

2016

What Lies Past Remission: The Perceived Late Effects of Pediatric Cancer

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What Lies Past Remission: The Perceived Late Effects of Pediatric Cancer

by

Monica L. Molinaro

Wilfrid Laurier University, 2016

THESIS

Submitted to the Department of Kinesiology and Physical Education

in partial fulfillment of the requirements for

Master of Science in Kinesiology

Wilfrid Laurier University

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Acknowledgements

I never truly understood the phrase “put your heart and soul into it” until I began this research. It consumes you. It becomes so personal – your participants have trusted you with stories of one of the most difficult times of their lives, in the hopes that your work can help and inspire others.

I never would have been able to do this without the help of my supervisor, Dr. Paula Fletcher. She makes me strive for an eighth of the compassion that she has. Without her unwavering support and belief in me, I could never have taken on and completed research of this scope. The infinite number of hours she dedicated to reading, editing, and listening to all things academic and personal are the reason why this document exists, and why I’d like to believe that after these last two years, I have become a much, much better person. You’re the best, Paula.

To my advisory committee, Drs. Michael Cinelli and Robb Travers – thank you for sharing with me your perspectives and stories. Your support, patience, and willingness to help me in any way you could throughout the progression of my research was tremendously appreciated, and I am beyond grateful. Thank you for being so confident in me.

To my parents, family and friends – thank you for your unconditional patience and love. Thank you for listening to me for countless hours about how stressed, confused, or tired I was, and for never making me feel ridiculous for feeling that way. Thank you for always motivating me to be my best, when I may have been acting like the worst. I can’t thank you enough, ever.

And, lastly, to my participants – a paragraph on an acknowledgements page will never be enough to thank you for sharing with me your stories, positivity, and love for life. You are some of the bravest, kindhearted, and passionate people I have ever met. Over the last two years, this became my heart and soul - I hope my words do yours justice.

Abstract

Objective

Pediatric cancer survival rates are increasing (Childhood Cancer Canada Foundation, 2011) and with this, so are the late effects of pediatric cancer (Oeffinger et al., 2006). This research examines the lived experiences of the perceived long-term effects of pediatric cancer on adult survivors and their primary support persons in order to understand the multifaceted nature of the illness on adults, and how it affects others close to them.

Methods

The theoretical orientation used to guide the research was phenomenology in order to present an accurate depiction of all the participants' lived experiences. Specifically, background questionnaires were administered and one-on-one semi-structured interviews were completed and transcribed verbatim for subsequent data analysis. Field notes, member checks, and triangulation were used to enhance the credibility of the study.

Results

From the analysis four themes emerged: (1) "There wasn't a lot of time to sit and think.": The Pediatric Cancer Experience, (2) "There is no before cancer...there's only cancer."; (3) "I don't know if I would change it."; and (4) "As long as you need me I'm yours.". All participants recognized that there were both negative and positive aspects to life after a pediatric cancer experience.

Conclusions

Overall, this study provides knowledge on how undergoing pediatric cancer changes survivors, subsequently affecting them and their primary support persons for their lives. Their stories can provide strength and comfort for individuals undergoing, or caring for an individual undergoing a pediatric cancer diagnosis and treatment.

TABLE OF CONTENTS

Chapter 1: Review of the literature

1.1 Introduction.....	1
1.2 Magnitude of Problem	2
1.3 Treatment	4
1.4 Short-Term Effects of Cancer Treatment on Children	5
1.5 Long-Term Effects of Cancer Treatment on Children.....	6
1.6 The Familial Perspective.....	14
1.7 Short Term Familial Effects.....	15
1.8 Negative Long-Term Effects	16
1.9 Positive Long-Term Effects	19
1.10 Research Purpose	22

Chapter 2: Methodology

2.1 Participants.....	23
2.2 Research Tools.....	24
2.3 Trustworthiness: Credibility, Transferability, and Confirmability	29
2.4 Data Treatment.....	31

Chapter 3: Results

3.1 Introduction to Participants.....	34
3.2 Themes	38
3.3 “There wasn’t a lot of time to sit and think.”: The Pediatric Cancer Experience.....	40
3.4 “There is no before cancer...there’s only cancer.”	45
3.5 “I don’t know if I would change it.”	59
3.6 “As long as you need me I’m yours.”	68
3.7“ Summary	74

Chapter 4: Discussion

4.1 Comparison to Previous Literature	75
4.2 Limitations	85
4.3 Implications.....	86
4.4 Future Directions	89
4.5 Conclusion	90

References and Appendices

References.....	91
Appendix A.....	96
Appendix B	97
Appendix C	99
Appendix D.....	111
Appendix E	112
Appendix F.....	113
Appendix G.....	114

CHAPTER 1: REVIEW OF THE LITERATURE

1.1 INTRODUCTION

Pediatric cancer, while uncommon, is a devastating illness for children and their families. The impact of cancer and its treatment are overwhelming - the effects are multifaceted and felt by the entire family unit throughout the diagnosis and treatment process. Survival rates have increased (Childhood Cancer Canada Foundation, 2011; Canadian Cancer Society, 2008; Oeffinger et al., 2006; Yi et al., 2014); however, the increased rates of survival have led to increases in the late effects of cancer treatment (Dieluweit et al., 2010; Geenen et al., 2007; Oeffinger et al., 2006; Yi et al., 2014). Research has begun to address the severity of the late effects of cancer, such as growth issues and infertility (Geenen et al., 2007, Yi et al., 2014), on the pediatric cancer survivor and family members, yet gaps in the literature exist. This research examines the lived experiences of the perceived long-term effects of pediatric cancer on the adult survivor and their primary support person in order to understand the multifaceted nature of the illness on the adult, as well as others close to them. To fulfill this purpose, the methodology being used is qualitative in nature, as qualitative methods allow for a more holistic understanding of a particular experience or phenomenon (Patton, 2002). Specifically, the theoretical approach chosen was phenomenology. To truly convey the nature of the phenomenon, interviews were conducted with both individuals who had pediatric cancer, as well as their primary support persons. These interviews allowed for a widely encompassing perspective into understanding how late effects may affect survivors of pediatric cancer. Implications for this research include the development of support services and networks for individuals with pediatric cancer and their families for what to expect past remission.

1.2 MAGNITUDE OF PROBLEM

1.2.1 Definition

Pediatric cancer, otherwise referred to as *childhood cancer* (American Society of Clinical Oncology, 2014; Childhood Cancer Canada Foundation, 2011; Oeffinger et al., 2006; Yi et al., 2014) is a term used to describe a multitude of cancers or tumors that occur in children (Buka, 2009). Depending on the type of literature, the term *pediatric* is used to identify individuals between the ages of 0 to 14 (Bray, 2009; Buka, 2009; Canadian Cancer Society, 2008; Canadian Cancer Society, 2014; Childhood Cancer Canada Foundation, 2011; Dockerty, Skegg, and Williams, 2003), and the term adolescent is used to describe individuals between the ages of 15 to 19 (American Society of Clinical Oncology, 2014; Bray, 2009; Buka, 2009; Canadian Cancer Society, 2008). However, often in the literature, the term *pediatric* may encompass both children and adolescents (Bray, 2009; Buka, 2009; Canadian Cancer Society, 2008; Nolan et al., 2014; Yi et al., 2014). Adolescents, while still receiving treatment and medical consultations at pediatric-specialized centers and hospitals, can also be assisted by non-pediatric oncologists because they are in critical development stages in their lives (American Society of Clinical Oncology, 2014; Oeffinger et al., 2006; Yi et al., 2014). In this paper, the term *pediatric* will refer to individuals aged 0 to 19 unless otherwise specified. This is because Canadian and American cancer databases and literature have recently begun referring to pediatric cancer as the amalgamation of the child and adolescent age groups (Canadian Institutes of Health Research, 2014; National Cancer Institute, 2015; Public Health Agency of Canada, 2013).

1.2.2 Pediatric Cancer Statistics

Worldwide, 160,000 cases of childhood cancer are diagnosed per year, and pediatric cancer accounts for approximately 90,000 deaths per year of children under the age of 15 (Buka,

2009). In Canada, roughly 1500 cases of childhood cancer are diagnosed each year (Childhood Cancer Canada Foundation, 2011), and that number has remained relatively constant since 1985 (Canadian Cancer Society, 2008). Childhood cancer accounts for less than 1% of all cancers diagnosed in Canada (Canadian Cancer Society, 2015). In the year 2014, there were 160 total deaths due to cancer of individuals between the ages of 0 to 19 (85 for males and 75 for females) (Canadian Cancer Society, 2014). However, it is important to note that pediatric cancer currently has a five-year survival rate of 80% (Childhood Cancer Canada Foundation, 2011; Yi et al., 2014). Morbidity from pediatric cancer is the lowest it has ever been, yet, it still accounts for the highest number of deaths of individuals between the ages of 0 to 19 in Canada per year – greater than the number of deaths of children from asthma, cystic fibrosis, diabetes, and AIDS combined (Childhood Cancer Canada Foundation, 2011).

1.2.3 How pediatric cancer differs from adult cancers

There are multiple forms of childhood cancers. Those that are commonly diagnosed in children differ from adult cancers in where they originate in the body, as well as the way they grow (American Society of Clinical Oncology, 2014; Canadian Cancer Society, 2008). It has been shown that different forms of leukemia (particularly lymphoid and acute myeloid leukemia), as well as tumors in the brain, nervous and lymphatic system, kidneys, muscles, and bones are the most common forms of cancer in children (Buka, 2009; Childhood Cancer Canada Foundation, 2011). The tumors found in children are generally more aggressive than those in adults, as they have shorter development times and metastasize to other parts of the body very quickly – potentially due to genetic mutations that lead to un-controlled and un-differentiated cell growth (Canadian Cancer Society, 2008; Canadian Cancer Society, 2014; National Cancer

Institute, 2015). However, due to the infrequency of occurrence of childhood cancer, it is difficult to determine the precise cause.

Almost all childhood cancers (75-90%) have no known cause. Very few cases of childhood cancers can be attributed to genetic factors (between 5-15%) and even less so to environmental and external factors (<5-10%) (Buka, 2009). What is known about the prevalence of childhood cancer is that children aged 0 to 4 years have the highest incidence of cancer, and that for every female diagnosed, there are 1.2 males who have been diagnosed (Canadian Cancer Society, 2008). Pediatric cancer treatment is dependent on the type of cancer.

1.3 TREATMENT

1.3.1 Treatment Types and Methods

There are three commonly known methods of treating pediatric cancer that can be used separately or in conjunction with one another, depending on the type of cancer that is diagnosed (Canadian Cancer Society, 2008; Childhood Cancer Canada Foundation, 2011; Miller, 2002). First, there is surgery, which is used to completely or partially remove tumors, as well as complete biopsies to determine the type of treatment to be used. Surgery is most commonly used in conjunction with other treatments, as surgery alone often cannot remove entire tumors or cancers that have spread to different parts of the body (Childhood Cancer Canada Foundation, 2011). The next, and most commonly known type of pediatric cancer treatment is chemotherapy, which is the use of a single drug or combination of drugs to kill cancer cells either orally or, more commonly, intravenously (Childhood Cancer Foundation of Canada, 2011; Miller, 2002). Depending on the type of cancer and severity of the diagnosis, the frequency and dosage of chemotherapy differs for all children (Childhood Cancer Canada Foundation, 2011; Canadian Cancer Society, 2008). Lastly, radiation therapy, or radiotherapy, is a series of radiation rays

targeted at specific cancer sites in the body to eliminate or stop rapidly growing cells. It is often used alone but can also be used in conjunction with chemotherapy or surgery depending on the type of cancer diagnosed (Canadian Cancer Society, 2008; Childhood Cancer Canada Foundation, 2011). Once the particular type of treatment is chosen, the length of treatment will also be determined.

1.3.2 Stages of Treatment

Treatment length is dependent on a myriad of factors and can last from months to years; however, all children diagnosed go through the same three stages of treatment: (1) induction, (2) maintenance/remission, and (3) completion of therapy. Induction is known as the intensive stage of therapy. The aim of this stage is to kill as many cancer cells in as short of a time as possible by administering many bouts of treatment. The maintenance stage occurs when no cancer cells are present, or when children are in remission, and includes maintenance therapies that are not as intensive as those used in induction. Once maintenance therapy has ended, children are in the completion stage, meaning that they are considered healthy but still must go for regular check ups with their general practitioner or pediatrician (Childhood Cancer Foundation Canada, 2011). In Canada, if children remain healthy and in remission for five years, they are considered “cancer free” (Canadian Cancer Society, 2008; Childhood Cancer Canada Foundation, 2011). However, treatment and remission do not go without their short- and long-term effects. These effects will be addressed in the next sections.

1.4 SHORT-TERM EFFECTS OF CANCER TREATMENT ON CHILDREN

1.4.1 Signs and Symptoms

While undergoing treatment, children may experience short-term cancer effects that may last throughout the period of treatment, as well as a few months after the treatment. These effects

may eventually disappear. Short-term cancer effects may occur at the onset of treatment and may include alopecia (also known as hair loss), aches and pains all over the body, bleeding, seizures, increased sun sensitivity, increased anxiety and heightened emotional response to otherwise “normal” situations, swelling of the face, nausea and vomiting, weight loss or gain, and fatigue (Canadian Cancer Society, 2008; Childhood Cancer Canada Foundation, 2011; Miller, 2002).

While these effects typically disappear once treatment is complete, other effects may appear years after. These effects will be discussed in the subsequent sections, including the effects the family unit endures during and post-treatment.

1.5 LONG-TERM EFFECTS OF CANCER TREATMENT ON CHILDREN

1.5.1 Definition

While much care and research has been invested in ensuring the survival of children and adolescents diagnosed with cancer, recent literature now includes the effects of cancer post-treatment and during remission (see, for example, Hudson et al., 2007; Wilson et al., 2014). With higher rates of survival and the greater effectiveness of treatment, it is especially important to place emphasis on the long-term effects of having pediatric cancer, as many of these effects appear later in life due to the treatment methods employed (Bray, 2009; Canadian Cancer Society, 2008; Dieluweit et al., 2010; Geenen et al., 2007; Oeffinger et al., 2006, Yi et al., 2014). These long-term effects are commonly referred to as *late effects*, and are described as “problems that develop after the completion of cancer treatment” (Canadian Cancer Society, 2008, p.62). It is imperative to understand that the late effects of pediatric cancer may not only affect the particular system or location of the body that was treated, but may also affect multiple organs, systems, and functional capabilities (Canadian Cancer Society, 2008; Geenen et al., 2007; Yi et al., 2014). The effects of treatment can also occur at varying times in children’s lifetimes,

although it is known that the effects from radiation and chemotherapy treatment typically become apparent several years after treatment for both children and adults alike (Canadian Cancer Society, 2008).

1.5.2 Review of the Current Literature On Long-Term (Late) Effects of Pediatric Cancer

In a study conducted by Oeffinger et al. (2006), chronic health conditions of 10,397 pediatric cancer survivors and 3034 siblings of pediatric cancer survivors in the United States were observed (more detail can be observed in Appendix A). This study was the first of its kind and used data from the Childhood Cancer Survivorship Survey, which observed longitudinal effects of pediatric cancer. The purpose of this study was twofold: (1) to determine the chronic health effects of cancer survivors versus otherwise typically developing members of the population, and (2) to determine the incidence of late effects in males compared to females, as well as the frequency of developing particular health conditions based on the type of cancer diagnosed and treatment administered. Participants aged 18 to 48, who were treated for their cancers between the years of 1970 and 1986, were included within the study and self-reported all results. For a comprehensive summary of all methodologies, explanations of the methodologies and results of this study (and subsequent studies examined) please refer to Appendix A.

The researchers defined chronic health conditions as “physical health conditions, including their age at the onset of the condition” (Oeffinger et al., 2006, p.1574-75), as well as any secondary cancers that were diagnosed as a result of treatment from the original cancer. To further understand the severity of the conditions listed (there were 137 effects itemized – an extensive but incomplete list), the Common Terminology Criteria for Adverse Events (version 3) was used, with conditions being ranked as grades 1 to 5, corresponding to the severity of each condition (refer to Appendix A). Some of the health conditions listed were congestive heart

failure, second malignant neoplasms, blindness or loss of an eye, ovarian failure, coronary heart disease, and cardiovascular accidents (Oeffinger et al., 2006).

While some chronic health conditions were expected in survivors of pediatric cancer, the results displayed a higher prevalence of issues than what was expected. Oeffinger et al. (2006) stated that out of all the survivors surveyed, 62.3% (or 6482 participants) had self-reported they had at least one chronic health condition, 37.6% (3905 participants) had two, and 23.8% (2470 participants) had three – all conditions attributed to having cancer as children. Twenty-seven and a half percent of those participants reported their condition(s) were of a severe or life-threatening/disabling nature. It was also found that those who had received chemotherapy or radiation therapy as children were more likely to develop any and/or more than one condition. As well, female survivors of childhood cancer were one and a half times more likely to have a condition deemed grade three (severe) or higher, and were also more likely than male survivors to have any condition at all. Sixty-seven percent of participants were diagnosed with at least one chronic health condition 25 years after diagnosis and 38.5% with multiple conditions 35 years after diagnosis. In comparison to their siblings, survivors of pediatric cancer were eight times more likely to develop a chronic health condition. The authors concluded that pediatric cancer survivors were more likely to have compromised health with age and were more likely to develop one or more physical health conditions as a result of their pediatric cancer than the general population. Once again, for the purposes of this study, any late effects were only those that were physical in nature (Oeffinger et al., 2006).

In a study conducted by Yi et al. (2014) in Korea, late effects were used to refer to any perceived physical and mental health problems and/or functioning issues. Like Oeffinger's study (2006), the data collected were the "perceived late effects", meaning that much of the data was

not verified by physicians, but rather self-reported by the participants. The participants in this study were between 15 to 39 years of age, with a mean age of 21.9 years. The sample size consisted of 225 participants (131 males and 93 females), a sample less than the Oeffinger et al. (2006) study. This was possibly due to the stigma associated with having cancer in Korea, as there was “a culture where talking about cancer is taboo” (Yi et al., 2014, p.146).

Similar to Oeffinger’s study (2006), Yi et al. (2014) observed that 73.1% of participants reported having a minimum of one health issue. Interestingly, participants cited growth issues (58.3%), chronic fatigue (35.6%), learning and memory issues (25.8%), and weak bones (22.7%) as their primary issues. Individuals who displayed a higher incidence of these outcomes were more likely to display a lower level of physical functioning than survivors without those outcomes. As well, participants who described having chronic fatigue and learning or memory issues had a higher incidence of having lower mental health function scores than other participants. Also similar to Oeffinger’s work (2006), females had more adverse health effects and additionally had poorer mental functioning. It was also found that females were more likely to have one or more adverse health conditions the longer the period of time since diagnosis. For more information pertaining to this study, refer to Appendix A.

Geenen et al. (2007) conducted a study of similar nature, with 1362 five-year cancer survivors (745 male and 617 female) that were treated in the Netherlands between 1966 and 1996. Similar to the previous two studies, the purpose was also to understand the long-term physical effects of pediatric cancer on survivors. Differing from Oeffinger’s research (2006), participants were medically assessed at a post-oncology treatment facility to determine their long-term effects, as opposed to self-reporting their conditions. However, as completed in Oeffinger’s study (2006), physicians were asked to rank the severity of their patients’ long-term

effects. Geenen et al. (2007) discovered that only 19.8% of survivors had no long-term effects, 59.0% had more than one effect, and 24.6% of survivors had five or more effects – a total of 83.6% of survivors having more than one physical effect. By the time the study was concluded, 3.2% (or 41 participants) had died due to an adverse health effect resulting from their cancer. Unlike previous work, this particular study reported a total of 3751 different long-term health effects, of which the most common health effects that were experienced were “orthopedic disorders (14.2%), second tumors (11.9%), obesity (9.4%), fertility disorders (8.9%), psychosocial or cognitive disorders (7.9%), neurologic disorders (7.7%), and endocrine disorders (5.3%)” (Geenen et al., 2007, p.2708).

In contrast with Oeffinger’s results, Geenen et al. (2007) stated that survivors who were treated with radiotherapy were at a higher risk of having late effects. Surprisingly, those treated with solely chemotherapy or solely surgery were less likely to experience late effects. As well, similarly with previously mentioned literature (Oeffinger et al., 2006; Yi et al., 2014), females were more likely than males to develop any sort of health condition, in addition to a condition with a higher severity rating. As well, female survivors had higher risks of fatigue and exhaustion, and, unlike the previous literature (Oeffinger et al., 2006; Yi et al., 2014), at the time of study, many of the female participants were taking oral contraceptives, so it was difficult to determine if any fertility issues were meaningful (Geenen et al., 2007).

Geenen et al. (2007) also found that of all of the late effects that were listed, survivors ranked psychosocial and mental effects with the highest severity. However, at no point in the study did researchers list what psychosocial and mental effects encompassed, so it was difficult to determine exactly how survivors were affected (for more detail about this study, refer to Appendix A).

While all of the previous studies have discussed physical long-term effects, one particular study by Dieluweit et al. (2010) studied solely psychological behaviours of adolescent cancer survivors and compared their stages of development with a typically developing population of adolescents. Adult pediatric cancer survivors (n=820; 402 males and 418 females aged 20 to 46) completed questionnaires regarding their perceived psychosocial and mental health behaviours, whereas the control population (matched to the survivors; n=820, mean age 30.4, 409 males and 411 females) had previously participated in the German Socio-Economic Panel Study (G-SOEP), a longitudinal survey conducted by interview in German households. The reason behind using the G-SOEP questionnaire was due to the overlap with the questions asked of the pediatric cancer survivors.

Dieluweit et al.'s (2010) statistically significant results revealed a distinct difference in some behaviours of the survivor versus control populations. First, it was shown that the cancer survivor population was delayed in their psychosexual development compared to controls, and that female cancer survivors scored lower in psychosexual development than any other population, namely male cancer survivors and the control group. Additionally, survivors who were treated with radiotherapy scored much lower on the psychosexual development scale than all others. Further, the younger survivors were more likely to be in long-term relationships compared to controls, whereas older-aged survivors were less likely to be in long-term relationships than the rest of the population. However, researchers did not state which age groups pertained to "younger" and "older" survivors. Also, it is important to note that the proportion of survivors who were married or had children was significantly lower than the control population. That said, cancer survivors were more likely to get married and have children later in life as compared to controls. Researchers speculated that these results were due to the

belief that pediatric cancer survivors were delayed in their social and emotional development. This could potentially be attributed to the fact that many of the participants were undergoing cancer treatment during their most integral developmental ages. Emotional and relationship development may have occurred later in survivors compared to their peers because development may not have begun until they were in the remission phase. Although this work sheds light on the social and emotional development of pediatric cancer survivors, further research is warranted.

Lastly, regarding some sex-specific traits, Dieluweit et al. (2010) stated that male survivors were the most likely to still be living at home with their parents, and female survivors expressed the highest interest in having children. Of the survivors, 119 self-reported being infertile, of which 49 were female. Of the 49 females who were infertile, 44.6% expressed the desire to have children. This study provided useful knowledge in understanding that the late effects of pediatric cancer are multifaceted and not entirely physical in nature. For further detail regarding this study, see Appendix A.

1.5.3 Gaps in the Current Literature

While the aforementioned research provides some understanding of the late effects of pediatric cancer, the research did not cover all aspects of survivorship and contained clear limitations. First, the number of participants varied in size, making comparisons difficult between studies (e.g., $n=10,397$, Oeffinger et al., 2006; $n=225$, Yi et al., 2014). Further, each study was from a different geographical region: Korea (Yi et al., 2014), the United States (Oeffinger et al., 2006), the Netherlands (Geenen et al., 2007), and Germany (Dieluweit et al., 2010) and it was difficult to determine whether culture played a role in these studies.

Additionally, some studies primarily focused on the physical long-term effects of pediatric cancer and did not address the social, psychosocial, or mental effects of cancer. For example, researchers stated that participants experienced certain social or mental effects, but did not provide details as to what they had specifically experienced or to what degree of severity they were experiencing these effects (Oeffinger et al., 2006, Yi et al, 2014, Geenen et al., 2007).

Additionally, the health conditions examined varied between studies and did not provide an exhaustive list of all conditions experienced by participants. For example, participants were only allowed to choose from a list of 10 conditions (Yi et al., 2014) to reporting a combined total of 3751 conditions (Geenen et al., 2007). Once again, although many of the findings were similar in nature, it was difficult to obtain a comprehensive picture of the late effects on survivors across studies.

Also, three of the four studies had participants self-report their signs and symptoms via survey or a list of conditions, and physicians were not consulted to confirm whether they truly were the result of pediatric cancer (Dieluweit et al., 2010; Oeffinger et al., 2006; Yi et al., 2014). As such, participants were only able to list the conditions they were experiencing and were unable to fully elaborate on the nature of the effects they were experiencing in relation to their cancer treatment.

Only two of the four studies had a control population for comparison purposes (i.e. Oeffinger et al., 2006, and Dieluweit et al., 2010). However, these controls were not randomly selected from the population, but rather, were siblings of the participants in the Oeffinger et al. study (2006) that were not matched for age or gender, or were participants of a household longitudinal survey (Dieluweit et al., 2010) who were not matched for age and were utilized out of convenience. A more representative control sample would have been a random sample from

the population matched for demographics such as age, gender, marital status, and environment. As such, neither of these control samples is the best comparison group.

Lastly, it should be noted that all studies were about the survivor; however it is important to also understand the role of the family in the diagnosis, treatment, and recovery from pediatric cancer, as cancer has been shown to affect the entire family (Clarke, Fletcher, & Schneider, 2005; Clarke & Fletcher, 2003; Fletcher, 2010; Fletcher, 2011; Fletcher, Schneider & Harry, 2010; Overholser & Fritz, 1991; Patterson, Holm & Gurney, 2004). As such, the next section will discuss the effect of cancer on the family unit.

1.6 THE FAMILIAL PERSPECTIVE

1.6.1 Pediatric Cancer Effects in the Family

While the majority of this literature review has focused on the late effects of pediatric cancer on adults, it is important to remember that during the pediatric cancer journey – diagnosis, treatment, and recovery – the children affected are not the only individuals experiencing a multitude of effects (Clarke, Fletcher, & Schneider, 2005; Clarke & Fletcher, 2003; Fletcher, 2010; Fletcher, 2011; Fletcher, Schneider & Harry, 2010; Overholser & Fritz, 1991; Patterson, Holm & Gurney, 2004). The families surrounding the children with pediatric cancer also undergo a variety of experiences that may last beyond the treatment phase and into remission as well. While much work has been invested in studying the effects of cancer on the individual, it is also important to understand the effect of a pediatric cancer diagnosis on individuals close to the children – particularly immediate family members, such as parents and siblings. Research that has focused on the effects on the family members described both benefits and costs of a pediatric cancer diagnosis. Each will be discussed in turn to display a broader interpretation of how a pediatric cancer diagnosis affects the family.

1.7 SHORT TERM FAMILIAL EFFECTS

1.7.1 The Family Unit

When looking at the immediate family of the children, some effects lasted while the children were in treatment. For example, it has been shown that during treatment, parents felt high levels of stress and fatigue, and sometimes had relationship issues with their spouses (Clarke, Fletcher, & Schneider, 2005; Clarke & Fletcher, 2003; Fletcher, 2010; Fletcher, Schneider & Harry, 2010; Patterson, Holm & Gurney, 2004; Phipps, 2005). As well, the family experienced financial issues, often stating that they had to work fewer hours or quit their jobs in order to care for their children (Cohn et al., 2003; Dockerty, Skegg, & Williams, 2003; Fletcher, 2010; Fletcher, Schneider & Harry, 2010; Overholser & Fritz, 1991; Patterson, Holm & Gurney, 2004).

1.7.2 Siblings

Research has also demonstrated that siblings of children with cancer may receive less attention from their parents, as reported by parents themselves (Fletcher, 2010; Patterson, Holm & Gurney, 2004). Additionally, children who did not have cancer stated that they felt that their issues were of less importance because of their sibling's sickness (Zelter et al., 1996). Siblings without cancer also experienced feelings of helplessness and negative health outcomes, such as stress and exhaustion, as a result of worrying about their siblings with cancer (Alderfer, Labay & Kazak, 2003; Fletcher, 2010; Zelter et al., 1996).

This worrying was exacerbated by the fact that siblings were often left with neighbours and family friends, as parents were providing care to their children with cancer (Fletcher, 2010; Fletcher, Schneider, & Harry, 2010; McCubbin et al., 2002). Siblings experienced fear of the future for themselves and their sick siblings, as they did not know if they would also develop

cancer or if their sick siblings would develop cancer again. As well, siblings of children with cancer were at a higher likelihood of acting out due to the fact that many children resented their siblings with cancer and the attention that they were getting (Alderfer, Labay, & Kazak, 2003; Patterson, Holm, & Gurney, 2004) even though the increased attention was a result of their cancer diagnosis.

1.8 NEGATIVE LONG-TERM EFFECTS

1.8.1 The Family Unit

While parents were relieved at the completion of their children's cancer treatment, undergoing such an ordeal has the potential to lead to the development of some negative long-term effects. For example, Overholser & Fritz (1991) conducted a retrospective study in the United States in which 44 children who had cancer (22 boys and 22 girls with a mean age of 10.34) and their families discussed the implications of pediatric cancer two to seven years after treatment. Many parents described that they were still undergoing financial setbacks from their children's treatment, as 45% of mothers and 20% of fathers had to alter their work schedules or quit their jobs to be with their children during their illness. Studies by Dockerty, Skegg, & Williams (2003), as well as Cohn et al. (2003) found similar results. As well, it was noted that parents who outwardly projected their stress and anxiety more often during their children's illnesses (in front of their children) reported poorer social relationships with family and friends after their children completed treatment. To add, parents who were able to effectively cope and not "lash out" on others while their children were sick expressed better long-term family functioning than those who were unable to cope as effectively (Overholser & Fritz, 1991).

Additionally, research conducted by Patterson, Holm & Gurney (2004) on 45 parents (aged 32 to 56) and their children (aged 3.8 to 26) whose cancer treatment had ended at least one

year prior aimed to understand the impact of childhood cancer on the family unit. Within their work they discovered that many parents experienced stress regarding the effects that cancer treatment would have on the future lives and health of their children. Many parents expressed worry concerning the fertility of their children with cancer and even went as far as to look into fertility treatments, including sperm banking. Further, many parents articulated that they were fearful of relapse, and that they were more vigilant in observing the needs of their children with cancer when they were sick. Lastly, parents explained that pediatric cancer fractured their family life and that they now had to relearn how to function together as a family unit. Many parents stated that they were still attempting to fully repair their relationships with their spouses after going through such a traumatic experience together (Patterson, Holm, & Gurney, 2004). Not only were parents fully cognizant of the severity of the cancer on their children, but, oftentimes, their “healthy” children were well aware as well. Seeing their sick siblings undergo many difficult experiences also affected the lives of healthy siblings for a long time after treatment.

1.8.2 Siblings

In a study conducted by Zeltzer et al. (1996), 254 siblings (aged 5 to 18, 129 males and 125 females) of children with cancer, as well as their parents and physicians, were asked to complete structured interviews and surveys with researchers in order to ascertain their current lifestyle and health outcomes while having a sibling being treated for, or having completed cancer treatment. A control group of children who did not have siblings with a chronic disease and their parents were also selected for comparison. More detail about the methodology can be observed in Appendix B.

It was found that parents of children with pediatric cancer were less likely to take “healthy” siblings to the doctor when they mentioned specific somatic problems compared to

controls. Some of these issues included complaining of stomachaches, having a stiff neck or chest pains, and complaints that they “hurt all over” (Zeltzer et al., 1996). When discussing the overall health of siblings of children with cancer, their parents ranked their children as having “excellent” health in 97% of cases, the siblings themselves stated they had excellent health in 90% of cases, and their physicians ranked siblings as having excellent health 82% of the time. As well, behavioural surveys were completed that corresponded to mental health issues, with a higher score representing a higher severity of issues. Both boys and girls who had siblings with cancer scored much higher on the surveys than control children - so high that their scores matched children who were referred to health care professionals for psychiatric issues. It was also shown that the children aged 12 and older who had a sibling being treated for cancer displayed a higher prevalence of risky behaviours: 35% of adolescents who had a sibling with cancer used alcohol a minimum of once per month compared to 3% of control adolescents, and, with tobacco use, 26% of adolescents with a sibling who had cancer reported using it once a month compared to controls, who reported 17.4%. Overall, this research revealed that parents were less likely to spend time with “healthy” siblings due to time spent with their children with cancer, and “healthy” siblings were more likely to develop risky behaviour patterns than controls (Zeltzer et al., 1996).

Additionally, in a study conducted by Alderfer, Labay, & Kazak (2003) 78 siblings (mean age 14.2) of children with cancer reported their experiences approximately 5.3 years after their siblings with cancer had completed treatment. It was found that 49% of siblings had developed mild post-traumatic stress reactions and 32% had developed moderate to severe post-traumatic stress reactions as a result of having a sibling with cancer. Siblings scored higher than fathers (30.0%) and the cancer survivors themselves (14.0%) in the incidence of post-traumatic

stress reactions, only scoring lower than mothers (40.0%). The authors did not include any information to explain why mothers scored highest, although it could potentially be stipulated that mothers typically were the most burdened during a childhood cancer diagnosis, as they were more likely to quit their job and spend more time taking care of their sick children. As well, siblings who were older than the age of six years at the time of their siblings' treatment were more likely to develop post-traumatic stress symptoms than those who were younger. This was attributed to the belief that they were more cognizant of what was occurring with their siblings while they were sick (Alderfer, Labay, & Kazak, 2003).

It is important to understand that while childhood cancer drastically affects the family unit, not all effects incurred by the family are negative in nature. Some of these effects are positive in nature – a surprising sentiment to have after going through such a difficult time.

1.9 POSITIVE LONG-TERM EFFECTS

1.9.1 The Family Unit

In a study conducted by Fletcher (2011), nine mothers aged 32 to 47 of children who were treated for, and, in some cases, died from their childhood cancer were interviewed about their experiences. The mothers stated that they reprioritized their lives when their children became sick. The turn of events they were experiencing forced them to focus on the positive aspects of their lives and live as much in the moment as they could. Mothers reported that one of the more positive aspects of their children undergoing cancer treatment was the overwhelming amount of support from family and friends. They felt that they could depend on many people in their lives, and also stated that friends or employers that they originally were not close with became an integral support network during their children's cancer treatment. These feelings of support, or feeling loved, allowed mothers to better cope with their children's cancer diagnosis.

Treatment centers also aided in this, as some mothers stated that the staff and treatment teams, as well as other parents undergoing the same process, made a difficult time much easier to experience. Mothers of children who both survived and died stated that they wanted to create positive aspects of undergoing such a negative process. As such, these families would raise funds for cancer initiatives, oftentimes raising funds in their children's memory and giving back to others experiencing pediatric cancer diagnoses. One mother stated that to give back, her child's body and organs were donated after he died, furthering research on pediatric cancer and potentially saving other children and parents from experiencing the same outcome. Regardless of the end result of treatment, many mothers explained that the family unit became closer, as their relationships with their spouses and children became stronger by undergoing the whole process together. Through this, mothers developed a greater sense of responsibility to their families, as well as others in their cancer journeys (Fletcher, 2011).

Similarly, Clarke & Fletcher (2003) interviewed 25 mothers (aged 31 to 46) of children who had cancer (aged 3 to 18), about their role in being at home and providing health care to their children (more detail can be observed in Appendix B). Many of the mothers discussed that going through pediatric cancer made them have a more positive outlook on life because they became more appreciative of the health of their family and everything that they had. As well, many of the mothers discussed how they came to terms with their feelings of sadness at the time, and were more forgiving of the fact that they were allowed to feel sad and live fully in the moment of what they were experiencing. Mothers learned to apply this philosophy to their current lives (Clarke & Fletcher, 2003). These sentiments were also discussed in research conducted by McCubbin et al. (2002). This information is important to understand, as many of the health outcomes reported are easily translated into long-term health effects, and, as such, it is

important to provide care not only to the pediatric cancer survivor, but to their family members as well.

1.9.2 Gaps in the Literature

While literature exists regarding individuals who experienced pediatric cancer as well as their families, there are some gaps in the literature that lead to an incomplete understanding of the toll of this disease later on in life. For example, some studies focused on the experiences of mothers and not directly on the fathers or siblings (Clarke & Fletcher, 2003; Clarke & Fletcher, 2010; Fletcher, 2010; Fletcher, 2011; Fletcher, Schneider, & Harry, 2010). Additionally, studies conducted on siblings were purely quantitative in nature, did not capture the “voice” of the participants, and only examined negative outcomes of the experience (Alderfer, Labay, & Kazak, 2003; Zeltzer et al., 1996). Other studies solely examined particular outcomes, such as the negative physical and mental outcomes (Alderfer, Labay, & Kazak, 2003; Patteron, Holm, & Gurney, 2004; Zeltzer et al., 1996), and did not capture the all-encompassing nature of a pediatric cancer diagnosis. As such, although previous research provides a picture of the pediatric cancer experience, it is not complete.

In regards to studying the survivor, his/her support person and his/her health events, it would be beneficial to conduct qualitative research studies. This is because the essence of lived experiences can emerge and allow for a greater understanding of the journeys of those affected by pediatric cancer diagnoses, as well as further provide a source of support for their siblings and parents. As well, more research needs to be conducted examining the multifaceted nature of the long-term cancer effects and how survivors and their support people feel about themselves, their environment, relationships, health outcomes, and the term survivor in itself. Lastly, of the existing literature regarding the late effects of pediatric cancer survivors, few were conducted in

Canada. As such, there is a gap in the literature regarding how Canadian pediatric cancer survivors live after their cancer treatment and what they and their support persons experience beyond treatment. As a result, research addressing these gaps is warranted.

1.10 RESEARCH PURPOSE

This research will examine the lived experiences of the perceived long-term effects of pediatric cancer on the adult survivor and their effect on their primary support person. For the purposes of this research, the term pediatric will encompass individuals between the ages of 0 and 19 years old. Within the research, three main research questions will be addressed:

1. How has having pediatric cancer influenced who you are today?
2. How do you identify yourself with respect to your experience with pediatric cancer?
3. In being a support person, how has caring for someone who had pediatric cancer influenced who you are today?

The proposed study provides an all-encompassing picture of the late effects of pediatric cancer on adult survivors and the affect of these late effects on survivors' primary support persons.

Implications for this research include developing resources for families and survivors of pediatric cancer to prepare for any future effects, as well as allow for medical professionals and charitable organizations to prepare their clientele for what lies past remission.

CHAPTER 2: METHODOLOGY

2.1 PARTICIPANTS

In order to accurately depict the lived experiences of pediatric cancer survivors and their primary support persons, participants who had undergone the experience firsthand (Patton, 2002) were asked to participate in the study. As such, purposeful sampling was used, namely criterion and snowball sampling. Purposeful sampling was used to recruit participants who were considered information-rich and could describe their experiences in great detail (Creswell, 2013). Criterion sampling is based on the principle that participants are included if they “meet some criterion” (Creswell, 2013, p.158), while snowball sampling allows for individuals to refer the researcher to other possible information-rich cases (Creswell, 2013, p.158).

Participants were recruited through word of mouth and advertisements to societies and support groups for pediatric cancer in Ontario. Participants were assessed for specific inclusion and exclusion criteria to ensure that they were information-rich and could provide a comprehensive interpretation of life post-cancer. For identification purposes, individuals who had pediatric cancer will be referred to as survivors, although it is important to note that not all individuals within this group would identify as a survivor. Additionally, their self-identified primary support persons will be referred to as primary support persons, or support persons. The inclusion criteria for pediatric cancer survivors included: (1) must be a resident of Ontario; (2) must be between the ages of 16 to 30; (3) must have completed cancer treatment a minimum of 3 years prior; and (4) must not be undergoing treatment for any secondary cancers, unless caused by the primary cancer. As well, the criteria were not exclusive to any particular cancer, meaning that survivors diagnosed with any cancer as a child were allowed to participate. Due to the rarity

of pediatric cancer, choosing participants based on cancer type may have created difficulty in recruitment and reaching saturation.

In terms of the perceived current primary support person, the inclusion criteria included: (1) must be a resident of Ontario; (2) must be over the age of 16; (3) must have a close relationship with the participant for a minimum of 3 years; (4) must have been a person the survivor frequently communicated with and was dependent on for any physical, emotional, mental, psychological, or other unspecified aspects of daily living for approximately six months; (5) must be knowledgeable of the cancer survivor's past cancer diagnosis and treatment but not necessarily there while it was occurring, and (6) must be considered to be the primary support person by the cancer survivor. To elaborate on point five, primary support persons did not necessarily have to have been present during the survivor's diagnosis and treatment, as they were being recruited to elaborate on any late effects the survivors were currently experiencing, and not the effects they experienced when undergoing treatment.

2.2 RESEARCH TOOLS AND PROCEDURE

2.2.1. The Qualitative Method

To fulfill the purpose and answer the research questions of this study, the most appropriate methodology to use was qualitative in nature, as these methods allowed for a holistic understanding of a particular experience or phenomenon. Specifically, the theoretical orientation chosen for this research was phenomenology. As described by Van Manen (1990), "Phenomenology asks for the very nature of a phenomenon, for that which makes a some-thing what it is - and without which it could not be what it is" (p.10). This theoretical approach was most fitting because the purpose of the study was to explore the lived experiences of pediatric cancer survivors and their primary support persons. In order to do this, "one must undertake in-

depth interviews with people who have directly experienced the phenomenon of interest; that is, they have ‘lived experience’ as opposed to ‘secondhand experience’” (Patton, 2002, p.104).

In addition to the interviews, a number of additional methods were used, including background questionnaires, field notes, and member checks, so that the true “voices” could be conveyed by participants in order for readers to fully understand the essence of their experiences.

2.2.2 Ethics

All tools and procedures were approved by the Wilfrid Laurier University Research Ethics Board. Participants read and signed an informed consent statement prior to participating, and were also given the opportunity to ask the researcher any questions prior to their participation in the study.

2.2.3 Background Questionnaires

Participants completed a background questionnaire specific to their roles (i.e. pediatric cancer survivor or primary support person). For the adult survivors, a background questionnaire was completed that consisted of: (1) demographic information such as age, education, employment, relationship status, and ethnicity; (2) their memories of their experiences with cancer as children; and (3) their current lives and any effects they may be experiencing as a result of their cancer. For the primary support persons, a background questionnaire was administered which consisted of items pertaining to: (1) demographic information such as age, education, employment, and relationship status; (2) their knowledge of the diagnosed individuals’ past cancer experiences; and (3) their role as primary support persons. The information from these background questionnaires was used to create context for the interviews.

2.2.4 Interviews

Each participant took part in a one-on-one, semi-structured interview conducted by the principal researcher. The interviews were arranged at a time and place convenient to the interviewee and were conducted either in person, via Skype, or via telephone. The lengths of the interviews were dependent on the participants' responses. For the survivors, the interviews lasted for an average of 61 minutes, with the shortest and longest times being 44 and 89 minutes, respectively. The interviews for the support persons lasted an average of 56 minutes, with the lengths of 31 and 88 minutes respectively being the shortest and longest.

Each interview for the pediatric cancer survivors consisted of 15 open-ended questions. Questions were asked regarding: their background and demographic information, their relationships with their primary support persons, their memories of their experiences with pediatric cancer, and their current behaviours and health in relation to their experiences with pediatric cancer (see Appendix C). For the primary support persons, each interview consisted of 13 open-ended questions. Questions consisted of their background and demographic information, information regarding the pediatric cancer survivors and their experiences with cancer, current life as support persons for the diagnosed individuals, and any late effects that the survivors were currently experiencing (see Appendix C).

Subsequently, each interview was transcribed verbatim so that data analysis could begin and the researcher could monitor saturation of information collected throughout the recruitment process. During data analysis, the information presented was examined for the recurrence of particular themes, discussion topics, and contrasts. Saturation was operationalized as collecting data until there was no new information acquired (Morse, 1995) and additional interviews would not add to the quality of the research (Patton, 2002). When the principal researcher felt

saturation had been reached, recruitment of participants ceased, and the data obtained was analyzed further.

2.2.5 Field Notes

Data collection was further enhanced by the collection of handwritten field notes. The researcher took notes prior to, during, and immediately following each interview. Field notes were taken to record participants' reactions, body language, and emotions in response to particular questions. This was done to provide additional context to their experiences and feelings towards the topics at hand. As well, notes taken during the interviews were also used to highlight important pieces of information disclosed by participants, which assisted in post-interview data analysis. Lastly, field notes were taken afterwards to record the reflective thoughts of the researcher after the completion of the interviews, also known as journaling (Janesick, 1999). The principal researcher, while personally never having undergone the experience of pediatric cancer, had previous experiences working with children and families diagnosed with pediatric cancer and undergoing treatment. From these experiences, the principal researcher was motivated to conduct research in the area, and utilized such motivations in aspects of conducting this study.

2.2.6 Member Checks

After transcription, participants were given copies of their transcripts in order to clarify any information they may have discussed during the interview, which allowed for greater accuracy of the data, as well as to build rapport and trustworthiness between the interviewer and the participants (Holloway, 2005). Member checks were also completed in order to give the participants an opportunity to "correct, amend, or extend" (Lincoln & Guba, 1985, p.236) information existing in their transcripts so that they were comfortable with the data being

presented in future research papers, posters, or presentations by the primary researcher. Participants were provided with a three-week period to complete the member checks, and if they were unable to return their member checks within the specified time period, data analysis proceeded without their input. Lincoln and Guba (1985) contend that providing participants with member checks add to data credibility. The member checks allowed the participants to evaluate the information within the transcript, address any areas of concern regarding accuracy of the data, and confirm the details shared throughout their interviews. Participants chose the format in which they wished to receive their member checks (either a physical hard copy sent via postal mail or an electronic copy sent via email). The researcher added any new responses and changes made to the transcripts, and the edited transcripts were used for subsequent data analysis. Eight participants returned their transcripts with very minor edits or no edits made, and the remaining eleven participants did not return their member checks. In regards to the member checks returned with clarifications, the edits made were to information regarding the past treatments received (ie. clarification of value of fluids drawn during a procedure), to answer questions pertaining to why certain emotions were experienced at multiple time points (eg. while their child was undergoing treatment, now while they are a young adult), as well as to provide minor grammatical changes to the transcript (eg. removing the word “um”) although the researcher did not make the last change.

2.2.7 Triangulation

The purpose of triangulation was to use multiple sources of information in order to corroborate and legitimize any findings during data analysis (Creswell, 2013). Data triangulation was used to increase of credibility of the study via utilization of multiple data methods, namely background questionnaires, field notes, one-on-one semi-structured interviews, and member

checks. Additionally, investigator triangulation was employed to strengthen the findings by having the primary researcher and her supervisor individually analyze and interpret the data. Also, a qualitative research group comprised of qualitative faculty members and MSc/PhD students aided in data analysis and interpretation. By employing two triangulation methods the credibility of the study was enhanced (Patton, 2002).

2.3 TRUSTWORTHINESS: CREDIBILITY, TRANSFERABILITY, AND CONFIRMABILITY

Lincoln and Guba (1985) contend that the trustworthiness of a particular study is essential to establishing the study's value. Credibility, transferability, and confirmability are three means by which to establish trustworthiness (Lincoln & Guba, 1985). Each of these concepts will be discussed in turn.

2.3.1 Credibility

Credibility is the ability to create confidence in the data presented (Lincoln & Guba, 1985). For qualitative research, Patton (1999) suggests that the following factors help to establish credibility: (1) rigorous methods and techniques to obtain high-quality data, (2) ensuring that the researcher is credible, and (3) a belief in qualitative research and its value.

The credibility methods previously mentioned (see 2.2.5: Field Notes, 2.2.6: Member Checks, and 2.2.7: Triangulation), allowed for greater integrity of the data to be established, as well as establishing trustworthiness between the researcher and participants (Lincoln & Guba, 1985). Also, constant communication with participants was maintained throughout the study, which allowed them to be contributors to the process.

Additionally, the primary researcher was an integral tool in the qualitative research process. As such, in order to gain an understanding of qualitative methodologies and theoretical approaches, the primary researcher completed a qualitative research course. As well, an

extensive review of the literature regarding the late effects of pediatric cancer on survivors and on the family unit was completed. This was done with the guidance and supervision of an experienced faculty member. Additionally, the researcher completed field notes and recorded any important information throughout the interview process in order to ensure that all other data sources used in the study were supported. Lastly, the researcher tried to remain neutral and acknowledged any biases being brought into the study through these field notes.

Finally, the primary researcher chose to complete a qualitative study due to the nature in which qualitative research methods allow for participants' voices to be heard. It allows for the true nature of the late effects of pediatric cancer to emerge, as well as address the multifaceted nature of these effects. As such, the primary researcher believed it beneficial to conduct a qualitative study on the topic.

2.3.2 Transferability

Lincoln and Guba (1985) described transferability as the ability to apply findings of a particular work in different contexts. To do such, the researcher must obtain a "thick description" of the topic at hand (1985). For the context of this study, transferability was maintained by ensuring that high-quality data was obtained. To do this, all participants were included on the basis that they were information-rich cases. The employment of this method allowed for theoretical saturation to be reached, thus enhancing the integrity and transferability of the study (Lincoln & Guba, 1985).

2.3.3 Confirmability

Confirmability, as reported by Lincoln and Guba (1985), is the degree of neutrality within a study, or how the participants and their responses, as opposed to the motivations of the researcher, shaped the data. To establish confirmability, Lincoln and Guba (1985) state that

using field notes (2.2.5) and triangulation (see 2.2.7) are integral to this process. Field notes were completed before, during, and after interviews to capture the feelings and perspectives of the primary researcher, as well as the participants during their interviews. The field notes captured the essence of the participants' experiences, and allowed these true experiences to emerge in the data. Also, two triangulation methods (i.e. investigator triangulation and data triangulation) were used to aid in this process as well. This once again allowed the participants and their interpretations of their experiences to shape the data used in this study.

2.4 DATA TREATMENT

2.4.1 Qualitative Analysis: Phenomenology

The theoretical orientation used to guide this research was phenomenology. Van Manen (1990) contends that phenomenology is the “explication of phenomena as they present themselves to consciousness” (p.9). He further stipulates that consciousness is “the only access human beings have to the world” (Van Manen, 1990, p.9). Patton (2002) describes phenomenology as

“how human beings make sense of experience and transform experience into consciousness, both individually and as shared meaning. This requires methodologically, carefully, and thoroughly capturing and describing how people experience some phenomenon – how they perceive it, describe it, feel about it, judge it, remember it, make sense of it, and talk about it with others.” (p.104)

As this research examined the lived experiences of pediatric cancer survivors and their primary support persons, phenomenology was the most appropriate theoretical orientation to use, as phenomenology allowed the phenomenon (i.e. pediatric cancer) to be examined and understood through the investigation of qualities and intricacies of the phenomenon in question (Van Manen, 1990).

Data gathered from the background questionnaires was used to provide a framework for the interviews and provided the researcher with context. As well, background questionnaires were also used when reviewing interview transcripts, and in collaboration with field notes to understand and maintain the context at that particular time. For survivors, the background questionnaires provided information for the interview regarding their past treatments, current side effects, as well as who they would consider their primary support persons. After participating in their interviews, survivors were asked whom they would consider their primary support persons, based on the individuals they had chosen in their background questionnaires. After selecting their support persons, survivors were asked if their support person would be willing to participate in the study. If support persons agreed, the primary researcher contacted them personally to obtain consent and provide them with information regarding the study, including their background questionnaires. In the questionnaires for the support persons, information providing context for interviews included: their knowledge of their survivors' past treatments, and aspects of their relationship with their survivors (eg. length of relationship, type of support given to survivors). Further, the field notes were used during the data analysis process so that particular phrases, reactions to questions, and emotional responses were reviewed during data analysis of transcripts. This allowed for a greater interpretation of the participants' stories, so that their voices were conveyed as realistically as possible.

A step-by-step analysis of the data, generally based around the framework of Moustakas (1994) was completed that allowed for themes to emerge. The experiences of all participants were divided into past and present (i.e. when they were experiencing their cancer and their current lives) by coloured coding labels on their transcripts. Additionally, while separating past and present experiences, the information was also colour coded for any positive or negative

effects experienced by having pediatric cancer, or being support persons for survivors. For the support persons that were not present during the survivors' cancer experiences, their transcripts were only coded for the current time period. From this initial coding process, transcripts were then re-read to examine the different effects experienced by survivors and support persons. Charts listing the potential aspects of their lives that were affected (e.g. physical, cognitive, social, career, etc.) were created for survivors and support persons and how they interpreted their own experiences. An additional chart was made for how support persons perceived these effects in survivors. The charts were also colour coded for the ways in which these particular aspects of their lives were affected for each survivor and support person (i.e. positively, negatively, or not at all). In doing such, multiple themes emerged regarding the late effects of pediatric cancer on survivors, and the effects that may be experienced by their support persons in caring for survivors. Subsequent to the discovery of the themes, transcripts were read again to highlight particular quotes that brought to life the way in which the facets of their lives had been affected. The quotes that were highlighted were colour coded by theme. These quotes were then re-read and utilized in this research to highlight the ways in which the lives of both survivors and support persons were affected. To do this, the verbatim quotes were utilized. The primary researcher then used investigator triangulation by meeting with her advisor, as well as a qualitative lab group, to discuss the themes that had emerged.

CHAPTER 3: RESULTS

3.1 INTRODUCTION TO PARTICIPANTS

This study was comprised of ten pediatric cancer survivors, and nine of their self-identified primary support persons for a total sample size of nineteen individuals. Once again, for identification, individuals who had pediatric cancer will be referred to as survivors, although not all individuals within this group would necessarily identify themselves as survivors. Additionally, their self-identified primary support persons will be referred to as primary support persons, or support persons.

Survivors' ages at diagnosis ranged from 2 to 19, and at the time of data collection, their current ages ranged from 21 to 28. They had experienced a variety of cancers: benign thalamic astrocytoma (1), acute lymphoblastic leukemia (6), acute myeloid leukemia (1), Hodgkin's Lymphoma (1), and Non-Hodgkin's Lymphoma T-Cell (1). While a benign thalamic astrocytoma is considered non-cancerous, the experiences of the individual and his primary support person were similar to the experiences of the other participants, and as such were included in the study. Additionally, the most common treatment received during their experiences included chemotherapy (9), surgery (3), and radiation (4). There were also additional interventions received during cancer treatment that can be seen in Table 1. Furthermore, the effects experienced by survivors were multifaceted in nature, and were described as both positive and negative in nature. For more detailed information regarding the demographics of the survivors, please refer to Table 1 on page 36.

The survivors, due to their current relationships, chose the support persons that they perceived to be integral to their current lives. Primary support persons' ages ranged from 23 to 73. The support persons included six mothers, one boyfriend, one fiancée, and one grandmother.

Of the nine support persons in the study, seven of them were also the primary support persons for the survivors while undergoing their pediatric cancer experiences (the six mothers and one grandmother). One individual was unable to provide a primary support person, as her support people felt uncomfortable with participating. For the majority of survivors, support persons provided psychological and financial support. Both survivors and support persons stated that participants were predominantly self-sufficient at the current time.

Table 1: Demographic information for pediatric cancer survivors

Participant	Dan	Savannah	Stephen	Danielle	Joey	Alyssa	Evelyn	Abby	Justin	Jolie
Diagnosis	Benign Thalamic Astrocytoma	Acute Lymphoblastic Leukemia	Acute Lymphoblastic Leukemia	Acute Myeloid Leukemia	Hodgkin's Lymphoma	Acute Lymphoblastic Leukemia	Acute Lymphoblastic Leukemia	Acute Lymphoblastic Leukemia	Non-Hodgkin's Lymphoma T-Cell	Acute Lymphoblastic Leukemia
Age at Diagnosis	8	3 ½	11	14	13	2	3 ½	19	15	17
Treatment	Surgery	Chemotherapy Blood transfusion Bone marrow biopsies	Chemotherapy Radiation therapy Bone marrow transplant	Chemotherapy Surgeries Homeopathy and alternative medicine (chiropractor)	Chemotherapy Radiation therapy Surgery	Chemotherapy	Chemotherapy Radiation therapy	Chemotherapy Radiation therapy Stem cell transplant	Chemotherapy Steroids	Chemotherapy
Current Age	25	22	27	25	21	28	24	22	22	24
Late Effects	Right homonymous hemianopia Ataxia Visual scanning delay Visual/Verbal short term memory	Lesser heart fibres Anxiety	Stunted growth Sexual health issues	Survivor's guilt Depression Right leg partial amputation Memory issues (chemo-brain)	Decreased lung capacity Weakened tooth enamel	Needle-phobia Claustrophobia	Poor eyesight Tooth formation issues	Joint pain Gall bladder removal Muscle spasms and cramps Migraines Fatigue Memory issues (chemo-brain) Menopause	Nerve damage in legs Sleep apnea Heightened Learning Disability Anxiety Depression	Avascular necrosis in bones – resulted in two hip replacements Bone in foot is dead
Self perceived overall health	Excellent	Excellent/	Excellent	Fair – Good	Good	Excellent	Good	Good	Fair	Good
Support persons' perception of overall health	Good – Excellent	Good – Excellent	Excellent	Fair – Good	Excellent	Good	N/A	Good	Fair	Good

Table 2: Demographic information for support persons

Support Person	Margaret	Meryl	Shannon	Barbara	Lisa	Chris	Beth	Catherine	Sharon
Support Person to:	Dan	Savannah	Stephen	Danielle	Joey	Alyssa	Abby	Justin	Jolie
Relationship with Participant	Mother	Mother	Mother	Mother	Mother	Boyfriend	Mother	Fiancée	Grandmother
Current Age	54	50	58	55	48	31	62	23	73
Present during cancer experience?	Yes	Yes	Yes	Yes	Yes	No	Yes	No	Yes
Perceived overall health	Good	Good-excellent	Fair-good	Fair - good	Good	Good	Excellent	Good	Good
Support provided to participant at present time	Emotional Financial	Emotional Financial	Emotional Financial Cognitive Physical Psychological Social	Emotional Financial Cognitive Physical Psychological Social “Pet babysitting”	Financial “Residence”	Emotional Physical Social	Emotional Financial Physical Psychological Social	Emotional Financial Cognitive Psychological Social	Emotional Financial Physical Psychological Social

3.2 THEMES

Survivors and some support persons reminisced about their cancer experiences, as well as commented on the effect that pediatric cancer had on their lives today. Discussing their previous cancer journeys aided in providing context for their current life experiences. A total of **four** themes emerged from the analysis of the data: (1) “There wasn’t a lot of time to sit and think.”: The Pediatric Cancer Experience, (2) “There is no before cancer...there’s only cancer.”; (3) “I don’t know if I would change it.”; and (4) “As long as you need me I’m yours.”. Theme 1 addresses the time period in which the survivors underwent pediatric cancer treatment from the perspective of both survivors and some support persons. Themes 2 and 3 pertain specifically to the effect that pediatric cancer has had on the lives of the survivors, while theme 4 addresses the current lives of the support persons. The themes and their respective subthemes are summarized in Table 3. Each will be discussed in turn.

Table 3: Themes and subthemes of the lived experiences of pediatric cancer survivors and their primary support persons.

Theme	Subthemes
1. “There wasn’t a lot of time to sit and think.”: The Pediatric Cancer Experience	N/A
2. “There is no before cancer...there’s only cancer.”	i. “I live with symptoms and side effects every day. And, they’re never gonna go away.” ii. “I completely changed.” iii. “I’m eternally grateful. I got chosen to have a second chance.”
3. “I don’t know if I would change it.”	i. “Stop and smell the roses.” ii. “I think it’s given me kind of a purpose.”
4. “As long as you need me I’m yours.”	i. Do their effects affect me? ii. “You realize what’s important and it sticks with you.”

3.3 “THERE WASN’T A LOT OF TIME TO SIT AND THINK.”: THE PEDIATRIC CANCER EXPERIENCE

Prior to discussing the results of the current study, which examined the current, or late, effects of pediatric cancer, it was important to first reflect upon the past in order to gain a contextual understanding of the effects that both survivors, as well as their support persons, were currently experiencing. As such, this section describes the time period during active treatment for pediatric cancer, and highlights both the positive and negative aspects of their journeys from the perspectives of both the survivors and their support persons.

Almost every survivor (except for those who were too young to remember) easily recalled the signs and symptoms or events that led to their eventual diagnoses (refer to Table 1 for diagnoses), as did their support persons who were present at the time. Many acknowledged the “nightmare” which came after diagnosis. Some of the most vivid memories for both the survivors and support persons were of the treatment side effects that the survivors experienced. These side effects were often severe, and, for the support persons, difficult to watch their children endure. For example, Shannon and Sharon, a mother and grandmother, shared the following from their memories of the side effects experienced by their respective son and granddaughter.

...during the bone marrow [transplant] ...you stay in isolation until your blood count starts to climb, and you can be very close to death and have, quite um, bloody diarrhea all those things... he never complained and when he had mouth sores they gave him morphine, they gave him an overdose of morphine which needed to be counteracted with narcs and, he almost went into respiratory distress. ~Shannon (Mother of Stephen)

...seeing her in the bed and all puffy and, all, tubed up. She would get these horrible ulcers all over her nose and her lips, from, whatever, whoever knew what that was from....I think about when she she got the port, got infected. And, we were there the day they were going to, they packed it and then they were going to unpack it....It was just horrible. ~Sharon (Grandmother of Jolie)

Survivors who were old enough to remember their experiences also recalled the following:

...there was a point, when I did get bedridden...I couldn't walk. When I got up I was too weak...I did basically relearn how to do that, 'cause I was also so far gone with my medication that I couldn't, tell, I could barely tell left from right half the time. ~Justin (Survivor)

...I was just so sick that I, I wasn't eating, I wasn't drinking, I wasn't, getting out of bed. I wasn't uh, really able to function at all as a human being at this point in time. It was, pretty terrible stuff....I [had] your very typical, chemotherapy reactions of nausea, vomiting, uh, just not wanting to eat, and having fatigue. ~Stephen (Survivor)

For Evelyn, her treatment altered her moods, which in turn affected her relationships with her family members.

Radiation I did for, two weeks twice a day every day, and then, I did chemo and I, was on a lot of steroids as well. I just remember...that the steroids really affected who I was. My cousin actually wrote, a little essay, and it said that the steroids took his sweet little cousin and turned her into, someone that I actually wasn't. ~Evelyn (Survivor)

Danielle experienced an extensive list of side effects – many which medical professionals never expected her to have.

...I did have a lumbar puncture [that] actually caused a clot in my spine. So I went completely paralyzed from the waist down, for over a month. From that, I have permanent nerve damage on the right side....they actually had to, put me in an [ankle-foot orthosis], so, I had to relearn how to walk...I was getting wounds and that sort of thing from the AFO....one time I had a yeast infection in my mouth and had to, suck on Canesten tablets which is disgusting....They always said that um, the complications that they would never, expect, I would always get. ~Danielle (Survivor)

The effects that survivors experienced were not only physical in nature. Some survivors stated that they underwent changes in their social relationships at school, as all survivors were of school-attending age while undergoing treatment. Survivors admitted that overall, their classmates and school administrators were supportive. However, there were survivors that encountered maltreatment from their peers. For example, Alyssa and Danielle described social relationships disappearing and disrespectful comments from their peers.

...because I was very actively involved in, Candlelighters, and, the Cancer Society it started getting out more and more that I was the cancer girl at school....But uh I was the cancer girl and they'd come and ask me stupid questions and pull my hair and some people would, not be around me. ~Alyssa (Survivor)

...when I first got diagnosed the rumour around high school was that I was pregnant. And then, that cancer was contagious. Um, and then, it wasn't, that I was really bullied. It was that, everybody dropped like flies like...everybody was scared to come and see me. So, I think I had, maybe one or two friends that, actually visited me and that was it. And I had a boyfriend at the time and he actually broke up with me over email. ~Danielle (Survivor)

For Dan and Joey, the side effects from their treatment sparked judgment from their classmates.

...I never felt like I was the cool kid I always tried to hide my, my hand and my arm, um, the tremor, and, you know I had a splint and I tried to hide that under my pants and, and all that stuff. Um, to try to normalize myself, and then in, I think it was like [deep inhale] grade seven or eight, um, I got bullied for um, I got called 'tumour boy'...one guy mocked me and it, and it actually continued on until the first year in high school. ~Dan (Survivor)

...I remember I went to the fair that summer and I had already lost all my hair, before school had started again, because I was diagnosed in June, so, by the time September rolled around I was, still, undergoing treatment. Hair was gone. And um, one of the, people who was a grade below me, who, really, had a chip on their shoulder....they, told me I was 'attention-seeking' - I had shaved my head and I was faking it. ~Joey (Survivor)

Survivors understood that comments of that nature were the result of a lack of knowledge or a lack of maturity from their peers. However, they believed that facing those situations made them better individuals, by making them stronger, and more confident in themselves.

Both survivors and their support persons remembered an overall description of how they felt or perceived the time during their cancer experiences. The mothers and grandmother that were present during cancer treatments expressed that they felt an array of emotions, but the dominant feeling was that of protecting their children.

I was mother bear...I can't run away. This is when my child needs me the most now...I dug deep, and, I really found, um, there is a lot of power in prayer, and, [pause] there's a lot of strength – that kept me strong, in order to, help Dan heal. ~Margaret (Mother of Dan)

The whole thing was a rollercoaster... you're scared, and then, you're nervous, and then you, you feel, terrible for them you'd take their place in a second. Um, and then you try and find the positives and you try to encourage them, so you put on a face. ~Meryl (Mother of Savannah)

I felt like I was in a nightmare and I couldn't wake up from it. I kept wanting to wake up. [pause] It was just, terrible. Just awful. If I could trade places with her I would've. ~Barbara (Mother of Danielle)

...you think, 'well why couldn't it be me instead of her? Why does she have to go through all these painful procedures?' and uh, you know you cry a lot, and, then you try to cover it up so she doesn't see how upset you are...you're on a such an emotional rollercoaster you know? ~Beth (Mother of Abby)

Survivors were also able to recall some of their familial struggles. Jolie and Dan remembered the stress their family felt, although their families displayed immense strength during that time period in order to keep them strong.

...my family was so, so tight...they were extremely supportive. They were always positive when they were around me. I never saw them shed a tear. I never saw them look really stressed, that I could see...supposedly after, when they'd leave, you know there'd be a lot of crying and stuff, uh, behind closed doors but they always wanted to create that, unified front. ~Dan (Survivor)

I remember, everyone, being, so strong, when they were around me. But like I could tell when, they had left for a little bit and [came] back [that] they and been crying and upset. ~Jolie (Survivor)

Throughout their journeys, survivors primarily remembered the strength and love that they felt that overshadowed the struggles that both they and their families faced.

...it was almost like a house divided, at some points. But at the time when I'd be home, it would be like, all that we're focused on was, like, trying to keep me healthy and trying to get me, to the, end of my treatment plan like that kind of became, the main priority within the house. Like everything else kind of, was pushed aside, I suppose. ~Danielle (Survivor)

I also remember, my parents just always trying to, keep me positive and uplifted....[my mom] stuck through it with me and kept going with me and, is still a major part of why I'm here today....not a day went by that, my family wasn't by my side. ~Evelyn (Survivor)

I felt loved. Like there was never a day where, somebody didn't come in and, and tell me that they loved me or that I was, you know, or that I was, doing, a good job like people always told me that. ~Abby (Survivor)

The fact that participants were able to recognize the strength and support from their families is extremely important. Although the cancer experience often had many negative aspects that took a toll on individuals and their families, the emergence of silver linings amidst the turmoil of diagnosis and treatment were often experienced.

For many of the survivors, the positives were some of the smaller aspects, like helping others during their stay at the hospital, or spending time with family and friends.

...one of my strongest memories was, my dad and my brother, got me a radio 'cause I loved to dance. They brought, the radio up to [me], and we were, caught dancing by one of the, nurses, and she actually joined in on it, and that's one of my, stronger, memories. ~Evelyn (Survivor)

...my mom had gotten me up and we played, air-hockey....there was one game my dad and I would play, take turns playing it was like, you know fighter planes kind of thing....yeah those would be the most prominent, I would say. ~Joey (Survivor)

...[there] was a, [little boy], and...he was uh, terminal....basically he would go for a stroller ride and...he couldn't talk because he was two. So me and his parents would just talk...they were, awesome....they found it really helpful because, they would ask me questions basically, that [he] couldn't answer. [pause] For himself....They were a lot of fun and then like, when I went to clinic I always saw them and hung out, so. Those were my best memories there. ~Justin (Survivor)

For some of the mothers and the grandmother, the positivity from their children gave them strength to continue on their journeys.

We laughed a lot. You know. 'Cause Jolie she was a fighter and she was...because cancer children are, they're amazing...oh lots of laughs one day she was feeling so lousy that instead of sitting in the clinic, they laid her on a bed and, her grandpa was with us and so. 'Come on grandpa get up here and lay on the bed' and oh my goodness they were being so silly! [laughs] But it was fun. ~Sharon (Grandmother of Jolie)

...they [had] to, paint every orifice, with antibiotic cream every day. He would make a joke out of it. He wouldn't let the nurses do it because, it involves putting antibiotic cream around, every orifice...and this little 11 year old, he would have us in stitches

while he was doing all of that. So I think he, got us through, the treatment. ~Shannon (Mother of Stephen)

Lisa commented that support from others helped her through that time period.

...at school, I hadn't seen it...some of the kids had put, on Facebook a 'Pray for Joey' link on Facebook. And that was just amazing to see that was just, one of my, getting to the breakdown point. I just sat and read that one night when the kids pointed it out to me and I it, the outpouring of support from people that you don't even know, is just, phenomenal you know people say thoughts and prayers don't mean a lot but they really do. ~Lisa (Mother of Joey)

Lastly, for Abby and her mother, Beth, their silver linings were finding out that she was going to have a stem cell transplant – a second chance at life:

...I remember, the day that they told me that I was gonna get cells from somebody and it was, it just takes you, right?...it took me a minute to like even say anything because, I had never heard of anybody being a stem cell donor before, all of this and to think that somebody in a completely different country and a completely different area, wants to help me and they don't even know me? There's good people out there. I think that was, the best memory, for me. ~Abby (Survivor)

...just this person that, had no knowledge of us or our situation but, had, you know um, had put their name on the donor list and then um, when approached, you know took the time to go and do this, so. As I said our daughter had a chance to live and that was a very special moment. ~Beth (Mother of Abby)

Despite undergoing hardships, both survivors and support persons recalled positive memories throughout their cancer experiences, which helped them through their cancer journeys. All of these pediatric cancer experiences laid the foundation for the survivors and support persons to live their lives today.

3.4 “THERE IS NO BEFORE CANCER...THERE IS ONLY CANCER.”

All individuals, particularly the survivors, acknowledged that at least one aspect of their being had been affected by their cancer experiences, such as their overall health (i.e. physical, emotional, cognitive), as well as characteristics of their personalities and social functioning. Within this theme, there are three subthemes: a) “I live with symptoms and side effects every

day. And, they're never gunna go away.”, b) “It made me grow up.”, and c) “I’m eternally grateful. I got chosen to have a second chance.”

3.4.1 “I live with symptoms and side effects every day. And, they’re never gunna go away.”

All ten survivors, as well as some support persons, stated that the health of the survivors had been affected by cancer. Each person expressed that these effects came about as a result of their cancer experiences and/or treatments. While some survivors emerged from their cancer relatively unscathed, for most, their cancer experiences took a physical toll. Some of the late effects experienced were due to their bodies’ reactions to treatments – effects they were often still experiencing currently.

Kinda, chemo like, literally froze my body. I, didn’t grow, really much during that time frame. And I haven’t [grown] much – I have not [grown] much since then....Yeah so I have sleep apnea now. [pause] Because of the excessive weight gain....I also have nerve damage in my legs. And that’s, pretty permanent. ~Justin (Survivor)

...I came out with having, different disabilities right? So in particular, uh, a right homonymous hemiopia...so, blindness in, the right side of both my eyes, um, and then also uh, ataxia or a tremor [on] my right side. ~Dan (Survivor)

...I, joke around about this all the time but I’m still waiting to hit puberty....the physical, limitations would be, just the fact that I, probably should be, 5’8 5’9 and 180, pounds. And that would, allow me to be, a different person in terms of my physical abilities....then in terms of emotional and, sexual health, being, uh, 115 pound, 27 year old male who can’t grow facial hair, certainly has an impact. ~Stephen (Survivor)

For Danielle and Jolie, complications that arose after their treatment resulted in major surgeries years after their cancer treatment had ceased. These operations caused effects that still persisted to this day.

...the surgeons actually wanted to amputate both of my legs below the knee but, because I wasn’t of sound mind my, parents made the decision to try and save as much as they could. So, they did a partial foot amputation on both feet....my right, partial foot amputation, was so painful and I was always having wounds and we were always having to do surgery and, just, walking, wasn’t feasible for me...I had, had really been contemplating for about two years to actually do the below knee amputation. Um, and then I finally decided to do that in my victory lap of high school. ~Danielle (Survivor)

...when I moved to college and I did that and in my, second year my hips, started really really bothering me. So then I had to have a hip replacement and, you can't really, you need about three months to, recover from those....I [had] my last, my second hip replacement in the summer, of, 2013 I believe....my, um avascular necrosis. Has, is, pretty much the big thing that has, affected me post treatment. ~Jolie (Survivor)

Abby is still currently receiving interventions to aid with the effects of her treatment.

Well the bone pain....they're treating, the iron in her blood...she goes to the out-patient uh cancer clinic, um, once a month and they take 400 ccs of blood [out]. ~Beth (Mother of Abby)

Further, some survivors stated that cancer might have affected their fertility, although no one was completely sure. At the time of the study, none of the participants were in the position of trying to conceive.

...I froze sperm before. And uh, so basically I still pay to have that done and because I have no idea if I am fertile or not. ~Justin (Survivor)

I never actually saw a number on what more likely than not was but I would assume about 99.9% certainty that I will not be able to have, my own children. ~Stephen (Survivor)

I've, hit menopause, so, I don't have periods anymore...I can't...there's a very high chance that I won't be able to reproduce. ~Abby (Survivor)

Their support persons reiterated many concerns about the physicality of the participants.

....there is some uncertainty as to whether or not Abby could ever have a child of her own. ~Beth (Mother of Abby)

...height and weight might both be attributed to, some of the chemotherapy. Um, of course he's going to, um, have to watch more closely cardiac effects so, blood pressure cholesterol, things like that, because, childhood cancer survivors, who are 30, have the hearts of, 50-60 year olds. ~Shannon (Mother of Stephen)

...it was the cancer that caused the chemo that caused, the bone problem right? Like she knows. She says 'if I become a mom, I will never be able to chase my child.' ~Sharon (Grandmother of Jolie)

While some survivors reported physical limitations from their cancer experiences, the health effects spanned beyond the scope of physicality. Survivors discussed the psychological

side effects resulting from their cancer. For example, some revealed that they experienced survivor's guilt, or often wondered why they survived when they had peers who may not have done so.

Knowing that, there's some people who, you know I, I look at them and go, they were a great person. What makes me so special that I'm still here, when they're not? ~Joey (Survivor)

Sometimes it makes me feel a little bit guilty, because, I was chosen to make it through my battle, and others were not. I don't understand why, but I'm eternally grateful, that I got chosen to have a second chance. ~Evelyn (Survivor)

I, as well as many other survivors I know, we carry a lot of survivor guilt. Um, so it just doesn't make sense as to why, you were, the one that was saved and, in remission, and then these other people that, had the will and strength to live and did nothing wrong and they, pass away...I don't know. ~Danielle (Survivor)

Additionally, some survivors stated that they developed depression or anxiety that has persisted to the present time.

...I get anxious every day....my anxiety is a little, different, then [other] people's anxiety these days you know....I get those anxieties too, but it's all relative. I think. In that sense, 'cause, my anxieties don't exactly match with my peers. They're a little, up, on the importance level I would say. I don't freak out about the little things. I can't. ~Abby (Survivor)

I am diagnosed with depression and anxiety. And before it was really only anxiety....I got depressed, during the cancer treatment....[the anxiety] it's horrible...if there's too many people like in Boxing Day or something, if I'm not feeling it, I can't go. I gotta like, bulk up on medication before I go in. ~Justin (Survivor)

...when I was in, the ICU, I got what was called ICU psychosis. Um, and it's where you are depressed and you have severe anxiety....they put me on antidepressants and I've been on the antidepressants since....like the depression itself is specifically related from the cancer. ~Danielle (Survivor)

Savannah developed an eating disorder in combination with her anxiety.

*...I did have, have anxiety for a long, uh a long time before I was, you know given the correct medication for it....I definitely, had a...co-morbid, um, uh, eating disorder with that, as well....my experience made me, just more, **aware** of things....the sensitivity definitely it, contributed to, me feeling anxious....I think it does have a um, a, a*

connection. To my, experience, with uh, pediatric cancer, for sure. ~Savannah (Survivor)

Other survivors developed phobias because of their experiences. For Alyssa, she and her boyfriend, Chris, acknowledged that her cancer treatment caused her to become needle- and claustrophobic.

...there was a lot, a lot of, needle pokes and needle starts. And um, from there as I got older I, am needle-phobic now I've developed a needle-phobia...I hated lumbar punctures. I'm, claustrophobic now, also because of the lumbar punctures. ~Alyssa (Survivor)

...she's needle-phobic which, she she, is convinced comes directly out of, you know is out of those kinds of experiences so....that is, kind of an example of maybe, one thing that just fear that, can, become, completely irrational and and you just know that you have it. And as you get closer to that situation you start to freak out so. Um, that's, an example of maybe how, she wouldn't, deal with stress the greatest. ~Chris (Boyfriend of Alyssa)

Jolie and her grandmother, Sharon, recognized that her experience with cancer created a fear of death.

...my day-to-day life like if I all of a sudden have, like a pain in my, like the middle of my leg or, just little things like I feel like I have a little bump or my throat hurts like, my head instantly goes to cancer....dealing with it has given me kind of like a fear of death. Like I'm, so scared I'm gunna die, and not be able to, do certain things or meet certain people or, see my, like watch my brother grow up. ~Jolie (Survivor)

Well, Jolie was probably the the bravest girl that I've ever known before this happened. Now, she's not quite so brave. She's a little bit, anxious, more so than she ever was. It did leave her that way I think. She has a few fears that she wouldn't have, you wouldn't have, said she had before. And one is dying. You know she, she's a little bit, she doesn't like to hear about anybody dying. And she doesn't like to think about it. ~Sharon (Grandmother of Jolie)

Undeniably, the mental and emotional health of participants was compromised as a result of their cancer and its late effects. In contrast, other survivors stated that their cancer experiences helped them cope more effectively with their anxieties and stressors.

I, really don't, stress about the little things....Anything else, it's like well is it really going to affect someone's life in a, major negative way? Probably not. Okay then we'll work around it. ~Joey (Survivor)

...I think I have really good adaptation skills and coping skills to deal with that stress and, considering I've gone through, cancer before in my life, the stress of going through medical school, seems, less significant, and certainly, the coping skills I developed helped to alleviate some of that stress. ~Stephen (Survivor)

Survivors addressed that they were also affected cognitively. Some stated that they have what is known as “chemo-brain”, namely issues with short term-memory as a result of chemotherapy. These issues persist currently.

...I wish I would have, um, wrote things down, more frequently, just because, your memory, like chemo-brain is a real thing so [laughs] um, my memory isn't as great, as it used to be. ~Danielle (Survivor)

Chemo-brain. That's a big one, as well. My short-term memory is not there. I, if I don't write it down, I'm not remembering it. ~Abby (Survivor)

Dan had not received chemotherapy, but also stated that he had cognitive difficulties as well.

...it was definitely cognitive deficits. I still struggle with, um, verbal short term memory and visual short term memory....in university I had to, um [pause] work, uh, I had to get extra time for tests and stuff like that not because I, I couldn't um, understand the information it just took me a bit longer to read it, and a bit longer to kind of comprehend, uh what was being asked of me. ~Dan (Survivor)

Other survivors stated that they had developed learning disabilities, or had previously diagnosed learning disabilities that became more prominent after their cancer treatment.

...probably the main thing would be my, slight learning disability, if you, categorize my spelling and grammar skills, they are, an elementary school level. And I will never, reach, high school or university level for that. No matter how hard I try. But that's probably the only thing that's really been delayed. ~Alyssa (Survivor)

...I did have, a learning disability....that learning disability has really come out. Strongly. Because of, I guess, chemo....chemotherapy makes it worse. Or can make it worse. [pause] So, um, [pause] I really see it come out now. And I didn't really see it as an issue when I was a teenager. ~Justin (Survivor)

Some of the mothers, as well as Catherine, Justin's fiancée, addressed different cognitive effects that their survivors were experiencing; however they could not comment on whether the effects were directly attributed to their cancer experiences.

...Dan can be impulsive, and that can be one thing that they had, um, they deemed – the physicians. And, um, the occupational therapist and physiotherapist had said that a lasting effect, could be impulsivity. ~Margaret (Mother of Dan)

...Savannah's directionally challenged. And, I'm not, I don't know if that's a correlation or not....like she doesn't like the whole, experience of of, sort of, 'let's go downtown today and, do this and experience this and that' she's never been, doesn't know how to go, there and hasn't seen it, then it's difficult for her. ~Meryl (Mother of Savannah)

...I find, in a lot of aspects of his life like he can't, think, things through, like he would if he had a proper education, I believe. Um, just, basically [pause] simple stuff too like, I tried to show him how to, like just, he can't read a map....Like if he's watching a movie, and you know how there's like, underlying plot and you can see it? Like he can't pull that out. ~Catherine (Fiancée of Justin)

Undoubtedly the cancer survivors experienced effects later from their treatments as conveyed by themselves and/or their support persons. Few survivors acknowledged that their health, or health strategies, had been positively affected (i.e. in their coping mechanisms). This sub-theme revealed that the cancer process negatively affected many individuals regardless of the diagnosis or treatment they received.

3.4.2 “I completely changed.”

When thinking about the way in which they approached their lives currently, all survivors believed that some aspect of their personalities had changed as a result of their past experiences with cancer. Individuals stated that they considered themselves more mature than their peers, or that they were forced to mature earlier than others as a result of their cancer diagnoses.

...I think I was forced to mature, mm, faster than everyone else. Like, um, [pause] I had to more, think about, surviving rather than, going out and partying and having a good time and living that whole, aspect of life. ~Jolie (Survivor)

...when you go through something like that, it just, you have to mature a lot faster just because you're dealing with things, a lot of kids shouldn't have to deal with and don't even have to think about. ~Evelyn (Survivor)

...I, think I matured a lot faster, than, my peers just because I was so young when I was diagnosed. So I understood, way more mature topics and mature notions, before any of my friends did. Like I could rattle off an entire medical procedure to you by the time I was seven. And I don't think most seven year olds could do that. ~Alyssa (Survivor)

Joey and Abby admitted that they currently feel more mature than their peers.

...mentally, I feel like I'm more mature, then most people my age. Emotionally, um, as well. ~Joey (Survivor)

I'm like 100 years old [laughs]I've just gone through so much that my, life experiences is, that of a 70 year old, right?....I've matured a lot. And I wouldn't want my friends to mature as much as me right now, because, that would mean that their life experience, is that of a lifetime. ~Abby (Survivor)

Most support persons' comments mirrored the opinions of the survivors regarding their necessity to mature faster than their peers.

...he's an old soul. As an 11 year old he coped, amazingly well. He did amazingly well. And he's, always been that way....you know not many 11 year olds have to face a terminal illness, so, uh, he probably matured, well before some of his peers, emotionally. ~Shannon (Mother of Stephen)

I think it forced him to mature a little faster. Quite honestly. You know he had to deal with things that a lot of kids don't have to deal with he had to be careful. And pay attention to what was, around him. Um, and take care of things and, everything had to be clean and, so I think it forced him to mature a little faster. ~Lisa (Mother of Joey)

Additionally, survivors stated that aspects of their personalities were altered because of their experiences. For those who believed that their personalities had changed, all acknowledged that the changes were positive in nature.

...I think also, like, I completely changed, from how I was in the beginning of grade nine to who I am now. Like I used to be very shy, and, quiet, and now like I have no problem, talking to people in public I do a lot of public speaking, um, if people ever have any questions about, myself or my treatment or my cancer story or that sort of thing I'm like, an open book so. I think also like, the treatment and the whole experience kind of changed me as a person. Like personality wise. ~Danielle (Survivor)

I think that, because of, [pause] being in the hospital I've learned from, the nurses and families just to, be kind and caring for, those around you. I find that I am good, socially with the families. Working problems through, listening, and comforting others. ~Evelyn (Survivor)

*...I'm rather positive....at one point I wasn't, and, it was all attributed to my, um, disabilities, where I really started focusing on my abilities?....I'd also say in terms of my, like, my drive to, when I'm told I can't do something, um, that's when I really am **pushed** to, to move forward because I was told I couldn't do a lot of things. ~**Dan** (Survivor)*

Support persons believed that the cancer experiences changed the survivors' personalities for the better.

*...I definitely think he's a more caring person....he, will go above and beyond for anyone, and he cares about, everyone, like, [pause] he will do anything, if they ask him to....like his parents always wish that he never had cancer, and I always tell them like that, may have caused him to not be the man he is right now. Um, 'cause he is, so much more, um, supportive and, there for you like, he cares. ~**Catherine** (Fiancée of Justin)*

*...she definitely has, um, a sense of caring, uh an empathetic side, to her that maybe she, wouldn't have come out this much had she not gone through it. ~**Meryl** (Mother of Savannah)*

*Oh she's much more confident now. [pause] Yeah. Well when you battle anything it makes you stronger. Yupp. Definitely. Oh she's a fighter. She's stubborn [laughs] when she wants something there's no stopping her [sniffs]. She's little but she's mighty. ~**Barbara** (Mother of Danielle)*

Overall, survivors believed that their personalities changed because of their experiences, and their support persons agreed. These changes were both positive and negative in nature – while survivors matured quickly due to the graveness of their disease, they became more confident, kind, and positive individuals.

3.4.3 “I’m eternally grateful. I got chosen to have a second chance.”

The title of this subtheme, shared by Evelyn, references the fact that she greatly appreciates surviving her cancer diagnosis, and is extremely thankful for the fact that she was given a second chance at life. This sentiment resonated with all of the survivors, who felt remarkably appreciative for the fact that they were alive. Alyssa was too young to remember life before her cancer, but knows the way she lives now is because she survived her cancer.

But I think, how I lived my life since....it's very much impacted on the fact that I had, cancer as a child....I think 100% cancer, has had a huge impact on my life, and has changed it, from what it would have been if I was just a normal average two year old that had never seen a hospital in [her] life. ~Alyssa (Survivor)

For Danielle, being on the brink of death inspired her to experience as much as she could with the second chance she was given.

...I like to, travel and experience things, um, I'm more adventurous now like I want to experience life so....I've gone skydiving. Um, I want to try hang-gliding like...I have a list, it's like a bucket list...that I started writing down when I was on treatment. [The list is] of things I actually want to do and experience so. It's kind of a to-do list that I would like to experience all of those things before, I die. Whenever that is. ~Danielle (Survivor)

Savannah discussed how beyond “grateful” she was to have been given a second chance as well, even though she acknowledged the time in which she was undergoing treatment was not a positive experience.

...it's kind of, a great impact on my life and, I definitely, wouldn't be who I am today without it...it's made me a stronger person, and, in general, it's made me, like, uh, learn how to be very – really sensitive to people's feelings, and, just to, you know, situations in general. And....I'm very, I'm grateful for the experience looking back on it even though it wasn't so great back then. ~Savannah (Survivor)

Abby summed up her sentiments of being a survivor with the following quote:

I'm very grateful to be alive. Very grateful. There, there was, many instances where, I, I could have not been alive anymore. Um, but, I am alive. And, I'm going to do, [bigger] and better things than, my cancer diagnosis....even though I face all these struggles and, and, and setbacks every day, um, there, I I'm just grateful. Like that's the only thing I can really say about it is that, there's, not one ounce of me that isn't grateful. ~Abby (Survivor)

Her mother supported her opinions and added:

But I think, she probably values, you know um, being healthy and being at university and being sort of a normal 22 year old, probably a lot more than, the average 22 year old.... She really sees that, you know she's fortunate to have made it through this. ~Beth (Mother of Abby)

However, “surviving” pediatric cancer, or being a pediatric cancer “survivor” did not necessarily encompass the views of all the individuals who experienced pediatric cancer in this

study. When speaking about the vernacular of cancer, the word “survivor” is often used to describe individuals who were diagnosed and treated for cancer, and have lived past remission (Bartels, 2009; NCCS, 1986). However, not all individuals may define the word survivor as such, or identify with the term, regardless of the type of cancer they had. This topic was discussed during the interviews with all participants. Both survivors and support persons conveyed their opinions on the term, as well as whether the survivors in the study actually identified as such.

Both survivors and support persons were asked to define the word survivor, or to describe what the term meant to them. In stating their definitions, there was a plethora of language pertaining to war and battle analogies used to help define survivor. The title of this subtheme became a shared sentiment of many of the survivors, as appreciation for surviving, and having a “second chance” was prevalent in these definitions as well. Some of the participants directly referenced themselves as “overcoming something” in their definitions.

...I have overcome something, that, [pause] there are plenty of people who haven't, and they've succumbed, to that, and I, it makes me feel like victorious...I did this...I survived cancer. ~Jolie (Survivor)

To me a survivor is an individual, that has fought, a hard battle, or cancer, or, any battle really in that sense, and has gotten through it. I think it just means, that, you're somebody that, has, been lucky enough, to keep going in life and that, you don't give up, easily, and that, you were given a second chance at life. ~Evelyn (Survivor)

To others, the term survivor was about “coming out the other side”, once again automatically placing themselves, or who they were caring for, in the definition.

...in it's simplest form she survived, the cancer right? Some people did not, some people did....if you're a survivor, things have been handed to you, and you've dealt with them and you've, come out better on the other side. You've survived. ~Sharon (Grandmother of Jolie)

...someone who has, been through, some kind of, tragedy or illness, or, kind of horrific, experience and made it out the other side. Relatively intact. ~Alyssa (Survivor)

...I overcame, the possibility of death I suppose...I overcame the possibility of death and that I also overcame, um, a very difficult life experience, and came out, the other side, like, in a positive way. ~Danielle (Survivor)

...someone who's, come out the other side of something, difficult...It could be physically, mentally, emotionally, um, any of those things. ~Meryl (Mother of Savannah)

For Barbara, the definition was solely about her daughter Danielle, her ability to beat her cancer, and how she has lived a second chance at life since her cancer experience.

She's alive. She has a good attitude. [pause] Uh, [sniffs, long pause] she's able to give back...She's able to, support others with cancer...She supports the cause...she was strong. [sniff] Uh, [sniff, pause] she beat the odds. ~Barbara (Mother of Danielle)

Many of the definitions provided were extremely positive in nature and were believed to epitomize the survivors. It is important to note that although the majority of individuals provided definitions similar to those stated, not all opinions were in congruence. For example, Dan believed the term survivor was all about how an individual personally identifies with the term:

...I guess for me, semantics....you can call yourself whatever you want, right? Um, I think that, that's good if that's, what's important for you. But for me it doesn't really mean, all that much. ~Dan (Survivor)

His mother, however, had a different opinion about survivorship.

Someone who's dug deep...and by being deep I mean really looking into themselves, and finding, the strength, the strength in themselves, to, deal with adversity, around them....developing wings, and just taking off. That's a survivor someone who, isn't just existing but who, is, being a contributing member to a society. ~Margaret (Mother of Dan)

Stephen and his mother, Shannon, shared the same opinion concerning the term survivor. They believed the term was overused.

...the term cancer survivor I think has a lot of those, [war and battle] connotations associated with it. Which, I personally don't, uh embrace any of those....To me, I was diagnosed with cancer, and I was treated by medical doctors. The medical doctors did, all of the work for that to happen. As a patient, I didn't do any work to battle cancer. ~Stephen (Survivor)

It's an overused term, that needs to be, taken from our vocabulary and stop labeling people as survivors...I don't know if someone's come up with, a term that really describes, but, I think that all people, battling illness don't want to be identified as their illness. They want to be, still recognized as [the] person they are...rather than, you know, a cancer survivor. ~Shannon (Mother of Stephen)

The term survivor conjured up different opinions among the survivors and their support persons. Some participants identified with the term, while others did not. As such, the word may not necessarily be the most accurate term used to describe this population.

After being asked to define the word survivor, all individuals were then asked whether or not they believed the participants to be pediatric cancer survivors. The responses were overwhelmingly in favour of the term, with eight of the ten survivors classifying themselves as such, and eight of the nine support persons concurring. Both survivors and support persons also shared their gratitude that the survivors did just as the term implied – they “survived”.

Catherine considered Justin to be a pediatric cancer survivor because he lived through his cancer experience. However, she conveyed that he was also still surviving, as he has continued to learn how to live with the late effects of his cancer.

Yes. [pause] I mean, he went through, cancer which was, pretty rough and, he has made it to the other side but, it's like, [sighs] it's a steady process. Like, there's certain little aspects that pop up and, he just keeps having to, um, get through them so like, life's not back to the way it was but, it's better. ~Catherine (Fiancée of Justin)

Other survivors in the study were in favour of the term and what it meant to them. Both Jolie and Alyssa considered themselves to be survivors in a more literal sense, in that they were alive because they received treatments for their cancers.

...if I were to go to the doctor right now, and they were to, do a bone marrow biopsy, my blood would be clean...whereas, in 2012, it was, full of mutated cells. ~Jolie (Survivor)

...I was diagnosed with, a potentially fatal illness depending...if I had been diagnosed 10, 20 years earlier, it may very well have been fatal. It, was, due to, technology and, science at the time that allowed me to survive, that type of, invasion on, my, body and my bodily systems. ~Alyssa (Survivor)

Savannah and Abby felt grateful to be considered survivors, as not all individuals who undergo the cancer experience can share the same sentiment.

But yeah I do even though it happened, you know, however many years ago. Um, I do consider myself a survivor. Um, and it means a lot to me, that I am one. ~Savannah (Survivor)

Yeah. I would consider myself a survivor, not necessarily just cancer, because, cancer is what I had. It's what, tried to kill me, but, I'm, I'm a survivor my disposition is to be a survivor. I was destined to be a survivor....being a cancer survivor, is, is special. And, there's not a lot of people in this world that can say that they are, so I'm very blessed to be a part, of, that community. ~Abby (Survivor)

This gratitude also extended to the support persons. For many support persons, considering their participants to be pediatric cancer survivors was a source of pride.

...it affected him in every possible way I imagine it could. Um, but he still, came through it. He's made a decision he's, he wants to do something and, he feels that he can change, I think [laughs] he feels he can change the world by himself. Um, but, I mean I guess the experience has helped him, to be more empathetic towards some people. ~Lisa (Mother of Joey)

Absolutely. Absolutely. Yes. Always going to be grateful, for the treatments, and the doctors and the hospital and the, oh, yes. Yes. [laughs] She's definitely a survivor and when she's at the Relay for Life she wears her survivor shirt, proudly. Absolutely. ~Sharon (Grandmother of Jolie)

'Cause she beat the odds. She went through an incredibly difficult, um, journey...with being in the ICU with having the stem cell transplant....Um she made it to her one year two year, and two and a half year transplant anniversary, um, stronger than ever...And she did it with grace, too. I mean she never whined, she never complained, she never once said 'why me?' ~Beth (Mother of Abby)

The three individuals that were not in agreement with the term were Dan, Stephen and Shannon. As Dan believed the term was a matter of semantics, he would not personally identify with the term.

I, I don't ever, consider myself a sur-sur-survivor....I don't necessarily like to [pause] give myself like, give, give a word like that, to, relate that to myself. ~Dan (Survivor)

Stephen and Shannon both understood why individuals who had undergone the cancer experience identified themselves as survivors, however neither would recognize Stephen as a survivor.

He is, the recipient of a bone marrow transplant that was successful, from his brother. He's not a childhood cancer survivor, he's Stephen because, this was an aspect of his life that he had to, go through. ~Shannon (Mother of Stephen)

...if it was not for the medical advancements that were made by Sidney Farber, who, treated the first chemotherapy agent, which was, methotrexate...it was used on, childhood cancer, patients, who had leukemia, in the forties. If he didn't do that I wouldn't be here today, so, I don't want to take, any credit for surviving cancer. I don't think that's...on me. ~Stephen (Survivor)

Even though Stephen would not consider himself a survivor, he acknowledged that living past his cancer provided him with many newfound chances to achieve.

...it's tough for me to say there are positives that come out of having cancer. ...but I certainly understand that there are. I have, had good things in my life happen since I've been diagnosed with cancer, and some of them have been directly related to, that cancer diagnosis. ~Stephen (Survivor)

All points made in the discussion surrounding survivorship were extremely valid, as the variety of definitions provided allowed for more multifaceted definitions and perspectives on the word. It also aided in understanding that not all individuals who experienced pediatric cancer identified with the term, and as such, grouping a set of individuals as “survivors” would not address all the views of the group. Regardless of the views on the term, all “survivors” were grateful to be alive, and discovered newfound ways to utilize this second chance at life.

3.5 “I DON’T KNOW IF I WOULD CHANGE IT.”

Despite the devastating effects of pediatric cancer as discussed in theme 1, all participants found a way to give back to the pediatric cancer community – through giving advice and mentoring others, in their schooling and career decisions, or in helping others understand the preciousness of life itself. The title of this theme, “I don’t know if I would change it”, was a

phrase shared by Danielle. She, like other survivors, had disclosed that they would not change having cancer, or aspects of their cancer experience, because their journeys changed the way in which they view and live their lives today. After going through cancer diagnoses and treatments, the survivors admitted that they were grateful for their experiences. Within this theme there were two subthemes: a) “Stop and smell the roses.”; and b) “I think it’s given me kind of a purpose.”.

3.5.1 “Stop and smell the roses.”

Within this subtheme, survivors discussed the positive changes within their family units, as well as the effects their cancer experiences had on their future schooling, career choices, and personal values. As stated by a multitude of the survivors, “stop and smell the roses” illustrates the fact that they cherish life more, and live life with the purpose of helping others, which they learned in undergoing their cancer journeys. Although a pediatric cancer diagnosis and treatment was extremely difficult for them as children and their families, many of the survivors recounted the strength of their families during that time period. They stated that their experiences brought their families closer, made them value each other more after the experience, and helped shape their family units today.

...The support that, um, my dad gave to my sister and the support my mum gave to me, was just uh, just really, fundamental in terms for our growth as [a] family. ~Dan (Survivor)

...My other sister had three kids. The house turned from me, them, and my parents into, my sister and, her boyfriend....they taught me it was kind of awesome....it really brought my family together. ~Justin (Survivor)

...I value my family a lot. They are literally my whole world. ~Jolie (Survivor)

I would just say that, my family and my friends were my biggest supporters. I probably don’t tell them this enough, but, if it wasn’t for them, I don’t think that I would’ve gotten through that situation, and had the outcome that I did. ~Evelyn (Survivor)

Support persons also concurred that the cancer experiences not only strengthened the bonds that they had with their children, but also the resilience of their family units.

...if I had had a choice, she would never have had cancer. Absolutely no - nobody should...But, in the way the family, worked together and, and what we did for her, I wouldn't change. ~Sharon (Grandmother of Jolie)

...that's something, that impacted my life the fact that, the family became closer and the fact that my husband and I became closer as a result. Um, if that was possible....being supportive for her and each other. ~Meryl (Mother of Savannah)

...we realized we're a strong family unit and I think that's, you know, certainly, very positive...we've had a lot of people say interesting things to us....you know if they had some sort of minor difficulties [laughs] they were going through, they would say, um, you know look at what that family's going through and look at how they're dealing...I think in some ways we became, we became, a little bit of an inspiration for some other people in kind of a weird way. ~Beth (Mother of Abby)

...it brought us very close together. Very close together. Yupp. We'd sit and watch House and we'd paint nails...when she was neutropenic of course we had to stay in that room...We'd spend hours together, look at magazines...No I wouldn't, I wouldn't trade it there'd be, nowhere else I'd be but, other than with her. Yeah like, there was no question about that. I wouldn't have been, anywhere else. ~Barbara (Mother of Danielle)

Chris, Alyssa's boyfriend, although not present during her cancer experience, knew that her family had become closer as a result of her cancer.

...you go through a lot, as a parent, in, having a child through, diagnosed with cancer. Um, and, I think that, that, uh, the fight, they probably had with Alyssa, um, trying to get her, uh, cured, or, feeling better was probably a really huge bonding one, for them, and her. And uh I think they came out of the other end of it probably appreciating her a lot more but being a lot more protective of her as well. ~Chris (Boyfriend)

It was remarkably apparent that both survivors and support persons had a powerful love and appreciation for their families because of their experiences.

Additionally, when speaking about appreciation, survivors indicated that their values had shifted since their experiences, and that they valued and prioritized their family, friends, and the fact that they lived beyond their cancer diagnoses. Many survivors expressed that their perspectives on life had been altered.

...it's changed almost every aspect of my life...The things that you go through, makes you, realize, not to focus on the little things in life but, focus on the big picture, just be grateful for, everything that you have and every day that you, are on this earth. ~Evelyn (Survivor)

...my morals and values have been redirected for the better....I value, um, not just, you know the big things in life but the little things in life....when you get into a position like that it's, you know, fight or flight right? You're either gunna retreat and you're not gunna, not wanna deal with anything or you're gunna fight it and you're gunna go head on. And I went head on and I think that that's how I deal with everything now. ~Abby (Survivor)

...I just think that I wouldn't be the person I am today without, my cancer experience...I mean I appreciate life more, I value experiences over things...my friends and family [clears throat] like the relationships I have, and I don't know what, I would do without the people in my life. ~Danielle (Survivor)

Other survivors concurred with Danielle's sentiments about not taking life for granted, and understood that although a negative experience, their cancer journeys provided them with life lessons in which to live their lives today.

Yeah it's given me a different outlook to, live every day to the fullest. Like I, I've been given a second chance, so I better do something with it....Live it to the fullest. You are not always promised tomorrow. ~Jolie (Survivor)

...it's, made me want to...take in every moment, and not, you know, uh, take anything for granted, for sure....So, I've, always just, l-learned to not take things for granted, because of it. ~Savannah (Survivor)

...it changed my outlook on, life, basically, the structure of life and, you know don't take it for granted and don't take stupid risks. ~Justin (Survivor)

...I was fortunate and the people around me also, uh, let me know, to be aware that I was fortunate.....I think that, it led me to, kind of look at life as something that, um, is full of opportunities...something where you kind of create your future because, um, whether I see myself as...an individual with a disability or...as someone who has a lot of capabilities who's able to do a lot of good things in the community, that really affects, where I go and, and so that, effects kind of my life outcome and my uh, life, outlook, for sure. ~Dan (Survivor)

Mothers reiterated these sentiments expressed by their children.

...I think he's, just like, everyone else and maybe, just maybe, he'd squeeze a little bit more out of life because he knows it's so precious. ~Shannon (Mother of Stephen)

I think it's made him believe that, you know he's got a second chance, at life and he's gonna make the most of it. ~Lisa (Mother of Joey)

The graveness of a cancer diagnosis often shifts the priorities of all individuals involved, and for these survivors, their priorities were redirected for the better.

3.5.2 “I think it’s given me kind of a purpose.”

The ways in which survivors made the most of their second chances were manifested in different ways. For many, their experiences influenced their schooling, career goals, and volunteerism paths that may not have originally been taken.

All participants stated that their career choices, or the careers they were striving towards, were chosen because of their cancer experiences. In many cases, they occupied positions in which they helped those going through the same experiences they had. For example, survivors were in school to become psychologists, physicians and social workers, while others had career aspirations that led them to different positions in hospital settings – like Alyssa, who became a Child Life Specialist to help children going through their pediatric cancer journeys.

If I hadn't gone through pediatric cancer, I wouldn't, have had such a strong, affinity and want to be in the health care system....I'd had such a positive experience, with the Child Life Specialist that I had....the fact that I get to do that now for other kids, I don't think I would have known about child life or even explored it if I hadn't have had cancer. ~Alyssa (Survivor)

...she's in Child Life which is, I mean that's closely related to care....her remembered or relayed experiences whatever, um, she, thought that there was, sort of a niche or room for it in the healthcare system. ~Chris (Boyfriend of Alyssa)

Additionally, Joey is a hospital security officer.

I hadn't really thought about, working at a hospital, uh at that point in time. I hadn't really thought about, building the stepping stones, towards, policing. I just thought security policing. But, um, seeing, how, you know, I was treated by the staff there....if I can...make somebody's day a little less [bad], why not? ~Joey (Survivor)

Further, Stephen is currently completing his degree in medicine to become a physician.

...seeing the talented professionals, in the [hospital] growing up, it, you know, you develop an admiration for what they do. You also develop a sense of, like amazement, and wonder, with what they can do. And that, shaped, the way that I, um, I guess that, changed the way I went through school. ~Stephen (Survivor)

Other participants simply wanted careers that allowed them to help others, not necessarily in the field of cancer.

...[my aspiration to work in recreational therapy] changed because I wanted to help people....I can relate to a lot of people because...well they're really stuck inside their bodies or minds and at one point I was too. So, [pause] it really helped me, having cancer. It kind of really helped me, decide what field I was going in to. ~Justin (Survivor)

Ever since I was little, I've always wanted to work with kids, and today I get to do that. I get to work with families that have, seriously ill or injured children, and, it's, awesome, I'm so grateful to be a part of their journeys. ~Evelyn (Survivor)

Abby shared how her orientation in the field of business was redirected after her cancer experience.

I came into [university] thinking that I was going to be the next Wolf of Wall Street...I was, so goal-oriented in getting through the business program, and uh, after my treatment I came back, and, I decided, that I wanted to work for non-profit organizations. So completely, the other end of the spectrum. From being money hungry to being, [laughs] charitable, right? So, um, yeah definitely changed my career goals. ~Abby (Survivor)

Her mother expressed a similar sentiment, stating that:

...her goal in life is to work for, non-profit organizations to raise funding to help other people so that, they don't have to go through what she went through. ~Beth (Mother of Abby)

Additionally, survivors did not only want to give back with their career choices. Many also volunteered, or had extracurricular work within the realm of helping others deal with their cancer experiences. As an example, some survivors were mentors to individuals going through cancer treatments.

...I volunteer for the Pink Pearl Foundation....I, am a mentor for young women and men....who are going through stem cell transplants or cancer treatments in general. I've talked to about, six people, since I've been diagnosed. ~Abby (Survivor)

I volunteer, like I said, with the Canadian Cancer Society, pretty much year-round....So, raising money, going out into the community trying to get donations. But I also, am a, peer support....if somebody needs somebody to talk to, then, the Canadian Cancer Society would send me an email, asking if I had the availability....I welcome the opportunity to help somebody through, something like that because...it sucks. ~Joey (Survivor)

Danielle spent her time speaking to others about her experiences to raise awareness and give back to the organizations that helped her through her cancer journey.

All of the volunteer opportunities have some relation to my experience. Um and, me giving back to, the organizations that helped me as well throughout my treatments....I've gotten opportunities from those volunteer opportunities to travel and speak to other, people that are also as passionate as, um, about those kind of things as I am so. ~Danielle (Survivor)

Her mother, Barbara, believed that it is part of her life purpose to give back what she was given.

...maybe it's, what she's meant to do maybe, like they say there's a reason for everything right?....why was she saved when other people aren't saved? Like, there has to be a reason for it....So, I mean she's raised a quarter of a million dollars she's, been to all these [sniff] conferences and relays and meetings and, she's met all these people and she's been given all these awards and, so I have to think that, that's part of the reason. ~Barbara (Mother of Danielle)

After her bout with cancer, Alyssa attended a camp for pediatric cancer survivors, an experience that altered many aspects of her life to this day.

I went to camp when I was five years old for the first time...and, that, changed my life....Not only, did I go there for 10 years as a child, but I, have now been there for 10 years on staff [laughs]....I wouldn't have ever met my boyfriend because I never would have been, on staff at, my camp. ~Alyssa (Survivor)

Chris acknowledges this as well.

...the way we met....is, directly and indirectly through the fact that she had cancer so that's a big one. Um, so that affected my life obviously because I met her through

that....she meets a lot of really, special people through those organizations. ~Chris (Boyfriend of Alyssa)

Additionally, for Alyssa, her parents wanted to give back after going through the cancer experience with her – they wanted to help others going through the same thing.

...I know my mum, got, super super involved in, Candlelighters and, the Cancer Society...she actually ended up starting, the Candlelighters chapter in, [city]. And then ended up being the Vice President of the Cancer, Children's Cancer Society or Candlelighters something like that she's really, high up there Vice President or President or something like that. Um so she was a really big advocate for, parents support and, support of, the children my dad went to a couple of groups but he preferred to stay, more to himself then to, get involved with other dads. ~Alyssa (Survivor)

Although the cancer experience was daunting, and often negative in nature, there were silver linings that emerged from their journeys. Survivors believed that it was important to give back to the organizations that helped them during their experiences, and to help others who may have to endure cancer themselves. Volunteer activities and career choices were two of the avenues used to express appreciation for the support they had been given in their times of need.

In addition to the unparalleled work the survivors already do in the name of cancer awareness and volunteer work, they were given the opportunity to voice words of encouragement to those currently undergoing, or who have undergone cancer treatment. When speaking in regards to individuals who had been recently diagnosed, survivors stressed that individuals needed to remain positive throughout the progression of their cancer treatment.

Much of the advice to stay positive was summed up by Evelyn.

...it's not going to be easy, but when you focus on those positive things, that is what's going to help you get through everything...find those relationships that will keep you motivated and keep you going, and those relationships that have your back, those are going to help you get through. ~Evelyn (Survivor)

They emphasized that this advice allowed many of the survivors themselves to come through their respective journeys. However, there were some distinct pieces of advice that, while having

remained positive, addressed other aspects of the cancer journey. Some survivors stated that individuals needed to advocate for themselves throughout their treatment:

...they just have to listen, to what the doctors are saying. Listen to what options they have, uh try – make sure, especially if they're a little bit older make sure they're involved in, their own care discussions that nothing is, hidden from them. ~Alyssa (Survivor)

...it's 80% mental and 20%, out of your control....you just have to come to terms with the fact that you have cancer, and, you're gunna fight it. And, you're gunna get better, and the only way to do so is to be positive and to listen. And be your own advocate. ~Abby (Survivor)

For Dan, it was about embracing differences.

...I'd say probably something along the lines of [long pause] your differences make you, make you special. Your differences make you, um a unique person and that's okay....being aware that like it's okay to be different and it's okay to, to have these experiences that doesn't make you less of a person. You should be confident and proud of yourself. ~Dan (Survivor)

Stephen advised to use their experiences to develop perspective.

...don't let cancer become who you are. Don't fixate on, being the kid with cancer, don't, make it, your, end all be all. Be yourself. Let that experience influence you, in a way that, it gives you perspective. Take something from the experiences that you had with cancer. Use them, to shape you, and, use them to your advantage but don't let it consume you. ~Stephen (Survivor)

Survivors were then asked what advice they would have for someone who had been through the experience, and were now older adults, like themselves. Again, responses overwhelmingly navigated towards remaining positive. Additionally, survivors stated that if they were to converse with another individual who had been through the cancer journey, they would want to share and compare experiences. Nevertheless, there were some unique perspectives brought forward by some survivors. Savannah described that, having been through the experience, it was about celebrating the second chance given.

...do things that make you happy. Um, 'cause you're already gone through a negative experience, and, I don't think, anyone would, would want to spend their life being, you know, being uh being that, um, down, again. ~Savannah (Survivor)

Alyssa described how individuals should use their experiences to shape their aspirations if they so desired.

Come get involved and, give back to the community you love, whether it's a, hospital volunteer or, a camp volunteer. If you want to stay totally, away from any of that, then that's fine to do too! ~Alyssa (Survivor)

And, for Dan, it was not about what to say, but rather, what to do.

...it's an obstacle in your life. We have a lot of things we face and uh, just being there as support, um being there as...a positive, kind of empowering person, um and, really motivating people who are in those situations to, keep pushing on and keep going through it. Um, I think that's all you can really do I don't think the, specific words you say are going to, gunna, matter as much as the [pause] the actual actions you, you make. ~Dan (Survivor)

All survivors conveyed that they wanted to give back in at least one way because of their cancer experiences. Through their own personal perspectives, careers, and volunteer work, survivors strongly believed that they would aid other individuals diagnosed with cancer in ensuring their lives would be changed for the better as well. With these views on how their cancer experiences shaped their lives, this concludes the themes discussing the effects of pediatric cancer on survivors.

3.6 “AS LONG AS YOU NEED ME I’M YOURS.”

This theme specifically addresses any effects experienced by support persons as a result of caring for pediatric cancer survivors. The quote “As long as you need me I’m yours” was shared by Sharon, grandmother to Jolie. At the beginning of her cancer treatment, Sharon explained that she often said this phrase to Jolie to let her know that, regardless of the circumstances, she would be there to care for Jolie whenever and in whatever ways she would need it. The same could be said with the other support persons recruited for this study, who all provided care for their survivors whenever they were in need. All support persons indicated that their lives had changed as a result of caring for the survivors, regardless of whether or not they

were present for the cancer experiences. The effects were not to the extent, or as negative as the effects described by the survivors; however, the experiences of the support persons were still integral in describing the lived experiences of life past remission for individuals who had pediatric cancer. Within this theme there are two subthemes: (1) Do their effects affect me? and (2) “You realize what’s important and it sticks with you.”. Each of these will be discussed in turn.

3.6.1 Do their effects affect me?

Support persons conveyed that they currently experienced no physical effects as a result of being caregivers for pediatric cancer survivors, although some of the mothers present for their children’s cancer journeys had experienced physical effects during that time period. Any physical ailments or difficulties experienced by support persons when interviewed were attributed to factors completely separate from their caregiving. Additionally, none of the support persons reported any cognitive effects in relation to their caregiving responsibilities. Conversely, some support persons claimed that they experienced compromised mental or emotional effects as a direct result of their cancer experiences with their survivors. The following quotes illustrated the constant worry and anxiety experienced by the support people.

...he’s easy to, make friendships, I think. And in some ways he can be naïve. I sometimes am concerned because I think he, trusts people, too much. And not everyone has good intentions, and most people do! But you just have to be careful. Um, and I don’t always know if he, can, read those signals? ~Margaret (Mother of Dan)

...I mean my life has definitely become more stressful, ‘cause I worry about him and I worry every time we go to a doctor’s appointment to see if it’s come back and, but like, [sighs] I would say my way of handling it hasn’t really changed. ~Catherine (Fiancée of Justin)

Mentally probably just, with, with the stress factor, and, 'cause you're always going always worried. Um, even now, you know when his, he has to go for his check-up I don't go with him. But I want him to text me and let me know [laughs] that everything's okay. ~Lisa (Mother of Joey)

Meryl believed that in being with Savannah during her cancer experience, she managed stress differently and became emotionally distant in order to protect herself from being hurt.

...I can probably tell you that I handle things differently. In terms of emotion. Um, I maybe, set, set things a little further away from me and maybe don't, don't let myself in, as, as often or as deeply as I once did. ~Meryl (Mother of Savannah)

Barbara developed severe anxiety and post-traumatic stress disorder as a result of Danielle's cancer experience, conditions that she still lives with today.

I've suffered post-traumatic stress disorder. [pause, lowers voice] Yeah, yeah it's been bad. I've been going to a psychiatrist ever since....I still get flashbacks....it still causes me anxiety....my psychiatrist is in [city] and when I drive that way past the hospital I still get anxiety. And I'm still on medication. ~Barbara (Mother of Danielle)

Conversely, Beth reported that her experiences aided her in coping with stress.

...you know you can kind of laugh at some of the things that, you're about to worry about...little minor details about you know, um 'oh I have to get this I have to get that' and you think 'well why am I stressing about that?' ~Beth (Mother of Abby)

It was evident that support persons very deeply cared for the survivors, and as such, experienced some psychological effects in caring for them, effects that persisted past the treatment phases and to the present time.

Like survivors, more than half of the support persons also felt that aspects of their lives had changed as a result of caring for their survivors. Other support persons stated that aspects of their lives were simply reinforced, rather than changed. Regardless of their presence during the cancer experiences, those who admitted experiencing changes acknowledged that aspects of their personalities had changed, primarily for the better. Shannon, having been diagnosed with

breast cancer after Stephen's cancer experience, knew that going through the experience with him helped prepare her for her treatment.

Definitely I think you um, you're hyper vigilant, over little things....I, guess I saw a more personal side of medicine, that, um, yeah I respected that so. I expected that when I started my treatments, that nothing would be held back. That I would be, um, responsible for my care as much as the oncologist. So yeah it did affect my personality. ~Shannon (Mother of Stephen)

Catherine became more accepting and tolerant of others, as she knew that anyone could have faced a hard battle unbeknownst to her.

...I would say I'm more aware of things now like...because, if you look at Justin from the outside like he looks happy he looks normal he looks, like you would never know he had cancer before....I've just learned that there's a lot under the surface to people that you don't, necessarily, see, or know of, but it can be there. ~Catherine (Fiancée of Justin)

Chris became more protective of Alyssa.

...I'm more aware like I have a lot of friends who smoke cigarettes, um so I'm more aware of that kind of thing when we go out. [I] try to like keep her away from that second-hand smoke a lot. ~Chris (Boyfriend of Alyssa)

Lisa and Barbara learned to advocate for their children. Although addressing the past, both Lisa and Barbara believed this allowed them to continue advocating for their children and other family members going through medical treatments to this day.

You have to learn to be patient [laughs] or more patient. Um, and you have to learn to advocate. If you don't understand something, or or, Joey didn't understand something, you had to push for an answer....So y-you, learn to advocate more so that was a, a good thing on my part. ~Lisa (Mother of Joey)

...I was very – well, hyper vigilant probably but, I was so careful. I went to every test with her and checked everything and, yeah...you really have to advocate for your children because, and they even said that to me the kids that do well are the ones that have parents who really advocate for them. And it's the poor little ones in there that don't have anybody watching for them that don't do well. ~Barbara (Mother of Danielle)

The support persons were in consensus that overall, they experienced changes as a result of providing care to pediatric cancer survivors. For some, the changes were mental in nature, while others shared that their personalities had changed.

3.6.2 “You realize what’s important and it sticks with you.”

Most support persons believed that their perspectives on life, as well as aspects of their lives that they valued, had changed because of their roles as support persons. More specifically, support persons discussed that they were more appreciative of the lives they have. Some of the support persons discussed how they valued their family and friends more than ever before as a result of their role as a caregiver for a pediatric cancer survivor.

...you have to make time for yourself and your friends and your family and, all this, running around and doing things for nothing is just, crazy. Like getting caught up in all that craziness of the world it’s just, you have to take time. ~Barbara (Mother of Michelle)

...I think sort of spending time with each other, being a part of each other’s, you know day to day life. I mean we value all those things. We did in the past, but uh, I think it’s a lot stronger now. ~Beth (Mother of Abby)

...you just, realize...what’s important. And you, go through those things, and you have, you know, you hug your kids every day, and...maybe you live in the moment a little more, uh and you understand...that emotion, and family, and people, are the most important...everything else can come and go. ~Meryl (Mother of Savannah)

After Dan’s surgery, and still to this day, it was all about the little things that happen in life.

Margaret commented:

I remember driving up a country road and smelling the flowers and I, we, stopped...I would have the kids in the vehicle and I would stop and go and we’d be sniffing the flowers, and it made me realize that, right now was all we have, and, it’s, it’s not the, how much, how big your house is or, how many cars you have or, a place in Florida or, how many trips you take a year, it’s the little things, that are really important, and that’s, what I’ve learnt. ~Margaret (Mother of Dan)

Once again, those who acknowledged that their values changed all agreed that it was for the better. Mothers believed they developed new outlooks on life. For Lisa, she had taken on a new life motto after caring for Joey.

...my new motto is uh, I get up and face the day and I, know there are days that I need a, kick in the butt but, somewhere somebody somewhere, has it worse than I do...that became my motto when we were going through this with Joey because you're, you're looking at, the ambulances that are coming in you're looking at, the families that have lost, their children and that's like, it sucks. But, he's still here. We're fighting it. You know, somebody, somebody's having a worse day than I am. And that's the, my new philosophy. ~Lisa (Mother of Joey)

Some mothers embraced appreciating the smaller things, and take time for those who were important in their lives.

...it changes, how you view the world like it makes you, appreciate what you have. It makes you [pause] it really gives you a different, perspective like you really, you make time for people. Like, one phone call can change your, your life right? Like I was driving home from work and I got that call, and your world stops. Like, it, it makes you take time for things. ~Barbara (Mother of Danielle)

*...you really put things into perspective. And you really understand, uh what's important. Um, in life at that point and [clears throat] and everything else, disappears. Um, and you feel, petty, you know for some of those things that you used to uh, you used to think about or that u-used to bother you or worry you. So, in terms of of figuring **that** out, that's something, that impacted my life. ~Meryl (Mother of Savannah)*

...people will come in and say 'oh I've turned 65' and I'll say 'congratulations. It's really good to celebrate a birthday.' You know? It's, it's so precious. And, that's what I learned. From, Dan's diagnosis, and, through all of this and seeing, different, um, different children at [hospital] who weren't coming home, who were affected by their, brain tumours, so much, more, and um, where they, you know they, they needed so much assistance. Dan's independent, and we're blessed. ~Margaret (Mother of Dan)

While some support persons believed that aspects of their lives remained consistent while supporting their survivors currently, many of them felt some sort of change in some part of their lives. And, although few support persons addressed the psychological effects they experienced, most agreed that the changes they underwent and were currently experiencing were positive, and for the better.

3.7 SUMMARY

The purpose of this study was to examine the lived experiences of the perceived long-term effects of pediatric cancer on adult survivors and whether these effects had bearing on their primary support persons. Nineteen individuals (ten pediatric cancer survivors and nine support persons) were recruited for the study, and took part in one-on-one semi-structured interviews. From the verbatim transcription and subsequent data analysis of these interviews, four themes emerged: (1) “There wasn’t a lot of time to sit and think.”: The Pediatric Cancer Experience, (2) “There is no before cancer...there’s only cancer.”; (3) “I don’t know if I would change it.”; and (4) “As long as you need me I’m yours.”. It is important to note that although the cancer experiences of all of the survivors and support persons were unique, themes emerged that were consistent within each of their stories.

All of the themes and subthemes illuminated a variety of effects that were experienced by both survivors and their support persons. For survivors, undergoing their pediatric cancer experiences altered aspects of their health, personalities, and their schooling and career choices. All participants gravitated towards careers that allowed them to give back in some way, and some of the survivors acknowledged going above and beyond with volunteer and extracurricular work to help others going through similar experiences. Support persons, although not as deeply affected as the survivors, illustrated some of the effects that they experienced due to their roles as caregivers. Some experienced negative psychological effects, however many acknowledged that there were positive aspects to their experiences that changed in their personalities and outlooks on life.

CHAPTER 4: DISCUSSION

4.1 COMPARISON TO PREVIOUS LITERATURE

These research findings, predicated on the narratives of pediatric cancer survivors and their primary support persons, revealed the existence of late effects among all participants as a result of their experiences with pediatric cancer. The survivors' and support persons' recollections of the time period in which survivors were undergoing treatment also added further context to the ways in which they perceive and experience their current effects. When describing their past experiences with cancer, the side effects experienced by survivors included, but were not limited to hair loss (alopecia), extreme weight gain or weight loss, nausea and vomiting, lethargy, and mood swings. Additionally, some faced the possibility of death during their experiences due to the aggressive nature of both their diagnoses and treatments. In addition to the physical effects, survivors also shared the social effects resulting from their cancer treatments. These effects have been discussed previously in the pediatric cancer literature (see, for example, Canadian Cancer Society, 2008; Childhood Cancer Canada Foundation, 2011; Miller, 2002; Monteleone & Meadows, 2007).

Previous research has discussed that children who undergo cancer treatments may endure potentially negative behaviors from their classmates and friends during their journeys, like teasing, or loss of friendships (Janes-Hodder & Keene, 2002). In the case of the current survivors, a few were bullied during their elementary and high school years as a result of the cancer effects, making their living nightmares even more difficult. Although the literature is relatively void of "bullying" in the pediatric cancer literature, this finding is important for the education system and parents in order to aid in accommodating children with cancer, not only for the individuals themselves, but for their classmates and peers as well. This finding is of

particular importance, as it could aid in the development of a zero-tolerance bullying policy in all school systems, regardless of the conditions or characteristics of the children being bullied. As well, informational resources for school administrators, teachers, and classmates of children with cancer could be provided to school systems in order to properly accommodate and handle a case of a student facing pediatric cancer.

The mothers and grandmother present during the cancer experiences described the time period as a “nightmare” or “rollercoaster of emotion”. This finding was echoed by Woodgate (2006), who interviewed parents during the duration of their children’s cancer treatments. The parents described how the cancer diagnosis and treatment were a blur, and that the time period of their children’s illnesses were primarily negative for them and their families (Woodgate, 2006). Interestingly, when speaking to the survivors about what they recalled from the time period (with regards to their family functioning), they addressed the strength and unity that their families had shown while they were ill. Survivors understood that the time period in which they were sick was extremely trying for their families, but even amongst the turmoil, they remembered the love that they had felt from their families. This notion is significant when examining pediatric cancer literature, as few findings are from the perspective of the individuals who underwent treatment, and, further, recognized the strength of their families during the time period. As well, the negatives often overshadow the positives that emerge in pediatric cancer literature. These results are not meant to downplay the anguish that families experience during pediatric cancer, but to highlight the aspects of their cancer journeys that kept them strong and provided some semblance of normalcy during such a difficult time.

Results from this study further supported the optimism of the participants. When asked to recall memories from their pediatric cancer experiences, many individuals in this study recalled

a positive memory. Seven of the survivors and five of the support persons were able to recall simple memories, such as playing games, dancing in their hospital rooms, and spending time together during treatment, and these prevailed as some of their strongest memories. There is a paucity of research that focuses on the positive aspects, or memories of individuals who underwent the pediatric cancer process. As such it is of importance to emphasize that health care professionals may need to encourage families to continue to function as “normally”, or attempt to maintain as much positivity as possible during their cancer journeys to provide some aspects of joy in such a trying time.

All individuals in the study described the current lives of the pediatric cancer survivors as adults. Coinciding with previous literature (Armenian, Meadows, & Bhatia, 2011; Geenen et al., 2007; Hudson et al., 2013; Oeffinger et al., 2006; Robison et al., 2005; Yi et al., 2014) survivors stated that they had experienced a variety of physical effects as a result of their cancer treatments. Some of these effects included but were not limited to bone aches and pains, avascular necrosis, ataxia, amputations and hip replacements, and stunted growth. However, Oeffinger et al (2006), found that 73.4% of individuals who lived through their pediatric cancer developed at least one chronic condition thirty years after treatment (Oeffinger et al., 2006). This relates to a small number of survivors in this study, who conveyed that they experienced little to no late effects from their treatments. It is important to note that the participants in this study were young adults between the ages of 21 and 28, and there is the possibility that they had not yet experienced late effects that may develop later in life. Oeffinger (2006) also contends that as age increases, so does the likelihood of developing late effects from pediatric cancer. Yet, having the survivors personally voice how they live with their effects and provide the framework for their day-to-day living differs from many previous works (see, for example, Dieluweit et al.,

2010; Geenen et al., 2006; Oeffinger et al., 2006; Yi et al., 2014) which examined late effects through quantitative means. This qualitative data collection method allowed for all survivors to provide contextual meaning around their effects, and for support persons to corroborate these effects. Further, the current research examined the psychological, cognitive, and social health effects, which has rarely been discussed in one cohesive study. This displays a need for more research that not only addresses the multifaceted nature of late effects from pediatric cancer, but also for one that is longitudinal in nature in order to monitor survivors at multiple time points to examine the progression or development of any late effects.

While still speaking to the health effects, the survivors and their support persons acknowledged that the survivors experienced some psychological effects as a result of their cancer experiences, particularly anxiety, depression, and survivor's guilt. Similarly, past works (Dieluweit et al., 2010; Geenen et al., 2006; Yi et al., 2014) have found that individuals who had pediatric cancer may experience negative mental health outcomes. When addressing survivor's guilt, it is important to note that while it is not legitimately a diagnosable disease or ailment, individuals who have faced cancer often feel guilty for surviving when other individuals they knew did not (Baker et al., 1999; Cantrell & Conte, 2009; Holland & Reznik, 2005). Cantrell and Conte (2009) contend that individuals who undergo a pediatric cancer experience may develop survivor's guilt when seeing their peers pass away from cancer, which was the case with some participants in this study. However, Cantrell & Conte (2009) reveal that individuals may also experience guilt from putting their families, especially their mothers, through their cancer experiences. The participants in this study did not mention feelings of guilt for having their families undergo these experiences – rather, when speaking about their families and their past cancer experiences, they were glad that they were the ones experiencing the cancer instead of

their family members. Additionally, many survivors stated that the experiences drew their families closer together. This was found by Fletcher (2011), who discussed how mothers of children who had cancer believed that going through such an ordeal had brought their families closer together and strengthened their relationships. Orbuch et al. (2005) also found that individuals who had or developed strong relationships with their family members during their period of illness were more likely to have a better overall well-being post-cancer. The results of this study coincide with this data – most of the participants recruited someone who was present for their cancer experiences to participate in this study as a support person, and subsequently discussed the closeness of their family as a result of their cancer. Survivors stated that their cancer strengthened their families and brought them closer together, and, as a result, they now valued their families more. Further, reflecting on the tremendously optimistic attitudes of the participants, some stated their cancer experiences allowed them to cope with stress-inducing situations better, and as such are more prepared to handle difficult experiences. It is important to note that much of the previous research that addresses psychological effects experienced were conducted outside of Canada (Geenen et al., 2007; Oeffinger et al., 2006, Yi et al, 2014). The Canadian health care system has made vast strides in encouraging those with mental health issues to be open about their experiences, whereas some of the countries from which studies addressed mental health outcomes may not have such an accepting culture surrounding psychological health (i.e. Yi et al., 2014).

Survivors also spoke about the cognitive difficulties they experience as a result of their treatments. In particular, chemotherapy drugs can affect memory and concentration, which is also known as “chemo-brain” (Boykoff, Moieni, & Subramanian, 2009; Hede, 2008). This effect was reflected in the stories of the survivors in this study, who stated that they experienced

chemo-brain, difficulties with visual scanning memory resulting from treatment, and issues with their short-term memory. Additionally, a few survivors spoke of their learning disabilities that developed as a result of treatment, or were exacerbated by treatment, which has also been discussed by Robison et al. (2005) and Landier, Armenian, & Bhatia (2015).

When examining the social effects of pediatric cancer, Baker et al. (1999) and Dieluweit et al. (2010) reported that oftentimes, it has been shown to delay individuals – that is, slow the development of maturity, as well as the attainment of certain milestones, such as completing school or developing social skills. However, the participants in this study were positive about the social effects pediatric cancer had on their lives. Although some participants admittedly missed years of schooling due to their treatments, survivors reflected on their social development and believed that aspects, such as maturity, was ranked as either on par or ahead of their peers. Support persons reiterated that the participants were very mature from a young age because of their cancer. This is somewhat similar to the results found by Quin (2005) who discussed how parents of individuals who had pediatric cancer found that their maturity levels had changed positively because of their experiences. However, the maturity of the survivors in this study could be seen as both positive and negative. Undergoing such an ordeal as children and potentially missing a part of their childhood, and having to mature as a result is undeniably negative. However, having heightened maturity at the current age of the survivors in this study could be perceived as an asset. Although the survivors in this study did not explicitly state their perspectives on their heightened maturity levels, they admitted that they developed a better understanding of the world they lived in and the fragility of life itself, which altered their perspectives on life. These results are seemingly novel, as at the time of this study it was

difficult to find literature that discussed the outlook of individuals who had pediatric cancer, and much less the fact that their outlook on life was positive in nature.

All survivors acknowledged that they “give back” to the cancer community or any individuals undergoing a difficult time, as they feel indebted to those who helped them during their cancer journeys, as well as empathetic to others who may be experiencing troubling times. Survivors did this through their career choices, or what they hoped would become their career – many now work in medical settings, or work in positions that allow them to help others. The participants with these careers stated that they did so because of their experiences with cancer, and if they had not been exposed to some of the careers that they witnessed while undergoing treatment, they would never have strived to hold their current positions. Additionally, survivors stated that they now volunteer specifically to help others, or to help those currently going through pediatric cancer. Many volunteer with organizations such as the Canadian Cancer Society, participate in survivorship camps and support groups, and act as peer mentors to other individuals who currently have cancer. Many of the support persons acknowledged that the participants wanted to give back because of their experiences, and for some, it was their life purpose. Fletcher (2011) discussed how mothers of children with cancer found it extremely important to give back to society after their children had completed treatment in order to help others who were facing the same scenarios. Also, when speaking to giving back, participants had the opportunity to provide advice to others going through or who had gone through pediatric cancer. The optimistic natures of the survivors in this study were present in their responses, which were consistent in their advice of “staying positive”. Saleh & Brockopp (2001), when studying adult cancer patients awaiting bone marrow transplantation, found that the participants’ optimistic nature and positivity throughout their treatment fostered their hope for their futures.

This positivity allowed Saleh & Brockopp's adult participants to view their cancer treatment from a more optimistic light, once again fostering beliefs that participants would successfully be treated for their cancer (2001).

Speaking in regards to the word survivor, the National Coalition of Cancer Survivorship (NCCS) states that, "from the time of its discovery and for the balance of life, an individual diagnosed with cancer is a survivor" (1986). In medical terms, the word survivor in regards to cancer refers to an individual who has been cancer-free for at least five years (Rowland, 2007; Twombly, 2004). All individuals in the study were asked to provide their definitions of survivor, as the term is very often associated with individuals who have experienced cancer (Bartels, 2009). Most of the survivors and support persons, when providing their definitions of survivor, discussed how the term was a source of pride. This is consistent with the views of Twombly (2004), who further stated that the term survivor could be empowering. The three individuals (Dan, Stephen, and Sharon – Stephen's mother) who did not consider themselves to be cancer survivors were not alone in their stances, as research conducted by Bartels (2009) conveyed that individuals may not want to identify as a survivor because it creates a direct linkage between their past disease and current identity. Further, persons may want to identify in a way that acknowledged that they previously had cancer, but their cancer did not define them as individuals (Bartels, 2009). As conveyed by Dan, it could be said that the term survivor is a matter of "semantics". Regardless of whether or not an individual refers to himself or herself as a survivor, he or she lived past the cancer diagnosis, or "survived" the cancer experience.

The support persons involved in this study, regardless of whether or not they were present during the cancer experiences, had stated that their lives had been affected as a result of caring for an individual who previously had pediatric cancer. Past literature has shown that

support persons (primarily parents) of individuals who had pediatric cancer mainly experienced mental or emotional effects (see, for example, Clarke & Fletcher, 2003; Kazak et al., 1997; Wijnber-Williams et al., 2005; Van Dongen-Melman, Van Zuuren & Verhulst, 1998; Pelcovitz et al., 1996). However, all of this literature addresses parents or caregivers that were present during the cancer experiences, and not persons that survivors may rely on in their current lives. Some support persons admitted that although their survivors' pediatric cancer journeys were over, they still experienced worry for them. This worry was primarily in regards to the survivors' health. Support people were not necessarily concerned that they would relapse, but more so that the late effects of their cancer may become worse, that they were not as careful with their health as they should be, or that the late effects had not yet been expressed. This is supported by the findings presented by Wijnber-Williams et al. (2005), who found that even after treatment, parents of pediatric cancer survivors still experienced clinical levels of stress in their day-to-day lives regarding their children, although levels were lower than the time of cancer treatment. Additionally, Van Dongen-Melman, Van Zuuren, & Verhulst (1998) reported that parents of children who had pediatric cancer have difficulty returning to a state of mental normalcy, meaning, they no longer feel completely relaxed, and question their abilities to cope should another traumatic event affect their lives (Dongen-Melman, Van Zuuren, & Verhulst, 1998). Further, Pelcovitz et al. (1996) conveyed that mothers of pediatric cancer survivors entering the maintenance phase of treatment had a higher prevalence of post-traumatic stress disorder (PTSD) compared to mothers of "healthy" children. These findings are consistent with findings from Kilpatrick et al., (1989) who found that individuals were more likely to develop PTSD if there was a higher possibility of death of a family member due to a threatening circumstance. These results coincide with the experiences of Barbara from this study, whose daughter,

Danielle, nearly died multiple times throughout the progression of her cancer treatment. It is important to note that some support persons explained that they felt they were now better equipped to handle stressful situations, as learning to cope through the cancer experience allowed them to develop better mechanisms of dealing with stress. This finding is of importance to health care professionals, who should be equipped to aid support persons of pediatric cancer patients and survivors, especially when the responses of each individual affected will differ. As such, health care professionals should be prepared for the variety of reactions and effects not only in survivors, but support persons or caregivers as well.

When discussing other aspects in which their daily living had been affected in caring for their survivors, the support persons were extremely positive in their narratives. Some of the support persons stated that their personalities had changed. For Chris and Catherine, who were not present during their significant others' cancer experiences, they stated that they were more aware and considerate towards others. In getting to know their survivors, they learned that it was difficult to truly know what individuals have gone through in their lives. Additionally, support persons who were present at the time of cancer treatment admitted that they had become more patient, and better advocates for their family members. Overall, all support persons felt that their treatment of other people changed as a result of their experiences, and that these changes were for the better.

Further, support persons acknowledge that their values had changed. Some state that they appreciate their families more and make a concerted effort to spend more time with their family and friends. The same results were discussed in a paper by Fletcher (2011), in which mothers discussed how their family and friend groups became extremely supportive during their children's cancer treatment, and that appreciation for their supports continued after the child had

completed treatment. Moreover, the support persons in this study stated that they lived their lives differently now, as they discussed how they valued life more, and appreciated how precious life can be. Fletcher (2011) discussed similar changes with her mothers' outlooks on life. The mothers discussed how they approached situations with positivity, did not stress over the small things, and, for those whose children lived, were beyond grateful. It is important to note that Fletcher (2011) discussed the perspectives of mothers whose children had just finished treatment, or had passed away from their cancer. Although Fletcher's sample was not entirely similar to the study at hand, the findings mirror the opinions of the support persons.

4.2 LIMITATIONS

There are some limitations in this research that need to be addressed. This study examined the experiences of survivors of pediatric cancer, as well as their current primary support persons. The cohort of primary support persons included individuals who were present during the cancer experiences (six mothers and one grandmother), as well as individuals who were not (one boyfriend and one fiancée). Due to this, the experiences of the support persons were not necessarily similar. The recruitment of only support persons present during the cancer diagnosis and treatment may potentially allow for greater information regarding how families cope when a member is diagnosed with cancer, as well as currently. However, it is still important to note that the experiences of each support person are multifaceted and unique in nature. As well, the survivors in this study were asked to recruit their current primary support person in order to provide the most in-depth perceptions regarding the survivors' late effects affecting them presently.

Additionally, the information presented in this study reflects the point of view of only one support person, one of who may not have been present during the cancer experience.

Information obtained from additional family members and other support persons present during cancer treatment would have allowed for a greater understanding of the effect that pediatric cancer has on survivors and their families, including siblings, fathers, and extended family and friends.

Further, most of the survivors that were recruited were members of a support group for individuals who had pediatric cancer. Due to this, there is a possibility that the individuals in this sample were more likely to embrace their cancer experiences, or more likely to participate in schooling, career, and volunteer activities pertaining to their cancer experiences, such as volunteering to participate in this study. As a result, the views of these survivors may not be reflective of individuals who had pediatric cancer and do not participate in activities related to their experiences.

Lastly, the majority of the research discussed the late effects that were experienced (and may continue to be experienced) by pediatric cancer survivors and their support persons. Effects and experiences that are not currently being experienced would be retrospective in nature. This may have limited the recollection of the survivors and support persons specifically concerning the time period in which they were undergoing cancer treatment, and their experiences during said time. As such, some details may not have been present in their narratives.

4.3 IMPLICATIONS

This study provides substantial contributions to literature surrounding pediatric cancer and pediatric cancer survivorship, as well as literature regarding families and caregivers for individuals who underwent pediatric cancer. As the survival rates of pediatric cancer continue to rise, so will the number of individuals experiencing a myriad of late effects resulting from their treatments. With this, survivors will need assistance and care navigating the health care system

and making accommodations for the physical, psychological, and cognitive effects they experience from their treatments, potentially for the remainder of their lives. Further, this research provides information to health care providers concerning how to better adapt support and resources for survivors for the time period beyond remission. This study also supports previous research that contends that not all effects of pediatric cancer treatment are negative in nature. Many individuals were able to recognize the silver linings that came about as a result of their past diagnoses, which can provide encouragement to those currently undergoing their own pediatric cancer journeys.

Additionally, the research presented is of importance for policy makers in government legislation and health care professionals. This study reiterates the importance of ensuring that pediatric cancer survivors have access to resources or support for their entire lives, and not just within the time period that they are undergoing treatment. As time progresses, the likelihood of developing additional effects as a result of past treatments is heightened, and knowing that there are resources available to cater to the unique experiences of each survivor later in life would be beneficial. To add, this study suggests that individuals caring for a pediatric cancer survivor may experience stress or health effects as a result of being support persons. This research illustrates that caregivers may experience the need for help in balancing the care for their pediatric cancer survivor, as well as additional family members as time progresses. It would be favorable for policy makers to create a framework that allows for caregivers of cancer survivors to have access to additional health care resources or support networks tailored to their specific caregiving needs. Additionally, as the nature of providing care is often multifaceted in nature, ensuring that any resources or supports for caregivers are accessible at all times would also be beneficial.

As well, this study provides valuable information for school administrators, teachers, and peers for individuals going through, or who have completed pediatric cancer treatment. School systems **could** provide assistance to children with pediatric cancer, including children or adolescents that are experiencing late effects, as their ability to complete their schoolwork may be compromised. Additionally, this research provides insight for teachers and peers to understand the pediatric cancer process, and how to familiarize themselves with the effects that cancer may have on children and adolescents. Lastly, the study acts as a platform for zero-tolerance policies on bullying in schools. The research revealed that children with cancer might potentially be bullied because of their cancer, and as such school systems and administrators may find this research beneficial in creating policies for all children so that they are not bullied because of their differences.

Moreover, the implications of this study are of importance to parents, family members, and significant others of individuals who had pediatric cancer. The development of support networks and resources available to caregivers of pediatric cancer survivors can provide immense help in understanding how to help with their late effects. Further, this research provides context for health care professionals in understanding that pediatric cancer survivors and their support networks may both experience effects from pediatric cancer.

Lastly, individuals who are currently going through, have gone through, or are supporting someone through their cancer experiences can take comfort in knowing that there are many others currently experiencing the same phenomenon. Their stories and experiences acknowledge the fact that pediatric cancer diagnoses, treatment, and life thereafter has silver linings that shine through the dark clouds of their past treatments and current late effects.

4.4 FUTURE RESEARCH

Currently, the majority of research surrounding pediatric cancer survivorship is quantitative in nature, and places substantial emphasis on the negative effects that individuals experience both during and after their treatments. Additionally, literature addressing the effects of pediatric cancer on caregivers primarily discusses the effects on the family members, or those who were present during the diagnosis and treatment time period. Once again, the majority of this literature is negative in nature. Most research addressing life after pediatric cancer is often conducted within a few years of the time period in which the participants completed their treatment. It would be beneficial to study individuals at later time intervals after their treatments, in order to examine the changes that occur over time. Lastly, from a methodological perspective, other than the flagship study conducted by Oeffinger et al., (2006), very few studies are longitudinal. Completing a longitudinal study that allowed for an examination of late effects over time would be fundamental in adding to the pediatric cancer literature. Tracking survivors at multiple time points past remission (eg. two, five, and ten years post-treatment) in order to examine how, and what types of late effects emerge as time progresses for pediatric cancer survivors would be beneficial.

It is imperative to continue to use qualitative research methods in studying health phenomena such as the pediatric cancer experience. By using the voices of survivors, researchers and health care providers can obtain a more extensive, holistic picture of the pediatric cancer experience and its subsequent effects. Additionally, research must continue to acknowledge the positives in order that individuals and their families facing pediatric cancer can use such works as a light at the end of the long, dark tunnel that they face.

4.5 CONCLUSION

This study aids in adding to past works regarding individuals who experienced pediatric cancer by providing evidence that the late effects of pediatric cancer are varied and complex in nature. All of the individuals in this study conveyed that their lives had been changed in some way as a result of their pediatric cancer experiences. The survivors were able to provide immense detail of how their lives had been altered by cancer both positively and negatively in reflecting upon their past and current experiences. Additionally, support persons stated that they were all negatively affected, but overall they also reaped benefits being support persons.

In conclusion, this study reveals how pediatric cancer radiates through individuals to affect not only themselves and their immediate support persons, but those who survivors help as well. The pediatric cancer experience undeniably takes, in physical, psychological, and cognitive ways, but for these participants, it also gave – it gave them their career aspirations, life purposes, and deeper understandings of the preciousness of life itself. The results and implications of this research could not be summed up better than by Joey, who when speaking about cancer, simply stated:

It's a word. Not a sentence.

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Table 1: A Comparison of Quantitative Long-Term Effect Studies on Survivors

Researchers:	Oeffinger et al., 2006	Yi et al., 2014	Geenen et al., 2006	Dieluweit et al., 2010
Location	United States	Korea	Netherlands	Germany
Participants	10,397 (survivors) (5593 Males and 4804 Females) 3034 (siblings)	225 (131 Males and 93 Females)	1362 (745 Males and 617 Females)	820 (402 Males and 418 Females)
Age of participants	18 to 48 Mean 26.6	15 to 38 Mean 21.9	No age range given Median 24.4	20 to 46 Mean 30.4
Methods	“List” of physical late effects Common Terminology Criteria for Adverse Events	Custom questionnaire Medical Outcomes Study Short Form-8	Medical follow-up at late-effects outpatient clinic	Custom questionnaires German Socio-Economic Panel Study Dutch Course of Life Questionnaire
Explanation of Methods	Participants check off their health conditions CTCAE grades events (1=mild, 2=moderate, 3=severe, 4=life-threatening/disabling, 5=fatal)	Questionnaire used to gage perceived health problems MOSSF-8 used to scale certain health problems	Doctors performing follow-up assessed and graded severity of adverse health condition	G-SOEP used as control DCLQ and custom used to gage developmental milestones
Main conclusions	62.3% of survivors had at least one chronic health condition 27.5% had severe/life-threatening conditions 73.4% incidence 30 years after cancer treatment	73.1% had at least one health issue; growth issues were most common The higher amount of health problems was associated with lower perceived physical and mental functioning in survivors	75% had one of more late effect; 24.6% had five or more 40% had at least 1 severe or life threatening condition	Female survivors had lower psychosexual development compared to controls Survivors were less likely to have children or be married than the controls 14.5% of survivors were infertile due to their cancer

NOTE: All literature was accessed via the Wilfrid Laurier University Library, and found on Web of Science, a database of scientific articles, as well as Google Scholar. Some of the keywords used to access this literature include but are not limited to: childhood cancer, pediatric cancer, late effects, family unit, siblings of children with cancer, physical effects, mental effects, and social effects.

Appendix B

Table 2: A Comparison of Quantitative and Qualitative Effect Studies on Mothers and Siblings (Part 1)

Researchers	Alderfer, Labay, & Kazak, 2003	Clarke and Fletcher, 2003	Clarke, Fletcher, & Schneider, 2005	Fletcher, 2010	Fletcher, 2011	Fletcher, Schneider, & Harry, 2010
Location	Philadelphia, Pennsylvania, USA	Southern Ontario, Canada	Southern Ontario, Canada	Southern Ontario, Canada	Southern Ontario, Canada	Southern Ontario, Canada
Participants	78	25	49	9	9	9
Age of Participants	Mean 14.2	31 to 46	29 to 50 Mean 39	32 to 47	32 to 47	32 to 47
Methods	Revised Children's Manifest Anxiety Scale Impact of Events Scale-Revised Posttraumatic Stress Disorder Reaction Index Assessment of Life Threat and Treatment Intensity Questionnaire	Telephone interview	Focus groups	Background Questionnaire Interview	Background Questionnaire Interview	Background Questionnaire Interview
Explanation of Methods	RCMAS: Self-report of anxiety IES-R: Intrusive thoughts and avoidance scale PTSD-RI: Parallels diagnostic criteria for PTSD ALTTIQ-rating agreement with statements assessing perceptions of life threat	Researcher spoke to each participant over the phone and recorded conversation	10 groups of ~5 women were interviewed at a time; interviews were recorded	One-on-one, face-to-face interviews were conducted with each participant; interviews were recorded	One-on-one, face-to-face interviews were conducted with each participant; interviews were recorded	One-on-one or face-to-face interviews were completed; interviews were recorded
Main conclusions	49% of siblings reported mild post-traumatic stress symptoms and 32% had moderate to severe levels of symptoms	Participants reported feeling angry and stressed and experienced marital and financial issues	Participants left work to care for their child and take on caregiving roles and duties	Families experienced financial, health, and familial issues	Positive aspects of having a child with cancer were discovered	Participants reported fear for the future and appreciating the present

Appendix B

Table 2: A Comparison of Quantitative and Qualitative Effect Studies on Mothers and Siblings (Part 2)

Researchers	Patterson, Holm, & Gurney, 2004	Overholser and Fritz, 1991	Zeltzer et al., 1996
Location	Stanford, California, USA	Minneapolis, Minnesota, USA	Los Angeles, California, USA Houston, Texas, USA Ann Arbor, Michigan, USA Rochester, New York, USA Salt Lake City, Utah, USA
Participants	44 children (22 boys, 22 girls) and their parents	45 parents (26 mothers, 19 fathers) 26 children (14 male, 12 female)	254 (129 Males and 125 Females)
Age of Participants	Mean 10.34	Parents: 32-56 Children: 3.8-26	5 to 18 Mean 10.65
Methods	Interviews Piers-Harris Self-Concept Scale Impact-On-Family Scale	Focus groups	National Health Survey Data(NHSD) Standardized Behaviour Checklists(SBC) Parent and Physician Measure Interview
Explanation of Methods	One-on-one, face-to-face interviews were conducted with each participant; interviews were recorded PHSCS: assessing child self-esteem IOFS: assess how current functioning is affected by chronic illness	7 groups of 5-9 parents were interviewed at a time; interviews were recorded	NHSD-health care utilization SBC-intensity of behavioural/emotional problems Parent/Physician Measure-health of children One-on-one face-to-face interviews recorded
Main conclusions	Families experienced fear of the future and multiple strains during the time their child was being treated for cancer	Many families were experiencing financial setbacks years after their child's cancer treatment	Siblings of children with cancer had a higher likelihood of developing risky behaviours and having poorer health than control siblings

Background Questionnaire: Late Effects Experienced by Adult Survivors of Pediatric Cancer

Pediatric Cancer Survivor Background Questionnaire

Thank you for taking the time to participate in this study. The purpose of this questionnaire is to obtain background information regarding you and your experience with childhood cancer, as well as your current health status and lifestyle. All personal information obtained from this questionnaire will be kept confidential and you will not be identified personally from any reports, posters, or presentations resulting from this research. Participation in completing this questionnaire is voluntary and you may refrain from answering any questions with which you feel uncomfortable. Please fill out the information to the best of your ability.

Background Information

This section will ask for some of your basic information.

1. What is your date of birth? (MM/YYYY): _____

2. How do you self-identify in terms of gender?

- Male
- Female
- Other (please specify): _____

3. How do you self-identify in terms of race or ethnicity?

- English
- French
- German
- Italian
- Scottish
- Irish
- Ukrainian
- Chinese
- Dutch
- North American Indian
- Jewish
- Polish
- East Indian
- Portuguese
- Greek
- Canadian
- Other (please specify): _____

4. What is the highest level of education you have achieved?

- Less than secondary school graduation
- Secondary school graduation
- Some post-secondary
- Post-secondary graduation
- Other (please specify): _____

5. Are you currently a student?

- No
- Yes

If yes, please specify what institution you attend, and what year and program you are in.

6. If you are not a student, what is your current occupation? If you do not have a current occupation, please write "N/A". _____

7. Was this occupation pathway determined in any way by your experience with pediatric cancer?

- No
- Yes

If yes, how?

8. What is your current relationship status?

- Now married
- Common-law
- Living with a partner
- Single (never married)
- Widowed
- Separated
- Divorced

9. Do you have children? If yes, specify how many.

- Yes: _____
- No

Pediatric Cancer Experience

This section will ask about being diagnosed with/undergoing pediatric cancer treatment. Please fill it out to the best of your ability.

10. What was your age at diagnosis? _____

11. What was your diagnosis? _____

12. What type of treatment did you receive, and how long were you in treatment? Please check all that apply.

Type	Length
<input type="checkbox"/> Chemotherapy <input type="checkbox"/> Radiation Therapy <input type="checkbox"/> Surgery <input type="checkbox"/> Homeopathy and alternative medicine <input type="checkbox"/> Organ Transplantation <input type="checkbox"/> Other	

13. Would you consider yourself in remission?

- No
 Yes

If yes, for how long?

Family Demographics

This section will be asking you for information about your family members.

14. List all the people that you reside/resided with:

Before your cancer diagnosis	During your cancer treatment	Presently

15. Most children diagnosed with cancer are too young to take care of themselves while undergoing treatment. Due to this, children will often have a primary caregiver during this time. Who would you consider to be your ***primary caregiver*** while undergoing treatment? If there was more than one, please check them as well.

- Mother
 Father
 Sibling
 Aunt
 Uncle
 Grandmother
 Grandfather
 Other (please specify): _

Life Post-Cancer

This section will be asking you about your life now, after your pediatric cancer experience.

16. Do you ever reflect upon your cancer experience?

- Daily
- Often (Weekly, Every Month)
- Sometimes (Every 2-3 Months)
- Rarely (Every 6 Months-1 Year)
- Never

17. Do you currently have any negative effects from your cancer?

(physical, cognitive, emotional, etc.). If there are more than what there is space available, please write on the back.

1. _____
2. _____
3. _____
4. _____
5. _____

18. Now that you are older and no longer require much of the care you needed while undergoing treatment, you may not necessarily need a primary caregiver(s). However, is/are there still (an) individual(s) that you rely on currently? If so, please specify.

- Mother
- Father
- Sibling
- Aunt
- Uncle
- Grandmother
- Grandfather
- Spouse
- Partner
- Other: _____

Thank you for taking the time to fill out this questionnaire. Your responses are appreciated.

**Background Questionnaire-Late Effects Experienced by Adult Survivors of Pediatric
Cancer**
Primary Support Person Background Questionnaire

Thank you for taking the time to participate in this study. The purpose of this questionnaire is to obtain background information regarding you and your relationship with the participant who underwent cancer treatment as a child. This questionnaire also aims to obtain information about any late effects that you have noticed the participant may be experiencing now as a result of their cancer treatment. Please fill out the information to the best of your ability.

Background Information

This section will ask for some of your basic information.

1. What is your date of birth? (MM/YYYY): _____

2. What is the highest level of education you have achieved?

- Less than secondary school graduation
- Secondary school graduation
- Some post-secondary
- Post-secondary graduation
- Other (please specify): _____

3. Are you currently a student?

- No
- Yes

If yes, please specify what institution you attend, and what year and program you are in.

4. If you are not a student, what is your current occupation? If you do not have a current occupation, please write "N/A". _____

5. What is your current relationship status?

- Now married
- Common-law
- Living with a partner
- Single (never married)
- Widowed
- Separated
- Divorced

6. Do you have children? If yes, specify how many.

- Yes: _____
- No

7. How long have you known the individual who had cancer? _____

8. What is your relationship with the individual (ie. parent, spouse, significant other)?

Pediatric Cancer Experience

This section will address the time period when the cancer survivor was diagnosed with/undergoing pediatric cancer treatment. Please fill it out to the best of your ability.

9. What was his/her age at diagnosis? _____

10. What kind of treatment did (name) have? _____

Relationship Demographics

This section will be asking you for information about the relationship between you and the individual who had cancer.

11. Would you consider yourself a primary caregiver of him/her while he/she was undergoing pediatric cancer treatment?

Yes

No

For either answer, please explain why.

12. How long have you and he/she been residing together?

<6 months

6 months to 1 year

1 year to 2 years

2 years to 3 years

>3 years

Do not reside together

13. In what ways are you providing support for the individual?

Financial

Cognitive

Emotional

Physical

Psychological

Social

Other (please specify): _____

Thank you for taking the time to complete this questionnaire. Your responses are appreciated.

Interview Guide-Late Effects Experienced by Adult Survivors of Pediatric Cancer
Pediatric Cancer Survivor Interview Guide

First, I'd like to thank you for agreeing to meet with me and discuss your past experience with pediatric cancer. The purpose of this research is to study the lived experience of adults of the late effects of pediatric cancer on adult survivors. To add to this experience, I will also be interviewing your current primary support person.

Some of these questions may bring up emotional memories and be difficult for you to answer. If at any instance you feel uncomfortable please let me know. If you need a break at any time please let me know and we will stop recording.

First, we are going to talk about you and some of your background information.

1. Please tell me about yourself.

Refer to background questionnaire. Probes:

- Upbringing/Family Structure
- Hobbies/Interests

2. Can you tell me about your current primary support person?

Refer to background questionnaire. Probes:

- Relationship with person
- Why do you consider him/her your support person?
- How long have you known him/her?
- Were they a support person for you while you were undergoing cancer treatment? If not, why?

Now, we're going to talk about your past experience with pediatric cancer.

3. What do you remember about your experience with childhood cancer?

Refer to background questionnaire. Probes:

- Diagnosis, treatment, side effects
- Family life during that time period; relationships
- Strongest memory from your cancer diagnosis/treatment?
- Feelings about self
- Effect on family members and friends?

4. Is there anything else you would like to tell me about the time period in which you were experiencing pediatric cancer?

We're now going to talk about your current life post-cancer.

5. Do you still see a specialist or your oncologist for any follow-up?

- If yes, how often?
- What for?
- Do you experience any stress when preparing for these appointments?

6. If you had to rate your current overall health (excellent, good, fair, poor) what would you rank it?

Probes:

- How do you feel in general?
- Are there any health issues you are concerned about (pain, etc.)?

After undergoing cancer diagnosis and treatment, there is potential for a variety of different late effects to be experienced, including physical, mental, emotional, and social effects. We're going to discuss some of these and whether you believe there are any effects you are experiencing – either positive or negative.

7. Do you think there are any milestones/health conditions that you reached later than your peers as a result of your cancer?

Probes:

- Delayed puberty
- Stunted growth
- Maturity levels
- Milestones such as marriage, going to school, finding a career, etc.

8. Are there any health effects that you are currently experiencing that were diagnosed by a doctor that are attributed to your experience with childhood cancer?

Refer to background questionnaire. Probes:

- Anything in the area that was treated?
- Were you warned of any potential physical health effects when you completed treatment?
- How do you feel mentally?
- Depressed, happy, anxious, etc.
- How would you compare your anxiety levels to your peers?

9. Would you say that experiencing pediatric cancer has changed any aspect of your life?

Probes:

- Career aspirations
- Personality traits
- Relationships
- Extracurriculars/volunteer organizations
- Morals and values
- Perspective on life
- Coping mechanisms, stress habits – positive/negative
- Positive/Negative

10. Do you believe that you approach social situations and relationships differently than your peers in your age group?

Refer to background questionnaire. Probes:

- Can this be attributed to your cancer experience?
- Differing levels of maturity
- Wanting to take life slow/fast
- Need/want to be in a romantic relationship
- Need/want to have children

11. Some people use the word “survivor” to describe living with cancer. What does the term survivor mean to you?

- Do you consider yourself a survivor?
- Why/why not?

12. What is something that you would tell an individual who has been diagnosed with pediatric cancer?

Probes

- Why would you say this?
- Are there certain aspects that you would emphasize?

13. What is one piece of advice you would give to those currently undergoing pediatric cancer treatment or who are currently an older adult?

14. Is there anything else you would like to tell me about your life now as a result of your experience with childhood cancer?

15. Is there anything that you would like to ask me?

Thank you for taking the time to participate in this study.

Interview Guide: Late Effects Experienced by Adult Survivors of Pediatric Cancer
Primary Support Person Interview Guide

First, I'd like to thank you for agreeing to meet with me and discuss your experiences with the individual who had cancer. The purpose of this research is to study the lived experience of the late effects of pediatric cancer on adult survivors.

Some of these questions may bring up emotional memories and be difficult for you to answer. If at any instance you feel uncomfortable please let me know. If you need a break at any time please let me know and we will stop recording.

First, we are going to talk about you and some of your background information.

1. Please tell me about yourself.

Refer to background questionnaire. Probes:

- Upbringing/Family Structure
- Hobbies/Interests

2. Can you tell me about (name) currently?

Refer to background questionnaire. Probes:

- Age
- Occupation
- Education
- Past experience with cancer
- Upbringing/Family Structure
- Hobbies/Interests
- How long have you known (name)?
- Do you and the diagnosed individual reside together?

3. Why do you believe he/she identified you as their primary support person?

Probes:

- Based on relationship
- Length of time knowing each other
- Frequency of time spent together
- Were you a support person while they were undergoing cancer treatment?

4. In what way are you a support person to him/her currently?

Probes:

- Physical needs
- Mental/Emotional needs
- Psychological needs
- Other

5. Has your life been affected in any way by being (name)'s primary support person or because of his/her experience with cancer? If yes, how?

Refer to background questionnaire. Probes:

- Positives
- Negatives

6. If you had to rank your current overall health (excellent, good, fair, poor) what would you rank it?

Probes:

- Why did you choose this ranking?
- Is there anything in particular that is causing you pain/issues/etc.?

7. How would you rank (name)'s current overall health (excellent, good, fair, poor)?

Refer to background questionnaire. Probes:

- How do you think they feel in general?
- Is there anything in particular that may be causing them pain/issues/etc.?
- Is there something they may have that you believe they are downplaying, or looking into too heavily?

8. Do you believe there may be any milestones or health conditions that (name) experienced/reached later than their peers?

Refer to background questionnaire. Probes:

- Growth
- Puberty
- Maturity
- Emotional health
- Milestones such as marriage, going to school, finding a career, etc.

9. How would you describe (name)'s approach to relationships with others?

Refer to background questionnaire. Probes:

- More/less trusting than others
- Takes longer/shorter time to build rapport/relationships
- Takes longer/shorter time to build trust
- Other factors that may not be comparable to the population

10. Are there any health effects that he/she may currently experience that could be attributed to their experience with childhood cancer?

Refer to background questionnaire. Probes:

- Anything in the area that was treated?
- Have any effects been diagnosed by a doctor/physician?
- Was he/she warned of any potential physical health effects when he/she completed treatment?
- How do you believe they feel mentally?
- Depressed, happy, anxious, etc.
- How would you compare their anxiety levels to their peers?

11. Do you consider (name) to be a pediatric cancer survivor?

Probes:

- Why/why not?
- What does the term survivor mean to you?

12. Do you think that experiencing pediatric cancer had changed any aspect of his/her life?

Probes:

- Career aspirations
- Personality traits; self-confidence, esteem
- Relationships
- Extracurriculars/Volunteer organizations
- Morals and values
- Perspective on life
- Lifestyle behaviours
- Coping mechanisms, stress

13. Is there anything you would like to ask me?

Thank you for taking the time to participate in this study.

Appendix D

Addressing Research Questions by Interview Questions: Pediatric Cancer Survivors

		Research Questions		
		How has having pediatric cancer influenced who you are today?	How do you identify with respect to your experience with pediatric cancer?	In being a support person, how has caring for someone who had pediatric cancer influenced who you are today?
Interview Guides and Question Numbers	Pediatric Cancer Survivor Interview Guide	<p>6. If you had to rate your current overall health (excellent, good, fair, poor) what would you rank it?</p> <p>7. Do you think there are any milestones/health conditions that you reached later than your peers?</p> <p>8. Are there any health effects that you are currently experiencing that were diagnosed by a doctor that are attributed to your experience with childhood cancer?</p> <p>9. Would you say that experiencing pediatric cancer has changed any aspect of your life?</p> <p>10. Do you believe that you approach social situations and relationships differently than your peers in your age group?</p>	<p>11. Some people use the word “survivor” to describe living with cancer. What does the term survivor mean to you?</p> <p>12. What is something that you would tell an individual who has been diagnosed with pediatric cancer?</p> <p>13. What is one piece of advice you would give to those currently undergoing pediatric cancer treatment or who are currently an older adult?</p>	N/A

Appendix E
Addressing Research Questions by Interview Questions: Primary Support Persons

		Research Questions		
		How has having pediatric cancer influenced who you are today?	How do you identify with respect to your experience with pediatric cancer?	In being a support person, how has caring for someone who had pediatric cancer influenced who you are today?
Interview Guides and Question Numbers	Primary Support Person Interview Guide	7. How would you rank (name)'s current overall health (excellent, good, fair, poor)? 8. Do you believe there may be any milestones or health conditions that (name) experienced/reached later than their peers? 9. How would you describe (name)'s approach to relationships with others? 10. Are there any health effects that he/she may currently experience that could be attributed to their experience with childhood cancer? 12. Do you think that experiencing pediatric cancer had changed any aspect of his/her life?	11. Do you consider (name) to be a pediatric cancer survivor?	5. Has your life been affected in any way by being (name)'s primary support person or because of his/his experience with cancer? If yes, how? 6. If you had to rank your current overall health (excellent, good, fair, poor) what would you rank it?

Appendix F

Addressing Research Questions and Interview Questions by Theme: Pediatric Cancer Survivors

		Research Questions		
		How has having pediatric cancer influenced who you are today?	How do you identify with respect to your experience with pediatric cancer?	In being a support person, how has caring for someone who had pediatric cancer influenced who you are today?
Interview Guides and Question Numbers	Pediatric Cancer Survivor Interview Guide	6. If you had to rate your current overall health (excellent, good, fair, poor) what would you rank it? Theme #1, 2 7. Do you think there are any milestones/health conditions that you reached later than your peers? Theme #1, 2 8. Are there any health effects that you are currently experiencing that were diagnosed by a doctor that are attributed to your experience with childhood cancer? Theme #2 9. Would you say that experiencing pediatric cancer has changed any aspect of your life? Theme #1, 2, 3 10. Do you believe that you approach social situations and relationships differently than your peers in your age group? Theme #2, 3	11. Some people use the word “survivor” to describe living with cancer. What does the term survivor mean to you? Theme #2 12. What is something that you would tell an individual who has been diagnosed with pediatric cancer? Theme #3 13. What is one piece of advice you would give to those currently undergoing pediatric cancer treatment or who are currently an older adult? Theme #3	N/A

Appendix G
 Addressing Research Questions and Interview Questions by Theme: Primary Support Persons

		Research Questions		
		How has having pediatric cancer influenced who you are today?	How do you identify with respect to your experience with pediatric cancer?	In being a support person, how has caring for someone who had pediatric cancer influenced who you are today?
Interview Guides and Question Numbers	Primary Support Person Interview Guide	7. How would you rank (name)'s current overall health (excellent, good, fair, poor)? Theme #1, 2 8. Do you believe there may be any milestones or health conditions that (name) experienced/reached later than their peers? Theme #1, 2 9. How would you describe (name)'s approach to relationships with others? Theme #2, 3 10. Are there any health effects that he/she may currently experience that could be attributed to their experience with childhood cancer? Theme #1, 2 12. Do you think that experiencing pediatric cancer had changed any aspect of his/her life? Theme #1, 2, 3	11. Do you consider (name) to be a pediatric cancer survivor? Theme #2	5. Has your life been affected in any way by being (name)'s primary support person or because of his/his experience with cancer? If yes, how? Theme #4 6. If you had to rank your current overall health (excellent, good, fair, poor) what would you rank it? Theme #4