Understanding the Role of Personal Transformation in Adults who have Survived Childhood Cancer

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A Thesis

In

The Department

of

Education

Presented in Partial Fulfillment of the Requirements for the Degree of
Magisteriate in Arts (Child Study) at
Concordia University
Montreal, Quebec, Canada

August 2010

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CONCORDIA UNIVERSITY

School of Graduate Studies

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and submitted in partial fulfilment of the requirements for the degree of

Magisteriate in Arts (Child Study)

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ABSTRACT

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Cathy Ann Goldstein

The narrative stories of transformation of childhood cancer survivors were examined in comparison to the established research in the same area. The established research that is available is based on statistical criteria, which examines the quality of life of adult survivors. Based on such criteria, the quality of life of childhood cancer survivors has indicated mixed results indicating that more research is needed to better serve the growing population of survivors. In contrast, this study sought to compare the outcome of a quality of life survey versus the individual stories of survivors. The findings suggest that the survey does not accurately reflect the quality of life of the adult survivors. Also by including narrative stories this study offers a forum for survivors by giving them a voice.

Keywords: adult, cancer, childhood, quality, life, narratives, stories, survivors

ACKNOWLEDGEMENTS

I would like to take this opportunity to acknowledge the people who have supported me throughout this lengthy process. First and foremost, I would like to thank Dr. Harriet Petrakos for encouraging me to pursue this topic for my thesis and for her unending patience with me. Her tireless dedication is a credit to the university. I am also very grateful to my committee members, Dr. Miranda D’Amico and Dr. Vivek Venkatesh. I am appreciative for Dr. D’Amico’s invaluable feedback and her support throughout. I would like to express my gratitude to Dr. Venkatesh for his generosity and his willingness to help me at all times. I would especially like to thank everyone for their time (especially during summer vacation), dedication, and support.

I am also grateful to the participants of this study for sharing their stories candidly. Their courage is beyond words. I wish them continued success and above all, a long healthy life.

I could not have completed this work without the medical team at the Montreal Children’s Hospital. Although many of the professionals have retired or moved on since my time with them, this program has saved and continues to save so many innocent lives. Dr. Mark Bernstein, I know you saved mine.

Finally, I would not be here if not for my parents, Maurice and Celine, and brother, Patrick, who continually stand by me and share all my dreams. I am especially grateful to Sean for sharing his life with me, for never letting me give up, and for encouraging me always. Special thanks to my friends and extended family for their support. I love you all dearly.

DEDICATION

I dedicate this to all the participants of this study and to all the courageous survivors whose voices remain unheard.

Dreams

Hold fast to dreams
For if dreams die
Life is a broken-winged bird
That cannot fly.
Hold fast to dreams
For when dreams go
Life is a barren field
Frozen with snow.

Langston Hughes

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A Narrative Study of the Role of Personal Transformation, Coping, and the Ability to Thrive in Adult Survivors of Childhood Cancer

In Canada, approximately 850 children are diagnosed with cancer every year (Canadian Cancer Society, 2008). It is the leading disease related cause of death in children and, in terms of overall mortality it is second only to avoidable injury. Today more and more children are surviving childhood cancers. The survival rate of children diagnosed with cancer has increased from 20% in the 1950's to approximately 80% in the 1990's (Goldsby, Taggart, & Ablin, 2006). It is now estimated that as many as 85% of pediatric oncology patients in Canada will survive their disease (Canadian Cancer Society, 2008). Fortunately, where once cancer was considered a death sentence for most children, it is now more of an obstacle, something to be overcome and defeated. However, this also means that there is a growing population of adults who are survivors of childhood cancers and although successful treatment is measured by survival there is still a great deal of research needed to examine the long term effects of survival.

Survival is often accompanied by physical, emotional, and social challenges that include dealing with physical disabilities, infertility, mortality, anxiety, and discrimination in adulthood (Parry & Chesler, 2005). Much research has focused on the physical impact of treatment on children with cancer but very little research has examined the long term psychosocial impact of surviving the disease. The research that exists offers mixed results. The majority of research offers negative quality of life outcomes, that is an increased risk for academic problems, social emotional difficulties, and psychological disorders (Goldsby, Taggart, & Ablin, 2006). Other identified problems of survivors include: excessive dependence on parents, lowered social competence, poor academic performance, and increased use of denial as a defence mechanism (Gray, Doan, Shermer, Fitzgerald, Berry, Jenkin, & Doherty, 1992). Although the benefits of treatment far outweighed the risks, there are still late consequences of treatment that need to be addressed as research indicates that there is a growing population of potentially psychologically distressed adult survivors.

There is a small growing area of research that is gaining momentum. This research is beginning to examine why certain survivors are able to overcome their circumstances and thrive in the face of serious illness. With the increasing population of childhood cancer survivors, it is becoming more and more important to examine the long term effects of such a traumatizing childhood event, especially the implications on psychological health.

Types of Cancer and the Physical Effects

The most prevalent forms (in no particular order) of childhood cancer are; brain tumours, Hodgkin's disease, Wilm's Tumour, osteosarcoma, neuroblastoma, non-Hodgkin's Lymphoma, Leukemia, soft-tissue sarcoma, and Ewing's Sarcoma (Goldsby, Taggart, &Ablin, 2006). Childhood cancer is treated with a combination of medication, chemotherapy, and/or radiation.

Research has mostly focused on the physical impact of treatment on children with cancer. Most often the physical impact of cancer is visible. Children may appear with puffy faces and lose their hair due to the treatment. Treatment with medication may also effect motor development. Certain medications such as vinca-alkaloids are known to cause clumsiness which results in poor coordination (Lahteenmaki, Huostila, Hinkka, &

Salmi, 2002). Surgery often leaves children with scars and, in some cases, the loss of a limb or body part.

Chemotherapy is often associated with nausea and vomiting which may seriously impede the growth of a child (Goldsby, Taggart, &Ablin, 2006). Tissue and/or organ damage as well as DNA damage are potential side effects of chemotherapy (Goldsby, Taggart, &Ablin, 2006). "Schilsky and Anderson (1979) report that prolonged treatment with various types of chemotherapy and radiation may cause a variety of serious conditions, such as peripheral neuropathy, cardiotoxicity, pulmonary fibrosis, and nephrotoxicity" (as cited by Forsbach & Thompson, 2003, p.118).

Goldsby, Taggart, and Ablin (2006) examined the long term physical impact of cancer on children. They found that there were physical consequences to treatment such as increased risk of neurological consequences, inhibited growth, obesity, impaired organ function, and sexual health problems. The long term effects of treatment may not be visible. Beyond physical health problems, childhood cancer survivors face an increased risk for academic problems, social emotional difficulties, and psychological disorders. These psychosocial effects are troublesome and had been neglected in past research on childhood survivors.

Factors Influencing Psychological Health throughout Childhood

A certain innocence is lost when a child must follow cancer treatment at a young age. The child must learn to navigate through life with a new outlook, whether it is positive or negative. However, since survival in itself is a feat, the child must still go through various normal developmental milestones while dealing with various childhood issues as well as integrating their role as a cancer survivor into their lives.

As previously mentioned, treatment for childhood cancer can have a serious effect on academic achievement. It has been suggested that children who received treatment for cancer were more likely to fall behind in school. Certain forms of cancer, and therefore their treatment, can cause children to suffer cognitive impairments. For example, children who receive cranial radiation along with chemotherapy display a sharp decline in IQ and intellectual skills due to treatment (Lahteenmaki et al., 2002).

Absenteeism from long hospital stays and treatment can also affect academic achievement resulting in a child falling behind. Fottland (2000) examined eight school children whose treatment had begun one or two years prior to the study. The participants were interviewed using semi-structured questions based on their experiences. Fottland investigated self-esteem and how it was affected by academic self-concept in students diagnosed with childhood cancer. Absenteeism was clearly a factor which negatively impacted the children both academically and socially. The data indicated that more than half (5 out of 8) of the children required extra help and had learning difficulties which may have been linked to the treatment itself (Fottland, 2000). Less than half of the children (2 out of 8), who had been strong students initially, did not receive special instruction and were able to succeed academically without extra assistance once they returned to school. Fottland found that those children were motivated to succeed and had better academic support throughout treatment. They also had better initial self-esteem which made re-integration into school easier.

A particularly interesting aspect of Fottland's study (2000) was that he also examined academic self-concept as an important factor contributing to the overall self-esteem of school children. Academic achievement and the ability to display self-mastery are often linked with self-esteem. Children who could acknowledge a difference between their abilities prior to and after treatment often have poorer self-concept (Fottland, 2000). He also found that children who are diagnosed later in their childhood had a greater potential for overall frustration in school. However, children who were able to return to class and be reintegrated into the curriculum without extra assistance were able to re-establish a positive self-concept (Fottland, 2000). Therefore, a child who is able to succeed in mastering those skills will often develop a positive self-concept and self-esteem that may prepare him or her for coping with the trials and tribulations of adulthood. This indicates that academic achievement is often linked with overall self-esteem.

Cantrell and Lupinacci (2008) investigated the health-related quality of life (HRQOL) of childhood cancer survivors and found a significant impact on self-esteem. An online survey examining hope, self-esteem, affect, social support, physical health, and HRQOL was created and posted through a webpage over the course of six months. Thirty-five respondents agreed to participate in the American study. Childhood cancer survivors were found to be socially and economically disadvantaged and females were at greater risk for developing long-term negative physical effects and therefore lower self-esteem. However, an interesting positive relationship was found between hopefulness, self-esteem, HRQOL, physical health status, and social support among childhood cancer survivors indicating that women who were hopeful had better self-esteem which resulted in better overall HRQOL than their counterparts (Cantrell & Lupinnacci, 2008).

Barrera, Shaw, Speechley, Maunsell, and Pogany (2005) also examined the impact of childhood cancer on educational and social development and the effects of the illness on clinical, personal, and familial characteristics. The study examined the long term educational and social outcomes; specifically physical health problems, stressful events, and self-esteem, and their impact on childhood cancer survivors. Data for this study was obtained through a mailed questionnaire which was completed by the participant's parents or guardians as part of the Canadian Late Effects Study, a national retrospective study of childhood cancer survivors (Barrera et al., 2005). Participants included 800 survivor parents/guardians and 923 control groups parents/guardians (Barrera et al., 2005). The questionnaire used sociodemographic questions to identify educational achievement and personal characteristics. Social outcomes were measured using questions from the Ontario Child Health Survey (Boyle, Offord, Hofmann, Catlin, Byles, Cadman, Crawford, Links, Rae-Grant, & Szatmari, 1987) and the Child Behaviour Checklist (Achenbach, 1991). Medical records were also obtained to analyze the type of cancer and treatment used.

Overall, children with leukemia and CNS tumours had the poorest social and educational outcomes. The results also indicated that a significant number of survivors had poorer educational outcomes than controls, fewer closer friends, and less likely to use friends as confidants (Barrera et al., 2005). Survivors whose parents had an educational level higher than secondary school, had better self-esteem and were also less likely to report educational difficulties. Low socioeconomic status was also related to poorer outcomes (Barrera et al., 2005).

Lahteenmaki, Huostila, Hinkka, and Salmi (2002) studied childhood cancer survivors in Finland. The participants were 43 school aged children (7 to 16 years old) with various types of malignancies (i.e., acute leukemia, Hodgkin's and non-Hodgkin's disease, etc.) who responded to a cross sectional questionnaire created by clinicians (Lahteenmaki et al., 2002). Teachers, siblings, and parents were also asked to fill out a questionnaire in order to provide more complete data. Rates of absenteeism and school grades did not differ significantly from that of healthy peers. The results indicated that, although the children were not registered in special education projects, they required significantly more tutoring than their peers regardless of diagnosis and also had overall more academic difficulty (Lahteenmaki et al., 2002).

Fraser (2003) examined 12 families with children with cancer aged four to 15 years old. This qualitative study examined children’s self-identity, acceptance by peers, and school experience. Physical changes in the appearance of cancer patients such as; weight gain, puffy face, hair loss, and stunting of growth were cited as the changes most apparent to a child’s peers. This rapid change was marked by a lack of tolerance by their peers and the result is teasing, rejection, loneliness, distress, and ultimately social isolation (Fraser, 2003). Physical changes are often thought of as personality changes by their peers and they remain months after the child reintegrates back into a normal school routine.

In his study, Fraser (2003) explained that these types of relationships, whether positive or negative, affected a child’s ability to form close relationships as adults. The illness often causes a child to reassess their friendships. Fraser found that friends either shunned or became closer to the ill child, thus forcing the ill child to learn early on who his/her friends truly are. He noted that survivors often became closer to teachers and other adults who were more compassionate than their peers. However, the “lack of friends can increase the likelihood of bullying and rejection which, in turn, creates a vicious cycle" (Fraser, 2003, p.150). Conversely, social inclusion and friendships were positively associated with school achievement, which suggests that children with cancer who do not have friends may demonstrate poorer educational achievement than children with friends.

Children's social relationships are highly impacted by peers' negative reactions to their physical appearance. Cancer survivors have been the targets of bullying and they are reportedly three times as likely to be bullied as other children (Lahteenmaki et al., 2002). This may have long term and far reaching implications for children's overall health and development. Re-entry to school after a period of treatment can be more negatively impacted by peer social exclusion and bullying (Lahteenmaki et al., 2002).

Gray, Doan, Shermer, Fitzgerald, Berry, Jenkin, and Doherty (1992) found that peer relationships were considered problematic due to rejection, ridicule, and a sense of loss of time "relating" to their peers, which resulted in sensitivity and cautiousness in entering new relationships. Negative peer reactions resulting in teasing caused social isolation, anxiety, and school phobia for some survivors. The fear that cancer was contagious was often cited as the reason why children avoided peers with an illness.

In a prospective study, Forsbach and Thompson (2003) examined the impact of cancer on interpersonal relationships. Participants were adult survivors of cancer who completed an online survey. One hundred and eleven participants completed the survey (Forsbach & Thompson 2003). They found that the adult survivors who went through cancer treatment at a later age, such as adolescence, reported that they were more self-conscious about their physical appearance because changes in their appearance occurred during a time when they could actively remember the way they once were (Forsbach &

Thompson, 2003). Another significant finding was that the later the age of diagnosis the more negative the impact on interpersonal relationships. The results indicated that cancer did have a significant impact on interpersonal relationships which is consistent with previous research. One of the greatest barriers in forming intimate relationships was the fear of relapse. An adult who had been sick as a child may have believed, with reason, that they may become sick again. It is not uncommon for adults to have cancer for a second time. There is a 25% chance that adult survivors will face cancer again throughout their lifetime (Goldsby et al., 2006). This fear made it extremely difficult for a survivor to want to initiate an intimate relationship, feeling that it would be unfair to become close to someone if there is a chance that they might not live.

Psychological Long Term Effects

Beyond the physical effects of surviving cancer there are often less apparent psychological effects that deeply affect a child for a lifetime. Bullying, isolation, inability to form interpersonal relationships, and poor self-esteem were some of the issues a survivor might face throughout their childhood. However, the long term effects on the survivor could have led to an overall poorer quality of life as an adult. There is still much debate as to whether adult survivors of childhood cancer will exhibit increased rates of psychiatric disorders and/or deficits in social emotional development.

Mackie, Hill, Kondryn, and McNally (2000) found that there were no significant differences in terms of increased rates of psychiatric disorders or social emotional development in childhood cancer survivors when compared to control groups. In their study, Mackie et al. examined 102 survivors of childhood acute lymphoblastic leukaemia (ALL) and Wilms’ tumour who were aged 19-30 years old, living in Manchester, England who had been in remission for at least 5 years. The goal of their study was to assess the psychosocial outcomes through interviews and psychiatric assessments in comparison to matched controls. The control group was matched by sex, age, and culture as well as locality. However, while Mackie et al. found that there were no significant differences in terms of increased rates of psychiatric disorders or emotional development in survivors versus control groups; they did find significant deficits in coping and overall functioning of survivors. Survivors were found to be more avoidant of close relationships. Survivors who presented themselves as coping poorly were also found to be of lower intelligence which may or may not be a direct result of treatment. This indicates that childhood cancer does have a strong impact on psychosocial development over the long term.

Goldsby, Taggart, and Ablin (2006) found negative long term difficulties associated with childhood cancer survivors. Survivors were especially at risk of poorer academic achievement, low employment rates, and low marriage rates. It was also stated that at least 30% of survivors would suffer from some form of psychological distress and were at an increased risk of a poorer quality of life over the long term. The difference in outcome measures may be related to the types of measures utilized in the studies.

In 2000, Eiser, Hill, and Vance conducted a systematic review of the results of studies, as well as the measures employed in those studies, used to determine the psychological consequences of surviving cancer. They found that very little research had been done in the area psychological health. Eiser, Hill and Vance examined 20 studies (17 from the US and 3 from the UK) and found that the studies reported that survivors displayed no significant deficits in terms of psychological health when compared to controls. However, they also found a large number of methodological problems that would explain the support of such findings. Eiser, Hill, and Vance cited discrepancies in poorly reported medical information, heterogeneous samples that were most often self-selected, unsuitable measures, and a lack of long term follow-up. They also found that certain studies focused on specific types of cancer (i.e., central nervous system tumour survivors may produce poorer results due to type of treatment needed whereas survivors of lymphoma have had better success rates) which could also have contributed to the findings. Eiser, Hill, and Vance concluded their review by drawing attention to the need for more longitudinal studies that focus on the developmental aspect of psychological health.

Recklitis, Parsons, Shih, Mertens, Robison, and Zeltzer (2006) examined the psychological distress and psychiatric disorders in children with cancer, by using the Brief Symptom Inventory 18 (BSI-18). In a large study of 8945 participants who were pooled from the Childhood Cancer Survivor Study, the results indicated that survivors displayed significantly less psychological distress than either adult cancer patients or community participants ((Robison et al., 2002; Recklitis et al., 2006).

Taieb, Moro, Baubet, Revah-Levy, and Flament (2003) examined 20 published studies of the occurrence of posttraumatic stress disorders (PTSD) symptoms in survivors. The main purpose of this study was to examine the prevalence of PTSD in survivors, as they believed that life threatening illnesses may cause PSTD symptoms. They found that although these symptoms varied across studies, a small number of survivors (2-20%) presented PTSD symptoms 5 to 7 years after treatment (Taieb et al., 2003).

In a more recent study, Lee and Santacroce (2007) found that 62% of participants had clinically significant levels of symptoms associated with posttraumatic stress symptoms (PTSS). They examined 45 long term childhood cancer survivors in the United States in order to determine the prevalence of PTSS, symptoms which are considered psychopathologic and often develop into full blown PTSD. However, the symptoms of PTSS alone are thought to play a role in significantly impairing everyday functioning. Characteristics symptoms of PTSS are divided into three clusters: "re-experiencing, avoidance of reminders and numbing of emotions, and increased arousal," (Lee & Santacroce, 2007, p.1407). Using self-reported questionnaires, Lee and Santacroce found that while 13.3% of the participants had full blown PTSD, 62% had symptoms of PTSS. Unemployment and a lower educational level were correlated with occurrences of PTSS in survivors which was similar to the findings of Langeveld et al. (2004). Therefore the prevalence of PTSS may be more widespread than was previously imagined thus indicating a potentially traumatic long term psychological impact.

Gray, Doan, Shermer, Fitzgerald, Berry, Jenkin, and Doherty (1992) examined the psychological impact of childhood cancer on 62 survivors who reported strong negative emotions associated with treatment. Various data gathering methods were used such as questionnaires, self-report inventories, and semi structured interviews. However, the experience was also found to have created a sense of maturity and seriousness that affected their view of life in what most survivors deemed a more positive manner indicated the ability to overcome the trauma. The authors caution that although most childhood cancer survivors managed to avoid serious psychological difficulty there were still a minority of survivors who had severe negative long-lasting difficulties such as:

strong negative memories, problematic relationships, employment difficulties, infertility, physical impairments, and overall higher risk for poor adaptation. An interesting hypothesis put forth by Gray and his colleagues is that survivors who present themselves as well adjusted may simply be masking potential suffering and psychological maladjustment with the development of a highly effectively defensive coping strategy (such as denial) which allows the survivors to, in a sense, overcome their difficulties (Gray et al., 1992).

Adults who are childhood survivors have been found to have had higher quality parent-child relationships. Orbuch, Parry, Chesler, Fritz, and Repetto (2005) examined the quality of the relationships between parent-child survivors and their quality of life. One hundred and ninety participants (respondents from a larger study of 900 survivors) responded to self-report questionnaire survey on survivors' reported on their perceptions of their relationships with their parents. The parent-child relationships were linked to their present sense of psychological well-being. The greater the strength of the family and the ability to be resilient, the more likely the positive outcomes for children and young adults in terms of quality of life (Orbuch et al., 2005). In addition, survivors had better relationships with their mothers than with their fathers. Reportedly, after-effects of treatment interfered with life resulting in overall poorer quality of life except when the psychological quality of life scores in regards to the relationship with the mother was high, indicating that children who were able to talk to their mothers about their fears had a better psychological outlook on life.

The quality of life was also found to be related to participants' long term worries (Zebrack & Chesler, 2001). Three hundred and sixty nine participants were randomly chosen from their medical records and completed a self-report questionnaire on long-term worry. Fear of relapse was found to be the greatest source of worry which affected the quality of life of survivors. Worry altered the way survivors interacted with others and was considered a predictor of the survivors' self-perception. The authors concluded "that although cancer alters the way all survivors view themselves, the positive or negative nature of that alteration depends less on their physical circumstances than on the meaning they ascribe to their experience and their related outlook on themselves and their lives" (Zebrack and Chesler, 2001, p.253). Dealing with cancer at a crucial point in their psychosocial growth may have resulted in adolescents adopting less confidence in their abilities but also a sense of appreciation for what they have overcome (Zebrack and Chesler, 2001). Again, the positive psychosocial outcomes indicated by survivors were treated with caution by researchers because they felt that it may be an indication of avoidance or defensiveness.

Another large scale study examined the long term (1963-1992) psychosocial problems of 500 survivors in the Netherlands (Langeveld, Ubbink, Last, Grootenhuis, Voute, & De Haan, 2003). A psychosocial instrument was created (in the form of a questionnaire) by the researchers in order to record educational achievement, employment status, and living situation/marital status/offspring. They found that although many survivors were functioning well and leading normal lives, a subgroup of survivors (approximately 300 participants) were adversely affected in terms education, living situation and marital status. Female survivors were less likely to complete high school level academics and a significant amount of survivors were considered to be learning disabled. More cancer survivors were also unemployed when compared to the control group although more survivors indicated that they were students or homemakers. In terms of marital status, more male survivors were unmarried and lived with their parents than participants in the control group. The survivor group also had significantly fewer children than the comparison group. The results were found to be consistent with past literature from the United States indicating that the impact of childhood cancer may be similar across cultures.

In a subsequent study, in 2004, Langeveld, Grootenhuis, Voute, De Haan, and Van Den Bos found that the quality of life (QOL) of 400 survivors (control group of 592) was similar in many dimensions to that of their peers indicating very little difference in terms of anxiety, psychological health, and physical capabilities. Interestingly in 2004, Langeveld, Grootenhuis et al. examined the effects of childhood cancer on the QOL of survivors, particularly in terms of self esteem and degree of worry. The results again indicated that female survivors reported poorer quality of life with significantly limited physical abilities and worry of relapse than the females in the control group and male cancer survivors (Langeveld et al., 2004). However, the male survivors reported *better* perceived health and overall *better* QOL than the males in the control group (Langeveld et al., 2004). There were no significant differences between the survivor group and the control group in terms of employment and overall QOL. Again, this directly contradicted the previous findings reporting that the overall quality of life for a substantial number of childhood cancer survivors was poorer than that of their peers.

More recently research has shifted from simply examining quality of life (QOL) to focusing on health-related quality of life (HRQOL). In 2006, Blaauwbroek, Stant, Groenier, Kamps, Meyboom, and Postma began to look at HRQOL as opposed to QOL because the latter is seen as a more “multidimensional psychological construct, which includes at least four domains: physical, cognitive, social, and emotional functioning,” (p.123). The Dutch study assessed 363 long-term survivors of childhood cancer (n=129 survivors > 20 years; n=184 survivors < 20 years) using the RAND-36. This instrument is a 36 item self-report questionnaire used to examine HRQOL through eight subscales (physical functioning, social functioning, limitations due to physical problems, limitations due to emotional problems, mental health, vitality, bodily pain, and overall general health perception) (Blaauwbroek et al., 2006). They found that there were more late effects in survivors that had been treated over 20 years ago. This finding was linked to the treatment given at the time however, an interesting subsequent finding was that being female, having psychosocial problems, and late effects were negatively related to HRQOL (Blaawbroek et al., 2006). Thus indicating, by providing more evidence, that females seem to be at a greater risk for overall poorer HRQOL as was found by Langeveld et al. (2003) and Langeveld et. al (2004).

Although recent changes have been made to define a construct which fully encompasses the multidimensional issues that face long-term cancer survivors, the available information indicates that there is a large discrepancy in the research. It is therefore clear that there is a subset population of survivors that demonstrated psychological distress. There were also, however, a percentage of survivors who were able to overcome the trauma and thrive in the face of adversity caused by a life threatening illness.

Transformation, Thriving, and Resilience

Past research has painted a bleak picture for survivors in terms of an increased risk of maladaptive psychosocial and emotional behaviour. There is very little doubt that surviving childhood cancer will have long term effects on the survivor. Research has shown that the negative effects can be profound however, the majority of the research has also been quantitative and have painted a picture based on categorical variables such as employment rates and marital status. While there are a handful of articles that provide survivors with a voice to express how cancer has impacted their lives, the literature focuses on the overwhelming faceless numbers that often accompany larger scale quantitative research.

It is unclear how the experience of surviving cancer as a young child impacts on one's outlook on life and how the experience may be transformative, both positively and negatively. Woodgate (2006) examined the narratives of 39 children (and their families) who were purposely selected to illustrate the core experiences of living with childhood cancer. Data was collected over a two year period through open-ended interviews and participant observation. Woodgate found that narratives gave a voice to survivors and allowed for the articulation of the cancer experience in a way that was more tactile that mere statistics. It also offered an outlet for meaning making. The children and parents described the various hardships; such as the losses (normal childhood, being able to be a cheerleader, relationships, uncertain future) they faced while living with cancer. An important theme that arose from the narratives was the theme of "moving forward, moving on". This ideology was used to maintain a sense of hope or optimism about the future. It allowed survivors and their families to come to terms with their losses but also to incorporate their illness into part of a plan for their new life."Viewing cancer as a test or challenge contributed to children and families living through cancer as opposed to just surviving cancer" (Woodgate, 2006, p.14). Woodgate discussed that narratives were fitting for childhood cancer research because it offered survivors an outlet to tell their stories. It is evident that cancer impacts children and their families however, the stories told by narratives again offer a means of better understanding the stressors and difficulties encountered by survivors.

Narratives provide an opportunity to personalize the stories of survivors. It is also within the form of narratives that we can begin to understand the personal journey of healing that accompanies the survival process. Kameny and Bearison (2002) investigated the narratives elicited from 27 adolescents and young adults in various stages of treatment for cancer. The narratives were categorized in terms of medical, personal, and social domains. They concluded that when given the opportunity to discuss their situation, patients were better able to cope. Kameny and Bearison found that emotion-focused coping strategies involve changing the way one thinks about a situation. By encouraging patients to express themselves they found that the patients were able to create better ways of coping which allowed for a more positive psychological outlook.

It is fair to say that having cancer as a child is an extremely traumatic event. There is a lack of control and the effects are long lasting. Depending on when the cancer strikes there may be a threat to one's identity. Fear and anxiety may also manifest as psychosocial difficulties.

Tedeschi and Calhoun (1995) were pioneers in the area of transformation theory. In their book, *Trauma and Transformation: Growing in the Aftermath of Suffering,* Tedeschi and Calhoun (1995) examined the different ways that trauma has impacted people's lives. They defined trauma as a shock, something that changes unexpectedly or suddenly which is likely to threaten our psychological well-being. Perceived lack of control and the degree to which its effects are felt over the long term and/or the reversibility of those effects can make an event even more traumatic. The impact of the crises on a particular moment in time in the person's life cycle is also extremely important. The consequences of the crises will have a different impact in childhood than in adulthood especially if the trauma clashes with an established identity it may be harder to accept than one that has been integrated into one's identity.

Tedeschi and Calhoun stated that the most frequently encountered responses following a major trauma are fear and anxiety. Depression can sometimes result from trauma leading people to withdraw from those around them. Therefore the overall likelihood of developing psychiatric disorders or physical illness due to significant trauma is increased.

However, they found that there were some individuals who used denial as a way of coping with the impact of trauma. They would push it out of their awareness which resulted in a lack of distress. This lack of distress may have reappeared later as repressed emotions and psychological problems however, some people may have simply used denial as a successful means of coping. These people were then capable of coping by removing the distress caused by the awareness and/or attention paid to the traumatic event.

Tedeschi and Calhoun also noted that there were a group of individuals who experienced positive changes in the perception of self and demonstrate emotional growth.

Colin, Taylor, and Skokan (1990) found that in a self-report of cancer patients, a sample reported feelings of being more self-assured and stronger emotionally. Another positive perceived change in self was often a stronger sense of self-reliance and personal strength. “If they are able to cope successfully with such rough times, they can cope with anything; that is, their self-reliance is substantially elevated beyond what it was before the trauma as a result of meeting the most difficult challenge they have faced (Tedeschi & Calhoun, 1995, p32). Tedeschi and Calhoun (1995) found that recognizing meaning in trauma was perhaps one of the most important coping strategies because it allowed the person to experience emotional relief in the face of the negative emotions that accompanied the questioning, searching, and despair people are confronted with during traumatic episodes. Perceived meaning making allowed the individual to create a new and more profound philosophy of life that may have altered that individual’s most basic beliefs about life and its meaning. Thus creating a philosophy in which the trauma was positively integrated into a new life narrative. This therefore helped the individual to accommodate what happened as an opportunity for psychological growth. This new found order and meaning facilitated the integration of all aspects of life into the new life narrative thus resulting in a greater sense of control, increased self-esteem, as well as a stronger sense of well-being. For growth to have occurred there must have been a positive change in oneself. While this may be harder to quantify, it is uniquely revealed through each individual whether it be through their beliefs and/or actions. These changes are recognized as having occurred as a direct result of the trauma incurred.

The development of a life narrative is then crucial to overcoming isolation. As an individual shares his/her story empathy from others is developed thus helping to overcome the sense of loneliness felt by the individual. This is an important part of coping. It is the "communalization" of the trauma (Tedeschi & Calhoun, 1995).

Carla Parry and colleagues (2003; Parry & Chesler, 2005) have been extremely active in examining the stories of childhood cancer survivors. In 2003, they interviewed 23 participants of a larger multi-method multistage study that sought to examine the QOL and transformational process of childhood cancer survivors. Parry sent out 190 questionnaires and purposefully selected 23 participants out of 108 who agreed to an in-depth interview. The interviews focused on both the positive and negative impacts of cancer specifically in terms of: physical, psychological, social, and spiritual outcomes. Central to the study, Parry examined the experience of uncertainty as a prominent theme throughout the life of a cancer survivor. Will I relapse? What will be the after-effects of both treatment and the type of cancer? These are just a few of the questions a survivor must continually struggle with. Parry (2003) examined how each participant coped with uncertainty in their lives due to their illness. While uncertainty has often been thought as a threat to psychological well-being, Parry found that it can also aid in coping. Survivors who were able to integrate uncertainty within their lives were found to be better adjusted than those who were unable to accept the lack of certainty. In fact survivors who described their experience in terms *transformational coping* (Aldwin, 1994) or *thriving* (Carver, 1998) stated that the experience actually enhanced their lives. For example, a participant named Karen explained how her life was better off for having had cancer:

> It's made me such a better person than I probably would have been without it.....I think it's made me so much better than anything I possibly could have dreamed of being. Because I am so much stronger, I'm very independent, I learned the art of

> positive thinking. (Parry, 2003, p. 237)

Parry found that nearly all participants reported the instances of uncertainty. Uncertainty was discussed in the context of worry and the after-effects of cancer. Some were able to integrate the uncertainty as a permanent part of their lives as part of their consciousness, while others thought of it only when important life events arose (i.e., weddings, funerals, check-ups). More importantly, the majority of participants did not associate uncertainty in a primarily negative manner and did not relate it to distress.

Perhaps, the most important finding was that some participants described uncertainty as a catalyst for change in terms of their outlook on life. Furthermore, this change was found to be positive. Participants described themselves as more confident, stronger, more optimistic, and more independent after having faced cancer. There were also a few narratives that suggested that the participants felt better off for having had cancer in that it made them better people. The narratives presented by Parry (2003) challenged the primarily negative outcome of survivors as damaged and maladjusted thereby indicating that distress caused by uncertainty may not necessarily be a negative construct but rather a precursor for healing and/or growth. The research also demonstrated that survivors were also capable of thriving offering a more positive long term outlook than demonstrated in previous research.

In the theoretical literature, thriving is defined as “the transformation of a threat into a challenge in such a manner that one’s functioning and well-being are ultimately enhanced by the process of negotiating the issue” (Parry, 2003, p.229). The possibility of thriving as an alternate to the negative outcomes often associated with cancer survivorship challenges the perceptions that coping is strictly a negative or neutral process. Within cancer research, the term “thriving” is often used to describe the resiliency demonstrated by individuals suffering from serious illness. Thriving is defined based on the presence of trauma and the ability to demonstrate growth despite it, which results in life changes altering one’s sense of self and the world around them (Parry & Chesler, 2005). The ability to cope is based on the way a child perceives cancer and how the child copes with it. Central to coping is the process of attaching meaning to the situation or creating a narrative or new life story out of it. Situational meaning making is used to describe traditional concepts of coping, such as a global meaning making, which ultimately is part of the deeper transformational changes involved in thriving that changes identity and outlook (Parry & Chesler, 2005).

Briefly, thriving differs from resilience in the sense that thriving is often associated with personal growth. The literature on “thriving” presents a deeper experience that is transformative and results in personal transformation (Tedeschi & Calhoun, 1995). It is a transformation that provokes a reaction where a person experiences growth in more positive manner which is reflected in a “better off than before” mentality. Much of the past research on resilience and thriving has focused largely on underprivileged children from low socioeconomic status with histories of abuse. Some research has also looked at children who suffer from chronic illness such as diabetes and asthma (Bolig & Weddle, 1988; Grey & Thurber, 1991; Vinson, 2002) however, very limited research has examined resiliency in childhood cancer survivors (Tedeschi & Calhoun, 1995, 1996, 2004; Donze & Tercyak, 2006; Parry, 2003; Parry & Chesler, 2005; Orbuch, Parry, Chesler, Fritz, & Repetto, 2005)

The ability to “bounce back” or overcome trauma/stress is also known as resilience. The concept of resilience was first studied by Werner and Smith in the 1970’s based on the research of high risk children in the Kauai Longitudinal Study (Johnson & Wiechelt, 2004). They examined how poverty affected the long term quality of life outcomes of the Kauai children over time as well as why certain children were able to overcome the adversity of their circumstances. Werner and Smith (1989) found that approximately 70% of children had negative life outcomes whereas 30% were able to overcome adversity thus demonstrating resilience. Werner and Smith also found certain protective factors (i.e., easy temperament, etc..) that they believed helped the children fare better. However, the concept of protective factors is still quite controversial because of the difficulty in studying and isolating protective factors after the fact. The majority of studies on resiliency that focus on protective factors uses data that has been collected through memory recall many years after the threat had been posed. For the purpose of this study, I intend to explore the positive or negative transformation that is described by individuals who have undergone difficulties that result from surviving childhood cancer rather than focusing on the protective factors.

In 2005, when Parry and Chesler examined the psychospiritual growth that resulted from surviving childhood cancer, they found instances of thriving. Survivors reported that they overcame the trauma and stress of the illness and that they attributed a better quality of life than they had previous to the diagnosis to their bout with the illness. They found that although many survivors reported psychological difficulties resulting from surviving cancer, the majority reported a variety of positive changes such as; “increased psychological maturity (65%), greater compassion and empathy (61%), new value and priorities (57%), new strengths (48%), and increased recognition of vulnerability and struggle (44%)" (Parry & Chesler, 2005, p.1061).

They also found that survivors who discussed a global sense of strength described a sense of self-reliance and resilience that they were able to apply beyond their battle with cancer to other life challenges, which resulted in greater optimism, happiness, and a greater ability to handle stress, uncertainty, and anxiety (Parry & Chesler, 2005). By embracing their mortality, many survivors came out stronger. Some survivors were able to look upon their scars or disfigurements as a sort of trophy or medal which served as a daily reminder of overcoming the illness. "This is the thriving narrative: a narrative of how some survivors experience tremendous pain and loss but embrace themselves in the experience, finding strength, courage, and ultimately, wholeness" (Parry & Chesler, 2005, p.1069). Nearly all survivors described how surviving cancer altered their outlook on life making them more appreciative of their relationships and helping them to prioritize their values.

It is important to note that the terms transformational coping, posttraumatic growth, thriving, and resiliency are often used interchangeably with quality of life (QOL) outcomes. It is equally important to clarify that the terms are not the same process or construct. Transformational coping, posttraumatic growth, thriving, and resiliency each denote a dynamic process (Parry, personal communication, February 20, 2009). Coping on its own refers to a more superficial process that may not include transformation. Quality of life outcomes are not dynamic but rather static. They are simply measured outcomes. These outcomes do not indicate growth or transformation but are reported recordable data facts. Therefore QOL research that tends to predict successful outcomes is not positively correlated with instances of thriving because thriving is a “threshold issue” which supports dramatic change or transformation (Parry, personal communication, February 20, 2009). In order to see evidence of thriving one must have a baseline of a poorer quality of life followed by a significant change that results in transformation. Quality of life outcomes (positive or negative) do not measure transformational change but simply report on the life outcomes (Parry, personal communication, February 20, 2009). Traditionally, according to Parry, research that has supported positive QOL outcomes has been negatively correlated with thriving (personal communication, February 20, 2009). Research has focused on the categorical outcome measures of surviving childhood cancer. The limited research examining the qualitative contribution of the transformative growth through which some survivors are able to attribute more positive meaning to their battle with cancer, is clearly understudied. Regardless of whether or not survivors feel that having cancer has had a positive or negative impact on one’s life, the effects are felt nonetheless. With a growing population of childhood cancer survivors, it is crucial to examine the long term psychosocial changes and narratives described by these adults.

Purpose of Study

The purpose of this study is to explore the narrative stories of adult survivors of childhood cancer and understand how they describe their quality of life. Limited research has shown that some survivors thrive and feel that they have more positive life experiences due to their illness. This study sought to learn from survivors of cancer who were asked to retell and discuss their own personal stories, as well as to provide an opportunity to retell and examine my own personal story as an adult who has survived cancer. Pseudonyms were used throughout to ensure confidentiality.

During this study I examined the following questions:

1) How do adults who survived childhood cancer describe the long term effects that cancer has had on them as young adults? What kind of coping skills have they developed that allow them to thrive? What has been the negative impact of this illness on their lives as young adults?
2) How does their definition of quality of life compare to past research on thriving and quality of life? Do more positive or more negative experiences emerge in their narrative stories? How does this compare to past research that used quantitative methodologies? Do childhood cancer survivors demonstrate more instances of thriving than past research has suggested?
3) Is there a relationship between self-reported quality of life outcomes (survey) and narrative themes that emerge in the adults' stories of transformational growth?

As previously stated, the majority of research available focuses on the poor QOL outcomes for childhood cancer survivors. It is therefore expected that the data collected from the survey will produce similar results with the exception of educational level which will be significantly different due to the sample selection. The narratives will provide another measure of quality of life that may allow for a more inclusive picture of themes related to or conceptualized as positive outcomes.

Method

Design

In order to examine this topic, I chose to follow Parry and Chesler's (2005) approach using a mixed methods design that included both qualitative and quantitative data. The design was multi-pronged in that the large focus of my research included qualitative data in the form of narrative stories and memories that were taken from interviews of survivors, as well as my own personal account of survivorship.

I gathered my initial quantitative data through a survey (Appendix A) that was distributed via mail once the participants had contacted me after the recruitment process. The survey allowed me to gather demographic data, as well as permission for further contact in the form of an in-depth interview.

Participants

Participants were recruited through online request. Adult survivors of childhood cancer were the target population. The proposed recruitment sample was to be the students at Concordia University however, this proved unsuccessful and various other organizations (i.e. the Leukemia and Lymphoma Society, Planet Cancer, the Lance Armstrong Foundation, Facebook, etc..) were contacted to circulate recruitment information.

Participants were selected based on the following characteristics: the participant had a cancer diagnosis between birth and 19 years of age and had a minimum of 5 years post-treatment. Using the above criteria, ten participants were recruited to participate (n=10). The participants were based in North America however, they were not from the Montreal area. The demographic information is presented in Appendix D. The participants ranged in age between 26 to 40 years of age. Of the sample, four participants (40%) were female and six (60%) were male. The participants had a variety of different forms of cancer; Wilm's Tumor (10%), non-Hodgkin's Lymphoma (30%), Hodgkin's Lymphoma (10%), Neuroblastoma (10%), Rhadomyosarcoma (10%), Ependoymoma (10%), and Leukemia (20%). Radiation and chemotherapy was the treatment received by 8 of the participants while 2 of the participants received only radiation as treatment. The age of diagnosis ranged from 10 weeks to 19 years old. Marital status was divided into three groups; 2 were committed in a relationship, 3 were married, and 5 were single. Level of education had four groups: two participants had some college education, 3 were college graduates, 2 had technical education, and 3 had post-graduate education. The majority of the participants were Caucasian (80%) with only two participants (20%) being of Indo-Canadian descent. Only one participant earned an income less than $25 000 while the majority (7 out of 10) earned between $26 000- $50 000 with two participants earning over $76 000. Four of the participants considered themselves to be of Christian faith and three participants felt that they did not subscribe to a religion. One participant felt that he was spiritual but not religious while two other participants were of the Hindu and Sikh religion respectively. Finally, 7 out of 10 participants had not had a recurrence of their cancer although 3 out of 10 participants had a recurrence after the initial treatment.

Procedure

After obtaining ethical approval, a preliminary recruitment poster (Appendix A) was circulated to various faculties within the University of Concordia (i.e., Department of Psychology, Education, Sociology, and Anthropology). Department administrators sent out the poster online via email. I chose to recruit participants electronically in order to purposefully choose a sample for further participation in the study. As previously mentioned, I intended to survey the adult population of Concordia University for the purpose of my data collection. The purpose for initially selecting this particular demographic was that the majority of previous research indicated that survivors who are resilient have created a role for themselves that is more than simply that of a “survivor”. However, recruitment through the university proved unsuccessful and thus it was necessary to contact a broader population via various online organizations (as previously mentioned; Facebook, the Lance Armstrong Livestrong Organization, Planet Cancer, Imerman’s Angels, etc...). Only one participant was recruited based on word of mouth. The participant was sent my information after a student from the university received a mass email through the department of education. Many other cancer organizations, such as the Leukemia and Lymphoma Society and Leucan, were contacted however, due to the large volume of researchers requesting help with their projects, the request was declined. They were also unable to post a recruitment poster.

The three online communities which offered to support this project were Facebook, Livestrong, Planet Cancer, and Imerman’s Angels. They posted a recruitment poster and contacted individuals with my contact information. To further explain, Facebook is an internet networking tool where people can search for people and/or join groups. It is also possible to form groups based on interests or hobbies. There are currently many established groups of young cancer survivors who are seeking to connect and share their stories.

The Lance Armstrong Foundation (http://www.livestrong.org/#) was founded in 1997 by Lance Armstrong, the world famous cyclist, after his own battle with testicular cancer. His goal is to raise awareness and fund research while promoting positivity and education.

Planet Cancer (http://www.planetcancer.org/) is an offshoot of the Livestrong Lance Armstrong foundation. It was created by a group of twenty year old cancer survivors and patients as an online community where people could connect and provide support for one another. The referral for this site came from the Livestrong Foundation.

Imerman's Angels (http://www.imermanangels.org/) was also contacted based on a referral from the Livestrong Foundation. It was created by Jonny Imerman in 2003 after his own battle with testicular cancer. This site provides one-on-one mentoring by connecting angels/survivors with those who have just been diagnosed with cancer and are seeking support.

A recruitment poster (Appendix A) was posted on the above mentioned sites and potential participants were given the means of contacting me through email. After a brief email exchange, qualified participants were sent an information package containing the consent form and questionnaire via mail. Participants who consented to participate in the interview portion of the study were contacted by telephone for the interview. Interviews ranged between 45 to 90 minutes and were recorded for reliability.

Data Collection

Due to the sensitive nature of the subject matter and the difficulty in recruiting participants, data was collected over the course of a year (August 2009-June 2010). Once the initial contact was made via email every attempt was made to ensure that the participants were made to feel comfortable with their level of participation. It was made clear on many occasions that they were free to not answer any questions they felt were too personal or uncomfortable and that they were also free to discontinue at any time. This was repeated in order to ensure that the participants never felt pressured in any way. The survey included a series of questions in order to obtain demographic information of the participant such as age of diagnosis, amount of time post-treatment, type of cancer, etc. (Appendix A). The survey was used to generate QOL data, as well as to provide an overall view of the participants. Respondents were asked if they were willing to participate in a follow-up study involving a more in-depth interview process. Participants who responded positively to participating further in the study were contacted via email in order to establish a suitable time for a telephone interview.

The interviews took place via telephone at convenience and comfort level of the participants and were audio-taped. A consent form (Appendix B) was presented to the participant prior to the interview to ensure that the participant was notified about confidentiality as well as his/her right to discontinue at any point throughout the interview process. The interviews were completed via telephone due to the geographical distance of the participants. The semi-structured interview sessions included open-ended questions that prompted discussions of both the positive and negative consequences of cancer in the following areas: physical, psychological, social, and spiritual (Appendix C). The narratives generated helped to create a better understanding of how the participants were able to cope with having cancer at such a young age as well as if the participant felt transformational growth had occurred. The interview provided the participants with a forum to voice their stories; it is hoped that this research would provide an opportunity for a deeper understanding of the topic.

Measures

In order to capture the data on quality of life (QOL) outcome for the participants of the study an initial survey/questionnaire was administered via mail. The initial survey/questionnaire was based on Parry's 2008 Survey Codebook, a standard questionnaire that she employs in her research (Parry, personal communication, February 20, 2009). Parry created her questionnaire by compiling various tools into one all inclusive tool that probed the four domains of QOL outcomes: physical, social, psychological, and spiritual. The questionnaire included; the Quality of Life Cancer Scale (QOL-CS, Ferrell, Dow, & Grant, 1995), the Posttraumatic Growth Inventory (PTGI, Tedeschi & Calhoun, 1996), as well as modifications to the QOL-CS by Zebrack and Chesler (2001). Since very little research has been done on the topic of survivors of childhood cancer, there are no standardized instruments. Zebrack has been a pioneer in the area of the impact of cancer research however, his work focused on adults who have overcome cancer rather than adult survivors of childhood cancer. For the purpose of this study I chose to use Parry's survey (2008) with slight modifications. Modifications were made to exclude questions that focused too heavily on medical history and issues not relevant to the four domains I sought to examine at this time. The following section will provide more detailed information about the tools used in Parry's survey.

Parry's survey codebook. Parry's Survey Codebook was last updated in 2008. It is part of her ongoing body of research and has been influenced by her work with Chesler and Zebrack (Parry & Chesler, 2005; Zebrack & Chesler, 2001). It includes straight forward questions which probe for demographic information as well as questions focusing on medical background, spirituality, social concerns, and physical well-being. Parry's questionnaire encompasses each of the four domains involved with QOL research while including portions of standardized instruments in order to address the cancer specific areas needed to be addressed for the purpose of this study. Parry's questionnaire has been tested on many occasions and validity has been established (Parry, 2008).

For the purpose of this study, my survey includes the Quality of Life- Cancer Scale (QOL-CS; Ferrell, Dow, & Grant, 1995) and the Posttraumatic Growth Inventory (PTGI; Tedeschi & Calhoun, 1996). I have modified Parry's original questionnaire in order to create a slightly condensed version for the accessibility of potential participants. Also, I eliminated certain questions that I felt focused too much on medical/spiritual details (i.e., questions about relapse, chronic illnesses, and religious traditions) as well as certain scales that dealt with worry and depression as Parry sought to examine uncertainty associated with worry. My survey omitted the Functional Assessment of Chronic Illness Therapy and Well-being scale (FACIT-SPR; Peterman, Fitchett, Brady, Hernandez, & Cella, 2002), the Self-report Depression scale for Research in General Population (CES-D; Radloff, 1977), and the Impact of Event Scale (IES; Horowitz, Wilner, & Alvarez, 1979). The omitted scales focused on spirituality (FACIT-SPR), depression (CES-D), and the impact of stressful events (IES) which Parry sought to examine in depth in her analysis of QOL based on uncertainty. Parry's study was more qualitative therefore her codebook reflects the thoroughness of her survey. These scales were not included at this time because the choice was made to focus on the QOL assessment scale (QOL-CS) and posttraumatic growth (PTGI) in order to balance the narrative quest for transformational growth as well as to generate data for comparison with previous findings on QOL research. The following is a more detailed breakdown of the scales that were included in the survey:

Quality of life-cancer scale. The Quality of Life- Cancer Scale (Ferrell, Dow, & Grant, 1995) was originally designed for adult breast cancer patients. It probes the four domains of QOL: physical, psychological, social, and spiritual; however, it targets an adult population and many questions were found to be unsuitable for survivors of childhood cancer.

Posttraumatic growth inventory. The Posttraumatic Growth Inventory (Tedeschi & Calhoun, 1996) is a 21-item Linkert scale tool which was designed for people who have encountered significant life crises. It was not created specifically for cancer research, however, it has been found useful in examining the psychosocial impact of cancer. The entire scale was included in the questionnaire in order to elicit more complete data on the psychological and social domains of quality of life.

My Role as Participant Observer

My topic is that of a personal nature as I am a cancer survivor myself. I was seven years old when I was diagnosed with non-Hodgkin’s Lymphoma. I do not remember ever actually being told that I had cancer. I was young after all and I do not think I would have understood even if they had explained it to me. I remember my parents going into a room while I waited outside in the play room. They came out crying and it was then that I knew that something was going to change. My life was never going to be the same.

I was the one who first discovered a strange “bump” that would later be confirmed to be cancer. After showing my parents I was taken to my paediatrician who suggested I go to the Montreal Children’s Hospital (MCH). What exactly happened after that was a bit of a blur, but needless to say it was not my last visit to the MCH. There was a biopsy followed by the much dreaded news. Radiation and chemotherapy became part on my now almost eight year old life. I would travel every Friday to the Montreal General Hospital (MCH) for radiation only to return to school in the afternoon after lunch. Chemotherapy happened everyday for a period of two weeks. Again, I would go to the MCH in the morning and return to school before lunch. My major chemotherapy treatments were given on the weekends where I would stay overnight (Friday to Sunday). Sometimes, there were bone marrow tests in which my bone marrow was checked for the white blood cell count to ensure that I was not becoming too weak. I had to be mildly sedated for those tests which left me groggy for the rest of the day.

I believe that my parents wanted me to try to have as normal a childhood as I could possibly have during this period of my life. My education was always important and since I could have missed a whole year of school due to my treatments, my parents tried to make sure that I attended as much as I could. This may have been a form of denial on their part, but I was rarely sick (due to treatments) so I simply went to school after my morning visits to the hospital.

The principal was alerted to my condition and offered to talk to the whole school. I was not present for the speech. While it was done with good intentions, I grew up in a small town off the island of Montreal, it also now changed my persona from “regular kid” to the “kid with cancer”. I was teased and laughed at.

Treatment lasted almost two years and after I was in remission. That was almost 25 years ago. Since then I went on to become a straight A student (in elementary school and graduated from high school with over 10 academic and school life awards). I joined various sports teams (basketball and badminton) and immersed myself into numerous school activities (student council, yearbook committee, talent show, etc...)

I attended Cegep where I graduated with honours while coaching (as an assistant coach) my former high school basketball team. I went on to complete a Bachelor's Degree in Psychology and have recently received a Bachelor of Education (graduating summa cum laude). The point of my including this information is not to sound pompous but rather to illustrate the fact that I am a childhood survivor who *thrived*. Also I feel that it is important to explain that based on the statistics presented on some QOL research I should not be where I am today.

My parents are not university graduates. I am a female who was diagnosed before reaching adolescence. I was bullied. According to the majority of research I should have been considered extremely at risk for negative QOL outcomes. Also, I am not married nor do I have any children. This would further reduce my life to one of being unsuccessful in term of QOL research. However, someone who would look at my career, my accomplishments, and/or my life as a whole would not say that my life has been unsuccessful, nor has the quality been poor due to my childhood illness.

When I entered the Master's program at Concordia University I was determined not to write a thesis, but rather to complete an internship project. I never wanted to defend a thesis. However, after writing a research paper on the topic for a class, I was encouraged to pursue the possibility of writing a thesis on this very topic. It occurred to me that I was researching a topic that was personal; I was curious about the data on long term survivors. The research shocked and saddened me. While some parts I read as if I it had been a page out of my life (i.e., the worry that accompanies surviving a life-threatening illness), I was outraged that the available research foretold such a bleak future for survivors like myself. I was also saddened by the lack of research that was available on a topic that affected the population so widely.

Why did I thrive? How did I incorporate having childhood cancer into my life? Am I a better person for having had cancer? What type of support did I have? What role did uncertainty play in my life? These are only a few of the questions that I have asked myself and sought to explore throughout my study. My role as a participant allowed me to answer these questions while my role as observer provided a forum for other survivors to express themselves through their own narratives thus enabling survivors, like myself, a forum to voice their stories. I concede that my role as participant/observer came with certain predisposed biases, however, I believe this study provides invaluable information for those in the field studying the long term effects of childhood cancer survivors.

As participant observer, my role was therefore two-fold. As a participant, my experience has allowed me to have a unique understanding of the medical procedures that many survivors had gone through. As an observer and researcher, my experiences also guided my questioning. Much as I have questioned myself about my own story of transformation, I also sought to explore and offer a forum for the stories of others. Therefore the following questions guided this inquiry:

1. How do adults who survived childhood cancer describe the long-term effects that cancer has had on them as adults?

To answer this question, the participants were asked a series of open-ended questions during an interview session. I sought to address the first research question by asking one or more of the following questions (Appendix C):

- Tell me your story about cancer.
- What is the impact of cancer on your life as of today?
- What are your perceptions of yourself?
- Has cancer physically impaired you in any way?
- How does having cancer fit into your present day life?
- Would you consider yourself a successful person?

The above questions helped to create the participant's story as well as illustrate the impact of cancer on the participant's life.

2. What kind coping skills have they developed that allow them to thrive?

In order to address this topic I probed the participant with the following question (Appendix C):

- What helped you post-treatment?
- What social supports were available to you throughout your childhood and adolescence?
- What impact did your family have on your ability to cope?

These questions addressed the social and family supports that may have aided in creating more positive coping skills, however, the initial probe allowed for participants to reveal internal coping strategies as opposed to external supports (family, etc...).

3. What has been the negative impact of this illness on their life as young adults?

This question addressed how the participant currently felt about his/her life and future outlook. A more negative outlook would be reflected in statements about poor self-esteem, lack of employment, poor relationships, and/or generally a bleaker outlook on life.

4. I was also interested in exploring how the participants' definition of success compares to past research assessments of thriving and quality of life. How do narrative inquiry methods add or differ from the survey data?

Transformative experience is difficult to quantify as it requires a baseline that demonstrates change. The narratives provided a personal account as to whether the individual recognizes the impact of cancer as being *transformational* which was purely relative to that person's sense of what their life would have been like if they had not had cancer as a child. Also, within the ideology of transformation is the notion of quality of life outcome which is affected by the cancer experience. Quality of life outcome is equally difficult to quantify as, like transformation, it is not a uniquely tangible outcome. Although much of the research previously cited maintains that it is quantifiable in terms of surveys and data, I sought to demonstrate that this method is seriously flawed and in need of revision. Therefore, at the core of my inquiry is my focus on the narrative stories provided by the survivors, as well as the way that cancer has impacted, and in some cases transformed, their lives negatively or positively. However, I also provided demographic data as well as the results of a survey to compare the data with how the participants felt cancer had impacted their lives.

Results

Quantitative Results

Although there is a great deal of debate as to the meaning behind measuring or quantifying quality of life, much effort has been put into establishing tools that look to assess the impact of cancer. However, the development of a standardized tool is used to capture data from large samples. For the purpose of this study, the participants completed a survey which evaluated the impact of cancer through the Quality of Life Cancer Scale (QOL-CS) as well as the change that has occurred in one’s life as a result of the traumatic event/illness.

Table 1

Demographic Information of Participants (n=10)

Participant	Age	Gender	Age of Diagnosis	Type of Cancer	Treatment	Marital Status	Level of education	Race	Income	Faith	Recurrence
Christopher	29	M	19 yrs	Non-Hodgkin's Lymphoma	Radiation/ Chemotherapy	Married	Post-Grad.	Caucasian	$26000-50000	Christian	No
Edward	36	M	11 yrs	Hodgkin's Lymphoma	Radiation/ Chemotherapy	Single	College	Caucasian	$26000-50000	Atheist	No
Cathleen	26	F	> 1 yr	Ependoymoma	Radiation/ Chemotherapy	Married	Some College	Caucasian	$26000-50000	Christian	Yes
Rebecca	38	F	4 yrs	Wilm's Tumor	Radiation/ Chemotherapy	Committed	College	Caucasian	$76000+	Atheist	No
Michael	38	M	> 1yr	Neuroblastoma	Radiation/ Chemotherapy	Committed	Post-Grad.	Indian	$26000-50000	Hindu	No
Anne	26	F	> 1yr	Leukemia	Radiation/ Chemotherapy	Single	Some College	Caucasian	$26000-50000	Atheist	No
Victor	32	M	6 yrs	Rhadomyosarcoma	Radiation/ Chemotherapy	Single	Technical school	Indian	$26000-50000	Sikh	Yes
Justin	40	M	15 yrs	Non-Hodgkin's Lymphoma	Radiation	Married	Technical school	Caucasian	$76000+	Christian	Yes
John	31	M	5 yrs	Leukemia	Radiation/ Chemotherapy	Single	Post-Grad.	Caucasian	$26000-50000	Spiritual	No
Melissa	26	F	14 yrs	Non-Hodgkin's Lymphoma	Radiation	Single	Technical school	Caucasian	> $25000	Christian	No

The survey was first analyzed in order to derive quantitative information based of the respondents' responses to the demographic questions and to provide descriptive statistics. The demographic results of the survey are presented in Table 1. Data was analysed using Microsoft Excel and the data was entered on a spreadsheet. Basic statistics, such as percentage, mean, standard deviation, and range were used to calculate the findings of the survey. Percentages were used to illustrate the descriptive statistics of the overall sample (n=10). As the sample size was 10, the percentage was calculated using each participant as a unit of measure of 10%. The participants had a variety of different forms of cancer; Wilm's Tumor (10%), non-Hodgkin's Lymphoma (30%), Hodgkin's Lymphoma (10%), Neuroblastoma (10%), Rhadomyosarcoma (10%), Ependoymoma (10%), and Leukemia (20%). Radiation and chemotherapy was the treatment received by 80% of the participants while 20% of the participants received only radiation as treatment. The age of diagnosis ranged from 10 weeks to 19 years old. Marital status was divided into three groups; committed (20%), married (30%), and single (50%). Level of education had four groups; some college education (20%), college graduates (30%), technical education (20%), and post-graduate school (30%). The majority of the participants were Caucasian (80%) with only two participants being of Indo-Canadian descent. Only one participant (10%) earned an income less than $25 000 while the majority (70%) earned between $26 000- $50 000 with two participants earning over $76 000. Most of the participants considered themselves to be of Christian faith (40%) however, a large number of participants felt that they did not subscribe to a religion (30% atheist). One participant felt that he was spiritual but not religious while two other participants were of the Hindu and Sikh religion respectively. Finally, 70% of the participants were fortunate to not have had a recurrence of their cancer although 30% had a recurrence after their initial treatment.

As was previously mentioned, the survey relied on two tools of assessment for the QOL results; the QOL-CS (Ferrell, Dow, & Grant, 1995) and the PTGI (Tedeschi & Calhoun, 1996). Both tools were included in Parry's survey codebook (2008). The survey probed the four domains of QOL: physical, psychological, social, and spiritual while also seeking to measure the traumatic impact of the illness itself. The overall results of the survey are presented in Table 2 (see below).

The Quality of Life-Cancer Scale (QOL-CS). The QOL-CS is a 41-item scale with four multi-item subscales; physical (QOL-physical), psychological well being (QOL-psychological), social concerns (QOL-social), and spiritual well being (QOL-spiritual) (Appendix A). It also includes two subcomponents; distress (QOL-distress) and fearfulness (QOL-fear). Each subscale or subcomponent has a series of items which examine various issues relating to the subscale. Participants rated each item on a scale of 0 to 10. "The wording of items is such that for some items, 0 indicates the worst score and 10 the best; for other items the anchors are reversed," (Zebrack & Chesler, 2001, p. 321). For the purpose of scoring this scale, the items were ordered so that 0 indicated the highest or best possible quality of life outcome and 10 indicated the lowest or worst quality of life outcome for each item. For the sake of consistency, the psychological and spiritual subscales were scored using the reversed scoring scheme in order to present results that followed the initial scoring scheme. Zebrack and Chesler (2001) followed the same scoring scheme and found very good internal-consistency reliability and moderate to high concurrent validity when performing a psychometric analysis of the QOL-CS. The following is the breakdown of each subscale described in more detail:

The QOL-physical scale. This scale examines the physical impact of having had cancer. For example, the QOL-physical has nine items which probe subjects such as: fatigue, appetite changes, aches, sleep changes, constipation, nausea, menstrual/fertility changes, overall physical health, and physical health affecting QOL. Each item is rated with 0 indicating *no problem* and 10 indicating a *severe problem*. In this subscale the two final items (overall physical health and impact of physical well-being) are both scored using reverse scoring. The numbers were reversed during data analysis in order to remain consistent when reporting the results for the entire scale.

The QOL-psychological well-being subscale. This subscale contains 10 items which include: coping, quality of life, happiness, control, satisfaction, memory, usefulness, appearance, self-concept, and psychological well-being. This subscale was scored slightly differently with 0 indicating *poor* psychological effects and 10 indicating excellent psychological health. For the QOL-psychological well-being, items I (coping) and P (impact on appearance) were analyzed using the reverse scale. The entire scale was then reversed a second time in order to present results in a consistent manner. Therefore the data presented follows the same scoring scale as the QOL-physical with 0 indicating *no impact* and 10 indicating *severe psychological impact*. Thus a higher score would demonstrate greater psychological impact or distress.

The QOL-distress component. This component measured the amount of distress caused by the illness. The 6-item component subscale was based on a similar scoring scheme as the QOL-physical with 0 indicating *no distress at all* and 10 *indicating a great* *deal of distress*. This component contained 6 items including: distress over diagnosis, treatment, post treatment, anxiety, depression, and overall distress.

The QOL-fear component. The next component examined to what extent a person is fearful of the future. This subscale has 5 items which include: fear over future tests, secondary cancer, recurrence, metastasis, and overall fear. The scoring for this scale is measured with 0 indicating *no fear* and 10 indicating *extreme fear*.

The QOL-social subscale. The fifth subscale examines the social concerns of surviving cancer. This subscale contains 9 items which include questions about: impact on family, support, personal relationships, sexuality, employment, home life, isolation, financial, and overall social well-being. The scoring for this subscale used 0 to indicate *no social concerns* at all with 10 indicating a *great deal of social concerns*. Reverse scoring was used for item BB (social support) which focused on the amount of support received from others.

The QOL-spiritual well-being. The final subscale is an 8 item subscale which focuses on spirituality and rates the importance of spirituality in a person's life. The items include: participation in spiritual activities, meditation, changes, uncertainty, positive changes, purposefulness, hopefulness, and overall spirituality. The scale is scored with 0 indicating *no importance* and 10 indicating *very important*. The uncertainty item (SPR-UNCR, item LL) was scored using reverse scoring to again maintain consistency within the subscale. Similar to the QOL-psychological scale, this scale was also reversed a second time in order to maintain a consistent scoring scheme for data reporting purposes. Therefore the results of this scale were presented using the following rating scheme; a rating of 0 for *very important* and 10 for *no importance*.

The overall results are demonstrated in Table 2. The overall mean of the physical well-being subscale (QOL-physical) was computed as 2.13 (SD= 0.69). According to the physical subscale, the participants were reportedly not greatly affected physically by the experience of cancer at a young age. The results for the QOL-psychological subscale was found to have a mean of 3.26 (SD= 0.82) indicating a positive overall psychological well-being. There was an almost even divide between participants in terms of how distressing certain aspects of the illness were perceived. The results of the distress component demonstrated the highest impact with a mean of 4.83 (SD= 2.06). The results of the QOL-fear component (M= 2.06, SD= 1.09) indicated that the participants generally felt little fear in terms of their future in terms of recurrence of cancer. The results (M= 2.98, SD= 1.82) of the QOL-social subscale indicated that there were also very few social concerns that resulted from of having had cancer as a child or adolescent. The impact on spiritual well-being was found to be slightly higher. The mean was 4.63 (SD= 1.80) indicated that for certain participants the spiritual impact was more profound. Overall, the participants demonstrated very little negativity throughout each subscale and a higher sense of positivity in term of psychological well-being as well as spiritual well-being.

Table 2

Survey Data (n=10): Quality of Life Cancer Scale (QOL-CS)

Quality of Life Domain	*M*	*SD*	Min	Max
QOL-Physical	2.13	0.69	0.89	3.11
QOL-Psychological	3.26	0.82	1.80	4.70
QOL-Distress	4.83	2.54	0.75	7.67
QOL-Fear	2.06	1.09	0.20	2.40
QOL-Social	2.98	1.82	0.56	5.67
QOL-Spiritual	4.63	1.80	1.25	6.13

The Posttraumatic Growth Inventory (PTGI). The PTGI is a 21-item scale which itemizes each item into one of the following five subscales: (a) new possibilities, (b) relating to others, (c) personal strength, (d) appreciation of life, and (e) spiritual change. The first subscale examines the degree of change in terms of being accepting of new possibilities that has occurred in the survivor's life as of today. The second subscale deals with the ability to relate to others after having faced a trauma. The third subscale examines the ability to appreciate one's own personal strength in the face of other traumatic experiences. The fourth subscale is based on the ability to appreciate life after a traumatic experience. Finally, the last subscale examines the spiritual change that may occur due to a traumatic event.

The results of the PTGI are presented in Table 3. Each subscale was analyzed using Microsoft Excel. Each item was scored on a scale of 1 to 6 with 1 indicating *I have not experienced a positive change* and 6 indicating [I have experienced a positive change] *to a very great degree.* The results of the *new possibilities* subscale indicates that the participants felt change to a small degree (M=3.12, SD= 1.03). The results of the *relating to others* subscale indicated again that the effect had been felt to a small degree (M=3.83, SD=1.11). The participants felt the change to a moderate degree (M=4.15, SD= 1.13) in the *personal strength* subscale. The participants again felt a moderate degree of change in terms of their *appreciation of life* after having experienced a traumatic event such as cancer (M= 4.30, SD= 0.84). The subscale with the lowest mean (M= 2.60, SD= 1.68) was the *spiritual change* subscale which participants rated as being felt to a very small degree.

Table 3

Survey Data (n=10): Posttraumatic Growth Inventory (PTGI)

Factors	*M*	*SD*	Min	Max
New Possibilities	3.12	1.03	1.80	4.80
Relating to Others	3.83	1.11	1.83	4.83
Personal Strength	4.15	1.13	2.25	5.50
Appreciation of Life	4.30	0.84	2.67	5.33
Spiritual Change	2.60	1.68	1.00	5.50

Overall, the results of the PTGI indicate that the participants felt change at every level due to their illness. While a moderate degree of change was felt in terms of personal strength and appreciation of life, spiritual change was only felt to a very small degree which contradicts the QOL-spiritual score that indicated a more profound sense of spirituality. This may simply be due to the fact that the sense of spirituality remained constant and that no significant change was felt.

The results of both scales (QOL and PTGI) would indicate that the participants were not impacted negatively by their illness as a child. In the QOL-CS scale the results demonstrated that there was limited negative physical impact, low fear of recurrence, and that there were few social concerns. The psychological impact was found to be positive and although there were some reports of distress, due to past diagnosis and treatment, most participants felt that they had little concern for the future. In terms of spirituality, the results indicated that the participants felt that spirituality was important and that they were hopeful for the future.

Qualitative Results

The second part of the study involved the interview process. A series of open-ended semi-structured questions (Appendix C) were used to elicit information on the four domains of established quality of life research: physical, psychological, social, and spiritual. The in-depth interviews were recorded in order to capture all the information discussed throughout each session. Data was based on the participant's recollections of their experiences with cancer, as well as their memories of their childhood and adolescence. In line with Parry and Chesler's (2005) work, I carried out my data analysis in accordance with the principles of grounded theory (Glaser & Strauss, 1967; Creswell, 2005) and reflexivity (Davies, 1999). Data was initially categorized into the four QOL domains and subcategorized into themes to encompass the emerging individual stories and topics that flowed naturally throughout the interviews (Parry & Chesler, 2005). The categories and subcategories were analyzed using methods of induction and constant comparison. As my research focus was on transformational growth and thriving, my categories, while based on the four domains of QOL research, systematically followed Parry and Chesler's (2005) categorization methodology as well as the organizational schemata of Tedeschi and Calhoun (1995). The meta-category of change found within the four domains, were derived inductively, then supported the change related to transformational growth and/or thriving. The relationship demonstrated by the transformational process of change was indicated through the narratives of the participants thus illustrating a coping strategy that may go beyond merely dealing with trauma, but rather overcoming or surpassing the traumatic event. However, it is also important to acknowledge that thriving or transformational growth is a difficult concept to capture and that it may not occur throughout my study. I merely seek to examine the participant’s awareness of the impact that having cancer at a young age has had on their life and whether or not that impact has been incorporated into a transformative narrative within one’s life.

As a participant in the study as well as a researcher, I also addressed issues of reflexivity. Self-reflexive memoing was used to explore how the narratives, as well as my own narrative, shape the findings as well as to document any relationships that may emerge between categories (Parry, 2002). Throughout each interview session I took brief notes, audiotaped the interviews and transcribed them. The transcriptions were coded and arranged according to common themes, focusing on career and educational goals, relationships with friends, positive and negative effects of having cancer, survivor identity, and coping skills/strategies (Parry & Chesler, 2005). The themes were based on the questions posed during the interview process (Appendix C) however, some themes emerged naturally through the course of the interview. The following themes emerged: (a) cancer story, (b) present impact of cancer, (c) post-treatment support/ support obtained during childhood/adolescence, (d) educational experience/bullying, (e) perceptions of self/cancer identity, (f) developmental milestones, (g) physical impairments, (h) ability to face other traumas, (i) definition of success, (j) impact of family/coping, (k) spirituality, and (l) future outlook. HyperRESEARCH software (ResearchWare, Inc., 2009) was used to aid in the organization of the interviews. Each interview was transcribed and entered as text data. Each transcript was then organized based on the above mentioned themes. Once coded, the data was then compiled across each individual participant based on theme in order to answer each of the research questions.

The transcripts were sent to the participants via email to verify accuracy and to ensure that the participants felt at ease with the information they shared which would be used throughout the qualitative section of this study. The participants were also assured that their privacy was to be protected therefore pseudonyms were used throughout this section.

The narratives were used to create vivid pictures of each participant and to describe their unique story of surviving cancer while analyzing the stories comparatively across individuals and established research. The focus of this study explored instances of transformational growth and the possible explanations for it across the individual cases.

Participant's stories

It is not surprising that having cancer has a profound impact on one's life. It is also not surprising that the impact may be even more profound on the life of a child. The purpose of this study was to examine the transformational narratives of adults who survived cancer. There were many themes that arose as well as similarities and differences in each person's story. The central purpose to this study is to allow the participants to have a voice. Throughout the results section the words belonging to the participants will be used to tell their story and the impact that cancer has had on their life. It is their words and the following stories are their stories:

Christopher

Christopher was no stranger to dealing with the effects of cancer. His father died of cancer when he was 13 years old. In 2000, Christopher was diagnosed on his late father’s birthday with non-Hodgkin’s Lymphoma at the age of 19 years old. It started as a persistent cough and shortness of breath. After initially being misdiagnosed with bronchitis Christopher was officially diagnosed with T-cell Lymphoblastic Lymphoma, an aggressive tumor that was growing in his chest.

Christopher’s treatment was the same treatment given to Leukemia patients due to the aggressiveness of the tumor. After six weeks of heavy chemotherapy, it was decided that Christopher required a bone marrow transplant. Fortunately his sister was a perfect match and the doctors proceeded with the transplant. After a long and laborious process that involved a four and a half month hospital stay, Christopher began to deal with life after treatment.

Christopher is currently working towards his doctorate in clinical psychology. He is married and is a step-father to his wife’s child from a previous union. Christopher lives with his in-laws while he is pursuing his studies.

Melissa

At first Melissa noticed that her balance was off. Then she became very nauseous. After a few months she was sick almost all the time. Melissa also had increasingly painful headaches similar to migraines. Due to her young age they thought that Melissa was depressed or simply making herself sick. Finally after nine months and a series of misdiagnoses, Melissa was officially diagnosed with Medulloblastoma, a form of lymphoma which affects the brain.

After the diagnosis the treatment followed quickly. First surgery followed by radiation for most of the summer. Following the treatment Melissa had difficulties with her memory and muscle spasms. Since Melissa’s ordeal began at the end of grade 8, she was able to complete grade 9 however, her ability to retain information started to decrease by grade 10. She was able to complete grade 12 without assistance. Although schooling continues to be a struggle Melissa is determined to persevere.

Melissa is active in her community and she is studying to be a massage therapist. She currently lives in a basement apartment in her parent's home. Melissa is currently single.

Rebecca

Rebecca's story is an alternative one. She was born in the United States to self-described "hippie parents". At the age of four she remembers having an enlarged stomach. Not so unusual for young children, many people were not concerned. However, when Rebecca started becoming physically ill, her parents decided to take her to the hospital.

Rebecca was diagnosed quickly with Wilm's Tumor. Wilm's Tumor is a form of cancer which affects the fetal kidney cells. The fetal cells do not develop into a kidney but into a tumor instead. Rebecca's tumor weighed six pounds. In a child who weighed approximately 30 pounds the tumor managed to push her other organs so that they were not visible upon the viewing of an x-ray of her abdomen. Rebecca spent approximately five weeks in the hospital where they surgically removed the tumor by opening up her abdomen removing her right kidney and part of her liver, leaving Rebecca with a large scar across her stomach. Unfortunately there were complications during the surgery which resulted in a second operation to clean up some potential damage to the gall bladder. The doctors also treated Rebecca with radiation and chemotherapy, as much as the four year old could handle. There were some experimental drug trials and eventually when Rebecca was stronger she was released as an outpatient. She returned to the hospital for chemotherapy and radiation treatments until her mom decided that she felt the treatments were not helping anymore. Her mom was told that discontinuing treatment could result in her death and that she could be held criminally accountable for any such outcome. Determined to take control of her daughter's health, Rebecca's mother sought alternative treatment through a parapsychologist. The parapsychologist put Rebecca on a strict diet regimen as well as handfuls of vitamins. There were a variety of other alternative treatments and Rebecca slowly disappeared from the mainstream medical system.

Rebecca is currently residing in the United States. She is successfully employed with the government. Rebecca is in a committed relationship and they share a home together. Due to her treatment, Rebecca is unable to have children.

Cathleen

Cathleen was 10 months old when she was diagnosed with Ependymoma, a form of cancer that attacks the ependyma the tissue of the central nervous system. It manifested on the left side of the lower ventricle of the brain. When Cathleen was 11 months the doctors performed surgery to insert a shunt. At 12 months of age she had her first tumor removed followed by chemotherapy and radiation treatment. Over the next few years there were many visits to the hospital for follow-ups and shunt remissions.

When Cathleen was almost four years old she had a reoccurrence in the same area of the brain and required another surgery to remove the second tumor. She had another round of chemotherapy and radiation. Since then she has had another tumor removed. Although the most recent tumor was benign it was removed as a precautionary measure.

Unfortunately Cathleen also had a sister who went through a similar battle being diagnosed with a tumor at two and a half years of age (Cathleen was four years old at the time). Her sister had a reoccurrence in 2003 at the age of 16 and sadly passed away shortly after.

Now 26, Cathleen has had more to deal with in her short life than some would think is humanly possible. Currently, Cathleen is married and a new mother to a young daughter. She is on maternity leave from her career as a child care worker.

Edward

In the fall when Edward was about to begin the sixth grade his parents noticed that he was scratching his neck quite a bit and that his glands seemed swollen. They also started to notice a growth at the base of his neck. Edward's parents took him to the family paediatrician where a biopsy was performed revealing that Edward had Hodgkin's disease.

In order to determine at what stage the disease had progressed major surgery was required. The doctors removed his spleen, part of his liver, and some lymph nodes. The diagnosis was stage 3A Hodgkin's lymphoma. The treatment included three months of chemotherapy, followed by three months of radiation, and another three month round of chemotherapy. After approximately nine months Edward was in remission. He has been cancer free since.

Edward has had to deal with a great deal of chronic pain due to his cancer and the treatment. Although this remains a daily obstacle, Edward is working towards a master's degree. He is employed as a federal employee for the United States government.
Edward is currently single and lives on his own.

Justin

Justin is a no nonsense kind of person. He was 15 years old when he found out he had cancer. While on a fishing trip with his father, they noticed a lump on Justin's forehead. A biopsy determined that Justin had non-Hodgkin's lymphoma. It was then decided that 8 weeks of radiation would be the course of treatment they would initially follow.

Approximately five months later Justin had a pain in his knee and they found that the cancer had returned and spread from his forehead to his knee. Chemotherapy was started immediately and the treatment lasted approximately six months. Luckily the majority of his treatment occurred during the summer and although he missed some school, his teachers were very supportive and flexible sending extra work in order to help keep him from falling behind.

Currently, Justin is married and the proud father of a son and a daughter. He is very successful at his job and takes great pride in his work. Justin is an active participant in his community and is well respected by those around him.

Michael

Unlike the other participants, Michael was actually born with his cancer. Michael was born with Neuroblastoma a form of cancer of the suprarenal gland which formed a tumor above his right kidney. Fortunately Michael's mother is a doctor and she detected the symptoms rather quickly. Michael had a big bulge on his side which the doctors would wave off as nothing serious however, Michael's mother was insistent that it was cancerous. After persistently requesting that a biopsy should be performed, Michael's mother worst fears were confirmed and he was diagnosed with Neuroblastoma.

Treatment with chemotherapy and radiation followed over the course of six years. Unfortunately there was a reoccurrence near Michael's eyes around the time that he began school. Radiation treatment was given through his eyes which resulted in cataracts causing Michael to become legally blind. After numerous surgeries (some experimental) throughout elementary school to try a restore his sight, Michael was able to regain some of his sight but still needed to wear thick eyeglasses. Finally at the age of 22, Michael was implanted with artificial lenses in both eyes significantly improving his eyesight. No longer considered legally blind, Michael continues to deal with health issues as a result of the cancer treatments given to him as a child.

Michael is currently self-employed in the IT business. He has earned his MBA and is working towards starting his own business within the food industry. Michael is in a committed relationship and lives on his own.

Victor

In 1984, at the age of six Victor was diagnosed with Rhabdomyosarcoma. A tumor was found in the right side of his middle ear. At first it was thought to be an ear infection however, it was discovered to be cancer and treatment began a short time later. Radiation and chemotherapy were given over the course of two years following diagnosis.

Victor became an active participant in various cancer related support groups. He went to camps that specialized in providing a safe place for kids dealing with cancer. He enjoyed being around kids his own age who could understand what he was going through and who would treat him as a "normal" kid.

Sadly approximately two years after diagnosis Victor lost his mother due to asthma. The family decided to move and Victor had to start over in a new town. He kept in contact with some of his friends from camp but did not have the same support group as before. Eventually his father remarried and a new family dynamic with step-siblings entered Victor's life. In 2002, he found a young adult support group and he added many more friends to his social network.

Unfortunately, in 2006 Victor had a reoccurrence when he found a lump on the right side of his face. He was diagnosed with a secondary cancer due to the initial radiation treatment received as a child. Victor continues to require surgery. He has had to have his jaw fused and he needed facial reconstruction surgery. Victor expects to have a final surgery (facial reconstruction) this fall which will hopefully allow him to look like he never had cancer.

Currently, Victor is extremely active as an advocate for cancer survivors. He has spoken at conferences and is working with some of the leading researchers on the creation of policy for more support for childhood cancer patients. Victor is well respected by those around him and he is presently working for his father while he continues to work towards obtaining a business degree. Victor is single and lives on his own.

John

John was diagnosed with Acute Lymphocytic Leukemia (ALL) at the age of five. He was born and raised in a small town and needed to go to various hospitals for treatment. John received radiation and chemotherapy over the course of six months. He went into early remission and has been cancer-free for approximately 26 years.

Similar to Victor, John attended camps for children with cancer. He found that there were other children in nearby counties that had had cancer, which helped him overcome his feeling of isolation. He also received a great deal of support from his family and his community.

Recently, John obtained his license as a mental health counsellor. He works with a variety of clients ranging from delinquents to cancer survivors. John is currently single and lives on his own.

Anne

Anne was approximately two and a half when her mother brought her to the hospital for the first time. She does not remember how or why her mother decided that something was wrong but Anne was soon diagnosed with Acute Lymphoblastic Leukemia (ALL). Being such a young child, Anne's memories have been reconstructed with the help of pictures and are based on the recollections of her family.

Anne has some memories of having had cancer but mostly her experience has simply become part of her life. For a short time Anne simply thought that everyone's life was the same as hers. She thought that her life was "normal", that every child went to the hospital on Wednesdays for blood tests, chemotherapy, and a battery of other tests. Anne's friends were from the hospital and had a similar life.

It was not until Anne started school (she started on time with her peers) that she noticed some differences. However, when children asked her questions about the scar of her neck or the shunt she had in place, she was able to respond with a child's honesty that allowed her to feel at ease and to make those around her comfortable as well. Anne continues to have yearly follow ups after her treatment was completed.

Anne is currently single and lives with her parents. She runs her own business as a successful daycare worker. Anne enjoys the company of her friends and is looking forward to moving out on her own.

Long term effects of childhood cancer

The impact of cancer can be seen in many different ways. It can be seen physically but there are many ways that it can manifest without being visible. Research has shown that there is a psychosocial impact that has not yet been fully investigated (Barrera et al., 2005; Cantrell & Lupinacci, 2008; Eiser, Hill, & Vance, 2000; Fraser, 2003; Goldsby et al., 2006; Gray et. al., 1992; Langeveld, et al., 2003; Mackie et al., 2000). As was discussed earlier, having had cancer may cause psychological trauma (such as posttraumatic stress), as well as emotional scarring that can lead to difficulties with social interactions as well as the overall quality of life (Barrera et al., 2005; Cantrell & Lupinacci, 2008; Eiser, Hill, & Vance, 2000; Fraser, 2003; Goldsby et al., 2006; Gray et. al., 1992; Langeveld, et al., 2003; Mackie et al., 2000; Zebrack & Chesler, 2001).

In order to fully investigate the long term effects of having had cancer as a child, I was interested in examining the following question:

Research Question #1. How do adults who survived childhood cancer describe the long-term effects that cancer has had on them as adults?

The impact of having had cancer can have far reaching implications that may inevitably form or alter one’s perception of oneself. When cancer strikes as a child, the child’s identity is still in a state of flux. It is not fully formed yet the impact of surviving a life threatening disease alters their normal trajectory. They may not meet the same developmental milestones as their peers. Their education may also be affected or interrupted due to absenteeism. They may encounter bullying and/or teasing. These children are also faced with hospital visits and procedures that many adults have difficulty dealing with let alone a child who is too young to fully comprehend what is happening.

Perceptions of self

Edward, John, and Rebecca all have different perceptions of themselves, however, for each one of them the impact of cancer can be felt in how they see themselves;

> Edward: I'm somebody who had a life-threatening disease, and I'm still trying to live my life in spite of it. And in many ways I'm succeeding. I often think that I should be handling these difficulties from the illness better than I am, seeing as other survivors have done. I often blame myself for these after-effects, even though I didn't do anything to cause them, but I'm still the one who has to deal with them on a daily basis.
>
> John: Typically, all in all, pretty normal. Funny, smart, very … my values have been shaped by my experience... A lot of them were definitely shaped by my experience. Having cancer was really horrible and in a lot of ways really sucked, but at the same time, I wouldn't change it, because I feel like it's giving me opportunities more out of my life from a younger age that a lot of adults won't face until they've had some sort of experience like that. You need a healthier perspective on life, and the value of life.
>
> Rebecca: I'm serious, a hard worker, honest, sensitive, and non-judgemental. I tend to live in my mind rather than in my body so to speak. I am interested in creating a more meaningful life but I am not sure how to go about doing that. I'm

> a glass half empty type of person. I tend to over think. I'm an idealist and a perfectionist. I definitively attribute some of my personality to having had cancer. Especially the seriousness.

Physical effects

The physical effects of cancer can also affect one's perception of oneself and especially how they are perceived by those around them. Unlike the psychological impact of cancer that tends to remain unseen, physical impairments alert those around that the person is different in some way. Scars, disfigurements, impairments affecting mobility and/or motor coordination are just some of the physical effects of surviving cancer. As a young child this is particularly apparent to peers at school and to those within the community. However, some physical effects, such as with issues relating to puberty and fertility, are not visible yet have a life altering impact on the survivor's future.

Six out of the ten participants have physical effects from having had cancer, sometimes resulting from the treatment itself. Christopher, Michael, and Victor have had the most severe physical impacts due to their cancer;

> Christopher: I have heart and lung problems from the radiation and the chemotherapy. I also have nerve damage; I've got foot drop in my right foot from the nerve damage from the radiation. I have chronic fatigue. I actually just developed cataracts, but it doesn't affect my vision at all. My vision's fine, but what the optometrist said… cloudiness. I also have early onset osteoporosis and I'm hopefully getting that improved upon.

> Michael: Well, a big thing occurred back in ’96. I started getting breathless and tired all the time, and eventually it came to the point where I would walk five steps and become completely breathless. My mom took me to the emergency room and they diagnosed me with heart failure. I was 24 years old at the time, in denial obviously, but after talking with several different doctors at the hospital where I had my cancer treated, they were telling me that one of the drugs that’s used to help cure cancer actually causes long-term cardio toxic problems. And back in the ‘70s when I had it given to me, they were giving me twice the dosage that they found was really necessary… I eventually went into atrial fibrillation in addition to heart failure...So then in 2005, around November, over thanksgiving break, they put in a defibrillator and pacemaker, which helped a little bit in the synchronization of my heart but really didn’t do too much else. I felt better for a little while, I got through the rest of graduate school, graduated on time, got a job, all that stuff. And then just as it came closer to… I just started getting really sick again and the pacemaker was doing all that it could really. Then I went in to the hospital emergency room again and they pretty much said it’s time for a heart transplant...So I got on the list in roughly November and I was really lucky a heart became available two months later.

Michael has perhaps been the most affected physically by his cancer. He has also had multiple eye operations, eventually having artificial lens implanted into both eyes, to improve his vision as he was considered legally blind as a child. Victor has some facial disfigurement due to the type of cancer as well as the treatment. He has had multiple corrective surgeries and likens his appearance to a person who has had a stroke.

Some physical effects while less noticeable have had longer and more far reaching impact on one's life. For example, Rebecca is very small in stature. Her growth was stunted due to the treatment. She also has been plagued with hormonal issues that have resulted in infertility. Rebecca also has scars across her abdomen from her surgeries and she has had health issues relating to the radiation treatment. Cathleen has a shunt in her neck which is slightly visible to those around her as well as issues with her balance; and Melissa continues to suffer from muscle spasms in her jaw, legs, and feet.

Most cancer survivors have scars. Some scars can be hidden underneath clothing or hair however, it is the visible scars that often force a survivor into telling their story. Victor offered an interesting perspective on how his outward appearance has helped him to deal openly with the ordeal rather than keeping it hidden:

> Victor: A lot of patients or survivors that go through the whole cancer ordeal, they come out of it looking as though nothing happened. But emotionally it's all inside compared to just outside. Whereas me I think it may have been obviously affecting the inside, but outside as well. And the fact that I have my head shaven every two weeks… and with my face and the way the nerves are, that sort of helps, just with the identity and the way I look. I think it's made me a unique individual, what I've had to go through.

Victor found that his appearance helped him to become more comfortable with who he is as an individual. It forced him to become open with his illness and what he went through. He could not hide his scars and was often asked what happened. Victor dealt with his physical appearance by talking about his cancer rather than withdrawing from those around him. Although he feels it has taken a toll on his self-esteem, he has become more outgoing and comfortable with who he is as a person.

Psychological impact

Psychologically, the impact of cancer is not so easily perceived. Depression and posttraumatic stress may be the most severe psychological outcomes, however, many survivors may also face long-lasting issues relating to self-esteem. Often survivors are reluctant to seek out medical assistance with counselling or therapy. In the interviews, only two participants, John and Rebecca, claimed to have had issues with posttraumatic stress and depression;

> John: I also was suffering, I was in college, and I was having some pretty serious post-traumatic stress symptoms. So I went and got some counselling done, just to figure out what was going on, and it was just that it got to the point where things started coming out, and it was long enough, I don't know why exactly it picked that moment in time, but just, memories, general anxiety, sleeplessness… got in, talked with a counsellor, and it just kind of made a lot of sense. It's just something that at that age, it's just not something you can really comprehend. The procedures were… bone marrow aspirations were just, probably the worst thing I experienced. I talked about my story and the connections I made, like "all right, I'm not crazy," it's clearly something that's bigger than me, that I wasn't able to handle on my own. Some guilt and shame go along with that. Even societally, people don't get the point, and I even have friends like "get over it, you were five," and can't get it. That's an experience you just don't get over. Clearly it's an event that impacts people for their entire life.

> Rebecca: I struggled with depression. I try not to focus on the side effects or to be a hypochondriac but my health is a constant thought in my mind. I do not let the worries alter my life but I also do not live each day to the fullest.

Other participants such as Edward and Christopher reveal the long-term psychological impact having cancer as a child has had on their lives:

> Edward: I saw a therapist for a number of years after the treatment and I've gone to some support groups and it really depends, some things will help… sometimes I'll come across a different way of coping with things that will help, at least in the short term…
>
> Christopher: I found it really helpful and comforting to be able to talk to others that knew what I had gone through and that had that shared experience. I felt that not many people really understood what was going on. It's more of a culture shock, trying to get back into the swing of things when you're a young adult. I feel like now being more involved with cancer foundations and other non-profits I feel like I could've been more involved than I was, going through school and surviving, going through my own recovery process.

Fortunately most of the participants did not have issues with bullying or teasing which can often compound the psychological effects of surviving cancer (Lahteenmaki et al., 2002). Michael was bullied at school, however, he attributed this to his small stature and the way he looked (he had thick glasses) rather than to the fact that he had cancer. In fact, because he had cancer at birth none of his peers knew that he had cancer, a choice that many children do not have.

Cancer Identity

The age at which cancer is diagnosed also may have an immense impact on how one can integrate their own cancer identity into one's life. For some participants, having cancer as a young child or infant caused them to adopt the cancer identity and integrate it into a whole, whereas for others, having cancer as an adolescent or young adult had more serious consequences in terms of conflicts between a more established sense of self or personality;

> John: I think the most interesting that really gelled for me was talking with actual young adult survivors, survivors that were diagnosed in their twenties. And it was the difference between, my cancer experience was completely internalized, and my development like that, that is as much a part of who I am as having blue eyes and white skin. It was just, it's what it was at that time, as opposed to they describe their cancer experience as something that happened to them. It was just like "cancer is just this thing that interrupted my life," where I was so used to cancer in my life, part of who I was. I think too was that they each were diagnosed, and I've noticed that experience with other survivors, between like five and twelve, especially before the teenage years, describe that too that developmentally it was such a giant impact, such a daily experience, that it was more of an identity thing than it was with somebody that could externalize it in their twenties. Because they already knew who they were, and then cancer happened. That's where it really hit me that it was much more of an identity thing than somebody who was older. Because I very much feel that way that cancer survivor is just who I am, how I breathe, how I live my life. It's there.

> Anne: I remember that I was about two and a half. And all of a sudden my mom takes me to the hospital and I was like "where are we going? Why am I here?" I was so young that it just became part of my life and I thought everyone did the same thing.
>
> Cathleen: It's just, that was normal for me. Especially dealing with it from such a young age. I've just always been that way.

Reaching developmental milestones

Developmentally, having a life threatening illness can thrust the child into very adult situations forcing the child to mature beyond his/her years. One area that is often affected is whether or not they will reach the same developmental milestones as their peers. It is difficult to think about prom and dating, when you are thinking about life and death. However, it is also unfair to be robbed of the freedom of childhood. Some participants felt cheated out of certain normal childhood experiences while others felt that over time they were able to reach the same milestones and that life evened things out:

> Christopher: That's definitely something that I remember being really bummed out about. I even wrote songs about it, like when I was still at the hospital and having my friends around me have normal high school experiences and relationships when I was home at my parents' and dirty sick.
>
> Melissa: I have [achieved the same milestones] in the sense that it's a hard thing to get through this and get to the other side and still be normal, but because of the memory thing I'm having a really hard time getting through schooling, getting through certain classes… I'm having a hard time getting past that barrier that changed my whole learning, changed my memory, changed when I went through

all of this, so that's been the biggest hurdle to try and get through, and I'm still doing it! I think I can credit my friends and things for that, because they didn't really treat me as a porcelain doll. I was still one of their friends, and I was still able to have all of those landmarks going through. We did our graduation and I went shopping with the girls, I did all of that stuff, but I kind of was forced to be a little more adult about it. I had to be the critical thinking one. I still bought my first car, and all of that still happened, and I can credit my parents and friends for that, for keeping life normal. There weren't any drastic changes in that sense. I'm sure on their part there was still that thought there, but if it was they didn't show it; they did a really good job of just keeping life normal for me. And it worked.

Justin: So really, my life has been very much on track. Again, like I say, it's one of those things where once I was treated I kind of put it behind me and I never really looked back. The surprise of having our son would have been the biggest awakening but it was over and done. It was behind me completely. One of my friends, she got married, she's got a son that's only one year younger than my son. We're almost identical families, we have two kids our son and a daughter, we're almost identical to each other, it's kind of surprising when you look back at everything.

Cathleen: I think I've achieved more than some of my peers. I think I had to try harder for a lot of things, whereas they may not have had to put in so much effort, so they just didn't. It's hard to say, I kind of just dealt with what came. I just did.

Victor: I mean some milestones, they're delayed, but I still haven't yet achieved a university degree, but at least I'm on my way working on that. I feel left behind in

> some facets, some people have really moved on, have a significant other, and even started a family. With Facebook in the last few years I've sort of met up with old people from elementary school and even high school, that have got families and sort of moved on with their lives, whereas I find myself still here trying to figure out what I want to do.

Educational experience

Their school experience may also be affected by having cancer at a young age. When a child is diagnosed with cancer the priority is making them well again. Everything else seems to stop. Education is altered due to absenteeism resulting from treatment. Academically, some survivors required special accommodations such as tutoring or extra assistance. For other participants extra assistance was simply not offered. The type of cancer and the treatment used to treat certain types of cancer can cause difficulties with learning. This impact can therefore have lifelong implications in terms of career and self-esteem:

> Michael: I missed a lot of school. Who knows how medication affects you, but I strongly believe that without it I could've been a lot better, but I don't think it was less than anybody.
>
> Melissa: I didn't need it [extra assistance] when I started. I had just finished grade 8 when all of this came to light, and I was okay in grade 9, but it hit 10, 11 and 12 and my ability to retain information just dropped. I think in my own stupid pride I really didn't want the help, cause I didn't think that I needed it. It was still pretty good! Aside from the learning aspect—my marks dropped considerably—I was still part of certain groups, and I was in the band, and I was in the theatre, and I

played sports, and that part didn't change. My balance is still off, so that made things a little bit harder, but aside from that I had a great high school experience.

John: I missed a ton [of school] because I was in and out of the hospital that whole year. Again, that was the benefit of being in a small town. The teachers were… I had to meet criteria, I could just get a pass on the first grade, but they worked really well with me and my family on being able to get homework, one year going to Iowa City, and my mom did a ton of work with me, we had some tutors coming into the hospital, it had a teacher on staff to come and work with the kids in the hospital. So I've been on the mark for every school year. And luckily… the delayed effects, and that's something I've taken a lot of time becoming an adult, having to take full ownership of my health care, one of the delayed effects I received was some cognitive brain damage. So specifically it was math and even some retention, like my brain's a bit slow, like working on dial-up, like it just takes a bit longer to retrieve information, as far as the actual diagnostics are concerned, I will never be able to do that without assistance. But they didn't know it at the time, so again it was just one of those things that nobody taught my parents, they said it might happen, and it did because my grades were terrible, again the support and the education, and at the time they didn't know any better, so they thought I was stupid for twenty years.

Edward: Actually, I didn't miss all that much school. After each treatment I was able to go back in the very next day. So academically it didn't really affect me much. I think it was the year after, when I entered middle school, when things got really tough, but I'm not sure that all of that had to do with the illness; I think it

> was just what a lot of middle schoolers go through. Well I was dealing with the chronic pain at the time, so that made it difficult to concentrate, but I managed to keep a good GPA and graduated with my class. I did get some tutoring but I don't think that had anything to do with the illness or treatment.

Impact of cancer as of today

The physical, psychological, and social challenges encountered in life will no doubt shape the individuals we become today. The individual stories as well as the obstacles each person has faced during their ordeal has begun to reveal the impact that cancer has had on each of their lives. For some it has made them who they are today:

> Christopher: I kind of felt that I had so many opportunities to share my experiences with people and really be a help and help out, and it was something that I was meant to do, to help other people with their treatment and recovery process and cope with the after effects of cancer and its treatments. So my vocational role is to counsel cancer patients and I'm planning on getting a doctorate in clinical psychology. But I think it's had a huge impact on so many different areas… Being in psychology I think about how it shapes who I was looking for to be in a romantic relationship and why I married my wife. It's life altering to say the least.
>
> John: [The impact of having cancer is] enormous. I'll tell people, I get a lot of "oh, you were so little, you don't remember anything," and just get a laugh. "Oh really, you almost died and poked and prodded for several years and painful medical procedures, and were too young to understand what they were completely about. That's something you tend to forget." I've thought of cancer every day

since I’ve had it; I can’t imagine there’s probably going to be a day that goes by I won’t think about it in some way, shape or form.

Michael: I definitely see it as a positive thing overall. I think it’s kept me very open-minded, it keeps me very compassionate, and it just really has, when you really connect with somebody, whether they’ve had cancer or not it just makes it all the stronger because you have that compassion for each other, you have that… whatever it is. You understand people better, you want to get to know people better, you want to get to know people a lot better in terms of what are their thoughts, what is their perspective on life, what is important to them, what shapes and forms their opinions… Certain sentimental moments with people just make it all the better.

Victor: It’s a part of who I am. I don’t think I’ll ever let it go, but I’ve done certain things in my life that haven’t completely revolved around it. The first thing I don’t do is I don’t pull a cancer card and say “oh, I’ve had cancer.” It’s just that when someone sort of looks at me, and wonders what’s going on, that’s when I come out and say that. After my surgery in fall of this year hopefully, and after things in my face start looking the way they’re supposed to, we’re back closer to what it should be looking like, then the identity will be a new identity, but I’m still not going to let the old one go.

Rebecca: It has made me a far more serious person. I was not a serious little girl. I had to relearn how to play. I am more aware of my own mortality and I wish I was not. It doesn’t go away. Intellectually I know I had cancer but I do not go

> around everyday thinking I had it. Rather I do not feel it, like it is ignored or repressed.
>
> Anne: I'm very different from my family, which I'm thinking is because of the cancer. I don't take life too seriously; there's always something that could be worse. My family is very stressed and I'm very laid-back. Everyone calls me the black sheep. I don't know if it's just my personality, but no one in my family, my uncles, both sides are not that way. I'm thinking it's because of that. And it always comes up. When I'm thinking about things, I mean my dad got sick last year, and it kind of brought back a whole bunch of stuff, and since then it kind of renewed that feeling, that things can go so much worse. So I'm pretty thankful for that actually.
>
> Cathleen: I think that it's made me who I am. Going through this I wouldn't be the person that I am right now. It's probably the hardest thing that I will have to go through ever, so it's kind of made me stronger, and other challenges aren't quite as big. Some are big, but they're not as big. I'm able to deal with some things a little easier. Some people blow things out of proportion and I'm like "No. Not that big of a deal." In the great scheme of things, it could be a whole lot worse.

For others it has not changed their life or who they are in any perceptible manner;

> Melissa: I'm more aware of hearing other people talk about it, and I think if I hadn't have had it, then I would still be just that mythical kind of thing that some people get. I guess I'm more sensitive to it now: when people talk about cancer I find it really emotionally hard to deal with... I can't really say that it's changed

> my life. It’s changed my thought process of what I was doing and where I was going in my life. I don’t know if I would be the person that I am had it not have happened. And I think it changed me for the good, for some reason? I wasn’t a happy person. I was a brooding young teenager…I kind of live in the moment now. If there’s a question of “am I gonna do it now or am I gonna do it later,” I’m gonna do it now, because you never know! That’s about it. It didn’t really completely change my life. It did in the sense that I’m not the person that I think I would’ve been, had it not have happened, but aside from that… I think after having that kind of initial change, life kind of just goes on for us here.
>
> Justin: Honestly I don’t think it’s really changed today. The best way to say it is that I don’t think much about what happened, I don’t think much about what could’ve happened. It doesn’t even really kind of affect my day-to-day thoughts, other than, I maybe worry a little bit more about my kids whenever something happens, we do get a little bit overly anxious whenever I discover… like, I had a bone spur in my foot, which was a very simple thing, but at first the thoughts of what it could be… Maybe that’s about the only major impact it’s had, that I’m a little bit more conscious about what we might find whenever I go to the doctor for a pain or a lump. Beyond that, not really much of anything.

And still for some having had cancer has been a constant struggle;

> Edward: It’s made it much more complicated, in terms of dealing with health insurance issues, because I have to have a lot of extra tests done routinely, and it’s something that I think about pretty much every day, not necessarily the experience itself, but how it continues to affect me physically and mentally. I

> have chronic pain as a result of the treatment. About nine months into remission, I came down with shingles, which was a result of the chemo that I had. That caused nerve damage in my lower back, and now I have constant discomfort because of that. Also, the radiation stopped my mantle area from developing, so I have muscle stiffness in that area. And some minor things that I deal with: hypothyroidism, as a result of the radiation, infertility…

Definition of success

Perhaps the best way to explain the long-term impact of childhood cancer is to examine one's life in terms of success. Defining success is a very individual notion. In a broad sense we may regard success as being happy or content with our lives with minimal regrets. However, what is deemed successful for someone may not be considered successful for someone else. Rather than focus on quality of life, each participant was asked to define success and to rate whether or not they considered themselves to be successful individuals:

> Christopher: Right now I don't feel too successful in my current job. I feel like I'm not really earning my potential and really earning my education level. In that respect I don't really feel too successful, but I do feel successful especially since the fact that this week I was able to get the young adult support group off the ground and that definitely lifted my spirits and rekindled my fire and motivation to help others and make a difference. I feel that is what I'm meant to do and I feel that I can be successful in that. I do feel successful in helping others in that respect. But going back to my work, I don't really feel too successful, mainly for the fact that I'm not making as much money as I would like. Although I do work

in social services, and not that I don’t feel successful in my position, or what I’m able to accomplish at work, it’s just struggling financially as a newlywed you don’t feel too successful.

Edward: In many ways yes [I am a successful person], but I still have a ways to go. I want to get married and start a family eventually, buy a house, move up in my career, and also pursue my side interests. I’m a musician; I played the saxophone and piano for many years. I play with a trio occasionally, but I’d also like to maybe do some of my own recordings.

John: Personal success for me, I’d say just being in line with those values I’ve talked about....Personally, career-wise I feel very successful; I’ve got a great job, I like what I do, that serves as peace. I spend every day providing service… With this much garbage in the world, if I know I’ve left a positive impact, I felt like I’ve done what I needed to do. I work with inner-city youth, and seeing the kids who are young get into college, who would be in jail by the time they’re going, that sort of thing with the cancer stuff, I can go present at a conference, it’s going to give a survivor feeling a little more normal, or some education, that’s phenomenal. I rebuild family dynamics, within my family, I’ve got a huge network of friends, and my faith is something I’m constantly engaged in, even if it’s not necessarily a traditional church or specific one, but if I’m in line with those values and my behaviours are meeting those, I feel I’ll be pretty happy when it’s time to go, that I’ve met what I’ve set out to do, and what I need to do in my life.

Jeffrey: I'm respected at work, I have very good friends, I have a terrific family, and we just don't spend a lot of time fighting or arguing, we spend time living. I would say that's a great success.

Melissa: Somebody who knows what they want and takes the appropriate steps to do it. I don't know that I could call myself successful because I'm not there yet. It's taken me a long time to get through what I've been trying to do and I'm still not there yet, so I can't really call myself a success, but that's what I think it is. Somebody who knows what they want in life and does whatever they possibly can to do it. And they're happy. I'm happy! I'm just not all completely there yet. For me right now it's schooling, and getting a job in my field and moving on.

Michael: I think defining success would really be, are you happy? Are you happy in terms of the people who surround you, and people who you're friends with, and are you able to get what you want in life? In terms of relationships, in terms of health, in terms of financial areas, social areas, and health areas. There's no, because someone's a millionaire doesn't mean that person is successful. Or just because one has optimal health doesn't mean that person is successful. I don't think one person can judge another person based on success. I don't think I could ever say "oh this person is successful." I may say "oh, my buddy is successful," but I'll kind of explain why. I think success is really your own definition and the way you see yourself. I would say 65% yes [I am successful]. 67%, so about two thirds. One third is health, the second one is social, and the third that is missing is financial.

Victor: Overall I think success is how happy you are with the quality of life that you're living. That makes more sense to me than anything else. It shouldn't be about money and power and stuff like that. I think it's more how you live your life. I think I am successful in the fact that I can live on my own and I have a place that I pay rent towards, and I've got two cats that keep me company, and I'm working. I think I am successful in that I'm above a certain level. I'm not extremely successful where I have extra savings, or I have enough money for my RRSP, to retire, but I'm not fully prepared for a situation if something happens in my life, like if I lose another parent like my dad, and at that stage I'm not set yet. …I'm hoping that in two, three years I'll know what it is I want to do, whether I want to have my own business or I'll be working for a successful company. And, you know, a certain wage level, and I'll be able to put money towards a house, to have a family as well. To me that's another goal for me at that point. Because I'm 31 now, and I love my friends, like I said they've already reached that level, they've already got their jobs and have their family started, and have started that side of life where I'm still waiting here and trying to figure it all out before I move ahead.

Cathleen: I've succeeded beyond what they thought I would. They didn't think I would be able to do what I've done, or get as far in life as I have, so I think I've succeeded a lot. I've gone a long way. For me I kind of set a goal for myself. It wasn't a huge goal, I just set a small goal and worked towards it, and then I set a bigger one and worked towards it, and finally I reached it. So success for me was just accomplishing those little things.

> Anne: Just being happy. I think I'm successful now, I mean I'm living in my mother's basement, but I have my own business, I'm happy, I have great friends… I don't know what else somebody needs. I'm not a money person; I don't think money makes you happy at all. I think it's the people around you and how you look at life.
>
> Rebecca: I define success as being happy and fulfilled. I am successful in that I own my own home, I have a good job, and I'm in a stable relationship. However, I have struggled with depression and I tend to base my decisions on comfort and security rather than trying something new. Sometimes I feel like something is missing.

While each participant had a different notion of success, they each felt that they were working towards the goal of becoming successful. No one stated that they would consider themselves completely unsuccessful yet many felt that it was an ongoing journey. Overall, each participant's story is a complex one. There are many factors which have impacted their lives. The age of diagnosis, the type of cancer, the treatment, their educational experience, whether or not they met the same developmental milestones as their peers, and the cancer identity that they have assumed or integrated into their personality are just to name a few. Each of the factors has demonstrated the long-term effects that have intertwined to form each complex story.

Coping, thriving, and the negative impact of cancer

In order to examine the ability to develop coping strategies as well as instances of growth/thriving and any negative outcomes that may have occurred as a result of overcoming cancer, I was interested in investigating the following question:

Research Question #2. What kind of coping skills have they developed that allowed them to thrive?

Support systems and services

As much as the illness impacted each participant differently so did they way they handled having cancer. Each participant dealt with their illness in their own way. Some had strong, positive support systems while others sought comfort through various outside sources such as youth camps and other support groups.

Victor, John, Edward, and Christopher were the only participants who participated in support programs. Victor attended a yearly camp for children who have battled or who are battling cancer. He felt that camp allowed him to connect with others who were like him and who could better understand what he was going through. Victor's experience was an extremely positive one. In fact Victor is still active in the camp community and will be visiting his former camp this year as a guest speaker.

John also attended camp. John found camp to be lifesaving especially coming from a small town. He had felt isolated and different. John was the only child in four surrounding counties that was battling cancer. Camp allowed him the opportunity to make friends and to feel normal again.

Edward sought out support groups a few years after treatment in order to help make sense of what he went through and the emotions that came with surviving cancer. Unfortunately Edward did not find the groups helpful in the long term:

> Edward: I guess in the sense that it helps to be heard by somebody who has some idea of what I'm talking about, and can understand, but I think my most common way of coping is just to get my mind involved in other things that aren't

> necessarily related to cancer, and have it engaged so that I won't focus so much on the problems that result from the treatment.

Christopher was older when he was diagnosed although his experience was not very different from Victor or Edward. He found it helpful and comforting to talk to others that shared his experiences however, he also had to cope with some negativity from other members. He had felt isolated by his illness especially that not many people his age understood what he was going through.

> Christopher: I had actually attended a young adult cancer support group at the Wellness Community when I was going through treatment and they were trying to have one and it wasn't too successful. I didn't find it too helpful cause there was only one other person there and he was incredibly negative. That was one thing that was very important to me, I felt like I wanted to have people that understood me.

While Victor, Edward, and Christopher sought help in terms of support groups, others like Melissa, Justin, Michael, Cathleen, Rebecca, and Anne received support from their family and friends in order to help them cope with their illness. Some, like Melissa, refused to attend camp because of the fear of acknowledging her illness;

> Melissa: No, and the stupid thought that it was my pride that took me back from getting the help for tutoring, for school, they told me that they were going to pay for me to go to… on this side they have something called Camp Good Times, and it's for young children with cancer, and young children going through therapy, and stuff like that… and I just didn't want to go. I didn't want to be associated with the mantra of… you see it on TV, with the sick kids that are bald, and thin,

> or bigger because of what their hormone levels are doing to them, and I just really didn't want to be associated with that. There were no pictures taken, there were no memories, there was no diary, I didn't want to have any memory at all of any of that time. Life just went on. Same thing with my family. I still had to do things, I still had to do the same chores, we still had to maintain the same rhythm in our family to make it all work, and it did. It made everything seem to just go by more easily. That's how they got me through. I think it could've been a very different situation if I was locked within my room and my bed and they fed me food on a silver platter with whatever I wanted… It could've been a very different situation.
>
> The normalcy of it I think is how I got through pretty "unscathed".

Melissa did not want to have any memory of her ordeal. This is not uncommon for childhood cancer survivors. This repression or denial of sorts is a form of coping that allows the survivor to focus on other goals as a means of avoiding the pain associated with overcoming a life threatening illness. While some will deem this avoidance to be psychologically unhealthy, Mia feels that it helped her get through her ordeal relatively unscathed.

As Justin was older when he was diagnosed he was able to rely on his friends and family to help him cope and to provide a sense of normalcy in an otherwise abnormal situation;

> Justin: My friends were my friends, they were true friends. The rest of the people I had learned not to worry about even at the age of fifteen. I know it was a social time for a lot of people, but for me, for one reason or another, I was the shy one that worked on having really good friendships and I didn't worry about the fifty

> other acquaintances-type stuff. That didn’t bother me. Again, it was my good friends, nobody else really bothered me. It didn’t slow down my summertime much; we still went on our family vacations, they were just shorter than they were normally. We went out to the lake, but it was shorter trips: we didn’t go for two weeks, we’d go for a weekend or something like that. We pretty much just kept our somewhat normal schedule. My parents and my really close friends [helped me cope]. When I made a friendship it wasn’t just a fly by night kind of thing. We were good friends through and through. I guess the best way to say it is, I kind of knew my best friends would support me, and yeah, they did. Of course my parents supported me too, they always do. I kept close to family and friends.

Anne explains that she feels that her age was an important factor in the amount of support she needed. Her friends were made at the hospital and since those friends were dealing with similar medical issues it was less isolating. Therefore she credits her friends and family for helping her cope with having cancer;

> Anne: Friends, family. And like I said, I didn’t really feel like I was different, so I didn’t really need any of that, because I was so young. If it would’ve happened when I was like fifteen I think I pretty much would’ve needed a lot of support afterwards, but because I felt so normal it didn’t really bother me. I remember all my uncles, everyone would come see me at the hospital. That made me feel comfortable. And all my friends at that time were from the hospital, because I was there from like two to four, and that’s when you start making friends, so all my friends from the hospital have pretty much the same thing as me. So we’re all the

> same. It’s only when I got to kindergarten that I realized “Okay. You don’t have one of those!”

An interesting topic that arose during the interview process, while discussing social supports, was that often this area was extremely lacking. The participants were diagnosed in the late ‘70’s and early ‘80’s. During this time, many participants were treated at hospitals for children however, pediatric patients had to be treated in adult hospitals because pediatric clinics were ill equipped to treat young patients. They simply did not have the machines or the technology was too new. As was mentioned before, when a child becomes sick the first priority is to cure the child. The medical aspect was the sole focus. Child Life Organizations, offering programs to help a child to manage life difficulties due to treatment and illness outside the hospital were only developing during the time the participants of this study were being diagnosed (http://www.childlife.org/). Therefore many children during this time were left to their own devices relying heavily on the support of family and friends.

Spirituality

Another form of coping is often found though a gain sense of spirituality. While some survivors will rely of their faith to help them through their tough time, many will become more spiritual after confronting their own mortality. A child does not have the same awareness of the world and faith is often brought into a child’s life through his/her familial beliefs. However, as the child grows and understands more about the impact of cancer on his/her life, they may develop their own sense of spirituality. John, Justin, and Michael found that their experiences made them more spiritual over time;

John: Yeah. For sure [I am more spiritual]. That's an ongoing process. But I think, definitely that's something that's been a huge journey for me. Again, developmentally I started questioning the God thing when I was fourteen. Looking back that's pretty typical, but more so in my situation, because those why questions all came in, so I've been searching for exact answers for a really long time. Reading through I just put everything on the table. I guess I don't necessarily identify as an exact faith, but I do believe in God, I believe that things have happened for a reason, there's a certain order to things, and part of my satisfaction, or coming to terms, whatever you want to say, is that I've realized that there's going to be a lot of things that I don't get and that's just going to be the way it is, and I'm just going to do the best I can with what I've got.

Justin: I'd say I'm a little bit more spiritual. Partially because of marriage too, but partially just because of that I do think that there are sometimes higher powers involved in what goes on. I don't know if I'd say I'm lucky. I don't know how really to describe it cause again I never really tried to focus on me specifically, so I look at it maybe more in the terms of it just wasn't my time. And I know at the time that I got that, I was even reading here a couple of weeks ago that it's one of the cancers that the survival rates aren't the best on. I think it said something like forty percent will pass away from that cancer. So yeah I suppose I was lucky, but I guess I don't look at it that way, I just look at it as it wasn't my time. I'm meant to be here for some other reasons first. I'd like to think it's because of my kids, but I'm sure there are many more reasons than that.

> Michael: I think I have [become more spiritual]. Before I guess I was less religious, now probably more religious even though I'm a bit lazy in terms of praying and all that, but I do believe in my experience that there is a god.

The majority of participants however, did not consider themselves to be more spiritual due to their illness. For example, Melissa did not feel as though she became more spiritual. She maintains her beliefs as a Christian and believes that there was some divine intervention behind her having had cancer;

> Melissa: I'm not spiritual like… what I think of when that's said is church. When we were little we went to church and we just don't anymore. I've had my own reserved feelings about church, and everybody… you have your own higher being, whatever that may be, and I think that really didn't change for me. I think that personally, I'm a Christian and I believe that everything that happens is for a reason. And for this to have happened to be it must have been for a reason! Like I said, I don't think I'd be the same person that I was if it had happened, and I think that was the plan. I think maybe somebody, whoever you may believe in, saw that I wasn't maybe going in the right direction, and they kind of gave me a slap, you know, "wake up!" And it worked. I think I'm a different person now, than I was in the direction I was going.

For Christopher, his experience actually made him less spiritual than before his illness;

> Christopher: I actually am less [spiritual]. It's weird, I think when I was going through treatment… my family was always going to church and very active, and I think when I didn't feel a presence I kind of shut it off. I kind of felt like I was doing it, not necessarily alone, but without spiritual input.

Interestingly spirituality was less of a factor for most of the participants and overall it did not seem to impact the development of coping strategies in line with spirituality.

Coping Strategies

Coping strategies are developed when a person encounters crisis or trauma. The strategies are often only revealed once we are faced with another ordeal. Once a person has overcome or survived having cancer, they may use the coping skills they developed during their illness to help them through any obstacle they may face;

> Cathleen: I think that it's [cancer] made me who I am. Going through this I wouldn't be the person that I am right now. It's probably the hardest thing that I will have to go through ever, so it's kind of made me stronger, and other challenges aren't quite as big. Some are big, but they're not as big. I'm able to deal with some things a little easier. Some people blow things out of proportion and I'm like "No. Not that big of a deal." In the great scheme of things, it could be a whole lot worse.
>
> Melissa: For me I just have to put it in perspective. If I fall and hurt myself, yeah that sucks, but it's not as bad as! Emotional things… for me, the things that happen to me now I look at as just, it could be worse. I'm okay, I'm alive, I'm breathing, it could be worse. I've seen worse, I've had worse, it kind of takes a lot to rock me right now. Personally it's gonna be a lot before anything really… things do affect me, but really I still get affected by things. We just had two grandparents die, and that was really emotionally hard for me to deal with, but aside from that, to deal with things like that, like I said, it could be worse. There's

> always something that could be worse than what happens, and I kind of just cling to that. Things are bad, things happen, but it could be worse. Like I said, I'm still alive, I'm still breathing, I'm good.
>
> Michael: I had the eye problems, and when I had heart failure I was in denial for a long time. Not necessarily denial, I just didn't want to accept that that was really what it is, and I was just like "no, no, no" and my mom had to force me to take medication and eat well and everything. Finally I just kind of said alright, these are the cards you've been dealt and you've just gotta go with that. So either that or when my heart just got worse and worse and they said "now you need this, now you need that, now you have this, you have that," I'm like "okay, just another day, another day in the life." Even my sisters were like "oh my god, how do you take this so calmly?" They were in tears whenever they'd find out something else. I was like "well, I could either cry and make things worse, or just keep going." So I guess whenever there is trauma, just staying calm and cool and dealing with it is really the best way. I guess when you panic it just makes things worse.
>
> John: But any challenge I face is the survivor mentality. I'll get through anything, I don't care how bad it is, I might not be the best or the quickest, but I'll get through it for sure.

The coping strategy that seems to unite the participants is that of the "survivor mentality". The survivor mentality focuses on surviving the ordeal by remembering that once you have overcome a life threatening illness there seems to be a sense that everything else is merely an obstacle. Although many survivors learned to cope with the impact of their illness, there still may be some lingering negative effects once they are considered cured or are in remission. Part of the process of surviving cancer at a young age is that there is, hopefully, a long life after the illness. However, this does not mean it is an immortal life. As was discussed previously, survivors may face many obstacles after battling cancer. There are a variety of health issues (both physical and psychological) that are more likely to affect survivors. Some effects are even related to the treatment given especially the treatment given during a time when the medical world did not know the effects of treating children with radiation and medication.

Future Outlook

Surviving a life threatening illness no doubt has certain negative outcomes. Physical impairments, low self-esteem, and difficulty relating to others may be some negative outcomes (Cantrell & Lupinacci, 2008; Forsbach & Thompson, 2003; Fottland, 2000; Goldsby, Taggart, & Ablin, 2006). As research focusing on negative outcomes makes up the majority of the available research, I also sought to examine the negative impact of having had cancer as a child. While it would be evident to focus on the impairments and late-effects caused by the illness and-or treatment, I chose to investigate the participant's responses on how they saw their future, as well as any negative responses or comments they shared throughout the interview.

Research Question #3. What has been the negative impact of this illness on their life as young adults?

Although many survivors faced late effects and will continue to deal with the impact that cancer has had on their lives, they felt that they still needed to live in the world. Each participant in this study felt that their future had a positive outlook regardless of the potential hardships related to late effects. Some they may not feel as though they were completely happy or worry-free however, they were able to plan for a future and set goals for themselves which demonstrates that they were looking ahead, towards a future where they were active participants. They were optimistic and they discussed how they perceived their future outlook:

> Christopher: My overall outlook I feel that my health is going to be something that I'm going to always have to be aware of and really diligent about maintaining a healthy balance. I can't say that I'm entirely positive about my health outlook, with having late effects this early in life. But not to say that that would be a negative outlook. It's just something that I'm aware of. I don't really know how I'm going to improve my finances but I'm still positive on that. I know I want to help others and it'll definitely be something that comes when there's a need. And as far as vocational or professional outlook, as far as what I want to do, I'm very positive about that because the recent high set in and I'm definitely stoked on the fact that I was able to start up my [research] group and I feel confident that I'm going to be able to finish up my research and move on to the next chapter. And I guess relationship-wise my outlook is definitely positive and hopeful to go through the in vitro process and expand my family, so bright. I'll reiterate: bright.
>
> Cathleen: When the baby's a bit older—well, we'd like to have more—but when the baby's a bit older I'd like to go back to school again. I want to go into art therapy. I've always had a passion for children, as well as a passion for art, and helping others. When my sister was going through treatment I did art therapy at a children's hospital. And it helped tremendously. I think that's really important to

me. My husband and I are thinking… he's thinking of studying abroad in Australia. So we're hoping to live down there for a little bit.

Edward: I'm hopeful that I'll have a good life ahead of me. I'm still trying to get the pain under control, and trying to cope with the emotional after-effects of the treatment. I'm confident that I'll achieve my goals eventually, I'm just not sure exactly when.

John: Good. I'm at a spot now I'm very satisfied with my life, where it's at. So I'm pretty well set up. We just got another counsellor hire at work, so that's going to ease my teach load. That's gonna help out. Generally I love what I do, my family is great, my health is good, so my outlook's really positive. I guess I feel I'm at a spot where very realistically the next twenty years of my life are going to be better than the first twenty were. So it's just a good spot to be.

Justin: Looking forward to being a granddad someday! Just continuing to enjoy life. Hoping maybe that… through these last few years both my wife and I have not necessarily done the very best physical care of ourselves, I hope we can get back to being a little bit more outdoorsy. Going hiking, spending family trips, and again, like I say, being grandparents, raising our grandkids, spoiling them as much as we can, and hopefully showing them the finer side of what Earth has to offer, … just be able to share that kind of enthusiasm with our kids and our grandkids, because, I guess I look at it as, we really need to know what life is really about. It's not about all the electronics and the toys and the politics of things. It's just about enjoying what's been given to you. So my outlook is basically to share that, to continue to be healthy and strong and share that with my future family.

Melissa: Outlook good. I think eventually when I get through schooling and I can start making enough money and I can really support myself, I’ll find a place where I can live on my own and just continue on. I think my outlook is good, that’s how I perceive it anyway.

Michael: Right now it’s just concentrating on my career, creating my business, really becoming self-reliant and being able to really support others who… I’m able to support people in different ways, but just not financially. I really hope to become financially strong so I can help other people, really being able to buy my mom, who I’m most close to, just a really nice something. A car, or a house or something, just cause she’s done so much for me. I think getting married is a significant part of what I want, it’s just finding that right person. I’m still curious whether I want to have children, I just want to make sure I’m healthy enough to have them. That’s one of my biggest concerns. That’s pretty much my outlook. Business and family. The future is bright. I hope so. I’m confident it will be.

Rebecca: I do have several physical characteristics and symptoms that are related to my cancer experience, both the disease and the treatment. They are likely to be with me in one form or another for the rest of my life, but I'm confident my health can be well managed if I pay attention and put in the necessary time, effort, and money, and if I have the support of good doctors. Though I still feel a bit nervous about being examined by doctors, I don't have an overwhelming fear that I will develop cancer again, probably because I was always told I was cured-- the word "remission" was never spoken in our household. In a mental/emotional sense, my

> outlook is less obviously encumbered. Probably like many people who aren't cancer survivors, I believe I can do most anything I set my mind to.

Defining Successful Quality of Life Outcome

One of the difficulties I have with defining quality of life outcomes is the fact that the focus is often focused on marital status, employment, educational level, offspring, and income (e.g., Barrera et al., 2005; Cantrell & Lupinacci, 2008; Goldsby, Taggart, & Ablin, 2006; Gray et al., 1992; Zebrack & Chesler, 2001). As was previously discussed defining success is a rather ambiguous ideology. Success is highly individual and personal. Although the participants in this study generally defined their idea of success with the same criteria, they also had set other personal goals they were working towards attaining. Tedeschi and Calhoun (1995) found that working towards a goal was a way of participating in one’s life, a way of making sense of the trauma and incorporating it into the narrative of one’s life. Parry (2003) was part of a group of pioneers (Parry & Chesler, 2005; Tedeschi & Calhoun, 1995) that sought to examine narratives as a valid form of research. Therefore, throughout this study I was also interested in examining how the narratives of the participants in this study compared to past research, as well as exploring how the narrative methods differ from the survey data.

Research Question #4. I was also interested in exploring how the participants’ definition of success compares to past research assessments of thriving and quality of life? How do narrative inquiry methods add or differ from the survey data?

Past research assesses quality of life based on physical, psychological, spiritual and social well-being, as well as the demographic information of marital status, educational level, employment status, number of offspring, and income (e.g. Barrera et al., 2005; Cantrell & Lupinacci, 2008; Goldsby, Taggart, & Ablin, 2006; Gray et al., 1992; Zebrack & Chesler, 2001). The demographic information demonstrated that 50% were unmarried, 30% had children, 40% had technical training or some college education, and that 80% of the participants' overall household income was below $50 000. Although the sample size was small, the results may indicate negative QOL outcomes in the social and psychological well-being subscales.

The survey also indicated that overall, the participants had minimal negative experiences due to their cancer. In fact, the scores on the psychological well-being subscale were fairly positive. In addition, the narratives demonstrated that the participants had minimal negative experiences and that their psychological well-being was positive. However, there were discrepancies that came through when analyzing the survey itself. For example, the QOL-Cancer Scale portion survey has been criticized as having items which do not fully reflect the difficulties faced by survivors (Zebrack & Chesler, 2001). For example, the QOL-physical subscale has items that question to what extent the following is problematic: fatigue, appetite changes, aches/pain, sleep changes, constipation, nausea, menstrual/fertility, overall physical health, and the impact of your physical well-being on your life. A number of participants in this study had issues regarding their physical well-being. Michael has had a heart transplant, Christopher has issues with his lungs, and Victor has had to endure numerous facial reconstruction surgeries. Rebecca has fertility problems and Edward suffers from chronic pain. However, when each of these participants responded to the survey they could only rate a few items as severely problematic because only a few items addressed their concerns. Not one of the questions actually addresses physical impairments.

Another section of the survey which does not address the needs of the participants is the QOL-distress component. This component contains the following 6 items: initial cancer diagnosis, cancer treatments, time since treatment was completed, anxiety level, depression level, and overall distress related to cancer as it impacts quality of life. The two initial items of the QOL-distress component examined initial diagnosis and the level of distress due to treatment. Both items were scored extremely high by half the participants perhaps because of their age when diagnosed. Christopher, Melissa, Justin, Edward, and John rated the two first items in a manner which would indicate high levels of distress. This may be explained by the fact that they were old enough (most were adolescents) to understand the diagnosis. Although John was only 5 years old when diagnosed, he may have rated the items highly based on his family's distress level. It would be hard to believe that a cancer diagnosis or the treatments that follow would not be distressing, however, if you were a young child as was the case with Michael, Rebecca, Cathleen, and Anne, it may be difficult to quantify the level of distress as many of the participants could not even recall those exact moments. For example, Anne based her answers on the memories that were reconstructed for her by her family. She admittedly responded to those questions in regards to the level of distress felt by her family. For others, such as Rebecca, Michael, and Cathleen, they simply answered the survey to the best of their ability, sometimes indicating with a little note that would say "from what I remember" or "for my family". The results of the two items were often split in that the participants would sometimes score the item dealing with diagnosis with a 0 or a 2 which would indicate a low level of distress while scoring the treatment item with a 8 or a 10 indicating a great deal of distress. This could be explained by the fact that either they could not remember the amount of distress that they felt or that they were too young to comprehend the diagnosis. Therefore the scale could not fully capture the distress felt by the participant because it could not explain all the variables that were potentially involved with how the participant responded to each item.

The QOL-social subscale is another scale with certain questionable items. The 9 item subscale examines the level of distress felt by family, level of support received, the effect of health care on personal relationships, effects of illness on sexuality, effects of illness on employment, effects of illness on home life, isolation, financial difficulties, and the effect of overall social well-being on QOL. As previously discussed, the first question addresses distress felt by the family which some participants may have answered previously in the QOL-distress component. Only one item refers directly to personal relationships and it does not differentiate between friendships or romantic relationships. The participants in this study who were single (i.e., John, Victor, Melissa, Anne, and Edward) describe how they faced some difficulties forming relationships. Therefore, with the survey, they would only be able to rate this difficulty on one item which may not be considered problematic if they rated the item in terms of friendship rather than romantic relationships.

Overall, the QOL-CS was found to be problematic. It does not address all the issues faced by survivors. For example, the QOL-physical does not address the physical issues faced over the long term by survivors. It can also be somewhat confusing as the rating scale is not uniform within each subscale which can be misleading if the participant does not pay close attention to the subtle changes within the subscale. That being said the QOL-CS does have its merits. The scale has been tested for construct validity and internal reliability (Zebrack & Chesler, 2001). It is a widely used tool that focuses on the four domains that are relevant to cancer survivors including physical, psychological, social, and spiritual domains.

The PTGI was found to be more useful as a tool for this sample. The tool is simple and straightforward. Each item is rated in the same way and the items are not separated by theme which may help avoid contradictions when answering. It was easier to score as there were no items that used reverse scoring. This tool is widely used by Parry in her ongoing work (Parry Survey Codebook, 2008). The results were consistent with the impact felt by the participants. For example, the overall results indicated that the participants felt *spiritual change* to a very small degree (M=2.60, Table 3). This was reflected in the narratives that emerged through the interview process. Also, in terms of *appreciation for life* a moderate change (M=4.30) was felt which again is reflective of the overall sentiments expressed in the narratives as some participants were more cognizant than others of this new found appreciation.

Tedeschi and Calhoun (1995) were explicit about the way the PTGI was to be utilized as a tool for quantifying posttraumatic growth. They recommended that the PTGI was to be used in conjunction with narratives in order to develop a more well-rounded understanding of the way that growth is experienced by the individual (Tedeschi & Calhoun, 1995).

Similar to Tedeschi and Calhoun's belief, Parry also sought to combine qualitative and quantitative methodologies in order to better understand the impact of childhood cancer on the lives of adult survivors. When combined with the narrative stories of the participants, the quantitative data gives us a very different picture that what has been previously reported in the available literature (e.g. Barrera et al., 2005; Cantrell & Lupinacci, 2008; Goldsby, Taggart, & Ablin, 2006; Gray et al., 1992). We see a much different and more positive outlook.

The concept of "thriving" is more difficult to assess as it requires a baseline from which to demonstrate an observable change or transformational growth (Parry, 2003). Having cancer as a child may make the observation of such a change unperceivable as a child does not have an established personality from which to observe a change. Each participant no doubt has had the presence of a trauma however, each individual was able to cope with the trauma in their own unique way.

The qualitative data gave us rich detailed insight into the lives of survivors, ordinary people who have overcome extraordinary circumstances. Each participant described their definition of success and each participant felt that they were successful. Although, they may not have felt entirely successful, they still felt content with their lives and had a positive future outlook. They had hope. To continue assessing survivors with tools that do not explore the qualitative stories and individual differences of cancer survivors leads to a negative view of a population that is unfortunately growing. In addition, it may unfairly create negative stereotypes of people who are struggling in their own way to make sense of their lives similarly to everyone else around them who may be struggling with life's uncertainties.

Narrative survey methods add to the research by allowing survivors to share their stories. It provides rich information that is otherwise not captured using a close-ended survey method. Surveys have the ability to survey the masses, something that was not easily done with narrative surveys. When analyzing the data for this study, I found that the surveys were flawed and did not truly capture the perceptions of the participant as they claimed to assess the different domains.

Discussion and Conclusion

The purpose of this study was to examine the role of personal transformation in adults who have survived childhood cancer. The reason for investigating this topic was two-fold; first there is very little research on this topic and as there is a population of survivors that is growing in numbers it is necessary to better support and accommodate that population, second it is personal in nature that I myself am a survivor. The available research is also somewhat divided in that the majority of the research suggests a poor quality of life outcome for adult survivors of childhood cancer while the other side suggests that the survivors are no different from their peers in terms of QOL. Still yet another small section of research indicates that there is a subgroup of survivors that are capable of transforming their trauma into growth and thrive in the face of adversity. Based on the available research, this study was guided by four main questions;

1. How do adult who survived childhood cancer describe the long-term effects that cancer has had on them as adults?
2. What kind of coping skills have they developed that allow them to thrive?
3. What has been the negative impact of this illness on their life as young adults?
4. How does the participants’ definition of success compare to past research assessments of thriving and quality of life?

These questions helped to examine the long term impact of the illness as well as to probe areas, both positive and negative, that currently affect the adult in terms of their quality of life.

As the majority of the available research relies on quantitative methods which use surveys and/or questionnaires to gather data, another goal of this study was to provide a voice to survivors through the use of narratives. This study closely followed Parry's (2003) work on uncertainty in long term cancer survivors. As a pioneer in her field, Parry used mixed methods in her research and sought to examine the narrative component of her subjects with interviews. Although utilizing a narrative lens was the focus of this study, this study was a mixed-methods study as well. A survey was administered and quantitative data was briefly analyzed for descriptive purposes. This was done to examine the validity of such tools commonly used to describe the impact of cancer on one's life. It was expected that there would be a large discrepancy between the methods; that the quantitative data would present itself as more negative while the narratives would be more positive. However, although there were differences between the information gleaned from the different measures, these differences were. In order to thoroughly discuss the results of this study, I thought it best to focus the discussion in terms of the four main domains associated with QOL research while addressing transformation and/or thriving within each of the following domains; physical, social, spiritual, and psychological(Zebrack & Chesler, 2001).

Physical Impact

The physical impact of cancer is more widely researched and is often the most visible. Goldsby, Taggart, and Ablin (2006) examined the long term physical impact of cancer and found that there were physical consequences to treatment. This study also found that many of the survivors suffered from effects from their treatment. Rebecca, Michael, Victor, Edward, Christopher, and Melissa all suffer from physical consequences of their treatment. Perhaps, Michael has been the most affected by his treatment as he necessitated a heart transplant due to the treatment he received as a child. In fact, he recalls that he received twice the dose necessary for a child as medical research treatment was still in the infant stage and it was not yet know what the impact of treatment would be in the long term. However, the participants' narratives also confirmed that childhood cancer survivors are at a greater risk for long term physical after effects due to treatment.

Social Impact

The social impact of surviving childhood cancer is less clear cut. As it may take years to discover the effects of treatment, it is important to begin with the early school years to better understand the long term psychosocial implications that may affect the survivor. Often times, depending on when the diagnosis occurs, it is the child that suffers silently through their academic years with learning disabilities and/or other social difficulties. Lahteenmaki et al. (2002) and Barrera et al. (2005) found that children who received certain types of treatment were at a higher risk for a sharp decline in IQ and intellectual skills as well as poorer educational outcomes. The results of our study indicate that both theories are substantiated. Certain participants, Victor, Melissa, Christopher, Anne, and Cathleen felt that they had difficulties in school which may have been a result of their treatment. As they were not tested prior to treatment or after treatment (they were never assessed for learning disabilities), it is difficult to say that it is directly attributable to treatment. However, each participant claimed to have memory problems that they felt was related in some way to the treatment they received.

Not all academic outcomes were negative however,. While the length of the treatment often necessitated absenteeism, some survivors may have thrived despite their illness. In his study, Fottland (2000) found that certain children were at risk for learning disabilities however, he also discovered an interesting outcome. Certain survivors who were motivated to succeed were able to master academic skills which led to a positive self-concept and self-esteem thus excelling academically. Similar to Fottland's finding, this study found that certain participants had had similar experiences. Michael felt that he excelled at school because he was motivated to do so. His mother was a strong supporter that he should have a good education despite his illness early in life, therefore he has excelled and attained post-graduate level studies. Christopher and John both strove to pursue academic careers in areas of counselling, despite difficulties they encountered due to treatment and maybe even as a consequence to these difficulties. They are currently helping others who are experiencing personal difficulties.

Another obstacle that stands to have negative social consequences is that of interpersonal relationships. Having cancer throughout the school years can be extremely difficult for a young child who is forming their own identity. Forming friendships can be especially problematic when your peers are afraid that they will catch your illness or that they simply do not want to be friends with the child that *looks* different due to treatment. Forsbach and Thompson (2003) found that survivors that were diagnosed at an older age had a greater negative impact on interpersonal relationships because they were more self-conscious about their appearance. This view was not entirely supported throughout this study. Half of the participants (n=5) were diagnosed in adolescence and they found that since they had already established their identity, they knew who their friends were and some even credited their friends for helping them cope during such a difficult time. Melissa and Justin both felt that their friends helped to keep things normal. However, participants who were diagnosed at a younger age seemed to have a more difficult time forming interpersonal relationships. Victor and Michael felt that they had more issues with trusting and relating to people, it was a lesson they were still learning. This is similar to what Fraser (2003) and Gray et al. (1992) observed in their prospective studies, that childhood cancer affected the ability to form close relationships as adults.

Gender differences have also been an interesting outcome of certain research studies. Cantrell and Lupinacci (2008) as well as Langeveld et al. (2004) both found that females reported a poorer QOL outcome than their male counterparts. However, this was not the case in this study. While there were only 4 female participants, each female participant expressed positive QOL outcomes. One participant, Cathleen was a mother of a newborn child and was looking forward to her future life with her family. Another participant, Melissa was very optimistic about her career path and was overall very positive about her life. Rebecca has a stable career that affords her a comfortable life where she is in a committed relationship. Anne owns her own business and is enjoying life to the fullest. Although the participants discuss positive QOL in terms of career, children, and lifestyle, it is the perceived optimism by each participant that came through during the interviews that is truly reflective of positive QOL outcomes rather than attempting to measure the life goals that were attained.

A final interesting factor in terms of the social impact of cancer is the support obtained by the survivor. The majority of the participants did not receive any social support or counselling throughout their treatment. Christopher, who was 19 years old when diagnosed, was able to seek out the support he needed either through counselling or support groups. Victor and John attended camp which they credit for helping them feel more normal. Melissa was offered a chance to attend camp however, she did not want to be reminded of her experience and felt that in order to get her life back to normal she would only participate in activities with other healthy adolescents, which was not uncommon for young survivors. Justin, Edward, Michael, Rebecca, and Cathleen were simply not offered social support because it simply did not exist at the time, either due to the fact that they came from a small town or simply because the hospitals did not yet offer this kind of support. There was often an attitude within the medical system that "you are now cured, go and live your life!". This attitude, while encouraging, does not help a child grieve over a potentially lost childhood nor does it begin to acknowledge the long term impact that cancer may have on one's life.

Spiritual Impact

Survivors of life threatening illnesses sometimes report a new found sense of spirituality during recovery (Parry & Chesler, 2005). Spirituality can also be associated with a form of coping or meaning making within the situation of the illness. Throughout this study, I examined whether the participants felt they turned towards their faith for support or comfort in the efforts to understand the role of spirituality on the ability to cope. The results were mixed. Some participants felt that they did develop a deeper sense of spirituality (e.g., John, Christopher, Melissa) however, the majority felt that either their sense of spirituality remained constant or was insignificant to their coping process.

While spirituality may be a form of meaning making for some, the participants' narratives did not support spirituality as a central component to coping for all participants. Although the QOL-spiritual scale, within the QOL-CS, reflected a stronger sense of spirituality as rated by the participants, I believe that this can be attributed to the type of questions that were asked within the scale. The questions focused more on meaning making as a whole as well as hopefulness for the future rather than the in depth spiritual practices of the participants. However, it is important to state that for the same reasons it may be difficult to understand the depth of a person's spirituality and the ability of that faith to act as a coping strategy. For the purpose of this study, the focus was rather on the ability to cope and thrive as opposed to why certain elements worked better for some individuals.

Psychological Impact

In the present available research, the psychological impact of surviving childhood cancer has had mixed results. Some research has indicated that survivors were more likely to display psychological distress and/or disorders (Goldsby, Taggart, & Ablin, 2006; Lee & Santacroce, 2007). While other more positive outcomes have indicated that there was no significant difference between survivors and control groups with respect to psychological outcomes (Eiser, Hill, & Vance, 2000; Gray et al., 1992; Mackie et al., 2000; Recklitis, et. al., 2006). The results of this study indicated the latter. Throughout the interviews the participants had an overall more positive outlook on life. Certain participants, Christopher and John, did feel the need to seek professional counselling to help them make sense of what they had gone through, however, they sought counselling on their own accord and it was not because they felt that they were at a point of psychological distress.

To further illustrate the positive outlook of the participants in this area, the results of our survey also supported this finding. The participants scored highest on the QOL-

CS in the QOL-psychological scale indicating that they had a positive psychological outlook.

Although both the interviews and survey results demonstrate a positive psychological outcome, it is important to interpret these results cautiously. As Eiser, Hill, and Vance (2000) found in their systematic review of 20 studies, the results may be somewhat biased based on the selection of participants. It is important to note that while the psychological impact was found to be positive, the type of individuals who chose to participate in this study may have been less affected psychologically and therefore, more open to participating. The participants who sought treatment in the past, did so voluntarily, which may not have been the case with those who were suffering with more severe psychological issues.

Coping seems to be the central issue to how well a survivor will manage in terms of psychological impact. The participants of this study credited family and friends for helping them deal with their illness. Orbuch et al. (2005) found that a strong parent-child relationship resulted in high quality of life for childhood cancer survivors. This is supported by this study. Christopher, Victor, Anne, Melissa, Cathleen, Justin, John, Rebecca, Edward, and Michael all credited their parents for helping them get through the time of their illness. Friends were also very important in creating a sense of normalcy which greatly impacted their ability to cope.

This study chose to examine the role of transformation in childhood cancer survivors. While coping is a central concept, it is just part of the issue. How well does one cope? Coping is a very individual notion as transformation is different for everyone. In order to fully understand transformation, coping, and eventually thriving, we must refer back to Tedeschi and Calhoun's (1995) General Model for Personal Growth resulting from Trauma. It is important to focus on this model as the outcome of this study aligned itself with this model. Although this study followed Parry's work (2003) methodologically, Parry also based her model on Tedeschi and Calhoun's model of transformation. However, it is important to mention that Parry's work examines uncertainty as the catalyst for transformative change. I will discuss Parry's model in more detail following the discussion of Tedeschi and Calhoun's model.

Tedeschi and Calhoun (1995) propose that the process of responding to traumatic events is a self-regulatory system which involves feedback loops. The first level of this model refers to the personality of the person in trauma. Tedeschi and Calhoun identify this person as being creative and adaptable; however, they also allow that the personality change may result out of the growth that occurs due to the struggle with adversity. For the purpose of our study, we did not examine the personality as it would be impossible to conceptualize the potential change in personality that may have occurred nor would it be helpful to say that the participants were all of a certain personality. It is however, important to understand, as was mentioned previously, that I acknowledge that the participants who responded to my recruitment process were a certain type of individual who were willing to answer questions comfortably and open to discussing their experiences.

The second level is the trauma itself (Tedeschi & Calhoun, 1995). The trauma we are discussing is that of childhood cancer. Each participant survived some form of cancer that took place as early as at birth and as late as at 19 yrs of age. Again personality may affect how well one is predisposed to deal with such a trauma. Although personality was not taken into account for the purpose of this study, it is clear that each participant brought his or her own unique personality into how they dealt with their illness. Justin felt that his shyness helped him deal with his cancer because he kept his illness quiet and simply dealt with whatever came his way with strength and dignity. Anne's laid back attitude helped her deal with her cancer because she never took things too seriously and kept a positive attitude throughout her ordeal. Christopher is a self-described procrastinator with a caring outgoing attitude. His credits his sense of humor and ability to reach out for help as what helped his deal with his illness. Melissa is an extremely positive person. Throughout her illness she looked ahead to the future, not allowing her illness to define her. Edward kept to himself wanting to keep his illness a private matter. He chose to deal with it on his own as he felt he was the only person who could understand what he was going through. John has an open and caring personality. He is very value-oriented and he dealt with his illness with the support of his family, friends, and faith. Michael is compassionate, warm, and funny. He dealt with his trauma by simply tackling it head on. Rebecca is a quiet, shy person. She is cautious and often prefers to take the more secure route. Rebecca has dealt with her illness in the same manner. She has kept the details of her illness to herself, confiding only in her close circle of friends. Victor is a soft spoken individual. He is open-minded and has a great sense of humor. Victor is an amazing advocate for childhood cancer survivors and although he has achieved so much in his young life, he is very humble. Very much the social butterfly, Victor dealt with his illness by participating in various groups and by being open about his illness. Cathleen is a person who perseveres. She credits her illness for making her the person she is today. Cathleen has overcome so many traumas in her life and despite this she continues to be an outgoing empathetic person. She deals with other traumas by putting things into perspective and then tackling them head on. While it is clear that each participant has a unique personality, each one managed to remain positive in light of their illness. Having only met each participant through email exchanges and a phone interview, it is difficult to distinguish the specific personality traits that they all share in order to determine a common trait that may be helpful for further research. Perhaps it is their differences rather than their similarities that should be noted. These differences attest to the fact that maybe it is not a single personality type or trait that allows one to overcome cancer in a positive manner. Perhaps the trauma of having cancer itself is an event that truly shapes an individual's personality. Regardless, this is a topic that deserves much more attention however, it should be noted that personality traits before trauma are difficult notions to isolate and should be treated with caution as it is important to not place limitations on a person's ability to overcome trauma despite certain predispositions such as personality.

The third level is the initial response (Tedeschi & Calhoun, 1995). Whether it was shock or denial or even non-existing in one's memory, as was the case with certain survivors, the response that occurs challenges our usual ways of operating or higher-order schemas (Tedeschi & Calhoun, 1995). As children, cancer is not something we are accustomed to dealing with therefore our usual responses can be challenged. Usual responses of fear may take place as ignorance. For example, Rebecca and Michael were too young to understand what their diagnosis truly meant. Denial might be the response of choice for others. For others, such as Melissa and Justin, they simply did whatever it took to get well again while not dwelling on the illness itself. Normal responses to normal events such as making friends in the park and not wanting to eat broccoli are then replaced by dealing with extended hospital stays and losing your hair. The physical reactions to the medical treatments and tests are observable. Children will scream and they will cry. They are forced to create new schemas in order to deal with the very adult situations they are now encountering.

As our traditional responses are challenged, *secondary responses* are set in motion. The next level, secondary responses, requires a re-evaluation of the traditional method of responding in attempts to discover ways of alleviating distress (Tedeschi & Calhoun, 1995). According to this model, this form of coping relies again on the personality of the person involved (Tedeschi & Calhoun, 1995). In this instance, some participants coped through being open about their illness (e.g., Victor, Cathleen) while others kept it quiet (e.g., Rebecca, Michael). Whether certain participants kept it quiet consciously or as a form of denial, it was a form of coping none the less. As Gray et al. (1992) put forth in their study; denial may be a highly effective coping strategy which allows survivors to overcome their difficulties. Regardless of the reasoning or the type of coping employed, each participant developed their own way of coping that was reflective of their uniqueness as individuals.

The fifth level refers to the people who surround and support the individual (Tedeschi & Calhoun, 1995). As was mentioned before, family and friends are often credited for helping the individuals cope. In this case, as a child we often look to our parents to help us create a sense of understanding of what is happening around us. In some cases the participants were so young (e.g., Michael, Rebecca, Cathleen, John. Justin, Anne, Melissa...) that it was their parents who made the decisions about treatment.

However, it was also their parents who guided and supported how they would understand their trauma. Parents who did not talk about the cancer may have helped to form a coping mechanism of denial. Parents and friends who were more open about discussing the illness may have promoted a sense of coping that was more externalized. Either way, based on those surrounding the survivor the survivor learns to find his/her own unique way of handling the situation.

The sixth level is initial growth (Tedeschi & Calhoun, 1995). Once the survivor has gone through each level, new goals are set and a new schema has been developed. The situation is once again perceived as manageable and growth takes form as a sense of personal strength with an appreciation for the meaningfulness of life (Tedeschi & Calhoun, 1995). A positive change in personality can be observed. Transformation has occurred (Tedeschi & Calhoun, 1995). Each of the participants was forced to create a new schema in order to manage the situation as cancer is outside of a child's realm of normal. As both Anne and Cathleen commented throughout their narrative, they thought that every child had gone through what they had gone through. It became their narrative of normal, their new schema. Some participants were deeply altered by their trauma. Both Christopher and John are pursuing careers in counselling in hopes of helping others who are going through their own traumas. Victor is actively involved in numerous cancer associations and speaks at conferences worldwide. Although some transformations may be more visible it does not mean that transformational growth has not occurred for each participant.

The final level, level seven is more growth (Tedeschi & Calhoun, 1995). It is the development of wisdom and the enhancement of interpersonal relationships. Meaning is formed from the traumatic experience and life is enhanced by the obstacles encountered throughout one's life. This continuation of growth may be viewed as thriving. When asked how they faced new obstacles or traumas, each participant felt that after having survived cancer everything else was easier to overcome. They felt that surviving cancer gave them a new perspective on life, one which allowed them to cope with other traumas more effectively because it could never be as bad as what they had already gone through. Even another cancer diagnosis would not be as traumatic because having survived it once before they would now know what to expect. The uncertainty was now eliminated and the schemas they created to deal with the first trauma of having cancer would allow then to be better equipped to handle new traumatic events.

While Tedeschi and Calhoun's (1995) model focuses on the trauma itself as the central event to cause change, Parry's (2003) model examines uncertainty as the catalyst for change. While uncertainty is often seen as a source of distress, similar to the event of trauma, Parry believed that it may over time turn into a means for profound positive change. Although this study followed Parry's (2003) methodology closely, it did not focus on uncertainty. The participants did not identify uncertainty as central worry in their lives. Uncertainty is a part of life for everyone not simply for cancer survivors. Rather than focus on uncertainty, I chose to use the trauma of cancer as the catalyst for change. While Parry's work on uncertainty is promising and offers a great deal of insight into survivorship issues, it may be difficult to assess uncertainty in general in cancer survivors. The common event or trait in all the participants of this study was the illness. Each participant dealt with having cancer as a child or adolescent. The themes derived from the narrative stories of the survivors themselves, indicate that they did not feel as though they had a poorer QOL outcome. This rich detailed source of information provided more information than the results of the QOL-CS and the PTGI alone. This study sought to provide a voice for survivors, but also to provide a deeper understanding of transformational growth and thriving that may occur as a result of cancer.

Transformational Growth and Thriving

The difficulty in trying to isolate the factors associated with transformational growth and thriving is that we are trying to examine factors based on information that is recollected and sometimes reconstructed. Families may be able to fill in the blanks of how a child behaved prior to having cancer, but even those recollections are of an identity or personality that has not yet been formed. It is clear that having cancer as a child is a transformative event, there is no way that it could not be. As Tedeschi and Calhoun (1995) discuss the trauma forces the individual to question everything around them. Regardless of the age, infancy or adolescence, the impact of cancer is felt in many ways. If we are to understand the process of transformation in cancer survivors using Tedeschi and Calhoun's model, change and/or growth must be perceived at every instance of survivorship. Every survivor has survived cancer and thus has learned to create schemas to aid in the coping. Some coping may be deemed negative; an instance of self-medicating with drugs or alcohol may prove to be a negative means of coping. Even denial may be seen as a positive coping strategy, if it allows the survivor to enjoy a positive QOL outcome. Regardless of the coping strategy, each participant found a way to make meaning of their experience with cancer.

Thriving is another concept that is difficult to assess. How can we measure thriving? Thriving was defined as the ability to demonstrate growth despite the presence of trauma (Parry & Chesler, 2005). The participants all demonstrated growth as elaborate in Tedeschi and Calhoun's model. However, I believe that thriving may also be related to the ability to surpass the expectations set by society as a whole. Each participant surpassed what was expected of them by doctors, teachers, and researchers who used pre-determined measures to assess transformational growth. If we are to use individual demographic variables, such as marriage status, socioeconomic status, parenthood status, etc... we may conclude that survivors have would poor QOL outcomes. If we were to rely simply on pre-determined quantitative interview questions we may miss out important information about the overall quality of life of individuals. However, by including narrative stories of individuals we can gain insight into thriving as it should be examined; based on whether or not the participant feels they have thrived.

The quantitative measures alone did not offer us much information about the individual issues that face survivors. Cancer survivors tend to report negative outcomes and much work needs to be done to establish tools that are more reflective of the problems that survivors encounter. It is a positive move that QOL has been recently renamed health-related QOL (HR-QOL) as it is more reflected of the medical aspects that are more easily quantifiable. However, it is noteworthy that these tools are not taken as the sole authority on the issues that survivors must face nor should it be entirely counted on to describe the impact of childhood cancer on future development. Tedeschi and Calhoun are strong proponents for mixed-method research as is Parry. It is important to heed this message in order to fully understand and service the needs of survivors.

In conclusion, while this study was small in size the value is no less important. The participants each developed their own way of coping with having had childhood cancer. Family and friends no doubt were huge positive impacts on coping. Personality of the survivors may also be an important factor, however, it should be treated cautiously as personality can change when confronted with a trauma. While the available research points to negative QOL outcomes, it is clear that there is a population of survivors that are thriving and living life to the fullest. It is crucial that we examine more of these narrative stories in order to better understand the long term impact of surviving childhood cancer.

Methodological Issues

There are some methodological issues that may have limited the interpretation of the results of this study. As previously mentioned the participants were pooled from various cancer support organizations. This predisposed my sample to being actively involved with a support group or organization, thus these participants may have been more comfortable and outgoing about this topic as opposed to a survivor who was more negatively impacted in terms of overall quality of life. The results of the quantitative survive suggest higher Quality of Life ratings and in the literature individuals with higher ratings are more likely to seek support. For example, the type of person who would want to participate in this type of research might be successful thriving individuals and thus not representative of the general childhood cancer survivor population. However, this limitation may also have been strength, as it may have possibly provided more insight into the mechanisms involved with coping, transformation, and thriving.

Of course another limiting factor is the sample size. The small sample size limits the generalizability of the results of the survey, however, for the qualitative interviews the sample size is adequate and allowed an in depth understanding of the participants' narratives.

My role as participant/observer may also be perceived as a limitation. Being a cancer survivor myself, my position as researcher is somewhat biased. However, again my own history and experience may be a strength as participants may have felt more comfortable discussing their experiences with someone who has gone through similar circumstances. My experience allowed me to provide a certain sense of sensitivity which may have also helped the flow of the conversation. As recruiting was difficult due to the sensitive nature of the topic, my own shyness could have inhibited certain aspects of the interview process as it may have impacted recruitment. I feel that perhaps someone with a stronger personality would have had more success in recruiting from the various organizations. Also the fact that interviews were done via telephone and email, was perhaps both positive and negative at the same time. It was positive in that it allowed for a sense of anonymity that would not have occurred had the interviews been done face to face, however, it may have inhibited the conversation for the same reason.

As a narrative researcher there is a theoretical lens through which this study was undertaken. The lens is a guiding perspective (Creswell, 2005) from which the structure of the research is developed. My being a survivor predisposed a certain bias in the way I understood the stories of the participants and no doubt guided the way I wrote their stories. However, this biased approach is understood within narrative research and that in no way reduces the realism of the experiences portrayed by each participant.

Finally, the survey itself may have been lacking depth. The survey was modified from Parry's survey codebook (2008). Scales (e.g. IES- Impact of Stressful Events scale, Cancer Needs Scale) were eliminated for the sake of accessibility and brevity for the participant however, the data results from our survey may have produced a less detailed picture than with Parry's original questionnaire. Never the less, the structural issue with QOL-CS remain the same and as this tool is widely used with childhood cancer survivors. The data obtained and the criticisms are still valid and worth considering for future studies.

Possible implications

The limitations of this study have been outlined. However, this study has several important implications. First and foremost, this study provided a forum for survivors to express how cancer has impacted their life both positively and negatively. Also within the same context we can begin to see the coping skills that some survivors have developed as a means of dealing with cancer.

The focus of this study was to reveal stories of transformational growth and thriving. This information is invaluable to professionals in the health care field as well as in the field of education. The study provided rich detailed experiences that may help various professionals to improve social support systems that can nurture future survivors in the hopes of enabling successful futures for all survivors.

Perhaps one of the most important implications was to consider that there is a need to bridge the gap between quantitative and qualitative research on this topic. The majority of the quantitative research is predominantly pessimistic, whereas the qualitative research using the individual experiences of cancer survivors tends to be more realistic and often more positive. The QOL-CS scale, although a valid tool, does not reflect the long term issues faced by survivors. The QOL-physical subscale lacks items which would probe into the physical impairments and/or disabilities that may be caused by treatment. The QOL-psychological scale is also lacking items that would truly discover the psychological issues faced by survivors. For example, it would be helpful to ask whether or not the participant had sought counselling in the past. It would also be useful to more detailed areas of depression such as sleeplessness and sadness.

As was discussed with the difficulties encountered with the QOL-CS scale, there are many items (e.g., QOL-physical, QOL-distress, QOL-social) that simply do not address the issues faced by survivors. It is recommended that more items should be included to examine; the physical impairments or other physical issues faced by survivors, the social difficulties dealing perhaps with trust and the issues faced within romantic relationships, a more uniform scale should be included to avoid confusion, and perhaps shortening the scale altogether to avoid ratings of 5 which do not offer a great deal of positive or negative information. More research needs to be done to create a tool that is more reflective of the difficulties faced by childhood cancer survivors. By gathering information through a mixed-methods approach future researchers would be in a position to understand how survivors who have positive quality of life outcomes thrive and continue to thrive. This information is valuable to an area of research that is highly understudied.

Finally, an important future recommendation is to better align social services with children’s hospitals. Although Child Life Organizations are promising, this study demonstrated that not every child with cancer has the opportunity to utilize such an organization. Programs need to be put into place for better integration into schools. Counselling services need to be accessible for the child and their family over the long term not simply during treatment. A system is required where each area, medical and social (e.g. schools, various community groups) can share information to better support the child in all areas, inside and outside the hospital. With a growing population of childhood cancer survivors in the world, it is increasing important to ensure that survivors are given the best opportunity to live their lives with the best possible outcomes.

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Appendices

Appendix A-
Survey

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Dear Student,

I am a graduate student in the Masters in Child Study program (within the Department of Education). I am presently preparing my thesis and am interested in examining the narratives of childhood cancer survivors. The focus of my study will be on how adults remember experiencing and surviving cancer as children and how that may have impacted your life as an adult. I hope to develop a better understanding of the coping strategies that survivors have used to deal with difficulties throughout their lives.

The purpose of this study is to provide health care workers, educators, and other professionals with insight into the lives of childhood cancer survivors in order to help create better support systems for children who are presently diagnosed with cancer.

Should you be interested in participating in the study simply fill out the survey below and provide me with your contact information. All information will be kept confidential and you may choose to discontinue at anytime. Please feel free to contact me or my supervisor Dr. Hariclia (Harriet) Petrakos, at 514- 848-2424 (ext. 2013) at anytime if you would like more information. Thank you in advance for your time and cooperation.

Sincerely,

Cathy Goldstein
Project Researcher
(514)-885-0517

Questionnaire

INSTRUCTIONS

Please answer every question to the best of your ability.

There are no "right" or "wrong" answers, so just answer the questions as best you can.

(Based on Parry, 2008 Survey Codebook)

Part 1: Background Information

Today's date_________________ [DATE-M] [DATE-D] [DATE-Y]

Your birth date (month/year):_____________________________[DOB-M] [DOB-Y]

What is your gender?

_____0 Female

_____1 Male

What is your current marital/relationship status? (***mark only one***)

_____ 1 Married

_____ 2 Committed relationship

_____ 3 Divorced

_____ 4 Widowed

_____ 5 Legally separated

_____ 6 Single *(never married)*

What is your current living situation? (***check all that apply***)

_____ 1 I live alone.

_____ 2 I live with my spouse or partner, with children.

_____ 3 I live with my spouse or partner, without children.

_____ 4 I live with someone else *(please specify)*

How many years of education have you completed? (***mark only one***) [EDUC]

_____ 1 6th grade or less

_____ 2 Some high school

_____ 3 High school graduate or GED

_____ 4 Some college

_____ 5 Associates degree or technical school

_____ 6 College graduate *(B.A. or B.S. degree)*

_____ 7 Post-graduate education

Are you employed, a student, or a volunteer? [WORKVOL]

_____ 0 No

_____ 1 Yes → *If yes,* do you work, volunteer, or go to school

______Less than 20 hours per week

______20-40 hours per week

______More than 40 hours per week

What is your racial/ethnic background? [RACE]

_____ 1 White (*not of Hispanic origin*)
_____ 2 Hispanic (*Mexican, Puerto Rican, Cuban, Central or South American descent*)
_____ 3 African American/Black (*not of Hispanic origin*)
_____ 4 Asian/Pacific Islander
_____ 9 Other *(please specify):*

Approximately, what is your household income? [INCOME]

Check one income range that best describes your household income for last year from all sources of income (salaries, wages, tips, social security, disability income or insurance, retirement income, and any other income).

_____ 1 Under $25,000

_____ 2 $26,000-50,000

_____ 3 $51,000-$75,000

_____ 4 $76,000-$100,000

_____ 5 $100,000+

How would you describe your faith? (***check all that apply***) [FAITH]

_____ 1 Spiritual, but not religious
_____ 2 Buddhist/Taoist
_____ 3 Christian: Catholic
_____ 4 Christian/Protestant: *Please note denomination:*
_____ 5 Hindu
_____ 6 Jewish
_____ 7 Agnostic or atheist

Part 2: Questions about Cancer Diagnosis and Treatment

When were you ***first*** diagnosed with Leukemia or Lymphoma?
____________MONTH______________YEAR

What type of cancer were you diagnosed with? [CATYPE]

_____ 1 Leukemia: ALL
_____ 2 Leukemia: AML
_____ 3 Leukemia: CLL
_____ 4 Leukemia: CML
_____ 5 Lymphoma (non-Hodgkin's)
_____ 6 Hodgkin's Lymphoma

What treatment did you receive for your cancer? (***check all that apply***) [TXFIRST]

_____ 1 Radiation
_____ 2 Chemotherapy

How long has it been since you finished treatment? [TIME_TX]

_____ 1 I am still in treatment
_____ 2 1-2 years
_____ 3 2-3 years
_____ 4 3-4 years
_____ 5 4-5 years
_____ 6 5+ years

Have you ever had a recurrence of Leukemia or Lymphoma? (***If you have had more than one recurrence, please answer based on the ***last*** recurrence.) [RECUR]

_____ 0 No

_____ 1 Yes → *If yes,* when? ____MONTH____YEAR

If yes, what treatment did you receive for the recurrence?
_____ 1 Radiation
_____ 2 Chemotherapy

If yes, when did you complete treatment for the recurrence?
______MONTH _____YEAR

Part 3: Cancer and Quality of Life

The following set of questions asks you about various aspects of your quality of life **currently**. For each question, please circle the number from 0 to 10 that best describes your experiences now.

Physical Well Being: To what extent are the following a problem for you?:

A. Fatigue
[PHYSFATG]

no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem

B. Appetite changes
[PHYSAPP]

no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem

C. Aches or pain
[PHYSACHE]

no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem

D. Sleep changes
[PHYSSLP]

no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem

E. Constipation
[PHYSCONS]

no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem

F. Nausea
[PHYSNAUS]

no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem

G. Menstrual changes or fertility
[PHYSFERT]

no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem

H. Rate your overall physical health
[PHYSOVER]

extremely poor 0 1 2 3 4 5 6 7 8 9 10 excellent

Looking at the above 8 questions, how much would you say your PHYSICAL WELL-BEING affects your quality of life? [QOL-PHYS]

(*Circle one number*.)

not at all 0 1 2 3 4 5 6 7 8 9 10 very much so

<u>Psychological Well Being</u>

I. How difficult is it for you to cope today as a result of your disease and treatment? [PSY-COPE]

not at all difficult 0 1 2 3 4 5 6 7 8 9 10 very difficult

J. How good is your quality of life?
[PSY-QOL]

extremely poor 0 1 2 3 4 5 6 7 8 9 10 excellent

K. How much happiness do you feel? [PSY-HAPY]

none at all 0 1 2 3 4 5 6 7 8 9 10 a great deal

L. Do you feel like you are in control of things in your life?[PSY-CTRL]

not at all 0 1 2 3 4 5 6 7 8 9 10 completely

M. How satisfying is your life? [PSY-SAT]

not at all 0 1 2 3 4 5 6 7 8 9 10 completely

N. How is your present ability to concentrate or to remember things?[PSY-MEM]

extremely poor 0 1 2 3 4 5 6 7 8 9 10 excellent

O. How useful do you feel? [PSY-USFL]

not at all 0 1 2 3 4 5 6 7 8 9 10 extremely

P. Has your illness or treatment caused changes in your appearance?[PSY-APPR]

not at all 0 1 2 3 4 5 6 7 8 9 10 extremely

Q. Has your illness or treatment caused changes in your self concept (the way you see yourself)?
[PSY-IDTY]

not at all 0 1 2 3 4 5 6 7 8 9 10 extremely

Looking at the above 9 questions, how much would you say your PSYCHOLOGICAL WELL-BEING affects your quality of life? [QOL-PSY]

(*Circle one number*.)

not at all 0 1 2 3 4 5 6 7 8 9 10 very much so

<u>How distressing were the following aspects of your illness?</u>

R. Initial cancer diagnosis [DIS-DX]

not at all distressing 0 1 2 3 4 5 6 7 8 9 10 very distressing

S. Cancer treatments (i.e. chemotherapy, radiation, or surgery) [DIS-TX]

not at all distressing 0 1 2 3 4 5 6 7 8 9 10 very distressing

T. Time since my treatment was completed [DIS-AFTX] not at all distressing 0 1 2 3 4 5 6 7 8 9 10 very distressing

U. How much anxiety do you have?[DIS-ANXY]

none at all 0 1 2 3 4 5 6 7 8 9 10 a great deal

V. How much depression do you have? [DIS-DEPR]

none at all 0 1 2 3 4 5 6 7 8 9 10 a great deal

Looking at the above 5 questions, how much would you say that DISTRESS RELATED TO CANCER affects your quality of life? [QOL-DIS]

(*Circle one number*.)

not at all 0 1 2 3 4 5 6 7 8 9 10 very much so

To what extent are you fearful of:

W. Future diagnostic tests [FEARTST]

no fear 0 1 2 3 4 5 6 7 8 9 10 extreme fear

X. A second cancer (a second type of cancer) [FEARCA2]

no fear 0 1 2 3 4 5 6 7 8 9 10 extreme fear

Y. Recurrence of your cancer [FEARREC]

no fear 0 1 2 3 4 5 6 7 8 9 10 extreme fear

Z. Spreading (metastasis) of your cancer [FEARMETS]

no fear 0 1 2 3 4 5 6 7 8 9 10 extreme fear

Looking at the above 4 questions, how much would you say that FEARS RELATED TO CANCER affect your quality of life? [QOL-FEAR]

(*Circle one number*.)

not at all 0 1 2 3 4 5 6 7 8 9 10 very much so

Social Concerns

AA. How distressing has illness been for your family? [SOC-FAM]

Not at all 0 1 2 3 4 5 6 7 8 9 10 a great deal

BB. Is the amount of support you receive from others sufficient to meet your needs? [SOC-SPRT]

Not at all 0 1 2 3 4 5 6 7 8 9 10 a great deal

CC. Is your continuing health care interfering with your personal relationships?[SOC-REL]

Not at all 0 1 2 3 4 5 6 7 8 9 10 a great deal

DD. Is your sexuality impacted by your illness? [SOC-SEX]

Not at all 0 1 2 3 4 5 6 7 8 9 10 a great deal

EE. To what degree has your illness and treatment interfered with your employment? [SOC-WORK]

No problem 0 1 2 3 4 5 6 7 8 9 10 severe problem

FF. To what degree has your illness and treatment interfered with your activities at home? [SOC-HOME]

No problem 0 1 2 3 4 5 6 7 8 9 10 severe problem

GG. How much isolation do you feel is caused by your illness or treatment? [SOC-ISOL]

None 0 1 2 3 4 5 6 7 8 9 10 a great deal

HH. How much financial burden have you incurred as a result of your illness and treatment? [SOC-FINL]

None 0 1 2 3 4 5 6 7 8 9 10 a great deal

Looking at the above 8 questions, how much would you say your SOCIAL WELL-BEING affects your quality of life? [QOL-SOC]

(*Circle one number*.)

not at all 0 1 2 3 4 5 6 7 8 9 10 very much so

Spiritual Well Being

II. How important to you is your participation in religious activities such as praying, or going to church, synagogue, temple? [SPR-ACT]

not at all important 0 1 2 3 4 5 6 7 8 9 10 very important

JJ. How important to you are other spiritual activities such as meditation? [SPR-MED]

not at all important 0 1 2 3 4 5 6 7 8 9 10 very important

KK. How much has your spiritual life changed as a result of your cancer diagnosis? [SPR-CHG]

became less important 0 1 2 3 4 5 6 7 8 9 10 became more important

LL. How much uncertainty do you feel about your future?[SPR-UNCR]

not at all uncertain 0 1 2 3 4 5 6 7 8 9 10 very uncertain

MM. To what extent has your illness made positive changes in your life? [SPR-POS]

none at all 0 1 2 3 4 5 6 7 8 9 10 a great deal

NN. Do you sense a purpose/mission for your life or a reason for being alive? [SPR-RSN]

none at all 0 1 2 3 4 5 6 7 8 9 10 a great deal

OO. How hopeful do you feel? [SPR-HOPE]

not at all 0 1 2 3 4 5 6 7 8 9 10 very hopeful

Looking at the above 7 questions, how much would you say your SPIRITUAL WELL-BEING affects your quality of life? [QOL-SPR] (*Circle one number*.)

not at all 0 1 2 3 4 5 6 7 8 9 10 very much so

People sometimes find that a crisis such as cancer may eventually lead to positive changes in their lives. For each of the items below, indicate the degree to which the change described in the item has occurred in your life—as of today—as a result of cancer. **PTG Scale.**

	I have **not** experienced a positive change	To a very small degree	To a small degree	To a moderate degree	To a great degree	To a very great degree
1. My priorities about what is important in life [PTG-1]	1	2	3	4	5	6
2. I'm more likely to try to change things which need changing [PTG-2]	1	2	3	4	5	6
3. An appreciation for the value of my own life [PTG-3]	1	2	3	4	5	6
4. A feeling of self-reliance [PTG-4]	1	2	3	4	5	6
5. A better understanding of spiritual matters [PTG-5]	1	2	3	4	5	6
6. Knowing I can count on people in times of trouble [PTG-6]	1	2	3	4	5	6
7. A sense of closeness with others [PTG-7]	1	2	3	4	5	6
8. Knowing I can handle difficulties [PTG-8]	1	2	3	4	5	6
9. A willingness to express my emotions [PTG-9]	1	2	3	4	5	6
10. Being able to accept the way things work out [PTG-10]	1	2	3	4	5	6

11. Appreciating each day [PTG-11]	1	2	3	4	5	6
	I have **not** experienced a positive change	To a very small degree	To a small degree	To a moderate degree	To a great degree	To a very great degree
13. I'm able to do better things with my life [PTG-13]	1	2	3	4	5	6
14. New opportunities are available which wouldn't have been otherwise [PTG-14]	1	2	3	4	5	6
15. Putting effort into my relationships [PTG-15]	1	2	3	4	5	6
16. I have a stronger religious faith [PTG-16]	1	2	3	4	5	6
17. I discovered that I'm stronger than I thought I was [PTG-17]	1	2	3	4	5	6
18. I learned a great deal about how wonderful people are [PTG-18]	1	2	3	4	5	6
19. I developed new interests [PTG-19]	1	2	3	4	5	6
20.I accept needing others [PTG-20]	1	2	3	4	5	6
I established a new path for my life [PTG-21]	1	2	3	4	5	6

As part of this research project some people who have completed this questionnaire will also have the opportunity to take part in an interview portion of the study. Would you like to be contacted to participate further in the study? Can I call you to discuss this part of the study with you?

________ yes ________ no

If you answered "yes" please add your name and contact information below:

Name:
Phone (and preferred time to be contacted):
Email address:

Thank you so much for taking the time to fill out the questionnaire!

Appendix B

Consent Form

CONSENT FORM TO PARTICIPATE IN RESEARCH

This is to state that I agree to participate in a program of research being conducted by Cathy Goldstein (Supervisor Dr. Harriet Petrakos) of the Department of Education, Concordia University.

Contact Information

Cathy Goldstein, Department of Education, Concordia University
ca_golds@education.concordia.ca
(514) 885-0517 cell.

A. PURPOSE

I have been informed that the purpose of the research is to understand how adult survivors of cancer describe their experiences with childhood cancer. This may provide a forum for the narratives/stories of adult childhood cancer survivors on their ability to cope with cancer over the years.

B. PROCEDURE

The research involves two parts:

(a) First, I will be asked to answer a series of survey questions on my experiences with having cancer and my quality of life.
(b) If I decide to continue in the second part of the study, the researcher will contact me at my convenience and interview me and ask me to tell my story as a childhood cancer survivor. The interview will be audio-taped and only my supervisor and I will have access to the data.

C. CONDITIONS OF PARTICIPATION

- I understand that I am free to withdraw my consent and discontinue my participation in the research at anytime without negative consequences.
- I understand that my participation in this study is confidential. Pseudonyms will be used to ensure confidentiality.
- I understand that the data from this study may be published and that direct quotes may be used without my real name or any identifying information.

I HAVE CAREFULLY STUDIED THE ABOVE AND UNDERSTAND THIS AGREEMENT. I FREELY CONSENT AND VOLUNTARILY AGREE TO PARTICIPATE IN THIS STUDY.

PARTICIPANT'S NAME (PRINT):_______________________________________

PARTICIPANT'S SIGNATURE:____

If at any time you have any questions about your rights as a research participant, please contact Adela Reid, Research Ethics and Compliance Officer, Concordia University, at (514) 848-2424 ext. 7481 or by email at areid@alcor.concordia.ca.

Appendix C

Open-ended Interview Questions

Open-ended Questions for Interview Portion of Study

1. Tell me your story about cancer.
2. What is the impact of cancer on your life as of today?
3. What helped you post-treatment?
4. What are your perceptions of yourself? Do you feel as though you have achieved the same milestones as your peers?
5. Has your cancer physically impaired you in any way? Elaborate.
6. What social supports were available to you throughout your childhood and adolescence?
7. As a cancer survivor myself, I’ve struggled with my “cancer identity”. How does having had cancer fit into your present day life?
8. How do you face other traumas after having had cancer?
9. How would you describe yourself?
10. Would you consider yourself a successful person? Please explain...
11. What impact did your family have on your ability to cope?
12. Do you feel as though you have become more spiritual due to your illness?
13. What is your future outlook?

Appendix D-

Copy of Concordia Ethics Approval Letter