-settings, some feel as though that in uncomplicated cases, collaboration between healthcare providers and the patient should inform a decision to transition from pediatric to adult facilities. There is also a desire for increased autonomy when discussing successful transitions including healthcare responsibility, independent decisionmaking, and self-efficacy [79]. Survivors also expressed their desire for information from providers that explain why they needed to transition and what to expect from adult-care. Young adult CCS repeatedly expressed that they expected continuity in their medical care, ultimately reliable transfer of medical information to new providers is essential, and consistent providers during their transition would be helpful.

Survivors in this study were receiving care in a model that provided longitudinal care from a pediatric social worker experienced in issues CCS may face. Survivors also described comprehensive survivorship care as including support for psychosocial and overall well-being.

Primarily, life transitions that occur around the time care transitions take place. Survivors often lend themselves to support from psycho-social providers such as social workers to discuss anxieties associated with achieving developmental milestones in young adulthood, but also the amplified effect on general well-being during potential stressful times. Survivors really highlighted the importance of support, including peer-support, when it came to psychosocial well-being.

This study amplifies the collective voice of CCS in their desire for continuity, and that it be prioritized in all levels of care around and during the transition from pediatric to adult settings with an emphasis on flexibility [79]. In essence, a successful transition includes effective communication through the collection, dissemination, and integration of their past medical and psychosocial history. Communication must be both consistent and flexible. Healthcare providers play a critical role in realising these as priorities for CCS and should prioritize these aspects of care in an effort to ensure a smooth transition. This study illustrates that transition plays a critical role in survivorship care and that there is a strong emphasis in understanding and prioritizing psychosocial aspects of survivorship into care.

2.2.2.3 Survivors' perceptions and mindset

Another Korean study explored survivors aged 15-39 and their self-perceptions as to what may have caused their cancer using attribution theory, that is, how survivors perceived the causes associated to their cancer diagnosis [55]. In-depth semi-structured interviews were conducted with 31 survivors [55]. Reportedly, over half of the participants stated they were not informed of their cancer diagnosis when they were first admitted to the hospital [55]. Although some children heard from parents or relatives that they were ill, most had been isolated from the medical decisions and did not comprehend the nature of their diagnosis. All the survivors expressed they wondered about their illness, but some felt agonized, asking "Why me?" as an outward expression of anxiety and despair rather than a specific question regarding cancer cause.

There were two noted types of causes attributed to their cancer diagnosis. Internal causes included perceptions of being a bad child which consisted of morally bad behaviour as the reason for cancer diagnosis. Other internal causes included unhealthy eating habits, magical thinking where survivors thought they had cancer because they had negative thoughts or karma. Biological susceptibility, and personality such as sensitivity or irritability was also listed as a cause for cancer. External causes included stressors, random events, living environment and medical conditions [55]. Despite the mean age of diagnosis being 11 years of age, survivors in their young adult years were still questioning why they got cancer. The result of this study is of great cultural significance for CCS in Korea, as most children diagnosed with cancer were not even aware of the name of their disease.

Regardless of cultural differences, survivors of childhood cancer are very self-reflective throughout their cancer journey as both a patient and survivor. A study using a constructivist approach with an interpretive descriptive design utilized semi-structured and open-ended questions to explore how young cancer survivors perceived negative and positive outcomes after having finished treatment. Twenty survivors aged 18-35 years who had finished cancer treatment within the last 5 years were recruited. It was noted that survivors experienced positive and negative outcomes in the aftermath of their cancer treatment [53]. The overarching negative theme: “The cancer still hampers me” includes 3 sub-themes outlining the negative associations survivors experienced because of their cancer which included impaired function and changed physical appearance, intrusive thoughts and feelings, and distress to relationships. The positive main theme: “I have acknowledged what’s important in life”, contained 3 sub themes which included personal growth, a changed perspective, and the significance of close relationships.

This study revealed a high occurrence of negative outcomes within the physical, psychological, and social aspect of survivor’s lives [53]. Primarily, participants experienced fatigue as the worst negative outcome as it impaired all areas of their everyday life. Findings indicate that positive outcomes may be the result of a coping or adaptive process [53]. Their experience with cancer propelled survivors to acknowledging what is important in life, taking nothing for granted and using the time they have to follow their dreams [53]. To prevent negative outcomes and elevate positive ones, the findings indicate that young adults CCS would benefit from close follow up, screening and interventions throughout their entire cancer trajectory. In elevating the positive aspects to survivorship, it could better equip survivors in adapting and coping with their cancer experience.

Further exploring how survivors cope with their childhood cancer experience and its long term consequences, a descriptive qualitative study recruited 21 survivors to share their experience through semi-structured interviews [80]. The sample included participants who were aged 14-25, had ended treatment for at least 2 years and diagnosed between 0-14 years of age. Survivors expressed that despite their cancer experience being in the past, it still had a significant bearing on their current functioning. The following coping strategies aided survivors in acclimating to their experience, despite feeling as though there were challenges in their way to achieving normalcy. Survivors coped by focusing on the “here and now”, as uncertain as their futures may be, they avoided confrontation with possible consequence and learned to defer having to deal with it [80]**.** Survivors also refrained from discussing their cancer experiences, stating that not talking about it enabled them to safeguard normalcy and found it crucial to not be seen differently by their close friends or relatives [80].

Additional coping strategies include preserving positive memories and redefining their experience in a positive way, this was achieved when sharing their cancer experience and feeling connected to others, as well as adjusting their outlook on the severity of their impairments in the context of life or death. A sense of togetherness also equipped survivors with the ability to have a positive frame of mind, a good connection with the health care professionals who were part of their journey was also positively associated with this aspect of coping [80]. Interestingly, topic avoidance as a method of coping has not been studied in adolescents and young adults in the context of surviving childhood cancer, however there is value in this function as a coping strategy though avoidance tactics may seem problematic or concerning.

Connections and effective support systems for survivors enables them in having a positive mindset, however, there is limited research exploring romantic relationships and physical intimacy in the context of cancer experience [81]. In fact, most of the previous research on sexual dysfunction among CCS has been quantitative/survey-based using surveys that are not specifically linking sexual issues and the cancer experience [82]. A total of 40 semi-structured interviews were conducted to assess the psychosexual issues faced by survivors who were 23-42 years old and 1037 years post diagnosis throughout their care and survivor well-being. There was a total of 6 themes derived from this descriptive study. Theme 1 reported negative effects on romantic relationships, theme 2 reported positive effects associated with relationships, theme 3 expressed no impact at all on romantic relationships, theme 4 reported that participants perceived they had fewer partners than peers, theme 5 included chronically physical conditions that directly affected sexual function and theme 6 expressed that cancer had no impact on sex lives [81].

Emerging themes demonstrated negative and positive effects of surviving childhood cancer on romantic relationships, whereas effects on sexual and physical intimacy were largely negative and a subset of survivors in the study, reported no effects. CCS are more likely to report sexual dysfunction than controls [81]. Delays in dating were commonly noted in this study, however, were more pronounced among those who were diagnosed in adolescence rather than childhood. Findings emphasize the need to explicitly address the long-term impact of the childhood cancer experience on romantic relationships and intimacy, especially being that adolescents are potentially missing out on what is important developmental milestones due to illness and frequent hospitalizations [81].

The mentioned studies depict with further context the extent of the psychosocial impact of cancer in different aspects of survivorship, specifically regarding interpersonal and intrapersonal relationships. The links between childhood cancer and psychosocial outcomes are deeply rooted. Delving into the minds of survivors to understand their perceptions and thought process further highlights that the psychosocial impacts of survivorship are relatively lifelong.

It is rare for studies to use a holistic approach when exploring psychosocial outcomes of childhood cancer [83]. A qualitative study aimed at exploring the views of childhood cancer survivors regarding how they perceived their illness to have influenced their subsequent lives was conducted in the North East of England. Participants were diagnosed with a cancer before the age of 18 and were aged between 18 and 30 at the time of study and treated at a hospital in the North East. The study included patients in long-term follow-up (LTFU) care. A focus group and telephone interviews had taken placed, both being semi-structured in nature and consisting of open-ended questions. Participants were prompted by their views on different areas of their life including relationships, education, careers and health. There was a total of 12 participants in the study from the initial 122 contacted to participate. There were 4 survivors in the focus group and 8 participated in individual phone interviews. The median age at diagnosis was 7 years and the median age at the time of study was 23 years [83].

The study revealed that there were differing views regarding the extent to which cancer had impacted their present lives and this did not seem to related to age at diagnosis or diagnosis. Four participants expressed they felt strongly that being a survivor was a continuing influence on how they led their lives, for a few their illness was firmly in the past. In general, however, it seemed that the impact of cancer on them and their subsequent lives was a difficult concept to consider due to their young age at diagnosis and hence their lack of self-awareness at the time. Several survivors however, stated that once in a while they gave thought to where they would be in life if they had not experienced the illness [83]. Despite differing views of whether cancer had influenced their life paths or not, there were no survivors who felt as though they were in a worse off place in life because of it. Ultimately, there were a total of 3 main themes; altered life perspectives, perceptions of self and lasting effects on relationships.

Survivors discussed how the cancer experience had influenced their current approach to life and were acutely aware of the unpredictability and uncertainty of life and how this approach also applies to their future health. Ultimately, survivors expressed that worrying over what may or may not happen and on things you could not control was counterproductive, preferring to live each day as it comes. There was also a strong desire for family, however, there were feelings of uncertainty regarding infertility among many survivors. Survivors felt as though they had to make the most of every opportunity and to be thankful and appreciative of what they had. Survivors also felt that their experiences led them to develop greater empathy and consideration towards others and inspired several to pursue or consider a career in healthcare.

Regarding self-perception, survivors who experienced any physical changes as a result of their cancer experience, came to accept this change as part of who they are. In fact, those diagnosed as teenagers really reflected on their initial self-consciousness as a result of their treatment. However, this seemed to have lessened with age, as time went on acceptance of a physical appearance altered by surgery was said to be made easier. Physical appearance was largely discussed in relation to how survivors felt they were perceived by others. Insight was developed among survivors as they self-reflected on their experience. Many survivors felt as though their cancer experience gave them the strength to deal with situations they found challenging. Survivors even expressed that this perspective was helpful in navigating academia, where several stated they were determined to perform well in school.

There were also lasting effects on relationships, where many survivors referred to how protective their parents were as they were growing up, and in some cases even felt restricted in their ability to achieve independence. Survivors expressed that even as young adults, their parents found it hard to let go. As far as developing a family of their own, only two participants were married and most reported to be in a relationship and did not express that their cancer had impacted their ability to meet a partner. Only one survivor was a part, and although marriage and children were expressed as a desired in most cases, the majority of survivors felt it was not a consideration at the present time. As for friendships, survivors ultimately reported there were no lasting effects on friendships. There were some negative influences on friendships however, including not wanting to cause anyone concern with a cancer diagnosis, worrying about peoples reactions to disclosing cancer history, anxiety at being viewed as different to others, missing out on the stage of life when other friends were making close bonds and feeling like there were little things in common with peers.

Ultimately this study aimed to explore the long-term impact of cancer from the perspective of young adult survivors and gain insight into how they perceived their cancer experience influenced their life paths. All participants shared the physical, emotional, and social impacts of their experiences which continued into adulthood. The overarching theme was that survivors perceived their experience to have influenced their overall outlook in life. This study has provided a holistic and explanatory approach to survivorship and the lives of survivors several years after their diagnosis, and how navigating these aspects of life may have been influenced by their cancer experience. This demonstrates that psychosocial impacts are long lasting and ever changing.

Qualitative studies propel the voices of survivors and their families forward to bring further awareness to the areas of survivorship that may seem difficult to navigate. The prospects of future research in the qualitative scope provide relevant insights to address the needs of survivors whether it be through establishing interventions or improving/modifying the resources already available to survivors as they navigate their cancer experience as a survivor for the benefit of themselves and their relationships.

2.3 Gaps in the literature

Understanding the human experience can be beneficial to shedding light on survivors' lives and perceptions, rather than viewing their experiences solely through the lens of healthcare utilization, morbidity, and mortality analyses. As much as studies try, an experience cannot be quantified, and while the data from the previously mentioned studies can be beneficial, qualitative approaches to survivorship are very promising. In fact, there is a need in addressing the psychosocial domain of cancer survivorship, specifically regarding reintegration after cancer treatment, in effect it is one of the most important challenges faced by survivors and is identified as a priority to address in the future of survivorship research [84]. This highlights the need for further exploration of the psychosocial experiences faced by survivors of childhood cancer, more importantly, it calls for a qualitative approach, where the focus can effectively be on the survivors and their stories. Furthermore, this emphasizes the need to focus on survivors' experiences with reassimilating back into society, and the challenges and positive experiences associated with their journey from patient to survivor.

Many facets encompassing survivorship have been effectively studied using both quantitative and qualitative approaches, such as long-term risks associated with rates in morbidity and mortality, as well as particular psychosocial aspects involving income, education and relationships [31-34, 85, 86]. However, there is little literature which uses holistic approaches that evaluate the psychosocial burdens of surviving childhood cancer, and how all of these interact collectively throughout the human experience. Particularly, within the context of transitioning from cancer patient to survivor and how this process of reassimilation impacts other aspects of the survivor's life experiences, is not well understood. The perspectives of the survivors are often lost. Astonishingly, there are few studies done in Canada that take on a more holistic approach when exploring the effects of survivorship. Nevertheless, the literature available demonstrates a need to address the gaps and barriers faced by CCS in research. The gaps in research include the following themes: "Health care system barriers" and "Psychosocial impacts associated with reassimilating back into society". These themes arose as they were not reflected in the literature review when exploring components of survivorship, particularly in the Canadian context and notably lacking when observing the survivor's experience. It is relevant to survivorship, and how these aspects of survivorship influence reassimilation receive little focus.

2.3.1 Health care system barriers

The needs of adult CCS continue to be largely unmet throughout their initial diagnosis, during treatment and well into survivorship [86,87]. This is due to the ongoing effects suffered from their experience with cancer treatment [31,33,34,50]. Solutions to improve psychological interventions and modifications to transitions to care from pediatric to adult facilities are imperative [85].

Importantly, there is no evaluation of barriers faced by CCS who are no longer receiving medical care [54]. Moreover, there must be an improvement to the transitions to care from pediatric to adult facilities [84,85]. In fact, there is an acknowledged need to improve communication between primary

care as well as pediatric care to aid in the transitions of CCS into primary care services [84,88,89]. A combination of risk-based and patient-oriented solutions are recommended to benefit both healthcare providers and patients [88]. However, it is unclear how intricately the transition from cancer patient to adult care may impact other aspects of socialization and in re-entering a work and school life, or if these recommended solutions were formulated with this aspect of survivorship in consideration.

To date, is it not well understood to what extent health status contributes to not only adverse psychological affects, but how this, as well as how other facets of life, interact and impact each other. However, health status may affect mood due to limited social, employment and school functioning [89,90]. The ability to reassimilate back into society, meaning after treatment, returning to work and school or social environments, is impacted. However, thus far the links associated with reassimilation have been either social or psychological, and do not explore if the dynamics of this relationship, impact any other aspects of the survivorship experience, especially in relation to barriers faced in the healthcare system. It is also unclear how or to what extent the barriers present in the healthcare system impact survivors' ability to reassimilate in society. This leaves room for research to be conducted to explore unmeasured experiences such as the aspects of survivorship that impact reassimilation, with an emphasis on how these experiences collectively interact.

There is an urgency to improve psychological interventions and to make modifications to transitions to care from pediatric to adult facilities [54]. However, the solutions provided range from improved communication between healthcare professionals and survivors, knowledge and education, early introduction to transition, greater collaboration between health care professionals as well as improving how the healthcare system is structured [50, 89-91]. It is not well understood the burden this transition has on survivor's psychological and social well-being when reassimilating back into society. An essential avenue to consider when looking to understand survivors' transition within or relationship to the healthcare system, would be to start with their experiences and perceptions regarding their preparedness in reassimilating back into society. These experiences are rarely documented, if even a focus, in studies exploring survivorship.

The ability to ascertain that there is a need beyond clinical care that extends into adulthood, is an important scope of research that requires further exploration. The province of Ontario has seven multidisciplinary clinics for children and adults treated for childhood cancer that provides free services. This would imply that resources for children and adult survivors are both relatively accessible and available. While these resources have certainly lowered emergency room use, as well as emergency clinic visits, unfortunately, most survivor care is limited to the pediatric years [92,93]. A combination of risk-based as well as patient-oriented solutions are recommended to benefit both healthcare providers and patients. While these solutions are note-worthy and needed, there is a lack of exploration as to how reassimilating back into society can aid in innovating and establishing these interventions. Particularly when considering that most care provided to survivors is during their pediatric years, understanding and exploring life after cancer would be beneficial in supporting and advocating for risk-based interventions. It is unclear whether these barriers have impacted survivor's ability to reassimilate back into society and if their psychological and social well-being is impacted.

Earnestly considering the implementation of alternate methods, such as risk prediction, burden assessment and cost-effectiveness modeling may provide innovative approaches to guiding survivorship care [49]. This provides ample opportunity for the trajectory of survivorship to be vastly improved. However, it is within the scope of research where significant and effective change can start. In providing and retelling the stories of CCS, it is possible to unveil details that are fundamental to the support provided to CCS. According to young adult survivors, social support, prioritizing close relationships and facilitating positive changes in values and life goals should be fostered during the entire cancer trajectory, and this care is especially crucial after cancer treatment [94]. Herein lies the opportunity for exploration among researchers, and where participants may benefit in participating in this domain of research.

2.3.2 Psychosocial impacts associated with reassimilating back into society

There are a variety of health concerns experienced by CCS. While these findings can prove to be beneficial regarding screening and treatment, the psychosocial aspects of these conditions and how they can contribute to the overall health of CCS is not often discussed. Survivors are impacted psychologically because of treatment and socially, relationships are impacted, however this is often explored in the context of fertility status [52,53,81]. Young adult survivors experience psychological burden, negative effects in romantic relationships, challenges in communication with healthcare providers as well as gender stereotypes associated with barriers to fertility. The exploration of these themes is much needed in the realm of survivorship, despite it being in the context of fertility, the well-being of CCS remains poorly addressed [95]. While fertility status is an important component of this, it is still unclear to what extent these themes interact in the process of reassimilating back into society, and what other contexts are relevant in this process as well.

There is still an unmet need well into survivorship [91]. In fact, there is a need for interventions that target survivors who are suffering from work as well as education interruptions due to cancer [78]. Reassimilating back into society is an issue that increasingly impacts survivors, following them into adulthood. Individuals cured of a childhood tumour, suffer greater social as well as educational risks including the inability to obtain educational qualifications for school or employment when compared to the general population [90]. Essentially, health status may affect mood due to limited social, employment and school functioning [76]. Interventions should target important health domains, namely psychological risks such as vitality/fatigue, discomfort/symptoms, sleeping, and mental functioning issues [89]. Indeed, implementing these interventions could improve the psychological effects associated with surviving childhood cancer, however, for these interventions to be effective, what kinds of factors should be considered to shape these interventions? In what way would these interventions be relevant to survivors and their personal experiences? These are relevant concerns to consider when establishing an approach that would ultimately have an influence on the trajectory of survivorship among CCS.

While there is an association between childhood cancer and CCS's ability to reassimilate back into society, it is unclear in what meaningful ways this has impacted the survivor's trajectory in their mental, emotional, and social development. To put simply, it is only clear that reassimilating back into society and childhood cancer are linked, and it is unclear to what extent this has developed among survivors, how this interacts in other facets of life, and the lasting impact these interactions have on survivors.

In addition to physical health risks, survivors may experience a host of emotional and psychological distress, including anxiety, depression, and PTSD [88,96, 97]. Moreover, due to the intensity of cancer treatment, survivors face challenges in work and school environments, in fact, among survivors of pediatric CNS tumours, only 40% of survivors achieved full independence as adults [55,97]. Perhaps refining treatment, and improving predictions in health outcomes could help drastically change health outcomes for survivors [97]? Perhaps future research should focus on identifying genetic susceptibilities related to psychosocial outcomes to provide opportunities for preventive interventions among CCS [55]? In essence, if future research can identify or focus on genetic susceptibility related to psychosocial outcomes, then preventive measures can be put in place since the potential for outcomes has been mapped out before they can arise. This is just one possibility. Improving treatment options, gives preface to the expectation that with clinical trials we can expect better treatment options, which should not only help with treatment but has the potential to help patients with survivorship [38]. What are the possibilities that moving forward, research will focus less on improving and bettering treatment options, and focus more on the toll survivorship itself has on survivors?

There is a need to address the psychosocial domain of survivorship, specifically in the realm of reintegration after cancer treatment, it is one of the most important challenges faced by CCS and is a priority to address in future research involving survivorship [88,98]. Essentially the goals in improving treatment may have potential in helping patients with their survivorship, however, shifting the focus from improving treatment to the toll survivorship has on survivors' ability to reintegrate is imperative.

As noted, there is a need among studies for survivors to express their experiences regarding reassimilating back into society and the hardships associated with this process. In no way does the lack of this representation nullify the facts presented by quantitative studies, however, it does require further research to be conducted in the qualitative realm to identify how childhood cancer survivorship impacts the survivors' ability to interact in social, work and school environments, and for more work to be done in the psychosocial aspect of survivorship. In highlighting the evident psychosocial risks that arise due to having survived childhood cancer, there is a lack of exploration in how the experiences of survivorship impact any other social or psychological aspects of the experience. This leaves room for research to be conducted to explore these experiences, with an emphasis on how the different aspects of the experience collectively interact.

While health impairments are a relevant and an ever-present topic of discussion among survivors of childhood cancer, as it is among researchers, the voices of the survivors are lost, especially among quantitative studies. Essentially, it is not well understood to what extent health status contributes to mental health and other aspects of life or how the experience with reassimilation back into society including work and school impacts the journey from patient to a member of society from the perspective of young adult survivors. It is also not noted in the literature how the transition from cancer patient to survivor, impacts the survivorship experience other than in the context of health care system barriers and service utilization.

CHAPTER THREE: METHODOLOGY

This chapter details the process in which this study took place. The study design and the tools used to answer the research question using a qualitative lens, the research team, population under study, recruitment process, synthesizing the interview guide, data collection and analysis are elements that are also discussed in this chapter.

3.1 Research Team

There are four researchers involved in this study. The research group consists of myself, a master's student, and two committee members; Manon Lemonde RN, PhD who is a qualitative and mixed-methods researcher with experience in oncology and an Associate Professor at my institution and Michael Taccone MD, PhD who is the founder of the organization Childhood Cancer Survivor Canada (CCSC), a partner in this project, and an Adjunct Graduate Faculty Member at my institution. There is one thesis supervisor, Otto Sanchez MD, PhD, who is a Professor at my institution and has research experience in oncology. I came across this thesis idea alongside my supervisor, and found I wanted to explore the realm of childhood cancer survivorship in more detail for personal and academic reasons. I then contacted CCSC to form a partnership in hopes of getting to know the participant population, as well as to ascertain and understand the needs and experiences of this community. As the primary researcher, I would like to contribute to this community, to me, this means having a meaningful relationship with my participants. I want to explore the meaning of their experiences alongside them, and for these experiences to bring meaning to others. Most importantly, I want to learn from, and to understand their life experiences and to foster an environment of self-reflection for both myself and the participants.

3.2 Participant Population

3.2.1 Inclusion & Exclusion Criteria

The participants included in this study are of the ages 18-29 as is typical for studies involving cancer and survivorship among young adults [99]. Additional inclusion criteria include being in current remission of cancer, with a diagnosis at the early, formative years of life, such as from ages 5-16 years [60]. Due to the nature of this study relying on participants to recollect their experiences with cancer, the age range 5-16 is appropriate although pediatric oncological studies typically include children ages 0-14. The amygdala is responsible for the perception of emotions and helps to store memories of events and emotions. After the age of 4 in both males and females, the increase in development to this area as it pertains to aging is non-linear. The maximum volume of the amygdala is typically reach between ages 9-11 years of age [100]. At this point in life, children are able to remember things consistently and the focus of this study relies heavily on recall, being able to comprehend and analyze one's feelings and experiences, as well as any notable changes to their new environments as a result of their cancer experience, making the ages 5-16 the most ideal age range to explore the nuances of survivorship.

The overwhelming majority of childhood cancer patients in developed countries are cured of their original malignancies, the 5-year survival rate is nearly 80% [32]. A cut-off of 5 years is appropriate for cancers where most patients survive more than 5 years, thus, participants who survived at least 5 years since their initial cancer diagnosis were included in the study sample. Exclusion criteria include ongoing cancer treatment/therapy, those who do not currently reside in Canada, and those who were not diagnosed and treated in Canada.

3.2.2 Sampling

Criterion sampling and snowball sampling were used for this study. Criterion sampling allowed me to select individuals that met the predefined criterion, the most prominent being having experienced the phenomenon under study [101] . While the phenomenon is shared, participant characteristics will vary (age, race, sex, cancer type, etc.) thus impacting their individual experience. The snowball method of sampling is when participants are referred by other participants or by a person who has access to potential participants [99].

The projected target for the study's sample was a total of 8 participants who will be recruited via CCSC, a partnering organization in this study. This sample size is considered appropriate as the usual sample sizes for phenomenological studies range from 6-10 participants [102]. As a gatekeeper, CCSC provides invaluable access, knowledge and connections with the research population [103]. CCSC also represents the population under study [104]. The goal is to include and emphasize the voices of the participants as much as possible throughout the research process as is typically done in interpretive phenomenology.

3.3 Recruitment

The recruitment process involved the use of social media as a strategy and tool. An announcement was placed on CCSC's Facebook and Instagram page on November 9th, 2021, and on their Instagram story and Facebook page on January 18th, March 21st 2022, April 7th 2022, and ended June16th 2022 (refer to Figure 2A). The link to the google forms to sign up for the study was deactivated August 23rd, 2022. There was a total of 9 responses. One had piloted the interview guide, 1 was a parent of a survivor, thus not meeting the inclusion/exclusion criteria, and 3 did not respond to follow-up emails. Potential participants were briefed on the purpose and aims of the study through clicking on the google forms link and accessing the consent form (refer to Figure

2A). During the consenting process participants could volunteer to participate in the Phase I of the study, which involved piloting the interview guide, and/or Phase II of the study, which involved data collection. Once the consent form was signed, participants were sent an email (refer to Figure 2B), to set an interview date. Once a date was confirmed, participants were sent the interview questions (refer to Figure 1A). A total of 4 participants were interviewed following the consenting process.

3.4 Interview guide

Two frameworks were used as a guide in synthesizing the interview guide. The frameworks used explored the psychosocial impacts associated with surviving childhood cancer [105,106]. Despite these frameworks being used in developing the interview questions, the format typically used in interpretive phenomenological approaches was maintained, for instance participants were asked to recollect their experiences by providing examples and in describing their feelings, this way the context behind the experience as well as the phenomenon itself can be understood [107]. Both frameworks evaluate the impact childhood cancer has on survivors, using the scope of social determinants of health and quality of life to assess physical, psychological, social functioning/wellbeing, and environmental conditions as well as the pathways by which social determinants may create health inequities at different points of the childhood cancer trajectory and how major determinants relate to each other [105, 106].

These frameworks were chosen based on the comprehensive structure it will provide the interview guide when assessing the different aspects of survivorship and what may affect them. The social determinants of health may create health inequities, impacting the trajectory of survivorship for survivors of childhood cancer. Utilizing these frameworks in shaping the interview guide provided the opportunity to assess the major aspects of survivorship and how these domains may relate to each other. In my analysis, this would enable me to assess how emerging themes interact with each other as a collective.

The “Childhood Cancer Continuum” is a conceptual framework based on the “Commission on Social Determinants of Health Framework”, specifically addressing the underlying mechanisms and pathways of social inequities in and after childhood cancer [105]. This is an enhancement to previous conceptual frameworks as it takes the course of childhood cancer into account and stresses that each phase of the childhood cancer continuum is impacted by varying social determinants of health. The conceptual framework of “Interrelated Processes of Managing Impacts and Effects to Achieve/Maintain Quality of Life for Childhood Cancer Survivors” describes past illness leading to lasting impacts as well as affects life, describing interrelated processes of positive personal coping and environmental supports that survivors used to manage the impacts and effects of having cancer [106]. Both frameworks have been synthesized when exploring survivorship and the elements of survivorship that are influential to life during and post-cancer.

The baselines used in the interview guide derived from the frameworks were “Adopting a positive outlook”, “Coping behaviours and Mental Health” as well as “Socialization, seeking others” [105,106]. Each baseline was molded to assemble the interview questions and aided in narrowing the research focus. Each major question addressed a specific focus in this study and was developed to address the context of reassimilating back into society (refer to Figure 1C). The interview questions were designed to encourage participants to analyze their experience and how this experience has interacted with other facets of their lives, as well as to generate an understanding of how these aspects of survivorship interact with one another and what it means to the survivorship experience.

3.4.1 Pilot

The interview guide was piloted with 1 survivor who met all the inclusion and exclusion criteria except one as they exceeded the age range under study by one year. The interview was approximately 60 minutes in duration with all questions being tested/asked. There were no adjustments or modifications made to the interview guide after it was piloted. As seen in the appendix, Figure 1A was made available to participants whereas Figure 1B was for my use as the interviewer.

3.5 Data Collection

3.5.1 Interviews

Individual in-depth semi-structured interviews were conducted by myself, the master student via Google Meets and lasted approximately 60 minutes each (refer to Figure 1B). During the interviews, based on the information provided by the participant, not all probes or questions needed to be asked. Note taking during interviews were omitted in this process as it was more advantageous to fuse my note taking with my analysis of the interview while performing reflective journaling and bracketing. Upon completing each interview, I conducted reflective journaling as well as bracketing [107,108]. A thank you email was sent out to the participants after their interview along with a list of support services (refer to Figure 2C).

3.5.2 Focus Group Discussion (FGD)

When all individual interviews were completed, participants who provided consent to being contacted for a focus group discussion received an email, asking for their availability. This process was approved by the research ethics board as an additional method of validation regarding the study's results and interpretations, providing participants the opportunity to make their own interpretations and be a part of the analysis process. Thus, new data was not being collected in this particular phase of the research process.

All 4 participants were interested and had consented to participating in the focus group discussion upon receiving their consent for participation, however, there was a total of 2 survivors who participated in the focus group discussion which was held November 11th, 2022. In this 50minute conversation, the work I shared included a description of each major code and sub-theme and the quotes associated with these sub-themes. After each code and sub-theme was shared, I provided the opportunity for discussion and the sharing of perspectives. Following this, my interpretations of these experiences was also shared and opened to discussion. Survivors communicated their thoughts concerning my analysis supplemented with their own interpretations of the findings.

3.6 Data Analysis

3.6.1 Transcription

Before the analysis of each transcript, all interviews were transcribed verbatim by hand from their recordings. Interviews were transcribed verbatim to assess participant's experiences and aid in the analysis process. Each audio recording was transcribed within the first two weeks and took 4-6 hours spanned across two days to transcribe. Every individual transcript was read twice alongside the audio recording before it was modified to be sent to participants and the research team. Birth date and any information provided that would have violated participants' confidentiality was blacked out. After being sent to the research team the recording was deleted. Transcripts were also given participant codes (P1, P2, etc.) to establish anonymity among the research team once shared. These modifications were done on word and converted to PDF before being sent out to the participant for validation and to the rest of the research team. The de-identified data was stored on dataverse as an unpublished dataset, which the research team had access to. The word and PDF format of the transcripts were also stored on my laptop and password protected.

3.6.2 Analysis

After an interview was transcribed, it was analyzed using interpretive analysis as well as Taguette, which is an open-access, free qualitative analysis software used to assign codes to transcripts [99]. Interpretive analysis is bound to the account of the experience as detailed by the participant. This method is used flexibly and can also be done during the interview as the participant is answering questions and being probed on suspected themes and experiences [109]. Essentially, it involves looking in detail for themes case by case, starting at individual experiences, and then progressing to look for patterns across cases, encompassing all other experiences. During the process of data collection, a list of significant statements/themes was generated, this was mainly derived from the notes I, the master student, made after each interview. These statements are a foundation to understanding the phenomenon [110].

After having developed these statements, grouping them into larger units of information allowed me to provide a general theme or code according to an experience lived related to the phenomenon [110]. Writing a description of what the participants experienced is known as "textural description", these descriptions were accompanied by verbatim examples [110]. These methods allowed me to reflect on the experiences as it is described by the participant and understand the themes that are shared among the differing events experienced as it relates to the phenomenon. While performing this phenomenological method of analysis, using "structural description", allowed me to reflect on the context and setting in which the phenomenon was experienced [110]. Combining the structural and textual descriptions provided the essence of the experience, representing the culminating aspect seen in phenomenological studies [110]. The analysis process is one that uses thematic analysis and a retrospective lens of interpretation of the interview transcript. Transcripts underwent a total of 3 analyses, the first, assigning major codes. The second, appointing subcodes; and the third, seeing where there was interaction between subcodes of different major codes.

3.7 Methods for Research Rigor

Implementing methods for credibility also enhanced the trustworthiness of my research which is essential in validating both the research process and its findings according to Lincoln and Guba (2000).

3.7.1 Credibility

Credibility demonstrates that there is truth in the presented findings and ensures rigor in the research process [110]. This was achieved by prolonging engagement with participants. A method that was implemented to ensure credibility was the process of member-checking. Member checking allowed participants to validate, clarify or elaborate on the research product at which point they might confirm my interpretations or challenge them [111] . This approach provided increased opportunities for participants to be included in the course of research. In the context of phenomenology, this process of validation is appropriate as the interpretivist approach relies on participants to be a part of the research process as researcher and participant work to understand the meanings associated with the experience.

The member-checking process was conducted as a two-step method. In the first step, once interviews and transcriptions were completed, and upon having received consent from participants, they received their interview transcript with personal identifiers removed, to review and confirm the data collected from the interview. A total of 2 out of 4 transcripts were validated. The first was validated May 10th 2022, and the second transcript was validated August 16th 2022. Once the transcripts had been sent and/or validated, participants also had the opportunity to participate in the second step of member-checking which involved a focus group discussion, not as a method of data collection but as a chance to share preliminary work and themes. This was a chance to bring participants back and share with them what was emerging from the data. It provided ample opportunity to determine how much these themes resonated with other survivors and the meanings these themes carry regarding their experience.

Not only are these methods of validation important in the context of credibility but establishing a constant relationship with participants throughout the process is exactly what is required from an interpretivist approach. I cannot infer meaning and interpret their experiences without their input, this process places value in their perspective and brings their voices to the forefront of the research.

To enhance credibility, I utilized theory triangulation. This process uses multiple theories or hypotheses when examining the phenomenon in a different perspective, these theories do not necessarily have to be similar or compatible [110,112]. I also used a holistic approach as opposed to exploring certain outcomes in isolation. This enabled me to gain an understanding of the relationships between outcomes and how several areas of a survivor's life are interconnected [90]**.** This was enhanced when synthesizing the interview guide as it permitted me to combine context to their experiences. Based on what was observed across the interviews, I generated statements that considered multiple instead of isolated contexts within the survivorship experience, this includes whether outlook on reassimilation, outlook on coping and outlook on cancer were connected in some way as revealed by the participant's responses.

3.7.2 Transparency

Transparency is an essential part of qualitative research. Without transparency it is unclear how much of the researcher's thoughts, feelings and biases may influence or obstruct the research process. Reflective journaling allowed me to document my opinions, thoughts, and feelings to enforce transparency throughout the research process [108]. My journal entries were private and was not shared with participants or the research team. It was also fitting to include bracketing, which is the monitoring of oneself. This allowed me to manage my subjectivity and assumptions or biases regarding the phenomenon under study [112]. This process was crucial in lessening any of my preconceived notions to prevent interference with data collection or analysis. These approaches were for my benefit as the researcher to mitigate my biases. Both methods were conducted after every interview, where I would write a summary of what stood out the most to me regarding the participant's experience. Writing down my own perspectives of their experiences reinforced transparency, in doing so I was able to understand my thought process by removing each thought and isolating them from the participants experience to understand their subjective experience.

CHAPTER FOUR: RESULTS

In this chapter, I share the study results obtained from individual semi-structured and focus group interviews. A total of 4 participants participated in this study and shared their experience with childhood cancer. And a total of 2 participants participated in the focus group discussion. Discussed in this chapter is the participant sample and the steps I took in performing my qualitative analysis.

4.1 Study Population

Patient Demographics	
Age at diagnosis	**P1:** 13 years, 15 years into survivorship **P2:** 10 years, 9 years into survivorship **P3:** 14 years, 11 years into survivorship **P4:** 16 years, 10 years into survivorship **Mean age of sample at diagnosis:** 13.25 years
Diagnosis	**P1:** MFH [malignant fibrous histiocytoma] or spindle cell sarcoma **P2:** Acute lymphoblastic leukemia **P3:** Stage 3 Hodgkin Lymphoma **P4:** Stage 4 B Hodgkin lymphoma
Treatment	**P1:** Chemotherapy for less than 1 year and surgery **P2:** Chemotherapy for 1 year, CAR T-cell therapy at relapse **P3:** Chemotherapy and radiation for 6 months **P4:** Chemotherapy for 9 months, radiation for 30 days and surgery
Ethnicity	**P1:** Caucasian and South American **P2:** Caucasian **P3:** Middle Eastern **P4:** Caucasian
Gender	**P1:** Female **P2:** Male **P3:** Female **P4:** Male

Employment Status	**P1:** Non-Student; personal trainer **P2:** Student **P3:** Non-Student; Call center employee **P4:** Student All participants obtained an undergraduate level of education.
Age at time of interview	**P1:** 29 **P2:** 24 **P3:** 27 **P4:** 26 **Mean age of sample at time of interview:** 26. 5 years

4.2 Codes

There were 3 major themes derived from the data collected during analysis (refer to Figure 3A). Each major theme was based on comparison, meaning the participants perspective reflected their sentiments either of themselves, to their environment, or provided a more objective account of their experience [58]. Each major theme was founded on the baselines used in synthesizing the interview guide. Different subthemes were generated based on specific sentiments associated with the major theme (refer to Figures 1C and 3B).

4.2.1 Outlook on Reassimilating

This code was assigned to quotes where participants explained their sentiments regarding the aftermath of their experience with cancer, including changes observed within their social environments such as family, friends, peers, and relationships and described as a theme. Outlook on reassimilating provided participant accounts on their inward perspective regarding their outside environment. There were 2 subthemes generated from this major theme which are the “perceived ability to reassimilate” and “forming connections”.

4.2.1.1 Perceived ability to reassimilate

The "*Perceived ability to reassimilate"* explored participant perspectives and sentiments on returning home, with reintegration into school, or work after having cancer. Specifically recalling in what ways their ability to reassimilate back into these environments were impacted.

For instance,

P1 stated,

> I think where the difficulty was, wasn't so much when I had time to process it. It was more in isolation; I couldn't be constantly reminded of how different and limited I was. And I was very athletic, and very independent, I've always been very independent. So, I think that was the more difficult portion, going into 10th grade and realizing that my teachers didn't want me to walk on crutches because they were scared I was going to fall, so they wanted me in a wheel chair still. And even standing up realizing how difficult it was to get from point A to point B in the 5 minutes we had between the periods, and things like that. That's where I think a lot of the trauma really happened because it was like "Deal with it, and life or death, right when it's happening" but then nobody bothered to transition me really into normal life, or to help me understand what I'd expect.

and P2 stated,

> I don't mean normal like I want to go hang out with my friends, I mean like I want to go to university, that's my goal. And when I have that goal, I was pretty behind.

and P3 stated,

> I went to high school, finished my 9th grade with marks that everyone was very generous to give me because I was missing for most of the year.

and P4 stated,

> At UOIT [University of Ontario Institute of Technology], it was fine. When I switched to McGill, nothing was recognized, and I really had to like "Bro I had cancer" (*laughs*). You know, it's like they just don't get it even though these people are like psychologists or whatever training. So that's been the toughest for me personally because I didn't really have any crazy side effects of treatment that physically have hurt me. It's been more of the like, education.

Participants shared their sentiments regarding their returning to school post-cancer, and what kinds of barriers were faced in this environment. Specifically, barriers associated with their ability to acclimate to a learning environment and the sentiments associated with this experience. Even years later in the pursuit of post-secondary studies, survivors shared that cancer had limited them in some sort of way. However, there were instances where participants felt they were able to overcome barriers faced in a work or school environment. For example,

P1 expressed,

> I learned how to work out in a way that isn't really normal for most people.

and P3 expressed,

> Going to class that was like the easy part, it's something I enjoyed. If I could spend the rest of my life just going to classes and going to university I absolutely would.

Participants also shared certain aspects associated with their ability to reassimilate, particularly regarding the deficiencies associated with the healthcare system and healthcare professionals (HCPs). For instance,

P1 stated,

> Initially, as a kid I saw myself as different or almost less. Because, again nobody really taught me how to transition back to life. And that's I think, the one thing that was really lacking and is lacking with a lot of cancer patients as kids.
>
> As someone, especially someone with a very physical limitation coming out of having cancer, nobody really taught me to expect that I wouldn't be able to do certain things.

and P2 shared,

> I kind of wish there was more stuff in place for that transition and was a lot more explicit than implicit, which I think kind of affected at least my first couple of years where I was sort feeling stuff out-I kind of wish there was more of a grey area than sort of me dealing

> with an extreme where, you know how they can go like fully into the university experience or just kind of away from it. Because I wasn't as maybe as emotionally prepared for that as I should've been or could've been.
>
> I wish I had more support groups.
>
> I feel like I never really got the social stuff, but I got a lot of the more institutional kind of deficits that you'd see and just, the support systems too that I didn't really feel were as promoted I would say.

and P4 stated,

> You kind of feel like, once you graduate from the childhood cancer to like the adult world you get a kick on the *** and that's it. You fought. After you've survived 5 years it's like "you're on your own" type thing… it's such a vulnerable age and emerging back into the world is really – these people are super, super – yes just vulnerable.
>
> It's definitely a culture shock going in and then coming back out of the whole cancer care system.
>
> I think it would have been like just more prepared. Or just have more – know what to expect.

4.2.1.2 Forming Connections

The second subtheme "*Forming connections*" determined survivors perceived ability to form connections with their peers, family, and friends after having cancer and how establishing or maintaining these connections were altered while reassimilating.

P1 stated,

> The way that I used to deal with meeting people and relationships was very different when I was in my teens just because I was so isolated at the beginning, that I found it very hard to become friends with people.
>
> In terms of friendships and meeting new people it was very, very, different and I didn't quite put in the same effort I think into keeping up with people because I knew that eventually it wouldn't work out.

and P2 expressed,

> Your expectations versus the reality when you go back to any social setting is a little, I mean it's a little overwhelming.

> When you go back you have a lot of people that are sort of being nice to you, and they're not really-its not really real or like genuine so then that can kind of go to your head a little bit.

and P3 shared,

> I would not really have any deeper relationships, still don't have a significant other either. It's like putting things at a distance, keeping everything as far away as possible without shunning them. So that it doesn't become obvious that this is what I'm doing. Just in case on the off chance it [cancer] comes back.

and P4 shared,

> People don't appreciate the gravity of the situation. And, I mean, you yourself don't appreciate it until – you know in retrospect.

Some participants also shared in what ways they felt their cancer experience altered their ability to connect with members of their peer group, ultimately altering what participants perceived as priorities and how their views fundamentally differed as to that of their peers. For instance,

P1 stated,

> I think I had to mature really quickly in that sense. And I was able to communicate better with doctors and nurses, and with other people who I considered more my peers at the time because I was able to talk to them properly.

and P1 also shared,

> I didn't even go to my convocation; I thought it was a waste of time. I didn't want to sit in a room and just have peoples name listed off, to me I didn't care about that. I didn't want to celebrate that the same way because it wasn't some huge change in my journey, it just seemed like another thing I was doing along the way.
>
> A lot of things that as a teenager or as a young adult that might seem like really cool important milestones weren't quite as important to me. I did want to do the same things, I did want to still have the same experiences, but it wasn't like this amazing, life altering, memorable, amazing event.

> Realistically making sure that my leg is feeling okay is always more important, and it does tend to take a way from a lot of the stuff that's happening in my life. But also, just because I didn't find it as big of an importance as other people would.
>
> I think things like that, have really changed my perspective because I know what things are truly important - when I truly look at it, small things that happen that are bad in my life aren't quite as important to me. It's just well, like "it didn't work out move on" vs. "my whole world falling apart" the way some people have, because that is the worst thing to have happened to them.

P2 stated,

> When you have people and you're trying to level with them, they're dealing with their mental health stuff because they're in early adolescence and they're trying to grapple with growing up and I'm grappling with just trying to be a survivor, that's a lot different. I don't want to diminish their mental health issues, but they're crying about more superficial things whereas I grappled with my mortality when I was 10.

P2 also shared,

> "You don't really know what this is like. You're upset that you broke up with your boyfriend or girlfriend" and I'm like, "My platelet count is down by 3 points, and I'm worried I'm going to get cancer again". The levels of stuff is very different. Just trying to tell people in my peer group that was really, really hard.
>
> You can't tell someone in your peer group "but I had cancer" that's not a valid excuse because they don't know what that is. They have no idea of the mental trauma that is cancer. The amount of times that you've beaten yourself up because you're like "man I wish I was out there playing with my friends and having fun but I'm throwing up in a bucket" and there were times too, everyone hated me because I would always tell people "Yes but I had cancer." And they'd always be like "what is that? You look so healthy, you're this and that." But I'm like "cancer isn't just the 5 years you're on treatment for, it's a lifelong thing".

Peer relationships were not the only relationships that were altered or seemingly remained unchanged, there are other accounts from survivors concerning their experience with cancer and how it impacted their family dynamic. For instance,

P1 stated,

> There were periods where we clashed quite a bit because she [Mom] didn't understand my need for independence and where it stemmed from, because she couldn't understand why I wouldn't just accept help. Her need to help me clashed with my view of my own value and how being helped all the time felt. So, I think that's always going to be a bit difficult forever because she's just – we're locked into that kind of state.
>
> My dad, is pretty much the same I think he was the least affected by it, stressed at the time but then we kind of went back into our old patterns of doing things.
>
> My brother I think, was the one that I kind of feel guilty about. He was in 5th grade, and he got almost completely abandoned when I got sick. My brother was very much more open, less shy than I was when I was a kid, and I think he completely switched because of me. And that's the one thing I do 'til this day feel bad about, he got really quiet, he got really shy. I think that's the one thing outside of my control that I really regret. Our relationship was never the same, we don't really talk.

and P2 expressed,

> My mom was very protective, she didn't really want me to go to the playroom and stuff like that, so I think even that kind of made it a lot harder and stipend my ability to assimilate when I went back to school too.

P3 shared, Sometimes she does travel, and then I do stay home alone. But it's still being in the same house that she stays in. It's still being in the same environment, it's always her friends who are calling to check up on me. It's like, come on, I'm like 18 and above. If I'm legally allowed to vote I can probably not set the house on fire (*laughs*). So yes, it's a lot of the stifling of the autonomy.

P4 stated, Post cancer, I don't think it changes at all. Certainly, during diagnosis, it brought us close together, and after I finished treatment, my mom was able to start back work again and like it's been good for me. I'm close with my brother and my family. I don't know how it is for them. I don't think my parents unpacked the whole situation, but there's definitely something there. But, yes it hasn't really changed. We moved, we did regular things, my parents still maintained their friends, we still stayed fine. My parents didn't divorce or anything.

Socializing seemed to be a barrier for most but not all survivors. Specifically, within the context of a learning environment, where social interactions were inevitable, and how missing what was considered an integral part of schooling impacted their ability to form connections. Those diagnosed as a child seemed to have suffered more from social exclusion rather than those diagnosed in adolescence though the experiences shared were similar. For instance,

P1 stated,

> The way that I used to deal with meeting people and relationships was very different when I was in my teens just because I was so isolated at the beginning, that I found it very hard to become friends with people.

also P1 also stated,

> I went to my first day of 9th grade and then was gone for like a week and a half. So that critical moment where you meet people is not really there. So, I think I just focused more on school and relationships with adults.

also P2 shared,

> I missed grade 10 and that was a big year. Because you can go from being a nerd to a super popular person, you're outgoing, you're going to parties you're like – you completely do a 180 transformation, so I wasn't there for that, and then I wasn't there for all the in-class gossip.

also P3 shared,

> The first year was a bit difficult because going back to school learning and then as well building a social life. At that time everyone already had a social group to be part of because it was like half of the year already done with. So, it was kind of weird that way.

also P4 shared,

> I was a year behind all of my friends. And so, when I came back it was like I knew these people, but they'd also grown beyond me or whatever. So that was kind of weird.

However, P4 also shared,

> My other friends were just like "If I get into Queens, that's all that matters, and I've peaked." And I was like "that couldn't, yes (*shakes head*) (*laughs*)– that doesn't appeal to

> me" So, it was more dealing with that and losing friends but it's-it's not like it affected me it was more like a calculation that I had made consciously myself.

In acclimating to their new circumstance, participants also shared their current experiences concerning social environments including friendships and relationships several years after reassimilating. For example,

P1 expressed,

> I did join a team and found kind of a more upper body sport, and then I realized that I could try to make relationships like that because it seemed like we were all mature enough at that point that we could deal with longer absences of not seeing each other and still keep up with things. It did get better and did evolve but, I still do have difficulty with that because of things like that, where I didn't have the same social relationships growing up, and the same went for relationships.
>
> I think the most difficult thing in the beginning when you're young is trying to figure out how much do you tell a person about what happened to you when you're trying to date someone and become friends with someone. I still don't think I really have that at the right spot.

and P2 expressed,

> Sometimes even now I feel like I have been stagnant since my first year of university and I'd like to grow out of that shell a little bit but even now I'm still unsure and uncertain about how to go about that, because just from a social perspective I'm not at the level of my peers.

and P3 expressed,

> I'm getting better at it now; making friends and meeting new people. But like I said it took 10 years to change that one for me.
>
> Very recently I'm trying to put myself more out there.

4.2.2 Outlook on Coping

This code was used for quotes that describe the participant's feelings regarding reassimilation but specifically within the context of acceptance and learning to embrace their new reality. Outlook on coping provided the account of survivors sharing further inward perspectives on themselves during their experience while exploring mental health and coping behaviours. There are a total of 3 subthemes which are the “ability to cope”, “views on oneself” and “coping tools”.

4.2.2.1 Ability to cope

This subcode describes perceived difficulties on accepting their new circumstances and learning to deal with their experience while reassimilating. For example,

P1 stated,

> I expect to just be like - continue to just deal with it or go right back into the way I was dealing with things before, which obviously with one less working leg, it was completely different. So that’s where a lot of the issues built up and a lot more of my trauma happened with a lot of the - all the complications that I actually got as a result of the cancer and all of the surgeries and stuff like that. So, I think that with each like new surgery or new issue, my ability to cope with it was worse, and worse, because there would be new hurdles constantly and it was like “enough is enough”.

also P2 stated,

> When I was younger, I was going out, I wasn’t really focusing on school, I was rebelling a little bit more because another thing too is when you have cancer and you go from well, “I have to live on to the survivors’, part of you that you have to reconcile is that you’re mad at the world.
>
> Then when you’re mad at the world it’s like “well why did this happen to me?” “Why did they chose me to have this disease?” Once you get over that, which takes you at least 4 or 5 years you begin to - you want to be more of a steward. You want to be able to take care of the next generation.

There are additional statements made by participants associated to their ability to cope. Specifically, in the context of accessing resources and having the appropriate support impacting their ability to cope when reassimilating. For example,

P1 shared,

> I felt very angry because not only was my body failing me, it felt like people were failing me because nobody actually taught me how to cope with it, or how to dealt with it or how to figure out how to get back to where I wanted to be.

P1 also stated,

> Nobody really kind of taught me tools to do on my own or things to like cope at the time. So, I think that was the most difficult part at the beginning.

and P2 shared, There's not really that support group and I think it's a lot of mental health kind of things there, just not a lot of promotion and a lot of awareness that goes on but it's kind of there implicitly, but it's not in your face. So, I kind of wish I had that.

> I wish I had more support groups.

and P4 shared,

> You graduate at 18 and you're out of the – children's hospital and 5 years out and there's nothing. There aren't – there's one survivorship program at Princess Margaret and you don't really get any follow-up through that. So, I think for me, it's been that. Not that I struggle severely with mental health issues, but at least having the reassurance or there's something or some sort of system in place that you could reach out to if you need that.

4.2.2.2 Views on oneself

This subtheme accounts what values have changed and any characteristics that participants felt were impacted by cancer in a self-reflecting context in relation to their transition from cancer patient to survivor. For instance,

P1 expressed,

> I almost saw myself as kind of less at the beginning, because the way I used to view myself, was as a very highly accomplished academic and competitive driven athletic person.
>
> It was a lot of frustration, feeling inadequate, feeling basically like a failure at the beginning.
>
> When I'd fall, I'd be angry at myself, I wouldn't want help, I wanted to be independent. So I think a lot of that, feeling a complete loss of control and independence and feeling like somehow I had become somebody who was-I wouldn't use the word crippled, because I've never really seen myself as a cripple, but more kind of just so incapable of doing things by myself, that at it was just-that at the beginning I was like "what is the point really, because I can't do anything by myself".

P2 shared,

> I was always pretty shy too, so I think it [cancer] kind of, amplified that in a way.

P4 stated,

> Before I was sick, I was definitely a different person. Before I got sick, I liked to party and hang out with friends or whatever but when I got back, it was like "**** I almost died, and I don't know what I want to do so I should clean up my act a bit".

However, these aren't the only changes faced by survivors, some participants shared how cancer has shaped all aspects of their transition using a positive outlook. Specifically, in regard to the people they are now. For example,

P1 stated,

> I think because of that and through sheer stubbornness, I pride myself in my independence to a fault now and I have forced myself to learn how to do more than even the regular post cancer survivor with missing parts of her body can do, right? So, I think that's a bit more different, I'm kind of, almost, I guess like I'm strong in spite of it, rather than because of it.
>
> I was powerful enough and stubborn enough, and strong and independent enough that I was able to kind of just – say " **** you" to my leg and kind of deal with it.

P2 expressed,

> I never really wanted, to be thought of as someone who was weak, or like a coward too so I think it made me mature a lot sooner than a lot of my peers and it made me a lot more resilient.
>
> There's a lot of times where, and I still kind of do it, where you just beat on yourself. And well I'm not, normal yet, and you sort of have to go beyond that and sort of say "well how am I now versus how I was 5 years ago" and you sort of need that comparison where every year I'm getting better and better.

Some participants also share what kinds of aspects they are facing now related to their assimilation and moving on from their cancer experience in a way that impacted their transition.

For instance,

P1 stated,

> There was that kind of fear of rejection, and like I said my own self worth was measured by how independent I was for a lot of my life. It was a bit difficult in that sense where I didn't see myself as somebody worthy of getting to know or dating because I didn't find myself, that I felt I had value because I was so, I guess dependent on other people. I think that was the difficulty and even now I still struggle with it at times, just more in terms of the judging my worth by my own views.

and P2 shared,

> From a more philosophy, kind of mentality type perspective, I think I'm light years ahead, but there's this thing where everyone at this age too they're at different levels to it, some people are catching up to me and some people are still sort of maybe have just gotten to that level too, so it's cool seeing that.

and P4 expressed,

> There's all these kind of setbacks that are attributed to cancer but also you don't want to make that a buck, or make that like a scapegoat type thing. So, it's kind of a tough game to play especially since I'm so far out of cancer treatment it's like, is it cancer? Is this an issue of survivorship, or is this me?

4.2.2.3 Coping tools

Participants described tools and methods, or protective mechanisms used to navigate and mitigate difficult situations while reassimilating back into society because of their experience with cancer. For instance,

P1 shared,

> I spent a lot of my young adult years ignoring it, and it doesn't really work out very well because the more you deal with it the more it becomes kind of an impartial thing.

and P2 expressed,

> Before I even discovered playing basketball, a lot of it was just not very good coping mechanisms. It led to a lot of paranoia and stuff too and uncertainty. I think for me the biggest thing was just talking to someone who was kind of outside my peer group, who wouldn't have a biased opinion that wasn't like my parents, who would kind of give me advice and stuff. So, I'd go see my guidance counsellor or my therapist and just talk stuff out with them. Yes, I guess that's the only ways I would cope with it
>
> You always want to show that you're strong. So, for me, it was you're balancing being weak and showing that you're progressing a little bit.

and P3 shared,

> Distancing myself as much as possible, just like being in a place where I didn't have to interact with a lot of people, and I didn't have to do that sort of thing with people.

Participants also shared some positive aspects to their coping mechanisms and how it aided them with their experience at the beginning of their reassimilation process and at present. For example,

P1 stated,

> Learning what coping mechanisms work and what works in what situations. So, it's more just knowing when I actually need to separate myself and be alone to bring down the level of anxiety that's happening and things like that.
>
> A lot of it is reminding myself that I do have control. When I know I have things coming up whether it's like physical or mental stress, a lot of it comes down to reminding myself and asserting my control over my own body and over my own actions as much as I can. So, separating myself from the situation and then doing what I can.
>
> Having to become very aggressive, and even to this day I got really good at being on the subway because you had to learn how to push past it, and it really did help me (*laughs*) with the amount of subway riding that I used to do in university, that I did learn how to kind hold my ground even on crutches to kind of push through people.

and P2 stated,

> Because all the teachers were nice to me, I went from rebelling and sort of maybe getting into some bad stuff because you would also sort of have mental health issues from being angry at the world. I sort of always had a bit of mild anxiety, but now I had mild depression,

> so I had to reach out to the school counsellor to sort of say "hey I have to get off hanging out with these people because they're not good influences on me".
>
> The way I would cope is to just go play basketball with my friends, so I guess basketball became my therapy in a way.

and P3 shared

> Humour. Sarcasm (*laughs*). That is the number one thing I'd call my main weapon.

and P4 shared,

> Everything I do is related to my diagnosis. My partner had childhood cancer. I'm surrounded by it in every degree of my life. I'm doing a panel for whatever as a survivor/ researcher thing. So, I think it's shaped fully everything that I do in a really healthy, and good way for me.

4.2.3 Outlook on Cancer

This theme was used on quotes where participants explained any sentiments regarding their experience with cancer as they were/are experiencing it and explores the participants understanding or interpretation of their experience as a theme. Outlook on cancer provides a perspective on what happened to them as a patient and the after affects post hospitalization. A total of 2 sub themes were generated, "perspective as a patient" and "the aftermath".

4.2.3.1 Perspective as a patient

Participants outline their sentiments regarding their experience being hospitalized as a patient, receiving their diagnosis and treatment, and understanding their circumstance. For example,

P1 stated,

> I was actually one of the happiest chemo patients while I was on chemo. I was there for so long that it became comfortable.

and P2 expressed,

> Every time I was in the hospital, whether I was 10 or 14 or like 15 I would always kind of keep to myself, I never really, talked to anyone other than the nurses or the social workers or the psychologists that were there.
>
> You develop really strong attachments to the nurses, the social workers, the doctors.

and P3 shared,

> Thinking back on it, I'm like, "I'm really grateful for morphine" because it just blocked out a lot of the memories that I just didn't want to think about because the ones that I do remember are not pretty.
>
> There were some good nurses and some bad nurses. There were some who would put more effort into care and some that would just joke around with you. Like a natural, meeting a new person sort of thing. But yes, it was generally a good experience just because I think because we were here at Sickkids being treated, and the doctors there are good. They're nice, they're personable and they have a sort of gravitas to them when needed as well.

and P4 shared, Diagnosis was so smooth, the physicians were great. I think it's a matter of like where you live, your access to and familiarity with the healthcare system and things like that. Where kind of make the difference or made the difference for me when I was diagnosed and didn't completely lose my mind.

Participant's experience with cancer was not limited to their interactions with staff, some participants also shared their sentiments as a patient facing barriers within the healthcare system.

For example,

P2 stated, Unless you're a [bone marrow] transplant center you don't really have the same ability as well to be able to have these support systems. So, if you go to Toronto or Montreal, or I assume Vancouver, or also Calgary I think as well is another one. They have a lot more infrastructure in place to be able to have this, whereas if you go to CHEO (Children's Hospital of Eastern Ontario) versus Sickkids, there's a big difference in terms of the size of the hospital, what they can handle, the amount of child life people that they have there versus, nurses versus doctors. Being from Ottawa and going to Sickkids you can see the drastic difference in terms of fundraising.

and P4 stated,

> It's a lot of mental health stuff because there aren't mental health services for kids with cancer.

> Kids with cancer are diagnosed when they're properly kids. I was diagnosed when I was 16 so I was immediately 1 of 3 kids on the floor so it's a very isolating experience beyond being physically and socially distanced because you have no immune system, it's like there's no-even in the children's hospital there's nothing for teenagers. The child-life services doesn't really accommodate to that so you're kind of alone. The psychologists and psychiatrists are for like when you're in crisis and they don't really accommodate for that either so you're in this weird kind of purgatory.

4.2.3.2 The aftermath

Participants communicate their attitudes regarding their experience as a survivor and their evolving relationship with cancer and their past experiences, including developing perspectives using the term "survivor" to describe themselves and their journey. For instance, P1 stated,

> I don't like the term survivor. Typically, what's associated with it is - I don't know overcoming something huge, as if you had a choice or kind of really almost like, you decided to go through with something and decided to push yourself through it when - and then basically making it sound like you're brave for going through it almost. In my mind, no matter who goes through it you really don't have a choice but to survive.
>
> What are you going to say like "Okay I have cancer, so I'm just going to sit here and give up?". No matter what, you're going to still be dealing with and it - it doesn't quite feel right, because it's true in a way we are surviving, barely.
>
> It doesn't quite adequately describe what happened and it sounds like we're just kind of either getting by or like it's something that we should be proud of.

and P2 shared, It's something that never leaves you because eventually you're going to be on 20

> pills, and you're going to be on kidney meds, lung meds, like all that stuff because the latent effects, and that's going to hit you in a bunch of different ways.
>
> When I think about being a survivor, it's to live on for those that have passed away and to be able to continue to, do the fundraising, do all the infrastructure that was already in place, but to make an impact on the world as well. And yes, I mean try and do as much social change as much as you can.
>
> You always have a sense that you have to give back and that you have to live on for the people that passed away.

and P3 shared,

> I don't tend to. I don't know, it's just kind of a saying that-it became normal at this point. I went through this thing, this is now my normal, this is now my life. Thinking of it in any other term just feels, I don't know. It just feels cheap to me, thinking of "I survived cancer" like dude I was just unconscious most of the time and they just pumped me full of medicine and I made it the other side." That's the way that I think about it at the end of the day. It doesn't feel like I did much, I kind of slept through the whole six months. So, I don't know, I Just don't – I never thought of that word for myself to be honest.

and P4 expressed,

> "Survivor" isn't really the term at all. It's more like "victim". Surviving implies a hard stop and moving on. Whereas I'm still dealing with my diagnosis or repercussions of my diagnosis which are not seen or appreciated by others in healthcare sectors and it's frustrating. It's a lifelong diagnosis for sure.

Some participants shared their experience in retrospect, including their current sentiments of indifference and impartiality when observing or recounting their experience with childhood cancer. For example,

P1 shared,

> It was such an emotionally triggering thing for me to be reminded how different things were and how awful it was to be different. But if I'd really dealt with it sooner, I think I would have been able to deal-to see it as something as just it happened, and it's not good or bad. It just happened. The same way that going through anything, you know enough times becomes less emotional. It's no longer an emotional thing for me and it probably hasn't been for about 8 years now. I think I'm at the point where I can talk about it pretty impartially and kind of almost laugh about the things that happened to me.

and P3 shared, I think by the time I went to university I sort of accepted it. It's the type of thing that I don't mention to people unless they specifically asked, or they bring up the conversation.

> I don't know exactly when the indifference came but I think it also has something to do with my beliefs personally.
>
> Everything happens for a reason, like you survived this because God willed you to survive but you did not survive it because that is his will. So having that in the background as well

> knowing that everything is just already written, it's already going to be happening. So it kind of puts this understanding in my head like "okay, this happened because he wanted this to happen so let's look at the bright side of this thing as much as I can". But yes, I don't know if that does affect the indifference or that it just happened so long ago, I don't think about it unless someone brings it up.

Using their own perspectives, participants provided insight and guidance for children who are now diagnosed with cancer and learning to navigate their current circumstance. For instance,

P1 stated, Really enjoy the fun times that you have, and don't see it as a bad thing. As much as it sucks there's going to be some good days and don't spend your good days stressing about the bad days that might happen. Because I think that's what happened to me, I really did not care. I had the greatest time, it was so funny, the nurses thought I was so strange at the beginning because I'd be the one laughing, watching TV, completely hyper, in pain, on chemo, literally not caring and they thought it was the most bizarre thing ever.

and P2 shared,

> Just dream, you're going to be in a hospital bed for 2 weeks to 3 months to a couple of years, really take that time to really learn about yourself and dream and have a goal like "hey when I survive this, I want to be able to do this, this and this." And I think for me, that really helped me develop the type of person I want to be, what journey I want to do post-treatment.

and P3 expressed,

> Well, the obvious, don't give up. You are much stronger than you think you are. You might not think you'll get through this thing but trust the doctors, get the support you need and also insist your parents get the support they need after the fact, I cannot stress that part enough (*laughs*), yes and then just live it day by day until you're ready to just realize that there's an entire life ahead of you that's just ready for you to live it.

and P4 expressed,

> It's hard telling somebody to advocate for yourself because you know there's this whole SES [socioeconomic status], education and all these structural barriers to at least begin to advocate in some sort of way so (*laughs*) that's not advice you can give somebody. It's just kind of like knowing you have to use all the resources that are given to you and if you think there's something missing, ask about it. Because there's so much money in childhood

> cancer and if you want to know about it, someone else is probably wondering about it too and they can start a program.

Using their own experiences, some participants provided insight and guidance for survivors managing their experiences post-cancer. For example,

P1 shared,

> I think now, would just be to really take the time and go into it. Break down everything that happened to you as a kid, and as much as it sucks it's better to work through it than ignore it.

and P4 shared,

> Incessantly call your oncologist and radiologist or whatever and keep getting the follow up as long as you can and try and get all of these things because there aren't programs in survivorship for people our age.
>
> In Quebec, it's impossible to get a family doctor, it's impossible to get a doctor. So, people like my partner who just moved here, has nothing. There's no structure, there's nothing. So, yes, it's hard and then trying to explain to a new physician once you're out of this oncology system your whole experience and then getting these physicians to try to link what could be caused is like pulling teeth. So, I think, just trying to stay aware and on top of yourself is helpful.

4.2.4 Integrating Themes

Once coding the major and subcategories was complete, establishing where these themes interact with each other was imperative. I curated statements that reflected my interpretations of the data. These statements were based on whether it seemed as though outlook on reassimilating, outlook on coping and outlook on cancer interacted with each other and to what extent as it pertains to returning to normalcy. These statements were validated through a focus group discussion, where I shared with participants my initial findings and emerging themes from my analysis.

4.2.5 Focus Group Discussion

I shared my interpretations with participants regarding the aftermath of cancer. Participants also shared their own interpretations of my findings. Not every survivor shares the same experiences, this has been shown through the different challenges faced due to cancer type, treatment received and how survivors perceived their reality. However, survivors have expressed that achieving a sense of normalcy or feeling as though they can successfully adjust to their new circumstances are of importance. For example, a quote that described a survivor's particular experience with being in a wheelchair when re-entering school and how it negatively impacted their perception of normalcy and success in their environment was shared.

P4 shared,

> Diversity in the disease that you have, like an osteosarcoma type situation would obviously be a very different experience coming back to school and reintegrating back. So I think that, yes, that's a good perspective to have there and that almost like forced disability that the teacher is putting on this student, even though they're trying to reintegrate and be as normal as possible. Just walking in whatever capacity they can and then just to avoid some sort of like workplace incident or paperwork. Forcing a kid in a wheelchair is intense.

P4 also stated,

> Childhood cancer isn't that rare at the end of the day. A teacher is going to have a student who gets sick at one point in their life with some sort of like critical illness. So, you'd hope that the awareness is there and that this stigma, be it cancer or any other illness isdoesn't exist.

P2 expressed,

> You're not really supposed to force accommodations on people as well. So, I think that aspect, can be pretty demeaning especially if you want that sense of normalcy. And I think, having that sense of normalcy is actually one of the keywords.

Participants shared their thoughts regarding my interpretations concerning the state of preparedness for reassimilation among survivors. As expressed by 3/4 survivors in this study, there was a disconnect between preparedness and reassimilation, which could positively or negatively impact the process of reassimilation. Participants shared what it meant to their survivorship journey. For example,

P2 expressed,

> I would just kind of use the metaphor of someone holding your hand and using the whole hand versus maybe one finger or something like that. Which might, in reality it might be like one finger versus the whole hand when they sort of tell you stuff, at least when you're in maintenance and like remission and stuff.

P2 also shared,

The deficiencies in the system is more just, I think an awareness thing than an actual deficiency thing. I think if it was in your face a little bit more and you sort of knew about that stuff, sort of at the different phases of your treatment, I think that would've helped as well. P4 stated,

It's like a perceived deficiency that’s like an external force onto these patients reintegrating.

Positive or negative coping outlooks may have an influence on the views survivors have on themselves which can have an overarching influence on outlook on cancer. This may have ultimately changed the kind of relationship survivors have with cancer when embracing a new chapter regarding their patient to survivor transition. It is entirely possible to have positive and negative views regarding cancer outlook. Participants agreed that there were positive and negative aspects to their experience not only with cancer but in navigating their experiences with their peers. For instance,

P2 shared,

> Positive and negative outlooks dealing with cancer itself, but also just dealing with like your high school experience as well and trying to balance that. You know and whereas maybe some of your peers are experimenting with other substances, you know, you feeling that peer pressure you might also interact differently. So you might have a positive outlook maybe going into high school, but then maybe throughout as you're kind of dealing with a lot of this negative coping it might also have an impact on how you perceive or, and can make it more negative.

P4 expressed,

> It can go one of two ways. Like, it's like, oh, great, alcohol exists and then it's like, okay, alcohol's a carcinogen. So, it's kind of like on one side of the coin there.

Some participants accredit having a relatively positive outlook as a patient to the support that was received from hospital staff during hospitalization. However, it has been expressed that there is a lack of communication between patients and hospital staff specifically regarding the psychosocial effects of survivorship, where survivors did not feel supported and do not feel prepared for reassimilation. Survivors reiterated this sentiment by expressing what gaps they felt were in place as it related to their care as a survivor. For example,

P4 shared,

> There are not programs that exist for kids with cancer to have care, like psychosocial care there are barriers for that care being that you have to be actively on treatment. And these things, even though you know they exist in some facilities, sickkids, probably, it's-it's only in hospital. It's like it's for a select few. And realistically, the care extends to the patient, the siblings of the patient, if they're our siblings, the parents, also the friend groups at school or wherever. Like it's, it's this whole holistic thing that is almost completely neglected in Canada.

P2 stated,

> I would also sort of say the programs are in place for me, I live in Ottawa and up until I think like 2014, they allowed sort of young adults to be able to have their bone marrow transplants in the adult cancer other center. That was really like eye-opening for me because you got to see all those support groups being advertised and being available and it-it would almost, I think, help to have a plan in place where you can kind of integrate that stuff a lot better.

P4 also shared,

> So many more adults have cancer and there's just so much more infrastructure for adult cancers, you see the benefits of that. Like you get the benefits of all the kind of-the groups there. Like you get the psychosocial support, all those other things. And I think it's, you know-places like candlelighters are excellent, but they're just, you know, there aren't cancer cases in some of these smaller towns.
>
> I grew up in Berrie, which is north of Toronto. 150,000 people live there and they're like 10-10 families that attend these candlelighters thing. Five of them come from up north, like it's over a 3-hour drive for them to just have some sort of community. And I think that's wild.
>
> We could just digitize it. But it's-it's hard to implement that. And it needs to be, for me, the only way that I see this working is at the hospital level.

P2 also expressed,

> From a policy perspective as well, just making sure that put enough money for the psychological care of patients as well. And I think that's going to be increasingly important, not just for cancer survivors, but just for everyone coming out of COVID.

I shared with participants that it ultimately seemed that having a program as an active part of cancer care could make a difference to their survivorship journey. Participants shared their own interpretation of this assessment, specifically how a digital intervention might have helped during and post-cancer care. For example,

P4 stated,

> Having access to these programs and knowing that if I need something, it's there for me. So I don't like-going into survivorship, I had no idea what to expect and all of these questions kind of come up. You never have the opportunity to you know, voice these opinions or questions. These are-you don't have the same sort of access. You're not going to get your blood work done every week. You're not going to follow up appointments monthly. So you're kind of left on your own. And without addressing these, I think it can lead to a lot of this, like maladaptive kind of, you know, coping or these unique trauma responses and this kind of PTSD [Post traumatic stress disorder]. So I don't know what necessarily goes into this sort of like online platform, but just knowing that I have access to information that isn't Google is reassuring.

Participants also shared their thoughts about the sustainability of digital interventions as an option for survivorship care.

P2 shared,

> I think again, it really comes down to maintaining those things, right? And making sure that you have enough funding to carry those things on as well.

P4 expressed,

> Essentially everybody, I think universally agrees that like some sort of online platform would be great, or just having access to this information, which obviously I agree with. But as [redacted] said, it needs to be updated and it needs to be funded. And a lot of people take on like masters or Ph.D. project of building this online portal and it's so good for the four years that you're funded and you do your research and then it's completely neglected. We just need to consolidate and actually have something for kids because these hospital specific hyper niche things are just, they can be really ****** and it just-it needs to be optimized. That's it at the end of the day. It could be so good and so powerful, empowering for people, but it's just not there.

CHAPTER FIVE: DISCUSSION

This study's purpose was to explore the psychosocial impacts of surviving childhood cancer on young adults and their ability to reassimilate back into society post cancer. In this chapter, I discuss my own and the participants' interpretations of the findings and compare my findings to that of current research. The strengths and limitations of this study are also discussed, as well as the implications the results make to cancer survivorship research for survivors, and how these results are relevant to survivorship care in the context of healthcare delivery, policy, and education. Exploring how these findings set the precedent for future research is also discussed to conclude this chapter.

5.1 Interpretations

In conducting my analysis, the goal was to avoid creating a linear relationship between the codes, and to ascertain how extensive the influence these experiences might have on each other or whether a relationship is present. Essentially, inquiring if these are isolated experiences that contribute to an overall experience or if they intermingle and in what ways they do, to provide the overall experience within the outlook on cancer, outlook on reassimilating and outlook on coping, as it pertains to reassimilation. Overall, personal outlook and healthcare system barriers play an increasingly influential role on the reassimilation process for survivors.

5.1.1 Survivor's Personal Outlook on Coping

A major finding based on my initial interpretations indicated that the ability to assimilate back into a work, school and social environments, would be influential in the participants ability to cope. But how much influence does the ability to cope have on assimilating into these environment and vice versa? Isolating the context behind a particular perspective enabled me to assess how participants outlook on cancer may have been influenced by their outlook on reassimilating, or their outlook on coping. For instance, in assessing how much bearing the overall outlook on cancer (evolution of their cancer experience including diagnosis and new relationship to cancer as a survivor) had on their experience, it seemed as though it would require a positive outlook, to then have positive views on oneself. As a result, it is almost impossible to enforce exclusivity into these aspects of the experience. Meaning, their outlook on cancer shifted depending on their perceived ability to cope, which ultimately relied on how they viewed themselves and their success in their environments. This aligns with other studies suggesting that a positive or negative perspective regarding childhood cancer experiences is more strongly associated with psychosocial well-being, more so than sociodemographic and medical characteristics [113,114].

To reiterate, the participant's perception of their environment, meaning how they can process their environment and their ability to perceive success in their environment will ultimately have an impact on their ability to cope. In fact, self-perception and changes in self-esteem may be the cause for difficulties in forming relationships, and problems faced in academic and employment environments[115]. Self-esteem was considered worse among survivors regarding interpersonal relationships, family life, environmental control, and academic success [115]. As presented with these findings, self-confidence, which in this study was expressed as the ability to be independent or having a sense of autonomy, strongly influences the trajectory of reassimilation.

Survivors' sentiments on preparedness, also seems to shape their perceived ability to cope, ultimately influencing their experiences while reassimilating. As expressed by many survivors, there was a disconnect between preparedness and reassimilation, hence resulting in positive or negative coping behaviours/tools, which can be understood as positively or negatively contributing to the process of reassimilation [80]. To reiterate, coping behaviours/tools are described tools and methods, or protective mechanisms used to navigate and mitigate difficult situations while reassimilating back into society because of their experience with cancer.

In this study, preparedness reflected how participants felt they were able to succeed in their environments post cancer. It is reflective of feeling ill-equipped or not really understanding what might be faced when reassimilating such as things to expect, the support available and the amount of support survivors felt they had. This includes access to information, access to support groups or support systems and resources. The lack of preparedness delayed the reassimilation process, and this was expressed as hindrances to coping, forming connections and shaped the overall outlook of survivorship.

Whether or not coping tools are positive or negative, can further influence the views they have on themselves, which in turn can have an overarching influence on their outlook on cancer. The relationship here is cyclical in nature. In fact, survivors may have experienced both positive and negative aspects regarding their cancer experience [45,54]. This corroborates participants sentiments regarding making the best of their experiences and taking advantage of the opportunities presented to them that they otherwise would never have experienced without cancer. Furthermore, outlook on cancer may ultimately change the dynamics of the relationship they currently have with cancer when embracing their new chapter, regarding their patient to survivor transition. Self-esteem has been utilized by researchers as an influential predictor of psychosocial outcomes such as academic achievement, contentment, and relationship satisfaction [115]. This study highlights that preparedness for reassimilation impacts self-esteem, thus influencing a host of other factors affected by survivorship such as relationships, coping, and perspective.

In terms of achieving milestones in comparison to their peers, it was not so much that survivors felt they did not achieve the same developmental milestones, but survivors felt as though there was a shift in what they felt were priorities compared to their peers. This exacerbated the difficulties perceived in forming relationships as survivors were more concerned with their health, making social development or educational attainment more difficult. Survivors felt as though this was due to a shift in maturity, where they matured a lot quicker than their peers which supports the findings of other studies [116,117]. In this study, survivors expressed that reconciling with their cancer experience has enabled them to feel emotionally removed or indifferent. Some felt these sentiments regarding the values their peers hold, such as partying, and forming romantic relationships. Ultimately, relationships, whether they be friendships, familial or romantic, have been impacted to a degree, leaving an impact on reassimilating. How lasting this impact is, is unclear since 3/4 of survivors have expressed that forming romantic relationships and new friendships is still something they are learning to navigate and have not quite figured out yet. However, it is evident that this aspect of survivorship is one that changes and is still evolving.

For other survivors, these indifferent sentiments arose concerning their personal cancer experience. Meaning recollecting and looking back at their cancer experience becomes less emotionally triggering the longer they are survivors. One survivor, expressed that their religious beliefs anchored them to mitigating certain challenges such as accepting their diagnosis, that what will happen, was meant to happen and nothing can be done about it [118]. The feeling of losing control was present, however their beliefs provided a sense of acceptance of things beyond their control. Two other survivors expressed that facing their issues with reassimilation and their new circumstances with cancer made the rest of their survivorship journey less emotionally tumultuous [119].

Evidently the trajectory of survivorship relies heavily on outlook. In turn, this aspect is heavily dependent on perception and confidence, especially as it relates to preparedness for life post-cancer. This study emulates the relationship these aspects of survivorship hold to each other and in what ways one affects the other, providing further evidence as to the holistic experience that is survivorship.

5.1.2 Healthcare System Barriers

Survivors accredited having a relatively positive outlook as a patient to the support received from the hospital staff during hospitalization. This is consistent with how other survivors feel according to another study with a larger sample exploring how a good relationship with staff influences outlook [80]. However, this study's findings corroborate other study results regarding the lack of communication between patients and hospital staff, especially the psychosocial effects of survivorship, where survivors not only do not feel supported but do not feel prepared for reassimilation [79,84,120,121,122]. It is unknown how effectively clinicians communicate the risks of late effects to CCS [123]. However, this study has revealed that there was very little to no information made available to survivors, especially in the context of reassimilation and the challenges they might face with their new reality. There is an emphasis on improving communication, reducing fear and anxiety as well as maintaining a positive outlook as it pertains to the unmet psychosocial needs of this population [87].

Interestingly, a Dutch study exploring the developmental milestones of 558 young adult CCS in the psychosocial context, suggests that survivors experienced no delay in psychosocial development compared to their peers who did not have cancer, however survivors of CNS tumours appeared to be at risk [124]. This is not conducive to the findings of this study, where all participants experienced a perceived developmental or psychosocial hindrance because of their cancer while reassimilating, whether it be in a social setting, educationally, emotionally in a self- evaluating context or within shifting family dynamics. It is also difficult to discern the extent of these hindrances in their long-term impact, as survivors still feel they are works in progress, and have either seen improvements to their social development, or are in the process of figuring it out. However, there is a lasting impact well into survivorship.

There are unmet needs among survivors and the quality of survivorship care is inadequate, especially regarding the accessibility of psychosocial support and resources. While it is acknowledged that the effects of cancer are long-term and life-long, there are hardly any resources or support provided to survivors tailored to assisting them in their post-cancer experiences [86, 120]. This lack of support was not only a barrier to effective survivorship care but burdensome to survivors, reducing the ability of survivors to effectively assimilate post-cancer. Early introduction to transition and better provision of information may improve the transition process [90]. There is also promise in implementing psychosocial resources in cancer and survivorship care. Interventions focused on increasing self-esteem, academic success and social adaptation should be improved to get survivors back and adjusted to a new normal [115].

As this study has demonstrated, survivorship care should be shaped with a holistic lens. This study has provided and highlighted how comprehensive survivorship is and how survivorship care and the types of resources available do not consider the comprehensiveness of survivorship. There is a dire need to reshape services to reflect the holistic experiences of survivors so that in their transition into survivorship they are equipped with the necessary tools to address most if not all aspects of their experiences.

5.1.3 Focus Group Discussion Interpretations

The focus group discussion provided an opportunity for survivors to interpret my analysis and to provide any addition direction and interpretations to the data that was presented. Ultimately this discussion highlighted that every CCS experience is different, and this can be associated to the cancer type, type of care received which is dependent on the treatment facility, accessibility to care and perception of success in their environment.

5.1.3.1 Access to support and resources amid transitioning from patient to survivor

My initial interpretations of how outlook on coping, outlook on reassimilating and outlook on cancer intertwined resonated with the focus group. Participants agreed that a positive outlook is practically needed to have positive self-views. As a result, it is very difficult to isolate these aspects of the survivor experience and experience them individually. Survivors also expressed that the ability to be independent strongly influences the trajectory of re-assimilation to a degree. As expressed by survivors in this study, there was a disconnect between preparedness and reassimilation, shaping their perceived ability to cope. The transition from patient to survivorship care has been illustrated as a hand-off, but instead of having access to the whole hand, survivors are holding on to one finger in their transition. The hand in this metaphor is the healthcare system and healthcare providers. The finger that survivors cling to represent the little information and support that is provided, feeling partially supported into their transition. This illustration between survivors and the healthcare system demonstrates the actuality of what is provided versus what may be available or is accessible. This illustration also brings emphasis to the lack of communication present between healthcare providers and survivors [58, 84, 85].

Accessibility was mainly described as the knowledge of resources available, whether resources are present and what support and opportunities available as a patient and survivor. Survivors explicitly expressed that the support available to survivors is not necessarily deficient, however it is not promoted, maintained or of good quality. One of the aims of this study is to highlight the holistic experience that is survivorship. Survivors have shared that the care provided, neglects this aspect, and lacks the comprehensiveness that encompasses all facets of survivorship [91]. Survivors collectively agreed that enforcing a psychological component to care is crucial, especially as it relates to the transition from cancer patient to cancer survivor. In identifying these gaps to the care being received, accessing reliant information is vital to the trajectory of a survivor's reassimilation process. Reliable information provides survivors with the comfort that if they have questions or concerns, these sentiments can be voiced, and solutions will be provided.

5.1.3.2 Positive and Negative experiences

Survivors have expressed that positive and negative experiences are intertwined throughout their reassimilation process. A negative perception can exacerbate negative coping mechanisms. How survivors navigate these positive or negative experiences can either be a positive or negative contribution to reassimilation. More positive experiences might help better navigate their survivorship experiences. In fact, social interactions, improving understanding of oneself, and having a place in a larger community can contribute to survivor happiness and positivity [125]. Additionally, social skill improvement may not only make survivors happier, but might impact future mental health and perceived general health [125]. Social development has been an emerging issue for survivors as they progress into young adulthood. Improving survivors experience at adolescence may lead to higher life satisfaction during young adulthood [125]. This FGD highlighted how relevant positive and negative impacts of childhood cancer can be influential to their survivorship experience. In fact, positive and negative impacts are associated with psychosocial well-being more than sociodemographic and medical characteristics, highlighting the importance of this aspect in the survivorship experience [45].

In the aftermath of survivors' experience, 3/4 of survivors in this study had their ambitions shaped by their childhood cancer experience. For instance, P1 had faced physical impairment because of their cancer treatment. Being an active child and adolescent, they were faced with the inability to play sports or workout in the way they used to, especially being that they did not receive any direction or support on how they could return to an active lifestyle from their physiotherapists and primary healthcare provider. While their circumstance took a toll on their mental and emotional well-being, as they progressed into their survivorship, they developed a passion for strength training and had to learn to be active in a way that was different from other people. Due to their persistence, they now work with amputees, and those who suffer from progressive neuromuscular conditions that would make strength training and physical activity very difficult for them. They feel empowered by their experience to help others in the way they did not receive the help they desired early into their survivorship.

Similarly, P2 had shared that their interest in policy stemmed from their cancer experience, and that they are grateful for having been exposed to opportunities they would otherwise never have had due to their childhood cancer experience. Public speaking and meeting government officials was a highlight of their experience, igniting a passion for advocacy and for pursuing an education in political science. Likewise, P4 dedicated their post-secondary studies to exploring childhood cancer. In sharing the impact of their experience, they stated that it has contributed immensely to shaping them as a person and in shaping all that they do in a healthy way. These examples depict how influential the experience of CCS is on outlook [77]. This also highlights the lasting impact their childhood cancer experiences have well into survivorship and how positive impacts contribute to shaping certain aspects of their experiences into their survivorship.

5.1.3.3 Digital Interventions

In the face of learning to navigate positive and negative experiences, survivors express an urgency to make digital interventions more sustainable for cancer and survivorship care. The support there is for AYA (adolescent and young adult), and pediatric survivors has been expressed as insufficient. There was a collective agreement among survivors in this focus group discussion that funding for psychological care of patients is increasingly important. With also having expressed that there is more infrastructure in place for adults with cancer, implementing an intervention at the hospital level will be considered more feasible and accessible if the care is digitized. Having access to digitized programs, can help mitigate some of the perceived negative experiences of survivorship.

This study highlighted that there is a greater need for emotional and informational support for survivorship care. As reflected in this study, survivors did not feel as though they could ask health care professionals for help, rather, relying on them to raise the topic. Similarly, AYAs share a reluctance to seeking support for their physical and psychosocial needs due to not wanting to ask for help, being told that what they were feeling was normal, or felt too embarrassed to ask for help [126]. There may be promise in utilizing a digital app to access peer support to address psychosocial concerns among cancer survivors. In fact, programs that can connect survivors of the same agegroup to each other to share knowledge and skills to navigate the healthcare system may be beneficial. Support from cancer peers can provide unique reassurance and practical information that reduces stress and enhances coping, these aspects are desirable to the survivorship experience and may also prove beneficial to pediatric patients and CCS [126,127,128]. In fact, peer support can serve as a complement to professional psychosocial care [129].

However, the question that is posed when referencing digitized programs is; are they sustainable? Digital interventions catered to improving the physical health of survivors show potential in feasibility, accessibility, and adherence [126,130,131,132, 133]. Perhaps an intervention tailored for aspects of survivorship that is beyond improving physical health can prove to be just as successful if not more so, being that the state of psychosocial well-being among survivors is not only a priority, but one that is unmet [134]. Curating survivorship care plans and providing this intervention digitally are acceptable and feasible for AYA survivors, with potential to help promote health-related knowledge and survivorship self-management [135]. This may bridge the gap between knowledge, access to information as well as support throughout the transition from pediatric to survivorship care.

In assessing the transition from patient to survivor, 3/4 of survivors in this study expressed that the treatment provided by healthcare professionals was insufficient in that they did not feel prepared for their transition into survivorship. A digital treatment provided by knowledgeable healthcare professionals may increase self-managed care [136]. This has potential in equipping survivors with the confidence and assurance they seek as they transition into survivorship. Digital interventions should be considered as acceptable and convenient approaches for delivering care to CCS, it can be used to understand positive and negative experiences to develop customized interventions to achieve positive health outcomes [137]. Digital interventions require advocacy, navigation, feedback, and multidisciplinary collaboration at the system-level to modify and develop relevant guidelines for implementation [137]. This much was expressed by survivors when expressing their sentiments regarding digital interventions and their sustainability.

Ultimately there is promise in restructuring digital interventions to suit the survivorship needs of CCS. Survivors expressed their expectations for interventions and in what way they were beneficial and not. The accessibility to a resource was seen as a benefit, however while digital interventions are useful in their insemination, the maintenance and investment into these types of programs are lacking and in turn, are not very useful to survivors when learning to navigate their survivorship. In fact, as requested by survivors in the focus group, tailoring an intervention that is holistically appropriate, in that it takes into consideration the age spectrum and the types of challenges survivors are expected to face based on what phase of survivorship they are in would be very beneficial in their transition.

It is evident that personal outlook and healthcare system barriers as they pertain to survivorship are deeply integrated at the start and throughout the course of survivors' journey post cancer. This study highlighted that care hardly considers the process of reassimilation as an essential component to survivorship. The call for meeting the psychosocial needs of survivors continues, especially in the context of returning to normalcy.

5.2 Strengths and Limitations

5.2.1 Strengths

5.2.1.1 Gatekeeper

Gatekeepers are essential mediators for accessing participants and curating the research setting [138]. Establishing a partnership with a gatekeeper such as CCSC ensured that the voices of survivors were at the forefront of this study. Encouraging an active role early in the research process is an emerging component in current research that shows promise in benefitting both the population under study and the researcher [104, 139]. Involving CCSC throughout the research process provided an opportunity as to what outlook survivors may have regarding their experience, this includes existing challenges, positive experiences, and any types of changes this population are facing at present, so that the research being conducted is not only relevant but relatable and sound to this group. This process allowed me as the researcher to better understand the study population's experiences. Considering what was previously explored among survivorship, this also enabled me to attribute different perspectives to the research question.

5.2.2.2 Interview Guide

Piloting the interview guide effectively aided in identifying flaws or limitations within the interview design. The questions were described as appropriate, non-violating and easy to comprehend. Due to the sensitivity of the topics being discussed during interviews, participants may not feel comfortable, and there was potential for participant withdrawal. Sharing the interview questions in advance allowed participants to emotionally prepare and understand what was to be discussed, as well as contributed to making them feel more comfortable. Implementing emotional checks throughout the interview to assess participant discomfort and emotional state was key to mitigating participant discomfort and drop-out. This was mostly done in observing body language and providing reassurance to participants when levels of discomfort was observed. Participants had the option of having their cameras off, although all participants kept theirs on in the individual interviews and in the focus group discussion.

5.2.2.3 Focus Group Discussion

Implementing a focus group discussion in this study was a crucial element to strengthening the credibility and validity of the research process. Not only is this a validating element, but it was essential to the phenomenological approach to the study [110,111]. In the design of this study, it was critical to include participants in nearly all aspects of the process and prolong researcher participant interaction which consists of synthesizing and piloting the interview guide and data analysis. Typically, phenomenological studies include samples of 6-10 participants [89]. Despite acquiring a sample of 4, the methods, tools, and design of this study emphasized phenomenological principles through exploring context and meaning [101].

5.2.2 Limitations

5.2.2.1 Recruitment

Though very few, there are impactful limitations present in this study. The biggest limitation would be the barriers faced in the recruitment phase. There was a total of 3 amendments submitted for ethics approval in this study. The first amendment was placed in September and sought to gain permission in sending out follow-up emails to participants who were interested in the study. This allowed me to actively pursue participants who initially showed interest and had either forgotten to reply or forgotten they had signed up through the google forms link. Participant engagement regarding the study has been very limited through Facebook and Instagram. The purpose of the second amendment which was placed in April, was to broaden my reach and mitigate any barriers there were to recruitment by reaching out to a larger audience such as the student body of Ontario Tech University to recruit potential participants and garner interest in the study. Upon approval an email was sent out via Global communications in May, to students enrolled in the spring/summer semester. There was no additional interest derived from this method. My third and last amendment was submitted as a final effort to include a wider range of participants in my study by increasing the age at diagnosis by 2 years. This meant that survivors diagnosed at the ages of 14-16 could also sign up to participate in this study. With this method, one participant was added to the participant pool.

There were 5 phases of research. Phase II projected the time it would take for recruitment and depended on how many participants were foreseen to be interested in participating in the study. This was essentially determined in evaluating the risks that were associated with participation and communicating with members of my committee whether the risks associated with participation would deter individuals from volunteering for the study.

The goal was to reach 8 participants, as a result the recruitment process was anticipated to be as short as a few weeks or as long as over a month. The objective was to start recruitment in August to late September and be completed in November, however, the recruitment phase for the study had not begun until November and was completed in June. The reason for delayed recruitment involved the amendment process, which prevented me from reaching out to participants in that time as our recruitment process for the pilot interview proved to take longer than expected, and the preference was for the interview guide to undergo piloting before using it for data collection. Additionally, the frequency of Instagram and Facebook posts were infrequent and did not have a set schedule. This was mainly due to perceived scheduling conflicts among participants as the age demographic is that of individuals who are typically pursuing a higher education or working full time. For example, posts were delayed in December and January at the time of exam testing because student's schedules prioritized school, making study engagement rather difficult.

To compensate for issues faced in recruitment, the study was renewed at the start of June as there were only 2 participants recruited in the time of November - May. Our goal in recruiting participants would have not been reached had we not submitted for a renewal. The decision to close recruitment was made pragmatically due to the time recruitment had already taken, thus it was closed with a smaller sample than was originally anticipated. With phenomenological studies, an appropriate sample size is dictated by data saturation [125]. The assumption was that 8 participants would provide the saturation point, therefore because of the sample size, it is not clear whether this study has reached its point of data saturation.

Additional concerns regarding the study's sample includes the representation. There was a total of 2 survivors who were diagnosed with Hodgkin Lymphoma. It is one of the most prevalent cancers diagnosed among children, however the study's sample is not reflective of the pediatric cancer population. With this being said, generalizability is often put into question when conducting qualitative studies and is not something that can really be quantified as a result, however, this aspect of the sample is important to mention as there are a number of psychosocial disparities across survivors of childhood cancer based on not only age at diagnosis but treatment type and cancer type. These aspects are quite influential in survivorship and can shape transition and reassimilation experiences.

As outlined in the consent process, participants would not be compensated for their time, participation in the study was completely voluntary. However, it is likely that compensation would have made a difference in recruitment. Interestingly, recruitment rates for trial and interventional studies are often higher than observational or questionnaire-based studies as the benefits of participation is more explicit [140]. Studies aimed at observing the psychosocial experiences of survivorship typically experience challenges to recruitment as the perceived burden is high and individual benefit is less clear [140]. Thus, incorporating compensation such as gift cards to Tim Hortons for example, could garner interest from participants, as there is an established benefit to participating in the study.

5.2.2.2 Recruitment Bias

Recruitment via CCSC may have resulted in recruitment bias. Survivors affiliated with the organization may have felt obligated to participate in the study. It was outlined to participants that participation is entirely voluntary, and withdrawal will in no way impact participants membership or support received from CCSC. However, it is likely that most if not all participants who were recruited are somewhat affiliated to CCSC, simultaneously excluding survivors who do not access or know of CCSC.

5.2.2.3 Inclusion & Exclusion Criteria

Additionally, the inclusion and exclusion criteria for the study may have posed as a barrier to recruitment. Being that the qualifications for participating in the study were narrow among a population that is already relatively small, could have excluded individuals who may have wanted to participate in the study. For instance, a parent of a CCS had signed up for the study but being that the study focus was on survivors and their experience, the interview could not take place. In addition to the low response rate, the study may have attracted survivors who were more motivated to share their experiences, or of higher mental and emotional functioning, which is a common occurrence as with previous research [140].

Another limitation to consider regarding the study population is that the experience and knowledge is within the context of care that was received over 9+ years ago. There was no evaluation or active consideration as to the differences present for children diagnosed with cancer in current and more recent years, and their experiences with reassimilating back into society. It would be reasonable to assume being diagnosed in 2009 is very different than a diagnosis in 2022, specifically highlighting the differences there may be in the quality and access to care. For instance, in 2017-2018 there was an estimated $9.2 billion dollars allocated to improving home and community services and mental health services [141] . Canadian provincial governments and policymakers have prioritized home-based care and community services, as well as public health and mental health, and have begun to consider these services as essential elements of patient centred care and should be integrated in health care systems [141]. This study shows a Canadian healthcare system pre-COVID and presumably unchanged. However, as stated, this is not an entirely accurate view.

5.2.2.4 Online Platform

There were also slight disadvantages to utilizing an online platform such as Google meets for the interview process of which included faulty internet connection. This was an expected and common disadvantage to using online platforms for interviewing participants [142]. This disrupted the flow of conversation and occurred in the pilot interview where audio quality as well as the ability to sign in was difficult for the participant. While it did not impact my ability to collect data, it was perceived as an inconvenience as the interview had started almost 20 minutes late as a result. Thankfully, the participant was flexible with their schedule on the day of the interview, however, it was considered a worry for participants whose schedule was not as flexible. Additionally, there was an inaudible portion in the first interview, which unfortunately could not be interpreted by myself or the participant. Presumably, this aspect of the study's design also leaves out survivors who may live in more rural areas and may not have access to internet or a computer excluding them from this study.

5.3 Implications

5.3.1 Implications for Research

This study has made notable contributions to the realm of cancer survivorship and to my knowledge is the first to explore the psychosocial impact of surviving childhood cancer in young adults and how it impacts their ability to reassimilate back into society using an interpretivist approach. The nature of the recruitment process has been a limitation to this study; thus, I strongly believe that there is an opportunity to explore what barriers may be in place regarding recruitment among this population. In fact, recruitment for cancer survivorship research in general poses a significant challenge and impedes research progress, yet there is a growing need to address the needs of this population particularly in supportive care in the psychosocial context [139]. Participation hinges on the nature of the study, for instance, in person participation in the middle of an infectious disease pandemic would certainly pose as a risk to survivors who would in fact be less likely to participate [143].

Nevertheless, this fear should have been mitigated with the online methods used in this study. Online recruiting methods are more successful in identifying younger participants, which should pose as a benefit in reaching the targeted population. However, cancer diagnosis among younger age groups is rare, consequently, perhaps the issue lies within the lack of prevalence among this demographic group and not in participant's perception of risks associated with participation, or participant interest [140]. Regardless, this can pose as a difficulty for researchers looking to conduct research with this population.

Moreover, there may be notable differences between survivors diagnosed in childhood versus adolescence as was presented in the literature and in this study [67]. Many CCS studies include a vast age range, grouping those diagnosed in childhood and adolescence all together. When in fact, adolescents suffer from separate or distinct complications as a result of cancer, for instance, their self-perception as being different poses as a barrier to reintegrating seamlessly within their social environments. Additionally, adolescents suffer from social disruption to peer relationships and experience accelerated maturity as a result of their cancer experience [117]. These aspects to reintegration were captured by all survivors in this study. Interestingly, the one adolescent survivor present in this study had not experienced a significant impact to their development as is typically expected among adolescence diagnosed with cancer [126]. However, their delays were predominantly experienced in an educational setting, where advocacy for accommodations was a barrier in their post-secondary studies. This highlighted that despite delays varying across all survivors, which may or may not be linked to age at diagnosis, there are significant psychosocial challenges faced by childhood and adolescent cancer survivors alike.

In Ontario, costs for treating children with cancer are higher relative to adolescents [144]. Cancers that were more common in children are more costly to treat whereas cancers that were less costly were more prevalent in adolescents, hospitalization is also higher among children than adolescents [144]. Cancer type can significantly impact survivor's trajectory when reassimilating. This data incentivises researchers to evaluate how age at diagnosis may impact survivors beyond healthcare utilization but inform cancer care and survivorship planning across the age spectrum, especially as it pertains to reassimilating.

5.3.2 Implications for Healthcare Professionals (HCPs) and Policy Makers

The scarcity of Canadian studies exploring psychosocial impacts of survivorship and the transition from patient to survivor begs the question: is Canada addressing the needs of survivors of childhood cancer in the context of reassimilation? The assumption is that due to Canada's universal health care, ideally there should be little to no barriers in place preventing individuals from accessing different types of care and services. As beautiful of a picture that paints about the aspirations of healthcare in Canada, as presented in the literature and this study, that is not the reality. There are much needed conversations and partnerships to be made among the healthcare system and CCS.

In conducting this study, survivors felt as though the transition from pediatric care to survivorship and adult care facilities is lacking in proficiency and delivery. Survivors felt there was ample opportunity and resources as children which shifted drastically to having difficulties with adjusting to life post cancer, due to the lack of knowledge of available resources, understanding, and preparation for survivorship. In the perspective of survivors, HCPs are mostly preoccupied in the treatment aspect of the child's cancer experience, the opportunities to educate the child regarding their health outcomes as a survivor beyond health is absent and can leave survivors feeling as though they are unprepared for life beyond cancer and hospitalization.

There are issues with diagnosis and misdiagnosis in less urban areas for childhood cancer. Because it is so rare, HCPs are encountering children with cancer infrequently throughout their career. Major urban areas such as the city of Toronto, encounter less of these issues as hospitals are equipped with the necessary and essential diagnostic and treatment tools for pediatric patients.

However, even HCPs in regions equipped with resources for advanced cancer programs results in misdiagnosis causing late specialist referral [145]. Patients should not have to suffer from symptoms of cancer for two years before obtaining a diagnosis and treatment, these kinds of barriers are faced by HCPs trying to assist children inflicted with cancer, and there are little ways these barriers can be mitigated without the help and support from policy makers. There are barriers still, beyond pediatric care. Many Canadian CCS do not have access to facilities specializing in long-term risk based survivor care and this access further decreases into adulthood [146].

It is evident that being a survivor can be difficult. The ideal would be to foster better communication between healthcare providers, policy makers and CCS. This can be addressed with health interventions, such as through a health aid provided by the health care system, or education and support, as provided by organizations such as CCSC. Essentially the implementing of psychosocial interventions or services and integrating it into pediatric cancer care can offer significant contributions to survivors managing their ability to cope with reassimilating back into society. Including the perceptions of HCPs into policy making may reveal practical issues with implementing psychosocial services to address the unmet psychosocial needs of CCS [104].

Equipping social workers, psychologists and other HCPs with the tools and education necessary to better aid these patients in their transition to survivorship would be beneficial to this population as well. Recommending and referring follow-up appointments for patients during and after their treatment specifically to discuss latent effects such as mental health and other psychosocial aspects can go a long way. Furthermore, advising and encouraging the use of available resources and programs based on patient demographics such as age and cancer type can provide a more personalized type of care and support. Advocating and encouraging survivors to seek out resources to supplement their survivorship experience will not only educate them on what to expect from their survivorship but can provide the necessary resources to aid in the process of reassimilation.

5.3.3 Implications for Educators

This study highlighted some difficulties children and adolescents may have faced in reassimilating back into a learning environment, where some survivors experienced social and educational exclusion. Elementary and secondary instructors must educate themselves on the latent effects, specifically the psychosocial aspects of surviving childhood cancer, to collaborate with survivors during their reassimilation. Understanding psychosocial impacts may aid educators in providing appropriate accommodations to survivors who require them because of their experience with cancer. This includes personalized learning so the student can feel as though their academic goals are feasible, as well as fostering an environment where the student is not constantly reminded of their condition or cancer experience. It is crucial that educators cultivate an environment where survivors are supported in regaining a sense of independence, autonomy, and normalcy. Unless expressed by the survivor and their caregivers, accommodations should be enforced for the benefit of the child in support of their physical as well as psychosocial needs.

5.3.4 Implications for survivors of childhood cancer

The study's findings support the needs for improved survivorship care. Survivors felt unprepared for their transition back into normalcy and did not know the realities they were to expect. While every survivor's experience might be different, improving the dissemination of information from HCPs to survivors can go a long way in addressing the issues survivors might face when reassimilating. Support groups for adolescents and young adults have demonstrated some success on web-based information sites and clinical resources in certain communities [127]. Access to these resources amid transitioning out of pediatric care could prove beneficial in mitigating some of the difficulties and challenges faced in the process of reassimilation. The psychosocial needs of survivors are complex, and while it is acknowledged that these needs are a priority in survivorship, integrating this care into oncology or other settings such as in survivorship programs, have not been well tested [147]. Understandably, if survivors do not know what to expect from reassimilation, they might not know what to ask or how to communicate with HCPs, however, survivors and caregivers are encouraged to ask and share any concerns with caregivers and HCPs regarding their reassimilation. The results of this study demonstrated that there are lasting impacts to reassimilation, organizations such as CCSC work to disseminate information and educate survivors throughout their survivorship journey and organizations such as this may be a beneficial supplement for survivors seeking guidance.

5.5 Future Directions

This study's findings highlight the need for further investigation into survivorship and reintegration into normalcy. What is especially necessary is understanding how this can be addressed and implemented as part of care within a healthcare setting, and if this kind of care is feasible to provide for HCPs. This study took on a more comprehensive approach to survivorship and was able to explore several aspects of survivorship as it pertains to reassimilating. An aspect of survivorship to focus on based on what survivors have expressed as challenges would be to further explore the psychosocial needs as it pertains to transitioning and to specifically evaluate in what way this kind of care can be provided within the context of reassimilating. Working alongside survivors may be an asset to exploring these aspects and in interventional and program development.

There is potential to further exploring the barriers associated with the lack of engagement among CCS in future research aimed at investigating the psychosocial needs of survivors. Facilitating quality partnerships between CCS and researchers can unveil additional challenges to not on1y the recruiting of survivors to studies, but further unveil the needs that are unmet in this group regarding the psychosocial aspects of survivorship, especially being that there is still a need to explore the process of reassimilation as it pertains to the transition from cancer patient to life post-cancer.

Reasonably, the kinds of resources survivors may need to access is dependent on not only their diagnosis but may hinge on their age at diagnosis. This factor requires further inspection to the differing circumstances of children and adolescent cancer patients and what they may require when reassimilating back into society. Additional avenues for future research in this area may include exploring the perspectives of individuals providing care to survivors in pediatric and adult care facilities. With these perspectives, researchers might understand and help bridge the gap of communication between survivors and the healthcare system particularly in the psychosocial scope of reassimilation.

Perhaps other avenues to include would be studies catered to incorporating the thoughts, experiences, and perspectives of HCPs in working towards implementing a program or psychosocial interventions in pediatric care for transitioning survivors. The primary focus for next steps would be to further elaborate on how the gap between reassimilating and psychosocial services can be addressed. Especially exploring the limitations that might be present among HCPs as it pertains to delivering psychosocial care for survivors. All in all, there is still much to understand about the survivor experience especially since each experience is unique.

5.6 Conclusion

The overall aim of my research was to explore the experiences CCS experienced with reassimilating back into society in a psychosocial context and determine how certain aspects of their experience contribute to their overall experience with reassimilation. Through this study I was able to identify the themes influencing survivors experience with reassimilating and how they interact with each other, succeeding in answering the research question. This study highlighted the degree to which themes interact, how they contribute to the survivorship experience as well as reveals the perspectives survivors have regarding their reassimilation. In answering the research question, I was able to address some of the gaps in survivorship research regarding the psychosocial aspects of survivorship, especially in the context of reassimilation, which has not been highlighted to the same degree as it is represented in this study.

I was also able to highlight the holistic experience that is survivorship and explore its trajectory. In doing so I was able to discern the meaning these experiences had to survivors' progress and process in returning to normalcy. I was also able to assess the lasting impact these interactions had on survivors and how it impacted their trajectory. This ultimately mattered the most to me as the researcher because participants played an active part throughout the research process beyond data collection but in ascribing meaning to their experiences throughout the analysis as well. This study demonstrated there is still a need to investigate areas of survivorship with a holistic lens.

APPENDIX

Figure 1A

Questions regarding demographic information What is your date of birth? (MM/YYYY)

How do you self-identify in terms of gender?

a) Female
b) Male
c) Non-binary/third gender
d) Other

If other, please specify:

How do you self-identify in terms of ethnicity? You may choose more than one if it applies to you. a) Asian b) Black
c) Caucasian
d) Indigenous
e) Latino/Hispanic
f) Middle Eastern
g) South Asian
h) Other

If other, please specify:

What is the highest level of education you have achieved?

a) Elementary level
b) Highschool level
c) College/University level

Are you currently a student?

a) Yes
b) No

If you are not a student, what is your current occupation?

Questions regarding past experience with cancer and its treatment What was your age at diagnosis?
What was your diagnosis?
What type of treatment did you receive, and for how long?

Interview Questions

1. Would you mind describing your experience with childhood cancer?
2. What does being a survivor mean to you?
3. Please tell me about the impact your experience with cancer has had on your relationships, such as friends, family, peers, significant others, and children.
4. Please tell me about the impact your experience with cancer has had on your mental health.
5. What is one piece of advice you would give to someone who is currently undergoing cancer treatment for their childhood cancer, or who is currently your age, trying to navigate their own survivorship?

Figure 1B

Interview Guide

Intro:

Thank you for agreeing to participate in this study. My name is Shanelle, and I am going to be facilitating this interview. The purpose of this study is to discuss the impact surviving childhood cancer has on your experience with reassimilating back into society. There are no right or wrong answers to these questions as I am interested in your experience.

Your participation in this study is completely voluntary and you can choose to withdraw at any time, for any reason. If you are uncomfortable with answering any of the following questions you can choose not to answer by stating "pass".

With your permission, I will record this session, once the recording is transcribed, the recording will be deleted. All information will be kept confidential; no personal identifiers will be used in the data. The de-identified information will be shared with the research team. This information will also be made available to you if interested.

Are there any questions?

Let’s start with telling me about…

Questions regarding demographic information What is your date of birth? (MM/YYYY)

How do you self-identify in terms of gender?

- e) Female
- f) Male
- g) Non-binary/third gender
- h) Other

If other please specify:

How do you self-identify in terms of ethnicity? You may choose more than one if it applies to you. i) Asian j) Black

- k) Caucasian
- l) Indigenous
- m) Latino/Hispanic
- n) Middle Eastern
- o) South Asian
- p) Other

If other, please specify:

What is the highest level of education you have achieved?

- d) Elementary level
- e) Highschool level
- f) College/University level

Are you currently a student?

- c) Yes
- d) No

If you are not a student, what is your current occupation?

Questions regarding past experience with cancer and its treatment What was your age at diagnosis?
What was your diagnosis?
What type of treatment did you receive, and for how long?

1. **Would you mind describing your experience with childhood cancer?**

   i) Tell me about what you felt when you were first diagnosed **and** How do you think you experiencing childhood cancer shaped your childhood?

2. **What does being a survivor mean to you?**
   a. What feelings arise when or if you use this term to describe yourself?
   ii) Looking back, what do you think has impacted you the most in your transition from a cancer patient to a survivor the more you settled into survivorship? a) How was your daily life impacted when you were first diagnosed? b) How has this adjustment made you view yourself?

   iii) What kind of changes did you notice in yourself when you transitioned from a cancer patient to a survivor? AND What kind of changes are you living with now?

      a. How did you feel about these changes?
      b. If you are still living with these changes, please describe how you are coping with them

3. **Please tell me about the impact your experience with cancer has had on your relationships, such as friends, family, peers, significant others, and children.**
   i) In what ways have your relationship with your family changed or stayed the same?

      c. How do you think this has shaped your journey as a survivor when returning to a social environment (ie. School, work, hanging out with friends, etc.)?
   ii) Can you describe a vivid experience that you had in returning to social life?
      a) Why does this experience resonate with you?
      b) how has it impacted you in your journey to reassimilation?
   iii) After you completed your last treatment, what was your experience returning to a school environment like?
   iv) Can you recall what interacting with or making new friends was like for you?

4. **Please tell me about the impact your experience with cancer has had on your mental health.**
   i) What kinds of stressful events do you experience as a result of your childhood cancer?
      c) How do you manage these stressful events?
      d) How did engaging in this strategy help you when going back to school?

        e) How differently do you think you manage stressful events compared to people who did not have childhood cancer?

    iv) What kinds of milestones do you think you achieved at a different point in time compared to your peers?

    v) How do you think experiencing childhood cancer shaped you as a person?

5. **What is one piece of advice you would give to someone who is currently undergoing cancer treatment for their childhood cancer, or who is currently your age, trying to navigate their own survivorship?**

Closing Statement:

Do you have any questions for me?

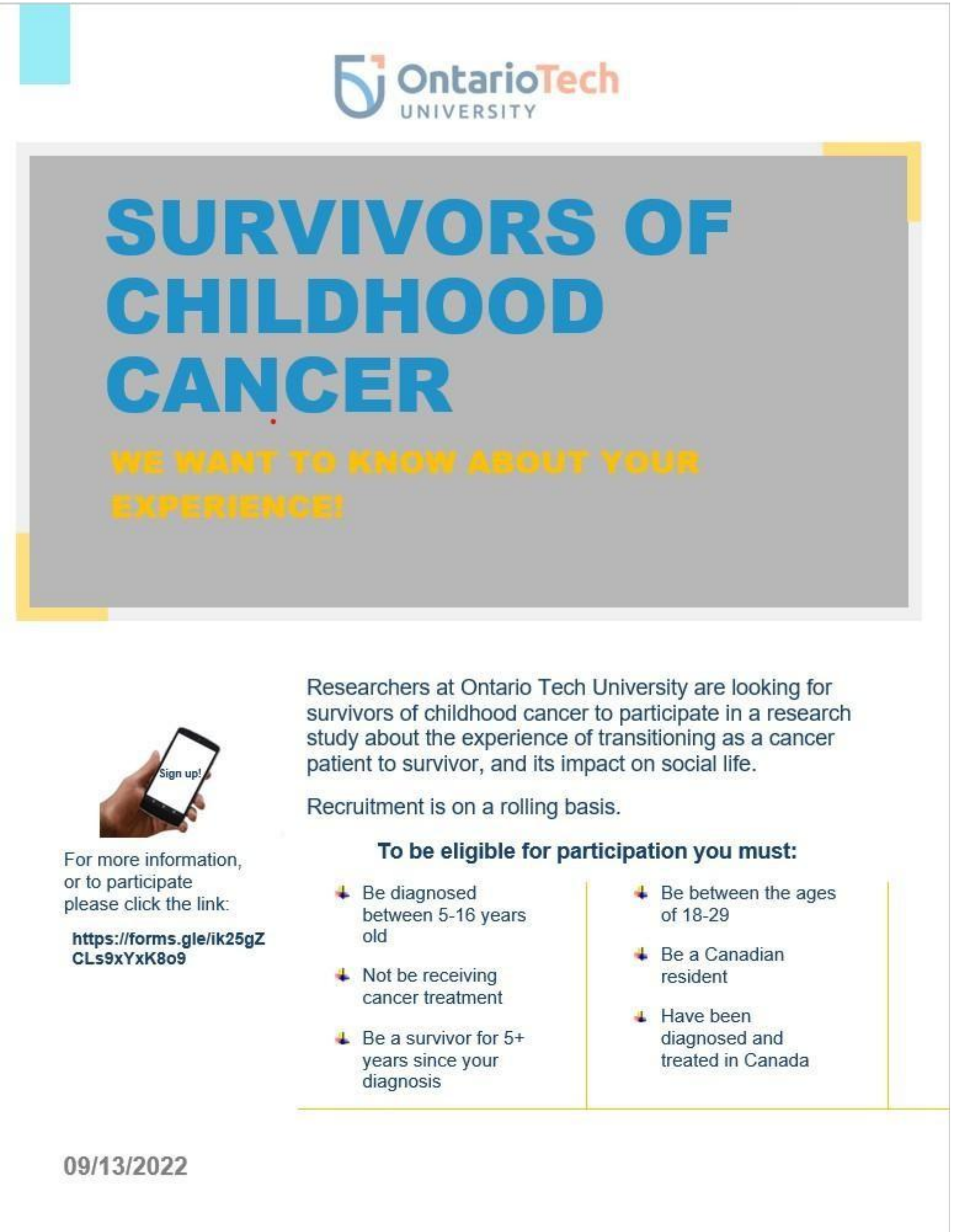
This concludes the interview, thank you so much for your participation in this study. If you think of anything else, you'd like to add or have any questions feel free to contact me via email: shanelle.racine@ontariotechu.net

If you are interested in receiving a transcript of this interview, I can provide that for you.

Figure 1C

Question	Domain
" Would you mind describing the kind of experience you had with childhood cancer?"	*Explores the outlook the participants have regarding their experience (positive or negative)*
" How did experiencing childhood cancer impact your daily life when you were first diagnosed?"	*Explores coping behaviours and outlook*
"Please tell me about the impact your experience with cancer has had on your relationships, such as friends, family, peers, significant others, and children."	*Explores socialization and seeking others*
"Please tell me about the impact your experience with cancer has had on your mental health."	*Explores Mental health, coping strategies and outlook*
"What is one piece of advice you would give to someone who is currently undergoing cancer treatment for their childhood cancer, or who is currently your age, trying to navigate their own survivorship?"	*Explores the participants outlook on cancer.*

Figure 2A



OntarioTech UNIVERSITY

SURVIVORS OF CHILDHOOD CANCER

WE WANT TO KNOW ABOUT YOUR EXPERIENCE!

For more information, or to participate please click the link:

https://forms.gle/ik25gZCLs9xYxK8o9

Researchers at Ontario Tech University are looking for survivors of childhood cancer to participate in a research study about the experience of transitioning as a cancer patient to survivor, and its impact on social life.

Recruitment is on a rolling basis.

To be eligible for participation you must:

- Be diagnosed between 5-16 years old
- Not be receiving cancer treatment
- Be a survivor for 5+ years since your diagnosis
- Be between the ages of 18-29
- Be a Canadian resident
- Have been diagnosed and treated in Canada

09/13/2022

Figure 2B

Good morning/Afternoon/Evening __________,

Thank you so much for your interest in this study, it's greatly appreciated!

I would be happy to interview you for the **Part I phase of this study: Pilot or Part II phase of this study: Research Study**

Please let me know your availability for this week and the next so we can arrange a meeting at your earliest convenience.

Looking forward to hearing from you! And please don't hesitate to reach out with any questions or concerns!

Thanks,

Shanelle

Figure 2C

Hi _______,

Thank you for taking the time out of your day for this interview.

If you would like to review your interview transcript, I will gladly send it to you once it has been transcribed and de-identified. This process simply removes any personal information that may reveal your identity and what I will be using for my data analysis.

Please contact me if you have any questions or concerns, attached below is a list of support services if you feel as though you would like to contact anyone because of your participation in this study.

I appreciate you taking the time in participating in this study and will keep you updated should you be interested in the study results.

Regards,

Shanelle

Shanelle.racine@ontariotechu.net

List of support Services

If this is an emergency or you require emergency support, please visit your closest emergency department or dial 911 **Canada-wide resources**

- Visit the Canadian Association for Suicide Prevention's webpage at http://suicideprevention.ca/need-help to find a suicide prevention crisis centre phone number or website in your province.
- Kids and teens can visit http://org.kidshelpphone.ca or call 1-800-668-6868.
- 211 is a free service that provides referrals for community, government, and social services. Dial 211 or visit the 211 webpage at http://211.ca for more information and availability. **Alberta**

- **Provincial Health Information Line.** Health Link. Visit www.albertahealthservices.ca/assets/healthinfo/link/index.html or call 811.
- Alberta Human Services: Find Supports and Services. Visit one of the websites below or visit www.humanservices.alberta.ca/abuse-bullying/15666.html or call one of the numbers.
    - Family Violence Info Line. Chat online at www.humanservices.alberta.ca/abusebullying/15666.html or call 310-1818.
    - Child Abuse Hotline. Visit www.humanservices.alberta.ca/abusebullying/14841.html or call 1-800-387-5437.
    - Bullying: Get Help. Chat online at www.humanservices.alberta.ca/abusebullying/bullying-get-help.html or call 1888-456-2323.
- Alberta Elder Abuse Awareness Council. Visit www.albertaelderabuse.ca or call 3101818.
- Sexual Assault Services in Alberta. Visit https://aasas.ca/get-help for more information.
- Mental Health Helpline. Call 1-877-303-2642.
- Addiction Services Helpline. Call 1-866-332-2322. **British Columbia**
- **Provincial Health Information Line.** HealthLinkBC: Call **8-1-1** or visit www.healthlinkbc.ca.
- VictimLink BC. Call 1-800-563-0808 or visit www2.gov.bc.ca/gov/content/justice/criminal-justice/victims-of-crime/victimlinkbc.

Child Abuse Prevention Website: Helpline. Call 310-1234 or visit www.safekidsbc.ca/helpline.htm.

BC Mental Health and Substance Use Services. Call 310-6789 (310 Mental Health) or visit www.bcmhsus.ca.

- Crisis Intervention and Suicide Prevention Centre of British Columbia. Call 1-8007842433 (1-800-Suicide) or visit http://crisiscentre.bc.ca.
- Here to Help. Visit www.heretohelp.bc.ca.
- Kids Help Phone. Call 1-800-668-6868 or visit www.kidshelpphone.ca/Teens/Home.aspx.

New Brunswick

- **Provincial Health Information Line.** Tele-Care: Visit www2.gnb.ca/content/gnb/en/departments/health/Tele-Care.html or call 811.
- Emergency Social Services. Visit http://www2.gnb.ca/content/gnb/en/departments/social_development/about_us/emergency_socialservices.html to find the number for the office nearest you or call 1-800-4429799.
- Adult Protection. Visit http://www2.gnb.ca/content/gnb/en/services/services_renderer.9335.Adult_Protection.html for more information.
- Fredericton Sexual Assault Centre. Visit http://fsacc.ca/en or call (506) 454-0437.
- Suicide Prevention CHIMO Helpline. Visit http://www2.gnb.ca/content/gnb/en/departments/health/Suicide_Prevention.html or call 1800-667-5005.

Ontario

- **Provincial Health Information Line.** Telehealth Ontario: Visit www.ontario.ca/page/getmedical-advice-telehealth-ontario or call 1-866-797-0000.
- Assaulted Women's Helpline. Visit www.awhl.org or call 1-866-863-0511.
- Elder Abuse Ontario. Visit www.elderabuseontario.com or call 1-866-299-1011.
- Distress and Crisis Ontario: Member Centres. Visit www.dcontario.org/centres.html to find the phone number for a crisis line in your calling area.
- Drug and Alcohol Helpline. Call 1-800-565-8603.

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- Mental Health Helpline. Call 1-866-531-2600.

Quebec

Provincial Health Information Line. Info-Sante. Visit www.santemonteregie.qc.ca/portail/services/info-sante.en.html or call 811.

Domestic Violence. Go to http://domesticviolence.gouv.qc.ca for more information.

- La Ligne Aide Abus Aînés (Elder Mistreatment Helpline). Visit www.aideabusaines.ca/en or call 1-888-489-2287.
- Batshaw Youth and Family Centres Foundation. Call Youth Protection Services at (514) 935-6196 or visit www.batshaw.qc.ca/en/need-help/report for more information.
- Drugs: Help and Referral. Visit www.drogue-aidereference.qc.ca/www/index.php or call 1-800-265-2626.
- Preventing Suicide. Visit http://sante.gouv.qc.ca/en/conseils-et-prevention/prevenirlesuicide or call 1-866-277-3553.
- Mental Health. Visit http://sante.gouv.qc.ca/en/problemes-de-sante/sante-mentale to learn more.

Saskatchewan

- **Provincial Health Information Line.** HealthLine. Visit www.saskatchewan.ca/residents/health/accessing-health-care-services/healthline or call 811.
- Victims of Crime and Abuse. Go to www.saskatchewan.ca/residents/justice-crimeandthe-law/victims-of-crime-and-abuse for a list of community-based organizations and their contact information.
- Child Abuse and Neglect. Go to www.saskatchewan.ca/residents/justice-crime-andthelaw/child-protection/child-abuse-and-neglect for a list of local child protection offices and their contact information.
- Age Friendly Saskatchewan Senior Neglect and Abuse Awareness. Go to www.agefriendlysk.ca/index.php?page=senior-abuse to learn more.
- Mental Health and Addiction Services. Go to www.saskatchewan.ca/residents/health/accessing-health-care-services/mental-

healthandaddictions-support-services for a list of local mental health and addictions services.

Yukon

- **Territorial Health Information Line.** HealthLine: Call 8-1-1 or visit www.hss.gov.yk.ca/811.php. If you are calling from a satellite phone, you can dial (604) 215-4700 to reach the Health Services Navigator at HealthLink BC.
- Family and Children's Services. Call 1-800-661-0408, ext. 3002, or visit www.hss.gov.yk.ca/family_children.php.

  VictimLink. Call 1-800-563-0808. Or visit the Department of Justice "Need Help? Phone Directory" at www.justice.gov.yk.ca/prog/cor/vs/phonedir.html.

  Alcohol and Drug Services. Call 1-855-667-5777 or visit http://hss.gov.yk.ca/ads.php.

Figure 3A

Outlook on cancer

This tag is used on quotes where participants explain any sentiments regarding their experience with cancer as they were/are experiencing it. This domain explores the participants understanding or interpretation of their experience.

Outlook on reassimilating

This tag is used for quotes where participants explain their sentiments regarding the aftermath of their experience with cancer, including changes observed within their social environments such as family, friends, peers and relationships.

Outlook on coping

This tag is used for quotes that describe the participant's feelings regarding reassimilating but specifically within the context of acceptance and learning to embrace their new reality.

Figure 3B

Outlook on Cancer *Inward perspective on their personal experience*	**Perspective as a patient**: this subcode outlines the participants sentiments regarding their experience as a patient and understanding their circumstance. **The aftermath**: participants outline their sentiments regarding their experience as a survivor and understanding their new relationship to cancer.
Outlook on Reassimilating *Inward perspective on their environment (social environments; work or school)*	**Perceived ability to reassimilate**: The participants perspective and sentiments on returning home, with reintegration into school or work after having cancer. **Forming connections**: Perceived ability to form connections with their peers, family, etc. after having cancer while reassimilating.
Outlook on Coping *Inward perspective on themselves*	**Ability to cope:** perceived difficulties on accepting new circumstances and learning to deal with their experience. **Views on oneself:** what values have changed, any characteristics that participant felt was impacted by cancer in a self-reflecting context and relates to the development of their new identity **Coping tools:** tools, methods or protective mechanisms used to navigate and mitigate difficult situations as a result of their experience with cancer.

OFFICIALTRANSCRIPT_P1.PDF
Participant 1 Interview Transcript

I: Alright - Okay! Hold on. Okay Awesome, so just going to start with some, demographic information here. So, can you just tell me your date of birth?

P1: [redacted]

I: Alright. And how do you self-identify in terms of gender? Female- P1:

Female.

I: - Male? Non-Binary? Okay.

I: How do you self-identify in terms of ethnicity? You can state more than one if it applies to you. So Asian-

P1: Caucasian and Latin American, or South American.

I: Oh-okay.

P1: Yes.

I: And what is the highest level of education you've achieved?

P1: Undergrad [Undergraduate degree], university.

I: Okay. Are you currently a student?

P1: No.

I: Alright, if you're not a student, what is your current occupation?

P1: I'm a personal trainer, I own my own private business, and I also do contract work for a small boutique gym, and I do massage cupping and scraping as well as - as a therapist as well.

I: Oh, awesome!

P1: Yes.

I: I'm just going to get into questions about your past experience with cancer and treatment. what was your age at diagnosis?

P1: I was 13.

I: Okay. And what was your diagnosis?

P1: They don't actually know. My story's kind of weird because I found out when my bone just snapped in half when I was actually just walking to get an MRI done, to figure out why it was hurting me so much. It actually spread a little bit to muscles and tendons and all this other stuff, so they treated me as if I had osteosarcoma and then even – they eventually, from the biopsy and eventually the full resection, they classified it as malignant fibrous histiocytoma, but I'm not sure if you know very much about that. That's pretty much the classification that they use when they don't know what it is. So, it's just kind of a lump, when the cells are too diff-de-differentiated. So there-depending on where I go, I'm either classified as MFH [malignant fibrous histiocytoma] or I'm classified as spindle cell sarcoma. But, neither is really accurate because they don't know.

I: That's really interesting. Can you tell me what type of treatment you received and for how long?
P1: It was a year of treatment-just under a year. I started it on-just before Christmas I believe, or just after Christmas of 2006, and I had doxorubicin and cisplatin. Basically, not together as they're supposed to be done, they were back-to-back because they accidently put in a single lumen port rather than double, and they realize that it burned my veins. So, they ended up having to put one first, and the other in through my port and then I would be off for a week, and then I would have methotrexate, high dose. And then I'd be off for like a week or two depending on my levels. Then I had that basically until November 4th, 2007. That was the day of my last treatment.

I: Okay. Thank you. Would you mind describing your experience with childhood cancer? Tell me more about what you felt when you were first diagnosed, and how you think your experience shaped your childhood?

P1: Like I said my story's kind of different than most people's because when I was supposed to be going towards Credit Valley Hospital to go get my MRI done of my knee, because at the time it was just knee pain that I was getting. And my bone literally snapped in half outside the emergency doors, or kind of between the emergency and the main doors. So, I was obviously in a lot of pain, and I stay overnight at Credit Valley then I was shipped to SickKids, but through out all that, I honestly don't remember much of the first month because I was on a lot of pain meds.

And I remember like the transfer, I remember the first night, I remember little bits and pieces of Christmas and new years. I remember the nurses coming in with the little headbands, but I don't remember very much so I don't think I had the same kind of reaction where it's like "oh you have cancer" and it comes over you because I kind of – I didn't really know it was happening but I kind of assumed it was happening based on what the doctor kind of - was whispering to my mom in the corner, and I couldn't remember too much. I was so hopped up on pain meds it's like a blur basically until mid-January. So, I think it was different for me to cope because I didn't really have that kind of full processing power to actually process it. I was kind of just suddenly more coherent because they lowered my dose and my pain was getting slowly more manageable because the initial swelling and trauma was going down and I kind of just, was there and it was kind of like I had to deal with it because I was in the hospital. And my first 6 months of treatment right until April from December 17th until April 7th I was in traction, at the hospital. So I would go up and down between the 5th floor in traction and the 8th floor to get my chemo [chemotherapy]. And then April 7th is when they did my surgery, where they actually took out the tumour and that was when I was detached from the bed because I was fully attached the whole time. And any kind of movements would be really painful, I kind of had to make dew with what I had. I was actually one of the happiest chemo patients while I was on chemo. I was there for so long that it became comfortable. *[Outlook on cancer]* I actually had trouble going back home. It was more traumatizing to be back home after my surgery and be away from the hospital and the nurses having to deal with the aftermath of the treatment and going back to the hospital for the last 6 months, than it was for actually having the chemo and losing my hair *[Outlook on cancer]*. My family was actually way more traumatized about that than I was. I didn't really care. I was pretty happy in the hospital, and the only thing I noticed was after, when I came back *[Outlook on cancer]*. So, I wasI had cancer-I got cancer in 8th grade. I spent most of 8th grade and 9th grade back and forth to the hospital. And then I think 10th grade is when I really started to notice the after affects because before that I was just in survival mode. *[Outlook on cancer]*Dealing with it, I wasn't having any issues with it, and I was so isolated from everyone else and everything that was happening as a kid that I didn't really notice *[Outlook on cancer]*.

6:43 I: So, I find it interesting that you mentioned it took you a while to really process what was happening being that, you know you were older right, it's not like you were 2 years old 3 years old where you really just probably don't have much memory. I mean you still say you don't remember as much but you're still old enough to kind of understand that something is happening and something's you know wrong, but it took you a while to really fully process it and get there. So, can you explain a little bit more about how like the difficulty in transition from being in the hospital and being relatively happy and it's great that you actually – that you felt like you had an environment where could feel like it was easier to kind of go through something like that. But can you speak a little more with kind of – I guess the shock with moving from the hospital and then coming home, and then really realizing oh wait this is-I'm fully processing this now?

7:51 P1: Yes so, I want to clarify, I understood what was happening. I understood-I processed it, it wasn't – it was just like I didn't really have another choice. Kind of like so –

I: Kind of like—

P1: This is what life is, I guess.

I: Yes, Okay.

P1: So, the first month was definitely rough because I was so-on so many pain meds and I was actually on pretty high doses of pain meds for quite a couple years afterwards. But for me it wasn't like the chemo-or the cancer. It wasn't an issue for me, I think I delt with that just fine. I was like "okay I'll just deal with it" and that's always been the way I've had things happen because I had a lot of complications afterwards. While it was happening the first-especially the first few times things happened, I was fine with it. I was like "you know what? Fine, I'll deal with it. I'm better in survival mode." But its when I had to try to be normal – **I**: Normal.

P1: - That I had issues, because there was such a big difference *[Outlook on reassimilating]*. So, I think where the difficulty was, wasn't so much when I had time to process it. It was more in isolation; I couldn't be constantly reminded of how different and limited I was. And I was very athletic, and very independent, I've always been very independent. So, I think that was the more difficult portion, going into 10th grade and realizing that my teachers didn't want me to walk on crutches because they were scared I was going to fall, so they wanted me in a wheel chair still.

And even standing up realizing how difficult it was to get from point A to point B in the 5 minutes we had between the periods, and things like that. That's where I think a lot of the trauma really happened because it was like "Deal with it, and life or death, right when it's happening" but then nobody bothered to transition me really into normal life, or to help me understand what I'd expect. *[Outlook on reassimilating]*So, I kind of was just like "well I've been surviving this long", I expect to just be like - continue to just deal with it or go right back into the way I was dealing with things before, which obviously with one less working leg, it was completely different. So that's where a lot of the issues built up and a lot more of my trauma happened with a lot of the - all the complications that I actually got as a result of the cancer and all of the surgeries and stuff like that. So, I think that with each like new surgery or new issue, my ability to cope with it was worse, and worse, because there would be new hurdles constantly and it was like "enough is enough" kind of thing. *[Outlook on coping]*

I: Okay. Thank you so much for, clarifying that. So, I want to talk a little bit more about your, I guess survivorship journey so what feelings arise when or if you use the term "survivor" to describe yourself?

P1: I don't like it. I actually really don't like "survivor" because – Actually, sorry one second, I actually just need to pull something out of the oven.

I: Yes, no worries (*laughs*). **10:54**

P1: (*shuffling*) [BREAK] **11:05 P1:**

Sorry.

I: No worries.

P1: I don't like the term survivor *[Outlook on cancer]*, because typically, what's associated with it is - I don't know overcoming something huge, as if you had a choice or kind of really almost like, you decided to go through with something and decided to push yourself through it when - and then basically making it sound like you're brave for going through it almost *[Outlook on cancer]*. Which I really don't like when people call me brave, I really don't like people who are impressed or proud of me because in my mind, no matter who goes through it you really don't have a choice but to survive. What are you going to say like "Okay I have cancer, so I'm just going to sit here and give up? ". No matter what, you're going to still be dealing with and it - it doesn't quite feel right, because it's true in a way we are surviving, barely. *[Outlook on cancer]* And that's the way it felt for a long time after when I got home and had to deal with all the different changes that happened to my life. It doesn't quite adequately describe what happened and it sounds like we're just kind of either getting by or like its something that we should be proud of. Whereas for me I used to actually get very upset when people would tell me they were proud or impressed or thought I was brave *[Outlook on cancer]*, in that sense.

I: Thank you for sharing that perspective, I've not quite - I guess, understood it in that way, but I do think it's very interesting how you're right, the idea that like "Oh you can accomplish this thing" and it's like "well I didn't really even ask for this thing" – **P1:** Yes.

I: Thank you for shedding light on that. Can you tell me how I guess this adjustment made you view yourself a little more? Not just the term survivor but, moving – transitioning from being a cancer patient and then into high school and being a student.

P1: Do you mean like how did it affect me? Almost –

I: Yes. Like how in terms of – **P1:** Like afterwards?

I: -Like how you viewed yourself, your identity, and how did that come into play when taking a look at yourself and being like "I guess I'm this person now"?

P1: Okay. Well, I guess, it really evolved a lot throughout the years. Initially, as a kid I saw myself as different or almost less. Because, again nobody really taught me how to transition back to life. And that's I think, the one thing that was really lacking and is lacking with a lot of cancer patients as kids *[Outlook on reassimilating]*, because there is that kind of "oh you are good, you're healthy, ring the bell be excited be so happy" and then just kind of go back to life. But that's where I had the most difficulty because as someone, especially someone with a very physical limitation coming out of having cancer, nobody really taught me to expect that I wouldn't be able to do certain things. *[Outlook on reassimilating]*

Logically I knew that, and I knew that obviously, I didn't have my quads properly anymore, like a lot of it was so swollen at the beginning –the first few years that my knee was barely workable, and it would just give in when I actually did manage to walk on it. But I almost saw myself as kind of less at the beginning, because the way I used to view myself, was as a very highly accomplished academic and competitive driven athletic person as well. *[Outlook on coping]*So, I was used to kind of overachieving, overperforming, and to suddenly come back, having missed an entire year and have to kind of do work extra to catch up and understand what's happening in that gap, because nobody really taught me too much in between because I was so busy being sick. And *[Outlook on coping]* trying to relearn how to walk properly again and realizing that I wouldn't be able to walk up the stairs normally. It was a lot of kind of, frustration, feeling inadequate, feeling basically like a failure at the beginning *[Outlook on coping]*. I felt very angry because not only was my body failing me, it felt like people were failing me because nobody actually taught me how to cope with it, or how to dealt with it or how to figure out how to get back to where I wanted to be. *[Outlook on coping]*And I wasn't somebody who liked failing so nobody-it was wither fail with the physios [Physiotherapists] which I hated and nobody really kind of taught me tools to do on my own or things to like cope at the time. So, I think that was the most difficult part at the beginning *[Outlook on coping]*, and even just like when I'd fall, I'd be angry at myself, I wouldn't want help, I wanted to be independent. So I think a lot of that, feeling a complete loss of control and independence and feeling like somehow I had become somebody who was-I wouldn't use the word crippled, because I've never really seen myself as a cripple, but more kind of just so incapable of doing things by myself, that at it was just-that at the beginning I was like “what is the point really, because I can’t do anything by myself” *[Outlook on coping]*. Whereas later on, I think because of that and through sheer stubbornness, I pride myself in my independence to a fault now and I have forced myself to learn how to do more than even the regular post cancer survivor with missing parts of her body can do, right? So, I think that’s a bit more different, I’m kind of, almost, I guess like I’m strong in spite of it, rather than because of it *[Outlook on coping]*. Because I don’t think it helped me with mental toughness or anything like that, it was more like I was powerful enough and stubborn enough, and strong and independent enough that I was able to kind of just – say “****you” to my leg and kind of deal with it, you know. *[Outlook on coping]*

I: I think-yes and my follow up question which I think touches really well or is a great one to what you just shared with me. What kind of changes did you notice in yourself when you transitioned from cancer patient and onward and what kind of changes would you say you’re living with now?

P1: I think part of it is. I do have a bit of mental toughness. And I’m very good under pressure or in survival mode. I am somebody who ended up with a lot of PTSD [post traumatic stress disorder] and anxiety disorders and things like that. As someone who’s probably had a bit of anxiety to begin with and then was made worse. I think that that’s the biggest thing. I’m very good when things go wrong, I’m very good when things go terrible. I am very good at pushing through and getting trough it because that’s what a lot of my life especially in my childhood and youth was, that I’m almost more comfortable in those situations than not. Which is a bit unfortunate because I still do have PTSD from the isolation, so I think initially it made me more stubborn and mentally tough but then later on was kind of a back and forth *[Outlook on coping]*. An example was my lung collapsed actually by chance from like an acupuncture needle like early 2020, like January-

P1: - and this is probably the like 10th thing to randomly happen to me. I’m very unlucky with the random spontaneous things happening to me. And I think if it had happened a year after chemo or two years after chemo, the way that – like my like metal screws breaking or my bone infection would have happened, I would have delt with it much better initially. I think with each passing new issue my body is less able to cope with it. Initially I was like “whatever its fine, I’ll just deal with it, I’ll move on” now its more of PTSD. Not necessarily of like flashbacks but of kind of panic attacks, like “I’m going to be isolated again”, “I’m going to be completely stuck again” and it takes me back to a lot of - a position where I literally had no control, I had no – I couldn’t do anything basically. *[Outlook on coping]* And then a lot of COVID isolation was like that for me as well. So I’m both-its weird, I’m both able to handle things better and I do a lot better under pressure but I also break down and fall a part a lot more under pressure too, when things happen that are like unexpected. *[Outlook on coping]*

I: So with these changes, how do you manage? How do you cope with them - with the battle between obviously being able to be prepared but then also kind of being triggered, how –at what point do you kind of just ease the tension between both sides.

P1: I think a lot of it is kind of instinctual at the beginning. When I - when things first happen, so it’s - I kind of like almost break down at the beginning and then I just have to figure out, pick myself up and kind of just deal with it. It does go up and down. I will have periods I think where I'm a bit more tired and I can't like cope as easily *[Outlook on coping]*and considering I'm somebody who has lived with like pretty intense anxiety for the past I would say 10 years. A lot of it just, learning what coping mechanisms work and what works in what situations. So, it's more just knowing when I actually need to separate myself and be alone to bring down the level of anxiety that's happening and things like that *[Outlook on coping]*. Also just, and I think I would say-kind of going with what works before.

And for me a lot of it is reminding myself that I do have control, *[Outlook on coping]* because I did - and this kind of goes hand in hand with the trauma and everything-but I did have difficulties with eating disorders in 11th and 12th grade. Partially, unfortunately caused by doctors, but it does come back when I do have loss of control because it is – it used to be back then the one thing I could control. And it wasn't body image really, it was fully control related. So that's where a lot of my issues stem. So, I think a lot of it was, when I know I have things coming up whether its like physical or mental stress, a lot of it comes down to reminding myself and asserting my control over my own body and over my own actions as much as I can. So, separating myself from the situation and then doing what I can *[Outlook on coping]*– and for me its fitness that's why I became a personal trainer, because its kind of proving myself that as much as my leg isn't 100% useful all the time, I still can do a lot of things, and I can still feel powerful while I'm lifting things and I'm stronger.

So that has made a big difference I think just in being able to remind myself that I can do a lot more, and just focusing on that part of what I can control.

23:16 I: That's awesome, thank you. So can you tell me a little bit about how, your experience with cancer, like the impact its had on relationships, making friends, family, peers. So just can you speak about in what ways has like your relationship with your family changed or if things have stayed the same?

P1: So I think it depends. My family's a bit different because its an ongoing thing. But I think the way that I used to deal with meeting people and relationships was very different when I was in my teens just because I was so isolated at the beginning, that I found it very hard to become friends with people, *[Outlook on reassimilating]* because obviously when you're in 8th grade you're still really young and I was gone for pretty much like the entirety of my 8th grade. I left in what December? And then I was pretty much gone after that and I ended up going to a high school most of my elementary school had not gone to so, I think initially it was very different. I think I had a hard time making friends. I was very friendly, but I was very shy. And that's something that I've always been, shy, and initially I wouldn't bother I think when I was younger because I knew that I would be there and then I would be gone, and then people would forget because I'd be gone for like two, three weeks straight sometimes. And when you're thirteen you know people's, memories are short when they first meet you when you're young like that, because I went to my first day of 9th grade and then was gone for like a week in a half. So that critical moment where you meet people is not really there. So, I think I just focused more on like school on like relationships with adults because like I knew –

I: (*barking*)

P1: - that they wouldn't be the same way obviously. *[Outlook on reassimilating]* I think I had to mature really quickly in that sense. And I was able to communicate better with doctors and nurses, and with other people who I considered more my peers at the time because I was able to talk to them properly. And I think that pretty much continued until like third year university because I was still having a lot of issues and complications *[Outlook on reassimilating]* and the same thing happened for the first two years of school basically in university. So in terms of friendships and meeting new people it was very, very, different and I didn't quite put in the same effort I think into keeping up with people because I knew that eventually it wouldn't work out. *[Outlook on reassimilating]* So, I think that was very different and I did evolve a lot in the 7 last couple years of university because I did join a team and found kind of a more upper body sport, and then I realized that I could try to make relationships like that because it seemed like we were all mature enough at that point that we could deal with longer absences of not seeing each other and still keep up with things. It did get better and did evolve but, I still do have difficulty with that because of things like that, where I didn't have the same social relationships growing up, and the same went for relationships *[Outlook on reassimilating]*. I think the most difficult thing in the beginning when you're young is trying to figure out how much do you tell a person about what happened to you when you're trying to date someone and become friends with someone. I still don't think I really have that at the right spot. *[Outlook on reassimilating]* I'm not someone who really cares to not tell people. If people ask and they see – because I got scars all over my legs – I think I've gotten to the point where I don't care. I'll wear shorts, if you want to stare at me that's cool, ask me if you want to ask me but don't be rude, you know? And I don't want mind talking about my entire history. It's no longer an emotional thing for me and it probably hasn't been for about 8 years now.
I think I'm at the point where I can talk about it pretty impartially and kind of almost laugh about the things that happened to me. *[Outlook on cancer]* It doesn't really limit me as much anymore, but at the beginning it really did obviously. *[Outlook on cancer]* There was that kind of fear of rejection, and like I said my own self worth was measured by how independent I was for a lot of my life. It was a bit difficult in that sense where I didn't see myself as somebody worthy of getting to know or dating because I didn't find myself, that I felt I had value because I was so, I guess dependent on other people. I think that was the difficulty and even now I still struggle with it at times, just more in terms of the judging my worth by my own views. *[Outlook on coping]* **P1:** With my family, I don't know, my parents are very over-protective and my mother especially, she's always been that way. And it got worse obviously when I got sick, so it was, even to this day she's very helicoptery and I'm 28. So, I think it goes up and down. . There were periods where we clashed quite a bit because she didn't understand my need for independence and where it stemmed from, because she couldn't understand why I wouldn't just accept help.

Her need to help me clashed with my view of my own value and how being helped all the time felt. So, I think that's always going to be a bit difficult forever because she's just – we're locked into that kind of state *[Outlook on coping]*. But she has gotten better over the years, and she also understands that she had anxiety that was exacerbated by my illness. My dad, is pretty much the same I think he was the least affected by it, stressed at the time but then we kind of went back into our old patterns of doing things. *[Outlook on coping]* We're very similar in the way that we are very stubborn, and we do also both value our independence to a fault, so I think he understood that leaving me be was probably better when I wanted to do things on my own. And it was pretty normal. My brother I think, was the one that I kind of feel guilty about *[Outlook on coping]*. He was in 5th grade, and he got almost completely abandoned when I got sick. *[Outlook on coping]* It was me, my mom and my dad and my brother who lived together when I was a kid, and my grandmother was I think about two, three blocks away, lived really close by in an apartment on her own. And when I got sick, my mom spent the entire time when I was in-patient, in the hospital with me. And my dad, my brother, would come over and my grandmother moved in with them to kind of help because my dad obviously worked, and my brother had to be watched because he was so young. Because my mom didn't work at the time, she used to bring us back for lunch and feed us and then take us back to school and stuff like that. My grandmother kind of took that role. My brother was very much more open, less shy than I was when I was a kid, and I think he completely switched because of me. And that's the one thing I do 'til this day feel bad about, he got really quiet, he got really shy. *[Outlook on coping]* I was very active as a kid in my school because I didn't like going out for recess, I hated the cold I hated playing outdoors. I used to be the one who used to hang out with the teachers and help them out, so I didn't have to go out in the cold. So, all the teachers would constantly ask my brother how I was doing and what was happening, and he was in 5th grade, he didn't know anything, he barely understood what was happening and I felt really bad he got really quiet because he didn't want to answer questions.

After that he was more quiet, more shy, wouldn't speak about his own issues, even when he was kind of I think hurting he wouldn't say anything, because everybody was so focused on me, and what was happening with me and the fact that I was constantly almost dying and things were always happening to me that, well even to this day when my lung collapsed like 2 years ago like everything – like "okay let's make sure she doesn't die". I think that's the one thing outside of my control that I really regret. Our relationship was never the same, we don't really talk. He doesn't talk about his issues – (*cries*)

31:49 I: Do you want to take a moment? **P1:**

[BREAK]

32:00 P1: In a way, I had it way better than he did, because I had at least the resources. He didn't. *[Outlook on coping]* And he was so much younger, and I know that in terms of his friendships, he's fine. He's normal in that sense, because his friends weren't asking about me but the way he deals with conflict, the way he deals with illness, the way he deals with other people's illness, he runs aways now. Because he didn't know how to cope, he'd be thrown into the hospital room with me, didn't know what to do. Couldn't stare at me, didn't want to look at me, because he was so stressed about me being sick and not acting like myself that even now, when I'm not feeling well, he'll run away. That's I think the one thing, that's the hardest for me. So I think that's the one relationship that was the most altered and the most difficult. Because everybody else, they're adults, they delt with it, they moved on, you kind of make your peace with it. *[Outlook on coping]* And as you grow up you kind of deal with it with them anyways. Because my grandmother had a very hard time with it too, because she had had cancer right before even though I didn't know it at the time. They hid it from me and my brother, and that's how I found out she had had cancer. But she was fine, their adults so they know how to cope with it a little bit better. So other than her panic at me losing my hair and being sick it was okay afterwards. I think it actually did bring us closer because eventually she actually did die from cancer –

I: I'm sorry to hear that.

P1: - and I think my own experiences helped me a lot to understand, to advocate, and to be able to cope with her illness and know what to do and kind of take over. I ended up spending the last three weeks of her life with her in palliative care. I slept on an air mattress on her floor. So I think in a way, that relationship with her was the most strengthened, and my dad's stayed the same and my brother's was the most difficult I think. Yes.

I: Thank you so much for telling me about your experience and what it was like for you and your family. Are you okay to move on to the next question or do you want to take a couple more seconds?

P1: No, I'm good.

I: Okay. Can you describe for me a vivid experience you had in returning to social life? Like do you have a memory that really resonates with you or anything specific that you feel like you still remember or still sticks with you in returning to-P1: In like a positive or a negative way?

I: It can be both. Either or.

P1: I don't think there was anything in particular, I think it was a series of little things that made me realize how different things were. I think the thing that sticks with me to this day that I remember the most is that the most frustrating thing about going back to school in a wheelchair is that nobody realizes your face is at backpack height. I think that's the one thing I remember the most about school *[Outlook on reassimilating]*. About having to become very aggressive, and even to this day I got really good at being on the subway because you had to learn how to push past it, and it really did help me (laughs) with the amount of subway riding that I used to do in university, that I did learn how to kind hold my ground even on crutches to kind of push through people. *[Outlook on coping]* But theres nothing in particular. It's kind of just weird moments like that where I'm like yes, way more aware of different limitations and frustrations than people who have physical disabilities face. And its not necessarily big things it's little things like that.

I: Right.

P1: I think that's what I remember the most.

I: And those little things, how would you say it's impacted your ability overall with reassimilating, would you say its kind of just something you had to deal with, like you were working through it or did it reinforce or emphasize anything about your ability to reassimilate.

P1: I don't think it was really anything, in particular. I think I just really learnt to deal with it because what else was I going to do? I think the biggest thing is it really did reassert my anger at little injustices *[Outlook on coping]* like that. And small stuff like that, where to this day if someone sees me parking at a handicap spot and makes a big deal about it, I'll fly off the handle. I'll get really mad. Things like that where its just, more the lack of awareness that other people have for the small difficulties, where even maybe invisible disabilities are. I think that's the biggest thing; being more aware of what other people's issues might be, and being more mindful, and being more self-aware of how I react to other things like that. *[Outlook on coping]* But otherwise, it was just something I kind of just like, may have frustrated me at the time and I may have broken down many times in the process, but now it was just something I kind of like dealt with. It happened, and I did what I had to.

I: Alright, so we're going to move on to our next question. I know we talked a little bit about, or you shared with me a little bit about your mental health journey, so can you just share with me, just because you did talk about the stressful events you had to face and how you coped with them. Can you tell me anything about how engaging in your strategies really helped you with being able to go through school, because you also did your undergrad, and you're working and you have your own business and what not, so how has this or these strategies really helped you in being able to just keep going in your school life and work life?

P1: Yes will I think, the one thing that I think the biggest strategy would be – well I wouldn't really call it a strategy – kind of a personality trait would be the pure stubbornness I had to have to kind of go through something like that where people were just – the doctors didn't know if I'd be able to walk, and then they were like assuming I wouldn't be able to go upstairs properly, they didn't think I would be able to squat or anything like that obviously. So, I think that it was more just, the stubbornness that I had, and the frustration that I had about gaps in physiotherapy when it came to teaching me enough to walk again vs. teaching enough to perform, or to be an athlete again, things like that. Those frustrations are really what kind of shaped me because I was stubborn enough to deal with it and go to the gym and figure it out, because trainers were too scared to touch me, and the physios told me I was fine. And I wanted to be more and do more, and be independent the way I used to, and I think that kind of almost anger at my body and pure determination, is what really helped me to become as mobile and agile and strong as I am today, *[Outlook on coping]* and to really understand everything that I possibly can. Like my need to understand everything about my body in its current state and to be able to anticipate any further complications and my kinesthetic awareness of my body, because not being aware could mean my leg could give out any moment. I think those things that I've had to deal with as someone who's had to go through chemo and had to go through a million surgeries, that's really made a huge difference because it means that I'm so much more knowledgeable and in tune with people I think, because I learned a lot about how to work out and I learned how to work out in a way that isn't really normal for most people. *[Outlook* *on reassimilating]* Anybody can go and be a personal trainer, and learnt the basics of working out and training and tempo, and sets and reps and everything but I think my need for creativity when I was trying to deal with my own stuff, and my need to just keep pushing until I found a work around or I found a way that worked for my leg, really made a big difference because it means I'm able to specialize in rehab clients and really take the most broken people who have no hope and really tell them that its not entirely impossible, that it might take a long time and they might never be exactly the same as everybody else but I think that I've been able to empower a lot of people who didn't think there was a lot of options for them just because I know so much about doing things in the most unconventional ways, *[Outlook on coping]* that I've been able to grow my business in that sense, and that place that I work with as a subcontractor, they work with older populations and a lot of what they wanted was rehab. So, these sorts of things have helped me a lot, and the fact that I wont stop trying until we find an option rather than just giving up or saying that's not possible. Its really made me realize that there is such a big disconnect there with fitness and how much again, I valued my body and myself was through that ability to be on my own and do things for myself. And in there saying, that's probably the way a lot of people with physical issues are, because we have such – so much independence ripped away from us without our consent that, that's the one thing we want the most. And a lot of people have– I've worked with like amputees, with spina bifida, things like that are not very normal in personal training and I've watched clients sit down and break down because like they are so tired of the chafing from their leg from their prosthetic and things like that that I can not only sympathize with, because I spent a year in a cast, and the chafing I understand all that, but it's just I know I can empathize and I can sit down and be not completely like, I'm not lying when I say it will be okay, we will figure out a way, it will be possible, and I think that's something that I really find that I have value in that sense, because I went through a lot in the first nine years trying to figure out how to deal with things and how to physically be able to do things. I think that in that sense I've become really successful, because I can help people without them having to – without the proper knowledgereally figure things out, that they don't have to go through the amount of torture that I went through and the amount of misery and depression, and anxiety, and actually help them get to, hopefully, close to where I am now.

I: That's awesome, [BREAK] sorry I'm just still processing here (*laughs*) so, how differently do you think, you-you're able to just manage these stressful events and really just, honestly inspire other people as well because of your experience. So how differently do you think you can manage these stressful events compared to people who perhaps didn't experience childhood cancer? **P1:** I think it's happened so many times, and there's been so many hurdles that I kind of - I might sometimes initially by reflex fall into a bad pattern but it's much easier for me to deal with it because I've had so many experiences with bad things happening that I wouldn't say I take it in stride because I definitely don't (laughs) but, I can much more quickly implement a coping mechanism or some sort of way to alleviate my anxiety *[Outlook on coping]* or just decide "okay well we're going to run with it because this is our only option" and I'm much better at that because I've done it so many times. So, I think I do have more, because of my experience with bad things happening it does make me more - I guess I would say it helps me deal with it a lot quicker, whereas people who've never had to deal with adversity or issues like that they wouldn't – at the beginning they're going to be lost the way I was when I was in 10th grade. It's different in that sense, that I'm able to kind of just deal with it and just move on, and not have it have the same profound, emotional and psychological impact the way it used to and the way anybody dealing with something for the first time would have. *[Outlook on coping]*

I: So, with that being said then, what do you – what kind of milestones do you think you achieved at a different point in time, whether it be earlier or later, when comparing, I guess yourself and your experience to your peers?

P1: A milestone? What do you mean?

46:06 I: Yes, so it could be anything regarding just, I don't know, development, whether it's physical, mental, emotional or even certain achievements with school, work or relationships.

What kind of I guess, life experience – I guess is the better word to describe what I'm trying to ask here, what I guess, different or kinds of life experiences do you think you've encountered or achieved at a different point in time when comparing yourself to your peers?

P1: So, you're saying like a milestone that my peers would have, like did I have it at like a different time or was it a different experience for me? Is that what you're asking?

I: Yes, so like (*pause*), yes (*laughs*)

P1: Okay. I feel like because I did have to deal with so many life altering, life threatening, very important big picture things, things like graduating school didn't really matter to me *[Outlook on cancer]*. It was important to get to the end obviously and finish my school, but I don't think I celebrated the way people would when they finished. I didn't even go to my convocation, I thought it was a waste of time. I didn't want to sit in a room and just have peoples name listed off, to me I didn't care about that. I didn't want to celebrate that the same way because it wasn't some huge change in my journey, it just seemed like another thing I was doing along the way. *[Outlook on reassimilating]* I think things like that, a lot of things that as a teenager or as a young adult that might seem like really cool important milestones weren't quite as important to me. I did want to do the same things, I did want to still have the same experiences, but it wasn't like this amazing, life altering, memorable, amazing event. *[Outlook on reassimilating]*Partly because I was still dealing with stuff here and there in between, and realistically making sure that my leg is feeling okay is always more important, and it does tend to take a way from a lot of the stuff that's happening in my life. But also, just because I didn't find it as big of an importance as other people would, *[Outlook on reassimilating]* I think. I still do have the same milestones, I think I still –now as an adult especially, I still do have them at very similar times. Its not like I'm doing things way later, or way differently than other people, I think its just for me, my differentiation for things that truly matter and don't, are like this (*motions hands far a part*), *[Outlook on reassimilating]* rather than like everybody, happening like random things like birthdays they're like a big thing for some people whereas for me its like realistically it doesn't matter to me, I want to enjoy it but I'm not going to see it as this incredible, world changing, life altering thing in my like – I'm not going to get all worked up and, the same thing would be if I had gotten married. I wouldn't see this as like this be all end all of-this amazing huge ceremony, it's just a wedding. I wouldn't see it as this one huge, big deal. So, I think things like that, have really changed my perspective because I know what things are truly important. The same way I don't fall a part at like small things, inconveniences, obviously if you're tired, you're going to fall a part (*laughs*) realistically- **I:** Yes, (*laughs*)

P1: - when I truly look at it, small things that happen that are bad in my life aren't quite as important to me. It's just well, like "it didn't work out move on" vs. "my whole world falling a part" the way some people have, because that is the worst thing to have happened to them kind of thing. *[Outlook on coping]*

I: Would you say then that essentially, its kind of shifted what you valued compared to what other people typically would value – **P1:** Yes.

I: - in your life?

I: Okay.

P1: Yes. A lot. Quite a bit.

I: Okay, thank you. Now with our last question. What is one piece of advice you would give to someone who is currently undergoing cancer treatment for their childhood cancer, or who is currently your age trying to navigate their own journey into reassimilating back into society?

P1: I think for someone dealing with childhood cancer, like as a kid, I would tell them that –really enjoy the fun times that you have, and don't see it as a bad thing. As much as it sucks there's going to be some good days and don't spend your good days stressing about the bad days that might happen. Because I think that's what happened to me, I really did not care. I had the greatest time, it was so funny, the nurses thought I was so strange at the beginning because I'd be the one laughing, watching TV, completely hyper, in pain, on chemo, literally not caring and they thought it was the most bizarre thing ever. *[Outlook on cancer*] And sure, it was really awful to get thrown back into reality later on. But I think just dealing with it in stride and saying like "have fun with it where I can" really did help me because I know people fully fell a part when they were in the hospital on chemo and didn't want to do anything. Chemo is hard enough without making it worse on yourself mentally. So, I think that's one thing. And I think now, would just be to really take the time and go into it. Break down everything that happened to you as a kid, and as much as it sucks its better to work through it than ignore it *[Outlook on cancer*], because I spent a lot of my young adult years ignoring it, and it doesn't really work out very well because the more you deal with it the more it becomes kind of an impartial thing *[Outlook on coping*]. I think that's the biggest thing, because it was such an emotionally charged issue for me at the beginning between that loss of control and feeling completely different, it wasn't so much the chemo, like I said, but that change was something I didn't want to deal with. And it was such an emotionally triggering thing for me to be reminded how different things were and how awful it was to be different. But if I'd really dealt with it sooner, I think I would have been able to deal-to see it as something as just it happened, and its not good or bad. It just happened. The same way that going through anything, you know enough times becomes less emotional *[Outlook on coping]*].

I: Awesome! Thank you so much. Do you have any questions for me?

P1: No not really, I think the only thing I want to know, is if you guys can give me the results of the study – **I:** Yes for sure––

P1: - or send me a **[INAUDIBLE 53:06]**

I: Yes once everything is like, analyzed and finalized I hope to, if you're still interested to bring back the participants for a focus group and really talk about my initial findings and be like "does this resonate with you guys", and generate a little bit of discussion.

P1: Yes for sure.

I: So yes I can for sure share that with you. So this concludes the interview, thank you so much for your participation in this study. If you think of anything else you'd like to add or have any questions, feel free to contact me, you have my email, and if you're interested in having like a transcript of this interview, I can also provide that for you.

P1: Yes please, if you could send that to me that'd be great.

53:54 I: No problem. Alright let me just close my notes here, sorry. And I will stop recording.

OFFICIAL TRANSCRIPT 2
Participant 2 Interview Transcript

I: Alright, so let's start with telling me about your date of birth, please.

[redacted]

P2:

I: Alright. And how do you self identify in terms of gender? So, Female? Male?

P2: I'm a male and I use he/him pronouns.

I: Okay. How do you self identify in terms of ethnicity? So you may use more than one if it applies to you.

P2: I'm a Caucasian.

I: Alright. And what is the highest level of education you have achieved?

00: 35 mins P2: Well I'm in my last year of university. So, I guess, high school technically. But, after I finish, its going to be university.

I: Okay, thank you. So, you are currently a student. So, I'm just going to ask some questions regarding your past experience with cancer and treatment. So, what was your age at diagnosis?

P2: I was 10. It was in 2009.

I: Okay. And what was your diagnosis?

P2: I had acute lymphoblastic leukemia.

I: Alright. And what type of treatment did you receive and for how long?

P2: So I – from 2009 to 2000-2010. I received, chemotherapy, prednisone, and. I forget what the injections were but they were basically just to make sure that your counts wouldn't teeter, so you wouldn't go like neutro-neutropenic. then I relapsed in 2014, I had a – had the normal kind of chemo regime. Then that didn't work. Then I had a bone marrow transplant, at the Ottawa General Hospital. I had a full body radiation for that then a year later that didn't work. And I went to St. Justine for CAR T-cell [Chimeric antigen receptor] therapy where they basically take out your cells and reprogram them to target the, the cancer cells in your body. So, for that I had, so for all the st-like stem cells, I don't know if you're aware of the process but you do high doses of chemo, then you do fully body radiation, basically just to kill off, your-curb sort of like immune system in a way. And then they basically try and hit the redo button, and they sort of give you a new stem cell which does all your blood and stuff. for the CAR T-cell because it's your own cells, I basically had a phlebotomy to like take the cells out, then they had to move them to Philadelphia and sort of do whatever laboratory magic that they do. And then, yes so, I think it's just like radiation and chemo, that I've had. And then kind of, post the CAR T-cell I've also had, I mean its not – I wouldn't really consider it to be– a treatment but I've - I'm also on immunoglobulin, for my white cells, because I don't have any B cells. Because the way that it will target the cancer cells well basically, it doesn't recognize bits like a T cell or if it's a B cell. So you don't have any immunity to things which kind of, sort of makes you a little bit, you kind of have to be, in what-like an area that has access to those drugs so you can really only be in Toronto, Ottawa, Montreal, kind of places. But, yes. **I**: Alright, thank you. so, we'll just start with our first question then. So would you mind describing your experience with childhood cancer. So if you can tell me a little bit about, what exactly it is that you felt when you were first diagnosed and how you think experiencing childhood cancer shaped your childhood a little bit.

P2: So when I was diagnosed, I was at a new school. So, I was, I was diagnosed in January, so it was basically the week we got back from the winter break, I was really tired, didn't really have a whole lot of friends too, which was kind of a bit of a unique experience because you kind of go from being that new kid that no one really knows, to then being diagnosed and everyone kind of knows as the cancer kid. I think too, I was always pretty shy too, so I think it kind of, like amplified that in a way. *[Outlook on coping]* and then, you know I think throughout the experience, you know, when you sort of hear those words that you're diagnosed with cancer, you cry you know, you think it's - you think that you're going to die and stuff like that and then, I think what kind of happens or what kind of happened with me is, you know I-I never really wanted, to be thought of as someone who was weak, or like a coward too so I think it made me mature a lot sooner than a lot of my peers and it made me a lot more resilient *[Outlook on coping]*and I would never really cry if I had like a needle or like a blood test or-and, that kind of continued throughout my whole experience. And then I think, you know, a lot of times too, during the whole ordeal, you sort of have people be fake nice to you and in some respects to you, so you have a lot of people that pretend to be your friend so it can kind of, artificially, boosts your ego too, so I think I kind of was dealing with that, mainly during I think my-so when I was in maintenance in like 2012 and then I sort of had this 2 year-sort of between 2012 and kind of like the start of grade 10 so probably like grade 8 to grade 10 where you know, you're always kind of - you know you're in , you're having growing pains both like, socially and just in general so I think, during that time that was kind of crazy time in terms of in just being able to socialize, school, all that kind of stuff but I mean throughout that whole experience too you do get a lot of, like you know get to meet people you normally would never meet too you know, like business people, if you do any like fundraisers and stuff like that as well, yes, you know like your children's wish too, that was a really cool experience. But, yes. I don't know, was there anything else that you kind of wanted to, - **I**: No – **P2**: - Me to elaborate on or?

I: No, I think you did a good job at just explaining your experience, and you know from what you could remember. Do you recall exactly, or can you touch a little bit more on your experience, I guess, like in the hospital, as a child and how you know your ability to kind of process exactly "okay I'm experiencing cancer" and how you feel like it -I guess the toll it really took on your ability to really be a kid?

P2: So I think to kind of put it into context, you-from a maturity standpoint, you know I was 10 and I feel like I was kind of grappling with like you know - I accepted that I was going to die basically right, so there's a lot of that kind of, and I think that's why a lot of the maturity stuff kind of hits you so hard. So when you're 10, you're kind of thinking you're a 14 year old *[Outlook on cancer]* right? So, there's always that, kind of, increased level of maturity and its not like the adult world where, I mean like it is when you're like a really young kid but when you're like 10, you're not really a teenager but, you're not really a kid. You're kind of in the middle of like, "I can't really go to the playroom" but there's, like "I can't really you know like hangout with the older kids too" so there's this weird middle ground that you're caught in. but I was shy so I never really I think talked to kids, so I didn't really have that level I think where I can sort of, you know talk things out with people and stuff like that. It was mainly just like me, my mom, and my dad, that were kind of there. They didn't even really speak to my brother about it. But yes, I mean I think, like you know for me, I think I was in the hospital initially for about 2 weeks. I think it took me, you know kind of going from the first night where you're sort of-your mom comes in or whichever opposite parent that's not there with you in emerge (emergency), or, I guess I should kind of go back. So when I-so originally, I thought I had the flu, so I - it was you know, want to go to recess but I couldn't really stand up, it felt like I was really out of it, and didn't have any energy, I always had to sit down, and stuff like that, I couldn't walk to the bus stop, which was maybe 4 to 6 houses down. So, then I go to the clinic – **I**: [*Drinks water*]

11:36 mins P2: - And then they're like, "you have to go to emerge", they rushed me through, so it was very quick, right. So it was very, literally as soon as they saw my face, they're like "okay he has cancer, we have to go". But they didn't confirm anything, right, because they had to do all the tests to make sure, but they basically knew because they see that everyday, right. So then it was very quick and then like before you know it, because you're so tired and it feels like it might be an hour but it's like a second to you because you're so overwhelmed, you're so out of it. So, I was doing, I think I had 4 bags of blood, right and – I didn't really hear it, but my dad would kind of tell me, "yes, if you didn't get this blood, you know, if you waited like an hour, you probably wouldn't be here." So stuff like that, where you kind of, it hits you, but because you're a kid, you're not really realizing *[Outlook on cancer]*, and I was never really into science so I never really understood that stuff so it took me maybe like 4 days after to really process it but even before then you know, like when my mom came in she was crying, and I was like "It's going to be okay, I'm good" but I was the patient, I had to comfort her *[Outlook on cancer]*. So, there's a lot of that stuff and I mean I remember when I was 8 and I heard Terry Foxx's story for the first time and I made a prayer and I said "I want to make the same impact as he did." And then 2 years later I was diagnosed with cancer, so there's a lot of stuff where it kind of hits you, but you don't realize it until a couple of days after or a couple of years after and then for me because I was so shy it was really hard for me to assimilate back *[Outlook on reassimilating]*because, I think when I went back, I think it was H1N1, so they-I was supposed to go back I think it was in February, but then they waited until like late march and I didn't really know the kids too so it was-there was a weird kind of experience *[Outlook on reassimilating]*. And, but now at school my energy levels were bad, and I mean, well not bad, but I mean - for me I was just occupying myself with sports and stuff like that so I wasn't even really in that school routine, and they tried you know, I guess, keep you up to date with school because they have a school in the hospital that you can kind of see. But I mean, I was in like grade-I think it was in like grade 4 or 5. So I was not even-I mean the stuff I was doing was kind of lame and like not really, engaging because I was only there for, I think like 2 or 3 days. *[Outlook on reassimilating]* But like for-for me, every time I was in the hospital, whether I was 10 or 14 or like 15 I would always kind of keep to myself, I never really, talked to anyone other than the nurses or the social workers or the psychologists that were there *[Outlook on cancer]*. And that's – that's also because my mom was very protective, she didn't really want me to go to the playroom and stuff like that, so I think even that kind of made it a lot harder and stipend my ability to assimilate when I went back to school too *[Outlook on reassimilating]*. And even talking to kids that were in the same situation as me you know, I could kind of level with and sort of talk to if I needed them. And then when you go back you have a lot of people that are sort of being nice to you, and they're not really-its not really real or like genuine so then that can kind of go to your head a little bit *[Outlook on reassimilating]*. And, yes, I don't know.

I: Thank you. So we'll move on to the second question so what does being a survivor mean to you? So, what feelings arise when or if you use this term to describe yourself?

P2: You know for-for me I think, when you're a survivor or even when you get that-or as soon as you get diagnosed, you're in this club where you're a cancer patient and then going from a patient to a survivor its very-its very hard I think to articulate the words because you feel that. And throughout my whole cancer journey I've done a whole lot of speeches about my story for different fundraisers, and I've gone out with different groups like candle lighters and stuff like that. But, I think you know, you always have a sense that you have to give back and that you have to live on for the people that passed away *[Outlook on cancer]* and I think I only really realized that towards the end of-during my last battle in like 2015 when I was, to put it bluntly I was on my death bed, you know and there was a lot of emotions that are kind of going through you and there was a lot of, planning right? So, for me, there's kids, that might be going to a party or might be, going to play basketball or soccer with their friends but for me I was in a hospital bed so *[Outlook on reassimilating]* for most of my journey when I was in high school I was in the hospital for 4 days then I would go play basketball with my friends for like 3 days, but during that time when I was in the hospital bed I would always think of like "what was normal? *[Outlook on reassimilating]*" right? And I don't mean normal like I want to go hang out with my friends, I mean like I want to go to university, that's my goal. And when I have that goal, I was pretty behind *[Outlook on reassimilating]*. I think I had to do-I had to finish 10 credits when I was in grade 11, so I did outdoor ed, I'm not sure if you're familiar with camp Oochigeas, the Toronto Sickkids cancer camp- **I**: Yes.

P2: - So, they had a outdoor program where you'd get a credit for that. Then I was doing a whole bunch of career planning, like all the workplace kind of throw away courses that they make people do if they just need all the credits to graduate. So I was doing that, and I think I did like 10 credits my last year, but throughout that time I was kind of like " well how am I going to do a career that's not in tech or whatever, how am I going to make enough money to go into-to give back in some way to the people that lost" *[Outlook on coping*]. So, my last battle that I had, I think I was-there were like 5 people that got this [treatment] right, and I was the first one in Canada, that it worked.

And, there was another kid who was from Ottawa as well and his didn't work. But he had down syndrome so there was a lot of other biological stuff that wasn't – and I think that's why it didn't work for him. But there were like 3 other people that, they died and they're just-the amount of cancer that they had just went to their brain and they just died. But when my mom told me that I was like "damn, I have to live on for those people" right. *[Outlook on coping]*So there's a lot of pressure I think too, that kind of builds up when you are a survivor because you want to live on for those people but at the same time there's a lot of remorse and guilt and stuff too because sometimes like I said people are fake nice to you and you look back at that like "was I boosting myself up? Was I being an ***hole then?" And stuff so there's a lot of regret *[Outlook on coping*]. And even when I was younger, I was going out, I wasn't really focusing on school, I was rebelling a little bit more because another thing too is when you have cancer and you go from well, "I have to live on to the survivors", part of you that you have to reconcile is that you're mad at the world. *[Outlook on coping]*So then when you're mad at the world it's like "well why did this happen to me?" "Why did they chose me to have this disease?" *[Outlook on coping]*Theres a lot of that stuff, so once you get over that, which takes you at least 4 or 5 years you begin to - you want to be more of a steward. You want to be able to take care of the next generation *[Outlook on coping*]so there's a lot of that stuff. So I think, to answer your question, when I think about being a survivor, its to live on for those that have passed away and to be able to continue to, do the fundraising, do all the infrastructure that was already in place, but to make an impact on the world as well. And yes, I mean try and do as much social change as much as you can. *[Outlook on cancer]*

22:20 mins I: Thank you, I never, heard someone describe their experience as taking it upon themselves to really make it their responsibility really, to not just live for yourself but for other people. It's really impactful. So can you actually, talk about, what you think has impacted you the most in transitioning from a cancer patient to a survivor as you started to settle more into, I guess your survivorship role.

P2: Well, I think when I went into university it kind of stalled. Because you didn't really have access to-so when you're in peds, or in pediatrics, theres a lot more money going into it, Its easier to fundraise for kids than it is for old people right? so theres a big difference between that. There's a little bit less opportunity, the Sens [Ottawa Senators] aren't going to go visit the Roger Greenberg Cancer wing, but they're going to visit 4 north or like the medical day unit so, theres a big contrast between that and I think, for me I had a lot more opportunity to see or to pick up on what were the deficiencies there that I wish that I had. So you'd do the classic, you'd go to a fundraiser do a speech and you'd get to network with people and do that stuff but you know when you transition say, being in peds to adulthood there's not that handshake. It's a lot of informal stuff that you don't really get. And you know I went from doing speeches and stuff to kind of just, not. So, I went from being like an 8 to being like a 5 in terms of like what impact I was making *[Outlook on cancer]* and stuff like that. So in a sense I think I peaked in that nature, and what I always wanted to do at university was sort of have a bit of a support group for survivors that were making the transition and stuff like that because for me, my first-usually your first two years of university you're having fun, you're doing frosh (college/university freshman week), you know going out, going drinking, you're having fun. I didn't get to do that because I was sick for like my first 2 years of university, I had chronic sinus problems *[Outlook on reassimilating]* and stuff like that. I didn't really get to experience that. I was in my shell, and I was living in the suburbs too unless I would stay on campus I would usually just go back home because my commute back home was like 2 hours if I took the bus. So, there wasn't really a lot of incentive for me to stay there and continue on and stuff like that. But yes, I went from being able to do speeches, see sort of like "okay, we need support groups" on the wing, in the like medical day unit where like a lot of the maintenance care is there, a lot of the – I forget all the phases now but its basically right after in your like induction you do your weekly chemos and stuff there. Theres not really that support group and I think its a lot of mental health kind of things there, just not a lot of promotion and a lot of awareness that goes on but its kind of there implicitly, but its not in your face. So I kind of wish I had that *[Outlook on coping]*, but I think a lot of the time for me at least I would just talk to the doctors, I would just talk to the psychologists and talk to the social workers and say "hey what are the – what specific deficits do you have that you wish, would change?" and for me as a patient I just wish that there was more, it was more like Sickkids where they have a lot more. They have camps, the camps are kind of in a way, support group and theres the playroom and the camp is kind of interconnected. *[Outlook on coping]* Now I think camp Ooch has merged, so they have like a new name and stuff because they merged with camp Trillium. Maybe you'd have to go there and see if it's a bit of a different circumstance, but I mean I wish I had more support groups *[Outlook on coping]*and stuff like that but you kind of go from-and like I can't drink too because all of my organs are completely fried so I can't drink, can't smoke. So, for me it was really hard to sort of, even when I was in high school, I would never go to parties because it was really hard for me to be the sober one. And not really, I don't know I wouldn't even want to try to attempt it because I'm already kind of a shy person, so it wasn't really for me. *[Outlook on reassimilating]*

P2: So, I feel like I never really got the social stuff, but I got a lot of the more institutional kind of deficits that you'd see and just, the support systems too that I didn't really feel were as promoted I would say *[Outlook on reassimilating*]. And, I would go to these fundraisers when I was a kid and you would meet with the chamber of commerce and there was a couple where I could go down to city hall and talk to city counsellors, so for me when I was in political science that's kind of how I started my career or entry point in there as well. But I would talk to all the staff and develop a rapport with them that were on a friend level I guess in a way, or like an acquaintance. So that's also what happens on those wards, you develop really strong attachments to the nurses, the social workers, the doctors *[Outlook on cancer*], and stuff like that too. So you implicitly see what's going on, but theres a strong contrast too because unless you're a transplant center you don't really have the same ability as well to be able to have these support systems. So, if you go to Toronto or Montreal, or I assume Vancouver, or also Calgary I think as well is another one. They have a lot more infrastructure in place to be able to have this, whereas if you go to CHEO (Children's Hospital of Eastern Ontario) versus Sickkids, theres a big difference in terms of the size of the hospital, what they can handle, the amount of child life people that they have there versus, nurses versus doctors. Being from Ottawa and going to Sickkids you can see the drastic difference in terms of fundraising. *[Outlook on cancer*] I remember in my last year when I was doing that outdoor ed thing, I would be like with my cabin and we'd just be going fishing with one of the campers or something and they'd be like "this is Mr. Rogers and he's a tier 1 donor and we would like you to speak to him about your experience at camp" and your like "okay, I guess I'm talking to a multimillionaire right now" you don't really get that when you're at CHEO and stuff too. So, there's a lot of different experiences that you get to be able to participate in, and sometimes they're good and sometimes they're bad but a lot of the times they're really good because it takes you out of your comfort zone *[Outlook on cancer*]. When I was in elementary school and when I was in secondary school there was a lot more of those chances, where then when I went into university there was not. So theres a very drastic, I guess fall in a way. Where you go from the extreme from where okay, you go and do fundraisers every month and you're doing speeches and stuff to nothing. Because when I was in maintenance, and when you're in the adult world, theres nothing. Its grey, its bleak [*laughs*], it's pretty depressing in some ways if you're used to just being in the children's hospital where everything's colourful, everything's vibrant and its not as bleak and then you go to the adult world, and you're with a bunch of old people and its like you're not really there *[Outlook on coping]*.

P2: So there's a very strong contrast, and I kind of wished that in the adult world, for youth, like more young adults there could be something between if you're 16 and 26 that you sort of are in that same age bracket because I think you're going through a lot of the – you're not transitioning from childhood to being a teenager, you're transitioning from being a teenager to being an adult, and I think for normal people that's a big change but for a cancer survivor, its even worse. *[Outlook on coping*] Because you're also like "well I need a job that has benefits." Because theres the-post-long term aftereffects from all the chemos. So, every year you have to go for your standard, you have to go for your respiratory tests, bone density, there's a whole spectrum of tests that you have to do because of all the effects of the chemo that has. So as for me, right now, I don't even have a doctor telling me this, but I would be happy if I lived to be 55. Just because the amount of – just the length of my treatment, you know I know the risks and stuff too *[Outlook on coping*]. And for someone like that it's like "okay well I need to be able to make an impact very quickly." too. I kind of wish there was more stuff in place for that transition and was a lot more explicit than implicit, which I think kind of effected at least my first couple of years where I was sort feeling stuff out, and sort of-I kind of wish there was more of a grey area than sort of me dealing with an extreme where, you know how they can go like fully into the university experience or just kind of away from it. Because I wasn't as maybe as emotionally prepared for that as I should've been or could've been *[Outlook on reassimilating*] because if I had peers and I could kind of maybe go out with people that were cancer survivors and not really have to say like "why aren't you drinking?" or like "why aren't you doing this or that?", which I think just I don't know, been just awkward and I would just be like "I don't really like this", you know? I don't know *[Outlook on reassimilating*].

35:58 mins I: Thank you for sharing that. You mentioned that you know, for example like going out to parties, already you were a shy person but your experience with cancer exacerbated that, can you speak on, so that relatively stayed the same, but can you speak on any kind of changes you noticed in yourself when you transitioned from a cancer patient to a survivor? And what kind of changes are you living with now as well?

P2: Yes, I'd say when you go from being in the hospital for a while and everyone kind of knows your name you get a confidence boost that you can't really describe. It's almost like you won the lottery in a way because everyone knows your name, everyone's trying to be friends with you and stuff like that, but they're not real friendships and they're not real people. They're just doing that for the clout in a way and they're not really there to support you *[Outlook on cancer*]and stuff like that. But for me, I kind of felt like when I transitioned from a patient to a survivor, there was this sort of - and I think with anyone, for me I think I missed grade 10 and that was a big year. Because you can go from being a nerd to a super popular person, you're outgoing, you're going to parties you're like – you completely do a 180 transformation, so I wasn't there for that, and then I wasn't there for all the in class gossip *[Outlook on reassimilating*] and stuff like that so when I went from being not even a survivor but when I went out of the hospital to being able to like be like at home, I would always meet like – so I usually would only have one or two friends that I would hang out with and talk to. So, I would always go over to their house, and I would always get caught up on all the gossip. But you're getting stuff second hand and you're not really like getting the full picture. Its like you're watching a movie whereas you should have read the novel first *[Outlook on reassimilating*]. And, for that, when I went back that was pretty wild because you would see people and you're like "Wait what? She was so – she used to have her head in the book and now she's going out, she's going to parties and on Instagram, and doing this and that". And it was the same thing for guys too where I was like "Whoa what's going on right now?" so that in itself too can be very overwhelming where you're– when I was in class in grade 9 everyone was normal, everyone was kind of the same as in grade 8, there wasn't a whole lot of contrast. And then you go back, and whoa, everyone's different. I didn't even recognize these people, so that was, I think a little harder to grapple with *[Outlook on reassimilating*]. And then, for me too, because all the teachers were nice to me, I went from rebelling and sort of maybe getting into some bad stuff because you would also sort of have mental health issues from being angry at the world. I sort of always had a bit of mild anxiety, but now I had mild depression, so I had to reach out to the school counsellor to sort of say " hey I have to get off hanging out with these people because they're not good influences on me". *[Outlook on coping*] And yes, I mean– you're expectations versus the reality when you go back to any social setting is a little, I mean it's a little overwhelming. *[Outlook on reassimilating]*Its hard to kind of speak about because I've kind of forgotten about it in a way. For me I went through I think a rough patch between being in maintenance and having all this confidence and then being a bit of a jerk and not a very nice person. Whereas before I was like a teddy bear, everyone liked me, I was really nice, I was really innocent and stuff like that. And then you take a 180 shift and theres a lot of anger and stuff like that, and it kind of developed into paranoia because I didn't really know if people liked me or if people didn't like me and stuff like that so there was a lot of second guessing. You kind of create different personas for yourself, because you don’t want to-you want to create a shell for yourself and you don’t want people to see you when you’re vulnerable *[Outlook on coping]*and even during my second bout, there were times I would go play basketball with my friends on chemo. Literally like a day after, I was coming off chemo and there were times I would be in the back just throwing up, because I would rather have that; hang out with my friends and them not seeing me being that vulnerable instead of being like “ hey guys, I don’t think I can play 3’s” *[Outlook on cancer*] or even at school – or sorry not at school, I would be with my friend on the bus, and we’d be walking, and we’d be walking for like 2 hours sometimes. I’d be like “Oh man, I feel kind of dizzy, I kind of feel like this but don’t tell people that I’m in this state” because you always want to show that you’re strong. So for me, it was you’re balancing being weak and showing that you’re progressing a little bit *[Outlook on coping*] too and stuff like that. But I mean the thing about being a patient versus being a survivor too is you can’t use – you can’t tell someone in your peer group “but I had cancer” that’s not a valid excuse because they don’t know what that is. They have no idea of the mental trauma that is cancer. The amount of times that you’ve beaten yourself up because you’re like “man I wish I was out there playing with my friends and having fun but I’m throwing up in a bucket” and there were times too everyone hated me because I would always tell people “yes but I had cancer.” And

They’d always be like “what is that? You look so healthy, you’re this and that.” But I’m like “cancer isn’t just the 5 years you’re on treatment for, it’s a lifelong thing” *[Outlook on reassimilating*] You know. Its something that never leaves you because eventually you’re going to be on 20 pills, and you’re going to be on kidney meds, lung meds, like all that stuff because the latent effects, and that’s going to hit you in a bunch of different ways *[Outlook on cancer]*. **44:10 P2**: But when you have people and you’re trying to level with them, they’re dealing with their mental health stuff because they’re in early adolescence and they’re trying to grapple with growing up and I’m grappling with just trying to be a survivor, that’s a lot different. I don’t want to diminish their mental health issues, but they’re crying about more superficial things whereas I grappled with my mortality when I was 10 *[Outlook on reassimilating*]. I thought literally, I thought as soon as I was diagnosed with cancer that I was going to die, and then I survived and

I’m 23 now, so there’s a lot of that stuff where you’re like “yes you don’t really know what this is like. You’re upset that you broke up with your boyfriend or girlfriend” and I’m like, “My platelet count is down by 3 points, and I’m worried I’m going to get cancer again”. The levels of stuff is very different. Just trying to tell people in my peer group that was really, really hard *[Outlook on reassimilating*]. And that’s also - when I had my victory lap, when I was in grade 12 for like 3 months, I would basically just hang out with my teachers I wouldn’t really hang out with my friends and stuff like that. But then as I grew out of that I was able to “ hey you know I’m really close with this teacher, so if you want to do a spirit week or something I could talk to the teacher and we could come up with an agreement” that was kind of cool *[Outlook on reassimilating]*but theres just a lot of – the levels of stuff that people are contemplating now in their last years of university I was dealing with when I was in grade 10, so there’s a lot of different dimensions to it *[Outlook on reassimilating*], and I don’t know, sometimes even now I feel like I have been stagnant since my first year of university and I'd like to grow out of that shell a little bit but even now I'm still unsure and uncertain about how to go about that, because just from a social perspective I'm not at the level of my peers *[Outlook on reassimilating*] but from a more philosophy, kind of mentality type perspective, I think I'm light years ahead, but there's this thing where everyone at this age too they're at different levels to it, some people are catching up to me and some people are still sort of maybe have just gotten to that level too, so it's cool seeing that. But there's just a lot of, I don't know, like incongruity of when you're a kid, you were at an 8 and they were at a 4 and then you were just waiting for them to catch up to you and sometimes they don't, so it's just that can be even harder *[Outlook on coping*] but, like yes.

48: 07 I: Thank you for sharing. And thank you for touching on I guess, more so your experience with how the things that typically matter for someone who's about 14/15, that really shifted for you because of your experience, so can you talk a little bit more about how you manage stressful events and how differently you think you manage those stressful events to the people who didn't experience childhood cancer?

P2: I think in a lot of ways it's the same as other people. For me, during my second bout I would basically do 4 days in the hospital and then 3 days out, so for that the way I would cope is to just go play basketball with my friends, so I guess basketball became my therapy in a way. *[Outlook on coping*] But before that, before I even discovered playing basketball, a lot of it was just not very good coping mechanisms. It led to a lot of paranoia and stuff too and uncertainty, but I think for me the biggest thing was just talking to someone who was kind of outside my peer group, who wouldn't have a biased opinion that wasn't like my parents, who would kind of give me advice and stuff. So, I'd go see my guidance counsellor or my therapist and just talk stuff out with them. Yes, I guess that's the only ways I would cope with it *[Outlook on coping*], yes.

I: Alright, thank you, so our last question. What is one piece of advice you would give to someone who is currently undergoing cancer treatment for their childhood cancer or who is currently your age trying to navigate their own survivorship?

P2: For me I think a lot of the times it's more trial and error. So, I think for me it's just trying to reach out to someone who's gone through it who you can kind of talk to. Because sometimes you can get a little lonely and you feel a bit alienated, so try and reach out to someone. Quite honestly too, just really try to enjoy the experience. You're going to get a lot of, cool opportunities, you're going to have your wish and you're going to have a whole bunch of different chances to meet people and stuff like that so really embrace that aspect of it. Even if you're shy, like for me I was totally out of my comfort zone and that's how I got into wanting to go into political science, and stuff too. Its just meeting people and hey you know "I really like that politician, so I'm going to try and get into that field". I think don't be too hard on yourself too, theres a lot of times where, and I still kind of do it, where you just beat on yourself. And well I'm not, normal yet, and you sort of have to go beyond that and sort of say "well how am I now versus how I was 5 years ago" and you sort of need that comparison where every year I'm getting better and better. *[Outlook on coping]* And just dream, you're going to be in a hospital bed for 2 weeks to 3 months to a couple of years, really take that time to really learn about yourself and dream and have a goal like "hey when I survive this, I want to be able to do this, this and this." And I think for me, that really helped me develop the type of person I want to be, what journey I want to do post-treatment *[Outlook on cancer]*. But having a longer term vision and thinking long term sometimes can be a lot better because even if you say you have like a year to live and I've never had that, but for me every time I would relapse, and there was someone I knew too who relapsed like 3 times, and I only relapsed twice so I was like "damn, that must be tough", and one thing you always pick up too is that theres always people that are in a better place than you and a worse place than you, so you got to keep that even keel mentality where you're like "well am I really that bad of a spot and if I do that deep thinking and self-reflection I could use this as an opportunity, my peers don't have 8 months at home doing homeschool" You're in a school 6-8 hours, I was only doing homeschool for 2 hours, I was able to do that, do work for like 30 minutes, then be able to go hangout with people. And if you're at a basketball court, there are people in like university you could hang out with, that you could gain experiences from. Every obstacle that you face, is always a new opportunity for you, and anytime you're faced with something that is-that you feel is the biggest mountain you have to jump over, its always an opportunity. Theres never something that you think is so bad and it's a catastrophe, its never as bad as you think its going to be. And once you overcome that, you're going to be a lot stronger for that, and you better take advantage of that and if you don't the guilt you're going to face later on because of that is going to be really overwhelming and you're going to want to say "hey I really wish I took advantage of that opportunity" and I think too, you don't want to live with any regrets. One thing you learn from having cancer is you never know when that day is going to come and you're going to pass away, and you're going to be on your deathbed, and you want to take advantage of everyday, but you shouldn't be hard on yourself that you're -living some social media guy or person, just live everyday like you normally would but have more meaning and value in the small things in life. Everything you do should impact you, but it doesn't have to impact you in a big way, it can impact you in a small way too. So just have perspective, if you're watching a movie or something that could inspire you to do something else, always have that mentality too where time is money, but time is also inspiration too, so there's always that kind of feel. But I don't know that's kind of all the advice I would have, it's a little hard because I don't know their experience too but yes, I guess that's it.

I: Awesome, thank you. So, this concludes the interview, thank you so much for your participation in this study. If you think of anything else, you'd like to add or have any questions, feel free to contact me, you have my email, if you're interested in receiving a transcript for this interview, I can provide that for you. So, do you have any questions for me?

57: 58 P2: No, I was just wondering is this your like MA thesis or PhD thesis?

I: Yes, so, I'm in my last year of my Master's in Health Science.

P2: Okay. **I**: So this is my thesis, I honestly didn't know I was going to be doing a master's until I was in my last year of undergrad and I was like, "this is a very interesting topic to explore" and I feel like not a lot of people really explore it, explore the meaning of just experiencing childhood cancer and what it's really like to reassimilate back into society, and I know there are so many different lenses and scopes of trying to really understand the experience but I just really feel like this specific study is unique.

P2: Are you trying to continue on to getting a PhD or getting into med school or?

I: Yes, so I want to pursue and MD/PhD, so I'm kind of overwhelming myself with school, [*laughs*] I did not have a break, high school, university, Master's, I plan on taking a year off after my defence so, yes.

P2: Yes, that's going to be pretty intense I guess eh, I've heard some [*laughs*] stories about how crazy that stuff can be.

I: Yes for sure.

P2: I would love to maybe get sent a copy of the study – **I**:

Yes.

P2: -Once it's done.

I: - yes for sure

P2: But yes, I mean thank you for doing this. I know there's a lot of cancer survivors who are going to appreciate this. And I think there's a lot of healthcare professionals too who are going to be really interested if this turns into a trend so that there's more research that develops from this. I mean I'm not really sure what the lit review would be like for this in terms of what prior research has done but I'm sure theres going to be a lot more of these kinds of studies that are going to emerge, and I think a lot of survivors are going to appreciate that.

I: Yes, I hope so. Thank you so much. If you don't mind also, if you know anyone that might be interested in the study because I'm still in the recruitment phase, I would really appreciate you sharing the link to the google forms or sharing CCSCs post or anything like that as well.

P2: Are you able to reach out to specific hospitals or does it have to be word of mouth?

I: Yes, so hospitals require their own research ethics board process, so it's a little too late now to reach out to hospitals and go through their process and then I would have to go back to my institution, Ontario Tech, and then do that REB process again. Yes, it would take a while so unfortunately, I can't. I was thinking of reaching out to hospitals at first but I looked more into support groups and I really, really liked what CCSC was doing, and was really excited to work with Michael.

P2: I would really recommend, if you want to continue on, volunteer, especially if you want to go into med school, they used to have a program where they would basically, I mean I'm not sure if you really want to be in a clinical setting, but, I mean even if you're not, they used to allow-partner up med students with cancer survivors too. So that could be a really cool opportunity if you want to get more of the, ethnography of it, and also maybe just volunteer at a camp too and see what that's like too. Because I think a lot of those camps are really cool settings to hang out with kids and see what their about, because a lot of them too, they're still going through chemo, they're still doing that and you get to see if there's a course or something you get to see them go out of their comfort zone and stuff like that too which I think is a really cool experience.

I: That's very interesting, I've actually never heard of that so thanks for bringing that up I'll definitely look into that more. Alright, I'll let you get back to studying, thank you so much again. Good luck on your exams.

P2: Yes, thank you very much and hopefully the study works out and everything goes well.

I: Yes, thank you.

P2: Alright.

I: Take care.

P2: Have a good one, bye.

1:03 mins I: Bye.

OFFICIAL TRANSCRIPT 3

Participant 3 Interview Transcript

I: Okay, awesome! So, lets start with your date of birth please.

P3: [redacted]

I: And how do you self-identify in terms of gender?

P3: Female.

I: Okay. How do you self-identify in terms of ethnicity?

P3: Middle east.

I: Okay. What is the highest level of education you have achieved?

P3: A very expensive bachelor degree.

I: (*laughs*) Are you s-are you currently a student?

P3: No.

I: Okay. So, if you're not a student what is your current occupation?

P3: Like a call representative on the-for airmiles.

I: Oh, okay.

P3: (*laughs*)

I: What was your age at diagnosis?

P3: 14 and 6 months.

I: What was your diagnosis?

P3: Stage 3 Hodgkin lymphoma with a side of Tuberculosis.

I: (*laughs*) with a side.

P3: (*laughs*)

I: What type of treatment did you receive and for how long?

P3: Treatment was like around 6 months. I think the last treatment was in February, but it was chemo and radiation after that. Chemo first and then radiation.

I: Alright. So, we'll jump right into the interview questions then. Could you describe your experience with childhood cancer? So, if you could just tell me a little about what you felt when you were first diagnosed and perhaps how you think experiencing childhood cancer shaped your childhood?

P3: Like back then, I didn't let myself think about it too much *[Outlook on cancer]*because it was kind of a – I had to get through this part whether I liked it or not. It was kind of a – I had to be, I don't really want to say strong, but I had to survive it at the very least. If not for myself, then for the rest of my family. And thinking now on it and thinking back on it, I'm like, " I'm really grateful for morphine" because it just blocked out a lot of the memories that I just didn't want to think about because the ones that I do remember are not pretty *[Outlook on cancer]*. (*laughs*) So it did like – did bring me closer to my family, definitely. But it's not an experience where if I'd have to go through it again, do not want to even think about that (*laughs*).

I: Okay thank-

P3: Not sure if that answered your question at all but, yes.

I: Yes, no that's great. Just whatever you're comfortable with sharing is fine! Are you able to talk about your experience in the hospital a little more, like what you do remember if you're comfortable with sharing?

P3: I remember waking up once, in the middle of the night. Hearing my mom in the cot next to me stop herself from crying. That was one of the things I remember the most. Another one was when they were wheeling me to surgery when my blood pressure was very low apparently. My brother was holding my hand, and as they were taking me there his hand was shaking. And it was like "this is my big brother, he's never scared of anything", yet his hand is shaking when I'm holding it, so It's just those little snippets of things I tend to remember the most. And they don't tend to leave (*laughs*).

I: Yes, I can't imagine, so, are you able to recall a little bit what your relationship with the doctors and nurses was like for you?

P3: There were some good nurses and some bad nurses. There were some who would put more effort into care and some that would just joke around with you. Like a natural, meeting a new person sort of thing. But yes, it was generally a good experience just because I think because we were here at sickkids being treated, and the doctors there are good. They're nice, they're personable and they have a sort of gravitas to them when needed as well *[Outlook on cancer*]. I remember when we walked in to diagnose me with cancer, and he was just very solemn, and very serious and said,

"Listen this is a 90% chance of survival, you will be fine". So that was kind of a nice touch with that as well.

I: Okay, thank you for sharing.

P3: No worries.

I: So, I'm going to the second question. So, we're moving onto survivorship a little more. So, what does being a survivor mean to you? So, what feelings arise if or when you use this term to describe yourself?

P3: I don't tend to. I don't know, it's just kind of a saying that-it became normal at this point. I went through this thing, this is now my normal, this is now my life. Thinking of it in any other term just feels, I don't know. It just feels cheap to me, thinking of "I survived cancer" like dude I was just unconscious most of the time and they just pumped me full of medicine and I made it the other side." That's the way that I think about it at the end of the day. It doesn't feel like I did much, I kind of slept through the whole six months. So, I don't know, I Just don't – I never thought of that word for myself to be honest. *[Outlook on cancer]*

I: Okay, so then can you speak a little bit more about what you think impacted you the most when you transitioned from a cancer patient back into just like live a normal life-

P3: - Yes

I: - the more you settled into post-cancer life?

P3: This is going to sound really bad actually, but I promise you, I am fine (*laughs*) but, when they were telling me the post cancer treatment – like "you have to get tested for everything, earlier than everyone else", in the back of my head I was like "oh, so I'm probably going to die earlier than everyone else as well." So, its kind of like it shortened my lifespan. *[Outlook on cancer]* In 2019 I hit the 10-year mark, and the day after September 17th, my knees just like weakened and I just couldn't believe I made it 10 years. I'm expecting – yes, I'm going to be fine now, I'm going to get cancer again, and that's it sort of thing. So, it – it was weird like assimilating to that because I never expected I needed to because it was like going through the motions until the end I guess. So now I'm trying to get back on, well you know what maybe I'm going to actually make it until my 40s, 30 is right around the corner. So, it's a bit of a learning curve that one as well.

I: Wow that must be really overwhelming, kind of like living your day-to-day thinking –

P3: Yes, maybe tomorrow – 6:22 **I:** Yes.

P3: It's not fun. Wouldn't recommend (*laughs*)

I: (*laughs*) So can you think of any changes you may have noticed in yourself other than your mental state being focused on "Okay I don't have long", what other changes have you noticed when making that transition and what kind of changes are you living with now?

P3: I noticed that-I knew-well I didn't know but I felt I didn't have much longer, so I didn't make the effort to build relationships with people, especially with new people. Old friends? Fine because you're already stuck with me, so you can be stuck with me for a little longer. But like, for everyone new I met, do I want to make this effort? Do I want to bother? She's just going to – If I become friends with them and I end up dying that's going to affect them in a very bad way. Better to just distance myself *[Outlook on reassimilating*], and I'm getting better at it now, making friends and meeting new people. But like I said it took 10 years to change that one for me *[Outlook on reassimilating*]. Maybe 10 years is the mark where I had to realize my life wouldn't be ending soon (laughs).

I: So can you speak a little bit about how-because I know you briefly mentioned, a little bit about how you kind of coped with these changes. So, if anyone was already in your life, you felt like it would be easier to be consistent with them versus making new friends. Can you talk about any other coping mechanisms that you might have equipped yourself with to just get through those 10 years?

P3: Humour. Sarcasm (*laughs*). That is the number one thing I'd call my main weapon *[Outlook on coping*]. But, I don't know, other than that it's just distancing myself as much as possible, just like being in a place where I didn't have to interact with a lot of people and I didn't have to do that sort of thing with people. *[Outlook on coping*] So I don't know, other than humour I don't think I had to like, develop anything new.

I: So, it's interesting that you said that humour was – other than those things you didn't have to develop anything new, so do you feel like before the cancer you had already – because at 14 you start to have your own personality, right? So would you say you were already more like reserved and shy or kept to yourself a little more and that stay consistent after your diagnosis?

P3: Yes. We moved to Canada when I was 12. So, 2 years later I get diagnosed with cancer. That's like middle school.

I: Yes.

P3: Middle school to high school. So, it was a lot of – and the language barrier as well. I spoke English and I speak it well, but I had a very thicker accent, and it was pretty obvious, and the first half of conversation "where are you from?" and its like "none of your business" (*laughs*) - **I**: (laughs)

P3: - it's like "listen, don't start with me" so, yes, that did not help at all. But it did not also help after the diagnosis because I kept pushing that habit as well. *[Outlook on reassimilating]*

I: Okay, that's really interesting, so can you actually speak a little bit more on like your experience – or how your experience with cancer may have impacted other relationships? Like your family, or just like needing to interact with peers in your class, or significant others or children if you have any? Like how, do you feel like your experience may have shaped the way you approach relationships or interact with family members and what not?

P3: Yes, like very recently I'm trying to put myself more out there *[Outlook on reassimilating*]. But before that, it was just like everything at arms length. I would not really have any deeper relationships, still don't have a significant other either. Its like putting things at a distance, keeping everything as far away as possible without shunning them. So that it doesn't become obvious that this is what I'm doing. Just in case on the off chance it [cancer] comes back. *[Outlook on reassimilating]*

I: Okay. Do you have any vivid memories or experiences that you had when you returned to a social life? Did anything stick out to you that was – or resonated with you like "wow, this is an obstacle or okay this is a little different than before?"

P3: Yes, somewhat. In February or March when I was still getting the radiation treatment which was milder from the chemo, I was put back into high school. So I went to high school, finished my 9th grade with marks that everyone was very generous to give me because I was missing for most of the year *[Outlook on reassimilating]*. I still had the pick line attached to my arm, so it was still showing. I was mostly bald because that didn't grow back as fast as it should. It was like walking through the hallways and trying to ignore the stairs if there were any. My brother was in the high school the same time as me so he was always ready to assist if I needed it and I would just hang out with him sometimes and his friend group. But like, the first year was a bit difficult because going back to school learning and then as well building a social life. Like at that time everyone already had a social group to be part of because it was like half of the year already done with. So, it was kind of weird that way. *[Outlook on reassimilating*] And the friend I had in middle school, didn't get in contact with me at all when I was sick, so I wasn't going to talk to her, so I just cut ties completely with that as well. But yes, that one was a bit of a weird situation.

I: So, have you noticed any other changes in the dynamics of your other-let's say like family ties, like were there any other changes between you know your brother or between your mother and dad or whatever after-during or after your cancer experience?

P3: They got very protective, overly protective. It was ridiculous, they wouldn't even let me go to a university out of the city because of how protective they were. *[Outlook on reassimilating]*I still live with my mother at almost thirty (laughs) which in this economy is a good thing – **I**: Yes! (*laughs*)

P3: - but like when I wanted to go the university, because I applied to one in Ottawa, she was like no that's too far away. And then she just wants to keep me close and stuff. Yes, it got us closer during the sickness, during the cancer just because before that they were very distant as well. There was a lot of benign neglect growing up, it's just they were there physically, but they were not there when you actually needed them. And then after that it was like a 180, they're always there. They're always around. On one hand, great but on the other, now you show up? (*laughs*) so it's a bit of a learning curve, we're still working on the boundaries right now. My mom is a trooper in learning and assimilating in that way as well, but my dad is like "nope", he's still being overly protective needlessly in my opinion.

I: So, in what other ways do-like do you feel like this new dynamic now-how do you feel like it impacted your ability to reassimilate? Do you think that it made things easier? Do you think that it made things harder? Because it seems like now, they really wanted to support you with more like emotionally and mentally through it right? So how do you think that it's affected your ability to reassimilate?

14:59 mins P3: I don't think it helped much. I noticed that when I'm around them and like other people I do push-pull my self back. But when I'm alone with other people, or like one-on-one or like a group of my peers or my friends I'm like a bit more social *[Outlook on reassimilating]*. And it surprised my mom then working at a call center because she's like "you hate making phone calls, you don't like talking to people" and I'm like, it can be like " its mostly because you're around and I don't like talking to people when you're around because you always take over the conversation and it just doesn't work that way" so, it's – they-doesn't help when they're around but it does kind of push me when I'm separate from them. So, they're… I lost my train of thought (*laughs*).

I: (*Laughs*) **P3**: Okay, basically it's just I do become a different person whenever I'm not around them because I try to be what they want me to be and also make them not feel that they're – no, never mind it's gone (*laughs*).

I: (*laughs*)

P3: It just disappeared (*laughs*)

I: (*laughs*) No worries. So do you feel like – so were there any difficulties – well I guess you briefly mentioned how your choice of school in terms of location, was an issue. Do you feel like that may have impacted your autonomy? Like your ability to be independent. Because you mentioned you're a little more – like you shelter yourself a little more when you're around them but in other social circles your more open socially, so can you speak about that, maybe a little more?

P3: Yes, I think that has affected it. And like, the last since before like, since my diagnosis until like I was 24, it was kind of all of my friends who were outside of school were like relate-somehow related to us or are family friends. So, like "we're going to go to this person's house","I don't want to go", "no we have to. It's a social obligation" and I'm like "you guys just made this meeting two days ago, its not a social obligation, its just an impromptu visit that you want to go to see them, and I'm just being dragged along." So, it's a lot of the "You're going there because I said you're going there". It's not always the case. Sometimes she does travel, and then I do stay home lone. But its still being in the same house that she stays in. It's still being in the same environment, it's always her friends who are calling to check up on me. It's like, come on, I'm like 18 and above. If I'm legally allowed to vote I can probably not set the house on fire (laughs). So yes, it's a lot of the stifling of the autonomy as you said, that did not help at all in that regard. *[Outlook on reassimilating]*

I: Thank you for clarifying that for me. So, is there anything else you can think of or want to mention about maybe your schooling or education? Sitting in school, going through class, navigating your courses or relationships with teachers or anything like that, that you think is worth mentioning?

P3: I don't know. I think by the time I went to university I sort of accepted it. It's the type of thing that I don't mention to people unless they specifically asked, or they bring up the conversation *[Outlook on cancer]*. I do have some people ask what happened here (*points to neck*) I had the scar because I had a biopsy on the neck, and it was one of the first lymph nodes found. So, I do have some people ask me about that one and I'm just like "yes, I was 14 and I got cancer, it was fun." But yes, I don't mention it to other people unless they specifically ask or just point it in conversation or its just, I've known them for a while, and it just feels weird not mentioning it at that point. But building relationships and going to class that was like the easy part, it's something I enjoyed. If I could spend the rest of my life just going to classes and going to university I absolutely would *[Outlook on reassimilating]* but unfortunately capitalism exists so I cannot do that (*laughs*).

I: (*laughs*) That is true. So, correct me if I'm wrong but I feel like you briefly mentioned that you, I think when we spoke about the term being a survivor, you briefly mentioned almost like an indifference now about your experience. How would you describe that – those kinds of sentiments developing as soon as you had your last treatment to now? What was the process like for you to kind of just be like "it happened, and that's it for me"?

P3: Yes, I don't know. I think when I got the all clear from them, I do remember crying and I do remember being like it's a relief that this is gone from me at that point. But I don't know exactly when the indifference came but I think it also has something to do with my beliefs personally. Because it's like everything happens for a reason, like you survived this because God willed you to survive but you did not survive it because that is his well. So having that in the background as well knowing that everything is just already written, it's already going to be happening. So it kind of puts this understanding in my head like "okay, this happened because he wanted this to happen so let's look at the bright side of this thing as much as I can". But yes, I don't know if that does affect the indifference or that it just happened so long ago, I don't think about it unless someone brings it up *[Outlook on cancer*] (laughs).

I: Thank you for sharing that! So, we'll move on to – I guess this is our second last question. So, can you maybe describe what kinds of stressful events you may have experienced as a result of your childhood cancer, and I know we briefly spoke on a few but, a little bit – maybe more into how you feel like you might have differed compared to your peers in being able to manage stressful events? So if you were to, I don't know if graduation was stressful for you or whatnot, how do you maybe feel like you managed that event compared to your peers being that obviously you experienced childhood cancer and they didn't?

21:49 mins P3: That's a very good question, I don't know to be honest. Like I said, it became a normal "This is what I've gone through" and I just don't tend to think how other people are going through things because it's like, one that's too much energy to spend on thinking about someone else going through the exact same thing like "oh he's going through graduation I wonder how he's getting ready for the day". I could be thinking of that, or I could just be thinking about how I'm getting ready for the day or how to push my parents away from like "please do not be weird" (*laughs*) "I have friends here, they know me so do not be weird"(*laughs*) But, yes, I honestly don't know.

I: Okay, thank you. So what about maybe do you feel like there were milestones that you feel like you achieved at a different point in time compared to your peers? So maybe like you matured more faster than them? Or things like-certain novelties that maybe mattered to them, weren't a priority for you at the time? So maybe can you speak a little more about those kinds of aspects of your experience?

P3: I guess. I remember in high school they were talking about TV shows and movies that they were watching and I just could not bring myself to care *[Outlook on reassimilating]*. Even now if I have to watch a movie you have to tie me down and bribe me with something because making me sit in front of a screen or two hours and doing nothing but absorbing the story is just not going to work. I remember going to the movies with my brother the other – before the pandemic hit and we were watching the movie and I remember my eye drifting from the movie to the speaker and just watching the speaker for like half of the movie. **I**: (*laughs*) **P3:** It's like, I just could not bring myself to care about the movie (laughs). Yes so I don't know if my attention span was affected by that one but I just don't care about media in that sense. So that also didn't help with making friendships, but I did develop friends that would enjoy playing video games for example and that was more of an active entertainment rather than a passive one *[Outlook on reassimilating]* so. I know that if you make me pay attention to it or if I'm doing something that affects the story, or I have to pay attention because of the affect of the story then yes I would care but, otherwise I'm like please don't put me in this movie theatre (*laughs*). **I**: (*laughs*) **P3**: Yes. **I**: That's interesting so are there any other milestones that you feel like differed for you compared to maybe other people?

P3: I don't-nothing that would have been related to the surviving cancer, it was – I tend to. Most of my life I was wearing my brother's hand me downs. And I still do wear similar clothes to this day. So that didn't affect anything, that didn't start because of that [cancer], that's just always been the case on going, after the fact so. Its just like – its not something that is completely related to surviving cancer I don't think, it was something that was just developing before and then just kept moving on.

I: Okay. So, our last question then. What is one piece of advice that you would give someone who is currently undergoing their cancer treatment for their childhood cancer, or who's currently trying to navigate their life post cancer?

P3: Well, the obvious don't give up. You are much stronger than you think you are. You might not think you'll get through this thing but trust the doctors, get the support you need and also insist your parents get the support they need after the fact, I cannot stress that part enough (*laughs*), yes and then just live it day by day until you're ready to just realize that there's an entire life ahead of you that's just ready for you to live it *[Outlook on cancer]*. (Laughs)

I: Okay, thank you – **P3**:

No worries.

I:- so, this is not a part of the interview but I do want to ask this question just because you did mention it. So, what are your plans now for the next 10 years now that you survived your first 10.
P3: Oh jheez – (*laughs*)

I: (*laughs*) **P3**: (*laughs*) I don't have plans to be honest. I just want at this point to get a job that pays well, survive as much as I can in the economy and just be content if not happy. I don't have a career prospect, its-like I like creating art but I don't want to do this for the rest of my life because it will absolutely burn me out and I'd grow to hate it, so I don't want to go into that field. So, I'm just sticking with the customer service and hopefully get a different position in the same company somewhat soon but yes, other than that I just don't have much plans, just give me a good paycheck and let me do what I need to do over the weekends (*laughs*).

I: (*laughs*) cool!

P3: Yes.

I: Sounds good. Alright so, this concludes this interview, thank you so much for your participation in this study. If you think of anything else you'd like to add or have any questions feel free to contact me, you have my email. If you're interested in receiving a transcript of this interview, I can provide that for you. Do you have any questions for me?

P3: No, just out of curiosity, what started the whole-you interviewing people about childhood cancer if you don't mind my asking of course. **I**: Yes, so I'm currently in my second year of my master's degree. It's supposed to be my last year. So I came across this topic mainly because I was in my last year of undergrad and I was kind of starting – I thought I had this whole path set up for me. Like I would go into med school and then I'm fine, and then I did a research project in my last year which kind of threw me in for a loop, so I was like oh my gosh, research is so cool, let me do more research on that. So, I looked into doing a masters degree in health science and the kind of projects I would be interested in doing, and its funny because in high school someone who's locker was beside me had cancer, and it was – a weird turn of events happened and he ends up being my moms patient because she's a nurse. And she was like "oh your friend says hi" and I was like "what are you talking about" and then it just became this whole full circle moment that I was like "wow literally what happened to him? I remember seeing him around and then he just disappeared" So I guess that kind of inspired me to do a little bit more research on the experience that some people might have with having to return to life, and - beyond their cancer experience. So that's kind of the gist of it (laughs).

P3: (*laughs*) that's good. I hope he's doing well as well.

I: Yes, he is actually, really. He's really well.

P3: Oh that's good.

I: Thanks, alright so I'll let you go, I don't want to hold you any longer unless you have something you want to add or say. So yes, I can send the transcript to you if you want to see it, I typically just do it anyway just in case people are like "Oh – **P3**: clarifying.

I: - yes exactly.

P3: Yes if its all the same for you id like a copy as well.

I: alright awesome. Thank you so much for making the time again, I really appreciate it.

P3: No worries. I wish you all the best and good luck on your master's and your research.

I: Thank you, enjoy the rest of your day.

P3: Thank you, take care.

I: Bye.

29: 43 mins P3: Bye

OFFICIAL TRANSCRIPT 4

Participant 4 Interview Transcript P4:

So, this is the pilot, right?

I: This is for the part two, the research study portion.

P4: Nice, and what's your sample size you're aiming for? **I**: So,

the goal is to get 8, but recruitment has been a little tough – **P4**:

Yes.

I: - So right now you're my fourth interview.

P4: Cool. So, I can get you my partner for sure.

I: Oh, that's awesome, thank you.

P4: And I can send to a couple other friends and hopefully I can persuade them. Maybe I can get four other people potentially.

I: Wow, okay. That would be awesome. I do plan on shutting down like recruitment next week –

P4: Next week? Okay.

I: - So I'm going to kind of need to cram a little, which I don't mind but I just won't be waiting too long. Just because I've been recruiting since like November.

P4: Yes. Okay I can get you [redacted] probably for sure. What time are you shutting down next week do you know?

I: Honestly –

P4: Like by end of week?

I: - Most likely by – Yes, like by Thursday. Most likely.

P4: Yes, yes okay I can probably get you at least [redacted] by the end of the week so you can have 5.

I: That would be a dream.

P4: You might just have to do the interview a little bit later in the day if that's fine with you.

: Oh no that's totally fine.

P4: If you do want more people. But if you don't want more work then that's totally cool too.

I: (*Laughs*). Yes, no that's fine. That's great.

P4: Okay.

I: Thank you, I really appreciate that. Alright so, let's start with just some demographic information.

P4: Yes.

I: So, can you just tell me your date of birth please?

[redacted]

P4:

I: And how do you self-identify in terms of gender?

P4: Male.

I: Alright, how do you self-identify in terms of ethnicity. You may choose more than one if it applies to you.

P4: Caucasian.

I: What is the highest level of education you achieved?

P4: Master's.

I: Are you currently a student?

P4: Yes.

I: Alright. So – Sorry just a little lost here. What was your age at diagnosis?

P4: I was 16.

I: And what was your diagnosis?

P4: High-risk, stage 4 B Hodgkin Lymphoma.

I: And what type of treatment did you receive and for how long?

P4: Chemo, rads [radiation] and surgery. And it was 9 months of chemo, and then 30 days of radiation – 15 days of radiation but it's double dose so, equivalent of 30 days.

I: Okay. Thank you. Would you mind describing your experience with childhood cancer? So, how about we start a little bit with what you may have felt when you were first diagnosed and how you think experiencing childhood cancer kind of shaped your childhood a little bit.

2:43 min P4: So, like, diagnosis in the sense of like actually – the formal diagnosis or like leading up to?

: I can be like leading up to – leading up to, and the formal and kind of the hospital environment a bit for you.

P4: Yes, yes, but I'm sure you know diagnostic delays and lag times in treatment are like a huge issue so. Especially coming from like a smaller town-well I mean its not even like a small town the population is like 140 000 where I grew up. And seeing a family doctor who you know, family doctors would only see maybe a handful of cases of childhood cancers in the entirety of their careers. The opportunity for misdiagnosis and things like that is super, super high. So, I went two years with symptoms, without actually receiving a diagnosis which was like at the time – at the time realizing I had cancer was like distressing. And then presenting to-like I was never sick before having symptoms of what was stage 4 cancer. Just going to the hospital and getting all the bloodwork was – it was really overwhelming. And especially being naïve and not being exposed to a hospital environment. I went to a community hospital and they're like "You need to go to Sickkids", I go to Sickkids and immediately was referred to the oncology floor but I didn't know what oncology meant and you just see 4 year olds running around bald and hooked up to IVs. So, it's a bit jarring in that sense. But yes, diagnosis was so smooth, the physicians were great. I think it's a matter of like where you live, your access to and familiarity with the healthcare system and things like that. Where kind of make the difference or made the difference for me when I was diagnosed and didn't completely lose my mind. *[Outlook on cancer]* **I**: Alright thank you –

P4: Feel free to prompt me in any way if you want more information. Because, sorry I'm not looking at the questions –

I: Yes, no worries –

P4: - immediately. So, yes if you want more, prompt me.

I: Yes, no worries. Thank you. So, looking back a little bit. When making that transition from being a cancer patient and just trying to reassimilate back into society, what feelings arise if or when you use the term survivor?

P4: I mean survivor isn't really the term at all. It's more like victim *[Outlook on cancer*]. Its more of like – You kind of feel like, once you graduate from the childhood cancer to like the adult world you get a kick on the ass and that's it. You fought. After you've survived 5 years its like "you're on your own" type thing. And a lot of the, I mean all of the risks come after that 5-year period so its like all of the worry of disease recurrence, or your actual treatment is going to give you cancer again. Or the idea of knowing that you will die and knowing you're probably going to die because of cancer or you're going to die of cancer or of some crazy accident, whatever it is in your lifetime. It's like pretty gnarly for some people and its such a vulnerable age and emerging back into the world is really – these people are super, super – yes just vulnerable *[Outlook on reassimilating]*. I've got friends who are also survivors that are like cult vibes and really into the whole like (*laughs*) naturopathic medicine type thing. But for me personally it was like – sorry ask me the question again. It was like emerging back into the world after surviving. Or how does survivorship-sorry go ahead.

: Yes, yes, no worries (*laughs*). I was just asking in that transition from being a cancer patient, back into like-back reassimilating into society, how do you feel about the term survivor, what kind of feelings arise, and do you use this term to describe yourself?

6:56 mins P4: Yes. No. I mean I did until as of recently. But I feel more like a victim than anything. Surviving implies a hard stop and moving on. Whereas I'm still dealing with my diagnosis or repercussions of my diagnosis which are not seen or appreciated by others in healthcare sectors and its frustrating. It's a lifelong diagnosis for sure. *[Outlook on cancer]*

I: For sure. Can you speak a little bit more on what you think has impacted you the most in that transition – from cancer patient to kind of trying to move on with your life?

P4: In terms of like psychologically or in terms of like what is the actual thing – like residual side effect of treatment in survivorship that is causing issues?

I: Yes, it can be anything that comes to mind that really stuck with you that really threw you in for a loop in just trying to reassimilate back. So, like "Oh okay, this is a little different" or "Oh I might have to approach these aspects of my daily life a little differently now" So.

P4: Right. It certainly changed over time. Immediately out of treatment I was like "What the hell am I doing? I'm exhausted all the time" and then like having zero attention span and that's something that's kind of stuck with me. I had undiagnosed ADHD before, and you just take those crazy steroids and its like okay I really can't do anything longer than 2 minutes. So, it's been kind of like trying to advocate for these-individual medication plan type thing or accommodations with the school *[Outlook on reassimilating*]. Like at UOIT [University of Ontario Institute of Technology], it was fine. When I switched to McGill, nothing was recognized, and I really had to like "Bro I had cancer" (*laughs*). You know, it's like they just don't get it even though these people are like psychologists or whatever training. So that's been the toughest for me personally because I didn't really have any crazy side effects of treatment that physically have hurt me. It's been more of the like, education. *[Outlook on reassimilating]*

I: Thank you for sharing that. Can you actually speak on anymore changes that you may have noticed in yourself when – in that transition phase and what kind of changes, or what other kind of changes you might be living with now?

P4: I mean it's a lot of mental health stuff because there aren't mental health services for kids with cancer. *[Outlook on cancer]* Kids with cancer are diagnosed when they're properly kids. I was diagnosed when I was 16 so I was immediately 1 of 3 kids on the floor so it's a very isolating experience beyond being physically and socially distanced because you have no immune system, its like there's no-even in the children's hospital there's nothing for teenagers. The child-life services doesn't really accommodate to that so you're kind of alone. The psychologists and psychiatrists are for like when you're in crisis and they don't really accommodate for that either so you're in this weird kind of purgatory *[Outlook on cancer*] and then you graduate at 18 and you're out of the – children's hospital and 5 years out and there's nothing. There aren't – there's one survivorship program at Princess Margaret and you don't really get any follow-up through that. So, I think for me, its been that. Not that I struggle severely with mental health issues, but at least having the reassurance or there's something or some sort of system in place that you could reach out to if you need that. *[Outlook on coping]*

I: Thank you for sharing that. I wasn't really aware – but I guess the participants I've been speaking to are kind of spread out a little bit-

P4: -Yes

I: - So depending on like accessibility and what not and what they felt they had transitioning was different – I mean for other obvious reasons too because it depends on cancer type and whatnot but –

P4: Yes –

I: - do you think that maybe or – how would you say having more access to those resources would have been able to support you a little more in your transition. Would it have made reassimilating perhaps a little easier? What kind of changes or differences do you think you would have seen had those have been more readily available to you?

P4: I think it would have been like just more prepared. Or just have more – know what to expect. *[Outlook on reassimilating]* There's nothing about-the only thing they talked about for-like preserving your ability to have children or whatever was like a conversation we had in like 5 seconds. And then it was like "you have to start chemotherapy next week so if you want to freeze sperm or whatever it is its like you got one shot" and they just blow over it, and it's not something that they go over again. It was something that I had to bring up 7 or almost 10 years out of diagnosis. And it's like, I had to bring that up, there's nothing in the survivorship program that does that. So just having access to like more perfect information would have – I would have had some idea what to expect rather than kind of like – it really is a binary-you're finished treatment, see you later type thing *[Outlook on coping]*. You go from seeing a physician once a month – **I**: Wow.

P4: - or weekly to basically to once a year type thing. If you've got to be followed more often its like every 3-6 months. So, its like – it's definitely a culture shock going in and then coming back out of the whole cancer care system. *[Outlook on reassimilating]*

I: Thank you for sharing that. Are you able to describe any vivid experiences you may have had in returning to a social life? Because I know you mentioned the culture shock of kind of just – you faced within the healthcare system but in like a social setting what kind of social experiences kind of stuck with you that you may have had.

13:25 min P4: I mean every school has like – every high school has that kid with cancer. And then every high school has that kid that thinks they have cancer. So, it was like you know going to parties and seeing my friends when I was like finishing up treatment and kids being like "Oh my God, like I have stage 4 brain cancer" and you're like "shut up" (*laughs*) - **I**: (*laughs*) **P4**: - "No you don't" or like lung cancer or something like that, that you can obviously see through because, whatever. It's just – It's weird because you know because people don't appreciate the gravity of the situation. And, I mean, you yourself don't appreciate it until – you know in retrospect. *[Outlook on reassimilating]* But, yes, it was very – I didn't have any like-there wasn't anything crazy. I mean fortunately we had the whole like Sickkids and most of the Ontario hospitals they've got the camp Oochigaes or Camp Fire Circle or whatever it's called now. Where its kind of like you go to camp, you see people. Most of those kids – like I was one of 5 kids on treatment because everyone as I said earlier has cancer when they're like, infants. So, its weird being the only one on treatment in a cancer camp but its also, you have this shared experience, so it makes it easier. *[Outlook on cancer]* So, its kind of like a halfway house before you fully enter the high school system again. So anyways, I found it was fine.

I : Okay, can you recall what it was like making new friends or interacting. I know you mentioned there was a little bit of awkwardness with being like one of the older kids at the camp, are there any other instances that you may have recalled in terms of interaction with other people?

P4: Sorry, say that again.

I: Yes, sorry that was a little wordy (*laughs*).

P4: (*laughs*)

I: Do you recall any – any kind of moments where interacting with or making new friends was, not an issue but may have been a different experience as opposed to like the pre-cancer.

P4: Not necessarily but I certainly – before I was sick, I was definitely a different person. Before I got sick, I was just like, I liked to party and hang out with friends or whatever but when I got back, it was like "**** I almost died, and I don't know what I want to do so I should clean up my act a bit". *[Outlook on coping]*So, it was definitely more intense than previously, so it was also weird and like coming back to school, I was a year behind all of my friends. And so, when I came back it was like I knew these people, but they'd also grown beyond me or whatever. So that was kind of weird. *[Outlook on reassimilating]* They're there to support but it was kind of – high school friends and things happen and just they progressed, and I had to stay back a year with a couple of people. But yes, it was different being more intense and more actively trying to do things in school and trying to plan ahead where my other friends were just like "If I get into Queens, that's all that matters and I've peaked." And I was like "that couldn't, yes (*shakes head*) (*laughs*)– that doesn't appeal to me" So, it was more dealing with that and losing friends but its-its not like it affected me it was more like a calculation that I had made consciously myself. Not that I was awkward or coy or whatever it was. *[Outlook on reassimilating]*

I: I see, thank you for clearing that – clarifying that a little bit for me. Can you maybe speak a little bit on how the relationship between you and your family, the dynamic may have changed just a little bit post cancer?

P4: Yes, post cancer, I don't think it changes at all. Certainly, during diagnosis, it brought us close together, and after I finished treatment my mom was able to start back work again and like its been good for me. I'm close with my brother and my family. I don't know how it is for them. I don't think my parents unpacked the whole situation, but there's definitely something there. But, yes it hasn't really changed. We moved, we did regular things, my parents still maintained their friends, we still stayed fine. My parents didn't divorce or anything, *[Outlook on reassimilating]* I don't know what the stats are for kids that die of cancer but like 90% of them divorce or something like that. Like it's insane.

I: Yes.

P4: But yes, we didn't have any of that in our family.

I: That's awesome. So I know we talked a little about mental health and emotional-emotional health, sorry I'm like tripping over my words. What kinds of stressful events do you experience as a result of your childhood cancer, so I know you mentioned issues about fertility and how kind of grasping that was a bit of a struggle because I mean you were diagnosed at 16 and then having that 2 second talk, so are there any other stressful events you may experience and how do you manage these stressful events?

P4: It's literally just like getting people to appreciate the diagnosis and the residual effects of if they exist or if its completely psychogenic. It's still something that's like there – **I**: Yes, for sure.

P4: - and needs to be understood and accommodated in a way. So, it's mostly being like, getting people to see eye to eye and I'm not taking advantage of something either. It was really tough here at McGill because they assume that everybody's cheating for everything. Especially in a graduate program, it's like you'd think that these people would be understanding, or you know have some sort of knowledge *[Outlook on reassimilating]*. Does that kind of answer your question?

I: Yes, for sure-

P4: - You can repeat it if you want - okay.

I: Thank you, so would you say that you kind of managed these stressful events a little differently compared to people who didn't have childhood cancer? Like, you mentioned that you have to explain and make people aware –

P4: Yes-

I: - of the issues revolving childhood cancer. Do you feel like, you know you have to explain yourself in a way whereas people who didn't have childhood cancer don't really have to go through…?

P4: Yes, I've go to – I'm doing it right now. Wrote my comprehensive exam, failed the second part of it. And I was like "okay I've got to write it again next year and have to explain to the prof. that they didn't give me the actual accommodation that I'm entitled to." So, it's like, "okay its going to be met with-they're not going to like it because I have to either re-write the exam or they have to completely restructure it around me." So, I'm certainly more intense. I will blatantly tell them what I need and why I need it and just like "if you need a doctors note I've already got it, and here's their number." Like its no bull**** anymore because I'm kind of just over it *[Outlook on reassimilating]*.

I: Yes.

P4: But yes, I'm definitely different than what other kids would do. It's more like "I need this, this is what I'm entitled to. This gives me an equal playing field", so where it's at.

I: For sure, for sure. So, do you feel like maybe that-I mean taking that into consideration, maybe, you achieved certain milestones at different points in time compared to your peers? So, this could be maybe throughout high school into your graduate studies-P4: Yes.

I: - or with relationships or with career or whatever.

P4: Yes, I feel like -

: What kinds of milestones do you feel like –

P4: Yes, definitely I graduated high school after all of my friends. Started, school after all my friends and then it was nice – the timing was good in that I didn't have – I outgrew or all my friends kind of outgrew me so I didn't really have people to compare myself to so it just kind of made it nice. Like I set my own trajectory and I made everything to my own agenda. But now that I'm like really back in it and I'm with a cohort of people who are the same I'm seeing that milestone kind of change like getting a practicum for my masters was like after all of my friends because no one works in the area I wanted to work in and now I'm doing a comprehensive exam and I failed it and all my friends passed and I'm like okay, now I've got to write it again *[Outlook on reassimilating*]. So, there's all these kind of setbacks that are attributed to cancer but also you don't want to make that a buck, or make that like a scapegoat type thing. So its kind of a tough game to play especially since I'm so far out of cancer treatment it's like, is it cancer? Is this an issue of survivorship, or is this me? *[Outlook on coping]*

I: It's interesting that you pose that question because in speaking with a few survivors, they've mentioned that once you kind of - once you've overcome the emotional attachment to your experience you become a little indifferent about it like "oh yes, that did happen to me." Usually, they don't even speak about it or don't even really remember it half the time unless someone brings it up because its just something that's happened. So, in certain situations when you know it calls for remembering their experience, they're like "oh does it have to do with this? I wasn't really thinking about this." So, it's interesting to see how the mind really understands your situation because of your experience.

24:05 mins P4: Yes and I think it's different for me because I work in childhood cancer like through my studies and I'm – everything in my life since I've been like 16 is childhood cancer so it's like I'm constantly surrounded by it so I'm always like "oh maybe it's this", "maybe it's this". "Bump on your skin, oh my god I've got some sort of sarcoma" (laughs *[Outlook on cancer]*) so.

I: For sure. So can you actually, because you mentioned you're still really engaged with childhood cancer, how do you think maybe, not just experiencing it but like looking to pursue a career – I'm just assuming here – a career in childhood cancer, how do you think, keeping those aspects in mind may have contributed to you as a person, like in shaping you as a person.

P4: I – it's fully. I mean everything I do is related to my diagnosis. My partner had childhood cancer. I'm surrounded by it in every degree of my life. I'm doing a panel for whatever as a survivor/ researcher thing. So, I think it's shaped fully everything that I do in a really healthy, and good way for me. Because I mean Hodgkin Lymphoma is like the flu of cancer, so you couldn't ask for a better one to get. So, I'm very, very, fortunate obviously. I got the best of it *[Outlook on coping]*.

I: That's awesome. Alright so, our last question. So, what is one piece of advice you would give to someone who's currently undergoing cancer treatment for their childhood cancer or who is currently your age trying to navigate their own life post-cancer?

P4: That's tough. I remember being in high school and like my friend's parents were being diagnosed with cancer and I was just coming back from treatment. And they're like "what do I do" and it was like "okay what I did was read everything that I could." That I could at least understand a little bit and like know what to expect. And then you know in retrospect I'm telling these people to read everything and trying to understand what a Kaplan-Meier curve is and they're like "oh my god my parents are going to die in 9 months". So, I don't know if I'd give them that same advice but that's the only advice, I have for someone that's like newly diagnose and going through treatment. And like its hard telling somebody to advocate for yourself because you know theres this whole SES [socioeconomic status], education and all these structural barriers to at least begin to advocate in some sort of way so (laughs) that's not advice you can give somebody. It's just kind of like knowing you have to use all the resources that are given to you and if you think there's something missing, ask about it. Because theres so much money in childhood cancer and if you want to know about it, someone else is probably wondering about it too and they can start a program *[Outlook on cancer]* and you know, whatever. And for the people that are in survivorship in my boat, its just like incessantly call your oncologist and radiologist or whatever and keep getting the follow up as long as you can and try and get all of these things because there aren't programs in survivorship for people our age. In Quebec, it's impossible to get a family doctor, its impossible to get a doctor. So, people like my partner who just moved here, has nothing. There's no structure, there's nothing. So, yes, it's hard and then trying to explain to a new physician once you're out of the this like oncology system your whole experience and then getting these physicians to try to link what could be caused is like pulling teeth. So, I think, just trying to stay aware and on top of yourself is helpful. But again, its not feasible *[Outlook on cancer]* (laughs).

I: (*laughs*)

P4: It's not good advice. It's like, very almost insensitive (*laughs*).

I: What would be sensitive advice, in that case?

P4: Take it easy.

I: (*laughs*).

P4: Like, you're sick. Take a sabbatical, if you can, ease up on yourself. That's the only thing that you can do, and like everything else figures itself out afterwards so.

I: Alright thank you. This concludes-

P4: Is there anything you want clarification on? Like is there any questions you want more on, because I can chat all you want.

I: (*laughs*). I don't think so we hit the major questions, we got a lot of probes. I'm trying not to be redundant, so I don't want to ask the same version of the same question but, yes no it was awesome thank you, you shared a lot with me I really appreciate that. I'm just going to do my closing spiel. So, this concludes the interview thank you so much for your participation in this study. If you think of anything else you'd like to add or have any questions feel free to contact me, you have my email, if you're interested in receiving a transcript of this interview, I can provide that for you. Do you have any questions for me?

29:44 mins P4: No, when you do the publication though send it my way, I'd love to read it.

: Yes, for sure, for sure. Thank you so so much for volunteering I really, really appreciate it.

P4: Of course, of course. **I**:

Let –

P4: I'll forward it to [redacted], and I'll get her to do it next week.

I: Yes, I was just about to say let me know if you need the link again so I can just forward that to you so she can fill that out

P4: Yes, that'd be awesome, that'd be awesome if you could send that to me.

I: Great. I'll do that. Alright, thanks again.

P4: Of course.

I: Take care.

P4: See you, thank you.

30:16 mins I: Bye.

FOCUS GROUP DISCUSSION

Focus Group Discussion Transcript

I: Okay. Awesome. So, before we start, if you're comfortable with sharing, can you please briefly introduce yourself with your name and share your cancer diagnosis? So, anyone can just start.

P4: Do you want to start us off?

P2: Sure. My name's [redacted], and I was diagnosed with acute lymphoblastic leukemia in 2009 and I relapsed twice.

I: Thank you for sharing.

P4: I'm [redacted]. I was diagnosed with Hodgkin Lymphoma when I was 16.

I: Okay, thanks. So, there are three major themes. There's the "outlook on re-assimilating", the "outlook on coping", and "outlook on cancer". So, starting with "outlook on re-assimilating", this code was assigned to quotes that talked about the aftermath of cancer experiences, including changes observed within a social environment like family, friends, peers, and relationships. The "outlook on re-assimilating", provided accounts on the inward perspective regarding the outside environment. So, there were two sub-themes from this major theme. The first one is the perceived ability to re-assimilate. So, this explored perspectives on returning home with reintegration into school or work after having cancer.

Specifically, what ways, your ability to re-assimilate back into these kinds of environments, were impacted.

I: For instance, and I quote; "I think where the difficulty wasn't so much when I had time to process it. It was more in isolation. I couldn't be constantly reminded of how different and limited I was, and I was very athletic and very independent. I've always been very independent, so I think that was the more difficult portion going into 10th grade and realizing that my teachers didn't want me to walk on crutches because they were scared I was going to fall, so they wanted me in a wheelchair still. And even standing up, realizing how difficult it was to get from point A to point B in the five minutes we had between periods and things like that. That's where I think a lot of the trauma really happened because it was like deal with it and life or death right when it's happening. But then nobody bothered to transition me really into normal life or to help me understand what I'd expect."

I: So you also shared certain aspects associated to your ability to re-assimilate, particularly referring to, any kind of deficiencies there might be within the healthcare system and among healthcare professionals.

I: For instance, and I quote; "you kind of feel like once you graduate from the childhood cancer to like the adult world, you get a kick on the ass and that's it. You fought after you've survived five years. It's like you're on your own type thing at such a vulnerable age and emerging back into the world is super, super, just vulnerable. It's definitely a culture shock going in and then coming back out of the whole cancer care system."

I: Are there any thoughts or feel free to interrupt me while I go on 'cause I'm probably going to be doing a lot of talking, so I apologize in advance for that, but, yes. Any thoughts so far?

P4: The first situation sounds pretty intense. I mean, just the crutches. It all sounds like, I mean, I don't know what your sample is like, but diversity in the, the disease that you have, like an osteosarcoma type situation would obviously be a very different experience coming back to school and reintegrating back. So I think that, yes, that's a good perspective to have there and that almost like forced disability that the teacher is putting on this student, even though they're trying to reintegrate and be as normal as possible. Just walking in whatever capacity they can and then just to avoid some sort of like workplace incident or paperwork. Forcing a kid in a wheelchair is intense, so I think that's a good, that's very well captured here. *[interpretation]* **I:** That's a very good point.

P2: I think as well, just the deficiencies in the system is more just, I think an awareness thing than an actual deficiency thing. I think if it was in your face a little bit more and you sort of knew about that stuff, sort of at the different phases of your treatment, I think that would've helped as well. But yes, I mean it's really, intense. Especially because, you know, you're not really supposed to force accommodations on people as well. So, I think that aspect, can be pretty demeaning especially if you want that sense of normalcy. And I think, having that sense of like normalcy is actually one of the keywords *[interpretation]* I think a lot. I like both of those quotes, that's-might be a little bit more complicity and not as specified within it.

I: Yes. I think you - **P4**: -

the point about - **I:** - oh,

sorry. Go ahead.

P4: No, go ahead. Go ahead. Go ahead.

I: Yes, I was just going to say, I think you mentioned a very interesting point about how the word deficiency might not be very accurate because it's more like the awareness isn't there really for it. So, thank you for bringing that up. you [redacted] had something you wanted to say?

P4: Yes, just piggybacking on that, it's like a perceived deficiency that's is like an external force onto these patients reintegrating. I think it'd be interesting to look at these by, you know, your analysis by time. I don't know what your sample is like, but you know, I don't know if this person was sick when, you know, 2009 versus 2016 versus whenever that was because I would at least hope that, you know, Childhood cancer isn't that rare at the end of the day. A teacher is going to have a student who gets sick at one point in their life with some sort of like critical illness. So, you'd hope that the awareness is there and that this stigma, be it cancer or any other illness isdoesn't exist. *[interpretation]* So, I think that'd be an interesting kind of angle or something that for us to think about going.

P2: For sure. I think as well it also sort of depends what hospital you're being treated at as well. Like someone who's treated, who's treated like maybe up north or in like London and Hamilton might have a bit of a different case than someone at-in Toronto or something as well just because of how big the cancer centers are and just how much more staff there are and stuff like that as well. So I think that can also impact that kind of deficiency and how much, people power they have to be able to kind of tell the school, “okay, you know, this is kind of what has happened before” and stuff like that “and this is the case” and don't make them feel like abnormal as well. So yes. **I:** That's very good. Are we okay to move on to the-

P4: (Head nod)

P2: (Head nod)

I: Okay. So, the next sub-theme in the same code outlook on re-assimilating is “forming connections”. So this was based on your perceived ability to form connections with your peers, family and friends after having cancer, and how establishing or maintaining these connections was affected during re-assimilation. So for example, I quote “the way that I used to deal with meeting people in relationships was very different when I was in my teens. Just because I was so isolated at the beginning that I found it very hard to become friends with people”.

I: Some of you also shared in what ways your cancer experience changed your ability to connect with members of your peer group, which ultimately altered what you started to perceive as priorities and how your views fundamentally differed as to that of your peers. For example, I quote; “you don't really know what this is. Like, you're upset that you broke up with your boyfriend or girlfriend and I'm like, my platelet count is down by three points and I'm worried I'm going to get cancer again. The levels of stuff is very different. Just trying to tell people in my peer group, that was really, really hard”. So are there any thoughts so far?

P2: I think that there's kind of-when you get diagnosed or sort of-you sort of go through different phases and stuff. And I, I think that sometimes in the system, it's not really like the psychology of, it's not really talked about more, it's more like just making sure that as a doctor that you're kind of taking care of the patient, making sure that they stay alive and stuff like that. And I think having that reintegration, especially when you're, in the moment but kind of throughout, sort of when you're in remission as well, might be better. Because in those moments sometimes it's hard to really have that level of perspective because you do feel like there is a big separation from you and your peers as well. *[interpretation*] But yes.

P4: Yes, very good point. Yes, I like the, I like the second point that really just kind of captures the essence of the experience as a teenager, at least.

10:01 mins P4: It's like your friends are at one point-you're just you know trying to play the new

Call of Duty and shotgun a beer and then you're worried about dying. It's like a completely different experience that you're going through. It's something that even now I'm 10 years out of my treatment or my diagnosis and like “what the hell are my friends doing?”,

“why are you worried about this?” Yes. So, it's just, it's so-yes. I can really connect with that person's experience and I think that's a nice thing to capture. *[interpretation]*

I: All right, so I'm going to move on to the rest of the quotes really quickly, and then open up for discussion if there are any thoughts. So, some of you experience an impact to your family dynamic while others haven't.

I: For example, and I quote; “sometimes she, [mom] does travel and then I do stay home alone, but it's still being in the same house that she stays in. It's still being in the same environment. It's always her friends who are calling to check up on me. It's like, come on. I'm like 18 and above. If I'm legally allowed to vote, I can probably not set the house on fire. So yes, it's a lot of the stifling of the autonomy”.

I: Another quote; “post-cancer. I don't think it changes at all. Certainly, during diagnosis, it brought us close together and after I finished treatment, my mom was able to start back work again. And it's been good for me. I'm close with my brother and my family. I don't know how it is for them. I don't think my parents unpack the whole situation, but there's definitely something there. But yes, it hasn't really changed. We moved, we did regular things. My parents still maintained their friends. We still stayed fine. My parents didn't divorce or anything.” Socializing also seemed to be a barrier for most, but not all of you specifically, how missing that integral part of schooling impacted your ability to form connections.

I: For example, I quote; “the first year was a bit difficult because going back to school learning and then as well, building a social. Like at that time, everyone already had a social group to be a part of because at the time it was like half of the year already done with, so it was kind of weird in that.” Some of you also shared your current experiences within social environments, including friendships and relationships, several years after, re-assimilating. For example, I quote, “I'm getting better at it now, making friends and meeting new people. But like I said, it took 10 years to change that one for me very recently. I'm trying to put myself more out there.” Are there any kind of concluding thoughts before we move on to the next?

P4: Yes, I just wonder about the, like the timing things that I mentioned before would be interesting because as [redacted] kind of suggested, like based on cancer facility that you were treated at there places like there are facilities like Camp Ooch [Oochegeas]or Campfire Circle or whatever it's called now that have in hospital programming or teen specific programming to kind of connect you with your peers. So, In 2008, this wasn't established, but in places like, you know, in 2013, 2016, 2018, there is a bunch of different infrastructure for these peer groups, and that would obviously differ based on population, the place you're treated at in time.

P2: Yes, absolutely. It'd be kind of interesting to see how, how much it's evolved too. Like if you're on treatment in 2015, have services grown or have they sort of stayed the same and stuff like that. Just to see that kind of program evolution might be interesting to catch.

I: Yes, that's a very-those are very good points. I think also too, there's a cancer survivorship program at Princess Margaret. I think that was only recently funded and recently accessible.

So, I think certain things like that too, the kinds of resources that are available are likely to be different now in 2022 versus, you know, 2009 for sure.

P4: Yes, and I mean, the Princess Margaret is - that program is poorly funded and it's a top 10 cancer institute in the world, so it's just kind of goes to show what support there is for AYA and pediatric survivors. *[interpretation]*

I: That's a good point. All right. Okay, so we'll move on to our next major theme that's the "outlook on coping". So this was used for quotes that describe feelings about, re-assimilating, but specifically within the context of accepting and learning to embrace a new reality. The

"outlook on coping" provided an account of inward perspectives on oneself during the experience while exploring mental health and coping behaviors. So there are three sub-themes. The first is the "ability to cope". So, this describes the perceived difficulties on accepting the new circumstance and learning to deal. Re-assimilating. So, there are statements addressing having access to resources and having the appropriate support impacting your ability to cope when re-assimilating.

I: For example, and I quote; "I felt very angry because not only was my body failing me, it felt like people were failing me because nobody actually taught me how to cope with it or how to deal with it, or how to figure out how to get back to where I wanted to be. Nobody really kind of taught me tools to do on my own or things to cope at the time. So, I think that was the most difficult part at the beginning".

I: Any comments before I move on?

P2: (Head shake)

P4: (Head shake)

I: No? Okay, all right. So, next one, "views on oneself". So this accounts what values have changed or any characteristics that you felt were impacted by cancer in a self-reflecting way as it relates to the development of a new-I mean, identity is probably the wrong word to use, but mainly referring to that transition from cancer patient to survivor.

I: So for example, and I quote, “when I'd fall, I'd be angry at myself. I wouldn't want help. I wanted to be independent. So I think a lot of that feeling a complete loss of control and independence and feeling like somehow I had become somebody who was, I wouldn't use the word crippled because I've never really seen myself as a cripple, but more kind of just so incapable of doing things by myself that it was just at the beginning I was like, what is the point really? Because I can't do anything by myself.” Some shared how cancer has shaped all aspects of identity using a positive outlook, specifically in regards to the people that you are now, for example, and I quote; “I never really wanted to be thought of someone who was weak or like a coward, so I think it made me mature a lot sooner than a lot of my peers, and it made me a lot more resilient.”

I: Some of you also shared. What you're facing now related to re-assimilation and moving on from cancer in a way that impacted your identity, for instance, and I quote; “There's all these kinds of setbacks that are attributed to cancer, but also you don't want to make that a scapegoat type thing. So, it's kind of a tough game to play, especially since I'm so far out of cancer treatment. It's like, is it cancer? Is this an issue of survivorship or is this me?” And

that's all I had for that one. Are there any thoughts so far on what I said? I know I kind of just said a lot, but yes, go ahead . [redacted]

P2: I think too, like, it'd be kind of interesting to see how maybe previous either learning disabilities or psychological profiles. If there's been anxiety in the past and stuff and how maybe that might be amplified sort of during treatment and then kind of after treatment, how that's resolved. I think for a lot of people, if you're extroverted, then you - Not fair a little bit-a little bit better, but just not have that anxiety that you already maybe had just be more amplified. And it'd be kind of like interesting just to see that comparison and how that could impact survivors and stuff.

I: Yes. So, thank you for bringing that up. Actually, in a lot of the papers I've read post traumatic stress symptoms and post-traumatic stress disorder, it's very common among survivors of childhood cancer. So, that includes issues with sleep, anxiety, depression, anxiety revolving around health, but then also I guess psychosocial anxiety. So yes, so it-it definitely is present and it definitely does has an impact on the ability to, you know, cope because it's almost like, like enduring like a physical battle, but then it becomes like a mental one too there.

20:02 mins I: Okay, so I'm going to move on to “coping tools” then. So, coping tools describes the tools and methods or protective mechanisms that were used to navigate difficult situations when re-assimilating. So, for instance and I quote “distancing myself as much as possible, just like being in a place where I didn't have to interact with a lot of people and I didn't have to do that sort of thing with people.” Some of you also shared some positive aspects to your coping mechanisms and how it aided you with your experience at present and at the beginning of your re-assimilation process. So for example, and I quote “humor, sarcasm. That is the number one thing I'd call my main weapon.” Are there any thoughts so far? Like does any of this like resonate with you?

P2: No.

I: Okay. Awesome. All right. I'll move on to my very last quote and then I'll get into my interpretations 'cause this is just sharing the data with you guys. So "outlook on cancer". This theme is used on quotes where you explain any feelings about your experience with cancer as you were and are experiencing it. It explores your understanding or interpretation of your experience.

It provides a perspective on what happened to you as a patient and the after effects. So there's a total of two sub-themes. So the first one is "perspective as a patient". So this one outlines any sentiments concerning about concerning hospitalization as a patient, receiving a diagnosis and treatment and understanding your circumstance.

I: For example, and I quote, "you develop really strong attachments to the nurses, the social workers, the doctors" participants also experience interactions-sorry, I just lost my train of thought here. Participants' experience with cancer was not limited to interactions with staff.

Some of you also shared your experiences as a patient facing barriers within the healthcare system. For example, and I quote, "unless you're a transplant center, you don't really have the same ability as well to be able to have these support systems. So if you go to Toronto or Montreal, or I assume Vancouver or also Calgary, I think as well as another one, they have a lot more infrastructure in place to be able to have this. Whereas if you go to CHEO, which is

the Children's Hospital, Eastern Ontario, Versus sick kids. There's a big difference in terms of the size of the hospital, what they can handle, the amount of child life people that they have there, versus nurses versus doctors. So you can see the drastic differences in terms of fundraising."

I: Okay. Are there any thoughts there? I know [redacted], I think you mentioned like an earlier thought about this, so it's nice to see it kind of come up.

P2: I, I think that's my quote actually.

I: All right. Any other thoughts? (silence) So I'll move on to the "aftermath". So this is the last one. This communicates any attitudes about your experience as a survivor and your evolving relationship with cancer and past experiences, including developing perspectives and using the term survivor to describe yourself and your journey.

I: So for example, and I quote, "survivor isn't really the term at all. It's more like victim surviving implies a hard stop and moving on. Whereas I'm still dealing with my diagnosis or repercussions of my diagnosis, which are not seen or appreciated by others in healthcare sectors. And it's frustrating. It's a lifelong diagnosis for me". Some of you shared experiences in retrospect, including current feelings of indifference and impartiality when observing or recounting experiences with childhood cancer. So, for example, and I quote, "it was such an emotionally triggering thing for me to be reminded how different things were and how awful it was to be different. But if I'd really dealt with it sooner, I think I would've been able to see it as something as it happened. And it's not good or bad, it just happened. The same way that going through anything enough times becomes less emotional.” So are there any kind of like thoughts about these quotes? Like, what resonates with you? How are you feeling?

P4: I think that last, the last point is-is interesting. Just the desensitization to the entire experiences. I mean, I'm sure I'm going to [redacted] like [redacted] could connect to that where, you know, you just, you know what to expect. It's-it's a fear, I think all cancer survivors have is like, you get sick again and it's like, ****, I have to get a pick line, or I have to get all of these things and like, you know, what's coming and that sucks. Cause when you do it the first time, it's like, okay, you know, you're, you're just naive. And I think the-I think the first quote was probably, it sounded like something I would say. But I think that, I think that does stand true and for people-you know, if you had an osteosarcoma or something and you are, you physically look different for the rest of your life, this is something you were reminded of your diagnosis and it persists for the rest of your life. *[interpretation*] It's just, yes.

I: Great. Thank you. [redacted], is there something you wanted to add?

P2: Not really. I mean, I think a lot of the like, aftermath stuff, I think kind of takes a while to sort of really hit you as well because at least for me, there was a period where I just didn't really remember because when I was focusing on it too much you sort of deal with more mental health issues and stuff like that. So, you sort of just want to try and focus on life. *[interpretation]* And, I think in that respect, it'd kind of be interesting to, I'm sure it's almost impossible, but graph, the optimism to like pessimism type scale, for survivors and how that's kind of evolved and changed, especially in like remission, how they might be more, skeptical or like pessimistic when they're on treatment and then like after if that stays with them or if that kind of goes and they have more joy and like optimism and stuff like that. Or if they're continue to kind of be more harder on them-like on themselves with some stuff. Especially they kind of deal with like survivor's guilt and other aspects depending o, you know, if they had clinical trials and stuff and maybe, you know, not everyone survived, you know, they were like by people and then three passed away or something like that. How do you deal with that long term and stuff like that. So it-it’d kind of be interesting just to see that scale of emotion and how that evolves as well.

I: Yes, no, those are very good points. And I think, what is awesome about the study is that, I really got to kind of explore just a little bit of the kind of emotional evolution a bit in terms of, you know, looking at not just developing relationships, friendships, but also understanding yourselves to some degree throughout, you know, like your experience and then kind of how you are now. And I think what's really also very interesting about the very last quote about, specifically just how it's not an emotionally triggering thing anymore and how, going through it enough times becomes less emotional was specifically in the context of it's not, it's not necessarily something that I'm going to speak more so-the conversation I had with this specific individual, but it's not something that they lead with anymore. It's kind of just like, If they're,- if it's brought up in conversation, it's not because they lead with it. It's not because, they feel like it's something that like everyone has to know. It's kind of just like, oh yes, you know, like this happened. And they're able to kind of share their experience without it-without the having shared it being traumatic for them. So the process of sharing isn't like a traumatic thing for them, and that's why there's just that level of emotional distance, I guess, about the experience. Or at least that's what my interpretation of-of it was. So, I just found that being able to kind of understand the emotional aspect in that way was very interesting.

All right. Oh, sorry. Did you have something you want to say?

P2: No. I was just going to say sometimes as well, at least for me, I've had cancer three times and there's some days as well where you're like, oh, you know your normal life sometimes is even harder than your cancer life because you sort of, you grow to that being your norm in a way. So sometimes there's times where it's kind of like, aw man, I have the resiliency for cancer, but I don't have the resiliency for life in some respects *[interpretation]*. So, yes, but I don't know.

I: Thank you for sharing that. That's a very interesting perspective on kind of like comparing like your now to your then.

30:06 mins I: Thank you for sharing that. All right, so I'm just going to move on to share my interpretations. So I have 1, 2, 3, 4, 5 main kind of statements and I just kind of want to get your thoughts on it. If it resonates with you, if there's anything you'd like to say about it or whatnot, then obviously feel free. So the first one, so it seems that a positive outlook is almost needed to have positive self views. So, it's almost impossible to isolate these aspects of your experience and experience them individually. So, the ability to perceive your environment, how you're able to process your environment and your ability to perceive success in your environment ultimately has an impact on your ability to cope. Are there any thoughts or does this resonate with you?

P2: (Head nod)

P4: (Head nod)

I: Yes. Yes. Okay. So the next one, self-confidence, which in the study was more so expressed as the ability to be independent strongly influences the trajectory of re-assimilation to a degree. So, your sentiments on preparedness. Seem to shape your perceived ability to cope, ultimately influencing your experiences with re-assimilating. So, as expressed by many of you, there was a disconnect between preparedness and re-assimilation. Hence resulting in having positive or negative kind of coping outlook, which can be understood as, positively or negatively contributing to the process of re-assimilation. How do you guys feel about that?

P2: I agree with it. I would just kind of use the metaphor of someone holding your hand and using the whole hand versus maybe one finger or something like that. Which might, in reality it might be like one finger versus the whole hand when they sort of tell you stuff, at least when you're in maintenance and like remission and stuff *[interpretation]*. I don't know.

P4: What was the-what was preparedness? How did you, how did you define preparedness?

I: Prepared?

P4: Yes.

I: So, preparedness in the study was more so expressed as like having the feeling like you you were able to succeed in your environment post cancer.

P4: So, it's those has that more reflective of resources. Is that like reflective of hospital resources majority or just like access to I think so like, sort of [redacted] described.

I: Yes. Yes, exactly. So it has more so to do with kind of just feeling not very well equipped or not really understanding what you're kind of getting into when re-assimilating or kind of like, you know, the things to expect, the support that you feel like you had. The access to information, access to support groups or support systems or resources, that kind of thing.

P4: Got it. And then it was better preparedness, better re-assimilation or more easy the transition to real-world type thing. Is that what?

I: Okay. Yes. So, yes, essentially like, expressing a positive or negative coping outlook. So how that contributes to positive or negative-negatively to the process of, re-assimilating.

Yes.

P4: Got it.

I: Okay. Any other thoughts? (silence) Okay, so positive or negative coping outlooks may have an influence on the views you have on yourselves, which can have an overarching influence on your outlook on cancer. So this may ultimately change the kind of relationship you currently have with cancer when embracing your new chapter regarding your patient survivor transition. So ultimately it's entirely possible to have positive and negative views regarding your cancer outlook. So again, cancer outlook is just your perspective as a patient and the aftermath of cancer. How do you guys feel about that? Like having like a positive and negative-both being present overall regarding cancer outlook?

P2: I would just kind of add that positive and negative outlooks dealing with cancer itself, but also just dealing with like your high school experience as well and trying to balance that. You know and whereas maybe some of your peers are experimenting with other substances, you know, you feeling that peer pressure you might also interact differently. So you might have a positive outlook maybe going into high school, but then maybe throughout as you're kind of dealing with a lot of this negative coping it might also have an impact on how you perceive or, and can make it more negative *[interpretation]*, I guess.

P4: Yes. I mean, it can go one of two ways. Like, it's like, oh, great, alcohol exists and then it's like, okay, alcohol’s a carcinogen. So it's kind of like either on one side of the coin there, *[interpretation]* but I think the point you bring up is interesting.

I: Yes. Awesome. Thank you guys. So, okay, so we kind of already talked about it earlier.

So, recollecting and looking back at your cancer experience becomes less emotionally triggering the longer you are you know, a survivor of childhood cancer. So, I guess we can move on from that one there if there’s nothing you want to add (silence) Okay. All right. So, moving on. So, some of you accredit having a relatively positive outlook as a patient to the support you received from the hospital staff as a patient during hospitalization. However, this study's findings corroborate other study results concerning the lack of communication between patients and hospital staff specifically regarding the psychosocial effects of survivorship, where you not only do not feel supported, but do not feel prepared for re-assimilation, how do you guys feel about this statement or this interpretation?

P4: Yes, I mean, that's-that is the experience. There are not programs that exist for kids with cancer to have care, like psychosocial care there are barriers for that care being that you have to be actively on treatment. And these things, even though you know they exist in some facilities, sick kids, probably, it's-it's only in hospital. It's like it's for a select few. And realistically, the care extends to the patient, the siblings of the patient, if they're our siblings, the parents, also the friend groups at school or wherever. Like it's, it's this whole holistic thing that is almost completely neglected in Canada. *[interpretation]*

P2: Yes. I would kind of echo those sentiments. But I would also sort of say the programs are in place for me, I live in Ottawa and up until I think like 2014, they allowed sort of young adults to be able to have their bone marrow transplants in the adult cancer other center. That was really like eye-opening for me because you got to see all those support groups being advertised and being available and it-it would almost, I think, help to have a plan in place where you can kind of integrate that stuff a lot better. *[interpretation]* Because I like a new thing as well. Part of the cycle of social stuff is that you-you also age a lot more when you speak, if you're 20, you kind of speak like you're 25 as well. So, I think even if you are with really old people maybe you don't want that, but if the resources are limited, maybe that's sort of what you have to do just to exchange just life advice and stuff as well. I don't know, it'd be kind of interesting to see that. But I, I know there's been a few, with Candlelighters and other sort of groups that, that have tried to do it. I think it's just a part of**40:07 mins P2:** -Maintaining it. So that might be a bit of a challenge. And I think something to maybe in the post-mortem section, maybe just kind of say like, how can we maintain these programs? If the sort of from a doctor-patient perspective is kind of like, well, I want you out there living your life, but I also have all this other baggage and my job as a doctor is really only to deal with like the most needed patients right now as well. So there's kind of that thing that you have to balance as well. But I don’t know.

P4: That's an interesting experience because you think that being a kid treated at an adult facility would suck like hell because you are essentially a one of one. No one else is like you.

This is just my perspective. I'm not trying-I'm not trying to project anything [redacted], so you'd think that-you'd think that it would suck, but because so many more adults have cancer and there's just so much more infrastructure for adult cancers, you see the benefits of that. Like you get the benefits of all the kind of-the groups there. Like you get the psychosocial support, all those other things. And I think it's, you know-places like candlelight are excellent, but they're just, you know, there aren't cancer cases in some of these smaller towns. I grew up in Berry, which is north of Toronto. 150,000 people live there and they're like 10-10 families that attend these candlelighters thing. Five of them come from up north, like it's over a three hour drive for them to just have some sort of community. And I think that's wild. We could just digitize it. But it's-it's hard to kind of implement that. And it needs to be, for me, the only way that I see this working is at the hospital level *[interpretation]*. And you know, [redacted] just kind of shows that if it's not there you don't really get it.

P2: I think it was, well, just from a policy perspective as well, like just making sure that put enough money for the psychological care of patients as well. And I think that's going to be increasingly important, not just for cancer survivors, but just for everyone coming out of COVID. *[interpretation]*And it would also kind of be interesting maybe for another study if the findings that people-or sorry, the psychological developments that happened during Covid, how similar they are to like cancer survivors' experiences. 'Cause just from talking to people I was like, yes I've already kind of dealt with this. I don't know about you, but the pandemic was not really a big thing for me 'cause I've already dealt with that three times over. But I think for some other people it was a really big impact because now they're sort of like a cancer survivor. They're left with their own thoughts and usually when you're left with their own thoughts, that's not a good thing. But I don't know that's kind of an aside.

I: No, that's a very interesting point that you brought up. Thank you for sharing that. Are there any other thoughts?

P4: (Head shake)

I: Okay, so it ultimately seems, if re-assimilation, kind of like having a program for that, if that was an active part of cancer care, it could have made a difference to your kind of survivorship journey. Is that a fair assumption to make?

P2: Yes. Based on kind of what was.

I: Okay. Yes. So, [redacted] I know you kind of mentioned briefly, having like a digitized intervention. So how much do you think a digital intervention might have helped you with your transition specifically, not just during cancer care, but also post-cancer care?

P4: Like what kind of differences do you-would've it have been able to make? Well, it's just, it's just having access to these programs and knowing that if I need something, it's there for me. So I don't like-going into survivorship, I had no idea what to expect and all of these questions kind of come up. You never have the opportunity to you know, voice these opinions or questions. These are-you don't have the same sort of access. You're not going to get your blood work done every week. You're not going to follow up appointments monthly. So you're kind of left on your own. And without addressing these, I think it can lead to a lot of this, like maladaptive kind of, you know, coping or these unique trauma responses and this kind of PTSD [Post traumatic stress disorder]. So I don't know what necessarily goes into this sort of like online platform, but just knowing that I have access to information that isn't Google is reassuring. *[interpretation]*

P2: I would also just say, I know that there's been platforms. I remember when I was at CHEO, there was, you populous, I think, or something along those lines. But, I think again, it really comes down to maintaining those things, right? And making sure that you have enough funding to carry those things on as well. But even having almost like a mini subreddit kind of thing that you can kind of just go to and just making sure that it's run by survivors and that survivors are on there as well. I think it'd really help and I mean, I think depending too, if you're in a rural community, even just having a Zoom function or something like being able to have a game night with a whole bunch of random survivors and stuff like that, I think might also help. *[interpretation]* But, yes, I don't know. And it would kind of be interesting as well just to see, now especially in like CHEO and sort of these other satellite cancer centers. How much intervention like camp oochigaes or campfire song has had, 'cause I remember when I was at, at CHEO, I think I was like the first kid from Ottawa to go to camp oochigaes and stuff like that. And that really opened my eyes because before there wasn't really that real integration between the camp and the in-hospital experience and stuff like that and helping that psychosocial with connections and stuff like that. So it would be kind of interesting to sort of get maybe people that are actually in the system or sort of coming out of it a little bit more, be like five years post or some, or not five years, like a year or two post. Just to get that evolution and how it's developed as well. And maybe it's improved. I'm not sure.

P4: Yes, to kind of, to piggyback off of [redacted] there. So I mean, essentially everybody, I think universally agrees that like some sort of online platform would be great, or just having access to this information, which obviously I agree with. But as [redacted] said, it needs to be updated and it needs to be funded. And a lot of people take on like masters or Ph.D. project of building this online portal and it's so good for the four years that you're funded and you do your research and then it's completely neglected. We just need to consolidate and actually have something for kids because these hospital specific hyper niche things are just, they can be really ****** and it just-it needs to be optimized. That's it at the end of the day. It could be so good and so powerful, empowering for people, but it's just not there. *[interpretation]* **P2:** For sure.

I: Thank you guys so much for those final inputs and honestly that kind of last question, I reallyWas just a super last-minute add, but I felt like it would be kind of an interesting thing to get your perspectives on. So I really, really thank you for your thoughtful responses.

I: So we're almost at five. Are there any final conclusions or questions before I let you go?

Because this is kind of all I prepared for this discussion, just sharing like the quotes and my interpretations.

P4: No, I, I've got no questions, but whenever you, whenever you submit to a journal or if you publish a pre-print, I'd love, I'd love to take a read of it.

P2: Yes.

I: Yes for sure. Yes, I'll send it to you guys for sure. Thank you so much. And I also appreciate the ideas you've given me for my Ph.D., so that's also awesome. I appreciate that.

If you have any questions or concerns about, you know, any of the quotes or interpretations, I can you can just email me, you have my email. If you guys would like a copy of the document that I used today that had the interpretations and the quotes, I can also send that to you as well if you're interested. So yes, just let me know. Other than that, I'll just, I'll let you guys.

P4: All Right. Okay, so thanks so much.

P2: Thank you guys so much. Take care.

50:00 mins I: Bye.

REFERENCES

[1] National Institutes of Health. (n.d.). NCI Dictionary of Cancer terms. National Cancer Institute. Retrieved May 17, 2022, from https://www.cancer.gov/publications/dictionaries/cancerterms/def/childhood-cancer).

[2] American Cancer Society. (2019). Types of cancer that develop in children. American Cancer Society. Retrieved May 17, 2022, from https://www.cancer.org/cancer/cancer-in-children/typesof-childhood-cancers.html

[3] Namayandeh, S. M., Khazaei, Z., Lari Najafi, M., Goodarzi, E., & Moslem, A. (2020). GLOBAL Leukemia in Children 0-14 Statistics 2018, Incidence and Mortality and Human Development Index (HDI): GLOBOCAN Sources and Methods. Asian Pacific Journal of Cancer Prevention : APJCP, 21(5), 1487–1494. https://doi.org/10.31557/APJCP.2020.21.5.1487

[4] American Cancer Society. (2022). About childhood leukemia. American Cancer Society. Retrieved May 18, 2022, from https://www.cancer.org/cancer/leukemia-in-children/about.html

[5] American Cancer Society. (2019). Childhood leukemia survival rates. American Cancer Society. Retrieved May 18, 2022, from https://www.cancer.org/cancer/leukemia-inchildren/detection-diagnosis-staging/survival-rates.html

[6] Lee, S. (n.d.). Treatments for childhood brain and spinal cord tumours. Canadian Cancer Society. Retrieved May 17, 2022, from https://cancer.ca/en/cancer-information/cancertypes/brain-and-spinal-cord-childhood/treatment

[7] American Cancer Society. (2020). About brain and spinal cord tumors in children - American Cancer Society. Retrieved May 18, 2022, from https://www.cancer.org/content/dam/CRC/PDF/Public/8572.00.pdf

[8] Girardi, F., Allemani, C., & Coleman, M. P. (2019). Worldwide Trends in Survival from Common Childhood Brain Tumors: A Systematic Review. Journal of Global Oncology, 5, 1–25. https://doi.org/10.1200/JGO.19.00140

[9] American Cancer Society. (2018). Survival rates for brain cancer and spinal cord tumors in adults. American Cancer Society. Retrieved May 18, 2022, from https://www.cancer.org/cancer/brain-spinal-cord-tumors-children/detectiondiagnosisstaging/survival-rates.html

[10] American Cancer Society. (2021). Neuroblastoma tumors: What is neuroblastoma? American Cancer Society. Retrieved May 17, 2022, from https://www.cancer.org/cancer/neuroblastoma/about/what-is-neuroblastoma.html

[11] American Cancer Society. (2021). Neuroblastoma survival rates. American Cancer Society. Retrieved May 18, 2022, from https://www.cancer.org/cancer/neuroblastoma/detectiondiagnosis-staging/survival-rates.html

[12] Colon, N. C., & Chung, D. H. (2011). Neuroblastoma. Advances in Pediatrics, 58(1), 297–311. https://doi.org/10.1016/j.yapd.2011.03.011

[13] Van Heerden, J., Abraham, N., Schoeman, J., Singh, E., & Kruger, M. (2021, June 17). Reporting Incidences of Neuroblastoma in Various Resource Settings. JCO Global Oncology. Retrieved May 19, 2022, from https://ascopubs.org/doi/full/10.1200/GO.21.00054#:~:text=The%20median%20and%20range%20incidences,%2C%20respectively%20(Table%201).

[14] American Cancer Society. (2018). What are Wilms tumors? American Cancer Society. Retrieved May 17, 2022, from https://www.cancer.org/cancer/wilms-tumor/about/what-is-wilmstumor.html

[15] American Cancer Society. (2018). Survival rates for wilms tumors. American Cancer Society. Retrieved May 18, 2022, from https://www.cancer.org/cancer/wilms-tumor/detection-diagnosisstaging/survival-rates.html

[16] Cunningham, M. E., Klug, T. D., Nuchtern, J. G., Chintagumpala, M. M., Venkatramani, R., Lubega, J., & Naik-Mathuria, B. J. (2020). Global Disparities in Wilms Tumor. The Journal of Surgical Research, 247, 34–51. https://doi.org/10.1016/j.jss.2019.10.044

---

[17] American Cancer Society. (2021). Hodgkin lymphoma treatment: Treatment for Hodgkin disease. American Cancer Society. Retrieved May 18, 2022, from https://www.cancer.org/cancer/hodgkin-lymphoma/treating.html

[18] American Cancer Society. (2020, October). Hodgkin lymphoma treatment: Treatment for Hodgkin disease. American Cancer Society. Retrieved May 18, 2022, from https://www.cancer.org/cancer/hodgkinlymphoma/treating.html

[19] American Cancer Society. (2021). Childhood non-hodgkin's lymphoma survival rates. American Cancer Society. Retrieved May 19, 2022, from https://www.cancer.org/cancer/childhood-non-hodgkin-lymphoma/detectiondiagnosisstaging/survival-rates.html

[20] American Cancer Society. (2022). Hodgkin lymphoma survival rates: Hodgkin disease survival rates. American Cancer Society. Retrieved May 19, 2022, from https://www.cancer.org/cancer/hodgkin-lymphoma/detectiondiagnosis-staging/survivalrates.html

[21] Chun, G., Sample, J., Hubbard, A. K., Spector, L. G., & Williams, L. A. (2021). Trends in pediatric lymphoma incidence by global region, age and sex from 1988-2012. Cancer Epidemiology, 73, 101965. https://doi.org/10.1016/j.canep.2021.101965

[22] American Cancer Society. (2018). About rhabdomyosarcoma. American Cancer Society. Retrieved May 18, 2022, from https://www.cancer.org/cancer/rhabdomyosarcoma/about.html

[23] American Cancer Society. (2018). Survival rates for rhabdomyosarcoma by Risk Group. American Cancer Society. Retrieved May 19, 2022, from https://www.cancer.org/content/cancer/en/cancer/rhabdomyosarcoma/detection-diagnosisstaging/staging-survivalrates.html

[24] Arboleda, L. P., de Mendonça, R. M., Lopez, E. E., Araújo, A. L., Palmier, N. R., de Pauli Paglioni, M., Fonseca, J. M., Hoffmann, I. L., Cardinalli, I. A., Chaves, A. L. F., Aranda, S., Brandão, T. B., Lopes, M. A., Ribeiro, A. C., Troconis, C. C., & Santos-Silva, A. R. (2020). Global frequency and distribution of head and neck cancer in Pediatrics, a systematic review. Critical Reviews in Oncology/Hematology, 148, 102892.

[25] American Cancer Society. (2020). Retinoblastoma. American Cancer Society. Retrieved May 18, 2022, from https://www.cancer.org/cancer/retinoblastoma.html

[26] National Cancer Institute. (2021, March 12). Global disparities in childhood retinoblastoma. National Cancer Institute. Retrieved May 19, 2022, from https://www.cancer.gov/newsevents/cancer-currentsblog/2020/retinoblastoma-global-disparities-low-middle-incomecountries.

[27] Lee, S. (n.d.). Survival statistics for retinoblastoma. Canadian Cancer Society. Retrieved May 26, 2022, from https://cancer.ca/en/cancer-information/cancer types/retinoblastoma/prognosisandsurvival/survivalstatistics#:~:text=Doctors%20often%20use%20the%20obser ve d,5%20years%20after%20their% 20diagnosis.

[28] American Cancer Society. (2020). Osteosarcoma. American Cancer Society. Retrieved May 18, 2022, from https://www.cancer.org/cancer/osteosarcoma.html

[29] American Cancer Society. (2020). Types of Ewing tumors: Ewing Sarcoma Research & Statistics. American Cancer Society. Retrieved May 18, 2022, from https://www.cancer.org/cancer/ewingtumor/about.html

[30] Welch HG, Schwartz LM, Woloshin S. (2000, June, 14). Are Increasing 5-Year Survival Rates Evidence of Success Against Cancer? JAMA. Retrieved fromhttps://jamanetworkcom.uproxy.library.dcuoit.ca/journals/jama/fullarticle/192788

[31] Cancer Care Ontario. (2018, February 26). Cancer Fact: Cancer rates increasing among children in Ontario. Retrieved from https://www.cancercareontario.ca/en/cancer-facts/cancerrates-increasing-among-children-ontario

[32] Robison, L. L., & Hudson, M. M. (2014). Survivors of childhood and adolescent cancer: lifelong risks and responsibilities. Nature reviews. Cancer, 14(1), 61–70. https://doi.org/10.1038/nrc3634

[33] Armenian, S. H., Armstrong, G. T., Aune, G., Chow, E. J., Ehrhardt, M. J., Ky, B., . . . Kremer, L. C. (2018, July 20). Cardiovascular Disease in Survivors of Childhood Cancer: Insights Into Epidemiology, Pathophysiology, and Prevention. Retrieved from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6804893/

---

[34] Hudson, M. M., Armenian, S. H., Armstrong, G. T., Chow, E. J., & Henderson, T. O. (2018). Optimization of Health and Extension of Lifespan Through Childhood Cancer Survivorship Research. Journal of Clinical Oncology, 2133-2134.

[35] American Cancer Society. (2019). After childhood leukemia treatment - american cancer society. Retrieved May 19, 2022, from https://www.cancer.org/content/dam/CRC/PDF/Public/8697.00.pdf

[36] Van der Pal HJ, van Dalen EC, van Delden E, et al. High Risk of Symptomatic Cardiac Events in Childhood Cancer Survivors. J Clin Oncol. 2012 [PubMed] [Google Scholar]

[37] American Cancer Society. (2018). After brain and spinal cord tumor treatment in children. American Cancer Society. Retrieved May 19, 2022, from https://www.cancer.org/content/dam/CRC/PDF/Public/8576.00.pdf

[38] Galligan A. J. (2017). Childhood Cancer Survivorship and Long-Term Outcomes. Advances in pediatrics, 64(1), 133–169. https://doi.org/10.1016/j.yapd.2017.03.014

[39] American Cancer Society. (2021). After childhood Non-Hodgkin Lymphoma Treatment - Cancer. American Cancer Society. Retrieved May 19, 2022, from https://www.cancer.org/content/dam/CRC/PDF/Public/8727.00.pdf

[40] American Cancer Society. (2018). After wilms tumor treatment - cancer. American Cancer Society. Retrieved May 19, 2022, from https://www.cancer.org/content/dam/CRC/PDF/Public/8882.00.pdf

[41] American Cancer Society. (2018). After hodgkin disease treatment - american cancer society. American Cancer Society. Retrieved May 19, 2022, from https://www.cancer.org/content/dam/CRC/PDF/Public/8653.00.pdf

[42] American Cancer Society. (2018). After treatment for rhabdomyosarcoma - cancer. American Cancer Society. Retrieved May 19, 2022, from https://www.cancer.org/content/dam/CRC/PDF/Public/8807.00.pdf

[43] American Cancer Society. (2018). After treatment for Retinoblastoma - American Cancer Society. American Cancer Society. Retrieved May 20, 2022, from https://www.cancer.org/content/dam/CRC/PDF/Public/8802.00.pdf

[44] American Cancer Society. (2020). After treatment for osteosarcoma - american cancer society. American Cancer Society. Retrieved May 20, 2022, from https://www.cancer.org/content/dam/CRC/PDF/Public/8772.00.pdf

[45] Bitsko, M. J., Cohen, D., Dillon, R., Harvey, J., Krull, K., & Klosky, J. L. (2016). Psychosocial Late Effects in Pediatric Cancer Survivors: A Report From the Children's Oncology Group. Pediatric blood & cancer, 63(2), 337–343. https://doi.org/10.1002/pbc.25773

[46] Advances in pediatrics, 64(1), 133–169. https://doi.org/10.1016/j.yapd.2017.03.014

[47] Ellison, L., & Janz, T. (2015, November 27). Health at a glance. Childhood cancer incidence and mortality in Canada. Retrieved February 1, 2023, from https://www150.statcan.gc.ca/n1/pub/82-624-x/2015001/article/14213eng.htm

[48] Ellison, L. F., Xie, L., & Sung, L. (2021). Trends in paediatric cancer survival in Canada, 1992 to 2017. Health reports, 32(2), 3–15. https://doi.org/10.25318/82-003-x202100200001-eng

[49] American Cancer Society. (2021). Living as a Ewing Tumor Survivor - American cancer society. American Cancer Society. Retrieved May 20, 2022, from https://www.cancer.org/content/dam/CRC/PDF/Public/8623.00.pdf

[50] Martin, D., Miller, A. P., Quesnel-Vallée, A., Caron, N. R., Vissandjée, B., & Marchildon, G. P. (2018). Canada's universal health-care system: achieving its potential. Lancet (London, England), 391(10131), 1718–1735. https://doi.org/10.1016/S0140-6736(18)30181-8

[51] Merriam-Webster. (n.d.). Assimilation. In Merriam-Webster.com dictionary. Retrieved February 2, 2023, from https://www.merriam-webster.com/dictionary/assimilation

[52] Newton, K., Howard, A., Thorne, S., Kelly, M., & Goddard, K. (2020, July 01). Facing the unknown: Uncertain fertility in young adult survivors of childhood cancer. Retrieved from https://pubmed.ncbi.nlm.nih.gov/32613442/

[53] Jardim, F. A., Lopes-Júnior, L. C., Nascimento, L. C., Neves, E. T., & de Lima, R. (2021). Fertility-Related Concerns and Uncertainties in Adolescent and Young Adult Childhood Cancer Survivors. Journal of adolescent and young adult oncology, 10(1), 85–91. https://doi.org/10.1089/jayao.2020.0058

---

[54] Hauken, M., Grue, M., & Dyregrov, A. (2019, September 10). "it's been a life-changing experience!" A qualitative study of young adult cancer survivors' experiences of the coexistence of negative and positive outcomes after cancer treatment. Scandinavian journal of psychology. Retrieved May 25, 2022, from https://pubmed.ncbi.nlm.nih.gov/31503342/

[55] Yi, J., Kim, M. A., Parsons, B. G., & Wu, Y. P. (2018, February 13). Why did I get cancer? perceptions of childhood cancer survivors in Korea. Social work in health care. Retrieved May 25, 2022, from https://pubmed.ncbi.nlm.nih.gov/29436970/

[56] Otth, M., Denzler, S., Koenig, C. et al. Transition from pediatric to adult follow-up care in childhood cancer survivors—a systematic review. J Cancer Surviv 15, 151–162 (2021). https://doi.org/10.1007/s11764-020-00920-9

[57] Brinkman TM, Recklitis CJ, Michel G, et al: Psychological symptoms, social outcomes, socioeconomic attainment, and health behaviors among survivors of childhood cancer: Current state of the literature. J Clin Oncol 36:21902197, 2018 Link, Google Scholar

[58] Belpame, N., Kars, M. C., Deslypere, E., Rober, P., Van Hecke, A., & Verhaeghe, S. (2019). Living as a cancer survivor: A qualitative study on the experiences of Belgian adolescents and young adults (ayas) after childhood cancer. Journal of Pediatric Nursing, 49. https://doi.org/10.1016/j.pedn.2019.07.015

[59] Hong, H. C., Min, A., & Choi, S. (2021). Living with the Late Effects of Childhood Cancer Treatment: A Descriptive Qualitative Study. International journal of environmental research and public health, 18(16), 8392. https://doi.org/10.3390/ijerph18168392

[60] Tonorezos, E. S., Barnea, D., Cohn, R. J., Cypriano, M. S., Fresneau, B. C., Haupt, R., . . . Oeffinger, K. C. (2018, July 20). Models of Care for Survivors of Childhood Cancer From Across the Globe: Advancing Survivorship Care in the Next Decade. Retrieved from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6053299/

[61] Flemming, K., Closs, S. J., Hughes, N. D., & Bennett, M. I. (2016). Using Qualitative Research to Overcome the Shortcomings of Systematic Reviews When Designing of a SelfManagement Intervention for Advanced Cancer Pain. International Journal of Qualitative Methods. https://doi.org/10.1177/1609406916670656

[62] Hudson MM et al. Health status of adult long-term survivors of childhood cancer: a report from the Childhood Cancer Survivor Study. JAMA 290, 1583–92 (2003). [PubMed] [Google Scholar]

[63] Tai E et al. Health status of adolescent and young adult cancer survivors. Cancer 118, 4884–91 (2012). [PMC free article] [PubMed] [Google Scholar]

[64] Rueegg, C. S., Gianinazzi, M. E., Rischewski, J., Beck Popovic, M., von der Weid, N. X., Michel, G., & Kuehni, C. E. (2013). Health-related quality of life in survivors of childhood cancer: the role of chronic health problems. Journal of cancer survivorship : research and practice, 7(4), 511–522. https://doi.org/10.1007/s11764-013-0288-4

[65] Lown, E. A., Hijiya, N., Zhang, N., Srivastava, D. K., Leisenring, W. M., Nathan, P. C., . . . Ness, K. K. (2016, September 01). Patterns and predictors of clustered risky health behaviors among adult survivors of childhood cancer: A report from the Childhood Cancer Survivor Study. Retrieved from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4992459/

[66] Rowland, J., Kent, E., Forsythe, L., Loge, J., Hjorth, L., Glaser, A., Mattioli, V., & Fosså, S. (2013, May 20). Cancer survivorship research in Europe and the United States: Where ... Retrieved May 25, 2022, from https://acsjournals.onlinelibrary.wiley.com/doi/full/10.1002/cncr.28060

[67] Snyder, C., Yuan, C. T., Wilson, R. F., Smith, K., Choi, Y., Nathan, P. C., Zhang, A., & Robinson, K. A. (2022). Models of Care That Include Primary Care for Adult Survivors of Childhood Cancer: A Realist Review. Agency for Healthcare Research and Quality (US).

[68] Scholz-Kreisel, P., Spix, C., Blettner, M., Eckerle, S., Faber, J., Wild, P., Merzenich, H., & Hennewig, U. (2017). Prevalence of cardiovascular late sequelae in long-term survivors of childhood cancer: A systematic review and meta-analysis. Pediatric blood & cancer, 64(7), 10.1002/pbc.26428. https://doi.org/10.1002/pbc.26428

---

[69] Gupta, P., & Jalali, R. (2017). Long-term Survivors of Childhood Brain Tumors: Impact on General Health and Quality of Life. Current neurology and neuroscience reports, 17(12), 99. https://doi.org/10.1007/s11910-017-08080

[70] Van der Plas, E., Spencer Noakes, T. L., Butcher, D. T., Weksberg, R., Galin-Corini, L., Wanstall, E. A., Te, P., Hopf, L., Guger, S., Spiegler, B. J., Hitzler, J., Schachar, R. J., Ito, S., & Nieman, B. J. (2020). Quantitative MRI outcomes in child and adolescent leukemia survivors: Evidence for global alterations in gray and white matter. NeuroImage. Clinical, 28, 102428. https://doi.org/10.1016/j.nicl.2020.102428

[71] Ikonomidou C. (2018). Chemotherapy and the pediatric brain. Molecular and cellular pediatrics, 5(1), 8. https://doi.org/10.1186/s40348-018-0087-0

[72] Van der Plas, E., Nieman, B. J., Butcher, D. T., Hitzler, J. K., Weksberg, R., Ito, S., & Schachar, R. (2015). Neurocognitive Late Effects of Chemotherapy in Survivors of Acute Lymphoblastic Leukemia: Focus on Methotrexate. Journal of the Canadian Academy of Child and Adolescent Psychiatry = Journal de l'Academie canadienne de psychiatrie de l'enfant et de l'adolescent, 24(1), 25–32.

[73] Barr, R. D., Inglis, D., Athale, U., Jaworski, M., Farncombe, T., & Gordon, C. L. (2021). Bone health in long-term survivors of pediatric acute lymphoblastic leukemia. An assessment by peripheral quantitative computed tomography. Pediatric blood & cancer, 68(12), e29218. https://doi.org/10.1002/pbc.29218

[74] Petersen, N. N., Hansson, H., Lie, H. C., Brinkkjær, M., Graungaard, B., Larsen, M. H., Larsen, E. H., Schmiegelow, K., & Fridh, M. K. (2021, October 12). A qualitative study of young childhood cancer survivors and their parents' experiences with treatment-related late effects in everyday life post-treatment. Journal of advanced nursing. Retrieved May 24, 2022, from https://pubmed.ncbi.nlm.nih.gov/34636441/

[75] Peikert, M., Inhestern, L., Krauth, K., Escherich, G., Rutkowski, S., Kandels, D., & Bergelt, C. (2020). Returning to daily life: A qualitative interview study on parents of childhood cancer survivors in Germany. BMJ open. Retrieved May 24, 2022, from https://pubmed.ncbi.nlm.nih.gov/32152163/

[76] Beeler, D., Paré-Blagoev, E.J., Jacobson, L.A. et al. Educating Childhood Cancer Survivors: a Qualitative Analysis of Parents Mobilizing Social and Cultural Capital. J Canc Educ 36, 819– 825 (2021). https://doiorg.uproxy.library.dc-uoit.ca/10.1007/s13187-020-01709-1

[77] Brown, M. C., Pearce, M. S., Bailey, S., & Skinner, R. (2015, September 22). The longterm psychosocial impact of cancer: The views of young adult ... Retrieved May 25, 2022, from https://onlinelibrary.wiley.com/doi/10.1111/ecc.12380

[78] Kim, Y., Lee, K.-S., & Koh, K.-N. (2018, September 22). Difficulties faced by long-term childhood cancer survivors: A qualitative study. European journal of oncology nursing : the official journal of European Oncology Nursing Society. Retrieved May 25, 2022, from https://pubmed.ncbi.nlm.nih.gov/30322503/

[79] Sadak, K. T., Gemeda, M. T., Grafelman, M., Neglia, J. P., Freyer, D. R., Harwood, E., & Mikal, J. (2020). Identifying metrics of success for transitional care practices in childhood cancer survivorship: a qualitative interview study of survivors. BMC cancer, 20(1), 898. https://doi.org/10.1186/s12885-020-07360-9

[80] Belpame, N., Kars, M. C., Deslypere, E., Rober, P., Van Hecke, A., & Verhaeghe, S. (2021). Coping Strategies of Adolescent and Young Adult Survivors of Childhood Cancer: A Qualitative Study. Cancer nursing, 44(6), E395–E403. https://doi.org/10.1097/NCC.0000000000000865

[81] Nahata, L., Morgan, T. L., Lipak, K. G., Olshefski, R. S., Gerhardt, C. A., & Lehmann, V. (2020, June 8). Romantic relationships and physical intimacy among survivors of childhood cancer. Journal of adolescent and young adult oncology. Retrieved May 25, 2022, from https://pubmed.ncbi.nlm.nih.gov/32091940/

[82] Geue K, Schmidt R, Sender A, et al.. Sexuality and romantic relationships in young adult cancer survivors: satisfaction and supportive care needs. Psychooncology. 2015;24(11):1368–76 [PubMed] [Google Scholar] [Ref list] [83] Brown, M. C., Pearce, M. S., Bailey, S., & Skinner, R. (2015, September 22). The longterm psychosocial impact of cancer: The views of young adult ... Retrieved May 25, 2022, from https://onlinelibrary.wiley.com/doi/10.1111/ecc.12380

---

[84] Howard, A. F., Kazanjian, A., Pritchard, S., Olson, R., Hasan, H., Newton, K., & Goddard, K. (2018). Healthcare system barriers to long-term follow-up for adult survivors of childhood cancer in British Columbia, Canada: a qualitative study. Journal of cancer survivorship : research and practice, 12(3), 277–290. https://doi.org/10.1007/s11764-017-0667-3

[85] Maule, M., Zugna, D., Migliore, E., Alessi, D., Merletti, F., Onorati, R., . . . Spadea, T. (2017, July 26). Surviving a childhood cancer: Impact on education and employment. European journal of cancer prevention : the official journal of the European Cancer Prevention Organisation (ECP), 26(4), 351–356. https://doi.org/10.1097/CEJ.0000000000000258

[86] White, J., Park, J., Russell, K. B., Reynolds, K. A., Madani, A., Carlson, L. E., & GieseDavis, J. (2018). Falling through the cracks. A thematic evaluation of unmet needs of adult survivors of childhood cancers. Psycho-oncology, 27(8), 1979–1986. https://doi.org/10.1002/pon.4754

[87] Maurice-Stam, H., van Erp, L. M. E., Maas, A., van Oers, H. A., Kremer, L. C. M., van Dulmenden Broeder, E., Tissing, W. J. E., Loonen, J. J., van der Pal, H. J. H., Beek, L. R., de Vries, A. C. H., van den Heuvel-Eibrink, M. M., Ronckers, C. M., Bresters, D., Louwerens, M., van der Heiden-van der Loo, M., Huizinga, G. A., Grootenhuis, M. A., & Dutch LATER study group (2022). Psychosocial developmental milestones of young adult survivors of childhood cancer. Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer, 30(8), 6839–6849. https://doi.org/10.1007/s00520-022-07113-3

[88] White, J., Park, J., Russell, K. B., Reynolds, K. A., Madani, A., Carlson, L. E., & GieseDavis, J. (2018). Falling through the cracks. A thematic evaluation of unmet needs of adult survivors of childhood cancers. Psycho-oncology, 27(8), 1979–1986. https://doi.org/10.1002/pon.4754

[89] Nandakumar, B.S., Fardell, J.E., Wakefield, C.E. et al. Attitudes and experiences of childhood cancer survivors transitioning from pediatric care to adult care. Support Care Cancer 26, 2743–2750 (2018). https://doi.org/10.1007/s00520-018-4077-5

[90] Landier, W., Skinner, R., Wallace, W. H., Hjorth, L., Mulder, R. L., Wong, F. L., Yasui, Y., Bhakta, N., Constine, L. S., Bhatia, S., Kremer, L. C., & Hudson, M. M. (2018). Surveillance for Late Effects in Childhood Cancer Survivors. Journal of clinical oncology : official journal of the American Society of Clinical Oncology, 36(21), 2216–2222. https://doi.org/10.1200/JCO.2017.77.0180

[91] Anestin, A., Lippé, S., Robaey, P., Bertout, L., Drouin, S., Krajinovic, M., . . . Sultan, S. (2018, August 07). Psychological risk in long-term survivors of childhood acute lymphoblastic leukemia and its association with functional health status: A PETALE cohort study. Pediatric Blood Cancer, Volume 65 (11). https://doi.org/10.1002/pbc.27356

[92] Wroot H, Afzal AR, Forbes C, et al. Fear of cancer recurrence among survivors of childhood cancer. Psycho Oncol. 2020;29(7):1132–1140. https://doi-org.uproxy.library.dcuoit.ca/10.1002/pon.5387.

[93] Erdmann, F., Feychting, M., Mogensen, H., Schmiegelow, K., & Zeeb, H. (2019). Social inequalities along the childhood cancer continuum: An overview of evidence and a conceptual framework to identify underlying mechanisms and pathways. Frontiers in Public Health, 7. https://doi.org/10.3389/fpubh.2019.00084

[94] Marina N, Hudson MM, Jones KE, et al. Changes in Health Status Among Aging Survivors of Pediatric Upper and Lower Extremity Sarcoma: A Report From the Childhood Cancer Survivor Study. Archives of Physical Medicine and Rehabilitation. 2013;94(6):1062–1073. [PMC free article] [PubMed] [Google Scholar] [Ref list]

[95] Peikert, M., Inhestern, L., Krauth, K., Escherich, G., Rutkowski, S., Kandels, D., & Bergelt, C. (2020). Returning to daily life: A qualitative interview study on parents of childhood cancer survivors in Germany. BMJ open. Retrieved May 24, 2022, from https://pubmed.ncbi.nlm.nih.gov/32152163/

[96] Recklitis CJ, Liptak C, Footer D, Fine E, Chordas C, Manley P. Prevalence and Correlates of Pain in Adolescent and Young Adult Survivors of Pediatric Brain Tumors. J Adolesc Young Adult Oncol. 2019. [PubMed] [Google Scholar] [Ref list]

[97] Lang, M. J., David, V., & Giese-Davis, J. (2015). The Age Conundrum: A Scoping Review of Younger Age or Adolescent and Young Adult as a Risk Factor for Clinical Distress, Depression, or Anxiety in Cancer. Journal of adolescent and young adult oncology, 4(4), 157–173. https://doi.org/10.1089/jayao.2015.0005

---

[98] Alessi D, Dama E, Barr R, et al. Health-related quality of life of long-term childhood cancer survivors: a population-based study from the Childhood Cancer Registry of Piedmont, Italy. Eur J Cancer. 2007;43(17):2545–2552. [PubMed] [Google Scholar] [Ref list]

[99] Moser, A., & Korstjens, I. (2018). Series: Practical guidance to qualitative research. Part 3: Sampling, data collection and analysis. The European journal of general practice, 24(1), 9–18. https://doi.org/10.1080/13814788.2017.1375091

[100] Uematsu, A., Matsui, M., Tanaka, C., Takahashi, T., Noguchi, K., Suzuki, M., & Nishijo, H. (2012).

Developmental trajectories of amygdala and hippocampus from infancy to early adulthood in healthy individuals. PloS one, 7(10), e46970. https://doi.org/10.1371/journal.pone.0046970

[101] Lopez, K. A., & Willis, D. G. (2004). Descriptive versus interpretive phenomenology: their contributions to nursing knowledge. Qualitative health research, 14(5), 726–735. https://doi.org/10.1177/1049732304263638

[102] Ellis P (2016) Understanding research for Nursing Students (3rd edn). Sage Publications, London

[103] McFadyen, J., & Rankin, J. (2016, October 1). The role of gatekeepers in research: Learning from reflexivity and Reflection. GSTF Journal of Nursing and Health Care (JNHC). Retrieved June 1, 2022, from http://dl6.globalstf.org/index.php/jnhc/article/view/1745

[104]Andoh-Arthur, J. (2019). Gatekeepers in qualitative research. Sage Research Methods. Retrieved June 1, 2022, from https://dx.doi.org/10.4135/9781526421036854377

[105] Erdmann, F., Feychting, M., Mogensen, H., Schmiegelow, K., & Zeeb, H. (2019). Social inequalities along the childhood cancer continuum: An overview of evidence and a conceptual framework to identify underlying mechanisms and pathways. Frontiers in Public Health, 7. https://doi.org/10.3389/fpubh.2019.00084

[106] Tsonis, M., McDougall, J., Mandich, A., & Irwin, J. (2012). Interrelated Processes toward

Quality of Life in Survivors of Childhood Cancer: A Grounded Theory. The Qualitative Report, 17(45), 1-18. https://doi.org/ 10.46743/2160-3715/2012.1709

[107] Alase, A. (2017). The interpretative phenomenological analysis (IPA): A guide to a good qualitative research approach. International Journal of Education and Literacy Studies, 5(2), 9. https://doi.org/10.7575/aiac.ijels.v.5n.2p.9

[108] Ortlipp, M. (2008). Keeping and Using Reflective Journals in the Qualitative Research

Process. The Qualitative Report, 13(4), 695-705. https://doi.org/10.46743/2160-3715/2008.1579

[109] Smith, J. A., & Osborn, M. (2015). Interpretative phenomenological analysis as a useful methodology for research on the lived experience of pain. British journal of pain, 9(1), 41–42.

https://doi.org/10.1177/2049463714541642

[110] Lincoln, Y. S., & Guba, E. G. (2000). Paradigmatic controversies, contradictions, and emerging confluences. In N. K. Denzin & Y. S. Lincoln (Eds.), The handbook of qualitative research (2nd ed., pp. 163–188). Beverly Hills, CA: Sage.

[111] Iivari, N. (2018). Using member checking in interpretive research practice. Information Technology & People, 31(1), 111-133. doi:http://dx.doi.org.uproxy.library.dcuoit.ca/10.1108/ITP-07-2016-0168

[112] Morrow, S. L. (2007). Qualitative Research in Counseling Psychology: Conceptual Foundations. The Counseling Psychologist, 35(2), 209–235. https://doi.org/10.1177/0011000006286990

[113] Van Erp, L., Maurice-Stam, H., Kremer, L., Tissing, W., van der Pal, H., de Vries, A., van den Heuvel-Eibrink, M. M., Versluys, B., van der Heiden-van der Loo, M., Huizinga, G. A., & Grootenhuis, M. A. (2021). A vulnerable age group: the impact of cancer on the psychosocial well-being of young adult childhood cancer survivors.

Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer, 29(8), 4751–4761. https://doi.org/10.1007/s00520-021-06009-y

[114] Zebrack BJ, Landier W. The perceived impact of cancer on quality of life for post-treatment survivors of childhood cancer. Qual Life Res. 2011;20(10):1595–1608. [PubMed] [Google Scholar]

---

[115] Tremolada, M., Taverna, L., Bonichini, S., Basso, G., & Pillon, M. (2017). Self-Esteem and Academic Difficulties in Preadolescents and Adolescents Healed from Paediatric Leukaemia. Cancers, 9(6), 55. https://doi.org/10.3390/cancers9060055

[116] Dattilo, T. M., Olshefski, R. S., Nahata, L., Hansen-Moore, J. A., Gerhardt, C. A., & Lehmann, V. (2021). Growing up after childhood cancer: maturity and life satisfaction in young adulthood. Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer, 29(11), 6661–6668. https://doi.org/10.1007/s00520-021-06260-3

[117] Anthony SJ, Robertson T, Selkirk E, Dix D, Klaassen RJ, Sung L, Klassen AF. The social impact of early psychological maturity in adolescents with cancer. Psychooncology. 2019;28(3):586–592. doi: 10.1002/pon.4982

[118] Valizadeh, L., Zamanzadeh, V., Ghahremanian, A., Musavi, S., Akbarbegloo, M., & Chou, F. Y. (2019). Experience of Adolescent Survivors of Childhood Cancer about Self-Care Needs: A Content Analysis. Asia-Pacific journal of oncology nursing, 7(1), 72–80. https://doi.org/10.4103/apjon.apjon_47_19

[119] Larsen, M. H., Hansson, K. E., Larsen, E. H., Fridh, M. K., Petersen, N. N., Mellblom, A. V., Ruud, E., Larsen, H. B., & Lie, H. C. (2022). The gap between expectations and reality: A qualitative study of psychosocial challenges of young childhood cancer survivors from the PACCS study. European journal of cancer care, 31(6), e13696. https://doi.org/10.1111/ecc.13696

[120] Levine, D. R., Liederbach, E., Johnson, L. M., Kaye, E. C., Spraker-Perlman, H., Mandrell, B., Pritchard, M., Sykes, A., Lu, Z., Wendler, D., & Baker, J. N. (2019). Are we meeting the informational needs of cancer patients and families? Perception of physician communication in pediatric oncology. Cancer, 125(9), 1518–1526. https://doi.org/10.1002/cncr.31937

[121] Gianinazzi, M. E., Kiserud, C. E., Ruud, E., & Lie, H. C. (2022). Who knows? information received, and knowledge about, cancer, treatment and late effects in a national cohort of longterm childhood, adolescent and Young Adult Cancer Survivors. Cancers, 14(6), 1534. https://doi.org/10.3390/cancers14061534

[122] Howard, A. F., Goddard, K., Tan de Bibiana, J., Pritchard, S., Olson, R., & Kazanjian, A. (2016). Adult childhood cancer survivors' narratives of managing their health: the unexpected and the unresolved. Journal of cancer survivorship : research and practice, 10(4), 711–725. https://doi.org/10.1007/s11764-016-0517-8

[123] Cox, C. L., Zhu, L., Ojha, R. P., Li, C., Srivastava, D. K., Riley, B. B., Hudson, M. M., & Robison, L. L. (2016). The unmet emotional, care/support, and informational needs of adult survivors of pediatric malignancies. Journal of cancer survivorship : research and practice, 10(4), 743–758. https://doi.org/10.1007/s11764-016-0520-0

[124] Liptak C, Chow C, Zhou E, Recklitis C. Psychosocial care for pediatric cancer survivors. In: Abrams AN , Muriel AC , Wiener L , eds. Pediatric psychosocial oncology: Textbook for multidisciplinary care. Cham: Springer; 2016:265-279.

[125] Weinstein, A. G., Henrich, C. C., Armstrong, G. T., Stratton, K. L., King, T. Z., Leisenring, W. M., & Krull, K. R. (2018). Roles of positive psychological outcomes in future health perception and mental health problems: A report from the Childhood Cancer Survivor Study. Psycho-oncology, 27(12), 2754–2760. https://doi.org/10.1002/pon.4881

[126] Bender, J. L., Puri, N., Salih, S., D'Agostino, N. M., Tsimicalis, A., Howard, A. F., Garland, S. N., Chalifour, K., Drake, E. K., Marrato, A., McKean, N. L., & Gupta, A. A. (2022). Peer Support Needs and Preferences for Digital Peer Navigation among Adolescent and Young Adults with Cancer: A Canadian CrossSectional Survey. Current oncology (Toronto, Ont.), 29(2), 1163–1175. https://doi.org/10.3390/curroncol29020099

[127] Bender J. Chapter 3: Cancer Virtual Communities in the Era of Personalized Medicine: Perspectives on Scope, Use and Impact. In: El Morr C., editor. Novel Applications of Virtual Communities in Healthcare Settings. IGI Global; Hershey, PA, USA: 2018. pp. 56–92. [Google Scholar] [Ref list]

[128] Bender J.L., Katz J., Ferris L.E., Jadad A.R. What is the role of online support from the perspective of facilitators of face-to-face support groups? A multi-method study of the use of breast cancer online communities. Patient Educ. Couns. 2013;93:472–479. doi: 10.1016/j.pec.2013.07.009. [PubMed] [CrossRef] [Google Scholar] [Ref list]

---

[129] Nilsson, S., Segerstad, Y. H. A., & Olsson, M. (2022). Visualizing the Invisible-The Needs and Wishes of Childhood Cancer Survivors for Digitally Mediated Emotional Peer Support. Current oncology (Toronto, Ont.), 29(2), 1269–1278. https://doi.org/10.3390/curroncol29020108

[130] Zürcher, S. J., Jung, R., Monnerat, S., Schindera, C., Eser, P., Meier, C., Rueegg, C. S., von der Weid, N. X., & Kriemler, S. (2020). High impact physical activity and bone health of lower extremities in childhood cancer survivors: A cross-sectional study of SURfit. International journal of cancer, 147(7), 1845–1854. https://doi.org/10.1002/ijc.32963

[131] Coven, S. L., Bibart, M., Frost, R., Gallagher, T., Guinipero, T., Valasek, A. E., & Olshefski, R. (2019). A Quality Improvement Approach to Increase Exercise Assessment in Survivors of Childhood Leukemia. Pediatric quality & safety, 4(4), e198. https://doi.org/10.1097/pq9.0000000000000198

[132] Lambert, G., Alos, N., Bernier, P., Laverdière, C., Kairy, D., Drummond, K., Dahan-Oliel, N.,
Lemay, M., & Veilleux, L. N. (2021). Home-Based Telehealth Exercise Intervention in Early-On Survivors of Childhood Acute Lymphoblastic Leukemia: Feasibility Study. JMIR cancer, 7(2), e25569. https://doi.org/10.2196/25569

[133] Ha, L., Wakefield, C. E., Mizrahi, D., Diaz, C., Cohn, R. J., Signorelli, C., Yacef, K., &
Simar, D. (2022). A Digital Educational Intervention With Wearable Activity Trackers to
Support Health Behaviors Among Childhood Cancer Survivors: Pilot Feasibility and Acceptability Study. JMIR cancer, 8(3), e38367. https://doi.org/10.2196/38367

[134] Hendricks, M. J., Harju, E., & Michel, G. (2020, November 20). The unmet needs of childhood cancer survivors in long-term follow-up care: A qualitative study. Wiley Online Library. Retrieved October 17, 2022, from https://doi-org.uproxy.library.dcuoit.ca/10.1002/pon.5593

[135] King-Dowling, S., Psihogios, A. M., Hill-Kayser, C., Szalda, D., O'Hagan, B., Darabos, K.,
Daniel, L. C., Barakat, L. P., Fleisher, L., Maurer, L. A., Velázquez-Martin, B., Jacobs, L. A., Hobbie, W., Ginsberg, J. P., Vachani, C. C., Metz, J. M., & Schwartz, L. A. (2021). Acceptability and feasibility of survivorship care plans and an accompanying mobile health intervention for adolescent and young adult survivors of childhood cancer. Pediatric blood & cancer, 68(3), e28884. https://doi.org/10.1002/pbc.28884

[136] Linge, H. M., & Follin, C. (2021). Mixed methods assessment of impact on health awareness in adult childhood cancer survivors after viewing their personalized digital treatment summary and follow-up recommendations. BMC cancer, 21(1), 347. https://doi.org/10.1186/s12885-02108051-9

[137] Cheng, L., Liu, F., Mao, X., Peng, W., Wang, Y., Huang, H., Duan, M., Wang, Y., & Yuan, C. (2022). The Pediatric Cancer Survivors' User Experiences With Digital Health Interventions:
A Systematic Review of Qualitative Data. Cancer nursing, 45(1), E68–E82.
https://doi.org/10.1097/NCC.0000000000000885

[138] McFadyen, J., & Rankin, J. (2016, October 1). The role of gatekeepers in research: Learning from reflexivity and Reflection. GSTF Journal of Nursing and Health Care (JNHC). Retrieved June 1, 2022, from http://dl6.globalstf.org/index.php/jnhc/article/view/1745

[139] Creswell, J. W. (2013). Qualitative Inquiry and research design choosing among five approaches (3rd Ed). Thousand Oaks, CA: Sage Publications.

[140] Hulbert-Williams, N. J., Pendrous, R., Hulbert-Williams, L., & Swash, B. (2019). Recruiting cancer survivors into research studies using online methods: a secondary analysis from an international cancer survivorship cohort study. Ecancermedicalscience, 13, 990. https://doi.org/10.3332/ecancer.2019.990

[141] Canadian Institute for Health Information. National Health Expenditure Trends, 1975 to 2019. Ottawa, ON: CIHI; 2019.

[142] Gray, L. M., Wong-Wylie, G., Rempel, G. R., & Cook, K. (2020). Expanding Qualitative
Research Interviewing Strategies: Zoom Video Communications. The Qualitative Report, 25(5), 1292-1301. Retrieved from https://nsuworks.nova.edu/tqr/vol25/iss5/9

[143] Fox, L., Wylie, H., Haire, A., Green, S., Kibaru, J., & Van Hemelrijck, M. (2021).

"Something Good Has to Come Out of the Horror": A Qualitative Examination of Cancer
Survivors' Attitudes Towards Participation in Research During the First Year of the COVID-19 Pandemic. Frontiers in public health, 9, 741188. https://doi.org/10.3389/fpubh.2021.741188

[144] De Oliveira, C., Bremner, K. E., Liu, N., Greenberg, M. L., Nathan, P. C., McBride, M. L., & Krahn, M. D. (2017). Costs for childhood and adolescent cancer, 90 days Prediagnosis and 1 year postdiagnosis: A populationbased study in Ontario, Canada. Value in Health, 20(3), 345– 356. https://doi.org/10.1016/j.jval.2016.10.010

[145] Mullen, C.J.R., Barr, R.D. & Franco, E.L. Timeliness of diagnosis and treatment: the challenge of childhood cancers. Br J Cancer 125, 1612–1620 (2021). https://doiorg.uproxy.library.dc-uoit.ca/10.1038/s41416-021-01533-4

[146] Ristovski-Slijepcevic, S., Barr, R., Bernstein, M., & Nathan, P. C. (2009). A cross-Canada survey of clinical programs for the care of survivors of cancer in childhood and adolescence. Paediatrics & child health, 14(6), 375–378.

[147] Recklitis, C. J., & Syrjala, K. L. (2017). Provision of integrated psychosocial services for cancer survivors posttreatment. The Lancet. Oncology, 18(1), e39–e50. https://doi.org/10.1016/S1470-2045(16)30659-3