The Education Experiences of Eight American Adolescents in Cancer Survivorship

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Abstract

The aim of this thesis is to understand the experiences of eight American high school students who have been diagnosed with cancer. By increasing understanding of the challenges that adolescents in cancer survivorship experience, better support can be identified. The experience of cancer survivorship influences the physical, psychological, and social experiences of patients. As the survival rate of childhood cancers continues to increase, death becomes less likely making the need to maintain educational engagement during survivorship increasingly important.

The research questions for this study were designed to address two main gaps in the current field of research. The first research question aims to address how the physical and psychological effects of cancer and treatment impact the participants' engagement with school. The second research question aims to understand the role that school plays for adolescents in cancer survivorship, including how participants experienced supplemental education during and after cancer treatment. This study uses a qualitative research methodology to address the research questions utilizing primarily semi-structured interviews and an adjusted version of the Adolescent Coping Scale. When used in combination with the interviews, the scale provides a picture of what the participants experienced and how they have been able to cope with the challenges they have faced. Interpretive phenomenological analysis was used to provide structure to the interview analysis.

The results of this study show that fatigue and a compromised immune system have an impact on school attendance more than other physical effects during cancer treatment. As a result, adolescents are most at-risk of experiencing challenges in educational engagement during treatment. The results of this study also show that the feeling of uncertainty throughout cancer survivorship promotes fear and the feeling of a loss of control. Once treatment ends, fear of relapse is common. Physical and psychological effects were felt to improve as time passed. Another key result of this study is that the cancer experience results in a shift in perspective that becomes incorporated into the formation of identity. Participants feel different from peers as a result of the physical and psychological effects of the cancer experience. The results from the Adolescent Coping Scale indicate that school achievement, relapse and the worsening of physical side effects, and being treated different by peers were common concerns for the participants regarding their school, illness, and social concerns, respectively.

Lastly, the participants view supplemental education as successful if it meets their personal academic and physical needs, is implemented consistently, and helps them to feel emotionally supported and socially connected. However, more research is needed that focuses on the implementation of policy at the state and district levels to discern whether this is a common challenge unique to this population of students with a physical or medical disability. The sample available for this research topic is not only limited to an extremely small population, but they are also a highly guarded population, making access for recruitment challenging. However, while generalization is difficult with a study of this size, the evidence collected on the participants' experiences during and after treatment provides valuable data on aspects of supplemental education implementation.

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CHAPTER 1

Cancer Survivorship

Introduction

The aim of this thesis is to understand the experiences of American high school students who have been diagnosed with cancer. This thesis focused on the physical, psychological, social, and educational challenges from diagnosis through treatment, based on the participants' retrospective account of their experiences. Since researchers in the United States are unable to contact pediatric patients directly, the study was carried out through the American Cancer Society, Great West Division, where I was able to gain access to adolescent cancer patients. The thesis aimed to explore the experiences of adolescents who were diagnosed with cancer, and how their diagnosis influenced the physical, educational, psychological, social, and familial aspects of the patient's life through and beyond treatment.

A term that is often used to describe the process of living following a cancer diagnosis is known as "cancer survivorship." This term is used to extend beyond the physical medical terms into the existential effect that cancer diagnosis and treatment can have on a patient's life. This includes the effects that cancer can have on social, professional, and psychological aspects of a patient's life. There are some researchers who define this as "quality of life," yet others debate that definition. Since there is no definition of quality of life that is agreed upon by field researchers specifically for childhood cancer patients and survivors, I looked into quality of life measurement tools in order to gain a better understanding of what constitutes quality of life in research in this field. The majority of quality of life measures particularly for children and adolescents with cancer focus on the physical, psychological, social, and spiritual domains, as well as school or work performance, demographics, and family life. This thesis uses the data gathered from the participants regarding their familial, social, physical, psychological, and educational experiences to understand cancer survivorship. As such, individual quality of life will be defined in this thesis in terms of the participants' subjective positive or negative accounts of their familial, social, physical, psychological, and educational well-being during cancer survivorship.

For the purposes of this thesis, I will use the terms "during treatment" and "post-treatment" to differentiate between the time during treatment and the time once treatment has ended. Otherwise the participants will be referred to as being in "cancer survivorship," to describe the time after diagnosis and beyond treatment.

What is cancer?

The National Cancer Institute uses the term "cancer" to define a "collection of related diseases" where "the body's cells begin to divide without stopping and spread into surrounding tissues" (2015). Cancer in children and adolescents is rare; however it is the "leading cause of death by disease past infancy among children in the United States" (National Cancer Institute, 2014). In 1975, more than 50 percent of children and adolescents who were diagnosed with cancer survived five years or more (Ries, Smith, Gurney, Linet, Tamra, Young, and Bunin; 1999). By 2010, the survival rate after five years for children and adolescents who were diagnosed with cancer increased to more than 80 percent (Howlader, Noone, Krapcho, Garshell, Miller, Altekruse, Kosary, Yu, Ruhl, Tatalovich, Mariotto, Lewis, Chen, Feuer, Cronin; 2014).

Cancer can vary in type and severity; however there are some cancers that are more common in children and adolescents than others. The table on the following page describes the types of cancer from most common to least common and includes a description of each diagnosis and common symptoms.

Table 1.1 Types of Childhood Cancer

Type	Frequency	Examples	Notes
Leukemia	33 percent of all childhood cancers	Acute Lymphocytic Leukemia (ALL) Acute Myelogenous Leukemia (AML)	Leukemia may cause bone and joint pain, weakness, bleeding, fever, weight loss, and other symptoms.
Brain and nervous system cancers	21 percent of all childhood cancers	Solid tumors	Most brain cancers of children involve the cerebellum or brain stem. In early stages they can cause headaches, nausea, vomiting, blurred or double vision, dizziness, and trouble walking or handling objects. Spinal cord tumors are less common than brain tumors in both children and adults.
Neuroblastoma	7 percent of all childhood cancers	Solid tumors	Starts in nerve cells found in a developing embryo or fetus. This type of cancer occurs in infants and young children. It is most often found during the first year of life. The tumor can start anywhere but usually occurs in the abdomen. It can also cause bone pain and fever.
Wilms tumor	5 percent of all childhood cancers	Solid tumors	Starts in one or both kidneys. It is most often found in children about 3 years old, and is uncommon in children older than age 6. It can show up as a swelling or lump in the abdomen. Other symptoms may include fever, pain, or poor appetite.
Lymphoma	4 percent of all childhood cancers 4 percent of all childhood cancers	Hodgkin lymphoma Non-Hodgkin Lymphoma	Starts in lymph tissues. These cancers may spread to bone marrow and other organs, which can cause different symptoms depending on where it is growing. They also can cause fever, sweats, weakness, and swollen lymph nodes in the neck, armpit, or groin.
Rhabdomyosarcoma	3 percent of all childhood cancers	Solid tumors	The most common soft tissue sarcoma in children. Starts in the same embryonic cells that develop into striated muscles. Can occur in the head and neck, groin, abdomen, pelvis, arms and legs. It may cause pain, swelling (a lump), or both.
Retinoblastoma	Under 3 percent of all childhood cancers	Solid tumors	Cancer of the eye. It usually occurs in children under the age of 4, and is seldom found in children older than 6.
Bone cancers	Under 3 percent of all childhood cancers More than 1 percent of all childhood cancers	Osteosarcoma Ewing Sarcoma	Occurs most often in children and adolescents. Primary bone cancer is different from metastatic bone cancer, which is cancer that has spread from another site to the bone. It often causes no pain or symptoms until swelling starts, but sometimes there is bone pain that keeps getting worse.

Table 1.1 The most common types of childhood cancer according to the American Cancer Society. Retrieved on 18 June, 2010 from http://www.cancer.org/docroot/CRI/content/CRI_2_4_1X_What_are_the_types_of_childhood_cancers_7.asp.

Types of treatment

Treatments for cancer depend on the diagnosis. If a solid tumor is detected, then surgery is usually the first treatment option to remove all or as much of the tumor as possible. Other forms of treatment include chemotherapy and radiation. Chemotherapy is a drug that can be taken intravenously (through an IV directly connected to the patient's vein) or orally (by mouth) to kill cancer cells (American Cancer Society, 2015). Radiation uses high-energy rays to kill cancer cells (American Cancer Society, 2015). It is also used to shrink tumors after surgery in instances where doctors are unable to remove the whole tumor. Other treatment types include hormone therapies such as stem-cell or bone-marrow transplants.

According to the American Cancer Society (2015) the most common side effects from chemotherapy include nausea and vomiting, loss of appetite, hair loss, mouth sores, and low blood cell count. A low blood cell count often results in a higher risk of infection, a risk of easy bruising and internal bleeding, and extreme fatigue. Side effects from radiation are less severe than chemotherapy and include skin irritation at the sight of treatment and extreme fatigue. Each patient's cancer can affect them differently and will often respond differently to treatments (American Cancer Society, 2015).

The Stages of Cancer

Understanding cancer survivorship begins with knowing the stages of cancer. Katz and Jay (1984) describe the journey from diagnosis to remission or death. The first phase is the pre-diagnostic and diagnostic phase. It is likely that children would have seen several doctors before the diagnosis is made. A wide range of emotional reactions is expected, including shock, denial, grief, anger, and depression (Katz & Jay, 1984). Once the diagnosis is made, initial and major adjustments are necessary.

Treatment begins, providing the patient and families with specific and concrete responsibilities that include managing medications, treatment schedules, medical procedures, changes in appearance, and general dependency (Katz & Jay, 1984). Returning to school while undergoing treatment can play a vital role. “The child’s school experience is increasingly important as survival increases, and a greater number of children must make their way in the adult world, uncompromised by their childhood illness” (Vance and Eiser, 2002).

Remission is the intended goal of treatment and can last days, weeks, months or years. Successful treatment can invoke multiple reactions, such as happiness that treatment has ended or fear that the protection of treatment is no longer there. The remission phase comes with a great deal of uncertainty. As the literature will suggest in the next chapter, there have been incidences of posttraumatic stress disorder among survivors (Hobbie, Stuber, Meeske, Wissler, Rourke, Ruccione, Hinkle, and Kazak, 2000; Pelcovitz, Goldenberg-Libox, Mandel, Kaplan, Weinblatt, and Septimus, 1998; Stuber, Kazak, Meeske, Barakat, Guthrie, Garnier, Pynoos, and Meadows, 1997).

Some patients may experience relapse (a recurrence of their cancer), which can impact on psychological adjustment processes. For example patients who experience a relapse of their cancer may have reactions similar to those they previously had during the initial diagnosis. At this point, new courses of treatment are discussed with the physician. Treatments often differ from the original course of treatment; experimental treatments and stopping treatment altogether are often discussed after a relapse of cancer.

In the instance where treatment fails, terminal illness and death become the focus of attention. Children, as young as preschool age (4 to 5 years old), have shown their understanding of this situation (Katz & Jay, 1984). The patient will discuss their wishes regarding their death with family, friends, doctors, nurses, or a hospital psychologist when they are ready. At this point, pain and anxiety management become the medical focus to keep the patient as comfortable as possible until their death. Finally in the post-death phase, families will handle their grief in a variety of individual ways. Hospitals will often provide families with psychological and community support during bereavement.

Background Information

Many cancer survivors regardless of age will experience residual physical effects from the cancer and its treatment after treatment has ended. According to the American Cancer Society, these effects may include impaired fertility, increased risk of second cancer, heart or lung problems, hearing or vision problems, pain or swelling in focused areas of the body, or hormone deficiencies (American Cancer Society, 2014). In some cases the residual physical effects will decrease over time, such as pain, swelling, and hormone deficiencies, for example hair growth. Even for those adolescent cancer survivors who make a full physical recovery, psychological distress is common in cancer survivorship.

Hobbie et al. (2000) conducted a research study that focused on the instances of posttraumatic stress disorder (PTSD) in young adult survivors of childhood cancer. They found that one-fifth of young adult cancer survivors exhibit symptoms of PTSD. Hobbie et al. (2000) conclude that this result stems from the dependency that children with cancer have on their parents/guardians during treatment, yet lose when treatment ends as they enter into adulthood and associated increased independence.

In a similar study, Kazak, DeRosa, Schwartz, Hobbie, Carlson, Ittenbach, Mao, and Ginsberg (2010) investigated psychological outcomes for pediatric cancer survivors in comparison to healthy controls. While Kazak et al. (2010) found no significant difference between survivors and controls, the researchers did find that adolescent survivors experienced significantly greater psychological distress in comparison to childhood cancer survivors. Furthering the conclusions made by Hobbie et al. (2000), Kazak et al. (2010) claim that the intensity of cancer treatment can increase the likelihood of PTSD symptoms as well as dependency, and conclude that adolescent cancer survivors should be considered at-risk of developing PTSD. According to Newby, Brown, Pawletko, Gold, and Whitt (2000), young adult cancer survivors exhibit less psychological distress and concern for relapse as time passes after treatment has ended, suggesting that cancer survivors adjust psychologically over time to survivorship.

The school setting is of specific interest to this study as it provides adolescents with opportunities for social interaction and development that might be denied to them if confined to a hospital setting. With the increased range of medical care available for pediatric oncology, adolescents in cancer survivorship can continue to attend school both during and after treatment, thus potentially providing them with a sense of normalcy. However, attending school during treatment is challenging when the student does not feel well enough to attend or stay engaged when attending school. According to the literature reviewed, Pini, Hugh-Jones, and Gardner (2012) claim that psychological adjustment, specifically in the domains of body image and self-concept, mediates educational engagement for adolescents in cancer survivorship. School attendance also suffers when the adolescent is undergoing treatment (Deasy-Spinetta and Spinetta, 1980; Vance and

Eiser, 2001), yet the impact on attendance decreases over time as the young person adjusts to cancer post-treatment.

Cancer treatments can also have an effect on academic achievement. Peckham (1989) suggests that children who receive cranial irradiation treatment should be considered at risk in terms of reduced academic achievement due to the side effects that radiation can have on the development of the brain. Raymond-Speden, Tripp, Lawrence, and Holdaway focused their 2000 study on the intellectual, psychological and academic functioning of cancer survivors long-term. They found that central nervous system (CNS) chemotherapy also has a significant effect on intellectual and academic functioning. Anderson, Smibert, Ekert, and Godber (1994) found similar results to Raymond-Speden et al. (2000), and also recommend early educational interventions for those pediatric patients receiving cranial irradiation or CNS chemotherapy treatments.

The brief background to the literature described above will be further discussed in chapters two and three of this thesis. However, this overview serves to demonstrate how cancer survivorship includes existential effects in additional to the medical aspects of a patient's illness. Since the literature suggests that adolescents are more likely to struggle with psychological challenges in cancer survivorship than children or adults (Hobbie et al., 2000), I wanted to focus on the adolescent age group . I was able to further focus my recruitment sample by seeking out adolescent cancer survivors who attended high school in an effort to provide consistency to the investigation of adolescent participants' school experiences in cancer survivorship. Since there is a clear cultural divide between middle school and high school in the U.S., I aimed to recruit for this study from only high school students, who were between the ages of 13 and 18 years.

Furthermore, the literature on adolescent cancer often indicates that the effects of cancer and treatment subside over time. I, therefore, wanted to conduct a research study that addressed the experiences of adolescent cancer survivors within one year of finishing treatment. The aim of this is to capture the experience of adolescents as they make the transition from treatment into remission. An added benefit of researching adolescents in this time frame is that their memories of treatment are also more recent than they would be if more time had passed since treatment finished.

Statement of the Problem

The aim of this thesis is to address two main challenges that American adolescents experience as part of cancer survivorship. The first challenge is making the transition from treatment into post-treatment. There is limited research available that focuses on a first-person account of what the experience of transitioning from treatment into post-treatment is like for American adolescents. As briefly outlined in the stages of cancer section above, cancer treatment can seriously affect an adolescent's everyday life. How adolescents choose to cope with the challenges faced during treatment can also have an effect on their experiences in post-treatment. For this age group, the cancer experience can have a drastic effect on the developmental stage of adolescence, which shapes the kind of adult the teen will eventually become. Since medical advances have resulted in higher rates of survival for pediatric cancer patients, it has become necessary to understand the challenges adolescents face in cancer survivorship in an effort to ease the transition in a way that promotes successful development.

Most of the current research in the field addresses the challenges associated with cancer "late effects," which are the residual side effects of cancer and treatment five years after treatment has ended. Current research also gathers data from parents, teachers, and medical personnel rather than the patients themselves. This thesis focuses on the first-hand experiences of American adolescents who were within one year of post treatment in an effort to better understand the transition from treatment into post-treatment.

The second challenge that this thesis aims to address is fitting into full time education during and after treatment. This thesis explores the extent to which educational policy for this population is perceived by a sample of adolescent cancer survivors themselves to have been implemented successfully. By attending school, adolescents in cancer survivorship in theory stay connected to the life they knew before they were diagnosed and can use the school as a place of support (Gartin and Murdick, 2009). However, it is difficult to achieve academically in school when coping with the physical and mental challenges of cancer survivorship. Cancer treatment can affect the cognitive function of a patient's mind. This is often referred to as "chemo brain," and describes the difficulty that patients and survivors have in retrieving or retaining information in the brain. These cognitive impairments require educational institutions to make adjustments to teaching in order to meet the needs of students in cancer survivorship. Students with cancer also regularly feel fatigued and have compromised immune systems as a result of cancer and treatment, making it difficult for them to attend school regularly. A lack of consistent attendance in school creates further challenges in academic success for students (Deasy-Spinetta & Spinetta, 1980).

In an effort to address the needs of this specialized student population, the United States has developed policies that are intended to provide free and basic education to children and adolescents with special needs. But given the complexities in policy implementation in the United States from the federal to the state to the city and district levels, the question becomes whether policies are being implemented in a way that adolescents in cancer survivorship would deem successful. This thesis aims to address how the participants define a successful school experience during and after their cancer treatment, as well as how their overall school experience, whether deemed successful or not, affects overall cancer survivorship.

Legal Rights

The United States has a national Department of Education that sets the standards for all students in the country to have access to free education. This includes a variety of school types within the 50 states and the outlying U.S. territories in an effort to provide education to all children. Many also have access to a private or parochial school if the family is able to afford tuition costs. All schools have to abide by specific standards in order to receive federal accreditation as an educational institution. Within the guidelines set by the federal Department of Education, each U.S. state also operates its own department of education. They are required to uphold federal guidelines, but are also free to devise state-specific policies to guide the educational standards of the schools within that state.

Looking first at the federal guidelines, the government has three main policies that address the needs of special education students. The most recently enacted law is the No Child Left Behind Act (NCLB). This law promotes school reform and provides schools that exhibit low achievement scores with assistance in educational areas such as literacy improvements, dropout prevention, and programs focused on the needs of at-risk children. The NCLB Act focuses on those children in a classroom who may require extra attention in their education in order to succeed to the next grade level.

The Individuals with Disabilities Education Act (IDEA 2004) is the second policy that supports the needs of children and adults who require specialized education due to physical or mental disability. This law requires that every government (public) school must provide free and appropriate education in the least restrictive environment to all students who require specialized education between the ages of three and twenty-one years of age (Keene et al., 2007). In practice, this law requires that children with special needs remain in a mainstream classroom as long as their learning needs will allow them to before being transferred to a specialized education classroom. According to the Department of Education, IDEA 2004 serves over 6.5 million eligible children with disabilities.

Lastly, and closely associated with IDEA 2004, is Section 504 of the Rehabilitation Act of 1973. Known as "Section 504," this policy protects individuals against discrimination based on their disability, thus making it illegal in the U.S. to deny specialized education to any student with a disability (US Department of Education, 2013). Section 504 applies when the child is not eligible for special education instruction, but still requires accommodations to be successful in a mainstream classroom. According to the Section 504 Fact Sheet, "under this law, individuals with disabilities are defined as persons with a physical or mental impairment which substantially limits one or more major life activities" (p. 1). The fact sheet outlines learning as one of the major life activities; consequently learning may be impaired when an individual has a disability. Cancer is listed as one of the examples of impairments; therefore, the law protects any adolescent's or child's right to receive an equal education in comparison to their healthy counterparts, despite having cancer. Examples of school accommodations may include carrying a water bottle, being able to have a mobile phone in class, waiving tardiness policies so that the student has extra time to get to class, or extra time to complete an assignment or test due to concentration problems, to name a few.

These policies describe how the federal system attempts to address special educational needs for students with a chronic illness such as cancer. What is unclear is how well these policies are implemented from the perspective of the student who is receiving them.

Given the gaps in the field of research, this thesis aims to answer two main research questions:

1) How do the physical and psychological effects of cancer and treatment impact the participants' engagement with school?
2) What role does school play in cancer survivorship for adolescents?
    a. How do participants define a successful school experience during and after cancer treatment?
    b. How does United States policy shape the school experience of adolescents in cancer survivorship?

Research Design and Limitations

Since each patient's experience with cancer is unique, it can be challenging to conduct research on cancer survivorship. For this reason, I chose a qualitative approach that aims to understand participants' individual experiences with cancer survivorship. Given the differences in how patients experience cancer survivorship, it was important to approach this topic using an empirical research design, rather than drawing on a particular theory or framework. By approaching this study empirically, I was able to focus on the individual experiences of the participants. However, the sensitive nature of this study required me to have background knowledge on adolescents in cancer survivorship in order to protect the participants.

In order to answer the above research questions and sub-questions, I chose semi-structured interviews and two scales that measure self-concept and coping mechanisms. The self-concept scale known as the Piers-Harris Children's Self-Concept Scale proved to be of less value in terms of addressing the specific research aims. Therefore I focused on the exploration of coping strategies using the Adolescent Coping Scale – Short Form (ACS – Short). Since cancer survivorship has an existential effect on a patient's life in terms of the physical, behavioral, and cognitive functioning, as well as social interactions and overall happiness, the ACS-Short enables the research participant to identify their largest concern in their own words, as well as how they choose to cope when addressing their concern. I split the ACS – Short questionnaire into three specific versions of the form. Each form is the same except asks participants to identify separately their main concern regarding their illness, school, and social interactions.

The initial design was to conduct a small pilot study based on a sample of five to ten participants with the intention of assessing how well the measures and semi-structured interviews worked in gaining information regarding participants' experiences with cancer survivorship. However, this proved to be challenging when attempting to gain access to the population. Thus the pilot study sample became the primary study sample. Eight participants sampled from the American Cancer Society – Great West Division volunteered to participate in the study (five male and three female).

Delimitations for recruitment included the following:

- Participants must be in a high school grade (ninth through twelfth grades)
- Participants must not have had cranial irradiation as a part of their cancer treatment
- Participants must have completed cancer treatment within one year prior to meeting with the researcher

The rationale for these delimitations was to fill the gap outlined in the brief literature above. By including participants in a high school grade, the research focused on participants who were currently in the adolescent stage of life while controlling for the educational level. This provided consistency when looking at participants' experiences with school since most high school frameworks operate similarly.

Since cranial irradiation can cause moderate to severe academic delays and hinder cognitive functioning, I wanted to focus on those students who were not already anticipating academic challenges as a result of their cancer survivorship.

Lastly, since there is limited research available focusing on the time of transition from treatment into post-treatment, I wanted to recruit participants who were experiencing that transition at the time of the interviews.

The decision to narrow the focus of the study to only include the above participants did create challenges during recruitment and resulted in a limited sample size. However in order to address the gaps in current field research, I believed it was important to focus on this specific age group, on a population who had not experienced cranial irradiation, and who were currently or had recently experienced the transition from treatment to post treatment.

Since this study aims to understand participant experiences in cancer survivorship the research design depends primarily on self-reporting by participants themselves. Semi-structured interviews, the Piers-Harris, and the ACS – Short rely on the assumption that participants are attempting to answer honestly and are recalling their experiences to the best of their ability. I was in addition able to compare respondents' responses to semi-structured interview questions with data collected from the above questionnaires in order to identify areas of inconsistency in participant responses. For example, if a participant listed that they had no medical concerns on the ACS – Short, yet described their fear of relapse in detail during their interview, this helped to identify areas where participants were better or less able to cope with their main concerns.

In conclusion, although the original research design could not be implemented as it was initially planned, I was able to rework the research design as a small, qualitative study that describes participants' experiences with cancer survivorship and the role schooling played during and after their treatment.

Chapter Summary

This thesis aims to understand the experiences of American adolescents in cancer survivorship. The term "cancer survivorship" will be used throughout this thesis to describe life after diagnosis, including treatment, for adolescents who are cancer survivors. To differentiate between the time during treatment and the time after treatment, I will use the terms "during treatment" and "post-treatment." Both the types of cancer and the types of treatment can affect patients differently. While common symptoms and side effects may be similar across patients, their experiences of how their lives are affected and how they choose to cope with cancer survivorship differ.

The following chapters explain and discuss the literature in the field, the research methodology, the research findings, and discuss the findings and conclusions in detail with regard to the research questions. The intention of this research project is to investigate the challenges of cancer survivorship for adolescents, understand the role that school plays for high school students in cancer survivorship, and determine whether policy is being implemented in a way that the participants would describe as successful.

CHAPTER 2

Effects of Cancer and Treatment

Introduction

The previous chapter explained how quality of life can be assessed by gathering data on the familial, social, physical, psychological, and educational experiences of adolescents with cancer. It also defined "cancer survivorship" and explained the most common types of cancer, the treatments for cancer, and the stages of cancer.

This chapter will present and review current literature on the effects that cancer and treatment can have on an adolescent patient in cancer survivorship. A cancer diagnosis poses specific challenges for patients who have been diagnosed during adolescence. The lingering physical and emotional effects that influence an adolescent's daily life contribute to overall quality of life. These lingering residual effects, often called "late effects," are physical, psychological, or developmental sequelae that continue more than two years since treatment has stopped. Since adolescence is a time that carries with it numerous physical, mental and emotional changes as the child transitions into adulthood, adolescent development tasks can also be affected by a cancer diagnosis and treatment.

The literature presented in this chapter will first discuss the residual effects of cancer and treatment with regard to quality of life. Next it will present literature regarding psychological functioning in cancer survivorship; this section will specifically focus on the incidence of posttraumatic stress disorder (PTSD). Then the review will present and discuss literature regarding cancer and treatment effects on adolescent development. Finally, I will discuss the gaps in the literature that need to be addressed with more research, as well as how the current study attempts to fill these gaps.

Residual Effects of Cancer and Treatment

This section will first present literature on how the residual effects of cancer and treatment can affect the physical and psychological aspects of health for young adult survivors of cancer. This section will also address how the residual effects of cancer and treatment can influence quality of life for young people in cancer survivorship. A cancer survivor may experience late effects depending on their disease, age at diagnosis, sex, treatment, genetic predisposition, and complications during treatment (Keene, Hobbie, and Ruccione; 2006). Late effects may include impaired fertility, increased risk of developing a second cancer, heart or lung problems (due to specific chemo or radiation treatment to the chest), hearing or vision problems (due to specific chemo or radiation treatment to the head), problems with other organs, pain or swelling in parts of the body, and hormone deficiencies (American Cancer Society, 2014). These physical effects can have an impact on daily life for cancer survivors, thus affecting overall quality of life.

Schwartz, Mao, DeRosa, Ginsberg, Hobbie, Carlson, Mougianis, Ogle, and Kazak (2010) investigated the self-reported health problems of young adult cancer survivors aged 16 to 29 years old in clinical settings in comparison to healthy controls. The researchers sampled 156 survivors and 138 healthy controls using the Health Knowledge Inventory (HKI), which measures health problems in three ways: knowledge of disease and treatment, perceptions of treatment and late-effect severity, and current medical problems. Schwartz et al. (2010) found that cancer survivors reported growth, hearing, thyroid, kidney, liver, immunologic, heart, and fertility problems almost four times more than healthy controls; however dermatological, gastrointestinal, bone and joint, weight, sleeping, and psychological problems were reported with equal frequency among the groups. The authors concluded that the problems reported by both groups are due to common challenges associated with the developmental stage of young adults. Schwartz et al. (2010) recommend that young adult cancer survivors should receive consistent follow-up care since the medical problems they are more likely to experience (cardiac, pulmonary, reproductive, vision, thyroid, kidney, growth, and bone and joint health problems) tend to require major medical interventions.

Schwartz et al. (2010) conducted a comparative study in an effort to improve survivor care by outlining how young adult cancer survivors differ from healthy controls. The study aimed at informing general practitioner treatment of medical conditions of survivors by developing distinctions between symptoms that are or are not cancer-related. However, while the study clearly articulated physical problems as reported by participants, the study did not clearly outline the associated psychological problems. While the authors briefly included examples of psychological problems as “cognitive, depression, and posttraumatic stress” (p.306), the data analysis did not include information on how many participants experienced cognitive problems versus depression or PTSD.

Another limitation of this study was the age range of the sample population. Health problems experienced by a 16-year-old in the midst of puberty may differ from those of a young adult in their late 20s. Including a large age group within a transitional developmental stage can provide inconsistent data since a 16-year old participant is closer to childhood and a 29-year-old participant is closer to adulthood, thus experiencing different bodily changes and possible health problems.

Furthermore in order to be eligible for the study, the participants had to be more than five years since diagnosis (and diagnosed before age 21) and more than two years since completion of treatment; meaning that participants who were 14 years old were at most 9 years old at the time of diagnosis and at most 12 years old at the time treatment was stopped. The cancer experience of being diagnosed at 9 years old might be expected to differ significantly from being diagnosed at 20 years old, since childhood cancers carry a different set of developmental and health challenges. Despite the vast age range of this study, the authors' recommendation that survivors require consistent follow-up care is widely accepted by other researcher in this field.

Quality of Life

Physical late effects can influence how a survivor views their daily life in terms of overall quality of life, self-perception, and how they feel amidst their peers. When receiving treatment for a major chronic illness, quality of life is often affected due to the severity of both the symptoms of the disease and the treatment. In order to fully understand the impact on quality of life of adolescents, data regarding their familial, social, physical, psychological, and educational experiences is important. Davis, Nicola, Waters, Cook, Gibbs, Gosch, and Ravens-Sieberer (2007) investigated why children and their parents report different health-related qualities of life. The study sampled 15 parent-child pairs. The researchers conducted qualitative interviews at the parents' homes and asked participants to complete a health-related quality of life questionnaire known as KIDSCREEN. KIDSCREEN is a generic health-related quality of life questionnaire that has been developed across 13 European countries targeting children and adolescents, aged between 8 and 18 years old. Davis et al. (2007) used the 27-item version of KIDSCREEN measuring physical wellbeing, psychological wellbeing, autonomy and parents, social support and peers and school environment.

Davis et al. (2007) found that parental views of quality of life are only moderately correlated with children's views on quality of life because parents and children often based their answers on different experiences. They also interpreted events differently, therefore leading to different responses. These varying perspectives between parental views on assisting their child to achieve some quality of life and children's views on their own quality of life demonstrated the challenges involved in helping an ill child achieve positive quality of life. Davis et al. (2007) concluded that their findings had significant implications in terms of parent proxy on medical decisions for the child if the parent does not fully understand their child's own view of their quality of life.

These findings raise another question as to whether a child is able to comprehend and assess their own quality of life so that it can be accurately described to parents and health care providers. Varni, Limbers, and Burwinkle (2007) conducted a literature review focusing on the ability of pediatric oncology patients to self-report with specific regard to quality of life self-reports. While no empirical study was conducted, Varni et al. (2007) reported that children as young as five years old understood the concept of quality of life and were able to accurately express their views regarding quality of life when an age-appropriate measurement was utilized. If children can validly articulate their perceptions of quality of life during and after cancer treatment, then they can work together with health care providers and carers to successfully manage it. Varni et al. (2007) recommended researchers utilize self-reporting measures to assess pediatric patient and survivor quality of life. They also suggested that parent-proxy should not be used in substitution for child self-reporting, except in instances of severe illness or impairment.

Physical effects, psychological distress, and social interactions can also influence a survivor's overall quality of life. Zebrack and Chesler (2002) conducted an empirical study focusing on quality of life in 176 childhood cancer survivors. Participants were between the ages of 16 and 28, and were five, ten and fifteen years since receiving cancer treatment at the time of the study. Using the Quality of Life – Cancer Survivors scale, the authors found that physical side effects of treatment faded after treatment was stopped. The scale is a 41-item visual analogue scale that assesses the participants' physical, psychological, social and spiritual well-being, as well as distress and fears. The authors reported that childhood cancer survivors have a strong ability to cope, but also tend to be uncertain of their future and fearful that their cancer may return. The authors also found that strong social support tended to be related to instances of higher quality of life. Although social support played a significant role for those who expressed a higher quality of life, Zebrack and Chesler (2002) concluded that current physical health has the greatest potential to influence overall quality of life.

In summary, the above findings promote the importance, in the case of adolescent and young adult survivors, of awareness of possible late effects and of the management of follow-up appointments as needed. Research by Zebrack and Chesler (2002) concluded that a longitudinal study would more accurately address survivor quality of life because it would enable a focus on how cancer symptoms and treatment effects dwindle over time. A comparative, longitudinal study would also clarify the role that development plays in affecting quality of life for this age group, as well as pinpoint late effects that are cancer-specific. As outlined above, Schwartz et al. (2010) conducted a comparative study that also addressed developmental changes versus residual effects of cancer for child and adolescent cancer survivors. This confirmed the importance of longitudinal research in this field. However, Schwartz et al. (2010) and Zebrack and Chesler (2002) did not use a longitudinal methodology, and therefore despite hypotheses made in the literature, neither study provided conclusive evidence on whether physical residual effects dwindle over time.

Davis et al. (2007) and Varni et al. (2007) reported the benefits of self-reporting measures within research into the experiences of cancer patients and survivors and how such experiences shape quality of life. While the current study was unable to employ a longitudinal design due to research constraints, self-reporting measures were chosen in order to collect data on the physical and psychological experiences of adolescents in cancer survivorship.

Psychological Functioning and Posttraumatic Stress Disorder (PTSD)

Woodgate described adolescent cancer as a “powerful life event that causes children and families to face many challenges including uncertainty, changes and restrictions in the daily routine, increased psychological and physical work, lengthy and intense treatment regimens, and multiple losses” (p. 9, 2005). Woodgate conducted a longitudinal study into adolescent experiences with cancer. Fifteen participants between the ages of 12 and 18 years old were interviewed through open-ended interviews, observed, and participated in focus groups. Woodgate reported her findings under three theoretical categories, namely (1) being in the world, (2) being almost the same person, and (3) being treated as the same person, but also special.

'Being in the world' meant that participants took on various and sometimes multiple personas that the author listed as the klutz, the prisoner, the invalid, the alien, the zombie, and the kid (Woodgate p. 11, 2005). These personas stemmed from feeling physically unreliable and having a body that would not cooperate due to shaking hands or weak muscles (the klutz); feeling dependent and needing help with the simplest of tasks (the prisoner); feeling intense sickness either from symptoms or treatment (the invalid); feeling as though they were not themselves due to hair loss, puffy face, weight loss or gain, and general strangeness (the alien); feeling fatigue due to the severity or long-term severity of feeling symptoms of treatment (the zombie); and feeling minimal symptoms or limitations of treatment or symptoms (the kid). Participants also felt as though they were the same person, but an altered version of their original selves. This can come from residual effects such as amputation and redefining their sense of self as an amputee, or from having minimal residual effects and feeling an optimistic and positive outlook on life as a result of surviving cancer. Lastly, Woodgate (2006) found that participants wanted to be treated as the same person they were before diagnosis; however at times, they also wanted to receive special treatment.

Woodgate (2006) concluded that cancer and treatment considerably affected an adolescent patient's sense of self. She recommended that nurses and other support personnel raise awareness of the psychological challenges that accompany a cancer diagnosis and treatment so that adolescents were supported in surviving cancer and treatment with a strong sense of self. As recommended by Schwartz et al. (2010) and Zebrack and Chesler (2002), Woodgate focused on a longitudinal study to assess psychological effects of cancer and treatment for adolescents over time. Unlike Schwartz et al. (2010) and Zebrack and Chesler (2002), Woodgate's study focused on adolescents within a narrower age range, which addressed the development challenges that adolescents experience in the midst of puberty.

Stam, Grootenhuis, and Last (2001) conducted a literature review of the social and emotional adjustment of childhood cancer survivors. Their literature review assessed study findings with regard to emotional and socio-behavioral adjustment while also accounting for factors such as demographics, diagnosis and treatments experienced, social support, coping, and family functioning. Stam et al. (2001) found that childhood cancer survivors did not differ from healthy controls in psychological adjustment; however, survivors did experience challenges in social functioning at the time treatment ended. Longitudinal studies included in the literature review indicated a decrease in psychosocial functioning challenges over time, suggesting that survivors became more adjusted as the effects of cancer and treatment fade. These findings suggest that initial reintegration post treatment is difficult for patients transitioning to survivorship; however it did not discuss interventions or recommendations for further study in order to aid patients in this transition process. These findings confirm the recommendations made by Schwartz et al. (2010) and Zebrack and Chesler (2002) that a longitudinal study can best capture the challenges cancer survivors experience over time.

Greenberg, Kazak, and Meadows (1989) investigated psychological functioning in cancer survivors and their parents. The researchers sampled 138 survivors and 92 controls. Greenberg et al. (1989) used the Piers-Harris Self-Concept Scale, the Nowicki-Strickland Locus of Control Scale, the Children's Depression Inventory (CDI), the Derogatis Stress Profile (DSP), and the Family Environment Scale (FES) as measures for the study. The Nowicki-Strickland Locus of Control Scale is a measure that assesses the extent of control participants feel they have over situations in their life. The CDI is a 27-item self-report measure for ages 7 to 17 years old that assesses the severity of depression symptoms in children. The DSP is a 77-item self-report questionnaire that measures stress levels in participants. Greenberg et al. (1989) found that although survivors showed lower self-concepts, they functioned within normal limits. There was no significant difference in depression scores between survivors and healthy controls. However severe late effects in participants resulted in low self-concept, and a higher incidence of depression. For those participants who experienced severe late effects, the authors recommended continuous interventions.

Greenberg et al. (1989) did not provide details in their recommendations as to what continuous interventions might look like. The age of the study is also limiting since more research since this study was published has been carried out into psychological assessments and possible interventions. However, the study focuses specifically on self-concept and instances of depression, which when considering Woodgate's description of adolescent cancer as a "powerful life event" (p. 9, 2005), might be expected to have uncovered higher instances of depression. Almost a decade later, Noll, MacLean, Whitt, Kaleita, Stehbens, Waskerwitz, Ruymann, and Hammond (1997) also studied behavioral adjustment and social functioning in childhood leukemia survivors between the ages of 5 and 15 years old. The researchers sampled 126 survivors of Acute Lymphoblastic Lymphoma (ALL) using the Child Behavioral Checklist (CBCL) and the Personality Inventory for Children (PIC), as completed by parents and teachers. Noll et al. (1997) found similar results to Greenberg et al. (1989), namely that survivors scored similar to the norm when assessed by parents and teachers. Treatment, including chemotherapy and radiotherapy, did not affect behavioral adjustment and school functioning for survivors of ALL.

These findings are disputed by Davis et al. (2007), who concluded that parents based their responses on quality of life measure on different interpretations and experiences than their child, thus providing different responses to that of their child. While the Davis et al. (2007) study focused on reports of quality of life, it is possible that parental responses on the PIC could indicate different results than if the researchers had utilized self-report measures by the children and adolescent respondents. It is also possible that parents may be projecting feelings of hope into their responses. Parents may wish that their child or adolescent with cancer is psychologically and emotionally unaffected by their illness and treatment, and respond in the spirit of that hope. Another explanation could be that parents have adjusted to caring for their child with cancer and do not perceive behavioral problems as parents of healthy children may perceive them. Due to the cancer diagnosis, parents of children and adolescents with cancer may provide their child with more behavioral allowances, using the cancer diagnosis to excuse abnormal behaviors.

While teachers can complete the measures based on present observations of the student with cancer, the data gathered from teachers cannot be used in making a comparison to student behaviors prior to diagnosis. Since they may not have known the child prior to cancer treatment, they would therefore have no basis to ascertain whether the child's behavior has been affected by their cancer experience. Also, teachers only see children and adolescents for a portion of the day and can only respond with regard to the participant's behavior while in school. Lastly, since the measures used in the study are behavioral, and not cancer specific, most mainstream teachers have only basic knowledge regarding cancer and treatment, and would not be aware of what behavioral or psychological changes to look for in the student in cancer survivorship.

Newby, Brown, Pawletko, Gold, and Whitt (2000) investigated social skills and the psychological adjustment of survivors. The researchers sampled 42 survivors from a follow-up clinic at a university medical center. Newby et al. (2000) created a disease severity index based on a literature review and input from two oncologists. It focused on four components of treatment history, medical and psychological late effects, the doctor's assessment of the diagnosis, and treatment variables. Scores on the disease severity index ranged from 4 (mild) to 12 (severe). The researchers also used the FES, the CBCL, the Teacher Rating Form (TRF), and the Social Skills Rating Form (SSRS) to assess the social skills for this population. The SSRS is a questionnaire that assesses children who have problems with behavior and interpersonal skills.

Newby et al. (2000) found that survivors exhibited normal social behavior and few behavioral problems in comparison to their healthy peers. The researchers also found that as more time passed since the last treatment, there was less concern for possible relapse and thus a better psychological adjustment by the survivor. Similar to the Noll et al. (1997) study, Newby et al. (2000) had only sampled parents and teachers regarding survivors' psychological and socio-behavioral adjustment. The authors recommended that future studies include a multi-informant sample to understand the full range of adjustment for young cancer survivors by including self-report measures to be completed by survivors themselves. Furthermore, while the findings indicated that young cancer survivors were within the normal range of psychological adjustment in comparison to peers, the authors stressed the importance of understanding the mild symptoms of PTSD in cancer survivors so that interventions could be applied to those who are at-risk (Newby et al., 2000). This recommendation might have had wider implications for research in this field if survivors, especially those older than the age of five years, were included in the assessment of psychological adjustment and quality of life (Varni et al., 2007).

PTSD is regularly associated with soldiers, war veterans, and victims of traumatic incidents such as severe abuse and rape; however it can occur in anyone who has experienced a highly traumatic event, particularly events pertaining to life or death. Cancer survivors can suffer from PTSD because of the psychological and emotional trauma that can occur from experiencing the harshness of both cancer and treatment. According to The American Society of Clinical Oncology's (ASCO) patient information website, feelings of anxiety, including worry and fear, are considered normal for cancer patients. If these feelings increase over time or interfere with daily life, they may be considered a symptom of PTSD. Symptoms of PTSD in cancer survivors may also include nightmares, avoidance strategies, strong feelings of guilt or hopelessness, trouble sleeping or concentrating, continuous anger, loss of interest in activities, self-destructive behavior, substance abuse, and difficulty feeling emotions (Cancer.Net Editorial Board, 2013).

Butler, Rizzi, and Handwerger (1996) investigated PTSD in pediatric cancer patients and survivors. They sampled the parents of 42 survivors and the parents of 30 patients still in treatment using the CBCL, the Personality Inventory for Children – Revised (PIC-2), and the PTSD Symptom Scale (PSS), which is a 17-item self-report questionnaire modified for their study to apply to cancer sufferers and survivors. The researchers recruited the parents of children from four treatment subgroups in order to explore whether the type of treatment affected the incidence of PTSD. The four subgroups included those who received cranial irradiation and chemotherapy, those who received only chemotherapy, those who had CNS cancer, and those who did not have CNS cancer. The researchers hypothesized that while the diagnosis plays a role in the incidence of PTSD, it is also the severity of invasive treatment that can affect the incidence of PTSD. Butler et al. (1996) found no significant differences in the incidence of PTSD across treatment subgroups; so from the parental perspective, there was no significant difference between the incidence of PTSD in survivors and the incidence of PTSD in patients.

A possible limitation of this study is the division of treatment subgroups. Cranial irradiation and chemotherapy are both types of treatment; however, CNS cancer and non-CNS cancer are both types of diagnoses. Particularly those patients and survivors who fit within the CNS cancer subgroup, might be expected to overlap with either the cranial irradiation and chemotherapy or only chemotherapy subgroups. The research findings did not report on the usefulness of the division of subgroups. Also like the findings presented by Noll et al. (1997), this study collected data from parents only and did not include any self-report measures to assess patient and survivor PTSD. As outlined above, the use of self-reporting measures to understand the experiences of a child or adolescent in cancer survivorship is highly recommended (Davis et al., 2007; Varni et al., 2007). Also, the PIC-2 is a measure for children only as young as age 5 while the authors used it in this study for participants as young as age 3. Therefore, the data collected using the PIC-2 from participants aged three and four years old may have limited validity.

Furthermore, Butler et al. (1996) included families whose child received cranial irradiation treatment, as well as those who were diagnosed with central nervous system (CNS) cancers. The researchers may have done so in order to investigate the differences between these diagnoses and treatments. Nevertheless, it is difficult to group patients with CNS cancers and cranial irradiation treatment with patients who have had other types of cancer and received chemotherapy treatment, because CNS cancers and cranial irradiation treatment can severely affect the human body in ways that chemotherapy treatment does not. A patient or survivor who has been diagnosed with a CNS cancer may have experienced severe side effects, including severe pain, paralysis, blindness, numbness, and limited motion, function, and sensation (Keene et al., 2007). A patient or survivor who has received cranial irradiation treatment has likely experienced cognitive delays, impaired skull growth, an expressionless face, impaired judgment, and seizures (Keene et al., 2007). Including participants who have experienced CNS cancer or cranial irradiation treatment in a study that also included patients with blood cancers and chemotherapy treatments may confuse study findings. While these two subgroups are often used in comparative research studies, Butler et al. (1996) does not clearly define the participant treatment subgroups. Therefore it is unclear whether the researchers are attempting to make a comparison of the types of treatment, or the comparison of patients to survivors, or both.

Pelcovitz, Goldenberg-Libov, Mandel, Kaplan, Weinblatt, and Septimus (1998) studied PTSD and family functioning in adolescents with cancer. They sampled 23 cancer survivors, 27 physically abused adolescents, and 23 healthy controls. Participants were between the ages of 13 and 23 years old. The authors hypothesized that adolescents with cancer would be more at risk of PTSD than those who have been victims of physical abuse, arguing that incidences of violence are intermittent while the experience of cancer and treatment is chronic. They also investigated family functioning to determine whether a cohesive, family support system could deter symptoms of posttraumatic stress. Measures used included the Parental Bonding Instrument (PBI), a 25-item retrospective questionnaire completed by participants over 16 years of age regarding how they remember their parents during their first 16 years; the Family Adaptability and Cohesion Evaluation Scale III (FACES III), a 30-statement questionnaire that asks family members to comment on relationships and attitudes to family life; a Structured Clinical Interview for PTSD, the SCL-90-R; and the GSI. Pelcovitz et al. (1998) found that there was a higher incidence of PTSD in cancer survivors than in abused adolescents or controls. Survivors' parents were more protective when compared to parents in the other groups. No significant differences between the subgroups were found in perceived family adaptability and cohesion; however, when comparing the adolescents with cancer who met the criteria for PTSD to those with cancer who did not, the adolescents with PTSD viewed their families as, "significantly more chaotic" than those who did not have PTSD (p. 216).

Despite the age of the study, Pelcovitz et al. (1998) have made a unique contribution to research by investigating PTSD in cancer survivors and PTSD in abused adolescents, which is a perspective that no other study had attempted at the time this was published. While the majority of adolescent cancer survivors do not experience symptoms of PTSD, this study has shown that PTSD is a possible late effect of the disease and treatment. Pelcovitz et al. (1998) recommended that more research should be conducted in comparing the two sample groups to control groups and to assess the role of family support. However, the authors also cautioned that in order to avoid possible research bias future research should recruit participants from similar demographic backgrounds.

Hobbie et al. (2000) investigated the symptoms of PTSD in young adult survivors of childhood cancer. The researchers sampled 78 survivors of childhood cancer, aged 18 to 40 years old, using the Impact of Event Scale (IES), a self-report measure designed to assess current subjective distress for any specific life event, in this case, a cancer diagnosis; PTSD Reaction Index, a 48-item semi-structured interview that assesses exposure during childhood to 26 types of traumatic events; the State-Trait Anxiety Inventory (STAI), which measures anxiety in adults; the Structured Clinical Interview for DSM III (SCID), a diagnostic tool used to diagnose mental and personality disorders; the Assessment of Life Threat and Treatment Intensity Questionnaire (ALTTIQ), which includes seven parallel questions on parent and child forms, with responses on a 5-point Likert scale; the Brief Symptom Inventory (BSI-18), which measures psychological distress and psychiatric disorders in medical populations in participants who are 18 years or older; the Intensity of Treatment Rating (ITR); and the Medical Sequelae Rating.

Hobbie et al. (2000) found that one-fifth of the young adult survivors of childhood cancer met criteria for a diagnosis of PTSD. This was an increased incidence of PTSD from the levels reported in younger survivors. The authors concluded that dependence is less likely for this age group. When the patient was receiving treatment as a child, the parents were responsible for the child's health. Subsequently as the patient ages, maintaining good health becomes the patient's responsibility. Experiencing the added daily responsibility of maintaining their health, young adult cancer survivors felt more stress. Hobbie et al. (2000) also concluded that young adult survivors had ongoing fears that their lives were still in jeopardy. This experience could be different from younger groups because medical advances and awareness of issues have changed as time has progressed. The medical treatment that a 20-year-old childhood cancer survivor experienced will be different from the medical treatment that a 40-year-old childhood cancer survivor experienced. The researchers recommended that health care providers were aware of and paid attention to symptoms of PTSD to avoid ongoing cancer-related distress.

In order for health care providers to assess the incidence of PTSD in childhood and adolescent cancer survivors, they must be aware of the symptoms and instances or experiences that may trigger symptoms of PTSD. Stuber, Kazak, Meeske, Barakat, Guthrie, Garnier, Pynoos, and Meadows (1997) investigated the effect of general anxiety, treatment intensity, and posttraumatic stress in cancer patients and survivors focusing on the predictors of PTSD symptoms in childhood cancer survivors. Stuber et al. (1997) recruited 186 survivors aged 8 to 20 years old using the Revised Children's Manifest Anxiety Scale (RCMAS), a self-report questionnaire that measures the level and nature of anxiety for children and adolescents aged 6 to 19 years old; the Social Support Rating Scale, a self-report scale that measure the amount of social support experienced by the participant; the PTSD Reaction Index; the ALTTIQ; the ITR; and Severity of Medical Late Effects.

Stuber et al. (1997) found that predictors of PTSD in childhood cancer survivors included whether they feel life threats during treatment and the severity of treatment, their general level of anxiety, a history of stressful experiences, time since treatment, whether female, and familial and social support. The authors were able to conclude that PTSD symptoms improved over time, but they did not account for interventions that survivors may have employed, such as therapy or medication. While symptoms reported were mild, the authors recommended that children with cancer received good medical care and were well informed as procedures and treatments improved. These recommendations date the study since the recommendation for “good” pediatric care is a current priority for oncologists treating children with cancer by focusing on consistent follow-ups, the presence of psychological interventions being available, and promoting social support interventions. Patient awareness and strong doctor-patient communication has been promoted since this study was published (Schwartz et al., 2010, Davis et al., 1997; and Woodgate, 2005).

Episodes of PTSD are often triggered during stressful situations. A stressful situation may include something as simple as driving near the hospital where the survivor had received treatment, thus triggering memories of going to the hospital for treatment, or it may be something more complex and the survivor may be experiencing symptoms of relapse, which prey on the survivor's fears and anxiety of their cancer returning. Varni, Katz, Colegrove, and Dolgin (1994) investigated stress and adjustment of long-term, young adult cancer survivors. They recruited 39 survivors aged 13 to 24 years old using the Adolescent Perceived Events Scale (APES), which measures major and daily stressful events during adolescence; the Symptom Checklist 90-Revised (SCL-90-R), which is a 90-item, 5-point Likert scale for participants over the age of 13, and measures a range of psychological problems; the Global Severity Index (GSI), which measures overall psychological distress levels in participants over the age of thirteen, and the Self-Perception Profile for Adolescents (SPPA), which measures self-perception in eight domains and provides an overall profile of self-worth.

Varni et al. (1994) found that higher perceived stress predicts increased psychological distress and lower self-esteem. Psychological distress was also positively correlated with age and type of diagnosis. Leukemias such as ALL[1] and

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[1] Acute Lymphocytic Leukemia

AML[2] resulted in significantly higher psychological distress than other types of cancer. The authors recommended stress management interventions to help cancer survivors improve their quality of life. The authors however did not address whether incidences of stress directly contributed to symptoms of PTSD.

A later study by Kazak, DeRosa, Schwartz, Hobbie, Carlson, Ittenbach, Mao, and Ginsberg (2010) compared survivors of childhood cancer to healthy controls with regard to psychological outcomes and health beliefs. They sampled 167 survivors and compared them to 170 healthy controls. Participants were given the BSI-18, the PTSD Checklist-Civilian Version, the Short-Form Health Status Questionnaire (SF-36), and the Health Competence Beliefs Inventory. The PTSD Checklist-Civilian Version is a 17-item Likert scale questionnaire. The SF-36 is a short-form generic health survey with 36 questions. It is intended to estimate disease problems and compare disease-specific benchmarks with general population norms. The Health Competence Beliefs Inventory is a 21-item questionnaire that measures adolescent and young adult perceptions of health and well-being.

Kazak et al. (2010) found no significant differences between survivors and healthy controls in psychological distress or quality of life; however, adolescent survivors had significantly greater psychological distress than childhood cancer survivors and exhibited more symptoms of PTSD and heightened emotional arousal. Furthermore, high treatment intensity also led to greater anxiety and fewer positive health benefits. The authors concluded that “while most survivors are psychologically resilient, disease-related variables readily known to care providers

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[2] Acute Myelogenous Leukemia

can help to identify the significant minority of those at risk for difficulties with psychosocial functioning” (p. 2006-7; 2010).

The Kazak et al. (2010) study made a comparison of childhood and adolescent cancer survivors with control group, which was a recommendation for future research in Pelcovitz et al.’s 1998 study. While the above studies vary in terms of sample groups and methodologies, there is a consensus that survivor’s psychological adjustment fall within a normal range and that survivors in general do not differ from healthy controls (Newby et al., 2000; Greenberg et al., 1989; Stam et al., 2001; Noll et al. 1997; Kazak et al., 2010). In some cases, survivors do experience symptoms of PTSD after cancer treatment (Hobbie et al., 2000; Pelcovitz et al., 1998), however symptoms reduce as time passes since treatment stops.

Cancer in Adolescence

This section will present and discuss research that focuses on the impact cancer can have when it occurs during adolescent development. Adolescence is the transition from childhood to adulthood. By looking at what adolescence involves for healthy children, the effect of cancer on this age group becomes more evident. Woodgate (2006) made the claim that adolescents are more affected by cancer and treatment because it targets how they view themselves and create their identity during development. Adolescent survivors also exhibit greater psychological distress and more symptoms of PTSD in comparison to their healthy peers (Kazak, 2010).

The American Academy of Child and Adolescent Psychiatry (AACAP) defines three main stages of adolescent development. Table 2.1 outlines the physical, cognitive, and social-emotional development for the three stages of adolescence: early, middle, and late.

Table 2.1 Stages of Adolescent Development

Stages of Adolescence	Physical Development	Cognitive Development	Social-Emotional Development
Early Adolescence Approximately 11 – 13 years of age	• Puberty: grow body hair, increase perspiration and oil production in hair and skin, Girls – breast and hip development, onset of menstruation Boys – growth in testicles and penis, wet dreams, deepening of voice • Tremendous physical growth: gain height and weight • Greater sexual interest	• Growing capacity for abstract thought • Mostly interested in present with limited thought to the future • Intellectual interests expand and become more important • Deeper moral thinking	• Struggle with sense of identity • Feel awkward about one's self and one's body; worry about being normal • Realize that parents are not perfect; increased conflict with parents • Increased influence of peer group • Desire for independence • Tendency to return to "childish" behavior, particularly when stressed • Moodiness • Rule- and limit-testing • Greater interest in privacy
Middle Adolescence Approximately 14 – 18 years of age	• Puberty is completed • Physical growth slows for girls, continues for boys	• Continued growth of capacity for abstract thought • Greater capacity for setting goals • Interest in moral reasoning • Thinking about the meaning of life	• Intense self-involvement, changing between high expectations and poor self-concept • Continued adjustment to changing body, worries about being normal • Tendency to distance selves from parents, continued drive for independence • Driven to make friends and greater reliance on them, popularity can be an important issue • Feelings of love and passion increase
Late Adolescence Approximately 19 – 21 years of age	• Young women, typically, are fully developed • Young men continue to gain height, weight, muscle mass, and body hair	• Ability to think ideas through • Ability to delay gratification • Examination of inner experiences • Increased concern for future • Continued interest in moral reasoning	• Firmer sense of identity • Increased emotional stability • Increased concern for others • Increased independence and self-reliance • Peer relationships remain important • Development of more serious relationships • Social and cultural traditions regain some of their importance

Adapted from the American Academy of Child and Adolescent Psychiatry's Facts for Families. **© All rights reserved. 2008**

A cancer diagnosis can thwart the typical stages of adolescent development as the effects of treatment begin to take hold. Physically, cancer can have the opposite effect on typical expectations associated with adolescent development. It can stunt growth, delay puberty, and cause drastic weight fluctuations. As a possible consequence of the physical effects of cancer adolescent cancer patients may struggle with self-concept, particularly with worrying about being normal and continued adjustment to a changing body. Negative self-concept may also influence social interactions in maintaining friendships and concerns with popularity. Therefore by late adolescence, patients who have successfully survived cancer may experience a stronger sense of identity and may place more importance on social and cultural aspects than their healthy peers.

During adolescence, a desire for independence results in making choices that create distance from parents. When a cancer diagnosis is introduced into the adolescent's life, the desire for independence may still exist, but the ability to be independent is almost impossible due to the physical constraints of the illness and treatment. Adolescents require regular assistance throughout treatment from doctors and parents. Since cancer is a "powerful life event" (Woodgate, p. 9; 2005), it can affect the normal process of adolescent development.

Zebrack and Isaacson (2012) conducted a review of the literature focusing on cancer in adolescence. They reported that adolescents were more likely to exhibit symptoms of anxiety and distress in comparison to children with cancer due to having the cognitive capacity to understand the severity of their illness. Also physical changes such as hair loss, weight fluctuations, scars, and amputations, made survivors' difference from healthy peers more apparent. Zebrack and Isaacson (2012) concluded that feeling different from peers could result in an altered sense of identity and low self-esteem, which could hinder adolescent development.

Nevertheless, facing these physical challenges may promote acceptance and incorporation of the changes into a new definition of normal for the patients' and survivors' everyday life (Zebrack & Isaacson, 2012). As adolescents with cancer are forming their identity for adulthood, they are incorporating their cancer survivorship into who they will become as adults. Concerns for the future remain prominent amongst adolescent cancer survivors. Survivors exhibit fears of relapse, future health problems, career and job challenges, and relationship challenges. Zebrack and Isaacson (2012) recommended adolescent cancer survivors engaged in support programs and interventions as needed. The authors also recommended young adult survivors of adolescent cancer participated as volunteers in these programs so that they could offer first-hand experience and advice to adolescents who were currently experiencing the transition from patient to survivor.

Unfortunately, not all survivors may be equipped to act as a volunteer for current patients, since one of the main symptoms of PTSD is re-experiencing the stressful event. This often happens through recurring nightmares, flashbacks and frightening thoughts, which can be triggered by words, objects, people, or situations that resemble the original event (U. S. Department of Health and Human Resources). Consequently, it may be controversial to ask young adult survivors of adolescent cancer to volunteer to help adolescents who are currently undergoing treatment. Young adult survivors of adolescent cancer that volunteer for such interventions need to be aware of the possibility of triggering PTSD in themselves as they may re-experience and remind themselves of the stresses they once felt. Conversely, volunteering to help others may help them to face their fears of re-living their experience and help others as well. Zebrack's and Isaacson's (2012) recommendations that volunteers who are survivors make an excellent resource as volunteers, should in practice be approached with caution.

Stiller (1994) published a brief overview of the literature on adolescents with cancer and how they differed from children with cancer, both medically and developmentally. The author called for provisions to be improved in order to address the emotional, educational and social needs of adolescents with cancer to avoid impairment to development; however, this brief overview did not include any information regarding research methodologies, and made reference to a limited range of studies. The recommendation for adolescents to be treated with a "multidisciplinary" approach (p. 1382; 1994), which would include psychological as well as physical treatment, was not based on the literature but came out of a review of practice. At the time this overview was published, the first adolescent oncology unit in Britain had opened four years earlier. Up until that time, adolescents would receive treatment from either pediatric units or adult units. The unit focused on addressing not only adolescent patients' physical health, but their mental health as well.

This resource serves as a reminder of how recently adolescent cancer care has come into focus as being unique to the care childhood and adult cancer patients and survivors receive. It shows that historically in Britain, the primary focus was on childhood cancer care and adult cancer care with little focus on patients who were making the transition as adolescents. Today, switching from a pediatric oncologist to an adult oncologist in the United States can happen when the patient is ready. Most patients switch doctors between the ages of 18 and 21, depending on their physical needs and overall comfort. Since the final stage of adolescence, according to the AACAP table above, occurs between ages 19 and 21, those who switch to adult doctors at 20 or 21 years of age are not uncommon.

The developmental tasks of adolescence do need to be addressed specifically and separately from research conducted into childhood cancer patients and survivors. A literature review conducted by Lewis (1996) on the challenges associated with experiencing cancer in adolescence showed loss of control as a common challenge for adolescents in cancer survivorship. Cancer effects challenge an adolescent's self esteem due to the physical effects from cancer, which can often result in absences in school, thus taking them away from their peers (Lewis, 1996). Having to experience uncontrollable physical effects, an inability to attend school, and an inability to socialize with friends can cause the adolescent with cancer to feel an overall loss of control in their lives. Lewis (1996) also reported that patients feel dependent on parents and healthcare professions for simple tasks, contributing further to a lack of control over their lives during a time when independence is meant to increase. Lewis (1996) stressed the importance of normalcy for adolescent cancer patients, and recommended that restoring normalcy would help them to regain their feelings of control. The author also recommended that health care professionals should be aware of the developmental process of adolescence that may be hindered due to cancer treatment.

Similar to Lewis's (1996) findings, Wicks and Mitchell (2010) conducted a qualitative study that focused on the developmental goals of adolescence during the cancer experience for participants in New Zealand. The authors recruited 10 survivors of adolescent cancer who were between the ages of 16 and 22 years old at the time of the study. Using semi-structured interviews and thematic analysis, Wicks and Mitchell (2010) found two main themes from the participant experiences: loss of control and benefit finding. 'Loss of control' stemmed from the participants' sense of frustration, feeling inadequate or angry, and non-compliance with treatment.

‘Benefit finding’ stemmed from the participants’ view of their improved personal attributes, strengthened relationships, and material gains, such as disability benefits and charitable donations. The authors recommended effective communication, ongoing psychological support, and treatment flexibility to address how participants experienced a loss of control during treatment.

This study was based on a small, non-random sample of participants, which limits the conclusions that can be drawn in terms of the wider population of adolescents with cancer. The authors also did not explain in detail what effective communication looks like in comparison to how participants are currently being informed regarding their illness and treatment. Lastly, recommending treatment flexibility is challenging because the patient’s diagnosis may limit choice as to the type of treatment required, nor would the patient be qualified to make such decisions. By providing patients with recommended options for treatment, it may address their sense of control; however, the side effects of the treatments they choose will likely still make their bodies react in a way that they cannot control. This may result in patient depression, and feeling as though they made the wrong choice.

While Lewis’ (1996) literature review is now dated, the findings and recommendations are strengthened by the qualitative results of Wicks and Mitchell (2010) namely that loss of control is a challenge that adolescent cancer patients face as a part of their experience. Both studies recommended that adolescent cancer patients receive psychological interventions that would aid them in venting frustrations and coping with their feelings. Also, both studies recommended that patients communicate effectively with healthcare professionals to understand what treatment options are part of the decision making process, and thus regain feelings of control. Lewis (1996) stressed the importance of familial and peer support and understanding in an effort to help the patient feel accepted and to maintain social interactions.

D’Agostino, Penney, and Zebrack (2011) presented a lecture at the “International Workshop on Adolescents and Young Adults with Cancer: Towards Better Outcomes in Canada” that focused on how to provide developmentally appropriate psychosocial care to adolescent and young adult cancer survivors. Relying on literature sources and their own practical experience, the authors in their published lecture emphasized the importance of maintaining normalcy. D’Agostino et al. (2011) did not specifically provide a definition for normalcy; however, the researchers stressed that achieving normalcy means that the adolescent with cancer is able to maintain a strong social connection, and is provided with flexible, but practical medical routines that promote a return to school.

Firstly, D’Agostino et al. (2011) recommended that healthcare communication should remain open and should be receptive to the patient’s maturity. This might include the medical professional removing the white coat before entering an adolescent patient’s hospital room to appear more approachable, not disturbing patients when conducting medical rounds during nighttime or early morning hours, and trying to plan treatment around important dates (birthdays, school dances, graduation ceremonies, etc.). Secondly, the authors acknowledged that questioning authority is normal in the development of adolescent patients. Often, this can result in treatment non-compliance when adolescent and young adult patients rebel against taking the proper medication or following treatment protocols. They recommended that health care professionals speak in positives, focusing on what the patient can do, rather than outlining what they cannot. D’Agostino et al. (2011) hypothesized that patients are more likely to stick to treatments if communication between them and the health care professionals is strong. Lastly, the authors stressed the importance of peer relationships and the ability of patients to remain connected to peers. They recommend that hospitals maintain accessible visiting hours, have a space in-hospital for patients to be social with visiting peers (such as a place to watch a movie, listen to music, or kick a ball outside), assisting the patient in maintaining school, and the ability to interact with other adolescent cancer survivors who are approximately the same age.

D'Agostino et al. (2011) concluded that health care professionals who comprehensively understand the tasks of adolescent development and are willing to be flexible and work around the patient's goal for normalcy will be more successful in treating the adolescent with cancer. Although this publication did not include specific methodologies that have been tested by the authors, it did review literature and made recommendations based on literature findings and the authors' own experiences with adolescents and young adults with cancer. The conclusions of D'Agostino et al. (2011) validate those made by Lewis (1994) and Wicks and Mitchell (2010) that communication should remains consistent and open, and that the role of peers is essential in maintaining normalcy. D'Agostino et al. (2011) took these recommendations a step further by providing specific examples of how to execute researcher recommendations in the healthcare setting.

D'Agostino et al. (2011) emphasized the importance of maintaining normalcy throughout cancer treatment to help patients cope with the physical and mental effects experienced. This is especially important during adolescence, when development shapes the identity that the child will grow into as an adult. As reviewed earlier, Zebrack and Isaacson (2012) also discussed how acceptance of the changes experienced in adolescent cancer treatment can be incorporated into adolescent development and contribute to forming a new definition of normalcy for the patient over time.

Zebrack (2011) conducted a literature review on the psychological and social issues adolescents face throughout their cancer experience. Zebrack (2011) posited that especially for patients with severe long-term effects of cancer and treatment (for example infertility, amputation, or visual impairments), acceptance of these effects will help the patient cope and adjust to redefine a "new normal." He reported that identity development occurs within the context of social interactions with peers, which confirms Woodgate's (2005) findings. Although this may be difficult for an adolescent with cancer, who could be physically unable to socially interact with healthy peers, Zebrack (2011) suggested that the perception of strong social support throughout treatment can be a valuable substitution in the absence of social interactions. Social interventions that include fellow cancer patients and survivors provide adolescents with the ability to accept the physical effects from cancer and treatment as normal.

Lastly, Zebrack (2011) reported that a focus on adolescent development can provide the patient with higher cognitive functioning. Zebrack (2011) concluded that social interventions (such as pediatric oncology camps, outdoor adventure programs, and picnics with other adolescents in cancer survivorship) and maintaining a consistent connection to school and peers during treatment can promote acceptance of their new normal. Acceptance of this new normal can promote a sense of control, coping, and adjustment for the adolescent with cancer.

Zebrack's (2011) literature review is thorough and accounts for a wide range of challenges experienced by adolescents with cancer, including physical effects, emotional effects, and social interactions. The research findings confirm the conclusions from Woodgate (2006) in how identity development can be severely affected by cancer and treatment. Where Zebrack (2011) and Zebrack and Isaacson (2012) differ from other literature on this theme is their recommendation on incorporating the cancer experience as a part of identity, thus redefining normalcy for the patient.

Jones, Parker-Raley, and Barczyk (2011) focused on the identity paradox for adolescents with cancer transitioning from patient to survivor. They conducted a qualitative study of 12 adolescents, aged 12 to 20 years old, using semi-structured interviews and thematic analysis. The authors found that participants sought out meaning from their cancer experience, which led them to a higher appreciation for life. This, in turn, led them to focus on personal growth as a part of their adolescent development.

Jones et al. (2011) also discussed the transition from the cancer identity, which is how participants view themselves during treatment, to the survivor identity, which is how the participants view themselves post treatment. In this study, the participants felt conflicting emotions during the transition, including relief that their cancer was gone and fear that it might return. The authors concluded that survivors have a difficult time returning to normal life because they attempt to recover their old identity prior to diagnosis. Survivors eventually incorporate their cancer experience into forming a new identity as a cancer survivor. Jones et al. (2011) recommended that future studies investigate risky behaviors amongst adolescent cancer survivors who may want to revert to the point of development at which they were diagnosed so that they have an opportunity to experience what they may have missed. For example, some young adult survivors of adolescent cancer may want to engage in rebellious behaviors that they may have missed out in due to treatment in an effort to revert to their former identity.

The findings of this study support the findings of Zebrack and Isaacson (2012), Zebrack (2011), and Woodgate (2006). It is clear that some survivors may struggle with the transition from patient to survivor, especially if they do not receive the level of attention, support, and care that they received during treatment. Interventions that will help the adolescent make the transition to survivorship and redefine their new normal may limit distress during development and reintegration to daily life.

In summary, adolescents with cancer are more susceptible to symptoms of PTSD than children or adults with cancer due to the developmental changes they experience at the time of diagnosis and treatment (Hobbie et al., 2000); although the incidence of PTSD is still within normal range (Kazak et al., 2010). Adolescents in cancer survivorship experience a loss of control over their lives, which can hinder the developmental process of gaining independence throughout puberty (Wicks & Mitchell, 2010; Lewis, 1996). The recommendations coming out of the literature suggest that adolescents with cancer and survivors of adolescent cancer be encouraged to accept their experience in an effort to create a new normalcy as part of developmental progress (Zebrack, 2011; Jones et al., 2011; Zebrack & Isaacson, 2012; Woodgate, 2005). The consensus of the literature reviewed above is that this can be achieved by striving for clear, consistent communication between the patient and healthcare professionals who are sensitive to the patient's developmental process, including the patient in treatment decisions to combat treatment non-compliance, and providing social opportunities for patients to interact with peers, as well as survivors and patients of a similar age (D'Agostino et al., 2011). However, further research needs to be done into the effectiveness of these recommendations.

It is easy to believe that the cancer experience has a distinct beginning and a distinct end. This is due to having a diagnosis date and a treatment finish date. It implies that once an adolescent has stopped treatment that he or she is able to reintegrate into the life her or she had prior to diagnosis, thus ending the cancer experience. The term *cancer survivorship* is used in this study to describe life after diagnosis. It includes treatment, post-treatment, and beyond, and represents the idea that once cancer is diagnosed, the patient cannot go back to life as it was before. Understanding cancer survivorship for adolescents will help parents, teachers, and counselors to promote adolescent development among this population.

Chapter Summary

This chapter reviewed current literature that focused on cancer and treatment side effects for adolescents, including residual effects of cancer and treatment, psychological functioning and PTSD, and how adolescent development may be affected by cancer and treatment.

Four main themes arose from the literature: communication and interventions, posttraumatic stress disorder, identity, and normalcy.

In order for a patient or survivor to be able to care for themselves beyond cancer treatment, they must maintain consistent communication with healthcare professionals. Healthcare professionals need to promote clear communication with patients to understand any developmental challenges, late effects, and psychological distress the patients may be experiencing in association with their illness and treatment (Wicks & Mitchell, 2010; Lewis, 1996; D'Agostino et al., 2011, Woodgate, 2005). Once clear and consistent communication has been established between the patient and health care professionals, interventions may be required (Zebrack & Isaacson, 2012; Zebrack, 2011; Stiller, 1994, Kazak et al., 2010, Woodgate, 2005). Interventions can vary from social reintegration efforts, such as pediatric oncology camps, to psychological provisions, such as support groups, depending on the varying needs of adolescent cancer patients and survivors.

Psychological interventions may be necessary to target symptoms of PTSD in adolescent cancer survivors. While numerous research studies conclude that there is no significant difference in PTSD between young adult survivors or patients and healthy controls (Butler et al., 1996; Noll et al., 1997; Greenberg et al., 1989; Kazak et al., 2010), there is a higher incidence in PTSD symptoms specifically in adolescent survivors of cancer, even though the findings are not significant (Pelcovitz et al., 1998; Hobbie et al. 2000; Kazak et al., 2010). Adolescents in cancer survivorship are at-risk from PTSD (Kazak et al., 2010).

The significance of cancer as a life event is magnified if diagnosis occurs during adolescence due to the developmental tasks that are experienced during this life stage. Adolescence is a time when children make the transition into adulthood. In doing so, they create and form the identity of the person they will grow into. Adolescents with cancer face the added challenge of creating an adult identity that includes cancer as a part of who they are (Woodgate, 2005; Zebrack & Isaacson, 2012; Jones et al., 2011; Zebrack, 2011).

Defining identity throughout adolescence is often done through interactions (Zebrack, 2011; D'Agostino et al., 2011). Being able to maintain social interactions during and after cancer treatment, not only helps the patient and survivor form their identity, but it also helps them to regain a sense of normalcy that may have been lost during treatment. Since cancer can be described a significant life event (Woodgate, 2005), survivors are not likely to return to the life they experienced prior to treatment once treatment ends. Instead, adolescent survivors must accept their cancer experience and incorporate it into the development of their identity (Zebrack & Isaacson, 2012; Zebrack, 2011). Once this is done, the survivor will be able to regain feelings of control and normalcy in their lives. It is important to note, that regaining normalcy will likely be redefined to account for the cancer experience, thus creating a new normal (Jones et al., 2011; Zebrack, 2011; Zebrack & Isaacson, 2011).

The physical, psychological, and developmental effects from cancer and treatment can drastically affect an adolescent's ability to function in school. The next chapter will address the importance of school in providing normalcy for adolescents in cancer survivorship. It will include a focus on treatment effects that may hinder intellectual functioning resulting in academic challenges, maintaining attendance during treatment, school behavioral changes, and special educational policies that include student and teacher collaborations and reintegration interventions.

CHAPTER 3

Cancer and Schooling

Introduction

Chapter 2 illustrated the main themes in the research to date regarding the physical, psychological, and developmental effects that cancer and treatment can have on adolescents. It outlined some of the main themes drawn from the literature, including the need for consistent communication and interventions, symptoms of posttraumatic stress disorder, challenges associated with cancer survivorship and developing identity, and regaining a sense of normalcy for adolescents. The chapter concluded that these physical, psychological, and development effects from cancer and treatment could drastically affect an adolescent's ability to function in school. Improvement in healthcare has resulted in a more complex system for transitioning students from the hospital setting to the school setting (Keene et al., 2007). Rather than a child being hospitalized for several weeks, a child with cancer may have one day of hospitalization, followed by outpatient clinic visits. Therefore the level of whole-child care has shifted from hospitals to now include parents, schools, and clinics.

Special education policies in the United States were outlined briefly in Chapter 1 of this thesis. This chapter will illustrate how the special education policies are put into practice for children and adolescents with medical needs. This chapter will also review literature on how the physical and psychological effects of cancer and treatment can affect school reintegration and academic functioning factors such as attendance, cognitive functioning in school, and classroom behavior for children and adolescents during and after cancer treatment.

Special Education Policies in the United States

Policies are created in education in an effort to operate consistently from one institution to the next, across states and districts. One of the most prominent difficulties in instruction is being able to tailor education to the varying needs of individual children. Educational needs vary from teaching basics such as tailoring the lesson to a student's particular learning style (such as visual cues, verbal cues, etc.) in the mainstream classroom to those who require a more specialized education (such as Braille instruction, speech therapy, etc.). Children and adolescents who have a chronic medical condition also require specialized education to aid them in keeping up with their grade level while absent from school or when receiving medical treatment while attending school.

Navigating the System

Keene et al. (2007) outline the necessary steps for families to initiate the process for their child to receive specialized education services. In order for students with a chronic illness such as cancer to have access to these services, they must first be referred to the school principal or counselor. Once the parents or teachers make a referral, the student is evaluated on their specialized needs. With parental consent, a team usually consisting of the teacher, a school district psychologist, a speech and language therapist, and a resource specialist meet to administer and evaluate the testing required. Once the results are received, the parent (and sometimes the student) confers with the team to discuss the results and recommendations. During this meeting, the student's eligibility for special services is discussed, as well as the development of an individualized education plan (IEP), and follow-up assessments and meetings are also discussed.

Children and adolescents with cancer are eligible for schooling with medical approval that they are able to continue their education during cancer treatment. Some may be able to attend mainstream school during treatment. For others, who are admitted to the hospital long-term or are unable to leave their home, some hospitals provide schooling programs to help the students from falling behind academically. Hospitalized children account for less than one percent of all special education students, which includes approximately 65,000 students who are receiving services (Keene et al., 2007). Hospital education is not only for children who are temporarily absent from school due to physical disability or illness, but also for children who are admitted to psychiatric hospitals.

After the doctor has cleared the patient to maintain education during treatment, the parent or guardian would continue the referral for specialized services. Some states such as Washington, for example, require the student to be medically absent and admitted to the hospital for more than four weeks for the child to receive services. In Illinois, a child must be absent and hospitalized for more than eleven school days to be eligible for services. Once the school or district determines that the student is eligible to receive hospital instruction, instruction begins as soon as possible. Teachers from the public school district are placed within hospitals to work with both the hospital and the school to provide the supplementary education for the child. This education in most states is recognized as a "supplementary" education.

Supplementary education is defined in the context of this thesis as schooling that aims to substitute learning outside of the mainstream classroom through tutoring or another form of school, such as Internet or homeschool. It is important to note that this does not necessarily mean providing an education that will continue to advance the student in his or her learning. Although in most cases the aim is to continue to progress education for the student, the special education policies outline that the aim is purely to maintain the knowledge that the student has already learned and is limited to no loss of knowledge. For those educational institutions that choose to meet the basic aim to prevent a loss of knowledge and do not aim to progress further learning for the student, the parents may choose to hire a private tutor or enroll their child into a form of homeschooling to get extra educational support for their child.

There are some challenges within the Home/Hospital programs and policy governed processes. One is that a hospitalized child may want services, and his or her parents may want the child to have services, but if the school or district does not deem that child eligible, then the child will not receive services from the district. This is an example of how parents may choose to progress their child's learning outside of the public school district. For example, parents may hire a private tutor to continue the child's learning, or they may enroll their child in a homeschool or Internet school until the child is eligible to return to the mainstream classroom. For those children who are admitted to a hospital and cannot attend school, many children's hospitals in the U.S. have teachers that operate under the management of the hospital, rather than under an accredited education institution. If the doctor deems the child to be eligible to maintain education during treatment and if the hospital is equipped to provide it to them, then the hospital will provide schooling for the student either bedside or in a hospital classroom. Some hospitals will try to communicate with the child's mainstream schoolteacher to keep the child up to speed with other students in the mainstream classroom.

There is also a challenge in providing for students who attend private schools. The process described above is for children who are admitted to the hospital who attend a public school within the public school district only. If a student is hospitalized and is eligible for education, they cannot receive education unless they are enrolled in a public school within the district of their residence. Parents can either re-enroll their child in a new school upon hospital admittance, they can hire a private tutor, or they can depend on the private hospital teaching program – if the hospital has one, as not all hospitals do. Similarly, if a child is receiving treatment for a chronic illness for an extended period of time at a hospital that is outside the city or state of their residence, the same rules apply as for private school students and the child must be enrolled in a local education institution.

In most hospital teaching programs, either public or private, the students will receive at least one hour of education per day for no more than five days each week. The educational environments vary depending on the amount of education the student will receive according to his or her IEP and the accommodations within the hospital. Some hospitals have teaching centers where children can interact with each other and learn in a classroom format. Other hospitals provide bedside instruction for each student. This is also dependent on the student's health status and whether they are physically able to leave their room.

Access to the information on these programs depends on the state. States that have a higher population and are larger, such as New York and California, provide information on the Home/Hospital program in great detail. Some states with lower populations such as Montana or South Dakota have very limited details on their supplemental education program and also may not have students within the state who require the program. Many states have details on psychiatric hospital schools, but not general children's hospitals.

Lastly, because each state is divided into school districts the Home/Hospital programs can vary further. Once again, the criteria for eligibility to receive education in a hospital will vary depending on both the state and the city. New York City, for example, has a large hospital school program that is governed by one principal and upholds the same standards for all five boroughs protected under the city: Brooklyn, Bronx, Staten Island, Queens, and Manhattan. Children who are hospitalized outside of New York City, for example in a city such as Albany, will not be eligible under this hospital school program. In California, Los Angeles has a different school district program than San Francisco. Students, who are hospitalized and reside in a city that is different from the location of the hospital, will receive the education determined by either the public, government-run school district, the private hospital school, if applicable, or a private tutor hired by the family. It is also important to note that a parent/guardian may tutor the student themselves, or the student and his or her parents will sometimes choose to halt education altogether during treatment, regardless of whether the doctor deems the patient eligible to continue his or her education during treatment.

Individualized Education Plan (IEP)

An IEP is a clearly defined plan for parents and teachers to identify, assess, and communicate the specific needs of a child when special instruction is necessary (Keene et al., 2007). All special education students have an IEP that can be used from teacher to teacher to provide continuous instruction, given the needs of the child. Generally, an IEP will include parental or guardian contact information and requests for their child, outline the participants involved (such as teachers, counselors, or doctors), the student's evaluation results, measurable short-term and long-term goals for the student, and daily accommodations or modifications in learning that the student may require. In severe cases, students may also receive an individualized transition plan that will assist the student in transitioning from the high school educational level to the university level, however these cases are rare (Keene et al., 2007).

State-by-State Implementation of Section 504[3]

A search for a state-by-state comparison of Section 504 implementation led me to an autism website that set out the details of each state's guidelines. The chart illustrates how each state and the District of Columbia operate on their own educational guidelines. Each state can choose to adhere to the federal definitions and eligibility standards (for example, Alabama and the District of Columbia), or they can create their own definitions and eligibility standards (for example, Arkansas, Delaware and Florida). Alaska, Montana, New Mexico, and North Dakota are examples of states that have no clear definition of homebound instruction.

Some states unclearly define homebound instruction, and some do not specify the standards for eligibility. Without clearly stating the standards for eligibility, the state cannot determine if a student qualifies for homebound instruction consistently from one case to the next. Seventeen states and the District of Columbia specify no further eligibility standards than those provided by Section 504. States such as Connecticut have highly specific eligibility standards, such as:

> *"Absence will be at least three weeks and: (1) physician certifies child unable to attend school for medical reasons along with projected date of return; or (2) student has disability of such severity it prevents child from safely learning in a school setting; or (3) special ed. program recommendation is pending and the child was home at the time of*

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[3] For the chart on the state-by-state comparison of Section 504 implementation, see Appendix p. 549.

> *referral; or (4) the child is pregnant or has given birth and a physician certifies homebound is in the child's best interest for a specified period of time."*

In some instances, a committee or Individualized Education Plan (IEP) Team will determine the eligibility of students (Alaska, California, Delaware, New York, and Oklahoma) for homebound instruction. The state of Maine sets out under its eligibility a description of homebound students, rather than a description of eligibility criteria, "Home instruction is usually appropriate for only a limited number of students, such as students who are medically fragile and are not able to participate in a school setting with other students." This statement begins to specify how the students qualify by including "students who are medically fragile and are not able to participate in a school setting with other students," but it does so by setting the precedent "is usually appropriate for only a limited number of students."

There are also differences in implementation of Section 504 between states in terms of the minimum number of hours to which the student is entitled during homebound instruction. Many states employ an IEP team that will determine the number of hours that would best suit the homebound students on a case-by-case basis. Twenty-four states specify no minimum or maximum hours of instruction, with no further guidelines. This implies that one student may receive an hour of instruction per week and another student may receive an hour of instruction per day, depending on their individual needs. In the case of Louisiana, the specifications under minimum hours of instruction refer to the teachers' eligibility rather than the students', "no minimum or maximum hours specified, however, itinerant teacher may serve no more than 10 students and on-site teacher may serve no more than 17 students."

There is a gap between the aims of Section 504 being addressed at the federal level and how it is being implemented at the state and school district levels. The state-by-state comparison chart illustrates how Section 504 is being implemented under different guidelines from one state to the next. Furthermore, school districts are entitled to generate their own guidelines, as long as they adhere to both the state and federal guidelines.

The reason for setting out the process I followed in researching these guidelines was to demonstrate how challenging it can be for a parent or guardian to find information on their child's special education options after being diagnosed with cancer. In most instances, the term "homebound" was necessary to find any information on the special education services available to this population, yet this is not a commonly used term and would not be something that parents might be expected to know. Therefore parents must rely on the recommendations of the hospital personnel (such as nurses, doctors or counselors), school counselors, or schoolteachers to instruct them on how to go about referring their child to initiate an IEP to maintain education during and after cancer treatment. Chapter 6 will present details on the participants' school district policies with regard to how they relate to the research participants' school experiences.

School Interventions

The above policies outline how the US government, states, and local school districts provide educational opportunities to students with special medical needs. This section will review literature on interventions that aim to make reintegration smoother for children and adolescents who are returning to school after treatment for a medical condition, and specifically treatment from cancer. Research is readily available into assessments of reintegration programs and policies for children and adolescents with medical needs, and specifically cancer, who are returning to school both during treatment and once treatment has ended.

Literature Reviews Focusing on Students with a Chronic Illness

Chronic illness is defined as, "a condition which: lasts for a considerable period of time or has a sequelae which persists for a substantial period and/or persists for more than 3 months in a year or necessitates a period of continuous hospitalizations for more than a month" (Thompson & Gustafson, 1996, p. 4). Shiu (2001) reviewed literature on the education of students with a chronic illness. She reported that children with a chronic illness were likely to have up to 50 percent more school absences than healthy peers. The author discussed the various reasons behind why absences were more common in children with a chronic illness in comparison to their healthy peers. One source suggested that parents choose to keep the child home from school due to over protectiveness, while another source suggested that children with a chronic illness become "school phobic" and do not want to attend school. Since there has been no recent research into school phobia in children with a chronic illness, Shiu (2001) recommended that teachers develop a good understanding of the student's chronic illness and encourage the student to attend as often as possible. Shiu also advised that regular absences might indicate symptoms of depression or difficulty in coping with the chronic illness (2001). She concluded that since absences separate the child with a chronic illness from their peers, it becomes more difficult for them to form friendships that can contribute to development of identity and social skills (Shiu, 2001).

Shiu (2001) claimed that students with a chronic illness are at risk of school failure and psychological maladjustment. Shiu recommended flexible support to help the student understand the physical expectations associated with his or her illness, as well as academic and psychological resources to help them cope with the constraints of their chronic illness (2001). Shiu also emphasized in her recommendations that avoiding frequent absences could help a student remain connected to their peers, which could in turn help them to develop coping skills and promote successful academic and psychological functioning (2001).

Shaw and McCabe (2008) also conducted a literature review focusing on the transition from hospital to school for children with a chronic illness. The review focused on chronic illnesses in general including: asthma, cystic fibrosis, HIV infection, insulin-dependent diabetes, brain injury, and cancer. The researchers reported that the academic needs of children with a chronic illness vary, depending on the specifics of their illness, symptoms, and treatments. The researchers also reported that side effects, such as fatigue or pain can distract the student from their schoolwork, resulting in a lack of academic motivation. Shaw and McCabe (2008) also found that rather than the diagnosis being the best predictor of school absences, the chronicity of the illness as well as physical functioning were better indicators as to whether absences would be more or less frequent. For example, a student with cancer might have less school absences than a student with severe asthma, depending on the severity of the symptoms and treatment and the student's ability to function in the school setting.

Shaw and McCabe (2008) described the three-phase model for most school reintegration programs for children with a chronic illness. The first step of the three-phase model began with community support, the initiation of specialized instruction either hospital or homebound, and educating peers. The second step continued with hospital-school communication regarding the student's academic needs with regard to his or her medical needs, and the development of transitional instructional support. The third step was when the student had been fully reintegrated into his or her mainstream school and included follow-up communication between the hospital, the school and the parents regarding the child's academic and medical needs.

Thies (1999) also identified the educational implication of chronic illness in schoolchildren through a review of literature. Thies (1999) reported that children with a chronic illness differed from those students who required special education due to learning disabilities or speech problems, claiming that a chronic illness does not always affect a child's ability to learn. Therefore, she recommended that schools must differentiate the chronic illness population from what was already considered as the special education population, thus creating a specialized school program for health needs. Thies (1999) argued that schools must recognize the growing population of children with medical needs as health care continues to improve and children with a chronic illness survive longer. The author suggested that school personnel, particularly the teacher, work together systematically with the student and his or her family to meet the student's academic, social, and behavioral needs.

As shown in the findings reported by Shaw and McCabe (2008), the side effects from chronic illness can often have an effect on the student's ability to be successful in school. For example, medications for epilepsy or diabetes can cause extreme levels of fatigue, which can affect a child's ability to learn. Therefore, both Shiu's (2001) and Shaw and McCabe's (2008) studies disputed the findings presented in Thies' (1999) study. While students with a chronic illness might have special school needs that differ from students who have a learning disability, perhaps the need for a specialized school program might be extreme for such a limited population. However, Thies' (1999) recommendation of collaboration between the student and the teacher was confirmed by Shaw and McCabe (2008).

Shaw and McCabe (2008), Theis (1999), and Shiu (2001) focused their literature reviews on reintegration interventions for children and adolescents with general medical needs relating to chronic illness. All three sources emphasized the importance of collaboration between parents, school, hospital, and student. Collaboration included consistent communication, avoiding absences whenever possible, and strong peer support to promote successful school reintegration.

Literature Reviews Focusing on Reintegration Interventions

Prevatt, Heffer, and Lowe (2000) reviewed literature that focused on school reintegration programs for children with cancer. They focused on four main areas including recent legislative mandates, school attendance, social and academic adjustment, and reintegration challenges. The authors first identified the policies of IDEA 1997 and Section 504, as outlined in Chapter 1 of this thesis. With regard to attendance, researchers found that cancer patients missed an average over 40 days of school during initial treatments and had inconsistent attendance beyond initial treatments (Prevatt et al., 2000). Prevatt et al. speculated that since frequent absences are generally associated with poor academic success and an increased drop out rate, that this number might be higher in children with cancer. However, the authors provided no evidence that this hypothesis was supported and would need to account for the absence frequency for healthy students in comparison to the absence frequency of students with cancer.

Prevatt et al. (2000) also reported that returning to school provided the patient with a symbolic message that the child's health is improving or has improved, allowing for them to regain a sense of control and increased hope. With regard to social and academic adjustment, the researchers reported that children with cancer experience isolation due to school absences and concerns regarding physical appearance due to physical side effects of cancer treatment, such as hair loss. Chronically ill adolescents also dated significantly less than their healthy peers, and made fewer plans for the future. The authors attributed this finding to lower self-perception in cancer patients in comparison to healthy peers.

Challenges with reintegration to school included absences causing difficulty in keeping up with classroom progress, learning difficulties (especially associated with patients who experienced CNS treatment or cranial radiation), a reluctance to return to school due to physical changes such as baldness or weight gain/loss, concerns that illness or treatment side effects will resurface while in school, uninformed teachers, and overprotection from parents. Prevatt et al. (2000) concluded that there are five main people that are involved in reintegration programs, and three main types of programs. Programs are comprised of five protagonists: the child with cancer, parents and family members, teachers and school personnel, peers, and medical personnel. The three types of programs include school personnel education programs, peer education programs, and comprehensive programs.

The school programs focus on reintegrating the child with cancer into the educational setting post treatment. The peer education programs aim to improve peer support and understanding for the child with cancer. Comprehensive programs aim to reintegrate the child with cancer both academically and socially into the school setting. Prevatt et al. (2000) concluded that limited sample sizes do not provide researchers with enough evidence on how to improve programs. The researchers also concluded that there were gaps between research and practice, implementation was inconsistent from one school district to the next, and the location of treatment and child's school might cause difficulties for reintegration programs.

The review by Prevatt et al. (2000) on reintegration programs was in-depth and focused on the limitations of each study in an effort to make recommendations for future research. The authors recommended that researchers focus on the role of a school psychologist, increase sample sizes in future studies, and conduct longitudinal research to investigate the benefits of reintegration programs for children with cancer returning to school.

Like Prevatt et al. (2000), Harris (2009) reviewed literature on reintegration programs for children with cancer. Harris (2009) aimed to expand upon the existing model for school reintegration, and to provide checklists for implementation that would assist educational consultants with reintegration for children with cancer. Harris (2009) created the model listed in figure 1[4] on page 76.

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[4] Copyright permission to utilize Figure 1 in this thesis can be found in Appendix p. 571.

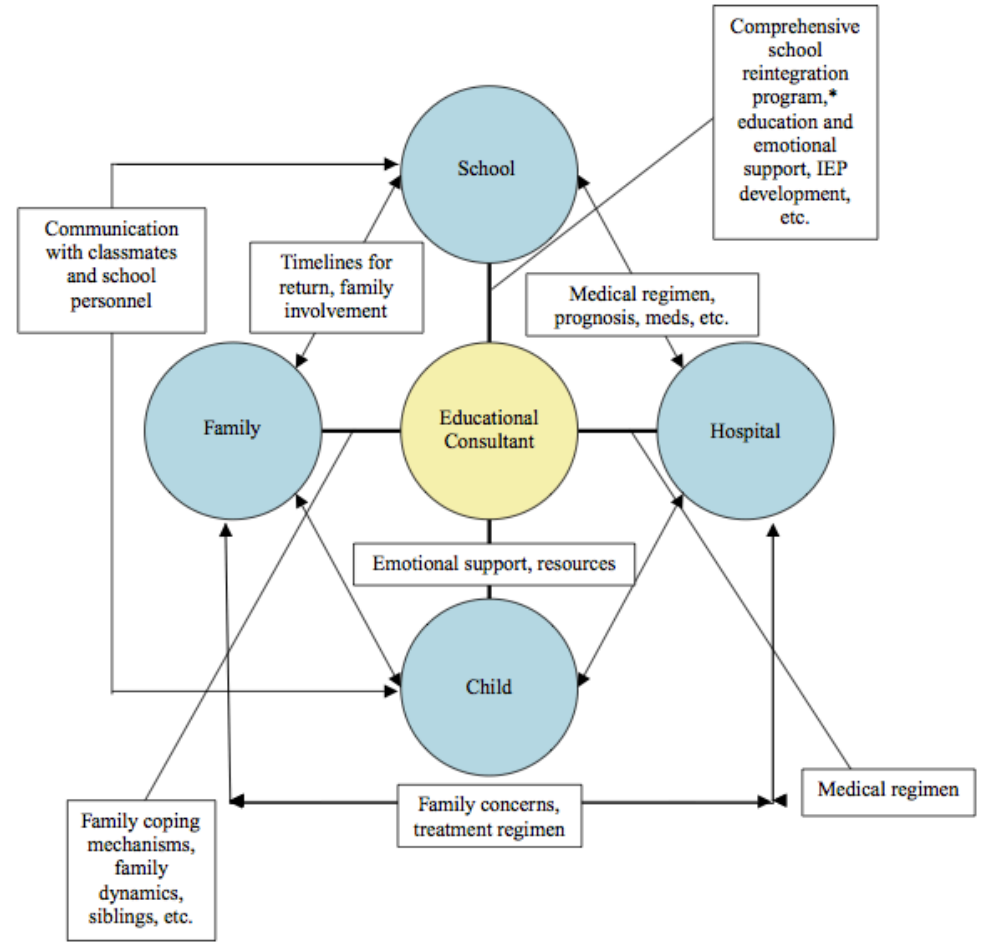

FIGURE 1. Schematic representation of the eco-triadic model of educational consultation.

The Educational Consultant-Family connection means that the consultant must understand familial relationships both before and after diagnosis to assess any changes that may occur and to assist the family with necessary coping or adjustments. The Educational Consultant-Hospital connection means that the consultant must be aware of medication treatment in order to be prepared for any side effects that may affect the overall wellness of the child. The consultant can also convey useful medical information to medical personnel. The Educational Consultant-School connection means that the consultant must understand educational policies and school protocols for special education that the child may require. The consultant can also convey useful information to school personnel regarding medical treatment that may affect the child's school behavior or academic functioning. The Educational Consultant-Child connection means that the consultant can treat psychological, behavioral, and academic problems associated with the child's cancer, and treat anxieties related to relapse or further treatments.

Harris (2009) also outlined the strengths and limitations of this eco-triadic model for reintegration. The author emphasized the importance of having a single person consult with everyone involved in the child's reintegration to school. Harris (2009) recommended that the consultant should be the school psychologist. This would equip the psychologist to provide direct psychological assistance to the child while consulting with and mediating between school and medical personnel. The school psychologist could also educate peers on cancer and its effects on the child with cancer. One main limitation Harris (2009) outlined is the lack of clear framework as to how the consultant can bridge the connections between everyone involved and how they can successfully implement the reintegration program for children with cancer.

Gartin and Murdick (2009) investigated school-related problems for the child with cancer. The authors focused their research findings on medical, physical, and cognitive problems that students with cancer and cancer survivors encounter in school. Gartin and Murdick (2009) outlined three responsibilities that educators should maintain as part of their role. The first was that the teacher should get as much information as possible as to the type of cancer, the present and past treatments, the prognosis, and side effects. The second responsibility highlighted was that teachers should assess their own attitude toward the diagnosis of cancer, fears and anxieties, and expectations to help maintain appropriate expectations of the child. Lastly, teachers should be ready to be the hub of communication between school personnel, parents, and the health care provider. The researchers recommended that with these responsibilities outlined and executed, the teacher could better assist the student in returning to the classroom.

Harris (2009) recommended that the school psychologist should serve as the hub of communication between parents, the school and health care personnel, while Gartin and Murdick (2009) recommended that the teacher fulfill this role. When looking at Harris' Figure of Educational Consultation on page 76, the figure shows that the school is one of four protagonists that are responsible for meeting the needs of the child with cancer (school, hospital, child and family). Therefore, Gartin and Murdick's (2009) recommendation that teachers fulfill this role might be unrealistic since teachers have the responsibility of not only meeting the needs of the student with cancer, but also the needs of all the other students in his or her class. Also, teachers are focused primarily on the academic needs of the child with cancer and may not be prepared to address the child's psychological needs throughout cancer survivorship. Lastly, students tend to move on to a new teacher and a new grade and classroom at the end of each academic year. For those students who undergo prolonged cancer treatment that lasts more than one school year, a school psychologist might be a better hub of communication and best placed to prepare the new school teacher for meeting the student's academic needs.

Gartin and Murdick (2009) created a checklist for educators to use when a child with cancer returned to the classroom. The goal of the checklist was for educators to acknowledge areas of limited understanding regarding the effects of cancer and treatment, and to prepare their classroom, students, and themselves accordingly for the ill child's reentry. Lastly, the review included resources that focus on cancer information for children and adolescents for educators to access to help them better understand the student's experience in order to successfully reintegrate the student into school.

Herrmann, Thurber, Miles, and Gilber (2011) reviewed literature on the reintegration of childhood leukemia survivors to school, and compared literature findings to a single case study of a 7-year-old female. Herrmann et al. (2011) reported that early diagnosis was associated with poorer outcomes of the disease. Females were also more prone to poorer outcomes than males. Cognitive problems, such as lower IQ, difficulty concentrating, and memory problems, were not immediately present following treatment, but usually emerged three or more years post-treatment. School problems were three to four times more likely in young survivors of ALL who received cranial radiation treatment in comparison to other cancer treatments. The case study patient received two years of treatment for ALL. Treatment did not include cranial radiation. Herrmann et al. (2011) conducted an initial assessment using the Wechsler Preschool and Primary Scale of Intelligence-Revised to measure cognitive functioning, and collected qualitative data from her mother regarding daily cognitive functioning (memory, concentration, and organizational skills as observed by the parent). The patient received limited special services at school to address possible cognitive effects from treatment. The parents communicated regularly with the school.

Herrmann et al. (2011) concluded that the patient's cognitive functioning was similar to the findings reported in literature. The patient did not exhibit symptoms of depression, which contradicted literature reported in this study. Lastly, the researchers concluded that while data collected from the mother was rich, her perspective on her child's functioning might be skewed and should not be solely relied upon. The authors recommended that school psychologists were ideally positioned to address the emotional, educational, and physical needs of childhood survivors in school.

The literature reviews conducted by Prevatt et al. (2000), Harris (2009), and Gartin and Murdick (2009) outlined specific recommendations for school counselors to address the needs of children and adolescents with cancer reintegrating to school, while stressing the importance of consistent communication between parents, teachers, medical personnel, and the student. This shows that the recommendations made by Shaw and McCabe (2008), Thies (1999), and Shiu (2001) for general medical reintegration interventions may also be applied to the reintegration for children and adolescents with cancer. However, the findings of Herrmann et al. (2011) show that cancer carries specific physical effects that can hinder reintegration to school, such as cognitive delays from certain cancer treatments. Therefore having an understanding of the effects of cancer and treatment would be beneficial for teachers and school psychologists who are assisting a student in cancer survivorship as he or she reintegrates into mainstream school.

United States policies presented at the beginning of this chapter address to varying degree the recommendations of the literature review. The policies provide students, who have special education needs, with the right to receive a specialized education. Most states outline the details of how much homebound instruction a student is eligible to receive once the doctor clears the student to continue school during treatment (such as Connecticut on page 67 of this chapter). However, there are little or no policies on reintegrating students with a chronic illness into the mainstream school setting. This is where US policy may be falling down. Based on the above recommendations, there needs to be a person who is the central hub of communication for the student in cancer survivorship. Ideally this would be a school psychologist who can maintain regular and clear communication between the hospital, the parents, and the school, as well as provide the student with any psychological interventions or counseling that may be necessary. Policies that standardize reintegration interventions can minimize absences and promote a better overall quality of life for this group of the population. Without these policies, students with a chronic illness such as cancer will continue to experience regular absences, therefore putting academic success and social proficiency at risk.

Empirical Studies

Harris and Farrell (2004) investigated the education of children and adolescents with medical needs in the United Kingdom by sampling eight Local Education Authorities (LEAs). The researchers conducted semi-structured interviews with teachers and school staff, collected policy documents, and conducted child studies by interviewing and collecting school-related documents. Harris and Farrell (2004) did not choose the eight LEAs at random because their aim was to present examples of successful reintegration programs for children with medical needs. By collecting data from children, parents, and documents on policy and school records, as well as the interviews and data collected from the LEAs, they provided a comprehensive assessment of what makes an LEA successful in addressing the educational needs of children with medical conditions.

Harris and Farrell (2004) identified five themes relevant to teachers and schools aiming to achieve successful reintegration of students: Mainstream ownership, partnership and collaboration, flexibility, responsiveness, and clarity. Mainstream ownership means the students' school should have a predominant role in the students' education in terms of the referrals, the monitoring procedures, and the reintegration interventions for the student. Partnership/collaboration is defined as how the hospital schools and LEA services work with the other educational services that the student may need. Flexibility refers to the organization of the services and how they are able to fit the individual needs of each student. Responsiveness refers to the ability of the LEA to uphold its responsibility to attend to the needs of the students, parents, mainstream schools, support staff, and medical professionals. Lastly, clarity refers to how comprehensible the policies are written and how clearly they outline all roles and responsibilities of each person involved (Harris and Farrell, 2004).

Lightfoot, Mukherjee, and Sloper (2001) also investigated the support that students with special health needs required in mainstream schools, namely in Australia. The researchers recruited 39 schools (19 primary schools, 20 secondary schools), 28 Special Educational Needs Co-ordindinators (SENCos), and 58 families using semi-structured interviews and focus groups. Lightfoot et al. (2001) found that young people attached a significant importance to school, and noted that teacher understanding can be vital in academic support. However, the authors also found that the lack of a clear framework for implementing flexible support made it difficult to address the needs of students with a chronic illness. Communication between school and medical staff was also found to be weak.

Lightfoot et al. (2001)'s study outlines how these types of policies are not easily implemented in reality. While the policies in the study by Lightfoot et al. (2001) do not directly apply to the present thesis, which is conducted in the US, the recommendations regarding increased, clear communication between teachers and health care personnel are relevant outside of Australia's education system to any child with a chronic illness attending school. The benefit of having "a teacher who understands" (p. 61) is an example of how positive support at school can improve upon the student's reintegration experience (Lightfoot et al., 2001).

Harris and Farrell (2004) and Lightfoot et al. (2001) conducted studies that focused on children and adolescents with a chronic illness. In line Similar with findings from the literature reviews above, the authors recommend clear, consistent communication between protagonists in all roles to promote successful reintegration. However, since Harris and Farrell (2004) and Lightfoot et al. (2001) were studies of general chronic illnesses, they did not take into account the effects of cancer treatments, such as cognitive delays, focus and memory problems, and fatigue.

Sullivan, Fulmer, and Zigmond (2001) aimed at developing an understanding of the role of school in the life of children with cancer. The researchers used interviews and collected medical data from eight childhood survivors of ALL (ages 10 to 12 years old) and their parents. Sullivan et al. (2001) found that children exhibited concerns regarding their academic progress during treatment, and were positive about their return to school. Parents viewed their child's return to school as a normalizing factor, and felt that they received strong support from schools. During treatment, six participants were eligible for and received homebound instruction to supplement their education during absence from normal schooling. Of these six participants, four parents were satisfied. Those parents who were dissatisfied explained that the type of homebound instruction provided was not sufficient to help their child keep up with their peers at school. Half of all parents wanted their child to have more contact with peers at school during their absence. Six participants received school reintegration support to ease their transition to the mainstream classroom. However, maintaining attendance was difficult for participants while undergoing cancer treatment.

Sullivan et al. (2001) concluded that school plays an important role for children in achieving normalization after diagnosis and during treatment. The researchers recommended that parents promoted school attendance whenever possible, despite feelings of over protectiveness. The researchers also recommended that educators communicated with families during treatment to facilitate positive school reintegration. This study aimed to assess the perspectives of children with ALL and their parents regarding the child's return to school during cancer treatment. Since the sample size was limited to eight participants, it is difficult to generalize these findings to the experiences of a wider population of young children with ALL who have returned to school during cancer treatment.

McLoone, Wakefield, Butow, Fleming, and Cohn (2011) researched reintegration to school for adolescent cancer survivors in Australia. The researchers conducted 70 interviews for their qualitative study with 19 adolescent cancer survivors, 21 mothers, 15 fathers, and 15 siblings in order to gather data on the experience of reintegrating to school after treatment. McLoone et al. (2011) found that problems experienced upon returning to school included fatigue, anxiety, and poor family and school communication. During the time of year when students were changing grades (usually in the summer), communication with the educational consultant became less consistent. Therefore, parents viewed the lessening communication during this time of year as a period of unmet needs for their children. Parents also reported that support from the school counselor overall was minimal. The researchers also found that support received from friends, teachers, tutors, and medical personnel was integral during reintegration to school. Overall, siblings did not report significant impact on their education. McLoone et al. (2011) concluded that school counselors have the potential to increase the amount of support that is provided to adolescent cancer survivors and their families.

Katz, Rubinstein, Hubert and Blew (1989) investigated the school and social reintegration of children with cancer. They recruited 49 cancer patients (aged 5 to 17 years old) as a part of a reintegration intervention group, and a control group of 36 survivors who were diagnosed within the last 36 months. Participants with brain tumors were excluded from the study. Participant's responses to a set of questionnaires were measured before and after the reintegration intervention. Measures included the Children's Depression Inventory (CDI), which measures symptoms of depression in children, and the Perceived Competence Scale for Children (PCSC), a 28-item scale that identifies the cognitive, social and physical capabilities of the child or adolescent. Parents completed the Child Behavior Checklist (CBCL), which focuses on activities, social competence, and school competence. Teachers completed the Deasy-Spinetta Behavioral Questionnaire, which is a 34-item questionnaire created to assess behavioral problems in children with cancer while in school, including academic, physical, social and emotional problems, and the Teacher's Rating of Child's Actual Competencies, which assesses the cognitive, social, and physical abilities of students. Teachers also included reports on the child's attendance and grades before, during, and after treatment.

Katz et al. (1989) found that parents of patients from the intervention group reported fewer behavioral problems after returning to school than parents of the control group. Patients who received reintegration intervention also were less likely to exhibit anxiety and symptoms of depression after they returned to school, and exhibited an increase in social competence and higher self-esteem. The researchers noted that depression symptoms for patients from the intervention group might lessen over time. There was no significant difference between groups regarding the frequency of absences or changes in grades. Classroom presentations increased peer understanding of cancer and the integration intervention was successful, as measured by social and academic success. Katz et al. (1989) concluded that early intervention was vital for successful reintegration to school.

Mayer, Parsons, Terrin, Tighiouart, Jeruss, Nakagawa, Iwata, Hara, and Saiki-Craighill (2005) researched physician perspectives regarding school reintegration of students after being diagnosed with cancer. The researchers developed a four-part survey, covering the following: communication with children aged 10 to 17 years and general attitudes, hypothetical clinical scenarios, communication in clinical practice, and respondent characteristics. Participants included 350 US oncologists and 362 Japanese oncologists. Participants were provided with hypothetical scenarios that included breaking the news, return to normalcy, treatment problems, imparting hope, and palliative care and patient autonomy.

Mayer et al. (2005) found that 84.5 percent of US oncologists recommended informing school officials and peers about a child’s diagnosis and treatment in an effort to facilitate reintegration. In contrast, only 25.9 percent of Japanese oncologists endorsed telling both school officials and peers about the child’s condition. Japanese oncologists were more likely to recommend informing everyone involved if the child had been informed at the time of diagnosis, if they did not believe that awareness of cancer affected the child’s sense of hope, and if the type of cancer the child had did not influence their understanding of their condition. Mayer et al. (2005) concluded that their findings reflected large cultural differences between the US, and Japan where it is not common practice to inform children who have cancer of their diagnosis. The researchers recommended that future research should investigate the outcomes of sharing information or not with regard to school reintegration of children with cancer.

While the hypothetical example used in the latter study protected a patient's right to privacy, the study would have benefitted from comparison to real life examples, which tend to involve a multitude of variables in terms of, for example, the type of school, type of cancer and treatment, disease and treatment side effects, cultural differences, age differences, and socioeconomic status. This study also assumed that the hypothetical patient in the scenario, Jodie, was aware of her cancer diagnosis, which was found to be inconsistent with Japanese culture traditions. This inconsistency may have biased the study results.

Moore, Kaffenberger, Goldberg, Oh, and Hudspeth (2009) examined the perceptions of nurses, school personnel, and parents towards school reintegration for children with cancer. The researchers developed a questionnaire that was administered to 118 nurses, 49 school personnel (counselors and teachers), and 59 parents. Moore et al. (2009) found that nurses reported performing few reintegration services, and rated such services as "moderately helpful" (p. 92). There was no significant difference between nurses' and parents' perceptions of the reintegration services that were performed by the nurses, although parents thought that the health care professionals should have provided more support. School personnel reported some reintegration support, and rated such services as "somewhat helpful" (p. 92). There was no significant difference between parents' and school personne's perceptions of educational support. Parents perceived no significant differences in child's cognitive ability or academic performance. There was a significant difference between the average days of school missed before and three years after diagnosis; however, there was no significant relationship between academic performance and absences.

This study had a number of limitations. The nurses who were interviewed did not necessarily provide healthcare services to the children with cancer whose parents were included in this study. This weakened the study's findings because the parents' perceptions of the hospital's reintegration interventions may be due to the intervention of nurses who did not participate in this study. The researchers included a questionnaire of their own design which was not standardized. Also the method chosen for measuring a child's cognitive ability and academic functioning only reported parental perceptions. To understand whether the children were actually experiencing differences in cognitive abilities and academic functioning after cancer, the use of cognitive assessment tools might have improved the study.

Szwed (2007) conducted a policy evaluation to reevaluate the role of Special Educational Needs Co-ordinators (SENCos) in the UK. The study's aim was to examine how SENCos were managing their role in light of recent developments in policy and practice in special education. The author mailed a questionnaire to 80 schools that were involved in an initial teacher-training program. With a 60 percent response rate, which is high for postal surveys, 48 surveys were returned. The sample included teachers who worked with children aged 3 to 11 years old and who had varying special education needs. Szwed (2007) found that SENCos faced the following challenges that impeded their ability to do their job: lack of time, lack of communication with staff, lack of communication with external agencies, bureaucracy, and maintaining a flexible role. Szwed (2007) concluded that SENCos are having difficulties fulfilling their roles in relation to addressing the special educational needs of students. She recommended a collaborative approach that included working with mainstream teachers and effective communication between teachers and outside agencies.

Szwed (2007) utilized a questionnaire that was developed from a larger-scale study survey. Gaining SENCos' perspectives on the challenges they face in fulfilling their role is valuable in exposing the gaps between policy and practice. However, findings from the study as to what the gaps were and also where the gaps were occurring were limited by the single method used for collecting data. Such evidence would have been helpful when addressing how to close gaps between policy and practice.

Section Summary

A review of the literature supports the assertion that school reintegration is most successful when consistent communication is achieved, the challenges associated with the illness are clearly understood, and school personnel are flexible in implementing interventions to accommodate the specific medical needs of children and adolescents (Shaw & McCabe, 2008; Thies, 1999; Shiu, 2001; Harris & Farrell, 2004; Lightfoot et al., 2001). Combining literature reviews with a mixed-method approach appears to provide the most thorough approach to understanding what is required to reintegrate students with cancer to school, including improving their psychological, social, behavioral, and cognitive functioning.

Policy supports the premise that all students with a chronic illness have a right to access education that is tailored to their specific, medical needs; however, research literature concludes that cancer and treatment effects can be severe and specific, requiring a clear understanding of what distinguishes cancer from other chronic illnesses (Harris, 2009; Prevatt et al., 2000; Gartin & Murdick, 2009; Herrmann et al., 2011; Sullivan et al., 2001; McLoone et al., 2011; Katz et al., 1989;

Mayer et al. 2005; Moore et al., 2009; Szwed, 2007). These differences and their impact on schooling and reintegration to school will be explored further in the next sections.

Academic Functioning

Literature Reviews

Vance and Eiser (2001) reviewed literature on the school experience of the child with cancer. The authors found that absence from school was the biggest problem in the year after diagnosis and decreased over time. Greenberg et al. (1989) and Noll et al. (1997) supported the findings of this study, namely that there appeared to be no significant behavioral differences between children with cancer and healthy controls. Yet patients who received radiotherapy, chemotherapy, and were diagnosed with cancers of the central nervous system, had academic scores that differed most from the norm. While behavioral scores were within the normal range, children with cancer had lower social functioning and restricted leadership and social skills in comparison to healthy controls.

Peckham (1989) discussed the incidence of learning disabilities in long-term childhood cancer survivors using various literature sources. She reported that children who received cranial irradiation as a part of cancer treatment achieved an average of two grades less than expected in reading and mathematics (Peckham, 1989). The author also reported that young children who received cranial irradiation were more likely to require special education, repeat a grade, and/or receive additional tutoring. Peckham (1989) concluded that children who received cranial radiation treatment should be considered at academic risk due to the side effects that radiation can have on the development of the brain.

Pini, Hugh-Jones, and Gardner (2012) reviewed literature focusing on the effects adolescent cancer has on the educational engagement of teenagers. By filtering five databases and 3209 possible articles, the authors reviewed 22 studies that focused on adolescents (between the ages of 13 and 19 years old) in cancer survivorship and their experiences with school, regardless of time since diagnosis. Pini et al. (2012) reported that school attendance, reintegration to school after absence, peer interactions, and long-term physical effects impact the educational engagement of adolescents in cancer survivorship. The authors concluded that while school absence can lead to academic challenges, it does not necessarily lead to a decline in academic achievement. They also concluded that peer groups and what they called 'self-concept', specifically body image, could mediate educational engagement among this population. This suggests that positive peer interactions and self-concept can promote educational engagement for adolescents with cancer, despite regular absences from school. The researchers recommended that further research should focus on the impact of peers and how educational engagement contributes to overall quality of life.

The literature above recommended consistent and regular monitoring of child and adolescent cancer survivors in an effort to help them function successfully within a school setting (Peckham, 1989; Vance & Eiser, 2001; Pini et al., 2012). Regular absences from school could impede a student's ability to maintain the same academic pace as their peers who attended school daily (Shaw & McCabe, 2008; Shiu, 2001; Vance & Eiser, 2001); however, the findings of Pini et al. (2012) are important because their review of research literature found that absences were not correlated with academic success but were correlated with social interactions and self-concept.

Empirical Studies

The type of cancer and treatment can severely affect how children and adolescents are able to function behaviorally and academically in school, specifically with regard to CNS tumors, brain tumors, CNS chemotherapy, and cranial irradiation (Keene et al., 2007). As shown in Chapter 1, effects such as hair loss are primarily cosmetic, while other effects such as fatigue, weakness, and a compromised immune system can prevent a student in cancer survivorship from attending school during treatment.

The previous section illustrated how frequent or lengthy absences from school can prevent a student from succeeding academically, developing socially, and building skills that will contribute to their future education and career (Shaw & McCabe, 2008; Shiu, 2001; Vance & Eiser, 2001). Other effects of cancer and treatment presented in the previous section, such as behavioral changes or cognitive impairment, can influence a survivor's ability to achieve once they return to school (Peckham, 1989; Vance & Eiser, 2001; Pini et al., 2012). Therefore it is important to understand how cancer survivorship can affect an adolescent's ability to succeed, and to overcome the challenges they may face in school while coping with the effects of their illness. This section presents empirical research studies on academic functioning of children and adolescents in cancer survivorship.

Raymond-Speden, Tripp, Lawrence, and Holdaway (2000) investigated the intellectual, neuropsychological, and academic functioning in long term cancer survivors. The aim of the study was to assess the effects of treatment on cognitive functioning. The researchers compared two groups of survivors of acute lymphatic leukemia (ALL), each group under different treatments (group 1, N=20; group 2, N=21), a group of healthy controls (N=21), and a group suffering from chronic asthma (N=21). The first group of survivors received both central nervous system (CNS) chemotherapy and cranial radiation. The second group of survivors received only CNS chemotherapy.

The researchers used the Child Behavioral Checklist (CBCL), and the Teacher Report Form (TRF), which focuses on academic performance, working hard, behaving appropriately, learning, and happiness, and is completed by the teacher using a 3-point Likert scale. Other measures included the Wechsler Intelligence Scale for Children-Revised (WISC-R), which is an intelligence test for children ages 6 to 16 years, the Wechsler Adult Intelligence Scale-Revised, the Wide Range Achievement Test (WRAT), which measures basic skills in reading, arithmetic, and spelling, the Trail Making Test for Children, which assesses brain function using 15 sections (instead of the 25-section adult version), the Benton Visual Retention Test, the Verbal Selective Reminding Test, which measures the short-term storage, long-term storage, and retrieval from long-term memory, the Token Test, and the Controlled Oral Word Association Test (COWAT), which measures verbal fluency.

Raymond-Speden et al. (2000) found that CNS chemotherapy, both with and without cranial irradiation, was associated with significantly lower levels of intellectual and academic functioning in comparison to healthy controls. Children with chronic asthma also obtained lower scores than the healthy controls. Cancer survivors were also found to have impaired emotional abilities when compared to controls, which confirms the findings of Glaser et al. (1997).

The study showed that there are educational challenges that may be present with chronic illnesses other than cancer, such as asthma. Yet the educational challenges for survivors of ALL, who received both CNS chemotherapy and cranial irradiation, were greater than for those with another chronic illness. The researchers recommended consistent neurological testing beyond the end of cancer treatment, as well as regular assessments of intellectual and academic functioning to help children and adolescents in cancer survivorship cope with cognitive functioning problems.

Deasy-Spinetta and Spinetta (1980) investigated how the classroom teacher viewed the behavior and functioning of children who had cancer in the mainstream school classroom. The sample included 42 school-aged children in kindergarten through to twelfth grade (ages 5 to 17 years old) who were in various stages of diagnosis and treatment. The teachers used observations and completed a questionnaire that was developed for this study known as the DSBQ for the child with cancer and for one other healthy child in the same class who was of the same sex and represented the "general characteristics of the class population" (p. 90, 1980) as a control. For children with cancer who had more than one teacher, the child chose which teacher would best be able to complete the questionnaire.

Deasy-Spinetta and Spinetta (1980) found that children with cancer did not differ from the healthy control group in areas such as willingness to attend school, apprehension regarding school, play habits, clinging behavior, or physical appearance. Children with cancer did however differ from controls in areas such as lower attendance, having difficulties concentrating, being underactive, and lacking energy (Deasy-Spinetta and Spinetta, 1980). Observations made by the researchers found that the children appeared introverted, less active, and less willing to try new things. Children with cancer also appeared to be less willing or able to express emotions either positive or negative. The researchers argued that these problems prevented patients from performing at their optimal school ability. They recommended that ways needed to be found for the school, hospital, and family to work together to help the child with cancer resolve problems that keep them from leading a normal school life.

The findings illustrate specific areas of classroom behavior where students in cancer survivorship differ from healthy controls. The questionnaire that was developed has been widely used by researchers in other studies since its creation. However teachers may not always be in a position to comment on certain aspects of the questionnaire used. For example, a teacher might not be best placed to comment on the following: *Attends School willingly; is able to concentrate; worries a lot;* and is *self-conscious or easily embarrassed*. If a student has not mentioned their feelings on these topics to the teacher it may be difficult for a teacher to know definitively if the student - does attends school willingly, has difficulty concentrating, does worry a lot, or feels self-conscious. Despite this limitation, since 1980, the DSBQ has become a widely used questionnaire to measure school behavior as assessed by a teacher.

Their approach to sampling the control group raises questions about the validity of their findings. The description of the study was unclear as to who chose the control sample. If the teacher completing the questionnaire chose the control from their classroom, this might have biased the control group. No sampling criteria were set out for the control group beyond the description of representing the "general characteristics" (p. 90, 1980) of the classroom population and being the same sex as the patient. The term "general characteristics" could be defined in terms of behavioral, classroom achievement, or physical characteristics; yet it is unclear in this study which criteria was used.

Glaser, Rashid, U, and Walker (1997) investigated school behavior and feelings of morbidity in post-treatment specific to patients and survivors of CNS tumors. They recruited 27 survivors and their siblings, and compared them to 25 healthy controls matched for age and gender. Survivors were between the ages of 1 and 13 years old at the time of diagnosis and between the ages of 6 and 17 years old at the time of assessment. Siblings were between the ages of 0 and 13 years old at the time of their sibling's diagnosis and between the ages of 6 and 15 years old at the time of assessment. Due to the wide age range of the participants, the researchers used several measures including the Health Utilities Index – Marks I and II (HUI-II and HUI-I), which focuses on health-related quality of life; the Lansky Play Performance Scale, a parent-rated instrument which records usual play activity as the index of performance for childhood cancer patients meant for all age groups; and the DSBQ.

Glaser et al. (1997) found that survivors had lower cognitive scores, impaired emotions, lower self-esteem, and were less likely to participate in organized activities. Siblings reported few school difficulties; however, they did show signs of psychosocial problems. The authors speculated that the problems experienced by siblings might have stemmed from feelings of neglect. Glaser et al. (1997) concluded that survivors of childhood CNS tumors experienced significant physical and psychological problems after completing treatment in contrast to their siblings and controls, who had fewer school related problems.

As outlined in Chapter 1 of this thesis, CNS tumors require treatment methods that can severely affect the body in comparison to chemotherapy or non-cranial radiation. While survivors of CNS tumors and treatment may exhibit average school behaviors in comparison to siblings and controls, they struggle with academic achievement due to lower cognitive scores and have difficulty expressing emotions. The study by Glaser et al. (1997) included a limited sample of participants, due to the rarity and severity of CNS tumors in children and adolescents. Five patients were excluded from the study because of a terminal diagnosis. Each of the five had passed away at the time the study had ended. By excluding participants with terminal diagnoses, the study's findings regarding feelings of morbidity may have been biased towards those who were more confident about their survival. The authors recommended longitudinal study designs in future research into child and adolescent CNS tumor survivors in order to assess the full extent of cognitive impairment. The authors also emphasized the importance of using multiple scales to attain a full picture of school behavior in survivors of CNS tumors.

Anderson, Smibert, Ekert, and Godber (1994) conducted a similar study to the Raymond-Speden et al. (2000) study. Anderson et al. (1994) investigated the intellectual, educational and behavioral effects after cancer treatment. The researchers divided participants into three groups: patients with ALL treated with cranial irradiation and chemotherapy (N=100), patients with acute myelocytic leukemia (AML), ALL or solid tumors treated only with chemotherapy (N=50), and a healthy control group (N=100). The measures used included the WISC-R, the WRAT, and the CBCL. Anderson et al. (1994) found that children who received cranial irradiation and chemotherapy scored lower in intellectual skills than patients only treated with chemotherapy or members of the healthy control group. In line with the finding presented above, the researchers recommended early educational interventions for this type of patient, and stressed the importance of maintaining consistent communication between the school and the patient regarding their health and educational needs.

Along with Schwartz et al. (2010), Zebrack and Chesler (2002), and Woodgate (2006) in Chapter 2, Peckham (1989) recommended that parents and teachers pay more attention to the challenges that the child or student may face in school as a result of their cancer and treatment. Yet Peckham (1989) did not address whether survivors themselves should be made aware of the educational challenges that they may face as a student. The age of the Peckham (1998) research and the fact that it was only a literature review might explain the limited nature of its findings; however, the findings of Raymond-Speden et al. (2000) and Anderson et al. (1994) support the earlier literature review's findings by Peckham on challenges faced by a child or student in school as a result of cancer and treatment.

Mabbott, Spiegler, Greenberg, Rutka, Hyder, and Bouffet (2005) aimed to evaluate academic and behavioral outcomes in survivors of brain tumors in the posterior fossa, which is a small space in the skull, found near the brainstem and cerebellum. Researchers included 53 patients who were treated for brain tumors and received radiation, as well as various other treatments, between 1983 and 2004. The measures used include the WRAT, third edition, the CBCL, and the TRF to assess cognitive and behavioral changes in survivors. Mabbott et al. (2005) found that the presence of fluid in the brain (known as hydrocephalus) was related to poorer academic achievement in survivors. The study also found that younger participants had poorer academic achievement and reading skills than older participants. However, school behavior was found to be within the normal range. Mabbott et al. (2005) concluded that cranial radiation was associated with lower academic abilities, social skills and attention deficits.

This study raises questions as to whether the treatments for brain tumors cause cognitive delays and academic challenges for survivors or if it is the brain tumor itself based on the presence of hydrocephalus and its correlation to academic functioning in survivors. The study also raises questions as to the inconsistency in behavioral findings that teachers and parents reported in comparison to those reported by survivors. Parents and teachers reported more internalization in behavioral challenges experienced by participants, yet participants reported experiencing no such behavioral problems. Mabbott et al. (2005) concluded that the inconsistency between parent and teacher reports and survivor reports in behavioral findings was related to family interactions and coping rather than to the brain tumor and its treatment.

It is clear from this study that self-reporting measures can be beneficial in understanding the school experience of cancer survivors. It is also clear that survivors receiving cranial radiation, CNS chemotherapy, or both are at risk of cognitive delays and academic deficits (Glaser et al., 1997; Raymond-Speden et al., 2000; Anderson et al., 1994; Mabbott et al., 2005).

Larcombe, Walker, Charlton, Meller, Morris Jones, and Mott (1990) investigated the impact of childhood cancer upon the student returning to school in order to analyze how cancer affects a student's school abilities in comparison to other chronic conditions. The researchers recruited 51 cancer patients and compared them to 66 controls (34 had a chronic disease, 32 had an orthopedic condition). Larcombe et al. (1990) used a structured questionnaire to interview parents and teachers in an effort to gain an understanding of the physical, psychological, academic, and behavioral problems these children may have been experiencing in school. The authors found that most physical problems reported by cancer patients seemed to be related to treatments. Most children fell behind in some or all school subjects, while all children reported negative behaviors and concerns about physical appearance (Larcombe et al., 1990). The authors concluded that consistent communication between teachers, parents, and students might help prevent students in cancer survivorship from falling behind in school and in promoting positive behaviors. Larcombe et al. (1990) recommended that teachers needed to be better informed and that a liaison person should mediate the communication between the hospital, home and school.

Larcombe et al. (1990) used terms such as “most,” “some,” and “seem” without providing clear details as to what percentage of children experienced physical problems. While such children might benefit from a liaison person to promote consistent communication between caretakers, this study is weak in evidencing how the authors came to such a conclusion, given the vagueness of the findings. This study is also more than two decades old, and more thorough research studies have been conducted on this topic since this study was published. For example research by Barrera, Shaw, Speechley, Maunsell, and Pogany (2005) compared educational and social outcomes for childhood cancer survivors. Using the CBCL to measure educational outcomes, the Ontario Child Health Survey to measure social outcomes, and the Childhood Cancer Survivor Study to measure physical health problems, researchers polled the parents of 800 survivors, aged 17 years or younger, and 923 controls matched for age and gender.

Barrera et al. (2005) found that significantly more survivors repeated a grade, participated in learning disability or special education programs, had school problems, no close friends, and were less likely to confide in friends than healthy controls. Survivors who were diagnosed with CNS tumors and received cranial radiation treatment were more likely to have difficulties in all of the aforementioned areas, which further reinforces the findings of Glaser et al. (1997), Raymond-Speden et al. (2000), Anderson et al. (1994) and Mabbott et al. (2005). Barrera et al. (2005) also found that survivors whose parents had postsecondary education were less likely to experience educational and social problems, and had higher self-esteem. This finding suggests that the role of parents can shape the coping experiences of young people in cancer survivorship.

In contrast to the Larcome et al. (1990) study, Barrera et al. (2005) included multiple measures that had been standardized to assess the social and educational experiences of the participants. While the two studies only surveyed parents , the results of the Barrera et al. study (2005) were presented in detail and research limitations were discussed. Barrera et al. (2005) concluded that children and adolescents with cancer require regular monitoring for educational and social problems, and that early interventions may assist the patient in maximizing their social and educational experiences.

Mancini, Rosito, Canino, Calzetti, Caro, Salmi, Bonsi, Marchi, Paolucci, and Missiroli (1989) investigated the school problems of children with cancer as perceived by the teacher. The study was conducted in Bologna, Italy. The researchers recruited 91 patients in elementary and middle school (aged 6 to 15 years old), who received treatment from the researchers' clinic between 1973 and 1987, and 273 healthy controls for comparison. Researchers used the DSBQ, which was completed by the elementary school teacher for elementary school students and the literary subjects teacher for middle school students. The scores from the DSBQ were analyzed by age of the patients at the time of the study, age at diagnosis, kind of school attended, type of cancer, patients on therapy versus patients off therapy, length of treatment, and period under observation in patients off therapy. Mancini et al. (1989) found that the behavioral scores of children in cancer survivorship as perceived by the teacher were statistically lower in comparison to that of healthy peers.

Although this study was conducted in Italy, and is a 25-year-old study, the findings were reported in depth and confirm the early findings of Deasy-Spinetta and Spinetta (1980) that children and adolescents with cancer experience behavioral problems in school, as observed by the teacher. Furthermore Barrera et al. (2005), Glaser et al. (1997), Raymond-Speden et al. (2000), Anderson et al. (1994), and Mabbott et al. (2005) confirm Mancini et al.'s (1989) findings that behavioral problems in children with leukemia may be attributed to the side effects of receiving CNS treatment.

Section Summary

As discussed in Chapter 2, development of identity during adolescence occurs within the context of social interactions (Zebrack, 2011; D'Agostino et al., 2011). The power of social engagement and support should not be underestimated in its ability to promote positive academic and psychological adjustment after cancer (Stam et al., 2001; Zebrack & Chesler, 2002). Also, D'Agostino et al. (2011) emphasized the importance of social interactions and recommended that hospitals provide social opportunities for patients who are currently undergoing treatment. As shown in this section, social interactions can be affected by cancer and treatment (Deasy-Spinetta & Spinetta, 1980; Vance & Eiser, 2001; Barrera et al., 2005). The types of treatment received, such as CNS chemotherapy or cranial radiation, can also severely affect an adolescent survivor's ability to engage socially while in school (Mabbott et al., 2005). The literature concludes that the academic and social challenges that children and adolescents in cancer survivorship experience when in school can be addressed with flexible and consistent reintegration programs. In many instances these programs are created through government policies that aim to provide children and adolescents, including those with a chronic illness, access to an education service that is fair and equal.

Chapter Summary

In the United States, all students have the right to a free and equal education. Special education policies were created to address the educational needs of children and adolescents with a chronic medical condition. In reviewing the literature, US policies appear to be providing specialized education to students with medical needs. However, the literature recommends that consistent communication between the parties involved (medical staff, educational staff, parents, and cancer survivors) can positively influence the reintegration into school, as well as academic functioning, for students in cancer survivorship (Shaw & McCabe, 2008; Thies, 1999; Shiu, 2001; Harris & Farrell, 2004; Lightfoot et al., 2001). While students with a chronic illness may be at-risk of academic challenges (Thies, 1999; Shiu, 2001; Shaw & McCabe, 2008), students with cancer are particularly at risk of declines in academic functioning (Raymond-Speden et al., 2000). Cancer is a chronic illness with severe side effects, both from the illness and treatment. For example young survivors of cancers that include CNS chemotherapy or cranial radiation treatment are likely to experience cognitive delays that can affect their ability to learn in school (Glaser et al., 1997; Raymond-Speden et al., 2000; Anderson et al., 1994; Mabbott et al., 2005).

The literature in this chapter has also concluded that identifying the role of mediator of communication between medical personnel, the student in cancer survivorship, parents, and school personnel can promote positive reintegration (Harris, 2009). While many of the aforementioned literature reviews recommend consistent communication between caretakers, there are no government policies that require the implementation of such recommendations, despite the growing amount of research that confirms the academic and psychological benefits of such action for children and adolescents in cancer survivorship.

The methodologies used in the research in Chapters 2 and 3 have demonstrated the value of a mixed-methods approach to providing in-depth understanding of the varying experiences of children and adolescents with cancer. The literature review identified a gap in research that focuses on adolescents, using self-reporting measures that allow the participants to retrospectively discuss their experiences in cancer survivorship. This current study was therefore designed to utilize interviews and standardized questionnaires to understand the school experiences of adolescents in cancer survivorship. Chapter 4 will explain and describe the measures that were chosen for this study, the analysis used to interpret these measures, limitations of the study and methodology, and ethical considerations.

CHAPTER 4

Study Design

Introduction

The literature presented in Chapters 2 and 3 illustrated the physical and developmental effects that cancer and treatment can cause. Chapter 2 discussed the physical effects of cancer and treatment, such as fatigue, hair loss, and a compromised immune system, that can severely impact an adolescent's self-concept. A negative self-concept for adolescents in cancer survivorship can result in a higher likelihood of PTSD. Adolescents in cancer survivorship also struggle with the development of their identity as they experience the physical and psychological effects of cancer and treatment, thus affecting the person they will become. Chapter 3 illustrated that these physical and psychological effects can influence their school experiences by resulting in a higher likelihood of absences from school and problems in academic functioning. This chapter will outline the study aims and research questions, introduce the researcher and participants, provide recruitment details and a fieldwork timeline, clarify the methodology chosen to address the research questions, and discuss methodological limitations.

Zebrack and Chesler (2002) and Schwartz et al. (2010) recommended the use of mixed-method, longitudinal research designs, and Davis et al. (2007) and Varni et al. (2007) recommended using self-reporting measures to understand the experiences of adolescents in cancer survivorship. Given the limitations of this study, including gaining access to the population and the time constraints, mixed-method, longitudinal research design was not possible. As a result, this study used qualitative interviews in combination with scaled quantitative questions to answer the following research questions:

1) How do the physical and psychological effects of cancer and treatment impact the participants' engagement with school?
2) What role does school play in cancer survivorship for adolescents?
    a. How do participants define a successful school experience during and after cancer treatment?
    b. How does United States policy shape the school experience of adolescents in cancer survivorship?

Study Aims

The purpose of this qualitative study was to describe the educational experiences of a small number of American adolescents in high school who have undergone cancer treatment. To address this aim, semi-structured interviews were combined with the Adolescent Coping Scale, Short Form (ACS- Short) to help describe the experiences of the participants.

Literature has shown that a cancer diagnosis and treatment can severely affect the educational achievement and school behavior of adolescents in high school (Deasy-Spinetta & Spinetta, 1980; Spirito et al., 1990; Barrera et al., 2005; Pini et al., 2012). As cancer survival rates have continued to increase, I felt it was important for this study to focus on the challenges that adolescents in cancer survivorship experience in coping with the effects of their cancer and treatment, as well as the role of school during and after treatment.

As explained in Chapters 1 and 3, there are several U.S. policies that address the rights of this population to access a fair and equal education in the least restrictive environment. What is unclear, however, is how the implementation of these policies is experienced from the perspective of the adolescent cancer survivor. This study aims to describe the educational experiences of adolescent cancer survivors, including challenges they faced and the role policy played in addressing their educational needs.

About the Researcher

I came upon this research topic through my experience both in volunteering with children who have cancer and in elementary school teaching. In 2005 I became involved with a summer camp for children and adolescents with cancer. I volunteered in a number of positions within the camp and learned more than I could have imagined regarding the experiences of children and adolescents in cancer survivorship. As a teacher, I naturally found myself inclined to investigate how these children continued schooling while undergoing treatment. The children and adolescents that I knew from the camp told me how much they enjoyed their classes at the hospital when they were admitted for long periods of time. Upon beginning my research, I was initially interested in assessing hospital schooling programs to understand how they operated and how successful they were for the patients. As I started scoping my research topic I came to understand the limitations that I would face in such a study. For example, for ethical reasons gaining access to cancer patients undergoing treatment for a doctoral research project was not feasible. As I continued my volunteer experience parallel to developing my research project, I began working with more adolescent survivors rather than child patients. They talked to each other about difficult friendships in school and how they felt being the only bald student in class. They came to me for guidance and advice regarding the challenges they faced outside of the camp environment. This experience shifted my focus from hospital school programs to education during and after treatment, and how it can contribute to their development of self.

As I reviewed the literature on the topic, and combined with my volunteer experience, I began to understand how deeply self-concept appeared to be impacted by cancer survivorship. I knew that it would be important to assess self-concept in the participants to understand the value that they place on their past and future experiences. But understanding experience could not be pigeonholed into the domains of a single scale. My supervisor suggested that the participants needed an open measure beyond interviews where they could express their greatest concerns as well as how they coped with their concerns. An open measure would help me to further understand what participants felt was most important in terms of their own experiences. Thus a coping scale was chosen in order to fit the study aims which identified participants' greatest concerns in their own words and which assessed the methods of coping they used to address their concerns. By combining this with interviews, I hoped that this approach would provide me with evidence of participants' experiences with cancer and school.

Despite the initial challenges of accessing the sample population, my connections with the American Cancer Society provided me with the support I needed to recruit survivors. And yet I still struggled to develop a concrete research design that was feasible and addressed the scope of the study. I knew that the design I chose would need to address accurately, sensitively, and successfully the experiences of adolescent cancer survivors across different diagnoses, treatments, school types, and sex. I knew that I needed in-depth qualitative data on the participants' experience of cancer from diagnosis through remission, as well as the educational experience throughout that time, to build an understanding of the challenges that this population faces during cancer treatment. What I had hoped to do was to recruit a sample large enough to be able to draw conclusions that could be applied to this population of cancer survivors as a whole. However, the challenges of recruiting from a limited population required me in the end to carry out a small qualitative study relying on in-depth qualitative data that may provide the basis for a larger research project combining quantitative as well as qualitative data.

In scoping this study I realized that the exploration of the educational experiences of adolescents in cancer survivorship needed to be addressed in a flexible manner since experiences vary. The treatments for cancer are standard: chemotherapy, radiation, and/or surgery. Often, the effects of treatment are similar from one patient to the next. However the adolescents' experiences of coping with cancer survivorship are unique. Through my volunteer experience, I came to understand that this research project needed to have a clear research design that would allow me to understand and appreciate the participant's experiences, but that was also flexible enough to apply to all participants despite their experiential differences. After conducting my fieldwork, I recognized that the measures I chose were a positive start to researching this topic as they built on the participant experiences without imposing my own expectations or evaluations.

Recruitment and Timeline

After the University of Oxford Central University Research Ethics Committee (CUREC) granted me consent to begin, flyers were created and sent to the American Cancer Society, Great West Division (ACS-GWD) office for review (Flyer and CUREC application, Appendix pages 306 and 307). Due to U.S. privacy laws that protect patient medical information, I was unable to contact the families directly. The ACS-GWD representative contacted the families on my behalf via mail to notify them of the study. The ACS-GWD is comprised of the following U.S. states: Alaska, Arizona, Colorado, Idaho, Montana, Nevada, New Mexico, North Dakota, Oregon, Utah, Washington, and Wyoming. In total, 293 flyers were mailed to potential participants. Families who met the study criteria and who were interested in participating in the study contacted me directly either by phone or email. Ten families responded to the flyer; however two families were unable to participate due to regular scheduling conflicts, resulting in a total of eight families. I explained the study verbally over the phone to parents, and answered their questions. Then I set up a time to meet the adolescents who were participating either in person or to conduct a phone interview.

I spoke with each participant for the first time between August 2011 and January 2012. School and extracurricular commitments and the winter holidays made it difficult to arrange scheduling for the first meeting in some cases. Two of the first interviews were conducted in person, and six were conducted over the phone. Two participants requested that their parent be present during our interview.

I conducted follow-up interviews in June 2012 with all participants. One interview was conducted over video conferencing, at the request of the participant. The other seven follow-up interviews were conducted over the phone. One participant had a parent present for her follow-up interview.

Since participants were given an opportunity to have one or both parents present during the interview, one participant had both parents present during the interview, two participants had their mother present during the interview, and five participants were interviewed without a parent present. A second interview of the participants lasting an average of approximately one-half hour was conducted to confirm and clarify comments from the first interview. The follow-up interviews were conducted over the phone for all participants between six to ten months after the first interview. In total, sixteen interviews of high school students who were within two years of cancer post-treatment were conducted.

Interviews

Interview Generation

I created the questions included in the semi-structured interview based on literature that included semi-structured interviews both on chronic illness and cancer specifically (Bossert et al., 1996; Harris & Farrell, 2004; Kupst et al., 1995; Leavitt et al., 1999; Lightfoot et al., 2001; Martinson et al., 1999; Sorgen & Manne, 2002). The interview schedule was designed to focus on the aim of understanding the participants' experiences with education during and after cancer treatment. To fully understand the participant's experience, the interview questions concentrated on the physical effects of cancer and treatment, educational experiences during and after treatment, and the social experiences of the participants with friends, classmates, and family members (Appendix p. 333). These topics guided the analysis in attempting to understand participants' experiences with cancer survivorship and the role school played. Chapters 5, 6, and 7 of this thesis include the specific interview questions that were addressed during analysis for each topic. The questions were designed to be sensitive to participants' emotional state when recalling their cancer experience. My experience in working with adolescent cancer patients and survivors also aided my ability to remain sensitive to participants' emotional state throughout the interviews.

Interview Procedure

I conducted individual interviews with each of the eight participants. Each interview was designed to be up to one hour long, although the interview times varied between 30 to 45 minutes, depending on the flow of conversation. This time did not include the application of the Adolescent Coping Scale. The interview schedules were implemented in a flexible manner that allowed me to assess the flow of conversation and make adjustments accordingly. Adjustments would be made, for example, depending on the participant's emotional state, or to delve deeper into a topic that required more clarification or discussion. As a result, questions may have been asked in a different order from one participant to the next.

The first interviews were conducted between August 2011 and December 2012, depending on the participants' schedules. When meeting with the participants in person, I first explained the consent forms to both the participant and his or her parent/guardian, and answered any questions that either might have regarding the study. Then I began the formal interview with the semi-structured interview, followed by the Adolescent Coping Scale. The scale was only completed during the first interview.

For phone interviews, the participants were mailed the questionnaire in advance with instructions to wait to complete this at the time of the phone interview. The same format was followed with phone interviews as with the in-person meetings, beginning with the explanation of consent forms, followed by the interview itself, and then completion of the questionnaire. During completion of the questionnaire I remained on the phone and answered any questions the participant had while responding to it. This also allowed me to prompt the participant when necessary as outlined in the administration instructions for the scale.

For one in-person meeting, the participant completed the questionnaire in my presence, after the interview. For the other in-person meeting I read the questionnaire orally for the participant, due to his vision impairment. Unfortunately, reading the questionnaire to the participant prior to the interview resulted in short responses, such as "a great deal" during our interview.

The lead into the semi-structured interviews included the opportunity for participants and I to exchange pleasantries and to establish rapport. Establishing rapport was a challenge during the phone interviews, however I proceeded with the formal interviews when I felt as though a connection was established. I was able to gauge when rapport was established based on when participants began speaking in detail about how they were doing and what was happening in their lives. Then I knew that they were open to talking and proceeded with the interview questions. Also, to help the participants feel more comfortable I waited to begin recording the conversations until starting the formal interview. During this time, the participants were given the opportunity to ask me any questions they may have had before the formal interview began so that they would feel comfortable in sharing their experiences. I responded to their questions honestly and openly.

The second round of participant interviews was conducted for clarification and consisted of questions that were generated from comments, answers and/or omissions from the first interview. The follow-up interviews were conducted with all participants in June 2012. The follow-up interviews began with exchanging updates on both how the participant was doing and how the researcher had been since the first interview. Then the researcher proceeded with questions that were generated from the first stages of analysis from the first set of interviews. Since these questions were generated based on the responses, or lack thereof, in the first interviews, there was no set list of questions for the follow-up interviews. In the transcripts of both sets of interviews, all identifying information was redacted to protect the identity of the participants.

All interviews were audio recorded and sent to a transcription service that specialized in both student and medical transcription services. The transcription service guaranteed confidentiality and quality.

Recruitment Criteria for Participation

The participants in this study included eight high school students who had undergone cancer treatment, and were not receiving active cancer treatment at the time of the study. Participants were eligible for inclusion in the study if they met the following criteria as outlined in the recruitment flyer:

Participants must:

- be in cancer post-treatment within the last two years;
- be in the age group 13 through 18 years;
- be in high school grades 9 through 12;
- be willing to communicate their cancer experience;
- feel well enough at the time of interview to engage in discussion;
- have no severe psychiatric illness, and
- have not received cranial radiation during cancer treatment.

The above criteria were developed in order to address issues raised by the literature review. Information on school reintegration for adolescent cancer patients and survivors was limited prior to the year 2000, except for Katz et al. (1989), who concluded that early interventions for cancer patients reintegrating to school were valuable in making a successful transition from hospital or home back to school. Since reintegration has been investigated more in recent years, I wanted to include reintegration in this study. I hypothesized that participants who were within two years of cancer post-treatment, were not only able to recall their recent experiences with cancer and supplemental education, but would likely also be able to recall their experiences with reintegrating to school.

Zebrack & Chesler (2002), Schwartz et al. (2010), and Woodgate (2006) recommend longitudinal studies to investigate the psychological effects that cancer and treatment can have on children and adolescents. Since this is a doctoral research study, I was not able to follow the participants from diagnosis through remission. Therefore, I chose to do a retrospective study that would allow the participants to describe their experiences from diagnosis through post-treatment. Conducting a retrospective study allowed me to understand the importance that participants place on their experiences as they remember them.

Since adolescents with cancer are more susceptible to symptoms of PTSD than children or adults due to developmental changes associated with puberty (Hobbie et al., 2000; Kazak, 2010), I wanted to focus this study on adolescents between the ages of 13 and 18 years old, and who were attending high school grades 9 through 12 at the time of the study.

For ethical reasons, I also wanted to include adolescent cancer survivors who felt well enough at the time of the study to communicate their experiences. I was able to measure the participants' willingness to communicate their experiences based on their desire to volunteer for the study. A cancer diagnosis and treatment not only affects adolescents physically, but it also affects them psychologically and developmentally (Woodgate, 2005). The psychological effects of cancer dwindle over time (Zebrack & Chesler, 2002; Schwartz et al., 2010; Woodgate, 2005). By allowing time to pass from the cancer experience, adolescents are likely to be more adjusted to their "new normal" (Zebrack, 2011) and are more willing to discuss their experiences openly and honestly (Jones et al., 2011; Zebrack & Isaacson, 2012; Woodgate, 2005).

Lastly, it was important that the participants have no severe psychiatric illness or received cranial irradiation during treatment. As shown in Chapter 3, children and adolescents who received cranial radiation are considered to be at risk of cognitive deficits that include developmental delays, attention deficits, and lower academic performance (Raymond-Speden et al., 2000; Anderson et al., 1994;

Peckham, 1989; Mabbott et al., 2005). I wanted to investigate the experiences of adolescent cancer survivors who received treatments that included less severe side effects, which is why survivors who received cranial radiation were excluded from the study.

Description of the Participants

All of the participants' names were changed in this study to protect their identity in accordance with US privacy laws. The participants are described in this section from the time they felt cancer symptoms to the time of the follow-up interview. They are presented in the order of recruitment.

Jamie

The first participant was a seventeen-year-old African American female. Jamie was diagnosed with Acute Lymphoblastic Leukemia (ALL) in October 2008, when she was 14 years old. She began intravenous chemotherapy treatment, which caused side effects that included hair loss and nausea. Jamie was absent for the whole of ninth grade, which at her public school was the last year of middle school. She attempted to return to school at the start of tenth grade, which was her first year of high school, but was unable to attend school regularly. Jamie and her mother decided that she should focus on getting well and not concern herself with school during treatment. After a year and a half of cancer treatments, Jamie's doctors told her that the cancer was gone and treatment was successful. As a medical precaution, she continued regular treatment for another six months and officially stopped treatment in November 2010, 10 months before her first interview. During her absence, Jamie was unable to use a school tutor and therefore received no supplemental education during cancer treatment. She aimed to graduate in Spring

2012 along with her classmates; however, she was unable to make up for the time absent from class due to treatment.

Tracy

The second participant was a seventeen-year-old Caucasian female. Tracy is an only child in a small, single-parent family. She requested that her mother be present for her phone interviews. Tracy experienced symptoms included weight gain, muscle weakness, headaches, hair loss and an inconsistent menstruation cycle. Around the time her symptoms began, Tracy also struggled to focus in school, which her doctors diagnosed as ADHD. After four years of experiencing these symptoms, she was diagnosed with Metastatic Capillary Thyroid Carcinoma (cancer of the thyroid) in August 2010, when she was 16 years old. Her doctors scheduled surgery for November 2010, two months after her diagnosis. Tracy recovered from surgery at home for two months. During her recovery period, Tracy was absent from her public school for one school quarter. During this time, her school arranged for a homebound tutor to help her keep up with her schoolwork while absent.

Due to Tracy's initial diagnosis of ADHD, she already had a 504 Plan in place at her school. Her mother added Tracy's medical needs to the 504 Plan, allowing her to leave class whenever necessary. Without a thyroid, she does not have the capability to regulate her energy levels or hormones and uses medication in order to regulate her metabolism. Dealing with high levels of fatigue and weakness while in school made it difficult for her to focus on schoolwork. She did not want to attend school and found it challenging to remain in school once there. The medication she was taking for the first year after surgery did not work as effectively as she needed. Nine months passed between Tracy's first phone interview and her follow up second interview. During her second phone interview, she explained that her fatigue and inability to focus during school had improved over time, thanks to new medication that addressed her needs much better than the first. Tracy began university in September 2012.

Caleb

The third participant was a 15-year-old Native American/Caucasian male. At the age of 14, Caleb was diagnosed with Hodgkin's Lymphoma in November 2010. He began three months of chemotherapy treatment and six months of radiation. He was in six months post-treatment at the time of the first interview. Like most patients undergoing chemotherapy treatment, Caleb became weak and suffered nausea and vomiting after his first treatment. The intensity of his treatment required Caleb to stay home from school. He was absent for one school quarter, during which time he received homebound tutoring through the public school district. Once he returned to school, Caleb's teachers worked with him as often as they could, asking him to come in after school to work one-on-one, or do extra credit work to make up for falling behind academically. Upon reintegration to school, Caleb's homebound tutor spoke with each of his teachers so that they could assess his needs for each class. After seven months of treatment, and missing one quarter of school, Caleb got the news that his cancer was in remission. At the time of the second interview, Caleb was focused on school but was not afraid to stop his hard work to take time to have fun with his friends.

Brandon

The fourth participant was a 14-year-old Caucasian male. The only symptom Brandon felt before his diagnosis was a lingering cough. After an urgent care visit, the doctor ordered an x-ray of Brandon's chest, where he found a mass in his chest.

Brandon was diagnosed with Non-Hodgkin's Lymphoblastic Lymphoma in September 2008. He was 11 years old at the time. Brandon received a year and a half of both oral and intravenous chemotherapy. He suffered common side effects from chemotherapy, including nausea, hair loss, and a lack of appetite. He also received regular lumbar punctures. The steroids that he took to help the lumbar punctures heal caused an increase in his appetite. During treatment, Brandon was too sick to attend school. His public school did not offer any supplemental accommodations during his absence. So his parents decided to enroll him in a digital homeschool that would help him maintain his grades until he could return to school again.

After being absent from his public school for one-year, Brandon returned to school for the last two weeks of sixth grade to help him acclimatize to the routine of school again. Brandon was told that his cancer was gone in June 2010. He needed to continue the course of his treatment, which would last another six months. During seventh grade while he was still receiving mild cancer treatment, Brandon was absent regularly, but was still able to keep up with his schoolwork. Brandon's first interview took place 12 months after he stopped treatment.

Aaron

The fifth participant was a 17-year old Caucasian male. After experiencing difficulty swallowing when he was 15 years old, Aaron was diagnosed with Mucoepidermoid Carcinoma (a cancerous mass on the salivary glands). During surgery, the doctors were unable to remove the entire mass because they did not want to jeopardize Aaron's vocal cords. After surgery he underwent 31 radiation treatments, five days per week, over a period of six weeks in total. During this time, Aaron was absent for two weeks of school, during his recovery from surgery. His school did not see a need for him to enroll in supplemental education since he was absent for a short period of time. His teachers allowed him to finish the semester without taking his final exams since he had exemplary grades throughout the semester leading up to his diagnosis.

Aaron finished his radiation treatments in March 2010; although he did not know if the treatments worked until he received the results of his first scan. He was informed in June 2010 that his cancer was gone. Aaron's first interview took place 18 months later. In January 2012, Aaron had a relapse scare when his doctors found that the lump they had left in his neck had increased in size. Aaron required a second surgery to remove the rest of the mass. The doctors were able to remove all of the mass and Aaron did not need further radiation treatment. As a result of his treatment, Aaron carries water with him at all times to help him produce saliva and avoids certain foods like dry breads or candy. Aaron began university in September 2012.

Tim

The sixth participant was a 14-year-old Caucasian male. Unlike the previous participants, Tim was never diagnosed with cancer. When he was 8 years old, he was diagnosed with Neurofibromitosis (a genetic disorder that causes abnormal cell growth in the nervous system, resulting in tumors). Tim had two benign tumors (one on each optic nerve) that were impairing his eyesight. Due to the nature of tumor growth, neurofibromatosis is often treated with cancer treatments to shrink or remove tumors. Tim experienced typical side effects from a year and a half of chemotherapy treatment such as weakness, some hair loss, and weight loss. During treatment, he attended his parochial school regularly, but was absent each Friday to receive his treatments.

The support that Tim received from his school was positive, but limited. The school was ill equipped to provide accommodation for Tim's regressing eyesight. Despite attempts to collaborate with the local public school district's Braille specialist, Tim still struggled to achieve academically. Tim and his family decided to enroll him in the state school for the blind in February 2011. Tim's first interview took place 9 months after starting at his new school. He attends school with 66 other students who have visual impairments, and lives in a cottage at the school with fourteen to sixteen other boys from Sunday to Friday. On the weekends he returns home to be with his family.

At the time of his follow-up phone interview in June 2012, Tim explained that his vision had mildly improved in the nine months since the first interview. However while his sight was beginning to improve, Tim began feeling pain in his leg. Behind his knee, a tumor approximately the size of a deck of cards was growing. Doctors surgically removed the tumor, and Tim was absent for the last month of school to recover from surgery. He was in a wheelchair for 3-4 weeks. The school for the blind accommodated him to complete the year without taking his final exams.

Kevin

The seventh participant, Kevin, was a 14-year-old Caucasian male who chose to have his mother present during the in-person interview. Kevin began experiencing headaches when he was 11 years old. He was diagnosed with a grade III Anaplastic Astrocytoma (a fast-growing cancerous brain tumor). Kevin had surgery in May 2009 to remove his left eye and his left optic nerve before starting six weeks of radiation and ten months of oral chemotherapy. He took his chemotherapy medication every night for five nights, followed by three weeks off. He suffered from continuous headaches and hair loss as a result of the radiation treatments. Kevin stopped treatment in March 2011, which was 21 months prior to his first interview.

Kevin and his siblings (two triplet brothers and one sister) were homeschooled before his cancer diagnosis. Since their mother was their homeschool teacher, it was difficult for her to keep up homeschooling while juggling the demands of Kevin's treatment. His siblings were given the choice to attend public school during his treatment, while Kevin stayed at home. Kevin finished treatment in June 2010, and received the news that his cancer was in remission. With only one eye, his depth perception is handicapped, making it more difficult for him to catch things or grab items in front of him.

Allison

The final participant was a 17-year-old Caucasian female. At 11 years old, Allison suffered from major migraines and was underweight for her height. Three years later at 14 years old she was diagnosed with a Pilocytic Astrocytoma (a brain tumor on her spinal cord) in October 2008. Her doctors scheduled surgery to remove the tumor eight days after diagnosis. She also received two years of intravenous chemotherapy to arrest the growth of the parts of the tumor that the doctors could not remove. Allison finished treatment in September 2010. Her first interview took place 15 months later. During treatment, Allison was absent from school for her first two years of high school. Being an advanced student, the school district was unable to support her academically during her absence. They offered her a school tutor, but Allison declined because the tutor was not able to tutor her in her advanced-level classes. Subsequently, Allison's mother enrolled her in an academic homeschool and taught her daughter herself to ensure that she would not fall too far behind her classmates academically.

Allison returned to school for 11th grade, in her junior year. She had to work hard in order to graduate from high school along with her classmates. She had a supportive counselor and was able to catch up to the academic level of her peers through extra credit schoolwork and summer school classes. Allison planned to attend university in Autumn 2012.

Participant Demographics

Initially, I had hoped to recruit purposefully for variation across diagnosis, gender, and grade level; however that was not feasible due to the small population size for recruitment and the sensitive nature of the topic. Table 1 shows the participant medical demographics. The diagnoses of participants in this study included: acute lymphoblastic leukemia (ALL), metastatic capillary thyroid carcinoma, Hodgkin's lymphoma, non-Hodgkin's lymphoblastic lymphoma, mucoepidermoid carcinoma, neurofibromitosis, anaplastic gastric carcinoma, and pilocytic astrocytoma. Three students were enrolled in ninth grade, one student was enrolled in tenth grade, one was in eleventh grade, and three students were enrolled in twelfth grade at the time of interview. The average age at onset of disease was approximately 13 years, while the average age at post-treatment was 14.5 years. The average age at the time of interview was approximately 15.75 years.

Table 4.1 Participant Medical Demographics

	Age at interview	Diagnosis	Date of diagnosis	Age at diagnosis	Treatment			Date stopped	Age at end of treatment
					Chemo	Radiation	Surgery		
Jamie	17	Acute Lymphoblastic Leukemia (ALL)	10/2008	14	X			11/2010	16
Tracy	17	Metastatic Capillary Thyroid Carcinoma	08/2010	16			X	11/2010	16
Caleb	15	Hodgkin's Lymphoma	11/2010	14	X	X		06/2011	15
Brandon	14	Non-Hodgkin's Lymphoma	09/2008	11	X			11/2010	13
Aaron	17	Mucoepidermoid Carcinoma	12/2009	15		X	X	03/2010	16
Tim	14	Neurofibromatosis	08/2005	8	X		X	02/2007 06/2012	10 15
Kevin	15	Anaplastic Astrocytoma	05/2009	13	X	X	X	04/2010	14
Allison	17	Pilocytic Astrocytoma	10/2008	14	X		X	09/2010	16

Student school types also varied as seen in Table 2: Participant School Demographics. School types at time of diagnosis included: six enrolled in public school, one enrolled in home school, and one enrolled in a parochial school.

Table 4.2 Participant Treatment and School Demographics

	Age at interview	Treatment			School type at diagnosis	Time absent	Supplemental education during treatment
		Chemo	Radiation	Surgery			
Jamie	17	X			Public	2 Years	None
Tracy	17			X	Public	1 Quarter	Tutor
Caleb	15	X	X		Public	1 Quarter	Tutor
Brandon	14	X			Public	1 Year	Homeschool
Aaron	17		X	X	Public	2 Weeks	None
Tim	14	X		X	Parochial	None	Accommodations
Kevin	15	X	X	X	Homeschool	1 Year	None
Allison	17	X		X	Public	2 Years	Homeschool

Looking at school type allowed me to explore whether specific types of schools might influence the role of school on adolescents in cancer survivorship. Supplemental educational provisions during treatment included: two enrolled in homebound schooling, two enrolled in homeschooling (arranged independently from the school district), three receiving no supplemental education during absence, and one receiving special accommodations while staying in school. Length of school absence during treatment included: two participants absent for two years, two participants absent for one year, two participants absent for one quarter of the school year, one participant absent for two weeks, and one participant who attended school regularly during treatment.

Interview Analysis

I used thematic analysis to analyze the participants' interviews. I borrowed the structure for this analysis from Interpretive Phenomenological Analysis (IPA). These steps are outlined by Smith, Flower, and Larkin (2009). The goal in analysis was to determine emerging themes so that they could be fully explored and compared between individuals, to understand the participants' experiences with education.

Step One – Reading and Rereading

Once the transcription service returned the documents, I needed to undertake initial familiarization with the data in preparation for analysis. I listened to all audio files while following the texts to check for any errors in transcription. I also noted any details that the transcription service did not include, such as (laughs), where appropriate to understand the context for the conversation. I enriched the transcripts in this way because of my own sense that long pauses and moments of laughter should be included in the analysis to describe, for later interpretation, the participants' emotional state at the time of interview. They illustrate psychological cues during conversation, which become more important particularly during phone interviews when the interviewer and interviewee are not able to rely on visual cues. I needed to be careful to avoid the implication of bias during this enrichment process of the transcripts, thus listing only audio cues such as (laughs) rather than making inferences such as (nervous laughter).

As a final step in getting acquainted with the data, I read the transcripts a second time alongside any notes that were taken at the time of the interview to check the match between my notes and the transcript. I also began to note words, phrases, or themes that were repeated by participants to keep a record of them. For example, my early notes show that the first participant, stresses normalcy during her interview when she talked about getting back to "normal" and made a negative comparison of herself to her peers for feeling different from them; while the third participant, stresses a positive shift in his life perspective, a desire to teach his friends how to appreciate life more and to generally embrace a more positive outlook.

Step Two – Initial Noting

At this stage, I began initial noting, or free textual analysis. Interpretive noting helped me to understand why and how the participant has the thoughts or concerns that are stated in discussion, which influences the meanings he or she places on a situation, thus affecting how he or she experiences a situation. Constant comparative methods (CCM), a strategy which was originally defined by Glaser and Strauss as "while coding an incident for a category, compare it with the previous incidents in the same and different groups coded in the same category" (1967: 106), is most often used in qualitative methodologies to create knowledge that is more generally descriptive or interpretive. Content analysis, naturalistic inquiry, and interpretive description are qualitative methods that depend on CCM to develop ways of understanding human phenomena within the context in which they are experienced. This is why I chose IPA as the method of analysis to interpret and understand the findings from the study.

Smith et al. (2009) stress the importance of flexibility in interpretation in IPA, making room to incorporate CCM into analysis. I used CCM with IPA to provide a framework during the coding process. This step involves reviewing the transcripts and assigning codes to words or phrases that are meaningful or may occur frequently. This stage of coding is flexible and is up to the researcher to interpret the value of the text. By observing how my supervisor coded an initial section of the transcript, I was able to begin the coding process. The lens through which I analyzed the text brought my past expertise in working with children and adolescents with cancer into play, allowing me to better understand the participant experiences as they were described. Corbin and Strauss define this step as, "the process of breaking down, examining, comparing, conceptualizing, and categorizing data" (1990: 61). Glaser and Strauss explain that CCM can be done by memory and at the researcher's discretion. Codes may be listed as simply one word (for example, "normalcy"), or they may be a series of exchanges between the interviewer and the interviewee. For example, the following was coded as "school tutor:"

> *"Allison: I was in all AP (classes) and (the tutor) was like I cannot help you with that. My mom went to a meeting with all of my teachers. My teachers did help; they gave my mom all the work, but (the tutor) said no I can't help you with it basically.*
> *Interviewer: You met her one time?*
> *Allison: She met with my parents one time, but she never met me.*
> *Interviewer: You never talked to her yourself?*
> *Allison: No. At the very end she wanted to come and be my proctor, my test proctor to watch me take my finals and my mom said no." (p. 3)*

Smith et al. (2009) explain that the codes derived directly from the data help the researcher comprehend the meaning behind participant experience. At this stage, I needed to use care in how interpretations were made and codes were assigned so as not to misinterpret the meanings participants place on their experiences.

Step Three – Developing Emergent Themes

The challenge in step three is to exercise focus on the text, while recalling interpretations during *Initial Noting* to understand statements where the participant has emphasized stronger meaning. As mentioned earlier in this chapter, the steps of analysis slowly become jointed in nature as the participants' experiences meet the researcher's interpretations (Smith et al., 2009). In developing emergent themes, the themes should reflect both participant words and researcher interpretation. I used some of the language from the adolescents to assist in coding, for example "routine" is a term that was mentioned often in the participants' own words. However I also coded items into my own words, for example listing "uncertainty" for instances pertaining to participant feelings of the unknown:

> *"I didn't know how to start back my life." – Jamie, on remission*
> *"I have no idea what I'm supposed to feel like." – Tracy, on remission*
> *"I didn't know what to think." – Tim, on his diagnosis*

The two codes, "uncertainty" and "routine," contributed to the overall theme of *Control* since "uncertainty" is the result of feeling a lack of control in what the participant is experiencing, which was most often associated with participant medical experiences. "Routine" is emphasized suggesting an attempt to regain control and structure in their life, which was most often associated with participant educational experiences. Creating the codes in the data using both participant and researcher language allowed for a joint overview of the educational experience during and post cancer treatment.

Using Dedoose 4.5.91 and Microsoft Word, I began to define the categories as themes emerged. The software assisted in being able to view the codes pertaining to a category outside of context, revealing the meaning at the heart of each statement or word. This illustrated themes more clearly in terms of what needed to be interpreted further in the text. Codes were merged into larger themes, for example: "comparison to others," "difference," "bullying," and "mocking" contributed to the overall theme *Negative Peer Interaction*. Codes were also merged throughout the analysis, for example: "tired," "sick," "hair loss," and "lack of focus" were codes that were merged into the new code "treatment effects" as it began to show how the effects of treatment influenced the participants' daily life and educational experiences. The themes comprised overall categories, for example "Negative Peer Interaction," "Comparison of Self to Others," and "Peer Support" contributed to the overall category *Social Reintegration*.

Step Four – Searching For Connections Across Themes

This step involves clarifying the context of the main themes to see how themes may fit together. At this point, Dedoose and Microsoft Word were helpful because they allowed me to compile the codes of one theme together, omitting other text, for a more focused analysis on each theme. I reviewed each code and how it fit into each theme to check for reliability, which "refers to the degree of consistency with which instances are assigned to the same category… by the same observer on different occasions" (Hammersley, 1992:67). The coding tree for the interview data can be found in the Appendix on page 542.

The five main ways of making connections across themes during the analysis are in line with those described by Smith et al (2009), as follows: Abstraction is matching similar themes, for example "like with like" (p.34). This was done often in this study. An example includes codes relating to *Responsibility*, particularly in reference to educational experiences. Subsumption is merging themes together, which was illustrated in the aforementioned *Treatment Effects* example. Polarization is connecting themes through oppositional relationships, meaning that the themes may be similar but the experiences were contrasting. This was done in the example of "uncertainty" and "routine." The codes indicate opposite experiences, where one describes a feeling of the unknown for what may come or how to proceed (uncertainty), indicating a number of possible outcomes in a situation, and the other describes the presence of structure (routine), which implies having direction and assurance. When these codes are applied together, it becomes clear that *control* is a theme where participants have applied value and meaning in their experiences. Contextualization requires the researcher to incorporate narrative elements, such as interpreting tones of sarcasm or humor when necessary or conditional experiences. I used this connection the least in this research project, since interpreting tones of voice would be challenging with phone interviews. Lastly, numeration refers to codes derived purely from the frequency in which they appear in the text. This connection was demonstrated with the code *Normalcy*, as the word "normal" was mentioned often throughout the interviews. Smith et al. (2009) explain that the researcher can choose to utilize all types of connections or only a few, but stresses that the more connections are made, the better participant experience can be understood.

Step Five – Move To Next Case

At this stage, I moved on to the next participant's interview. I was careful, however, that the depth in which I now understood the previous case did not influence how I viewed the current or following cases. This was done by allowing for a couple of days break between interpreting interviews, so that I would approach each interview with a fresh mind. I also analyzed the interviews multiple times. The first time, the interviews were analyzed in the order that they were conducted; however I also analyzed the interviews in a different order each time so that the previous interview was not influencing my interpretations. In each case, I repeated the previous four steps with all participants in the study.

Step Six – Patterns Across Cases

In this final step, I was aware of the prominent themes from each participant experience and could clearly understand the meaning the participants place on their experiences. I interpreted themes across participants to discern which themes occurred in multiple experiences despite varying details such as cancer type, treatment type, or school type. These themes addressed the research questions and provided the basis for describing the experiences of adolescents in cancer survivorship.

Analysis of Adolescent Coping Scale

The scales used to complement the semi-structured interview were initially intended to be the Adolescent Coping Scale – Short Form and the Piers-Harris Children's Self-Concept Scale. These scales were chosen to address the research questions, providing me with an understanding of the participant experiences with education during and post treatment. Through interviews, a participant can describe his or her experiences in his or her own words, making interviews the primary source of data in this study. It is less common to use standardized scales in experiential research, which relies primarily on interviews and observations; however, researchers are encouraged to be innovative in how IPA is approached (Smith et al., 2009). I initially chose to include the Adolescent Coping Scale – Short Form (ACS-Short) and the Piers-Harris Children's Self-Concept Scale (Piers-Harris) in this research project. Both scales can be used quantitatively in large-scale studies; however, both scales also include a qualitative global profile of the respondent. These profiles provide researchers with an understanding of the coping strategies for the ACS-Short and the self-concept for the Piers-Harris that each participant exhibits.

Upon doing the analysis for this study, it became clear that the Piers-Harris scale did not appropriately address the research questions. While a self-concept measurement would be useful in conducting future research on understanding the experiences of adolescents in cancer survivorship, the Piers-Harris scale is intended to assess self-concept in healthy adolescents. The participants in this study are in the Post-treatment stage of cancer, which is a transitional stage between sickness and health. Therefore the reliability of this scale to accurately assess the self-concept for this population is limited.

Therefore I relied on the Adolescent Coping Scale to gain additional insight into the participant's experience beyond the interviews. The scale asks the participant to identify his or her greatest concern in his or her own words. This contributes to the study because it illustrates how the participant places meaning on his or her experience through coping.

The biggest challenge in utilizing the scale in this way is that no other study has used this scale purely for qualitative purposes. Applied in conjunction with interviews, the Adolescent Coping Scale provided further information regarding coping strategies. This scale contributes to the research questions by illustrating how the participant is affected by his or her concerns and how he or she chooses to cope with the effects. Noting whether the participant is using productive or non-productive coping strategies provides insight into whether he or she is well adjusted to their concerns.

The Adolescent Coping Scale is intended to describe how each participant copes with the main concerns that he or she has in life. This instrument begins by asking the participant to recall something that is a concern for them and how it has affected their daily life, in an open-ended question. The instrument allows the participant to identify the concern that is at the forefront of his or her mind, which provides a great deal of insight regarding the participant's priorities and self-awareness. The scale continues into a Likert scale after the open-ended concern is identified, asking the participant to scale eighteen questions that focus on how often he or she uses various methods of coping with his or her main concern. The five-point scale ranges from "does not apply or doesn't do it" to "a great deal." Lastly, the scale includes an open-ended nineteenth question that encourages the participant to provide his or her own way of dealing with the concern that was not listed in the above eighteen questions. This question also provided a great deal of insight for the researcher into how the participant chooses to cope with his or her main concern because it is written in their own words. Unfortunately despite encouragement for participants to complete the nineteenth question, many left it blank stating that the other questions already covered how he or she chooses to deal with his or her concern. This scale helped me to understand the experiences of the participants more than just interviews alone because it provided insight not only into what participants identified as their major concerns, but also the methods they used to cope in addressing their major concerns.

Table 4.3 Adolescent Coping Scale Strategies

Coping Style	Productive Coping	Reference to Others	Non-Productive Coping
Coping Strategies	Focus on solving the problem	Seek social support	Ignore the problem
	Focus on the positive	Invest in close friends	Keep to self
	Word hard and achieve	Seek to belong	Wishful thinking
	Seek relaxing diversions	Social action	Tension reduction
	Physical Recreation	Seek professional help	Self-blame
		Seek spiritual support	Worry
			Not cope

I used the ACS – Short Form, which reliably assesses 18 distinct coping strategies, listed above in Table 4.3. The Short Form consists of 18 items drawn from the Long Form, which incorporates one item per scale from the long form. The Long Form consists of 80 items in total. I narrowed the focus of the short form assessment into three short forms (ACS – Short Sample, Appendix p. 335). Whereas the original short form asked the participant to identify their overall main concern, the adjusted short forms asked the participant to identify a concern specifically pertaining to his or her cancer experiences, school experiences, and social experiences.

Narrowing the focus of the scales does diminish the validity of the original scale concept, which is to ask the participant to identify their main overall concern. For example, if the participant indicated his or her overall concern as relapse, then the scale indicates that the recurrence of illness is the main daily stressor for that participant. If the participant indicated falling behind academically as his or her main concern, then it becomes clear that the participant’s absence during illness may have affected his or her school experience. However by specifying a topic for participant concerns, I was able to focus on how the participant views his or her experiences with cancer treatment, school, and social interactions. This also allowed me to assess whether the participant uses the same methods of coping for various concerns in his or her life. For example, if a participant demonstrates productive coping regarding his or her school concern, but non-productive coping in his or her illness concern, it indicates that the participant is having difficulty managing his or her concerns regarding illness. Similarly, if the participant exhibits one method of coping across all areas of concern (illness, school, and social), then his or her responses indicate consistency in coping. The findings from the Adolescent Coping Scale are discussed in Chapter 8.

Ethical Considerations

This study had ethical clearance from the Central University Research Ethics Committee (CUREC) at the University of Oxford. The CUREC application is included on page 307 and was approved on 1 February 2011, prior to the beginning of fieldwork. There were several ethical considerations when conducting a research project that includes participants under the age of eighteen and includes details of their medical history.

Gaining consent for adolescents to take part in this study was challenging. “Their participation is controlled by a hierarchy of gatekeepers including ethics committees, organizations, professionals, parents, caregivers and teachers” (Powell & Smith, 2009). These people influence whether a child or student can participate in research and to what extent their participation will continue. I gained voluntary, informed consent from a parent or guardian of the adolescent for their child’s participation. Once both the parent or guardian and the participant understood the details of participation, it was not difficult to gain consent.

To clarify the details of participation in the study, I first allowed the parent or guardian and the participant to read the forms on their own, and then I went through the forms verbally with them and answered any questions they had. During the verbal review of the consent forms, I emphasized the participant’s right to leave the study at any time. I also emphasized the participant’s right to report any inappropriate behavior on my behalf or any situation during fieldwork that caused them discomfort to the research supervisor, and were provided with necessary contact information. I kept the original signed forms, scanned them into digital copies, and emailed them to the parent or guardian to keep in their records. Blank copies of the consent forms are located on page 334 of the Appendix.

The United Nations Convention on the Rights of the Child (CRC) identifies article 12 as the child has a "right to express an opinion freely and have it taken into account on all matters that affect them" (Powell & Smith, 2009). This means that a researcher would not only need the consent of the parent or guardian for the adolescent to participate, but the adolescent must also provide his or her consent. "The unequal power relationship between children and adults may influence children's perceptions of the participation choices available to them, in particular the option of dissenting" (Coyne, 2010). It was important that the adolescent understood that he or she could opt out of research participation at any time should they choose to do so. This was explained to all participants at the start of the study, both verbally and through written consent, and was reemphasized at each meeting during the field study to ensure that the participant was always aware of their option to decline further participation, or ask me any questions as they may arise.

Everyone in the United States with a medical condition has their privacy protected by the Health Insurance Portability and Accountability Act of 1996 (HIPAA). The four parts to HIPAA that protect a child are privacy, security, identifiers, and transactions and code sets. Privacy is the most important of the four, stating in its simplest form that if a person has a right to make a health care decision, then he or she has the right to control information associated with that decision regarding their Protected Health Information (PHI). In the case of children and HIPAA, this decision is often left to the parent or guardian; however as children become teenagers they gain a certain amount of independence and control over their PHI. It was vital throughout the study that no privacy laws were violated. Therefore to protect the participants' rights for anonymity throughout this study, each participant was initially assigned a number. However this approach proved to be confusing when conducting in-depth analysis and discussion. As a result, at that stage I selected pseudonyms from a selection of common adolescent names in the US and were matched for participants' sex. Any further identifying information (such as school name, hospital name, family members' and teachers' names, and locations) was redacted or changed to protect the privacy of the participants and their families.

This is a highly sensitive research topic because it not only deals with participants under the age of 18 years old, but also medically sensitive information that can carry with it emotional sensitivity and expose intimate family relationships. I took into consideration possible psychological effects that cancer may have on an adolescent; although literature shows that there have been no significant differences in psychological distress between patients, survivors, and healthy controls (Anholt et al., 1993; Kazak et al., 2010; Spirito et al., 1990; Jamison et al., 1986; and Stam et al., 2001). My personal expertise was in working with young people, aged six to seventeen, who have experienced cancer. I received several years of training through volunteer experiences on how to speak with children and adolescents in cancer survivorship about their illness and how it affects their daily life. My training consisted of staff role-play situations, seminars and presentations from parents and adolescent and childhood cancer survivors, and talks by medical personnel. My experience in volunteering for eight years also provided me with the knowledge on how to best generate a conversational connection based in trust for sharing sensitive medical information. There was mild emotional sensitivity during data collection. The participants spoke openly and honestly regarding their experiences. As a part of the CUREC application, I was asked to identify someone who could support and advise me should I feel stress or strong emotional reactions to the interviews. While I had several people who were available for support, I did not require it for this study. At no time did I observe emotional or psychological distress in my participants or myself during data collection.

As children get older, their coping skills tend to increase (Perez, 1997; Zimmer-Gembeck & Skinner, 2011). When children are younger they have less control over their emotions, and situations such as a researcher asking them questions about a sensitive topic can be quite traumatic for them. It was for this reason that I chose to conduct this study with high school-aged adolescents rather than elementary school children. The ability of high school- aged adolescents to understand what it means to consent and participate in research, combined with their coping abilities lessened the ethical and emotional dangers that might have otherwise been associated with this research.

Study Limitations

This study has limitations that should be considered when interpreting the findings. Since this is a descriptive, small-scale study that focuses on the experiences of eight participants, generalization to the adolescent cancer survivor population may be limited.

Secondly, when accounting for the ethical constraints of recruiting participants who were under the age of 18 years old and have a medical condition, only those participants who volunteered for the study could be included. It is likely that these volunteers were participants who were comfortable discussing their cancer experience, as opposed to those survivors who were not as well adjusted and would not be comfortable recounting their experiences in a research study (Rubin and Rubin, 2005). Davies et al. (1998) emphasize that participation in a qualitative study can provide cancer patients and survivors with a sense of contribution in the hopes that it will help to improve the experiences of others. The participants in this study were made aware that this doctoral thesis was intended to contribute to the field of research for the population of pediatric cancer survivors, which may have encouraged honest participation.

Thirdly, another major limitation of this study was the approach taken to data collection. I intended to conduct in-depth interviews with the participants to understand their cancer and educational experiences in great detail. This was difficult due to several factors. Firstly, the widespread location of participants required me to conduct in some cases phone interviews. This hindered me in being able to respond to visual cues during the interview, which could have prompted the participants to explain their experiences in more depth.

Fourthly, given the sensitive nature of the research topic, it was challenging to encourage the participants to elaborate on their experiences without causing them psychological or emotional discomfort.

Fifthly, I prepared for the interviews through reviewing literature and consulting briefly with my supervisor. While I had some previous experience in conducting short interviews, my experience in conducting interviews that required this level of qualitative depth was limited. This resulted in missed opportunities during the interviews to prompt the participant to further explain his or her responses. Consequently, the interviews in this study do not contain the level of depth and detail that I had originally intended. Future consideration of this topic would require, based on my experience, expanding researcher sensitivity to in-depth interview styles, recognizing opportunities where more depth could be achieved in order to collect richer data on this sensitive topic.

Lastly, I varied my approach to combining a formal interview with the completion of a questionnaire scale. There was one participant who requested to fill out the questionnaire first. Due to his visual impairments, I read the questionnaire out to him and he completed the form verbally, while I transcribed his responses. However allowing the questionnaire to be completed verbally and prior to the interview unfortunately was found to affect his responses during the interview. For example, when asked if he felt as if his parents were supportive he responded, “a great deal,” which was one of the responses on the Adolescent Coping Scale, Short Form, which uses a Likert Scale structure. It is possible that the participant may have had a different response if he had not been so recently responding “a great deal” as a part of the coping scale. If repeating this type of study again, I would provide the questionnaire to participants either at a different time that is separate from the interview, or after the interview was conducted. I would also strive in future research for either in-person interviews or video conferencing, as the latter is now more available. I felt as though the ability to gain the participants’ trust and forge a connection during interviews was easier and stronger when it was possible to see each other. Another lesson for me, having completed the fieldwork, was that in future studies I would focus more on preparation of the interview schedule and piloting it beforehand so as to ensure there was a better balance between open-ended questions, rather than wording of questions that might have been leading.

Chapter Summary

This chapter presented the research questions and outlined the methodology that was chosen to address the study's aim of describing the experiences of adolescents in cancer survivorship. I chose a semi-structured interview and one scale, namely the ACS – Short Form questionnaire to understand participant experiences with cancer and education during and after cancer treatment. This chapter also included an overview of my expertise as a volunteer with the American Cancer Society, a description of the eight participants and their demographical make-up, details of how I analyzed the data using IPA to guide my thematic analysis, ethical considerations, and study limitations. The following three chapters will present the findings of the data collection. Chapter 5 focuses primarily on the physical experiences of the participants. Chapter 6 focuses on the participants' experiences with psychological effects. Chapter 7 focuses on the participants' experiences with school throughout cancer survivorship.

CHAPTER 5

Participant Experiences with the Physical Effects of Cancer and Treatment

Introduction

This chapter presents the findings from this research study regarding how the physical effects of cancer and treatment impacted on the participants' engagement with school. Educational engagement is defined in this study as, "the extent to which teenagers remain in contact with school and/or receive educational support whilst undergoing treatment or during recovery" (Pini et al., 2012, p. 686). This chapter is organized by the Stages of Cancer to illustrate the progression of the cancer journey. The participants' experiences with the physical effects of cancer and treatment, and how these effects impacted on their ability to maintain their educational engagement is discussed in each section.

The steps of interview analysis described in Chapter 4: Study Design resulted in approximately 500 codes that had been organized into themes. Each theme was further organized into overall categories. For example, codes such as: *vomit*, *compromised immune system*, *vision impairment*, and *hair loss* contributed to the theme "Physical Side Effects of Treatment" (Coding Tree, Appendix p. 538). This theme was organized within the category titled: Cancer Treatment. Throughout this process, I continuously checked the excerpts to make sure of their fit within the code title they were assigned. Some codes were repetitive and were therefore merged together, resulting in a single code. For example, *mom would bring medicine* was merged with the similar code *parent administers treatment*. Other codes were deleted due to repetition. As codes were merged and/or deleted where necessary, I checked the excerpts from transcripts to make sure that they still fitted within the code title they were assigned. This process resulted in a total of 503 codes for all interview transcripts. Lastly, I created larger classifications to promote organization of the data and to help me understand the connections between themes and across cases. For example, the category titled Cancer Treatment was grouped with other categories titled Pre-Diagnosis, Diagnosis, Transition from Treatment to Post-Treatment, Post-Treatment, and Relapse comprising the overall classification "Stages of Cancer."

The biggest challenge throughout analysis was organizing the codes when many overlapped in the way that the participants described their experiences. For example, an excerpt regarding sleeping in class could be coded as "*fatigue*" indicating an effect of cancer treatment, or "lack *accommodations in school,*" indicating that the participant was scolded by the teacher for dozing off while in class. Since there was so much overlap of how cancer and treatment effects impacted school and social interactions, many of these excerpts were assigned to multiple codes.

The physical effects of cancer and treatment can be severe, thus hindering the ability of adolescents in cancer survivorship to participate in daily activities, such as school. Healthcare continues to improve and more patients are surviving cancer long-term. By assessing what factors influence educational engagement throughout cancer survivorship, adolescents can be better prepared for how they can maintain their education throughout the treatment process.

Pre-Diagnosis and Diagnosis

Interview Questions Pertaining to Pre-Diagnosis

- What kind of cancer were you diagnosed with?
- When were you initially diagnosed?
- How did you handle getting that diagnosis?
- What symptoms were you feeling that prompted you to go to a doctor?

The Pre-Diagnosis stage of cancer is when initial symptoms are experienced and the patient begins to seek out medical attention. Physical effects that are felt during this stage are often in the form of symptoms of the cancer rather than side effects from any sort of treatment, since a diagnosis has yet to be made. The physical symptoms that the participants described in their interviews having felt prior to diagnosis resulted in 11 codes. Since the symptoms of cancer can vary depending on the type of cancer, only one code was described as having been experienced by more than one person. All other codes were described by a single participant. The most frequent codes included *headache*, *flu-like feeling*, *vision impairment*, and *weight changes*. This section presents the excerpts from the interviews regarding each of the above codes.

Headache

Headaches are a common sign that something is not right inside the body. Most often, headaches are a sign of minor problems such as allergies, head congestion, or dehydration. However, frequent and severe headaches can be a sign of a more severe medical problem. The two excerpts below show two participants who experienced headaches prior to their cancer diagnosis. Statements that refer to *headaches* have been highlighted in bold.

Table 5.1.1 Example of headache (1)

Allison, 17-year-old female, Diagnosed Pilocytic Astrocytoma 10/2008 *Treatment: Surgery (10/2008)/ intravenous chemotherapy, Treatment Stopped: 09/2010*
"It was October 20, 2008. There was, I do not know, I found out from an eye exam because ***ever since I was younger I suffered from migraines, really bad migraines to the point where half my body would be paralyzed and I could not see, talk, or anything. My pediatrician just kept saying that I had complicated migraines.*** *He never thought to give me an MRI, even though my mom asked him."*

Table 5.1.2 Example of headache (2)

Tracy, 17-year-old female, Diagnosed Metastatic Capillary Thyroid Carcinoma 08/2010 *Treatment: November 2010 – Surgery (11/2010), continues oral thyroid medication*
*"****I had a really bad headache. I would wake up with a headache and I would go to sleep with a migraine*** *and it would happen every single day. There was not a day that did not happen."*

The above excerpts show that the headaches that Allison and Tracy experienced were both frequent and severe, in some cases evolving into migraines. As Allison described in her interview, her pediatrician dismissed her headaches as migraines without seeking out a possible other cause for them. It was not until she went for an eye specialist appointment that they had concerns about an underlying cause for her headaches. The excerpt above from Tracy's interview shows that her headaches were so regular that they occurred daily. They would also transform from a headache into a migraine, as the day would progress.

While neither participant discusses how their school engagement was affected by the headaches they experienced, the regularity and severity with which they describe the headaches suggests that school engagement was likely affected.

When Allison says, “*really bad migraines to the point where half my body would be paralyzed and I could not see, talk, or anything*” (Table 5.1.1), it shows that she was physically debilitated by the headaches she experienced, likely making school engagement more challenging. Similarly, Tracy says, “*there was not a day that did not happen”* (Table 5.1.2), which also shows that she experienced these severe headaches while attending school, likely impacting on her ability to fully engage in school.

Flu- or Cold-like Symptoms

Common symptoms of cancer include feeling as though you may have a bad cold or flu. Many people experience a fever, fatigue, cough, and weakness, which can lead them to believe that they have the flu instead of something more severe, such as cancer. In this study, three participants discussed feeling flu-like, coughing, and looking sickly as symptoms prior to hearing their cancer diagnoses. Statements that fell within these codes have been highlighted in bold.

Table 5.1.3 Example of Flu- or Cold-like Symptoms (1)

Jamie, 17-year-old female, Diagnosed Acute Lymphoblastic Lymphoma 10/2008 *Treatment: chemotherapy, Treatment Stopped: 11/2010*
“At first, ***I thought I had the flu at first*** *and that’s why I came into the emergency room… It just felt like I had the flu all the time.”*

Table 5.1.4 Example of Flu- or Cold-like Symptoms (2)

Brandon, 14-year-old male, Diagnosed Non-Hodgkin's Lymphoblastic Lymphoma 09/2008 *Treatment: chemotherapy (oral and intravenous), Treatment Stopped: November 2010*
"I was going on a fieldtrip with the school, you go to San Francisco for three days and stay the night there, stuff ***and I had a cough, and my mom was just worried about it.*** *So we went over to this urgent care thing, to just check it out and get me on some medications so it could go away. They were slow so they just took and x-ray and there was a mass there so they just sent it over to the Children's Hospital and then the next day when my dad and me were on the bus there, the hospital called my dad and said, you have to get off the bus and come here right now."*

Table 5.1.5 Example of Flu- or Cold-like Symptoms (3)

Allison, 17-year-old female, Diagnosed Pilocytic Astrocytoma 10/2008 *Treatment: Surgery (10/2008)/intravenous chemotherapy, Treatment Stopped: 09/2010*
"I had always been thin when I was little so I always thought that was just what it was. ***Now that I look at pictures, I looked really sick****."*

Jamie explains that she felt as though she had the flu "*all the time*" prior to hearing her cancer diagnosis. As Allison looked back at photos of herself prior to diagnosis she realized that she looked very sick. Neither Jamie nor Allison's excerpts show whether their school engagement was affected by the physical symptoms they had experienced. However in Brandon's excerpt, his school engagement was clearly affected. He was about to embark on a three-day school field trip, when he was asked to leave the bus and head to the children's hospital. While it was not the cough itself that interfered with Brandon's school engagement, the diagnosis was urgent enough that he needed to leave his school activity immediately.

Cancer Treatment

Interview Questions Pertaining to Cancer Treatment

- Can you tell me what you had to do everyday for your treatment?
- How much medicine did you take?
- Did you take medicine at school?
- How often did you go to the hospital for your treatment?
- How long were you receiving that treatment?
- How did the treatment make you feel physically?
- Did your reaction to the treatment change each time you went, or did you feel the same way after each treatment?

In the Cancer Treatment stage, patients have already been experiencing some symptoms of cancer. The previous section showed the symptoms that the participants in this study experienced, and whether those physical effects might be expected have impacted on school engagement.

In the cancer treatment stage patients are aware of their diagnosis and have begun to take steps to treat their illness. Oncologists use a variety of tests and treatments, such as surgery, radiation, intravenous or oral chemotherapy, lumbar punctures, and radioactive iodine, to name a few examples. Each of these tests and treatments can have physical side effects that would impact on school engagement of the adolescent in cancer survivorship.

The physical effects that participants described having felt during cancer treatment in their interviews resulted in 29 codes. Some descriptions of treatment were specific to a single participant resulting in a single code, such as *burning sensation*, which was described by Allison as she received her intravenous chemotherapy. Some codes were described by six of the eight participants and coded 14 times, such as *hair loss*, and will be discussed further in this section. The frequency with which physical effects were discussed during the interviews illustrates the impact that they had on the participant. Similarly, physical effects that were discussed by multiple participants illustrate the commonality of the physical effects that are experienced as a part of cancer treatment. Furthermore, participants cope with and describe their experiences with the same physical effects in different ways, showing that while physical effects occur across participants, the way they are experienced may differ.

Of the 29 physical effects coded from the analysis of the interviews in the cancer treatment stage, the most frequent both in number of times coded and number of participants where codes were applied include *sick*, *fatigue*, *hair loss*, *vomit*, *compromised immune system*, *weight changes*, *pain*, *vision impairment*, *weakness*, *no appetite*, and *headache*. This section presents the excerpts from the interviews regarding each of the above codes.

Sick

Excerpts from the interview were applied to the code *sick* in the stage Cancer Treatment when the participant either used the word "sick" or referred to a general feeling of sickness or feeling unwell. Five out of the eight participants referred to feeling *sick* during the cancer treatment stage. Given the severity of the side effects of cancer treatments, it was common for the participants to discuss feeling sick and unwell during this stage. The two excerpts below show the participants' descriptions of how cancer treatment made them feel. Statements of being *sick* or not feeling well have been highlighted in bold.

Table 5.2.1 Example of feeling sick (1)

Allison, 17-year-old female, Diagnosed Pilocytic Astrocytoma 10/2008 *Treatment: Surgery (10/2008)/ intravenous chemotherapy, Treatment Stopped: 09/2010*
“Disgusting. It warms your blood – they have to actually push it in a syringe and it burns. I used to get hives and then ***I would get really sick afterwards, and they would give me a pill to knock me out for three days and I would not even remember because I would be really sick****.”*

Table 5.2.2 Example of feeling sick (2)

Caleb, 15-year-old male, diagnosed Hodgkin’s Lymphoma 11/2010 *Treatment: 3 months chemotherapy/6 months radiation, Treatment Stopped: 6/2011*
*“****It’s mainly just like sick, not feeling good*** *and just kind of got to hang out because you’re always tired.”*

Table 5.2.3 Example of feeling sick (3)

Brandon, 14-year-old male, Diagnosed Non-Hodgkin’s Lymphoblastic Lymphoma 09/2008 *Treatment: chemotherapy (oral and intravenous), Treatment Stopped: November 2010*
“Yeah, when you feel good, you just want to run and do everything because ***when you are down and feeling sick you just want to lie down and not do anything.*** *” – Brandon*

Table 5.2.4 Example of feeling sick (4)

Jamie, 17-year-old female, Diagnosed Acute Lymphoblastic Lymphoma 10/2008 *Treatment: chemotherapy, Treatment Stopped: 11/2010*
“Then tenth grade year, because I got diagnosed in ninth grade year. Tenth grade year, I tried to go back, but without doing like not really harsh chemo, but still chemo. That I was like doing inpatient and stuff like that. They put me on a half-day of school so I did one through fourth [period]. ***Then like I was just missing a whole bunch of days because I was really sick.*** *My mom just took me out then.”*

Table 5.2.5 Example of feeling sick (5)

Brandon, 14-year-old male, Diagnosed Non-Hodgkin's Lymphoblastic Lymphoma 09/2008 *Treatment: chemotherapy (oral and intravenous), Treatment Stopped: November 2010*
*"In Middle School, I was because I would have to go and get the lumbar punctures and **so I would have to miss a full day of school and maybe the next day if I was not feeling good.**" – Brandon, p.*

Table 5.2.6 Example of feeling sick (6)

Tracy, 17-year-old female, Diagnosed Metastatic Capillary Thyroid Carcinoma 08/2010 *Treatment: November 2010 – Surgery (11/2010), continues oral thyroid medication*
*"They would always text me and tell me what is going on at school. And one of them would come over and I didn't get **– I didn't have them come over a lot, just because I was never feeling good** or I was sleeping or we had family company or my mom's friends would come over that she had known for years just to say hi and see how I was doing. So I never had my friends come over because they wanted to go do something and I couldn't do it then."*

Tables 5.2.1 and 5.2.2 above illustrate how Allison and Caleb experienced cancer treatment physically. In Allison's experience, she suffered from an allergic reaction to her intravenous chemotherapy, resulting in hives, a burning sensation, and severe sickness. Caleb, who did not experience an allergic reaction to his treatment, describes his treatment as "*not feeling good*."

It has become common knowledge, however, to anticipate cancer treatment to cause patients to feel unwell. The severity of physical cancer treatment side effects can impact the on the ability of an adolescent to participate in daily activities. As Brandon explains in the above excerpt, he felt the need to embrace those moments when he felt well enough to participate in daily activities. The most common and arguably most important daily activity for an adolescent is to attend and participate in school. Students are absent from school or struggle to engage in school for a variety of health reasons, even the common cold. Yet the chronicity of cancer treatment calls into question the students' ability to attend school consistently throughout treatment. This finding confirms the findings from Deasy-Spinetta and Spinetta (1980) and Vance and Eiser (2001) that school attendance is impacted the most during cancer treatment. The excerpts above show how participants discuss how feeling sick affected their ability to attend school.

Jamie's excerpt (Table 5.2.4) shows how she attempted to return to school in the second year of her treatment when she felt it was more manageable. The school had made accommodations for her to attend school for a half-day. Yet she explains that while she felt as though her chemotherapy was more manageable it still caused her to feel sick and resulted in her absence from school. She and her mother decided to take her back out of school with the intention of returning when she completed cancer treatment. Jamie's experience with supplemental education in cancer survivorship is discussed further in Chapter 7. The second excerpt above shows that lumbar punctures caused Brandon to be absent from school for the day he would receive the treatment and the following day to recover. In both excerpts, attendance from school was directly affected by cancer treatments and the physical side effects.

When an adolescent is absent from school not only is their school engagement hindered, but their social interactions can also be affected. According to Zebrack and Chesler (2002), positive social interactions throughout cancer survivorship result in a higher quality of life. Therefore if social interactions are hindering during cancer treatment, the participant is experiencing a lesser quality of life. During adolescence, social interactions are an integral part of the transition from childhood into adulthood. Social interactions contribute to the formation of identity throughout adolescence and most often occur in the school setting since that is where most adolescents physically interact.

Tracy's excerpt above shows that mobile phone technology helps students with cancer that cannot attend school stay connected to their peers. However this excerpt also shows that she was unable to spend the physical time with her friends because she felt too sick due to her cancer treatment.

Fatigue

The code *fatigue* was applied to excerpts from the participants' interviews when they used the word *fatigue* or referred to feeling tired or having no energy as a result of their cancer treatment. Six participants discussed experiencing fatigue during their interviews. As with most illnesses, when the human body fights disease or infection, energy levels suffer so that the immune system can work at maximum capacity. As a result, fatigue is commonly reported as a side effect of cancer treatment. The excerpt from Caleb's interview in Table 5.2.2 shows that fatigue is often associated with feeling sick. This is shown when he says, "*kind of got to hang out because you're always tired.*"

The five excerpts below show how the participants experienced fatigue as a result of the various cancer treatments. The mention of feeling tired or fatigue has been highlighted in bold.

Table 5.2.7 Example of fatigue (1)

Tracy, 17-year-old female, Diagnosed Metastatic Capillary Thyroid Carcinoma 08/2010 *Treatment: November 2010 – Surgery (11/2010), continues oral thyroid medication*
*"**I didn't really do a lot at that point because I was so extremely tired I would come home and sleep until my mom made dinner**. She would wake me up, make me eat dinner and I would go back to sleep. I wouldn't even do my homework so I didn't have any time or it's not I didn't have any time – **I didn't have any energy to do anything.**"*

Table 5.2.8 Example of fatigue (2)

Caleb, 15-year-old male, diagnosed Hodgkin's Lymphoma 11/2010 *Treatment: 3 months chemotherapy/6 months radiation, Treatment Stopped: 6/2011*
*"During was really hard. Like most of the time I was sick and just like – well, actually not most of the time I wasn't sick**, just tired and couldn't really do much. Like, I'd want to do a lot of stuff so I'd go out and I'd just get tired really fast and burnt out.** So I'd have to come back. But, I'd hang out with friends as much as I possibly could."*

Table 5.2.9 Example of fatigue (3)

Brandon, 14-year-old male, Diagnosed Non-Hodgkin's Lymphoblastic Lymphoma 09/2008 *Treatment: chemotherapy (oral and intravenous), Treatment Stopped: November 2010*
*"**Well sometimes, they would give you different medications that make you feel different; they make you more tired sometimes. Sometimes they give you more energy like blood transfusions; you are energetic because you have an extra pint of blood. Some just make you super tired** and really sick and you could not eat or you would just throw up like instantly."*

Table 5.2.10 Example of fatigue (4)

Kevin, 14-year-old male, Diagnosed Anaplastic Astrocytoma 05/2009 *Treatment stopped: Surgery/Radiation/Chemotherapy, Treatment Stopped: 04/2010*
"I was tired when I took it. Of course, I was also tired from the radiation which was just terrible *because I went in every morning – the ray went through my nasal glands and made a terrible smell when I was in there having the radiation. I can't describe it but I guess it smells almost like burning flesh. I don't know, it was terrible."*

Table 5.2.11 Example of fatigue (5)

Allison, 17-year-old female, Diagnosed Pilocytic Astrocytoma 10/2008 *Treatment: Surgery (10/2008)/ intravenous chemotherapy, Treatment Stopped: 09/2010*
"I would get really tired. Once your blood count gets low, you feel really heavy, like you cannot do anything, *you are just really weak. I would feel nauseous and I would have a lot of drugs and pain too. I had a lot of drugs and my mom would make me go out and go shopping with her sometimes, like one thing per day."*

These excerpts show that fatigue is a common side effect of cancer treatment. The participants who spoke of their fatigue above were given various treatment types: radiation, intravenous chemotherapy, oral chemotherapy, and surgery. Yet the fatigue they experienced was similar despite their differences in treatments. Allison explains that she attributed her fatigue to having a low blood count. Yet Brandon explains that certain medicines made him feel tired, whereas a blood transfusion provided him with extra energy.

Feeling extreme levels of fatigue affected the participants' ability to engage in daily activities. Tracy explains in her excerpt that she had to be woken up to eat dinner and then would go back to sleep again. Caleb says that he would want to do things and would go out and "*get tired fast and burnt out.*" In Allison's case, her mother would encourage her to join in on running daily errands in an effort to motivate her to do at least "*one thing per day*."

These excerpts above show how fatigue had drastically impacted on the daily lives of the participants while undergoing cancer treatment. As Tracy also states, she did not complete her homework from school because she did not have the energy to do it. The participants' experiences with fatigue during cancer treatment exemplify Woodgate's (2005) "*zombie*" persona. This shows that not only do simple daily activities, such as eating dinner, become a struggle for adolescents during cancer treatment, but also that school engagement is likely to be affected.

Four excerpts from three interviews below illustrate how school engagement is impacted by fatigue during the cancer treatment stage. The mention of feeling tired or fatigue has been highlighted in bold.

Table 5.2.12 Example of school engagement and fatigue (1)

Jamie, 17-year-old female, Diagnosed Acute Lymphoblastic Lymphoma 10/2008 *Treatment: chemotherapy, Treatment Stopped: 11/2010*
"I do not know. I guess I really just – ***I was just tired a lot.*** *And after being out of the school that whole year, I guess I really did not have motivation to do it. I do not know,* ***I was just tired with being sick in bed.*** *That it was hard... I mean, it had just been me alone. Everybody coughing and stuff. I got sick a lot. I was just missing a whole bunch of days. My counselor thought it was like it would be best for me not to – just to go home and get dropped out after the second – after first semester."*

Table 5.2.13 Example of school engagement and fatigue (2)

Tracy, 17-year-old female, Diagnosed Metastatic Capillary Thyroid Carcinoma 08/2010 *Treatment: November 2010 – Surgery (11/2010), continues oral thyroid medication*
"Tracy: Last year I left early probably one, two, three times a week. And this year I probably leave early like once a week or I come to school late or – *Interviewer: Is that because of the headaches or because of other reasons?* *Tracy**: I don't want to go. And I just want more time to sleep in**."*

Table 5.2.14 Example of school engagement and fatigue (3)

Allison, 17-year-old female, Diagnosed Pilocytic Astrocytoma 10/2008 *Treatment: Surgery (10/2008)/ intravenous chemotherapy, Treatment Stopped: 09/2010*
*"[My school counselor] did. He just made sure that I wasn't walking too far just because **I was having problems with my energy levels at that time.** He was a very good person."*
*"Allison: Yeah, and I mean, I struggled with some teachers**. I would sleep a lot in my classes** and they would yell at me for it....* *And I mean, it was extremely frustrating because I had an '0' and there was no reason for them to be yelling at me. But **I had a hard time sleeping at nighttime after chemo just because my dose was all wrong and I didn't have a regular sleep schedule, so I would be sleeping in class** but I would do my work. They would still yell at me, though, for sleeping."*

These statements from the interviews show how fatigue has interrupted or impacted on school engagement for these adolescents in some way. The first excerpt from Jamie shows that it was a combination of both fatigue and sickness that kept her from being able to attend school regularly. In Table 5.2.4 in the previous sub-section, "*Sick,*" she stated that her mother chose to take her back out of school, yet this additional excerpt shows that her school counselor also recommended that she leave school. It is clear that Jamie was unable to maintain attending her mainstream school while actively undergoing cancer treatment. Jamie was advised to leave school by her mother and her school counselor. This is in contrast to Tracy's excerpt, where she had the freedom to leave school when she wanted, and frequently chose to do so due to her fatigue. Her excerpt is an example of how school attendance is impacted on by fatigue, thus making school engagement even more difficult.

In Allison's excerpts in Table 5.2.14 above, it is clear how fatigue has impacted on her school engagement, as well as how the school responded to her needs. The first of the final two excerpts shows that Allison's school counselor helped her to feel supported at school. He provided her with class locations that would be easier for her to get to without having to walk too far around the school. In the final excerpt above, Allison explains that her fatigue caused her to fall asleep in class. This resulted in being scolded by her teachers, despite her high academic achievement. This is particularly interesting because the other participants' experiences show how their fatigue negatively affected their school experience in some way. Although Allison was talking about falling asleep in class, she also talked about how her academic grades were unaffected by her fatigue. This excerpt shows that while physical effects of cancer treatment can challenge school engagement, Allison was able to overcome her physical challenges and still achieve good grades in school.

Hair Loss

It is common for hair loss to be associated with the physical side effects of cancer and treatment. In some instances, cancer patients will experience a full hair loss, while in others hair loss will be localized to a single location or will simply thin out rather than fall out. During the Cancer Treatment stage, five participants experienced hair loss as a physical effect. Two participants experienced localized hair loss. Aaron and Kevin got bald spots on their heads due to radiation treatment.

Neither participant commented on how they felt about it, which suggests that they were not bothered enough by the loss of their hair in a localized area to discuss it during the interview. Statements about hair loss have been highlighted in bold.

Table 5.2.15 Example of hair loss (1)

Brandon, 14-year-old male, Diagnosed Non-Hodgkin's Lymphoblastic Lymphoma 09/2008
Treatment: chemotherapy (oral and intravenous), Treatment Stopped: November 2010

> *"Interviewer: Did it make you feel, I mean how did you feel socially not having any hair?*
> ***Brandon: I did not like it**.*
> *Interviewer: Can you explain?*
> *Brandon: That is kind of a hard question too.* ***How did I feel not having hair? I would just wear a hat or a beanie or something.***
> *Interviewer: So it was not that awkward for you?*
> *Brandon: No, I do not think so."*

Table 5.2.16 Example of hair loss (2)

Allison, 17-year-old female, Diagnosed Pilocytic Astrocytoma 10/2008
Treatment: Surgery (10/2008)/ intravenous chemotherapy, Treatment Stopped: 09/2010

> *"Interviewer: Okay. You said that you never lost your hair.*
> *Allison:* ***No, I didn't lose a lot, but I have really, really thick hair so it got thin.***
> *Interviewer: Okay, so your hair thinned out.*
> *Allison****: It was really hard thing to go through because I have blonde really pretty hair and I wish I did not cut it off.****"*

Table 5.2.17 Example of hair loss (3)
Jamie, 17-year-old female, Diagnosed Acute Lymphoblastic Lymphoma 10/2008 *Treatment: chemotherapy, Treatment Stopped: 11/2010*
"The treatment just stopped me from doing all that with me being sick. Then, of course I didn't want to go out. ***I was bald headed.*** *I was just awful. The treatment was worse."*
"He would ask me about school and stuff. He asked me if I had a boyfriend. ***Of course I don't have a boyfriend! I don't have any hair.****"*
"It depends on what kind of things they want to know. Sometimes they take it as a joking matter. I will tell them… because I make jokes about it. ***When I first started losing my hair I said I was like fire marshal Bill. Then I said when I shaved it all off I looked like Mini Me.*** *Some people take that and run with it. I am like, okay. I said that as a joke, but don't keep saying it. So, I guess it depends on how much they ask."*

The excerpt from Brandon's interview (Table 5.2.15) shows that he did not like being bald, but that he also did not feel awkward about it because of the way in which he coped by wearing a hat to cover it up. The male participants do not express much frustration or unhappiness in their interviews regarding their experiences with hair loss. The female participants, however, had a more difficult time coping with the hair loss that they experienced, as the second and third examples illustrate above.

Hair loss in adolescent cancer patients can be difficult because of the role that appearance and self-concept play during adolescent development. The excerpts above show that the female participants struggled to cope with the changes in their appearance due to hair loss more than the male participants in the study. Allison's choice to cut her hair short because of her expectation that it would fall out illustrates how hair loss is commonly associated with the image of a person with cancer. In her experience her hair did not fall out, and she regretted the decision to cut her hair. She identified herself as a girl with pretty blonde hair and that part of her identity was altered when her hair was affected by treatment. Social interactions in adolescence are closely tied to attractiveness, according to De Bruyn & Van Den Boom (2005); therefore the hair loss that adolescent cancer patients experience can impact on their ability to socially interaction with friends and peers.

Jamie's excerpts from Table 5.2.17 show that her reaction to hair loss goes beyond self-concept and influences how she interacts with her peers. Jamie makes the assumption that she could not have a boyfriend due to her hair loss. She also feels uncomfortable socializing and "going out" because of her lack of hair. In the last excerpt above, Jamie coped with her hair loss by using humor. However, when her peers would use a similar coping strategy by also using humor to address her hair loss, she took it personally. It is clear from her excerpts above that the hair loss she experienced influenced her social interactions. While hair loss may not directly impact on school engagement, the social interactions that occur in response to hair loss can impact on the level of comfort that an adolescent in cancer survivorship may feel while in the school setting.

Nausea/Vomit

Another common physical side effect of cancer treatment is nausea and vomiting. Cancer treatments are designed to attack cancer cells in the body. Chemotherapy and Radiation treatments often attack healthy cells along with the cancer cells, resulting in the patient feeling nauseous or unable to keep food down. Six of the eight participants experienced nausea and vomiting as a side effect of cancer treatment. As shown in Brandon's example in Table 5.2.9, the various medications he took would cause changes in his energy as well as cause him to throw up. The excerpts below show that vomiting is a common side effect of cancer treatment, and that it can also lead to other realizations and challenges. Statements about nausea or vomiting have been highlighted in bold.

Table 5.2.18 Example of Nausea/Vomit (1)

Allison, 17-year-old female, Diagnosed Pilocytic Astrocytoma 10/2008 *Treatment: Surgery (10/2008)/ intravenous chemotherapy, Treatment Stopped: 09/2010*
“We went and it was a big room of chairs. At first it did not hurt, that first one did not even hurt it was it was progressing. They did not really do anything to me. ***I got sick and puked but it was not anything compared to the other ones.*** *I felt pretty healthy.”*

Table 5.2.19 Example of Nausea/Vomit (2)

Mother of Tracy, 17-year-old female, Diagnosed Metastatic Capillary Thyroid Carcinoma 08/2010 *Treatment: November 2010 – Surgery (11/2010), continues oral thyroid medication*
“Tracy Mother: Yea, because ***there were days where just the nausea and vomiting were huge issues, that is tapering off as well but she needed to be able to just leave if she you know, felt that sick.*** *She was needing to run to the bathroom because she was going to throw up. It is more facing that for us.”*

Table 5.2.20 Example of Nausea/Vomit (3)

Jamie, 17-year-old female, Diagnosed Acute Lymphoblastic Lymphoma 10/2008 *Treatment: chemotherapy, Treatment Stopped: 11/2010*
“I guess when I started to receive my heavy doses of chemo ***and I was always throwing up. I would throw up so much and I was like, oh, my gosh, I don’t think people should be throwing up this much.*** *I was always in the hospital. That is when it started getting real. I could really die.”*

The first excerpt in Table 5.2.18 above shows how Allison experienced vomiting as a side effect of her intravenous chemotherapy treatment. Since her initial reaction to her treatment was an allergic reaction, Allison felt that the more common side effect of treatment (vomiting) was tolerable in comparison. Allison’s excerpt shows a reaction to the physical side effect. Tracy's mother explains in the second excerpt above that school accommodations were necessary in order for Tracy to cope with the nausea and vomiting that she experienced. Tracy's school engagement was clearly impacted on by nausea and vomiting if she required accommodations that would allow her to run to the bathroom in the middle of class to throw up. In her case, she knew that if she experienced a physical side effect while at school she would have the freedom and comfort of knowing that she could take care of herself and not get into trouble with her teachers for leaving class abruptly.

Table 5.2.20 above shows how a physical effect of cancer and treatment can result in having a substantial psychological impact. In Jamie's experience, throwing up so often is what made her cancer diagnosis seem real to her. Feeling physically ill made her realize for the first time that in having cancer she was possibly facing death. A realization of this magnitude for an adolescent would overshadow any other life concerns at the time including her fears regarding her appearance and hair loss, school status and achievement, and social interactions. The psychological experiences of the participants with cancer survivorship are discussed further in Chapter 6.

Compromised Immune System

Another side effect of cancer treatment is having a compromised immune system. This means that patients undergoing cancer treatment are more susceptible to catching infections and illnesses that people with healthy immune systems would fight off. Having a compromised immune system also means that seemingly mild illnesses, such as the common cold, can quickly evolve into more severe illnesses, such as pneumonia. A mild sinus infection or common cold can result in a trip to the emergency room or hospital stay for the patient with cancer. Two out of eight participants expressed having a compromised immune system. The excerpts below show how a compromised immune system as a side effect of cancer treatment interfered with the participants' ability to participate in daily life. Statements relating to experiencing a compromised immune system have been highlighted in bold.

Table 5.2.21 Example of compromised immune system (1)

Brandon, 14-year-old male, Diagnosed Non-Hodgkin's Lymphoblastic Lymphoma 09/2008 *Treatment: chemotherapy (oral and intravenous), Treatment Stopped: November 2010*
*"I do not really know because **I could not really hang out with them because I had a low immune system. So if I got sick I would be in the hospital.** So I could not really talk to them about it."*

Table 5.2.22 Example of compromised immune system (2)

Jamie, 17-year-old female, Diagnosed Acute Lymphoblastic Lymphoma 10/2008 *Treatment: chemotherapy, Treatment Stopped: 11/2010*
*"After that month they told me I couldn't go back to school because **they didn't want kids breathing on me and getting sick.** It was not a logical thing that I was going to be back at school."*

The above excerpts show that Brandon and Jamie experienced a compromised immune system as a result of cancer treatments. In Brandon's excerpt, having a compromised immune system prevented him from interacting with his friends and peers. As a result, he did not feel as though he could talk to his friends, even when he found out that his cancer was gone. Jamie's excerpt (Table 5.2.22) shows how having a compromised immune system prevented her from attending school. Being unable to attend school due to the risk of getting an infection or illness makes it difficult for adolescents to maintain their education during cancer treatment.

Weight Changes/No Appetite

Cancer treatments affect the body in many different ways. Three participants discussed experiencing weight gain or weight loss as a result of cancer treatment. Various medications can impact on appetite, which can affect weight changes during treatment. The excerpts below show how weight fluctuations were experienced during cancer treatment. Statements that include weight changes have been highlighted in bold.

Table 5.2.23 Example of weight change/no appetite (1)

Brandon, 14-year-old male, Diagnosed Non-Hodgkin's Lymphoblastic Lymphoma 09/2008 *Treatment: chemotherapy (oral and intravenous), Treatment Stopped: November 2010*
"Brandon: Sick, ***no appetite at all, I would have to force myself to eat.*** *Except when I got the lumbar punctures****, I have to take steroids so make me heal up faster and it makes you super hungry. So you would be super full but you still felt like you were starving and you had not eaten for weeks.*** *Interviewer: Wow, how did you change physically? Did you lose your hair? Did you gain weight? Did you lose weight?* *Brandon:* ***During when I would take the steroid pills, I would gain 20 pounds in a week. Then when I was off those, I would just lose it all again because I would not eat.*** *I lost my hair instantly."*

Table 5.2.24 Example of weight change/no appetite (2)

Kevin, 14-year-old male, Diagnosed Anaplastic Astrocytoma 05/2009 *Treatment stopped: Surgery/Radiation/Chemotherapy, Treatment Stopped: 04/2010*
"I – well, I think it was more like I had to get through all my cancer stuff. Then like the aftermath was a little more. Like not now as much, but later – before I thought about not having one eye. ***I was big and heavy at that time. Food was kind of my comfort, something that just comforted me.*** *That is the family. I just felt that I was. I felt like a person who had completely changed."*

In Brandon's excerpt in Table 5.2.23, he explains how his body reacted depending on the medication he was given. When he received chemotherapy treatment, he felt as though he had no appetite and would struggle to eat. When he was given steroids, he felt hungry all the time and would eat more. Kevin's excerpt (Table 5.2.24) shows how food acted as a comfort for him during a time when he was struggling with the loss of one of his eyes. The statement he makes at the end of his excerpt (he felt like a changed person) shows the impact that physical effects had on him. His cancer experience changed him. Similar to the participants' experiences with hair loss, visible weight fluctuations can also impact on social interactions for adolescents. As social interactions are affected throughout cancer survivorship, the adolescent's quality of life suffers (Zebrack & Chesler, 2002).

Visual Impairment

Two participants experienced vision impairment as a result of their cancer treatment. As shown in the previous section, Kevin had to have one eye removed, due to the location of his brain tumor. Tim also experienced vision impairment due to the location of his two tumors, one on each optic nerve.

Table 5.2.25 Example of visual impairment (1)

Kevin, 14-year-old male, Diagnosed Anaplastic Astrocytoma 05/2009 *Treatment stopped: Surgery/Radiation/Chemotherapy, Treatment Stopped: 04/2010*
"Kevin: I would say ***being able to drive with one eye, I would say that is a big concern for me because I don't want to be – I mean I would have to look everywhere around me, which is bad, you know.*** *Interviewer: How are you with distance?* *Kevin:* ***It is harder for me to catch things than it was before.*** *I have never been good at catching balls and stuff.* ***Sometimes when I go to grab something I grab something like that and I don't know how far it is and it is harder to tell distance with my one eye.****"*

Table 5.2.26 Example of visual impairment (2)

Tim, 14-year-old male, Diagnosed Neurofibromatosis (8 years old at diagnosis) *Treatment: 18 months of chemotherapy – tumors still present, but stable*
"Interviewer: So when you see, can you describe to me what you see? How you see things? *Tim:* ***Nothing in my left eye.*** *Interviewer: Nothing out of your left…* *Tim:* ***And tunnel vision on my right.*** *Interviewer: Okay.* *Tim:* ***I can't see very far. Probably twelve feet.***

In Table 5.2.25, Kevin explains that he struggles with depth perception. When he said during his interview, "*When I go to grab something I grab something like that,*" he put a glass in the middle of the table and reached to grab it to illustrate that he reaches less than the distance of the glass, thus grabbing at the air in front of the glass. In Tim's case, his mother explained during his interview that it was "*during the chemo is when he lost most of his eyesight.*"

In both Kevin's and Tim's experiences, their vision impairment is a permanent physical side effect of treatment. Kevin's visual impairment has not impacted on his school engagement. However, Tim's visual impairment caused problems for him in navigating his way around the school halls, and caused social challenges since he was bullied often in school. Instances of bullying have been highlighted in bold in the excerpts on the following page.

Table 5.2.27 Example of bullying as a result of visual impairment (1)

Tim, 14-year-old male, Diagnosed Neurofibromatosis (8 years old at diagnosis) *Treatment: 18 months of chemotherapy – tumors still present, but stable*
"Tim: ***They were calling me names, pushing me around. One kid said, 'I'll kill you.'*** *Interviewer: Wow.* *Tim Mother: Well, one of the biggest issues was in the lunchroom. Since he can't see he uses his hands a lot, and somebody threw... at the boys' table... somebody threw a bag of some food in Tim's direction. He picks it up and* ***the boy became upset and basically choked... tried to choke him and pushed him against the wall and just because he couldn't see it, "don't touch my food" and there was...*** *he was just excluded... he had really no boy friends; he was excluded from basically any play or activities regarding boys. Wouldn't you say? (Turns to Father)* *Tim Father: Yes."*
"Interviewer: What was that like for you before you got to go to a school where other kids could relate to you? I mean, I can imagine that felt... (pause) *Tim: Stressful.* *Interviewer: Stressful?* *Tim: Yeah*. ***Because I didn't know what was going to happen to me that day.*** *Interviewer: It's interesting that you use the word stressful... can you explain what you mean by stressful?* *Tim: Yeah*, ***I didn't know what kids were thinking that day or what they were feeling and they usually took all their anger out on me.****"*

Tim's visual impairment ostracized him from his peers so much so that his parents chose to enroll him in the State School for the Blind. At his new school, Tim has not experienced any bullying and feels more comfortable around other students who also have visual impairments. Tim's ability to keep up with his schoolwork was also affected by his visual impairment.

Table 5.2.28 Example of visual impairment impacting educational engagement (1)

Mother of Tim, 14-year-old male, Diagnosed Neurofibromatosis (8 years old at diagnosis) *Treatment: 18 months of chemotherapy – tumors still present, but stable*
"Well, the public school provides the visual lessons in Braille and gives us access to large print books through the braille and auditory library... and there also were the ones... Tim had to go out of school after school to have his visual instruction and then he was receiving orientation mobility where he was learning to use the white cane and that teacher was the one who recommended we go to this school for the blind because ***we were having so many meetings on why he was falling behind academically. His braille skills were inadequate.*** *I had gone to a camp for independent living skills for the blind and there were other visual teachers there and these kids were way ahead of him so that's how the transition happened."*

Once Tim's parents discovered that he might learn better with the specialized accommodations at the state school for the Blind, they promptly enrolled him in the new school. Once his visual impairment was adequately addressed within the education setting, Tim's academic progress began to improve. Tim's experience with supplemental education and his transition into a new school is discussed further in Chapter 7.

Pain/Headaches

In many instances, medical treatments can be painful. Cancer treatments can be painful depending on the type of treatments, such as lumbar punctures or bone marrow transplants. They can also cause headaches as a physical side effect. Four of eight participants experienced pain or headaches as a result of their cancer treatment. Statements that show pain and headaches are highlighted in bold in the excerpts on the following page.

Table 5.2.29 Example of pain/headaches (1)

Aaron, 17-year-old male, Diagnosed Mucoepidermoid Carcinoma 12/2009 Treatment: Surgery (12/2009)/Radiation, Treatment Stopped: 03/2010 Relapse: 01/2012, Surgery 03/2012
"It shot the layers inside and then both layers came to the surface. For a couple weeks, it ***was just as if I had a big sunburn on my neck and it was peeling pretty bad and it hurt****."*

Table 5.2.30 Example of pain/headaches (2)

Brandon, 14-year-old male, Diagnosed Non-Hodgkin's Lymphoblastic Lymphoma 09/2008 Treatment: chemotherapy (oral and intravenous), Treatment Stopped: November 2010
"Interviewer: How often were you in pain from your treatment? Brandon: ***When I would get lumbar punctures, sometimes my back would hurt maybe that night or the next day. Sometimes I would get a headache or something.****"*

Table 5.2.31 Example of pain/headaches (3)

Tracy, 17-year-old female, Diagnosed Metastatic Capillary Thyroid Carcinoma 08/2010 Treatment: November 2010 – Surgery (11/2010), continues oral thyroid medication
*"****Not as much – I don't have [headaches] every day. I get them maybe once a week.*** *It has been worse now I think maybe because it got cold last week and it has been extremely hot here. I think it is just like – and my allergies are bugging me right now. I think it is the temperature drop and change and everything that has caused it the past couple of days, but I mean usually it is only like once a week and I have medicine to take for it, so."*
*"****Probably just the headaches.*** *That was the most annoying thing ever. There was no getting ready for it. I just woke up and would go to school for maybe an hour and then after that I would be back to the regular headache, migraine."*

Table 5.2.32 Example of pain/headaches (4)

Kevin, 14-year-old male, Diagnosed Anaplastic Astrocytoma 05/2009 *Treatment stopped: Surgery/Radiation/Chemotherapy, Treatment Stopped: 04/2010*
"Kevin: And the first day I had my when I had ***radiation I got a really bad headache*** *and unfortunately, we were going to a musical that night so it was very loud and –* *Kevin Mother:* ***There were a few times you had headaches****; not every time though."*

In the Table 5.2.29, Aaron received radiation treatment on his neck to target his salivary gland tumor. Since radiation burns through the skin to attack the tumor, it results in burnt skin around the area that is targeted. Aaron describes the feeling as though it was "sunburned" and "peeling." Brandon's lumbar punctures caused some back pain and headaches (Table 5.2.20). And Kevin got a headache the first day of his radiation treatment (5.2.32). But none of these examples show how school can be impacted on by pain and/or headaches. Tracy experienced headaches often as a result of her cancer treatment. In Table 5.2.31 above, she explains that the headaches she experienced occurred while at school. In Table 5.2.33, Brandon explains that his school engagement was affected as a result of the pain felt from his cancer treatment.

Table 5.2.33 Example of pain impacting educational engagement (1)

Brandon, 14-year-old male, Diagnosed Non-Hodgkin's Lymphoblastic Lymphoma 09/2008 *Treatment: chemotherapy (oral and intravenous), Treatment Stopped: November 2010*
"In Middle School, I was because ***I would have to go and get the lumbar punctures and so I would have to miss a full day of school and maybe the next day if I was not feeling good.****"*

Brandon experienced this after he had returned to school for the seventh grade, but while he was still finishing up his cancer treatments. The pain from his lumbar punctures would cause him to be absent from school, thus impacting on his ability to maintain school engagement during cancer treatment. In both Brandon's and Tracy's experiences, their ability to participate in school was hindered as a result of the pain/headaches they each experienced.

Post-Treatment

Interview Questions Pertaining to Post-Treatment

- How long has your cancer been in remission?
- Do you remember the date? How did you deal with that news?
- Was that when your treatment stopped as well?
- How have things changed since stopping treatment?
- How did your family and friends react?
- Was there any reaction at the school?
- Do you still receive any treatments for the cancer?
- How often do you go for check-ups?
- Do you have any concerns anymore about your cancer?
- When you think about your remission, what thoughts do you have about your future?
- How did it feel when you returned back to school?

The Post-Treatment Stage is a transitional stage in the cancer journey. It denotes the time from when treatment has been stopped, due to the cancer being stabilized or no longer found in the body, but before remission can be declared. Generally, a person in cancer survivorship can claim to be "in remission" when they are five years post-treatment with no experience of relapse. For this reason, the post-treatment stage can still carry with it physical effects left over from treatment, known as lingering effects. Some of these effects are expected to dwindle as time progresses. For example, the hair loss that was experienced during cancer treatment is likely to begin growing back in this stage. However the altered depth perception that Kevin described in Table 5.2.25 of this chapter is an example of a permanent effect of cancer treatment that is unlikely to improve as time progresses.

Lingering effects were coded in this study and resulted in a total of eight codes. Four codes were applied in instances where effects were said to have improved over time.

Precautions

Many patients in cancer survivorship must take precautions in Post-Treatment to avoid discomfort or other more severe problems. The excerpts below show how the participants struggled with the lingering side effects of treatment and the precautions they must take. Statements referring to the precautions related to lingering effects are highlighted in bold.

Table 5.3.1 Example of precautions (1)

Aaron, 17-year-old male, Diagnosed Mucoepidermoid Carcinoma 12/2009 *Treatment: Surgery (12/2009)/Radiation, Treatment Stopped: 03/2010* *Relapse: 01/2012, Surgery 03/2012*
"I have a hard time swallowing sometimes. It has gotten better progressively, ***but bread is probably the worst just because it is so dry. I carry a water bottle around with me at school and I have to take a drink every once in a while****."*
"Probably, the most difficult thing, probably just the physical challenges. As I said before, ***always having to have a water bottle*** *and having a hard time swallowing sometimes.* ***There are some candies that I like and completely stay away from because they just hurt my throat.****"*

Table 5.3.2 Example of precautions (2)

Caleb, 15-year-old male, diagnosed Hodgkin's Lymphoma 11/2010 *Treatment: 3 months chemotherapy/6 months radiation, Treatment Stopped: 6/2011*
"Caleb: Not really physical but like ***I can't do heavy lifting weights anymore.*** *Interviewer: Because you get tired easily?* *Caleb: No, not that. It's just like I'm actually better than I used to be like with – I'm actually a lot less tired now than I used to be. It's just like okay with the sickness I had and the treatments I went through some other person like a long time ago had the same exact treatments and he died while lifting weights.* ***So it's like just precaution. Like its nothing really but if something happened to someone – you know what I mean. It's nothing really but it's just precaution so nothing can happen.****"*

Table 5.3.3 Example of precautions (3)

Jamie, 17-year-old female, Diagnosed Acute Lymphoblastic Lymphoma 10/2008 *Treatment: chemotherapy, Treatment Stopped: 11/2010*
"They told me that I could take junior ROTC to get a credit. ***I know that's strenuous exercise - I would not be able to do that.*** *I haven't been active for two years, so I am trying to get back."*

Having a difficult time swallowing is not a common side effect or lingering effect of cancer in general. However, Aaron was diagnosed with a mucoepidermoid carcinoma, which was treated by removing one of his salivary glands. The result of which is that he struggles to generate saliva in his mouth. This is a lingering side effect that is specific to the type of cancer and treatment he experienced. The above first two excerpts show that Aaron needs to carry water with him at all times, including while he is at school. While needing to sip on water regularly may not substantially impact on his school engagement, it is a precaution that Aaron must take in order to cope with the physical effect of his treatment. Two other precautions that he mentions in each excerpt are that he must avoid certain kinds of candy and bread.

Caleb's example in Table 5.3.2 shows that he cannot lift heavy weights since having cancer treatment. While he has not personally experienced any problems with lifting weights, he was instructed to avoid that activity as a precaution since another individual died while doing it. Some physical education programs in high schools have weight lifting as a part of the class. Caleb would have to opt out of participating in this kind of strenuous activity, if it were a part of his school's program.

In the third example above, Jamie describes how her cancer experience prevents her from participating in a school class. While her abstention from ROTC (Reserve Officers Training Corps) is not a doctor-recommended precaution, Jamie shows in this excerpt that she is aware of the amount of physical activity, or lack thereof, she is able to endure after undergoing two years of cancer treatment. The above excerpts show that while cancer treatment has stopped, physical effects and precautions still linger and can impact on participation that an adolescent can have in school.

Improvements Over Time

In the excerpt on the previous page, Caleb says that he is "*a lot less tired now then [he] used to be.*" This is an example of how physical effects that were experienced during the Cancer Treatment stage can improve as treatment is stopped and as time progresses. Four participants, including Caleb's previous excerpt, discussed how a physical effect they had experienced has improved since stopping cancer treatment. Statements that show these improvements over time have been highlighted in the excerpts below.

Table 5.3.4 Example of physical effects improving over time (1)

Tim, 14-year-old male, Diagnosed Neurofibromatosis (8 years old at diagnosis) *Treatment: 18 months of chemotherapy – tumors still present, but stable*
*"Tim: **My eyesight's improved a little**.* *Interviewer: So, how is it that you see now? How do you notice the improvements?* *Tim: **My left eye used to always see shadows and things and now I can count fingers sort of.*** *Interviewer: Well, great! Is that something that you're expecting to continue to get better?* *Tim: Yes…* *…Interviewer: So with your eyesight improving did you notice that school was getting a little bit easier with your eyesight improving or have things been pretty much the same, would you say?* *Tim: The same."*

Table 5.3.5 Example of physical effects improving over time (2)

Allison, 17-year-old female, Diagnosed Pilocytic Astrocytoma 10/2008 *Treatment: Surgery (10/2008)/ intravenous chemotherapy, Treatment Stopped: 09/2010*
*"**I have long hair now and it has thickened**."*

Table 5.3.6 Example of physical effects improving over time (3)

Tracy, 17-year-old female, Diagnosed Metastatic Capillary Thyroid Carcinoma 08/2010 *Treatment: November 2010 – Surgery (11/2010), continues oral thyroid medication*
*"I do a lot, I do more things with my friends now. I was out until 11 last night and yea. **I do a lot more things now, I am not as tired**. I am still trying to get back up to being not tired anymore."*

The above excerpts show how the participants experienced improvements in the physical effects they had initially experienced during cancer treatment. These findings exemplify the claims made by Zebrack and Chesler (2002) that physical effects of cancer and treatment lessen over time. Allison's excerpt shows how her hair has returned to how it was prior to diagnosis, and Tracy's energy levels have been increasing, although she still struggles with fatigue. Even Tim's eyesight has improved a little bit. Although when asked about whether his slight vision improvements have positively impacted on his school achievement, he said that things at school remained the same for him.

Since there are few codes regarding lingering physical effects in this study, it suggests that as treatment stops, the physical effects of cancer and treatment improve. School engagement at this stage is also not as substantially impacted on as it is during the cancer treatment stage. This suggests that as physical effects improve, school engagement improves as well.

Relapse

Relapse or cancer recurrence is a possibility that can happen any time in the Post-treatment stage. Relapse is when the cancer that was initially treated returns. It should not be confused with "second cancers." Many cancer treatments result in an increased likelihood of getting other forms of cancer. A "second cancer" is when a person who has survived one form of cancer gets another form of cancer. This often occurs years after the first cancer was cured. Only one participant experienced relapse during the research study. Aaron only experienced one physical effect as a sign of his relapse, which was a growth in his neck. Statements about the physical effects of Aaron's relapse have been highlighted in the excerpt below.

Table 5.3.7 Example of relapse (1)

Aaron, 17-year-old male, Diagnosed Mucoepidermoid Carcinoma 12/2009 *Treatment: Surgery (12/2009)/Radiation, Treatment Stopped: 03/2010* *Relapse: 01/2012, Surgery 03/2012*
*"**They actually found another lump** because when I had radiation a couple years ago, they didn't do a spot right in the middle like right where my Adam's apple is, and **this is where they actually found the lump**. And so they took that out and I actually had another big surgery and they took out more and just got it really good, got a lot of it out. **And they actually redid my old scar, too, so I had like a twenty-inch scar from the surgery**."*
"But I knew it was going to be easier because I just had a surgery, I didn't have radiation or anything. And I didn't let it ruin my senior year, so I just had surgery, recovered, and went back to school."

The second excerpt in Table 5.3.7 shows how Aaron's school engagement was only minimally affected by his relapse experience. The excerpt shows that he had clear expectations for the treatment. He focused on recovering from the surgery and returned to school determined to not let it impact on his final year of high school. This excerpt suggests that to a limited extent, the adolescent in cancer survivorship determines how severely their experience can impact on their school engagement. It was important to Aaron to not allow his relapse to "*ruin [his] senior year.*" If he felt otherwise, and wanted to get away from having to attend school, he could have chosen to take more time to cope with his relapse. But this was not the case. Aaron chose how much or how little he wanted his relapse to impact on his school engagement.

Discussion and Chapter Conclusion

The participants' experiences throughout the stages of cancer presented in this chapter illustrate how physical effects begin in the Pre-Diagnosis Stage as the early symptoms of cancer begin to show. Then the physical effects of both cancer and treatment are experienced as treatment begins, and linger throughout the Post-Treatment stage. In one case in this study a participant experienced a relapse of their cancer that was successfully treated. If educational engagement is defined as "the extent to which teenagers remain in contact with school and/or received educational support whilst undergoing treatment or during recovery" (Pini et al., 2012, p. 686), then by looking at the physical effects of cancer and treatment as experienced by the participants, it becomes clear how to best mediate educational engagement during cancer survivorship.

Of the stages of cancer, the Cancer Treatment Stage is when the vast majority of physical effects were experienced. Most physical effects began to improve over time in the Post-Treatment Stage. Some participants experienced precautionary effects, such as avoiding certain foods or activities. It is during the Cancer Treatment Stage that the educational engagement of adolescents in cancer survivorship is most at risk since the physical effects are at their peak both in quantity and in severity. Specifically, a general feeling of sickness was the most prominent physical effect as described by six of the eight participants. This feeling can impact on the adolescent's ability to attend school. However, Tracy's experience shows that she remained connected to the social interactions at school via mobile texting with friends. This shows that technology can be used to help cancer patients feel connected to the educational setting if they are unable to physically attend classes.

The second most prominent physical effect that the participants discussed was fatigue. Not only can fatigue impact an adolescents' ability to attend school, but also it can make it difficult for them to stay awake while at school, as shown in Allison's experience, thus impacting on participation in school as well as attendance. Extreme levels of fatigue, combined with having a compromised immune system (the third most prominent physical effect as discussed in the participants' interviews) result in inconsistent school attendance or an inability to attend school regularly at all. The first conclusion that can be made from these findings is that these physical effects explain why absences from school are the biggest problem for adolescents in cancer survivorship, particularly during cancer treatment. This conclusion confirms the findings of Gartin and Murdick (2009), Pini et al. (2012), Deasy-Spinetta and Spinetta (1980), and Prevatt et al. (2000).

As adolescents in cancer survivorship experience hair loss as a physical effect of cancer and/or treatment, their self-esteem is often distorted. In this study, the female participants spoke about how not having any hair influenced their self-view, whereas the male participants did not express any concerns regarding their appearance as a result of their hair loss. Social interactions can influence an adolescent's desire to attend school since the educational setting is where the majority of social interactions take place in adolescence. Since social popularity is often equated with attractiveness (De Bruyn & Van Den Boom, 2005), adolescents in cancer survivorship are likely to struggle with self-concept if they have experienced hair loss or weight changes as physical effects of cancer treatment. The findings from the current study indicate that female adolescents are more sensitive to the social repercussions of hair loss than males. Negative social interactions can result in a stressful and unpleasant school environment, as illustrated by the bullying that Jamie and Tim experienced at school as the result of their altered physical state. These findings confirm those reported by Barrera et al. (2005) who found that self-esteem is mediated by physical health problems associated with cancer treatment.

Social interactions play a significant role during adolescence. Barrera et al. (2005) found that "repeated absences from school have been associated with survivors' poor social integration" (p. 1757). However, the findings from the current study show that physically attending school is not an option for many adolescents undergoing cancer treatment. One question that is raised from these findings is whether staying socially connected to peers may be a positive step in an effort to maintain educational engagement during cancer survivorship. If peers can notify the adolescent in cancer survivorship what occurred in school each day, both academically and socially, the adolescent will likely feel more connected to school.

Another conclusion that can be made from these findings is that the physical effects of cancer improved over time as treatment stopped. Permanent physical effects, such as surgery to remove glands or visual impairments were incorporated into daily life and as needed into educational accommodations. However, another question that arose from these findings is whether choice plays a role in educational engagement. In the second excerpt from Table 5.3.7, Aaron says, "*I didn't let it ruin* *my senior year.*" This indicates that he wanted to exert some control over how he coped with his relapse and he chose to remain as engaged in his education as possible. It is perhaps that Aaron was better mentally prepared for what to expect from his relapse treatment that made it possible for him to mediate how his life would be impacted on by his relapse. This excerpt in combination with the finding that the participants were able to make adjustments to how they operated on a daily basis, how they viewed themselves, and how they mentally prepared for future challenges indicates that coping and psychological adjustment play a significant role in adolescent cancer survivorship. The incorporation of cancer survivorship into identity and how the participants psychologically cope with their cancer experience will be analyzed and discussed in the following chapter.

CHAPTER 6

Psychological Effects of Cancer and Treatment

Introduction

The aim of this chapter is to present the findings from this research study regarding how the psychological effects of cancer and treatment impacted on the participants' engagement with school during and after treatment. As presented in Chapter 5, the physical effects of cancer and treatment can prevent the participants from being able to physically attend school and can mediate to what level they are able to engage in school throughout the stages of cancer. Physical effects of cancer, as well as the diagnosis and treatment of cancer, can have an impact on the patient's life psychologically. Since having cancer is a life-altering event, the measures that participants use to cope with the various stages of cancer can impact on their identity and how they are able to cope with future challenges.

I have chosen to organize the chapter by the stages of cancer to illustrate the progression of the cancer journey as the participants have experienced it. It is important to understand this progression since each phase of cancer comes with new challenges that trigger physical and psychological experiences that are individual to the participants. Each section begins with the interview questions that address the section topic. Given that the interviews were semi-structured, however, questions varied for each interview depending on the participants' responses and the flow of conversation. The questions included were utilized during the fieldwork as a guide for conversation in an effort to gain in-depth understanding of the participants' experiences with both cancer and education during and after treatment. It is important to note that the participants' experiences are individual and as such some questions did not apply to all participants.

Pre-Diagnosis and Diagnosis

Interview Questions Pertaining to Pre-Diagnosis and Diagnosis

- What kind of cancer were you diagnosed with?
- When were you initially diagnosed?
- How did you handle getting that diagnosis?
- What symptoms did you feel before diagnosis that prompted you to see a doctor?

Response to Diagnosis

The participants did not discuss their psychological experiences prior to diagnosis during their interviews; however, they were asked to recall how they felt upon hearing that they had cancer. The responses to diagnosis varied from negative feelings of "breaking down" and wondering "why me?" to disbelief, shock, and denial, to feelings of positive strength by not crying, feeling relieved, and remaining calm. The analysis of excerpts resulted in 17 codes. Of the 17 codes, six were coded as the participant feeling shock or disbelief. Statements that refer to shock or disbelief have been highlighted in bold.

Table 6.1.1 Example of shock or disbelief (1)

Caleb, 15-year-old male, diagnosed Hodgkin’s Lymphoma 11/2010 *Treatment: 3 months chemotherapy/6 months radiation, Treatment Stopped: 6/2011*
“Well, at the very beginning like I really didn’t know what to think. Like, you’re like okay ***and you’re like this just didn’t happen to me*** *and that goes on for a few days actually until like you’re like, okay, this is actually going to happen. Then, you have to go meet your doctors and everything, your whole team of doctors and like, okay, this is actually going to happen, okay. And, you kind of just like break down a little, and really think about everything.”*
*“****It was actually mainly a lot of shock in the beginning but like towards like the very beginning*** *I’m like you got to do what you got to do just to get through it.”*

Table 6.1.2 Example of shock or disbelief (2)

Brandon, 14-year-old male, Diagnosed Non-Hodgkin’s Lymphoblastic Lymphoma 09/2008 *Treatment: chemotherapy (oral and intravenous), Treatment Stopped: November 2010*
“It was hard to take, ***you hear about people getting it, it does not really affect you and then once you actually hear that you have it, it is like, it breaks your heart****.”*

Table 6.1.3 Example of shock or disbelief (3)

Aaron, 17-year-old male, Diagnosed Mucoepidermoid Carcinoma 12/2009 *Treatment: Surgery (12/2009)/Radiation, Treatment Stopped: 03/2010* *Relapse: 01/2012, Surgery 03/2012*
*“****It was pretty unbelievable.*** *We have all heard stories about the kids who have gotten it and I was just hoping I would not have it. I do not want to be that person I guess.* ***It was just unbelievable****.”*
*“****Part of it was why me and the other part was probably in shock, yeah****.”*

Table 6.1.4 Example of shock or disbelief (4)

Allison, 17-year-old female, Diagnosed Pilocytic Astrocytoma 10/2008 *Treatment: Surgery (10/2008)/ intravenous chemotherapy, Treatment Stopped: 09/2010*
"The MRI doctor, the neurologist said that I had a brain tumor and he took us back into the room and I saw it. ***I did not believe it because he said he was 99% sure that I did not have one and have no problem so I just felt like it was not real.****"*
"I had Pilocytic Astrocytoma and it was a brain tumor on my spinal cord. My MRI that I got at first showed my spinal cord was pushed almost to a ninety-degree angle so they do not really understand why I am alive. I am really lucky about that, but when I first found ***I felt like my whole life was being taken away like I did something wrong that I got it. I just did not understand why, why me.****"*

A similarity between the above excerpts is that each of these four participants expressed an initial disbelief of their diagnoses. Examples in Tables 6.1.1 and 6.1.3, such as "*you kind of just like break down a little,*" and "*it breaks your heart,*" show the gravity of the cancer diagnosis for Caleb and Brandon. In both cases they felt initial denial or shock, followed by devastation that "breaks" them in some way. In Table 6.1.1, Caleb explains that while initially he felt disbelief upon hearing his diagnosis, meeting with his doctors to discuss treatment action helped him to understand the reality of the diagnosis. He says in his second excerpt in Table 6.1.1, "*you got to do what you got to do to get through it.*" This shows that regardless of any feelings of disbelief the treatment must begin, leaving little time for mentally processing and coping with the severity of the diagnosis.

In the Tables 6.1.3 and 6.1.4, Aaron and Allison wondered "Why me?" People often ask themselves this existential question in negative or critical situations. In both of these cases, it denotes that Aaron and Allison were feeling a lack of control upon hearing their diagnoses. The question, "why me?" indicates a search for understanding to process this new information in an attempt to regain control of what is happening to them. Allison takes this search for understanding and puts it on herself as though she is being punished for something she did, when she says in Table 6.1.4, "*I felt like my whole life was being taken away like I did something wrong that I got it."* This explanation is Allison's attempt to answer the question, "Why me?" as she struggled to understand her diagnosis. It is an example of her attempt to control the situation.

Lastly, Brandon and Aaron both make statements in Tables 6.1.2 and 6.1.3 that indicate how society views cancer. When Brandon says, "*you hear about people getting it, it does not really affect you,*" (Table 6.1.2) he is referring to the fact that cancer in children and adolescents is known to be rare enough that it happens to other people, rather than to yourself. He goes on to say, "*it does not really affect you,*" (Table 6.1.2) which indicates that he disassociated himself from the possibility that he would ever be diagnosed with cancer. This disassociation may have contributed to shock he felt upon hearing his diagnosis, which resulted in him feeling as though it "*breaks [his] heart*" (Table 6.1.2).

In Table 6.1.3 Aaron's says, "*We have all heard stories about the kids who have gotten it.*" The way he said this is almost as though he was referring to kids who get cancer as some cautionary fairy tale that children are told before bed. But he continues to say, "*I do not want to be that person I guess.*" This sentence suggests that a cancer diagnosis is more than a medical assessment, but that it contributes to identity: "The person with cancer." Furthermore, this statement shows that Aaron does not want to be that person, suggesting that the "person with cancer" has a negative connotation associated with it.

Not all participants reacted with disbelief or shock, however. The excerpts on the following pages show alternative reactions that the participants had upon hearing their diagnosis. These reactions included relief, calm, not feeling scared, and concerns about hair loss. These sentences have been highlighted in bold.

Table 6.1.5 Example of relief (1)

Tracy, 17-year-old female, Diagnosed Metastatic Capillary Thyroid Carcinoma 08/2010 *Treatment: November 2010 – Surgery (11/2010), continues oral thyroid medication*
*"Tracy**: It was more of a relief rather than, what's the word?*** *Interviewer: A relief rather than a concern?* *Tracy:* ***Yes, because we had been dealing with it for four years.*** *Interviewer: Okay. Well, let's talk about your cancer diagnosis; what were you feeling when you were told by the doctors that you had cancer?* *Tracy:* ***I wasn't scared of it. I wasn't scared. I don't know, I guess, nervous because I knew I had to have surgery and I was going to be alone in surgery.*** *Interviewer: Okay. But you said that you were not scared?* *Tracy: No, not really.* *Interviewer: Why do you think that is?* *Tracy: Because* ***we were just looking for a diagnosis, didn't really care what it was or anything. We just wanted to find out what was wrong.****"*

Table 6.1.6 Example of calm (1)

Kevin, 14-year-old male, Diagnosed Anaplastic Astrocytoma 05/2009 *Treatment stopped: Surgery/Radiation/Chemotherapy, Treatment Stopped: 04/2010*
"I was very calm about it. I wasn't really, really scared. I was, you know, scared because I knew what I was going to have to go through and what I didn't know I had to go through and I wasn't that – I wasn't really scared about it, I was pretty calm about it.*"*
"I knew I had to be calm and if I didn't I would just not be able to handle it well, *so I just stayed calm."*

Table 6.1.7 Example of calm (2)

Mother of Kevin, 14-year-old male, Diagnosed Anaplastic Astrocytoma 05/2009 *Treatment stopped: Surgery/Radiation/Chemotherapy, Treatment Stopped: 04/2010*
"He never – he never asked why me, he never cried about it, ***he never was scared about it.*** *I don't know if it goes back to the – my husband and I were pretty upset about it, of course and* ***he just is a very calm person anyway*** *and I don't know. I think divine intervention."*

Table 6.1.8 Example of concern regarding appearance (1)

Jamie, 17-year-old female, Diagnosed Acute Lymphoblastic Lymphoma 10/2008 *Treatment: chemotherapy, Treatment Stopped: 11/2010*
"So, before I was sick I was like… I always thought of myself of being like the pretty girl in school. I wanted to be a cheerleader. Everybody liked me. I was skinny and had a cute shape. ***My first concern was like, 'oh my gosh, I am going to be so ugly.' My hair is going to fall out. So, it was never my concern of like this is a situation where I can die. That was never my first concern but as I got into my treatment, then that started to be a concern.****"*

As shown in Chapter 5, while other participants experienced a cough, vision changes, or headaches that were indications of their cancer, Tracy experienced a multitude of symptoms that went undiagnosed for four years. The result of that experience is that Tracy felt relief upon hearing that the problem causing those symptoms was finally identified and could now be treated. Since cancer can be life threatening, one would not expect someone to feel relief upon hearing that diagnosis. However, the experience of not knowing what is causing your symptoms for many years results in the desire to pinpoint the problem so that it can be properly addressed and finally treated. This is the case with Tracy.

In Tables 6.1.5 and 6.1.6 above, Tracy and Kevin both say several times that they were not scared when they heard their diagnoses. While Tracy was focused on finding answers, Kevin remained calm because he felt as though he would "*not be able to handle it well*" if he allowed himself to feel scared. He clarifies in the second excerpt that he felt a bit scared because he did not know what to expect with the treatments, but that when it came to the diagnosis, he remained calm. His mother supports Kevin's claim in the fourth excerpt above when she explains that Kevin was not scared. She says that he did not ask "why me?" as Aaron and Allison did. This shows that rather than react to the lack of control that he was experiencing in the way that Aaron and Allison did, Kevin chose instead to exert control over something he could control: his reaction. He chose to remain calm as he heard his diagnosis in an effort to feel control over what was happening, despite any concerns he had about what to expect from treatment.

Lastly, Table 6.1.8 shows that Jamie initially worried about her appearance upon hearing her cancer diagnosis. She says the statement, "*My first concern was like, 'oh my gosh, I am going to be so ugly.' My hair is going to fall out.*" Similar to the excerpts in Tables 6.1.2 and 6.1.3 where Brandon and Aaron talk about hearing about others who have gotten cancer, Jamie has also heard stories about people with cancer. Specifically, she was aware that a common side effect of cancer and treatment is hair loss. It was this societal view of "the person with cancer" that concerned Jamie initially. But it was not specifically the loss of hair that concerned Jamie. Her actual concern was about how her identity will be impacted by her diagnosis. She talked about "*being the pretty girl in school,*" wanting to "*be a cheerleader*," being "*skinny and had a cute shape*," and the fact that everyone liked her. As a female adolescent in high school, her appearance is a large part of her identity. Jamie's concern about being diagnosed with cancer was that it would impact on how her friends and peers viewed her.

At the end of her excerpt, Jamie explains that while her initial concern was not that she could die, that did become a concern as she started to experience cancer treatment. Of the participants in this study, Jamie was the only one who overtly used the term “die.” Caleb and Brandon talked about feeling “broken” as they processed their diagnosis. Allison talked about feeling as though her “life was being taken away.” While Jamie’s initial concerns were about her appearance, and therefore her identity, it was not until the cancer treatment stage that she truly felt as though she was facing death.

Cancer Treatment

Interview Questions Pertaining to Cancer Treatment

- Can you tell me what you had to do everyday for your treatment?
- How much medicine did you take?
- Did you take medicine at school?
- How often did you go to the hospital for your treatment?
- How long were you receiving that treatment?
- How did the treatment make you feel physically?
- Did your reaction to the treatment change each time you went, or did you feel the same way after each treatment?
- Had you been absent from school often because of your cancer?

Uncertainty and Routine

One of the most common psychological challenges during the cancer treatment stage is the uncertainty of what to expect from treatment.

Table 6.2.1 Example of uncertainty and routine (1)

Jamie, 17-year-old female, Diagnosed Acute Lymphoblastic Lymphoma 10/2008 *Treatment: chemotherapy, Treatment Stopped: 11/2010*
*"**The first couple of times it was like, oh Lord, what are they going to do to me?** Poking me with needles. **After a while, I got used to it. I know they going to do the same thing.** They want to measure my pee. They want to know whenever I use the bathroom. They're going to wake me up in the middle of the night to take blood. **I just kind of got used to it. After a while, I could start doing my own vital signs. I would just write them down for them and give them to them. I can do it myself after a while.**"*

Table 6.2.2 Example of uncertainty and routine (2)

Caleb, 15-year-old male, diagnosed Hodgkin's Lymphoma 11/2010 *Treatment: 3 months chemotherapy/6 months radiation, Treatment Stopped: 6/2011*
*"Actually, **you pretty much get used to it.** It's just really the first time because **like you don't know what to expect so you're kind of just like a guinea pig** and they just like – you just got to go through it, but **the second and third time was just routine. Everybody, everything was just normal.**"*

Table 6.2.3 Example of uncertainty and routine (3)

Aaron, 17-year-old male, Diagnosed Mucoepidermoid Carcinoma 12/2009 *Treatment: Surgery (12/2009)/Radiation, Treatment Stopped: 03/2010* *Relapse: 01/2012, Surgery 03/2012*
*"**The first time I was just wondering,** I had never known about treatment stuff. I was just waiting for instructions I guess. **After a while, after probably a week/a week and a half, it just became routine. I just went in, followed the doctor, and went back to the table and something like a routine.**"*

In the tables above, Jamie, Caleb, and Aaron explain that while initially they did not know what to expect from treatment, they quickly became accustomed to what to expect. Jamie, who was admitted to the hospital often during her treatment stage, felt so comfortable with the process that she felt she could take her own vital signs after a while. Tables 6.2.2 and 6.2.3 show that the transition from uncertainty into routine occurred quickly for Caleb and Aaron. Caleb felt as though he was in a routine by the second and third treatment. Aaron felt as though he was in a routine within a week/a week and a half.

These experiences are evidence that the fears of uncertainty related to cancer treatment are fleeting. Once treatment has been experienced for the first time, the participants know what to expect, having been through it at least once prior. However, the severity of the physical effects of cancer treatment can impact on the participants psychologically.

Table 6.2.4 Example of facing death (1)

Jamie, 17-year-old female, Diagnosed Acute Lymphoblastic Lymphoma 10/2008 *Treatment: chemotherapy, Treatment Stopped: 11/2010*
"I was always in the hospital. ***That is when it started getting real. I could really die.****"*
"I do not know. I do not know, I guess like anything to like make you die. ***But knowing that I am dealing with life, a life threatening disease that can really take my life.*** *It is just like instantly.* ***That my chances of dying is like way more higher than anybody else's.*** *Or, just the average person is.* ***It is scary to know that I was like so close to like being gone or being… You know.****"*

Of the eight participants, Jamie is the only participant who discusses feeling as though she was facing death during cancer survivorship. The previous section showed that Jamie's initial concerns upon being diagnosed with cancer were about how her identity would be affected by any changes in her appearance (Table 6.1.8). Yet once she experienced the severity of the physical side effects of cancer treatment, she felt as though she was facing death. The way Jamie described how scary it was for her to feel close to death is evidence of the impact a cancer diagnosis can have on an adolescent. For example, common fears for healthy adolescents may include failure at school, disappointing parents, and criticism from friends. However for the adolescent who has been diagnosed with cancer the fear of death overshadows these more common fears. Jamie's excerpt above shows that this was the case for her.

Post-Treatment

Interview Questions Pertaining to Post-Treatment

- How long has your cancer been in remission?
- Do you remember the date? How did you deal with that news?
- Was that when your treatment stopped as well?
- How have things changed since stopping treatment?
- How did your family and friends react?
- Was there any reaction at the school?
- Do you still receive any treatments for the cancer?
- How often do you go for check-ups?
- Do you have any concerns anymore about your cancer?
- When you think about your remission, what thoughts do you have about your future?
- We all know that it is not pleasant to have cancer, but let's first look at it from the positive side. Can you think of any good things that have come from your experience?
- What are some of the more difficult things you've faced in having cancer?
- Do you feel different from your peers? How?
- Do you have any concerns about your friendships?
- Do you mind when people ask or talk to you about your cancer experience?
- How did it feel when you returned back to school?

Participant Reactions to Remission

People in cancer survivorship feel happiness, relief, fear and uncertainty upon hearing that their cancer is stable or no longer present in the body. These reactions to the news that cancer treatment is coming to an end can indicate how the patient feels about their treatment experience and how they are going to approach life in post-treatment.

Table 6.3.1 Example of happiness (1)

Caleb, 15-year-old male, diagnosed Hodgkin’s Lymphoma 11/2010 Treatment: 3 months chemotherapy/6 months radiation, Treatment Stopped: 6/2011
“**I was extremely happy**, like, because I was thinking this was going to be it because it was kind of the plan like if you get a PET scan and you see where you’re at. So it could be impossible and you had to continue treatment or you’re fine and we just go to radiation or actually you’re just done. **And, after they told me I was done with chemo I was thrilled.**”

Table 6.3.2 Example of happiness (2)

Kevin, 14-year-old male, Diagnosed Anaplastic Astrocytoma 05/2009 Treatment stopped: Surgery/Radiation/Chemotherapy, Treatment Stopped: 04/2010
“The same when I learned, **of course I was very happy when I learned that it was gone and I knew that it would end, so I was very, very happy.**”

Table 6.3.3 Example of relief (1)

Brandon, 14-year-old male, Diagnosed Non-Hodgkin’s Lymphoblastic Lymphoma 09/2008 Treatment: chemotherapy (oral and intravenous), Treatment Stopped: November 2010
“**It was like a big weight taken off my shoulders.** I know [it was a] big weight taken off my parents’ shoulders and everyone that knew me and stuff.”

Table 6.3.4 Example of relief (2)

Aaron, 17-year-old male, Diagnosed Mucoepidermoid Carcinoma 12/2009 Treatment: Surgery (12/2009)/Radiation, Treatment Stopped: 03/2010 Relapse: 01/2012, Surgery 03/2012
“Aaron: I was way excited. Interviewer: Can you explain, “Way excited?” Aaron: (laughs) Yeah sorry, just **I felt like a huge burden had been lifted off my shoulders, I felt free. I do not know how else to describe it**.”

Table 6.3.5 Example of fear/uncertainty (1)

Jamie, 17-year-old female, Diagnosed Acute Lymphoblastic Lymphoma 10/2008 *Treatment: chemotherapy, Treatment Stopped: 11/2010*
"To be honest, ***I wouldn't say that I was upset. I was kind of used to everybody doing stuff for me*** *and I wasn't in school.* ***I missed school, but I was having fun not going to school.*** *So, it's like,* ***what do I do now?*** *This is what I have been doing for two and a half years.* ***I don't even know how to start back my life.****"*
*"****I wanted it to be gone, but at the same time I didn't want it to be gone because it became like a habit. Not a habit, but something that I was used to. I was kind of like oh. It wasn't that I like being sick, because of course I don't like being sick. But, it was just like I didn't know what to do with my life. It was like cancer was all that I knew.*** *I never did anything else other than treatment so that was all that I knew all the time."*

Most of the participants were happy when they found out that there are no detectable traces of cancer in their bodies. This is exemplified in Caleb and Kevin's excerpts in Tables 6.3.1 and 6.3.2. Brandon and Aaron described their positive feelings as though a burden was lifted from their shoulders (Tables 6.3.3 and 6.3.4). This weight is a combination of the fear they likely felt for their future and the stress of undergoing severe cancer treatments. Aaron also describes this experience as feeling "free." The description of freedom makes the comparison that the process of cancer from diagnosis through treatment made him feel restricted. As shown in Chapter 5, the physical effects of cancer can be severe. They cause the patient to feel as though they do not have control over what is happening in their body. When Aaron talks about feeling "free," he is talking about an end to those physical restrictions. Hearing that cancer is no longer present is an event that marks the transition from feeling a lack of control to regaining independence.

For some cancer patients, this transition can be intimidating. Jamie's first excerpt in Table 6.3.5 exemplifies this. She says, "*I wouldn't say that I was upset,*" which indicates that she was not initially happy when she was told her cancer was gone. However, it is not that Jamie was unhappy to hear such positive news. She had become so accustomed to the years of severe treatment that the transition into health was intimidating to her. Whereas Aaron felt free once he heard his cancer was gone, Jamie felt uncertain of how to proceed. She had become accustomed to special treatment by her family. She enjoyed the attention and routine of not having to attend school. Yet perhaps the strongest statement she makes in Table 6.3.5 is, "*I don't even know how to start back my life.*" This statement exemplifies the fear and uncertainty she felt of having to leave her routine of treatments behind and reintegrate to life post-treatment. There is further evidence of this feeling as Jamie explains in the final excerpt above when she says, "*It was like cancer was all that I knew.*"

Family/Community Reactions to Remission

The support that people in cancer survivorship receive throughout their treatment can be both helpful and detrimental. For example, a patient who has received an outpouring of positive support from their peers and community may help them to feel connected to their life outside of their cancer experience. This can ease the transition from treatment into post-treatment. Similarly, a lack of community and peer support can cause the patient to feel as though they are alone in their cancer experience, thus causing them to feel different from those around them.

Table 6.3.6 Example of church support (1)

Jamie, 17-year-old female, Diagnosed Acute Lymphoblastic Lymphoma 10/2008 *Treatment: chemotherapy, Treatment Stopped: 11/2010*
*"**My church as all like running around, like, 'oh my gosh.' My pastor would always make me stand up and testify every Sunday.** I am like 'oh my gosh,' I do not what to do this. **Yeah, everybody was happy**."*

Table 6.3.7 Example of family support (1)

Caleb, 15-year-old male, diagnosed Hodgkin's Lymphoma 11/2010 *Treatment: 3 months chemotherapy/6 months radiation, Treatment Stopped: 6/2011*
*"**Yeah, oh, they were so like – they kind of like looked – let's not get too happy before anything happened** but like me – because my grandma was down here. **Me and my grandma were thrilled when it happened but my dad just wanted to make sure like everything was perfect like we knew for a fact that we were just going to go to radiation.**"*

Table 6.3.8 Example of family support (2)

Brandon, 14-year-old male, Diagnosed Non-Hodgkin's Lymphoblastic Lymphoma 09/2008 *Treatment: chemotherapy (oral and intravenous), Treatment Stopped: November 2010*
*"**Oh, they were so happy, because they knew that I was going to be fine and that someday I would be out of treatment and everything.**"*

Table 6.3.9 Example of peer support (1)

Kevin, 14-year-old male, Diagnosed Anaplastic Astrocytoma 05/2009 *Treatment stopped: Surgery/Radiation/Chemotherapy, Treatment Stopped: 04/2010*
*"**Well, they were surprised. They were happy when they heard that I was done with – that it was gone and one time when I came home from Camp Rainbow, I think the first time, they actually waited outside for me with a banner and just the kids came over and made a banner for me.** It was really nice."*

The patient’s family and community are also affected by the patient’s experience with cancer even though they do not personally experience the physical and psychological effects. This is especially true for the families of adolescents with cancer since, unlike adults, adolescents are dependent on their parents. Similar to the patient’s reactions in the previous section, most family and community members are happy when they hear the news that the adolescent’s cancer is gone. This is the case with Brandon and Kevin, as shown in Tables 6.3.8 and 6.3.9 on the previous page. In Caleb’s excerpt, however, he and his grandma were “thrilled” but his father was hesitant to celebrate the good news until they had further confirmation that his cancer was going into remission. The caution his father exhibited during this time is an example of the level of fear that parents experience when they have a child who has cancer. Caleb’s father was likely very happy to hear that his son’s cancer is gone, however, he wants further confirmation before he feels as though he can truly celebrate this good news.

In Jamie’s excerpt in Table 6.3.6, her pastor insisted that she share her story with her church community. He encouraged her to focus on the fact that she was a fighter who survived a long, difficult experience. Jamie’s pastor viewed her as a role model to her community. His encouragement is an example of how she should, in his view, incorporate her cancer experience into her post-treatment life in a positive way.

Peer Reactions to Adolescent’s Return to School

Returning to school after cancer treatment is often considered to be a marker of health for adolescents in cancer survivorship. Since absence from school is most often due to illness, the lack of the student’s presence is a reminder to peers that he or she is ill. Thus the student’s return to school denotes regaining a level of health.

Peer reactions to the student's return to school can include happiness, surprise, behaving as though nothing has changed, and making a big deal of their return by asking many questions.

Table 6.3.10 Example of happiness (1)

Caleb, 15-year-old male, diagnosed Hodgkin's Lymphoma 11/2010 *Treatment: 3 months chemotherapy/6 months radiation, Treatment Stopped: 6/2011*
“Yeah, ***it was definitely like crazy, like surreal like, you just look at everybody and everybody's like freaking out because you're back.*** *And, I mean just –* ***I couldn't wait to get back to my old routine and everything. Like, you think its fun to be away from school but definitely not that long.*** *” – Caleb*

Table 6.3.11 Example of normal (1)

Brandon, 14-year-old male, Diagnosed Non-Hodgkin's Lymphoblastic Lymphoma 09/2008 *Treatment: chemotherapy (oral and intravenous), Treatment Stopped: November 2010*
*“**They just kind of acted like everything was normal**.”*

Table 6.3.12 Example of surprise (1)

Jamie, 17-year-old female, Diagnosed Acute Lymphoblastic Lymphoma 10/2008 *Treatment: chemotherapy, Treatment Stopped: 11/2010*
*“**When I tried to come back for my sophomore year; a lot of people were surprised.** When I went back for my sophomore year I was still doing my heavy dose of treatments.* ***So, a lot of people were surprised. “Oh my gosh, what is she doing here?” They were always so careful.*** *I used to get out of class a few minutes early because I had my pot and they didn't want anybody to bump it.* ***They were really protective and surprised like I was some big thing or something. It was hard to do… The teachers, my nurses, my principle, everybody. Everybody knew me. People I didn't even know knew me.*** *”*

Table 6.3.13 Example of feeling judged by peers (1)

Allison, 17-year-old female, Diagnosed Pilocytic Astrocytoma 10/2008 *Treatment: Surgery (10/2008)/ intravenous chemotherapy, Treatment Stopped: 09/2010*
"I do not know, just knowing people are looking at you and [thinking] 'oh, they have cancer.' ***In one of my classes when I first went back, a kid that I did not know very well was talking to me. He goes 'I thought you were retarded' and I just looked at him and was like – what?*** *I had no brain damage from that. I have some damage in my nerves and the back of my leg****. I do not have any brain damage from it. I have a 4.0 and this kid was not the brightest kid in the world and I was like 'are you kidding me?' Just having people judge you.****" – Allison*

Table 6.3.14 Example of questions, feeling like the center of attention (1)

Tracy, 17-year-old female, Diagnosed Metastatic Capillary Thyroid Carcinoma 08/2010 *Treatment: November 2010 – Surgery (11/2010), continues oral thyroid medication*
*"****It was weird. Everybody was staring at my neck because it was super red at that time.*** *Usually my friends would just, I always had friends to walk to class with.* ***One of my friends would try to come up and hug me and one of my best friends would put their arm around me and be like stay off her neck. They were making jokes out of it and yea, they protect me. So they if they saw people staring they would say let's walk this way or they would turn me and try to have me walk a different way and stuff.****"*

Table 6.3.15 Example of questions, feeling like the center of attention (2)

Mother of Tracy, 17-year-old female, Diagnosed Metastatic Capillary Thyroid Carcinoma 08/2010 *Treatment: November 2010 – Surgery (11/2010), continues oral thyroid medication*
*"**She didn't want anybody to make any big deal about having her been gone. She was really concerned about people coming up like, 'oh my gosh, where have you been, what happened?' She just wanted to slide in under the radar.** So I had sent... I had addressed that with her counselor, who was beyond fabulous and instrumental in organizing everything, keeping everything on track. And so **I emailed her teachers and just said, you know, Tracy kind of wants to slide back in under the radar. You know, she doesn't want kids bugging her or asking a bunch of questions. And so they just... So what Tracy told me is she kind of walked back into class – she only attended like half days at the very beginning or she'd go a couple periods and then come home. She didn't go back full time until after winter break. But her teachers just kind of... She said they just went about their business. They didn't 'oh my gosh, are you okay, are you feeling...' They didn't, they just let her slide back in the door and nothing really was said, which is how Tracy wanted it**."*

Peer reactions to an adolescent with cancer returning to school can vary as illustrated by the excerpts in the tables above. Of the excerpts in this section, Jamie's shows her attempt to return to school while still undergoing treatment (Table 6.3.12). I have included it in this section because while the return to school can be attempted in any phase of cancer, it is most commonly attempted in post-treatment. The surprise her peers had regarding her return shows how cancer is perceived amongst adolescent peers, particularly while the adolescent is still undergoing treatment. It is the perception that she is too sick to attend school, thus the questions regarding, "*What is she doing here?*" Allison had a similar experience upon her return to school in post-treatment when a boy in her class was surprised to see her in school because he thought she had brain damage from her cancer experience (Table 6.3.13). In both Jamie's and Allison's experiences they both felt as though they were maybe too well known amongst their peers because of their cancer experiences.

Caleb and Brandon's peer reactions in Table 6.3.10 and 6.3.11 show both extremes of reactions that an adolescent in post treatment experiences upon returning to school. Peers are either excited to have the student return or they behave as though everything is normal.

As shown in Tracy's, Jamie's, and Caleb's excerpts above, their use of the word "*everybody*" when referencing the reaction to their return indicates that they felt as though they are the center of attention. Jamie also says, "*people I didn't even know knew me*" to indicate the level of fame she experienced upon returning to school. This kind of attention does not seem to be what the participants want, however. Caleb talks about wanting to get back into his former routine as fast as possible. Jamie says that it was "hard" being back at school with that kind of attention. Tracy's talks about how her peers would stare at the scar on her neck and her friends would get protective and encourage her to walk a different way to get to class. Furthermore to avoid any excess attention, Tracy's mother had contacted the school prior to her return to request that the teachers do not draw any extra attention to her. This request allowed for the teachers to not contribute to any additional attention that Tracy may have received from her peers upon her return to school.

The attention that the participants experience upon returning to school is something they have expressed wanting to avoid. This is an indication of the fact that having cancer has already made them feel different from their peers, given their experience. Returning to school is an indication that they are returning to their life without cancer treatments. While they may have changed as a result of their experiences, it is clear from the data that they do not want to draw additional attention to the fact that they feel different from their peers. The experience of having cancer has changed them in comparison to the experiences of their peers. It has resulted in a shift in life perspective and how they choose to incorporate their cancer experience into their post-treatment life. These will be covered in the next sections.

Shift in Perspective

The substantial impact that cancer can have on a patient's life often results in a shift in how the patient perceives the world around them. After experiencing severe treatment that often causes patients to feel as though they are facing death, many people in cancer survivorship have an optimistic perspective on life once their cancer is gone. For adolescents, the consequence of this positive shift in perspective is that it can cause a rift in how they interact with their peers who have not had similar experiences.

Table 6.3.16 Example of a positive shift in perspective (1)

Caleb, 15-year-old male, diagnosed Hodgkin's Lymphoma 11/2010 *Treatment: 3 months chemotherapy/6 months radiation, Treatment Stopped: 6/2011*
*"**Just like I appreciate like everything – just like I just make sure I have fun every day, just live life, have fun, do good, like get good grades, just do everything I always wanted to do**… Yeah, like I was always just that way but just way more so after everything. Like, I'm still that way definitely. **Like I always think of everything and I like just look at the big picture of everything. Like, I try to stress so much that I'm still alive.**"*

Table 6.3.17 Example of a positive shift in perspective (2)

Aaron, 17-year-old male, Diagnosed Mucoepidermoid Carcinoma 12/2009 *Treatment: Surgery (12/2009)/Radiation, Treatment Stopped: 03/2010* *Relapse: 01/2012, Surgery 03/2012*
"Yeah, my family became a lot, a lot closer. In addition, you would really be surprised at what you can go through because some people probably think I could never do that, but ***after going through that I feel like I can do a lot more now. I have a different perspective on things. Some things really are not as bad as they seem. Life is a gift and it is really precious.****"*

Table 6.3.18 Example of a positive shift in perspective (3)

Kevin, 14-year-old male, Diagnosed Anaplastic Astrocytoma 05/2009 *Treatment stopped: Surgery/Radiation/Chemotherapy, Treatment Stopped: 04/2010*
"Kevin: ***I would say my attitude has changed and made me a better person.*** *Interviewer: What was your attitude like before?* *… Kevin: Like* ***I felt that I thought differently. I did different things from before. I just completely felt different*** *so I was scared of that. But,* ***I realize that I think it made me a better person than I was before.*** *Interviewer: Ok.* *Kevin:* ***Things, like you know how the things that do not kill you make you stronger.****"*

Table 6.3.19 Example of a positive shift in perspective (4)

Allison, 17-year-old female, Diagnosed Pilocytic Astrocytoma 10/2008 *Treatment: Surgery (10/2008)/ intravenous chemotherapy, Treatment Stopped: 09/2010*
“Allison: My friend and I, I met her when I was 14, we were both going through the same thing, but she had a really rare type of bone marrow cancer and she passed away when we were 16, that was really hard. She fought so hard, she had it so much worse than me. She was on a ventilator. ***I think it was good to see. I think it was good to see you have these people that have it 20 times worse than you and she fought and gave me a reason to…I think getting a really good value on life that I was not to waste my time on people that do not deserve it. I fought so hard. Whenever I had a problem my mom was really, “it was really worse fighting for her life. Is this really, what you want to spend your time on?”*** *Interviewer: That keeps it in perspective for you?* *Allison: Yeah definitely.”*

The above tables stress how the perspective of these four participants shifted positively as a result of their cancer experience. As Kevin emphasizes in Table 6.3.18, “*what does not kill you, makes you stronger.*” Having survived cancer has caused these participants to feel as though they have a second chance to live their life as optimistically as possible. In Allison’s excerpt above, it was not only her own cancer experience that caused this realization, but also the experience of a friend who did not survive her cancer. Surprisingly Allison says above, “*I think it was good to see*” (Table 6.3.19). This statement does not imply that Allison enjoyed seeing her friend pass, but instead that seeing her pass helped Allison to realize that cancer can result in death. It is this realization that triggered her shift in perspective.

However, cancer survivorship is a rare and unique experience for adolescents. While adolescents in cancer survivorship may experience a shift in how they view life, often times their peers have not had such an experience. This results in adolescents in cancer survivorship feeling different from their peers, especially once they have returned to school. They come out of their experience changed while their peers have remained the same.

Table 6.3.20 Example of feeling different from peers (1)

Jamie, 17-year-old female, Diagnosed Acute Lymphoblastic Lymphoma 10/2008 *Treatment: chemotherapy, Treatment Stopped: 11/2010*
*“**When we go to school, I feel like they know everybody. I am kind of like at least know them because they have been in school like the whole time and I have been like off and on. So, I feel like I am left out.** I don’t feel as pretty as they do. Oh my gosh! I guess it's something... They don’t understand. They are like, I’ve been short [tempered] more than they have I think because of what I have been through, but they are still stuck in this, “Oh my gosh, I hit my knee on the door. I am going to die. I need to miss a week of school.” I am like, “Seriously?” You can push through that kind of stuff. **I feel like... not that they are beneath me, but I feel like we are on different levels in that perspective that I can’t even go talk to them about things that I am dealing with like that.**”*

Table 6.3.21 Example of feeling different from peers (2)

Caleb, 15-year-old male, diagnosed Hodgkin’s Lymphoma 11/2010 *Treatment: 3 months chemotherapy/6 months radiation, Treatment Stopped: 6/2011*
*“I think – **I might appreciate life more than they do, not in like the sense that a different or a better way, just different.**”*

Table 6.3.22 Example of feeling different from peers (3)

Aaron, 17-year-old male, Diagnosed Mucoepidermoid Carcinoma 12/2009 *Treatment: Surgery (12/2009)/Radiation, Treatment Stopped: 03/2010* *Relapse: 01/2012, Surgery 03/2012*
*“**The hardest part was probably my friends, maybe it was me or them, but I just felt like we both kind of acted different towards each other**... I do not know, probably that **I felt a little distance from them because I had been out of school for like two weeks and just because of what I had been through.** I do not know if it was because they did not know what to say or whatever... **Even though there is a whole support system at school, I just felt really different.** It was nice to still just let that out. **I did not want to feel really different from everybody else.**”*

Table 6.3.23 Example of feeling different from peers (4)

Brandon, 14-year-old male, Diagnosed Non-Hodgkin's Lymphoblastic Lymphoma 09/2008 *Treatment: chemotherapy (oral and intravenous), Treatment Stopped: November 2010*
"Interviewer: Did you ever have a feeling like you were different from your friends, given your experience? *Brandon:* ***Sometimes****.* *Interviewer: Can you explain that?* *Brandon: I don't really know but actually, sometimes I'd have to go and get LPs and I'd have to leave for that. And then sometimes the next day, too, or my friends would ask and I'd have to explain.* *Interviewer: What was that like, trying to explain what an LP is to other kids at the age of thirteen, fourteen?* *Brandon:* ***It's really difficult. They don't get it really.****"*

Table 6.3.24 Example of feeling different from peers (5)

Tim, 14-year-old male, Diagnosed Neurofibromatosis (8 years old at diagnosis) ***Treatment: 18 months of chemotherapy – tumors still present, but stable***
"Interviewer: How did your friends react before you went to the school for the blind? How did your friends react at school with your blindness? Were they helpful? *Tim: Some were most weren't.* *Interviewer: Most were not. What did it feel like for you being in a school where there probably were no other blind children?* *Tim:* ***I felt like the only one. Like I was different.*** *Interviewer: What was it like to feel different from everyone else?* *Tim:* ***Frustrating****.* *Interviewer: Were you able to easily get from one class to the next?* *Tim: There... sometimes it was a challenge because everyone was around and the halls were so small.* *Interviewer: Did you have any friends that helped you out?* *Tim: No."*

Table 6.3.25 Example of feeling different from peers (6)

Allison, 17-year-old female, Diagnosed Pilocytic Astrocytoma 10/2008 *Treatment: Surgery (10/2008)/ intravenous chemotherapy, Treatment Stopped: 09/2010*
"It was really weird, I was home schooled for that whole period and I got myself through all of that which was my main concern. I did not mind it after school. ***I was scared; I cried the first thing I came home. It is like really different going from having these tons of problems to worry about your life to going to school and hearing people complaining about their hair. You are lucky your hair did not fall out!****"*

The participants regularly mentioned feeling "different" from their peers throughout the interviews. Table 6.3.20 to Table 6.3.25 above are examples of how the participants' experience shifted their perspective and caused a rift in how they interacted with their peers. In Tables 6.3.20 and 6.3.25, Jamie and Allison gave examples of what they implied to be mild problems, such as complaining about hitting your knee on something or a bad hair day. Jamie and Allison's perspective on levels of pain and what truly matters to them are clearly different from their peers. For Allison, this difference was so drastic between her and her peers that she cried after her first day back at school in post treatment. She also says that she was "*scared*" to return to school and go back to a life after treatment because she felt so different from her peers (Table 6.3.25). This is similar to the uncertainty Jamie expressed in Table 6.3.5 when she said, "*I don't even know how to start back my life.*" Given that Jamie and Allison experienced two years of treatments, much longer treatments than the rest of the participants, it indicates that the length of treatment can have an impact on how prepared the adolescent may feel to return to life in post treatment.

However, the length of treatment may not be the only contributor to the feeling of being different from peers. Aaron's excerpt above shows that he was only absent from school for two weeks. Yet he says, "*just because of what I went through,*" indicating that it was the gravity of the cancer experience that caused him to feel different. Similarly, Tim continued to attend school during cancer treatment, but felt different from his peers because of his visual impairment.

These findings indicate that there are three factors that can contribute to adolescents in cancer survivorship feeling different from their peers. The first is the cancer journey itself. It is a rare and unique experience for adolescents that automatically set them apart from their peers. The second is the severity of the effects from treatment. Tim's visual impairment caused him to feel like an outcast amongst his peers. The third is the length of time away from peers. The more time spent separated from peers due to cancer treatment, the more disconnected adolescents will feel upon their return in post treatment.

Incorporation of Cancer into Post-Treatment Life

Patients in cancer survivorship who have reached the post-treatment stage must learn to incorporate their experiences into their lives. Chapter 5 showed how the participants in this study had to incorporate the physical effects of their experience into their post-treatment life. Yet the weight of this life event is often incorporated into post-treatment life in other ways as well.

Career Choices

Interview excerpts that address how the participants' experiences have shaped their career choices and desires resulted in 22 excerpts from six participant interviews.

Table 6.3.26 Example of experience has shaped career choices (1)

Tracy, 17-year-old female, Diagnosed Metastatic Capillary Thyroid Carcinoma 08/2010 *Treatment: November 2010 – Surgery (11/2010), continues oral thyroid medication*
“Interviewer: That’s always so fun. What are you hoping to study at college? *Tracy: **Exercise science**.* *Interviewer: Really?* *Tracy: Mm hmm.* *Interviewer: And why is that?* *Tracy: **Because I want to do occupational therapy for kids who are diagnosed with cancer.*** *Interviewer: Excellent. And is that because of your experience?* *Tracy: **Yup**.”*

Table 6.3.27 Example of experience has shaped career choices (2)

Caleb, 15-year-old male, diagnosed Hodgkin’s Lymphoma 11/2010 *Treatment: 3 months chemotherapy/6 months radiation, Treatment Stopped: 6/2011*
*“Caleb: Yeah, because we were in Boston so we were like – I was like let’s stop by [the college] because that was the college I wanted to go to. And it was amazing. Like it was intense, like it was crazy so but I always think about like that was always just my number one choice **but then I would think about like just going into – what do you call it – just as like a childhood cancer doctor.*** *Interviewer: An oncologist?* *Caleb: **Yeah, like kind of just like my doctors, like Dr. Smith and Dr. Jones. They’re like the specialists so they’re like the doctor that like tells you like what you’re like – what’s going to happen and like they were like the doctors that like gave me my game plan. Like, this is like the chemo you’re going on and like they help you through everything and talk with you through everything.**”*
*Caleb: **So I always think about that stuff because I don’t know. I just think it would be cool like actually being after everything and going back in the same field that I got treated from.*** *Interviewer: Yeah. Well, I mean you’d be able to give your patients a little bit more perspective.* *Caleb: Yeah, exactly, yeah.* *Interviewer: Because you know what it was like to go through it?* *Caleb: **Yeah, that’s why I thought it’d be like – and it's a really rewarding like area.”***

Table 6.3.28 Example of experience has shaped career choices (3)

Aaron, 17-year-old male, Diagnosed Mucoepidermoid Carcinoma 12/2009 *Treatment: Surgery (12/2009)/Radiation, Treatment Stopped: 03/2010* *Relapse: 01/2012, Surgery 03/2012*
"Interviewer: Do you think your experience with cancer has pointed you towards something like a dentist, doctor, or anything like that? *Aaron: Yeah, before I wanted to be a doctor because they made a lot of money.* *Interviewer: Okay.* *Aaron: And are well off and* ***after I went through treatments I realized that I would really want to do it because I really like to help people and just help them out and do what I can to make their lives better.****"*

Table 6.3.29 Example of experience has shaped career choices (4)

Kevin, 14-year-old male, Diagnosed Anaplastic Astrocytoma 05/2009 *Treatment stopped: Surgery/Radiation/Chemotherapy, Treatment Stopped: 04/2010*
"I think that I would love to be [a firefighter]. I think it would be a really interesting job. But I can think of a few things that would really hinder that. Like having my – on my… My dad talked to me about… Well, before I wanted to be a police officer even more than a fireman. He said that there was a physical that they had to go through. ***Me not – only having one eye might be – might not get me through. He said there is a very good chance that I will not be able to go through with just having one eye.****"*

Table 6.3.30 Example of experience has shaped career choices (5)

Allison, 17-year-old female, Diagnosed Pilocytic Astrocytoma 10/2008 *Treatment: Surgery (10/2008)/ intravenous chemotherapy, Treatment Stopped: 09/2010*
“Allison: It definitely has. ***When I got sick, I kind of wanted to be a nurse and then I just found it’s really hard for me to watch people in pain,*** *especially when I was at primaries. Like I’m not going back to primaries anymore. I’m actually going to be doing my MRIs [interruption] memory, just be like all those children being sick.* ***So I kind of want to be more behind the scenes or dealing with the disease just because I don’t actually want to, like to inflict any pain on anyone.****”*
Allison: Yeah, I mean, not to say that they didn’t help you in the long run. I just don’t want to see the pain on people’s faces. *Interviewer: Yeah. Do you feel if you were to see that kind of pain on their faces, do you feel like it would make you automatically remember what you went through?* *Allison****: It does, definitely. It’s really hard to go… Like I had my last MRI a few months ago before I left and that was probably a really hard decision. My life was so good at that point. You know, I was getting ready to move and I’m going to college and I see all these people. And I’m a rarity in that kind of situation to come out so well when so many people are damaged for the rest of their lives.****”*

Unlike adults in cancer survivorship, adolescents are still planning for their future in terms of their career. High schools put pressure on students to begin focusing on a long-term plan for life after high school as a part of college preparation. Adolescence is a time when children let go of the fantastical career dreams (such as astronaut, princess, tight-rope walker, or super hero) and begin to pursue career dreams more deeply rooted in reality (such as a doctor, lawyer, musician, or athlete). This shift is often a byproduct of adolescent experiences. For example, an adolescent who likes music and plays several instruments may want to pursue a career as a musician. An adolescent who loves to learn and read may pursue a career in teaching or academia. It is therefore not surprising to hear that half of the participants in this study expressed a desire to use their cancer experience to help others. The participants' career aspirations will be further discussed in the *Graduation* section on page 262.

In Tables 6.3.26 and 6.3.27, Tracy and Caleb talked about wanting to use their cancer survivorship experience to connect with children and adolescents who are diagnosed with cancer. Tracy wants to become an occupational therapist, which is a career in which she would be helping children and adolescents participate in the things they want to do, but were otherwise unable due to a physical or psychological disability. Given that she struggled for many years with extreme fatigue that kept her from participating academically and socially, it is possible that she chose this profession as a direct result of her cancer experience.

Caleb talked about originally wanting to be a musician, but he now understands that he would be able to connect with children and adolescents diagnosed with cancer due to his experience. The two doctors he mentions in his excerpt above, Dr. Smith and Dr. Jones, clearly had a substantial impact on his experience since they are the role models he hopes to be like one day. Caleb describes pediatric oncology as "*a really rewarding area*," which also contributes to his desire to pursue that career path. However, this may be due to the fact that his cancer experience was positive. He may have had a different perspective if his experience had been more painful or if he had known someone who did not survive his/her cancer.

Allison is an example of someone who has been affected by her cancer experience in this way. She explains in Table 6.3.30 that she would not be able to be a nurse, as she had originally wanted. She explains two reasons for this: The first is that she does not think that she can inflict pain on others. The second is that she fears that she would relive her experience as she witnesses others go through it. For these reasons, Allison hopes to focus on being a mortician or a pathologist. In both professions, the person is able to help families through hard times either through comfort (mortician) or providing them with answers (pathologist). Allison's reasoning says a lot about her experience. She experienced quite a bit of pain throughout her cancer survivorship. This is something she hopes to avoid in the future. However, she still hopes to help people who have gone through a similar experience to hers. Therefore she found an area where she is able to help people while also staying within her comfort zone.

Lastly, Kevin hopes to be a police officer or a firefighter when he grows up (Table 6.3.29). However, the physical effects of his cancer may prevent him from being able to do that. Whereas the other participants have chosen to use their experience to guide their career choices, the physical effects of Kevin's experience has introduced limits on his choices. Unlike Allison, Kevin is only beginning to face the challenges that could prevent him from doing the job he would like to do. Therefore he has yet to seek out a suitable alternative as Allison has done. However, at the time of the study, Kevin is four years younger than Allison. This means that he has not had to focus as much on his future as she has. For Kevin, a career is still more of an idea or a dream rather than a plan.

Role Model

Regardless of whether the participants are thinking about their future career plans, their desire to pursue opportunities where they are able to be a role model and of service to others is a common theme. Three participants talked during their interviews about using their new perspectives as role models for others. Statements that refer to being a role model or using their new perspective to help others have been highlighted in bold.

Table 6.3.31 Example of being a role model for others (1)

Jamie, 17-year-old female, Diagnosed Acute Lymphoblastic Lymphoma 10/2008 *Treatment: chemotherapy, Treatment Stopped: 11/2010*
*“**Other people look at me as strong.** I get a lot of… the lady that goes to my church, she just got diagnosed. She is in remission now, but she got diagnosed with cancer a while back. When she finished her treatment she was like, **you were the person I always thought about when I went into my treatments and you are my inspiration. So, that makes me happy that people look up to me, even older people look up to me even though I am young**... Or, what does not kill you, makes you stronger. I do feel way more stronger than when I did. Just know that I overcame something that a lot of people do not**. In that, I am here, which I can tell people about my experience. Like somebody that is going through what I am going through. If they are feeling like giving up. Or like I can help them. Just tell her what I have been through.** I do feel a lot stronger and being so – being at such a low point. Then down looking back over and being able to conquer it. Yes, it was a good feeling.”*

Table 6.3.32 Example of being a role model for others (2)

Tracy, 17-year-old female, Diagnosed Metastatic Capillary Thyroid Carcinoma 08/2010 *Treatment: November 2010 – Surgery (11/2010), continues oral thyroid medication*
*“**I think it was a good learning experience for new people that I meet.** They are like, ‘what’s that scar on your neck?’ I say, ‘Oh I had thyroid cancer last year,’ and they just like they never stop asking questions. They always come up with new questions every day. People were like, infatuated with touching my neck because it feels so different from everybody else’s because there is nothing protecting my muscle and stuff right there. Whereas, everybody else has a thyroid there protecting it so they feel that squishy thing right there and mine is hard muscle and my bones and stuff. It is like – **people are like intrigued with what happened and everything and that I am still in school and not depressed about it or anything.**”*

Table 6.3.33 Example of being a role model for others (3)

Caleb, 15-year-old male, diagnosed Hodgkin's Lymphoma 11/2010 *Treatment: 3 months chemotherapy/6 months radiation, Treatment Stopped: 6/2011*
"Caleb: It's back to normal but the things we do are like we're a lot crazier now I guess you could say. *Interviewer: How so?* *Caleb:* ***Like, we just do anything that we think is fun like the stupidest things possible.*** *Interviewer: And, this goes back to your desire to make sure you live every day to its fullest?* *Caleb: Pretty much, yeah.* *Interviewer: Okay, well, at least you're doing it with friends.* *Caleb:* ***Yeah, exactly and hopefully maybe teaching them to live life to its fullest as well.****" – Caleb*

The previous section showed that five of the eight participants, as a result of their cancer experiences, wanted to pursue careers that aimed to help others. This desire to help others stemmed from having successfully overcome a challenging experience and feeling the need to use their "second chance" productively. The above excerpts are evidence of how the participants have used their experiences to help educate the people around them. The ability and the opportunity to help others by serving as a role model for peers and community members allows cancer survivors to add meaning and purpose to their experiences. People in cancer survivorship can create something positive out of a challenging and negative experience. By using their shift in perspective and incorporating their experiences into their post-treatment lives, people in cancer survivorship are accepting their experience and making it a part of their identity, thus creating a "new normal."

Fear of Relapse

One of the most common concerns for cancer patients in post-treatment is the uncertainty of whether their cancer will recur, which is known as relapse. Five of the participants discussed their feelings about the possibility of relapse during their interviews.

Table 6.3.34 Example of the fear of relapse (1)

Jamie, 17-year-old female, Diagnosed Acute Lymphoblastic Lymphoma 10/2008 *Treatment: chemotherapy, Treatment Stopped: 11/2010*
*"**Scared, scared, oh so scared. Even though I didn't do my treatments like I was supposed to, I just really don't want it to come back. So, mostly scared and like failure. Man, that is failure. If it comes back, what did I do that made it come back? Obviously I did something. It's not supposed to come back. There is like 70% chance that it's not supposed to come back or something like that.**"*
*"My friend just passed away. She had the same cancer as me. **That kind of threw me for a big scare because when I was coming onto my treatment she was going into remission.** She just passed away. **I am scared. We had similar types of cancer and she was going to the month [follow-up appointments]. I don't know. I am kind of scared of that. I will check my own blood. I don't want it to come back. I think I have made so much progress in this time, that if it comes back I am going to be so messed up.**"*

Table 6.3.35 Example of the fear of relapse (2)

Aaron, 17-year-old male, Diagnosed Mucoepidermoid Carcinoma 12/2009 *Treatment: Surgery (12/2009)/Radiation, Treatment Stopped: 03/2010* *Relapse: 01/2012, Surgery 03/2012*
*"Aaron: **There is always the thought in the back of my mind that part of it does come back, but I feel really confident that it is gone.** Interviewer: How often would you say that thought crosses your mind? Aaron**: Probably very occasionally, maybe every once a month or so, sometimes twice a month. I try to stay positive though and just not think about that.**"*

Table 6.3.36 Example of the fear of relapse (3)

Tim, 14-year-old male, Diagnosed Neurofibromatosis (8 years old at diagnosis) *Treatment: 18 months of chemotherapy – tumors still present, but stable*
"Interviewer: Okay. I think that's a good way to look at it. Do you have any concerns about the tumors starting to grow again? *Tim:* ***I kind of wonder when will it happen? Will there be any signs?*** *Interviewer: Signs like what?* *Tim:* ***Well, when my sight... will it ever go... will it ever go again… will the tumors start growing again?"*** *– Tim*

Table 6.3.37 Example of the fear of relapse (4)

Allison, 17-year-old female, Diagnosed Pilocytic Astrocytoma 10/2008 *Treatment: Surgery (10/2008)/ intravenous chemotherapy, Treatment Stopped: 09/2010*
*"**I would worry a lot about it coming back. All that was in the back of your mind because there is still a piece left.** The tumor was too close to my spinal cord that the surgeon could not get it out. **It is always back in your mind, but it has been stable now for a year.**"*
*"Allison**: I do not think it will. If it does I do not think it will for a really long time, but yeah I do worry about it.*** *Interviewer: How often would you say that you think of that?* *Allison:* ***Usually only when I am really, really happy.*** *Interviewer: That's interesting.* *Allison**: I was for a long time when I went to school I did not talk to anyone, I did not try to make any friends because I felt like if I am happy again, that it would be taken away.**"*

Table 6.3.38 Example of the fear of relapse (5)

Tracy, 17-year-old female, Diagnosed Metastatic Capillary Thyroid Carcinoma 08/2010 *Treatment: November 2010 – Surgery (11/2010), continues oral thyroid medication*
"Interviewer: Great. Now, you had mentioned to me that you have concerns about cancer returning in other places of your body. ***How often would you say you think about that?*** ***Tracy: Every day.*** *Interviewer: Every day.* *Tracy:* ***When I don't feel good and my stomach starts to hurt or I can't breathe. My doctors think I got asthma or something, whatever. When I can't breathe I always think the thyroid cancer likes to go to your lungs and liver and I think that maybe there is cancer in my lungs and maybe that is why I can't breathe. Not a day passes that I don't think about it.****"*

A patient in cancer survivorship cannot claim to be in "remission" until they are five years post-treatment and still cancer free. If cancer recurs prior to the five-year anniversary of post-treatment, it is referred to as a cancer recurrence or a relapse. If cancer is diagnosed after the five-year anniversary of post-treatment, it is referred to as a second cancer, and is considered to be a separate diagnosis from the initial cancer diagnosis. People who have been diagnosed with cancer once are more likely to have cancer a second time either through cancer recurrence or a second cancer than a person who has never been diagnosed with cancer before. The likelihood of cancer recurrence or second cancer depends on many variables such as the type of cancer, the type of treatment, and whether the treatment successfully removed all cancer cells the first time (Cancer Research UK, 2014; American Cancer Society, 2013). The idea of cancer returning can be scary; especially in instances when initial treatment had a substantial impact on the patient psychologically. The above excerpts show the fears that the participants' had regarding relapse. According to Newby et al. (2000) and Zebrack & Isaacson (2012), these fears are common and often dissipate over time as the adolescent adjusts to life after cancer treatment.

In Table 6.3.34 above, Jamie expresses adamantly that she would be, "*scared, scared, oh so scared*" if her cancer were to recur. Although she admits to not adhering to her treatments all the time, she also says in the first excerpt above that she would feel as though she failed if her cancer were to return. This idea that she would feel failure if her cancer returns is likely attributed to her choice to not adhere to treatments. Yet this idea of failure also is evidence of her attempting to exert some control over her medical situation. Adhering to treatment is one way that a patient can feel in control during a time when their body is behaving in ways out of their control. In the second excerpt above, Jamie explains that she had a friend who had the same cancer as she did. This friend passed away after her cancer recurred after being cancer free for two years post-treatment. Jamie says, "*I will check my own blood,*" indicating that to avoid missing a possible cancer recurrence she will do the tests herself. While Jamie does not have the trained skills or equipment to actually conduct her own blood tests, this excerpt is evidence of how desperate Jamie is to avoid experiencing a cancer recurrence. Not only does it exhibit the fear she feels, but it also shows how severely her treatment impacted on her. This is apparent in her final sentence of the second excerpt, which says "*I think I have made so much progress in this time, that if it comes back I am going to be so messed up*."

Aaron, Allison, Tim, and Tracy do not openly express fear of relapse in Tables 6.3.35 to 6.3.38 above, but they do express worry. Tracy explains in Table 6.3.38 that every time she feels slightly ill, she wonders if it is her cancer returning. For most people shortness of breath is simply due to a cold, allergies, or asthma, but Tracy fears that her cancer has returned every time she feels short of breath. Similar to

Jamie, this worry is an example of not wanting the cancer to return but also an example of how she was affected by her experience. Yet Tracy had no signs that cancer still exists in her body.

In Table 6.3.37, Allison explains that part of her tumor remains because the doctors were unable to remove all of it. In cases like Allison's, cancer recurrence is more likely since the tumor or cancerous cells are still technically present in the body. They become stable but they are technically still present and can begin growing again at almost any time. Patients whose cancer cannot be removed entirely likely worry more about cancer recurrence since it is more likely in their situation.

Similarly Tim, who has neurofibromatosis, must prepare for multiple tumor growth since that is the nature of his condition. Table 6.3.36 shows that he feels uncertain of what future tumor growth would feel like, thus contributing to his worry. Furthermore, he also expresses concern that the tumors on his optic nerves will begin to grow again, hindering his eyesight further. In Tim's case, future tumor growth is not a matter of if it will happen, but when. The nature of his condition means that his tumors are most likely to be benign; however, tumor growth can cause other problems, as is the example with the optic nerve tumors.

Tumor Recurrence

Table 6.3.35 shows that Aaron remained positive that his cancer was gone, despite any worry that he felt. However, Aaron experienced a recurrence of his cancer between the time of the first interview and the time of the follow-up interview. Similar to Allison, Aaron's doctors were unable to treat the entire tumor because they did not want to jeopardize the vocal cords if they could avoid it. This resulted in a recurrence of his cancer. Tim also experienced new tumor growth in the time between the first interview and the follow-up interview. The excerpts from Aaron's and Tim's interviews that refer to their recurrence are in Tables 6.3.39 and 6.3.40 below.

Table 6.3.39 Example of cancer recurrence (1)

Aaron, 17-year-old male, Diagnosed Mucoepidermoid Carcinoma 12/2009 *Treatment: Surgery (12/2009)/Radiation, Treatment Stopped: 03/2010* *Relapse: 01/2012, Surgery 03/2012*
"Interviewer: So I wanted to talk… Your mom had told me back in January that you had a little scare with relapse. *Aaron: Yeah, I did.* *Interviewer: What happened?* *Aaron:* ***They actually found another lump because when I had radiation a couple years ago, they didn't do a spot right in the middle like right where my Adam's apple is, and this is where they actually found the lump.*** *And so they took that out and I actually had another big surgery and they took out more and just got it really good, got a lot of it out. And they actually redid my old scar, too, so I had like a twenty-inch scar from the surgery."*
"It's kind of scary. But this time, I knew that if they did it last time they could do it this time and get pretty much all of it out. Because they missed that spot and that's where it showed up, I felt like a little better that it wouldn't come back. *But I knew it was going to be easier because I just had a surgery, I didn't have radiation or anything. And I didn't let it ruin my senior year, so I just had surgery, recovered, and went back to school."*

Table 6.3.40 Example of new tumor growth (1)

Tim, 14-year-old male, Diagnosed Neurofibromatosis (8 years old at diagnosis) ***Treatment: 18 months of chemotherapy – tumors still present, but stable***
"Interviewer: What where you thinking when you found out that you had a tumor in your knee? *Tim:* ***Well, when did this happen? How long has it been there? Why hadn't I felt it before?*** *Interviewer: Yeah, especially at that size.* *Tim: Yeah."*
"Interviewer: Do you think that going through that helps you to kind of prepare yourself for it if it should happen again? *Tim:* ***Yeah. If it did, so I would know what nerve pain feels like and what it feels like when you have a tumor.*** *Interviewer:* ***So you feel more physically prepared and you know what signs to look for?*** *Tim:* ***Yeah."***

While Aaron explains that his relapse was "scary," he remained positive and confident that the doctors were able to remove the entire tumor the second time around. In his case, knowing that the entire tumor had been removed actually provided Aaron with comfort that it would not recur a third time. He further explains in the second excerpt in Table 6.3.39 that he "*didn't let it ruin [his] senior year.*" This shows that he was both mentally and physically prepared for treatment the second time around. He knew treatment would be easier to experience since it would not be as intense as it was the first time now that he did not require radiation treatments. He stayed focused on what was important to him, which in this case was enjoying his final year of high school without allowing his cancer recurrence to interrupt it as best he can.

The fact that Aaron knew what to expect from treatment, combined with the fact that he had already successfully beat cancer once, gave him confidence in undergoing treatment a second time. It is possible that the level of preparedness a patient has for treatment may impact on how psychologically they prepare themselves for what is to come. In Aaron's case, uncertainty has been completely removed from his experience. Once he was on the other side of the full cancer journey, he did not wonder about what treatment would be like, whether he would successfully beat his treatment, or whether his cancer would recur. His experience indicates that it is the uncertainty of what may happen that instills the most worry and fear into the overall cancer experience.

Since Tim was aware that one day more tumors would grow, he did anticipate it happening eventually. Similar to Aaron, this experience showed Tim what to expect as future tumors grow. This experience has eliminated some of the uncertainty that he was initially experiencing regarding when it would happen and what it would feel like.

Follow-up Appointments

Since relapse is more likely in patients who have already been diagnosed with a first cancer, follow-up appointments are necessary to catch any cancer recurrence early. Some people in cancer survivorship find these appointments comforting while others find them to be worrying. Three participants explained how they view their follow-up appointments. Their views have been highlighted in bold.

Table 6.3.41 Example of follow-up appointments being worrying (1)

Jamie, 17-year-old female, Diagnosed Acute Lymphoblastic Lymphoma 10/2008 *Treatment: chemotherapy, Treatment Stopped: 11/2010*
*"**I guess I feel normal every day until that one-month check up when I realize that I am not like any other girl.** So, I guess the one-month checkup or when I am like watching TV or something and the little happy birthday commercial from the Cancer Society comes on. I am like 'oh my gosh,' and then I think about it."*
*"I think it's one year after you go every other month to give blood. **I am kind of like iffy about that because I am scared. Two months? That is like a lot can happen in that time. I am nervous about that.**"*

Table 6.3.42 Example of follow-up appointments being worrying (2)

Tracy, 17-year-old female, Diagnosed Metastatic Capillary Thyroid Carcinoma 08/2010 *Treatment: November 2010 – Surgery (11/2010), continues oral thyroid medication*
"Interviewer: Is it now just really normal for you when you walk into that doctor's office or do you feel any kind of nerves or worry or apprehension? *Tracy: **Yea. It's just the biopsy guy that I get nervous with because I do not like that place.** Every other doctor I'm like, "Hey, what's up?"* *Interviewer: Does the biopsy, when you get things any time you visit that doctor, does it make you nervous because you are afraid you are going to find something? Or does it make you nervous because it is painful?* *Tracy: Well, it's not painful anymore because they have nothing to biopsy. **They do an ultrasound on my neck and it just makes me nervous that he is verifying something else or…**"*

Table 6.3.43 Example of follow-up appointments being comforting (1)

Brandon, 14-year-old male, Diagnosed Non-Hodgkin's Lymphoblastic Lymphoma 09/2008 *Treatment: chemotherapy (oral and intravenous), Treatment Stopped: November 2010*
"Interviewer: So when you think about being in remission, what kinds of thought do you have about your future? *Brandon**: I think I will be good and I will not have any health problems or anything.*** *Interviewer: You do not think you will have any more health problems?* *Brandon: **No, I know it will not come back and if it does, they will get on it right away.*** ***Interviewer: You feel that way because you continue to go for treatments so regularly?*** ***Brandon: Yeah.**"*

Jamie and Tracy's excerpts in Tables 6.3.41 and 6.3.42 show how the follow-up appointments can serve as a reminder of the difficult experience they had during treatment. Although they are showing no signs of cancer being present, the necessity of follow-up appointments exist because cancer can return. It is this possibility that causes them grief when they attend their follow-up appointments. However, Brandon finds comfort in his regular appointments, as shown in Table 6.3.43. He trusts that his regular appointments will catch any cancer recurrence early enough to treat it successfully. Brandon's excerpt is an example of how follow-up appointments can be viewed optimistically, which is to catch cancer recurrence as early as possible so that it can be successfully treated.

While Newby et al. (2000) and Zebrack and Isaacson (2012) identify that a fear of relapse is common amongst adolescent cancer survivors, neither study identifies ways that fear may be triggered. The participants' perspectives on follow-up appointments may be mediated by the severity of the treatment experience. Both Tracy and Jamie have had challenging treatment experiences. Jamie's was a long treatment process with severe side effects that fully removed her from her daily life. Although Tracy's treatment was fairly quick in comparison, it was a long diagnosis process with the challenge of finding the best medication to help mediate her treatment effects. The fear that they both exhibit in the excerpts above regarding relapse exists because they do not want to go through those experiences again. The follow-up appointments trigger that fear. Brandon, on the other hand, has throughout his interview referred to his treatment as though it did not have a large psychological impact on him. Although he underwent treatment for one year, he does not express being psychologically changed by his experience. He trusts that his doctors successfully treated his cancer and will catch any cancer recurrence early.

Discussion and Chapter Conclusion

This chapter was organized by the stages of cancer to illustrate the emotional and psychological journey that the participants experienced. Their reactions to diagnosis illustrated the gravity of what it was like to hear that they had cancer. This confirms Woodgate's (2005) claim that cancer is a major life event. As a result, this life event influences the formation of identity for adolescents.

Chapter 5 showed that the physical effects of cancer were most severe during the cancer treatment stage. For the participants in this study, psychological effects are most prominent during the Post-treatment stage. As the participants progressed from the Cancer Treatment stage to the Post-treatment stage, they made emotional and psychological adjustments during the transition. Knowing that the worst of the experience is behind them provided the majority of the participants with comfort regarding the future of their health. These findings confirm the findings reported by Jones et al. (2011) that adolescents shift from the cancer identity during treatment to the survivor identity in post-treatment. The present study also exemplifies the findings from the Jones et al. (2011) study in that the participants experienced conflicting emotions in the Post-treatment stage such as relief that their cancer is gone as well as fear that it may one day return.

The uncertainty that the participants experienced throughout their cancer journey also exemplifies the loss of control that is commonly experienced in this population (Lewis, 1996; Wicks & Mitchell, 2010). Lewis (1996) and Wicks and Mitchell (2010) argued that the loss of control during adolescence hinders the body's developmental task to gain independence throughout puberty. It is therefore paramount that adolescents in cancer survivorship rely on support from medical personnel, parents, the school, and peers to develop a routine. The current study showed that the presence of a regular routine provided comfort for the participants, thus regaining a sense of a control.

The majority of the participants in this study felt different from their peers, especially upon reintegrating into the school setting in the Post-treatment stage. This finding confirms the reports of Stam et al. (2001), who found that adolescents in cancer survivorship experienced challenges in social functioning during the Post-treatment stage. This makes reintegration to school even more difficult and hinders educational engagement for this population.

Since adolescents in cancer survivorship have experienced cancer, a "powerful life event" (Woodgate, p. 9; 2005), they are changed by it. As a result they experience a shift in their perspectives, resulting in a new normal. Zebrack (2011) introduced the concept of the new normal for adolescents in cancer survivorship. The findings in the present study confirm the findings of Zebrack (2011) and Zebrack and Isaacson (2012). As time passes the participants in this study became more adjusted to their identity as a cancer survivor, which confirms the findings reported by Stam et al. (2001) and Newby et al. (2000). Lastly, the shift in perspective that the participants in this study reported focused on their pursuit to derive meaning from their cancer experience and to use that experience to positively influence people around them.

It is important to look at the physical and psychological experiences of the participants in order to understand the challenges they faced in maintaining educational engagement. While physical effects may hinder an adolescent's ability to physically attend school, this chapter has shown that psychological effects can impact on their ability to interact with peers. This chapter has also shown that psychological effects impact on their ability to focus on maintaining education during a time when they feel their life has been threatened. Thus they emerge from their experiences forever changed. Adolescents in cancer survivorship attempt to adjust to this change while also attempting to reintegrate into a life in post-treatment.

Chapter 7

Participants' Experiences with School

Introduction

Cancer patients who receive a positive prognosis will eventually return to a post treatment life. For adolescents, a return to normal life includes reintegrating into school that may have been interrupted due to treatment. The previous chapters have shown that in some cases, reintegration will carry with it minor residual physical effects of the cancer and/or treatment, while in others, life will never be the same as it was prior to diagnosis. Adolescent cancer survivors must have access to education that accommodates all varieties of physical, mental, and emotional needs. Successful reintegration into school depends on a variety of factors including accommodating physical effects that linger during and after treatment, the input of counselors and teachers in school, and social interactions with classmates and friends. This chapter presents findings regarding the participants' school experiences in cancer survivorship, including supplemental education during treatment, reintegration into school, and the role of social interactions as a part of reintegration.

Interview Questions Pertaining to the Participants' Experiences with Education

- Let's talk about school. How are you doing in school?
- Do you have any concerns about school?
- Do you feel supported by your school?
- How many different teachers do you see in a day?
- Are they accommodating with regard to your schoolwork?
- Is there any special education that you received during treatment?
- Is there any special education that you are currently receiving?
- (If so) Do you think that it's helpful?
- (If not) Do you think extra accommodations would be helpful?

Education During Treatment

The eight participants in this study fall within three categories regarding their supplemental education experiences during cancer treatment. The first category includes those participants whose school or district provided supplemental education during treatment, and was accepted by the participant. The second category includes those participants whose school or district offered supplemental education during treatment, and was either declined or was deemed to be insufficient. The third category includes those participants whose school district did not offer supplemental education; either because the participant did not require it or the participant did not meet the eligibility requirements for the school district. Table 7.1 on the following page illustrates how each participant fits within each category.

During the interviews, the participants expressed either positive or negative feelings regarding their supplemental education experiences. The participants who expressed positive feelings regarding their supplemental education experience indicated that the supplemental education that they received was satisfactory in helping them maintain their education during treatment. Those participants who expressed negative feelings regarding their supplemental education experience indicated dissatisfaction with how sufficiently their education needs were met during cancer treatment. This section will present the data on the participants' positive and negative supplemental education experiences during cancer treatment.

Table 7.1 Overview of the Participants' Experiences with Supplemental Education

Supplemental education is offered by the school, and accepted by the participant.	**Supplemental education is offered by the school, and is either declined or is insufficient for the participant's needs.**	**The school district did not offer supplemental education, either because the participant did not require it or the participant did not meet the eligibility requirements for the district.**
Tracy - attended public school at time of diagnosis - absent 1 school quarter - received supplemental educational provision through the public school - describes overall supplemental education experience as **positive**	Tim - attended parochial school at time of diagnosis - absent every Friday for 18 months - received supplemental educational provision through the public school system at parochial school, but was unsuccessful - describes overall supplemental education experience as **negative**	Aaron - attended public school at the time of diagnosis - absent 2 weeks - school deemed that supplemental education was unnecessary due to current student achievement and length of absence - describes overall supplemental education experience as **positive**
Caleb - attended public school at time of diagnosis - absent 1 school quarter - received supplemental educational provision through the public school - describes overall supplemental education experience as **positive**	Allison - attended public school at the time of diagnosis - absent 2 school years - received offer of supplemental educational provision through the public school, but denied it - parent arranged for personal tutoring during treatment - describes overall supplemental education experience as **negative**	Brandon - attended public school at the time of diagnosis - absent 1 school year - was not offered any supplemental education services by public school - parents enrolled him in digital homeschool to maintain education - describes overall supplemental education experience as **positive**
	Jamie - attended public school at time of diagnosis - absent 2 school years - received offer of supplemental educational provision through the public school, but denied it - describes overall supplemental education experience as **negative**	Kevin - attended homeschool at the time of diagnosis - took one year off from homeschool studies - had offer to receive supplemental education from public school, but denied by parent - avoided falling behind academically due to the flexibility of the homeschool structure
	Kevin - attended homeschool at the time of diagnosis - took one year off from homeschool studies - had offer to receive supplemental education from public school, but denied by parent - avoided falling behind academically due to the flexibility of the homeschool structure	

Positive Supplemental Education Experiences

Table 7.1.2 Example of positive supplemental education experiences (1)

Mother of Tracy, 17-year-old female, Diagnosed Metastatic Capillary Thyroid Carcinoma 08/2010 *Treatment: November 2010 – Surgery (11/2010), continues oral thyroid medication*
*“A lot of times it is **just whether the school will actually be supportive and compassionate**... I don’t think all schools are in the district... We were just extremely fortunate with her counselor.”*
*“**She belongs here. She is part of our campus... This is where she needs to be. This is where her friends are and this is her school**.”*

Table 7.1.3 Example of positive supplemental education experiences (2)

Caleb, 15-year-old male, diagnosed Hodgkin’s Lymphoma 11/2010 *Treatment: 3 months chemotherapy/6 months radiation, Treatment Stopped: 6/2011*
*“**It wasn’t much time but it was enough to help me with what I needed... My only concern was to make it through ninth grade without having to repeat it and that happened** so everything worked out.”*

Table 7.1.4 Example of positive supplemental education experiences (3)

Brandon, 14-year-old male, Diagnosed Non-Hodgkin’s Lymphoblastic Lymphoma 09/2008 *Treatment: chemotherapy (oral and intravenous), Treatment Stopped: November 2010*
“It had all the stuff and I would just print it out and do it. Then I would just email it to the teacher and then I would just get the grade that way.”

Table 7.1.5 Example of positive supplemental education experiences (4)

Aaron, 17-year-old male, Diagnosed Mucoepidermoid Carcinoma 12/2009 *Treatment: Surgery (12/2009)/Radiation, Treatment Stopped: 03/2010* *Relapse: 01/2012, Surgery 03/2012*
*“**I did not have to take a final on two of my classes, they just said do not worry about it, you have done well in class, just get better**.”*

Four out of eight participants expressed positive views of their supplemental education experiences during cancer treatment as shown in Tables 7.1.2 to 7.1.5 on the previous page. Tracy and Caleb both fall within the first column on page 237, namely those participants whose school or district provided supplemental education during treatment, and were accepted by the participant. Despite differences in cancer diagnosis, and cancer treatment, Tracy and Caleb both attended public school, were absent for one school quarter only, and had a homebound tutor provided to them by the school district to help maintain their education.

In Tracy's case, the school gave her a special schedule for her mid-term examinations and a teacher from her school volunteered to pick up her schoolwork and bring it to her house each day. Her homebound services were put in place immediately, due to her 504 Plan already being in place from her ADHD diagnosis. Tracy's science teacher volunteered as the homebound tutor. For every two days that Tracy was absent, she received one hour of tutoring. Her science teacher tutored her in all subjects, but was unable to tutor her in maths. Tracy's mother arranged for a neighbor, who was a maths teacher, to come to the house and tutor Tracy in maths for thirty minutes at a time. Tracy's school counselor arranged all tutoring with homebound services (excluding the neighbor who acted as her maths tutor).

Her mother works for the school district and explained how each school can operate uniquely under these circumstances. In an effort to accommodate the school, Tracy's mother offered to take her off the school roster so as not to affect the school's yearly progress, which are examinations put in place by the district. Some school districts have school evaluations that test the achievement of the students as a measure of how the school is achieving overall and how well the teachers are teaching. Her mother explained that the school responded supportively.

As her science teacher was unable to tutor Tracy in maths, Tracy's mother chose to ask a neighbor to tutor her daughter in an effort to keep her up to date with her maths schoolwork. This exemplifies how parents can get involved when supplemental education tutoring is insufficient. Despite the positive supplemental education experience that Tracy had, her mother still had to seek out alternative methods of tutoring to help her daughter maintain educational engagement during cancer treatment.

Caleb's supplemental education experience during cancer treatment was similar to Tracy's experience. Caleb was provided with a school tutor from his local school district as a part of homebound supplemental education services. His tutor came to his house five days each week for one hour at a time to tutor him in all subjects. This is a standard structure of supplemental education for homebound tutoring in the United States. During the hours when the tutor was not present, Caleb continued to do work on his own and would have homework ready for review when the tutor arrived.

In summary, both Tracy and Caleb received supplemental education from their school districts and expressed positive feelings regarding their experiences. They were each enrolled in public school at the time of diagnosis and were both absent from school for one school quarter (approximately eight to ten weeks).

Aaron and Brandon did not receive supplemental education from their school districts, although both expressed positive feelings regarding their experiences with supplemental education during treatment.

Brandon was not offered supplemental education by his local school district. While his school helped his family to raise money to offset some of the medical costs of treatment, they did not accommodate Brandon's educational needs during treatment. Upon hearing that the school would not provide supplemental education for their son, Brandon's parents sought out alternative education and decided to enroll him in a digital homeschool. Digital homeschool allowed for Brandon to attend school using the Internet and his own computer. He completed homework and would submit it online to a tutor. This allowed him to continue the sixth grade without falling behind a school year. After one year when Brandon was ready to return to mainstream school, the digital home school transferred his grades back to his school. Brandon was able to begin seventh grade amongst his peers at his mainstream school. Despite occasional absences due to lumbar punctures for treatment, he was able to attend his mainstream school regularly and does not feel as though his education was jeopardized due to his cancer treatments.

In Aaron's experience, his school reviewed his grades and his anticipated absence of two weeks. Taking into account his good grades and the timing of his absence (leading up to the winter break), the school decided that he did not need supplemental education. The school told him that he could take the absence and not have to concern himself with making up the missed schoolwork. They asked him to focus on getting well and not to worry about school during his treatment. Aaron said in his interview that he felt supported by his school. He returned to class after his surgery when winter break ended. Aaron is the only participant that indicates that his grades - namely having good grades - affected the implementation of supplemental education during his absence.

Negative Supplemental Education Experiences

Table 7.2.1 Example of negative supplemental education experiences (1)

Allison, 17-year-old female, Diagnosed Pilocytic Astrocytoma 10/2008 Treatment: Surgery (10/2008)/ intravenous chemotherapy, Treatment Stopped: 09/2010
*"**My school really screwed me over actually**… **[The tutor] did not even know how to teach AP classes so my mom had to teach me them**."*

Table 7.2.2 Example of negative supplemental education experiences (2)

Mother of Tim, 14-year-old male, Diagnosed Neurofibromatosis (8 years old at diagnosis) Treatment: 18 months of chemotherapy – tumors still present, but stable
*"**We were relying on the public school systems to provide visual support and Braille lessons and we weren't getting the support we needed**."*

Table 7.2.3 Example of negative supplemental education experiences (3)

Kevin, 14-year-old male, Diagnosed Anaplastic Astrocytoma 05/2009 Treatment stopped: Surgery/Radiation/Chemotherapy, Treatment Stopped: 04/2010
*"When I had my treatment I was tired and it was very hard, but, **we didn't do too much school because it was very hard to do.**"*
*"**My brother and sister… wanted to go to school, but [my other brother] didn't want to. He tried going to school for a little, but he really didn't like it.** He got to stay home and my brother and sister wanted to see how public school was, so they went."*
*"**I was very alone.** Of course, I had had all three of them every day here and then it was just me here. **And I was – I was very bored.** I just had nothing because we play around all the time and I – I just didn't like it at all."*

Table 7.2.4 Example of negative supplemental education experiences (4)

Mother of Kevin, 14-year-old male, Diagnosed Anaplastic Astrocytoma 05/2009 *Treatment stopped: Surgery/Radiation/Chemotherapy, Treatment Stopped: 04/2010*
*“**It was just crazy at that time; trying to meet all of his appointments and school them at the same time**.”*
*“**We just didn’t do anymore school after that until after the summer.** Because they tested ahead we didn’t worry about it.”*

Table 7.2.5 Example of negative supplemental education experiences (5)

Jamie, 17-year-old female, Diagnosed Acute Lymphoblastic Lymphoma 10/2008 *Treatment: chemotherapy, Treatment Stopped: 11/2010*
Interviewer: Hmm. But you mentioned in our last conversation that – that you had a tutor but it “fell through.” When did you have the tutor? Jamie: **He came my freshman year. When I first started chemo. But it didn’t work out.** Interviewer: It just didn’t work out? Jamie: No, ma’am.
Jamie: Yes, ma’am. **They sent out e-mails to my teachers telling them my situation.** They had me on like a 504 plan. A 504 plan is like for a student. You know what a 504 plan is? Interviewer: I do, but I would like to hear you explain it. Jamie: Ok. Well, what I was told, a 504 plan is for students that like miss school or whatever. It is supposed to help you stay current, but not get you ahead of anybody. **My 504 plan, it fell through because even when I was not in school. I had not been sick. I had never got any of my work. When I used to try to come back to school and get my work, it was like stacks of like homework that was just like ridiculous. My 504 plan really did not work, so.**

Allison, Tim, Kevin, and Jamie each expressed a negative view regarding their supplemental education during cancer treatment, as shown in Tables 7.2.1 to 7.2.5 above. Jamie and Allison experienced the longest cancer treatments in comparison to the other participants, which may have had an effect on their supplemental education provisions.

During her initial absence from school, Jamie received attempted educational support through a homebound tutor. Jamie was not forthcoming in her interview regarding her supplemental education experience with her tutor; however she did say a few times that it "*didn't work out.*" Jamie's experience is unique in that she attempted to return to school at the start of her sophomore year, ten months into cancer treatment. Despite her attempt at returning to school, she still had several absences due to treatment effects. Family problems combined with the severity of her treatment made it difficult for her to remain in school. After one month, she and her mother decided that it would be best for her to stop school and focus on getting well again. She did not return to school until after treatment ended, nor did she receive further supplemental education from a tutor.

In Allison's case, the school district offered her a homebound tutor during treatment. However due to Allison's advanced placement classes, she felt as though the tutor was unable to meet her needs. As shown in her excerpt above, Allison's mom arranged to be her home school tutor during her absence. Unlike other homebound tutors that would usually cover several subjects in an hour per visit, Allison and her mother were able to tailor her supplemental education to meet her individual needs. They chose to focus on subject blocks for as long as Allison was comfortable before moving onto another subject. This meant that they would often focus on a single subject for weeks before moving onto the next subject, rather than teaching each school subject every day. The homebound tutor remained the point of contact between Allison and her school and relayed all the necessary schoolwork to Allison's mother, who then taught Allison herself. When Allison says, "*my school really screwed me over,*" she is clearly expressing negative feelings regarding the supplemental education she was offered during cancer treatment. Similar to

Brandon's parents and Tracy's mother, Allison's mother chose to intervene and find an alternative supplemental education that worked for her daughter.

Tim's experience with supplemental education is slightly different from the other participants. Tim attended a parochial school during his cancer treatments. His school accommodated him by allowing him to be absent from school on Fridays so that he could receive his treatments and recover from any side effects over the weekend. Tim felt as though his teachers were supportive during treatment and helped him by assigning him less homework in comparison to his peers. They also sat him closest to the front of the class so that it would be easier for him to see the teacher and anything written on the board. During the course of his treatment, Tim's eyesight began to fail due to side effects from chemotherapy. The public school system was invited to work with the parochial school by bringing in a visual impairment specialist to work with Tim on learning to read Braille after school. He also had orientation mobility lessons on using a white cane. However despite the efforts of the school to work with the public school system, Tim's schoolwork was still suffering and he began to fall behind his classmates academically.

Kevin also had a negative experience with supplemental education during treatment, but his experience was unique in comparison to the other participant since Kevin and his siblings were homeschooled by their mother. However it became difficult during Kevin's treatment to maintain homeschooling for his two brothers and sisters. His parents decided to encourage his siblings to attend a local mainstream charter school so that they could maintain their education while Kevin was being cared for at home.

Kevin's brother and sister had to be tested upon their attendance at public school to assess the grade to which they belonged. The test proved that Kevin's brother and sister were academically two years ahead of their same-age peers in public school. Since all siblings were at the same educational level at home in their homeschooling, Kevin's mother concluded that Kevin and his other brother, who chose not to attend the charter school, were two years ahead as well. Once his parents realized how far ahead in schooling their children were, they decided to stop Kevin's supplemental education during treatment and allow him to focus on getting well again. One of the benefits of homeschooling for Kevin was that his mother was his teacher. Therefore she was able to discern whether he could continue with school during treatment or take time off. In the above excerpt, Kevin said he not only found it difficult to focus on his schoolwork during treatment, but he also found it difficult to be away from his siblings when they opted to attend mainstream school. Ultimately, mainstream schooling did not work out for Kevin's brother and sister. They preferred to be homeschooled together after Kevin finished with cancer treatment. Kevin's mother began homeschooling all of her children, including Kevin, after the summer.

Kevin's refers to his supplemental education experience as negative because he felt so alone, and because he struggled to focus on schoolwork during cancer treatment. The flexibility that homeschooling provided allowed for Kevin's supplemental education to be tailored to his needs during cancer treatment.

Section Summary

The participants who felt positively regarding their supplemental education experiences included Tracy and Caleb who received consistent supplemental education from their school or school district, which they felt was sufficient in helping them maintain their education during treatment. Positive experiences also included one adolescent whose parents enrolled him in digital homeschool during treatment (Brandon) and one adolescent whose school made allowances for his absence since he had high academic achievement prior to diagnosis (Aaron).

In these instances, Tracy, Caleb, and Aaron all experienced shorter absences from school due to treatments, suggesting that shorter absences may disrupt an adolescent's life less than longer absences, resulting in a more positive supplemental education experience. In contrast, Jamie and Allison, who experienced long absences from school, describe their supplemental experiences as negative.

Unlike Jamie and Allison, Brandon experienced a long absence from school but still expressed having a positive supplemental education experience. This is likely due to the role his parents played in finding an alternative supplemental education option for their son, suggesting that the role parents play during supplemental education can influence positive or negative experiences for adolescents with cancer.

Both Allison's and Tracy's parents assisted with the supplemental education that their children were scheduled to received. Allison views her experience as negative, however the fact that her mother homeschooled her during absence kept her up to speed to graduate with her peers, despite her two year absence.

Lastly, length of absence may be overshadowed by the severity of treatment side effects with regard to how supplemental education is viewed. For example, Tim regularly attended school during cancer treatment, but his visual impairment was severe enough to result in a negative supplemental school experience. Tim's negative supplemental education experience was due to the inability of the public school district to adequately provide Braille instruction to him at his parochial school. The severity of Tim's physical effects of treatment may suggest that treatment severity could affect supplemental education experiences.

Jamie and Allison also experienced severe treatment effects and similar to Tim, they also describe their supplemental education experiences negatively. However, Tracy experienced several years of cancer symptoms and severe physical effects from treatment and had a positive supplemental education experience, thus contradicting the suggestion that negative supplemental education experience is influenced by treatment severity alone.

In conclusion, the three main factors that influence supplemental education experience based on the experiences of the participants include severity of treatment effects, length of absence from the mainstream school setting, and the flexibility of accommodations to meet the physical and academic needs of the adolescent. In Tracy's, Caleb's, Brandon's, and Aaron's experience consistent and adequate educational support is the only common factor. In Jamie's, Tracy's, and Tim's experience the support they were given was either inconsistent or inadequate to meet their needs. While Kevin recounts his experience as negative since he felt so alone being away from his siblings, in terms of academic achievement the flexibility of homeschool was beneficial. However, being separated from his siblings resulted in his feeling that his experience was negative overall. This demonstrates the importance of social interactions during treatment.

Participants' School District Policies

The differential effects on participants of school district policies regarding specialized education for children and adolescents with a chronic illness bring into focus how United States special education policies can shape the school experiences of adolescents in cancer survivorship.

As indicated in the previous section, participants' experiences with supplemental education during treatment are affected by the school district policies and how consistently and adequately their education needs are addressed during cancer treatment. In order to investigate this further, I investigated the special education policies for each of the participants' school districts. This section outlines my search, indicating the accessibility of the policies and discusses whether the participants' experiences with supplemental education reflect the special education policies of their school districts.

Upon searching Jamie's school district website, no accessible information was found on the special services webpage regarding home/hospital instruction, or anywhere else on the school district website. Given my past volunteer experience with this population, I was aware of the term "homebound" instruction and decided to use that term in my search for the details of specialized instruction through the search bar for the district website. Unfortunately, this did not result in any further information. Continued investigation into this school district through other avenues yielded no results. Upon calling the school district to ask where I could find the information I was looking for, my call was transferred multiple times before I was told the details by someone who worked in specialized services, but was provided with no written documentation of the special education policies. Jamie's unwillingness to discuss her tutor in detail makes it difficult to understand whether she chose to ignore specialized education services that would have been otherwise adequate to meet her needs or if there was a breakdown in policy implementation. However, written education policy information should be accessible to the public, yet I was unable to find details of the policy within Jamie's school district.

Tracy and her mother had explained during Tracy's interview that she had positive support from her school. I had researched her school district website, but found little accessible information under special services. After typing the term "homebound" into the search bar, I was directed to the 147-page Special Education manual, which is available to the public online. The term "homebound" is found on nine of the pages within the manual. Once found, the sections on homebound instruction in the manual were written clearly and the home/hospital program appears to be well organized. The manual outlines the eligibility standards for students and how the system is held accountable for their continued progress. It also clarifies expectations that the student and his or her family, as well as the homebound instructor, should have throughout the instructional process.

Caleb and Brandon attended different schools within the same school district; therefore I was able to research their home/hospital instruction policies at the same time. In both cases, the home/hospital instruction was not easily accessible under special services on the school district website. Again, a search of the term "homebound" within the school district search bar resulted in two sources. The first was the School District School Board Policies and Administrative Regulations. It mentions homebound education as a source of alternative instruction, but with no details defining the alternative instruction available or the eligibility requirements. The second source is the 78-page 2012-2013 curriculum guide for the school district. Upon another search of "homebound" in the PDF search bar, I found the term listed on a single page. The curriculum guide explains the eligibility standards for the homebound instruction as such: “If a student will be out of school for an extended amount of time (30 days or more), the school district’s Home and Hospital program may arrange for a tutor to help eligible students work at home on a limited basis. There are several specific conditions that apply to students involved with this program including a limited number of courses that can be proctored by the Home/Hospital teacher. Contact a Counselor for more information. Students who are out of school for a week or more due to illness may call the counseling office to request homework. Please allow teachers at least 24 hours to prepare assignments” (p. 24).

Despite Caleb and Brandon living in the same school district, they had different experiences with homebound instruction. Caleb was absent for one school quarter and had an overall positive homebound instruction experience. He felt fully supported by his tutor and his school and had little interruption to his academic success. On the other hand, Brandon was absent for all of sixth grade. He explained that no special education was offered to him through homebound instruction and that his parents had to find alternative means of instruction for him. The differences in experience between Caleb and Brandon could be because of the difference in their age: Caleb was in high school during his absence and Brandon was in elementary school. The differences in experience between the two participants could also be attributed to the length of absence: Caleb was absent for one school quarter, while Brandon was expected to be absent for the entire school year. However, both participants view their homebound instructional experiences overall as positive.

Aaron had a unique supplemental education experience in that he was only absent from school for two weeks and his teachers agreed to allow him to finish the semester as already completed. Despite not requiring supplemental education, I was interested to compare how clearly the policies were within his school district. Similar to the other participants' school districts, I found no easily accessible information on the school district website. By typing the term "homebound" into the school district webpage search bar, I found a short description of homebound instruction, including the adoption date in 2003 and the revision date in 2009. The webpage explains when homebound instruction is applicable and lists the time of absence as "two weeks." It does not, however, specify whether homebound instruction applies if the student is absent for more than two weeks or if the two-week absence must be consecutive school days. The webpage outlines the homebound process to initiate services, as well as the number of hours of instruction. Aaron also viewed his supplemental education experience positively because he appreciated the allowances his teachers provided for him, as well as the support and accommodations they provided for him upon his return to school.

Tim received Braille instruction from a public school district, even though at the time he attended a private, parochial school. As with many of the other school districts, the information was not easily accessible on the school district website without doing a specific search using the search term, "homebound." The search resulted in a direct link to a two-page policy section on the procedure of "Home or Hospital Instruction." It clearly outlines what homebound/hospital instruction is, how to request services, the role of the tutor, how to conclude instruction, suggested procedural guidelines for instruction, and even tutor compensation.

Kevin was homeschooled by his mother along with his siblings; however his mother explained during the follow-up interview that as part of homeschooling, they are affiliated with a local public school district. This is intended for homeschool students to have access to extracurricular activities and any needed specialized services, such as homebound instruction. Kevin's mother had the option of bringing in a homebound tutor for her son, but since he was assumed to be ahead of his grade level, she decided that externally provided homebound instruction was not necessary. Upon searching the school district website, I found easily accessible information on both homebound instruction and accommodations for students in private or home schools. The homebound instruction was located clearly on the website, but only briefly describes the services as being available when needed. It directs the parent to contact the school if they are in need of homebound services. As Kevin's mother explained during the follow-up interview, if she had wanted homebound instruction for Kevin, she would call the school district, and they would enroll Kevin in homebound instruction. The school district also uses a specifically titled program (which will not be named here to maintain participant anonymity) that is intended for students attending private and home schools to use if they require any special education, such as learning disability, physical disability, and homebound instruction.

Lastly, Allison's school district website had easily accessible information regarding home/hospital instruction. I also searched the website using the term "homebound" to be sure that this was the only information the website had available. I was able to see two links that directed me back to the desired section. Both links were entitled Homebound Instruction and were listed as the policy and procedure of homebound instruction. The policy manual outlines homebound instructed as adopted in 2000 and revised in 2004. It includes a clear outline of eligibility, referral procedures, and the roles of the homebound tutor, the student and parent, and the classroom teacher. It is written as follows, "Students are eligible if they are of school age, enrolled in school, but are unable to attend regular classes because of a medical condition. The anticipated absence must not be less than ten (10) consecutive days, nor more than six (6) weeks, and the student's medical condition must be certified by a licensed medical doctor. Additional time may be approved by the school, student, and parent" (p. 1). As Allison explained during her interview she was offered a homebound tutor, despite the fact that she was absent for much longer than six school weeks (her absence from school was two years).

Section Summary

Federal policy Section 504 of the Rehabilitation Plan was put in place to assist people of all ages during medical and physical disability, protecting them from discrimination. Section 504 is intended to serve students with a physical or medical disability so that they can receive the same or similar education experiences as their healthy peers. The participants' experiences illustrate a disconnect between the intention of Section 504 being adopted at the federal level and how it is being implemented at the state and school district levels. The state-by-state comparison chart (Appendix p. 549) illustrates how Section 504 is being implemented under different guidelines from one state to the next. While school districts are entitled to come up with their own guidelines they must still adhere to both the state and federal guidelines, which in some instances are vaguely written.

It is noteworthy that different students within the same school districts did not receive similar access to specialized education, as in the cases of Caleb and Brandon. The experiences of participants in this study appears to be that policies are being implemented on a case-by-case basis, with half of the study sample having positive supplemental education experiences and the other half negative experiences during cancer treatment.

Reintegration into Classes in School

Physical side effects from treatment often linger beyond the treatment end date especially in instances of severe treatments, such as surgery and prolonged chemotherapy. Each participant has experienced physical effects of treatment, as exemplified in Chapter 5. The majority of the participants returned to school after treatment ended while experiencing residual effects of their treatments. These physical effects often create a need for the student to have special education accommodations for learning in school or extra attention from teachers and counselors to help the student to reintegrate into classes smoothly after absence. For those participants whose lives were considerably interrupted due to treatment, returning to school in post treatment was challenging. These participants often felt a great deal of pressure to catch-up to the level of their healthy peers who did not experience interruptions in attendance. This is especially true for participants in their last two years of high school, where there is an emphasis on applying and being accepted to university.

In-School Accommodations

Table 7.3.1 Example of in-school accommodations (1)

Mother of Tim, 14-year-old male, Diagnosed Neurofibromatosis (8 years old at diagnosis) *Treatment: 18 months of chemotherapy – tumors still present, but stable*
"CCTV is a monitor that's basically like a projector he puts his book underneath and you hook it into a computer and it puts the words on the computer and he can magnify it to bigger or smaller fonts. And then Amigo is a portable CCTV basically a little smaller than that he lays on the book and it magnifies it. And then the acrobat short arm is... He can see the board, it's like a camera he can put on the board and then it would be transmitted into his laptop and he can see the board."

Table 7.3.2 Example of in-school accommodations (2)

Tracy, 17-year-old female, Diagnosed Metastatic Capillary Thyroid Carcinoma 08/2010 *Treatment: November 2010 – Surgery (11/2010), continues oral thyroid medication*
*"**I have to take medicine at school. It was just more of a- to cover my back if I needed to get out of class to call my mom, if I had a problem, if I didn't feel good. You need to be able to call my doctor or she knows more about my medicine than I do and she can kind of tell me if I'm like if I forgot to take my medicine in the morning and I needed it third period because I completely had forgotten and I needed to call her to see if I could take my second dose, I needed to be able to do that.** Some teachers will be like no you can call at lunch, but I needed to call right then it's not something you can wait like that. **It is something you need to take care of right then when you remember. So I did it to cover my back so I wouldn't get in trouble with my teachers if I have to call my mom or whatever.**"*
*"**My counselor lets me come down whenever I want to just to sit in her office if I don't want to be in class anymore if I just can't like focus or something she will let me go down to her office** and some teachers won't let you do that."*

Table 7.3.3 Example of in-school accommodations (3)

Allison, 17-year-old female, Diagnosed Pilocytic Astrocytoma 10/2008 *Treatment: Surgery (10/2008)/ intravenous chemotherapy, Treatment Stopped: 09/2010*
*“**My counselor actually helped a lot once I was back in school. He made sure my classes were all really close so I did not have to walk very far.** I do not know**, he made sure I had the classes that I needed to graduate.**”*
*“After the whole mix-up with, like, the home schoolteacher… **he really helped me out. It was kind of like he was trying to right the wrong. He was a good counselor.**”*

Table 7.3.4 Example of in-school accommodations (4)

Caleb, 15-year-old male, diagnosed Hodgkin’s Lymphoma 11/2010 *Treatment: 3 months chemotherapy/6 months radiation, Treatment Stopped: 6/2011*
“[My teachers] definitely worked with me. Like, I’d have to – I just had to go in a lot and learn extra stuff but they were fine with everything. They would just let me kind of slide through with what I had to but I’d do a lot of work. But, the things that they knew I couldn’t like handle like that they learned prior to when I was there they would be fine with.”

Table 7.3.5 Example of in-school accommodations (5)

Jamie, 17-year-old female, Diagnosed Acute Lymphoblastic Lymphoma 10/2008 *Treatment: chemotherapy, Treatment Stopped: 11/2010*
"She signed me up for a Brigham Young class. ***She never checked on me to see how I was doing. I actually kind of fell off my class last year because I was too busy worried about the other eight. I still had to take my final exam and tests with everybody else.*** *Actually, at the end of the year I had told her I missed a week when I got sick and the final exam was the following week. So, I came in and told her I don't know if I am going to be able to pass my test. If I don't pass my final exam I am not going to pass the class and I need this credit to graduate.* ***She was just kind of like, 'You know what you have to do. You have to study and it's up to you if you pass the test or not.' I was like okay. I don't know what to do.****"*
*"****I feel like if they do that people would be giving me a grade because they knew that I had cancer. I don't ever want people to feel sorry for me. If I get a grade I want to be able to earn it. I would benefit from accommodations, but I would rather do it the way everybody else is doing it.****"*

When residual physical side effects of cancer treatment hinder a student's ability to attend, participate, and achieve in class, United States educational policy (as outlined in Chapter 3) mandates that the student must be accommodated to ensure special needs are met so that they have access to a form of education. For students in cancer survivorship, this is often done through a 504 Plan. A 504 Plan is intended to communicate information regarding a student's education needs to various teachers from one school year to the next. The goal of a 504 Plan is not only to meet the academic and physical needs of a student, but also to keep the student in the least restrictive learning environment. This means that when students with specialized education needs are able to learn in the mainstream classroom with healthy peers, they will remain in the mainstream classroom. Only in instances where physical or learning needs are severe is the student removed from the mainstream classroom and placed in a special education classroom.

In Tim's supplemental education experience, the Braille instruction that he received ended up being inadequate to meet his needs. Therefore he and his parents decided to transfer him to the state school for the blind. At his new school, Tim feels "*so much happier. Everyone there feels how everyone feels, and sees*." In spite of being with peers who also have visual impairments, Tim has access to technology that the other students do not have access to. As exemplified in the excerpt from his mother above, he uses a CCTV, an Amigo, and a short arm to aid him throughout class. Once Tim's needs were properly accommodated, he began doing well academically in school.

Tracy also received necessary accommodations in her school as implemented through a 504 Plan. By having her needs outlined clearly for her teachers, Tracy was receiving an individualized education that met her needs, but it also gave her peace of mind. For a student who would feel fatigue and nausea often in school, having the freedom to leave class suddenly was important to Tracy. She also felt as though she had a supportive school counselor. The same counselor who organized her supplemental education during treatment also organized her 504 Plan and supported Tracy whenever she needed extra help in school.

However, not all students require a 504 Plan in order to receive extra school support. As shown in Tables 7.3.3 and 7.3.4 above, Allison and Caleb had supportive school counselors although they did not have 504 Plans in place. Since Allison did not have major residual physical effects from treatment, she did not require special instruction or treatment from her teachers, necessitating a 504 Plan. Instead her teachers were supportive and understanding, providing her with extra credit schoolwork to help her make up the credits that she missed and enrolling her in summer school.

Caleb's experience was similar to Allison's, despite his much shorter absence from school. His teachers were supportive by giving him extra credit work and helping him to make up the time he missed. His counselor made sure that Caleb's teachers were aware of his medical situation and they implemented accommodations in their class for Caleb as needed.

In his interview, Caleb explained one example involving his Spanish teacher, who would allow him to "*go with the flow*" of the class by not forcing him to participate until she was able to tutor him one-on-one after class to help him learn what he had missed during his absence. The extra help he was receiving was not implemented through a mandated 504 Plan, but was volunteered by the teachers on their own terms and based on their assessment of Caleb's needs. Since treatment, Caleb said he felt as though everything has returned to "normal," and that he has caught up to the level of his classmates.

By having the flexibility to individualize education for students with medical needs, teachers are better equipped to reintegrate them into school after treatment. In Kevin's experience, he had the smoothest transition in returning to school in post treatment since he was homeschooled. Since his mother was also his teacher, and his school environment was also his home, Kevin's mother/teacher was able to tailor his education to meet his individual needs. This was especially useful given the challenges he faced in maintaining focus since experiencing cancer treatment. Since Kevin and his siblings were academically advanced in comparison to students of his age group, he was able to return to schooling after stopping it for a year without falling behind academically.

Not all participants said that they had supportive counselors upon reintegration to school in post-treatment. Jamie struggled with reintegration into school. She would regularly visit her counselor to find out what she could do to make up the two years of school that she missed during treatment. In Table 7.3.5 above, Jamie felt conflicted in needing extra help to successfully complete her classes, but does not want any special treatment. Ultimately, she did not feel as though her counselor was supportive. Despite her counselor's attempt to help Jamie make up for lost credits, Jamie required assistance to complete the class successfully. Yet when asked if she would benefit from having special accommodations in class, Jamie was adamant about being treated just like everyone else.

On one hand, Jamie expresses a need for help to successfully finish her classwork and on the other hand, she refuses any help that would be offered to her. It is clear from the above excerpts that Jamie struggles with accepting the fact that she needs additional academic accommodations. She feels as though her teachers would give her a grade without her earning it, but in reality accommodations are implemented in schools by providing the student with extra help or attention to aid them in earning the grade on their own. It is also possible that Jamie is seeking extra attention rather than extra school help. During her treatment, she received a great deal of attention from her family and her community. She said in her interview that she had her mother doing everything for her and that she wanted to get better at doing things on her own. Therefore, her struggle to finish her schoolwork may be due to a conflicting desire to be "normal" again and denial of the reality that her cancer survivorship has had a considerable effect on her.

Jamie and Allison had similar cancer treatments that lasted a similar amount of time. The difference between the two appears to be in the motivation and attitude regarding how they each approached their reintegration experiences. Allison experienced the same amount of missed credits that Jamie experienced due to their absences. Allison had a supportive school that offered her extra credit work and summer school opportunities, which she accepted. Jamie does not feel as though her school was supportive. She was unable to keep up with the extra credit work that her counselor had arranged for her and refused special treatment from the school.

Graduation

Table 7.3.6 Example of the pressure to graduate (1)

Jamie, 17-year-old female, Diagnosed Acute Lymphoblastic Lymphoma 10/2008 *Treatment: chemotherapy, Treatment Stopped: 11/2010*
"I never got to experience really my high school years. I am not even experiencing now because I am busting butt trying to make up for the credits that I missed. *They didn't give me any leeway on my credits. I have to still get 22.5."*
"I am behind all my friends. My friends have cars and they have jobs. I just got a job, but my friends have a job and ***they are all like ahead of me. I feel like dang. I am so behind everybody and we are all the same age. I feel like I have a lot of catching up to do****."*

The year a student is in high school will affect the pressure that their school places on them. Freshmen and sophomores (years one and two in high school) are generally expected to focus primarily on their school achievement, whereas juniors and seniors (years three and four in high school) are generally expected to focus on school achievement as well as the processes of applying and getting accepted into a college or university, if they choose to pursue higher education. As of October 2012, 66.2 percent of 2012 high school graduates were enrolled in colleges or universities, according to the United States Department of Labor statistics. For cancer patients in post treatment, this pressure to pursue higher education still exists, as well as the pressure to finish high school after four years (on time) and with their classmates; however, for the cancer survivor there is also a strong focus on maintaining their renewed health.

Of the eight participants, half of them talked about graduating or graduation. Jamie, Tracy, Aaron, and Allison were 17-years-old at the time of the interview and in their last two years of high school. Caleb, Brandon, Tim, and Kevin were in the first two years of high school, and did not talk about graduation during their interviews. The fact that the older participants talk about graduation and the younger participants do not illustrates the added pressure and excitement that graduation can exert in a high school student's experience. Having a shorter absence due to treatment may affect how successful the reintegration will be in post treatment.

Aaron and Tracy were able to limit their absences during treatment to two weeks and one quarter, respectively. Even though Aaron continued with mild treatment while returning to school and experienced a relapse in his senior year, his attendance contributed to how well he felt he reintegrated after treatment. His teachers supported him and despite the physical challenge of needing to drink water regularly, he was able to graduate along with his classmates.

Tracy also struggled with physical challenges in school, as outlined above. Her short absence combined with a supportive school environment made it possible for her to make up any schoolwork she missed during absence and catch up with her peers in post treatment. Once she was able to find a medication that worked best to regulate her metabolism, she was able to motivate herself to attend school daily, complete her work to the best of her ability, and to graduate with her classmates.

Participants who experienced longer absences and were in the last two years of high school at the time of their interviews were Allison and Jamie. Allison explained above that it was her counselor who helped her to catch up with her peers. Missing half of the high school experience due to cancer treatment meant that she would have to complete four years of high school in two years if she wanted to graduate with her classmates. She struggled to finish, but was able to complete extra credit homework and take summer school classes to meet the credit requirement for graduation. Allison's hard work paid off and she also graduated with her classmates.

Jamie unfortunately did not experience the school support that the other three older participants experienced. Like Allison, if Jamie wanted to graduate along with her classmates she would have had to complete four years of high school work in two school years. Her attempt to do that took away some of what she referred to as the high school experience (Table 7.3.6).

Jamie made an attempt to catch up with her peers academically and graduate with her class. In her first year back in school after treatment ended, she took nine courses and two online courses in comparison to the norm of eight courses per semester for students. But as she explained in reference to her counselor, above, it was too much for her to handle such a large course load. In the first meeting Jamie had with her counselor regarding her coursework and timeline, her counselor informed her that her aim to graduate with her class was unrealistic, and that she would not be able to graduate until 2014 due to her absence for the first two years of high school. At the time of Jamie's follow-up interview, she was not able 'to walk with her class' at graduation, as she still had a few school credits left to complete.

High school-aged students are responsible for their own achievement in school. This responsibility means that they must be able to ask for help when necessary and take on only the amount of work that they feel they can handle without jeopardizing their health. In focusing on the school experiences in post treatment of Allison and Jamie there appears to be only one major difference between their experiences aside from the type of cancer they had. Allison received some form of supplemental education during treatment and completed some school credits through tutoring while Jamie refused supplemental education during treatment. It is likely that Allison's education during treatment influenced her ability to reintegrate successfully and graduate on time with her classmates. While Jamie's lack of supplemental education during treatment meant that she had to complete a full four years of high school upon her return to school as a junior, causing extra pressure and stress upon reintegration into school in post treatment.

Chapter Discussion

This chapter presented the data regarding the participants' experiences during supplemental education and reintegration into school. Adolescents in cancer survivorship may experience similar physical side effects of treatment, however, their experiences with how they progress in their daily lives can vary greatly. Despite the differences of school type and school year, the participants who had negative experiences indicated that they had inadequate services that did not meet their physical or academic needs. This included Tim, Allison, Jamie, and Kevin. Negative supplemental education experiences were also associated with challenges in social interactions. This is exemplified in Tim's bullying experiences, Jamie and Allison both feeling disconnected from peers, and Kevin missing his siblings during supplemental treatment.

Furthermore, two of these participants also experienced social challenges upon reintegration into school when Jamie felt socially behind her peers, and a boy asked Allison if she had brain damage. When Kevin was able to socially interact more with his siblings, he felt much more social support after starting homeschool again. Tim, having moved schools to the School for the Blind so that his visual impairment needs would be appropriately accommodated, felt much more welcomed by his peers who also shared his experience with loss of sight.

Both the positive and negative experiences of the participants in this study exemplify the need for both consistent and flexible supplemental education during cancer treatment. Harris (2009) recommended the eco-triadic model for education consultation to address supplemental education implementation for reintegration to school (page 76). This model focuses on the need for supplemental education to be flexible. It must meet both the physical and academic needs of the individual student in order to be successful. Furthermore, once the supplemental education has been agreed on, it needs to be implemented consistently. When looking at the participants who experienced positive supplemental education during treatment, they had supplemental education tailored to their needs and it was implemented consistently. This is shown in the examples of Tracy, Brandon, and Caleb. Jamie's negative supplemental experience is an example of both of these factors failing. First she felt as though the tutor was provided support inadequate to her needs. Then she attempted to return to school while still undergoing treatment. When that did not work either, she declined any further supplemental education tutoring that may have otherwise helped her maintain her educational engagement during cancer treatment. Therefore her supplemental education was both unable to meet her needs and inconsistent.

The role of parents in both seeking out and implementing supplemental education is vital. Parents can positively or negatively influence their child's supplemental education during cancer treatment. Brandon's parents, Allison's mother, and Tracy's mother sought out supplemental education alternatives when they realized that what the school was offering would be inadequate. Barrera et al. (2005) reported that survivors whose parents had postsecondary education were less likely to experience educational problems during supplemental education. Parental education levels were not assessed as part of this study. However, parental involvement clearly had a positive impact for the participants in the current study, since Brandon and Tracy view their experiences as positive, and Allison was able to maintain educational engagement during treatment thanks to her mother's efforts, despite her negative view of the initial supplemental education-tutoring attempt. Conversely, Jamie's mother encouraged Jamie to focus on her health and not worry about maintaining her education during cancer treatment. While this decision was made in the best health interests of her child, it may have contributed to Jamie feeling further separated and different from her peers, causing problems upon reintegration to school.

Several research studies have created models for successful reintegration into school after cancer treatment (Harris, 2009; Harris & Farrell, 2004; Gartin & Murdick, 2009; Shaw & McCabe, 2001). However none of the participants in this study experienced a standardized reintegration program. Tracy was on a 504 Plan upon her return to school. Jamie’s school attempted to implement a 504 Plan for her, but she claimed that it did not work for her. It must be noted that the 504 Plan is not intended to be a reintegration program, but rather its goal is to lay out the framework that outlines what the reintegration program will look like for the individual student. The physical and psychological effects that this population experienced, as shown in Chapter 5 and 6, illustrates how educational engagement can be impacted upon during cancer survivorship, confirming the findings of McLoone et al. (2011). By implementing a framework that is tailored to the needs of the individual adolescent, these effects can be mediated and both educational and social engagement can be promoted.

CHAPTER 8

Adolescent Coping Scale (ACS – Short)

Introduction

This chapter discusses the findings from the Adolescent Coping Scale. The Adolescent Coping Scale – Short Form (ACS – Short) was chosen for this study for a few reasons. Firstly, the scale asks the participant to identify his or her greatest concern in his or her own words. When information is identified and volunteered by the participant, rather than being extracted by the researcher, it carries more value because it highlights what the participant deems to be important. This data adds to an understanding of participant experiences.

Secondly, the ACS – Short provides insight into the specific coping mechanisms that the participant uses when addressing his or her greatest concern. This information shows whether the participant is using productive or unproductive coping methods, thus providing insight as to whether he/she is well adjusted to his/her experiences. Adolescents who are poorly adjusted to a significant life event, such as cancer, may be more likely to have problems coping with challenges in the future.

Lastly, the ACS – Short provides an overall profile of the coping strategies that the participant uses. This information can be used qualitatively and provides insight into whether the participant is using productive or unproductive coping strategies. This information not only indicates how affected the participant is from his or her experiences, but it also indicates whether the participant may require further guidance in addressing his or her main concerns. As described in Chapter 4:

Methodology, I asked that each participant complete the scale three times, identifying their main concern in three areas: illness, school, and social interactions.

Scale Structure and Scoring

The first page of The ACS – Short collects identifying information on the participant and then instructions on how to complete the scale. I also reviewed the instructions verbally with participants in an effort to minimize any mistakes or misunderstandings regarding how to properly complete the scale. The scale begins by asking the participant to identify his or her main concern regarding one of the three main areas: illness, school, or social interactions. The second page includes 18 questions, followed by a Likert-style scale that ranges from 1 to 5. The participant must circle the number that corresponds to how often they employ that coping strategy. The nineteenth question is open for the participant to complete at his her discretion. Table 8.2 on the following pages includes the scale questions.

The scale manual includes instructions for scoring the participants' responses to provide an overall profile of the coping strategy that the participants use least or most often. Table 8.1 below illustrates the coping style and the strategies that correspond to each style for the Short Form. Lastly, the final table (Table 8.3) is an example of the coping profile. Once the score is added and adjusted according to the manual instructions, the researcher places the score on the profile scale (Table 8.3) to gain an understanding of how often the participant uses each coping style.

Table 8.1 Adolescent Coping Scale Style by Strategy

Coping Style	Solving the Problem	Reference to Others	Non-Productive Coping
Coping Strategies	Focus on a solution	Seek social support	Ignore the problem
	Focus on the positive	Invest in close friends	Keep to self
	Word hard and achieve	Seek to belong	Wishful thinking
	Seek relaxing diversions	Social action	Tension reduction
	Physical Recreation	Seek professional help	Self-blame
		Seek spiritual support	Worry
			Not cope

Table 8.2 Adolescent Coping Scale – Short Form

	Doesn't apply or don't do it	Used very little	Used sometimes	Used often	Used a great deal
Talk to other people about my concern to help me sort it out	1	2	3	4	5
Work at solving the problem to the best of my ability	1	2	3	4	5
Work hard	1	2	3	4	5
Worry about what will happen to me	1	2	3	4	5
Spend more time with boy/girl friend	1	2	3	4	5
Improve my relationship with others	1	2	3	4	5
Wish a miracle would happen	1	2	3	4	5
I have no way of dealing with the situation	1	2	3	4	5
Find a way to let off steam; for example cry, scream, drink, take drugs, etc.	1	2	3	4	5
Join with people who have the same concern	1	2	3	4	5
Shut myself off from the problem so that I can avoid it	1	2	3	4	5
See myself as being at fault	1	2	3	4	5
Don't let others know how I am feeling	1	2	3	4	5
Pray for the help and guidance so that everything will be all right	1	2	3	4	5
Look on the bright side and think of all that is good	1	2	3	4	5
Ask a professional person for help	1	2	3	4	5
Make time for leisure activities	1	2	3	4	5
Keep fit and healthy	1	2	3	4	5
List any *other* things you do to cope with your main concern	1	2	3	4	5

Table 8.3 Profile of Coping Styles – Short Form

Style	Not used at all		Used very little		Used sometimes		Used frequently		Used a great deal
Solving the Problem	18	27	36	45	54	63	72	81	90
Reference to Others	20	30	40	50	60	70	80	90	100
Non-productive Coping	18	27	36	45	54	63	72	81	90

This scale provides additional data that can supplement qualitative tools used to explore the social experiences of participants in post-treatment. Understanding the participant's social concerns highlights aspects of the participant's experiences that they consider to be important. Productive coping means that the participant utilizes problem solving while attempting to remain physically active and socially connected. Non-productive coping indicates the use of avoidance strategies that are generally associated with an inability to cope with stressors.

Illness-Specific Form

Solving the Problem Coping Strategy

The "solving the problem" coping strategy is a productive style of coping that includes working towards a solution while remaining positive, physically fit, calm, and connected to peers.

Table 8.4.1 Participant identified concern on ACS – Short, Illness (1)

Tracy, 17-year-old female, Diagnosed Metastatic Capillary Thyroid Carcinoma 08/2010 *Treatment: November 2010 – Surgery (11/2010), continues oral thyroid medication*
"Cancer coming back somewhere else."

Table 8.4.2 Participant identified concern on ACS – Short, Illness (2)

Caleb, 15-year-old male, diagnosed Hodgkin's Lymphoma 11/2010 *Treatment: 3 months chemotherapy/6 months radiation, Treatment Stopped: 6/2011*
"The signs of it coming back and how fast it could happen."

Table 8.4.3 Participant identified concern on ACS – Short, Illness (3)

Aaron, 17-year-old male, Diagnosed Mucoepidermoid Carcinoma 12/2009 *Treatment: Surgery (12/2009)/Radiation, Treatment Stopped: 03/2010* *Relapse: 01/2012, Surgery 03/2012*
"How hard will it be to go through treatments, and how long will it be before I can be better?"

Table 8.4.4 Participant identified concern on ACS – Short, Illness (4)

Tim, 14-year-old male, Diagnosed Neurofibromatosis (8 years old at diagnosis) *Treatment: 18 months of chemotherapy – tumors still present, but stable*
"Losing more eyesight."

Table 8.4.5 Participant identified concern on ACS – Short, Illness (5)

Allison, 17-year-old female, Diagnosed Pilocytic Astrocytoma 10/2008 *Treatment: Surgery (10/2008)/ intravenous chemotherapy, Treatment Stopped: 09/2010*
"That my happiness could be taken away again because of it."

Although there are five examples listed above, six participants employ the "solving the problem" coping strategy when addressing their main concerns. The reason for this is that Brandon wrote that he did not have any concerns regarding illness, yet he continued to fill out the scale as if he had a concern in mind. It is possible that Brandon has no immediate concerns regarding his cancer; but since he still completed the scale, I interpreted his responses in terms of general illness concerns. If Brandon is unable to articulate a main concern with regard to his illness, this could be a sign of non-productive coping. Despite the fact that his profile indicates the “solving the problem” coping strategy when interpreted as general illness concerns, the inability of an adolescent to identify a primary concern suggests an inability to cope productively.

Of the other five participants who employ the “solving the problem” coping strategy when addressing their main illness concerns, three had concerns regarding relapse, one was concerned about side effects getting worse over time, and one completed the form retrospectively and articulated concerns about treatment. The fact that five of the eight participants choose to employ the “solving the problem” coping strategy with regard to illness is evidence of their attempts to exert control. The participants completed this scale while in post-treatment. This raises the question as to whether they would have similar responses with regard to illness if this scale were administered at the time of diagnosis or at the start of cancer treatment. During the early stages of cancer when uncertainty is at its peak, adolescents may be less likely to feel capable of productive coping.

Reference to Others Coping Strategy

The “reference to others” coping strategy is a productive style of coping where the participant seeks out peers, seeks out professional help, and relies on spiritual or religious practices when addressing his or her concern.

Table 8.4.6 Participant identified concern on ACS – Short, Illness (6)

Kevin, 14-year-old male, Diagnosed Anaplastic Astrocytoma 05/2009 *Treatment stopped: Surgery/Radiation/Chemotherapy, Treatment Stopped: 04/2010*
“Not growing as tall as I would have.”

Kevin’s primary illness concern is related to a side effect of his treatment. In this case, his concern is that he may not grow as tall as he would have had he not been diagnosed with cancer. While other participants were concerned with relapse, Kevin said in his interview that he is confident that his cancer will not return. So it is not surprising that he is mainly concerned with a residual effect from treatment rather than the return of the cancer itself. The insecurity that Kevin feels knowing that his growth is stunted as a result of his treatment is common amongst adolescents in cancer survivorship. By using the "reference to others" coping strategy, Kevin is relying on people around him who can relate to his concerns, such as his peers at the cancer camp that he attends in the summer.

Non-productive Coping Strategy

The "non-productive" coping strategy suggests that the participant uses avoidance strategies and does not address their main concern in a healthy way.

Table 8.4.7 Participant identified concern on ACS – Short, Illness (7)

Jamie, 17-year-old female, Diagnosed Acute Lymphoblastic Lymphoma 10/2008 *Treatment: chemotherapy, Treatment Stopped: 11/2010*
"That my cancer will come back and all the progress I have made will be worthless."

Similar to Tracy, Caleb, and Allison in Tables 8.4.1, 8.4.2, and 8.4.5, Jamie's main illness concern is also that her cancer will relapse. However, unlike the other three participants who share this concern, Jamie does not address it productively. Non-productive coping includes worrying, ignoring the problem, wishful thinking, and self-blame. Self-blame is evident in Jamie's concern when she says that if her cancer returns she would feel that the progress she has made would be worthless. Cancer recurrence is something that is often not within the patient's control. Therefore the responsibility that Jamie feels regarding the possibility of relapse indicates that she is still struggling with her cancer and treatment experiences.

Jamie's coping profile indicates that she uses non-productive coping when thinking about her cancer recurring. An inability to cope can lead to poor decision-making during adolescence and as the adolescent enters into adulthood, they can be prone to mental problems.

School-Specific Form

Solving the Problem Coping Strategy

Table 8.5.1 Participant identified concern on ACS – Short, School (1)

Tracy, 17-year-old female, Diagnosed Metastatic Capillary Thyroid Carcinoma 08/2010 *Treatment: November 2010 – Surgery (11/2010), continues oral thyroid medication*
"Get my GPA up for college."

Table 8.5.2 Participant identified concern on ACS – Short, School (2)

Caleb, 15-year-old male, diagnosed Hodgkin's Lymphoma 11/2010 *Treatment: 3 months chemotherapy/6 months radiation, Treatment Stopped: 6/2011*
"I must stay focused and make sure I have enough time to finish my work."

Table 8.5.3 Participant identified concern on ACS – Short, School (3)

Aaron, 17-year-old male, Diagnosed Mucoepidermoid Carcinoma 12/2009 *Treatment: Surgery (12/2009)/Radiation, Treatment Stopped: 03/2010* *Relapse: 01/2012, Surgery 03/2012*
"Could I keep my grades up while I was sick?"

Table 8.5.4 Participant identified concern on ACS – Short, School (4)

Tim, 14-year-old male, Diagnosed Neurofibromatosis (8 years old at diagnosis) ***Treatment: 18 months of chemotherapy – tumors still present, but stable***
"Failing."

Table 8.5.5 Participant identified concern on ACS – Short, School (5)

Kevin, 14-year-old male, Diagnosed Anaplastic Astrocytoma 05/2009 *Treatment stopped: Surgery/Radiation/Chemotherapy, Treatment Stopped: 04/2010*
"[It] takes longer to finish work and to get good grades."

This scale provides greater detail relevant to understanding the school experience of participants in post-treatment. Understanding the participants' school concerns highlights the aspects of their experiences that they consider to be important. Since high school students are responsible for their own academic achievement in school, it is not surprising that six out of eight participants used solving the problem as their primary method of coping with school concerns. As with the illness scale, Brandon wrote that he did not have any concerns regarding school, yet he continued to fill out the scale as if he had a concern in mind. Therefore I interpreted the scale in terms of general school concerns. Brandon's inability to articulate a main concern regarding school could be a sign that he is using avoidance, which is considered to be a non-productive coping strategy.

The participants' school concerns listed above illustrate that achievement is a primary concern for them. There is a lot of pressure on adolescents to achieve in school because it can help them to access the best opportunities for life beyond high school. For some adolescents, getting good grades can directly impact on the quality of the university that they can attend. For others who choose to take a job, good grades are useful when being considered for employment. This is a daily concern that even healthy adolescents experience.

What is unique about this population is how they manage school concerns amidst cancer survivorship. Aaron, who again completed the scale retrospectively, was primarily concerned with whether he could maintain good grades while undergoing cancer treatment. For the other participants above, good grades are a regular concern. The participants' choice to deal with these concerns by using the "solving the problem" coping strategy is not surprising. Adolescents are responsible for their school achievement; thus using a productive method of coping that includes relying on friends, working hard, remaining positive, and seeking out help when needed exemplifies their acceptance of this responsibility.

Reference to Others Coping Strategy

Table 8.5.6 Participant identified concern on ACS – Short, School (6)

Jamie, 17-year-old female, Diagnosed Acute Lymphoblastic Lymphoma 10/2008 *Treatment: chemotherapy, Treatment Stopped: 11/2010*
"That I won't graduate on time"

Table 8.5.7 Participant identified concern on ACS – Short, School (7)

Allison, 17-year-old female, Diagnosed Pilocytic Astrocytoma 10/2008 *Treatment: Surgery (10/2008)/ intravenous chemotherapy, Treatment Stopped: 09/2010*
"That I would be able to keep my 4.0 GPA."

Similar to the other six participants, Jamie and Allison are also concerned with their school achievement. However, unlike the previous participants, Jamie and Allison both have school concerns that illustrate how their school engagement has been impacted on by cancer survivorship. Jamie's concern that she "*won't graduate on time*" and Allison's concern that she "*would be able to keep [her] 4.0 GPA*" shows how they each stress about how their schooling has been impacted on by their cancer experiences. Both Jamie and Allison experienced long and severe treatments. They were both absent from school during that time for two years of high school.

Jamie's primary school concern is not only to achieve in school (the achievement of graduation), but also to do so "on time" and with her class as if she did not lose any time due to cancer treatment. Allison's primary concern was that she would maintain the high school achievement that she had prior to diagnosis and treatment. A 4.0 GPA is a perfect grade point average and would be highly regarded by all universities. For Allison, who in her interview said she wanted to go into the medical career field, a high GPA is the first step to achieving her career goals. Her greatest school concern was that her goals would be jeopardized by her cancer experience.

Fortunately, all participants in this study address their school concerns using productive coping strategies. By relying on peers and friends, seeking out professional help when necessary, remaining optimistic, focusing on a solution, and seeking relaxing diversions, the participants are handling their school concerns appropriately. By understanding their school concerns and dealing with them in a productive way helps the participants to progress into adulthood and associated concerns. Brandon, who was unable to articulate a primary school concern and who denies having any concerns regarding school, may not yet have accepted the responsibilities of adolescence that would prepare him for adulthood. Since Brandon is one of the youngest participants in this study at only 14 years old, his inability to articulate his concerns could be explained by age, or by his understanding of the questions involved. However if he is to cope productively in the future, it might be expected that being able to articulate and understand what concerns him is important to approaching such concerns in a healthy and positive manner.

Social-Specific Form

Solving the Problem Coping Strategy

Table 8.6.1 Participant identified concern on ACS – Short, Social (1)

Caleb, 15-year-old male, diagnosed Hodgkin's Lymphoma 11/2010 *Treatment: 3 months chemotherapy/6 months radiation, Treatment Stopped: 6/2011*
"I mess around too much and may sometimes be unfocused."

Table 8.6.2 Participant identified concern on ACS – Short, Social (2)

Aaron, 17-year-old male, Diagnosed Mucoepidermoid Carcinoma 12/2009 *Treatment: Surgery (12/2009)/Radiation, Treatment Stopped: 03/2010* *Relapse: 01/2012, Surgery 03/2012*
"Will my friends treat me differently? Will they still want to be around me?"

Table 8.6.3 Participant identified concern on ACS – Short, Social (3)

Tim, 14-year-old male, Diagnosed Neurofibromatosis (8 years old at diagnosis) ***Treatment: 18 months of chemotherapy – tumors still present, but stable***
"Losing a friend."

Social concerns during adolescence are prevalent even for those who are not in cancer survivorship, since adolescence is a time when peer interactions increase as the adolescent's dependence on his/her parents decreases. Caleb, Aaron and Tim each express different social concerns, but cope with their concerns using the "solving the problem" coping strategy.

Caleb knows that his social interactions and desire to have fun and enjoy life can get in the way of his schooling, which is why he articulated his concern as having too much fun and being unfocused. This is likely a result of his cancer experience since he experienced a drastic shift in perspective after surviving cancer. He now believes that life is a gift and that he should live each day to the fullest. Based on his social concern, he fears that this newfound perspective may interfere with some of his adolescent responsibilities.

As with his previous two scales, Aaron completed the social scale retrospectively. He recalls worrying about whether he will be treated differently by his friends and wondering whether they would want to be around him once word got around about his cancer diagnosis. Since cancer in adolescence is rare, these concerns are expected. How adolescents fit in with their peers is a large part of the social dynamic at that age. Physical changes in particular can influence the social dynamics in adolescence. Since cancer is often associated with the image of a sick person with no hair, it is not surprising that Aaron would be concerned about how his social interactions would be influenced by his cancer diagnosis.

Lastly, Tim's concern regarding losing a friend likely stems from his experience of being bullied at his former school. As presented in Chapter 5 in Table 5.2.27, Tim experienced severe bullying as a result of his vision loss. Changing schools during adolescence can be challenging, even when the change is considered to be a positive one. As previously stated in this chapter, friends play a large role during adolescence. The loss of a friend during adolescence can be both positive and negative. For example, the adolescent begins to form their adult identity and this can result in the gain or loss of friends during this time. This can sometimes occur in a dramatic fashion and sometimes this occurs calmly. But either way the gain or loss of friends during adolescence is natural. Similarly, but seemingly more negative, the loss of a friend during adolescence can also result in the adolescent feeling unwanted or insecure about themselves. This can impact on them as they form their adult identity in various ways. Adolescents who lose friends against their will may become more reclusive and insecure, yet they may value the friendships that they still have more than previously. In Tim's case, the social acceptance or lack thereof of his visual impairment has had a large impact on the formation of his identity. As a result, his main concern is losing a friend.

Reference to Others Coping Strategy

Table 8.6.4 Participant identified concern on ACS – Short, Social (4)

Tracy, 17-year-old female, Diagnosed Metastatic Capillary Thyroid Carcinoma 08/2010 *Treatment: November 2010 – Surgery (11/2010), continues oral thyroid medication*
"People not understanding when I'm tired compared to them being tired."

Table 8.6.5 Participant identified concern on ACS – Short, Social (5)

Allison, 17-year-old female, Diagnosed Pilocytic Astrocytoma 10/2008 *Treatment: Surgery (10/2008)/ intravenous chemotherapy, Treatment Stopped: 09/2010*
"That I was too different to even have a social life."

Both Tracy and Allison express social concerns that are directly related to their cancer experiences. Allison and Tracy have both been affected by their cancer experience and understand that their social interactions may also be influenced as they incorporate their cancer experience into their identities. Tracy's concern is that people will not understand the fatigue she experiences as a result of having her thyroid removed. Since Tracy experiences side effects of her cancer well into post-treatment, it is important to her that her peers understand that she still requires special consideration even though she is beyond her cancer treatment.

Yet similar to Aaron's concerns in Table 8.6.2, Allison understands that being an adolescent with cancer is rare and sets her apart from her peers. As a result, she is concerned that being so different from her peers would make her less relatable, thus leaving her without social interactions of any kind. In Chapter 6 Table 6.3.13 shows an example of how Allison felt ostracized as a result of her cancer experience when a boy in her class asked if she had brain damage.

Non-productive Coping Strategy

Table 8.6.6 Participant identified concern on ACS – Short, Social (6)

Jamie, 17-year-old female, Diagnosed Acute Lymphoblastic Lymphoma 10/2008 *Treatment: chemotherapy, Treatment Stopped: 11/2010*
"People not liking me because of my looks or what I have been through."

Table 8.6.7 Participant identified concern on ACS – Short, Social (8)

Kevin, 14-year-old male, Diagnosed Anaplastic Astrocytoma 05/2009 *Treatment stopped: Surgery/Radiation/Chemotherapy, Treatment Stopped: 04/2010*
"I have no concerns in this area."

Three participants use non-productive coping styles when addressing social concerns. Both Kevin and Brandon claim to not have any social concerns. If Kevin and Brandon cannot identify any concerns they may have regarding their social lives, no matter how mild the concerns may be, then they will not be able to cope productively. When prompted during the interview about whether he had any social concerns, Kevin felt adamant that he had no concerns in this area; however while he is content with his social interactions and experiences, he said that he would like to meet new people and make new friends.

In his interview Brandon expressed some social challenges during the cancer treatment stage when he struggled to explain his treatment to his friends. Since then, however, Brandon claims his life has returned to “normal.” It is possible that Brandon’s life perspective may have changed when he received his cancer diagnosis, which may explain why he does not indicate any concerns in his life. He may be happy to have survived his cancer and treatment, and therefore less willing to admit to life concerns; however, he may also be using avoiding strategies as a way to protect himself from further emotional challenges. The data is not conclusive as to why Brandon does not express any concerns regarding his illness, school or social aspects of his life.

Jamie’s concern is that her cancer experience hinders her ability to interact with her peers socially. During her interview, she expressed fears regarding how her physical appearance changed throughout cancer survivorship and it is clear from this scale that her physical appearance is still a concern for her. Similar to Tracy and Allison, Jamie is also concerned that her cancer experience sets her apart from her peers in a way that makes her less relatable. The difference, however, is that Tracy and Allison cope with their concerns in productive ways, whereas Jamie uses avoidance strategies such as ignoring the problem, using self-blame, feeling helpless, and not confiding in friends or professionals regarding her concerns.

Chapter Summary

The participants in this study use a variety of coping strategies when dealing with their illness, school, and social concerns. The ACS – Short scale has contributed to this study in two ways. Firstly, it allowed the participants to articulate their main concerns regarding their illness, school, and social interactions in their own words. This provides insight into the areas of each domain where they place the most importance. For example, the ability to maintain good grades in school is a primary concern for a majority of the participants. This is a common concern amongst adolescents in high school because they are encouraged to take responsibility for their academic achievement.

When it comes to illness concerns, several participants are concerned about relapse or side effects worsening over time. This result confirms the findings of Newby et al. (2000) who reported that relapse is a common concern in initial post-treatment. This result also confirms the findings reported by Zebrack and Isaacson (2012) that fearing relapse is a primary concern for this population. Zebrack and Isaacson (2012) further suggest that these fears can become incorporated into the formation of identity for adolescents. Thus it becomes vital to understand how well adolescents are coping with these fears to help promote positive coping strategies; as well as to determine those adolescents who may be at risk of not forming an identity that is able to manage substantial concerns in a productive way.

Lastly, several participants expressed social concerns with regard to how their cancer experience has impacted on their interactions with peers. Numerous literature sources report that social interactions for adolescents in cancer survivorship can be strained throughout the cancer experience (Lewis, 1996; Zebrack, 2011; Woodgate, 2005; D'Agostino et al., 2011; Prevatt et al., 2000; Vance and Eiser, 2001; Pini et al., 2012; and Barrera et al., 2005). Furthermore, Zebrack (2011) suggests that the development of identity during adolescence occurs within social contexts. This means that if adolescents in cancer survivorship experience more social strain than their healthy peers, then they may struggle to form their identity; thus hindering their adolescent development. As with the illness scale, understanding whether the adolescent in cancer survivorship is using productive coping strategies can help to predict whether their adolescent development is within a normal range.

The second way that this scale contributes to the study is that it identifies whether the participants are using productive methods of coping when addressing their main concerns. This is important because it shows whether the participants are adjusting to their post-treatment lives in a healthy way. Jamie, for example, uses non-productive coping when it comes to her illness and social concerns. This is a sign that she is not able to positively move on from her cancer experience, which can hinder her as she faces new concerns in adulthood.

Similarly, Brandon chose not to articulate any concerns in the three scales. Coping cannot happen without self-regulation, and self-regulation cannot occur without self-awareness (Frydenberg and Lewis, p. 4; 2012). Therefore if Brandon cannot articulate any concerns in each of the three domains, he will be unable to learn the necessary skills for productive coping in adulthood. The size of this study makes it difficult to say whether unproductive coping strategies are uncommon amongst adolescents in cancer survivorship. However in this study a majority of the participants were found to utilize productive coping strategies and have positively dealt with their main concerns in each of the three domains.

CHAPTER 9

Discussion and Conclusion

Statement of the Problem

The main aim of this thesis is to understand the experiences of American high school students who have been diagnosed with cancer. In particular, it aims to address two main gaps in current research adolescents in cancer survivorship. The first is that current research tends to exclude first-person accounts of adolescent experiences as they transition from treatment into post-treatment with regard to their educational experiences, and specifically in relation to the physical, psychological, and social challenges that this group of adolescents encounter. The second gap in the research literature is a review of current educational policy on supplemental education from the perspective of adolescents in cancer survivorship that explores whether the participants feel such policy is implemented successfully and the reasons why not.

To address these two gaps in the research literature, this thesis aimed to answer two main research questions using semi-structured interviews and the Adolescent Coping Scale – Short version:

1) How do the physical and psychological effects of cancer and treatment impact the participants' engagement with school?
2) What role does school play in cancer survivorship for adolescents?
    a. How do participants define a successful school experience during and after cancer treatment?
    b. How does United States policy shape the school experience of adolescents in cancer survivorship?

Cancer survivorship can drastically impact the developmental stage of adolescence, which shapes the kind of adult the teen will eventually become. As medical advances increase survival rates for pediatric cancer patients, it has become necessary to address the challenges that adolescents face in cancer survivorship in an effort to ease the transition in a way that promotes successful development.

The first research question is divided into two main parts: the physical effects of cancer and treatment and the psychological effects of cancer and treatment. The findings from the interviews that address this research question were presented in Chapters 5 and 6 of this thesis. The second research question focuses on the supplemental education that the participants experienced during and after cancer treatment, if any, and whether they view their experiences with supplemental education as successful. The findings from the interviews that address the second research question were presented in Chapter 7 of this thesis.

Lastly, the Adolescent Coping Scale – Short Form was modified for this study and used to understand the main concerns that participants had regarding a) their illness, b) schooling, and c) social interactions. This scale was also used to identify the primary coping strategy that each participant uses when addressing his or her main concerns. This approach was found to provide insight into whether the participants utilized productive methods to address their main concerns in a way that promoted their successful development. The findings from the Adolescent Coping Scales were presented in Chapter 8 of this thesis.

Conclusions

Physical Effects

How do the physical effects of cancer and treatment impact the participants' engagement with school?

The findings from this study indicated that the Cancer Treatment stage is when the physical effects of cancer are the most severe. During this time, fatigue and a compromised immune system have an impact on school attendance more than other physical effects. As a result, the Cancer Treatment stage is the stage when adolescents are most at-risk of experiencing challenges in educational engagement.

This conclusion supports the findings reported by Prevatt et al. (2000) that children with cancer experience isolation due to school absences and concerns regarding physical appearance due to physical side effects of cancer treatment, such as hair loss; and De Bruyn and Van Den Boom (2005) that since social popularity is often equated with attractiveness adolescents in cancer survivorship are likely to struggle with self-concept if they have experienced hair loss or weight changes as physical effects of cancer treatment. Therefore changes in appearance can impact how adolescents in cancer survivorship view themselves and how they interact with their peers within a school environment. The study found that physical effects that are visible, such as weight changes or hair loss are more likely to have an impact on social interactions for adolescents in cancer survivorship. It was noteworthy that females in this study were more sensitive to the social repercussions of hair loss due to cancer treatments than males were.

The participants' experiences with physical effects began to improve once treatment stopped and continued to improve as time passed (American Cancer Society, 2014; Zebrack & Chesler, 2002; Schwartz et al., 2010; Vance & Eiser, 2001).

These findings indicate that quality of life is impacted more during the Cancer Treatment stage and improves once the patient moves into the Post-treatment stage of cancer. However, permanent physical effects, such as visual impairments and stunted growth, are less likely to improve over time. As such, permanent physical effects will impact quality of life for an indefinite amount of time.

Psychological Effects

How do the psychological effects of cancer and treatment impact the participants' engagement with school?

The findings from this study indicated that the feeling of uncertainty throughout cancer survivorship promotes fear. Uncertainty is experienced in the Pre-diagnosis, Cancer Treatment, and Post-treatment stages of cancer. When participants felt familiar with a process or an environment, referred to often as "routines," their feelings of fear and uncertainty were reduced. The uncertainty that participants experience is often associated with a loss of control. This finding confirms the conclusions made by Lewis (1996) and Wicks and Mitchell (2010), namely that adolescents in cancer survivorship experience a loss of control. Whether routines addressed treatment or education, they provided the participants with a sense that they have regained control over the daily interactions of their lives. This finding also confirms the conclusions made by Lewis (1996), namely that by restoring normalcy adolescents in cancer survivorship can regain their feelings of control.

If adolescents in cancer survivorship do not feel as though they can exert control over their experiences, even in a limited way, they may feel as though they cannot cope with their situation. This may in turn result in instances of PTSD. Stuber et al. (1997) outlines the predictors of PTSD for cancer survivors. Predictors include whether the patient feels a life threat during treatment, the severity of treatment, their general level of anxiety, a history of stressful experiences, time since treatment, being female (as a gender they are more at risk), and familial and social support. Most of these predictors, are out of adolescents' control. However, given that levels of anxiety can be assessed and treated, knowing that things will improve over time can provide comfort, and requesting more support from family and friends, if this is lacking, can all help an adolescent in cancer survivorship to feel as though they are regaining a sense of control over their lives. The participants in this study highly valued the support they received from peers, family, and the community during the Post-treatment stage as they reintegrated into life after cancer treatment.

The study found that the Post-treatment stage is when the majority of psychological effects take place as the recovery process begins. During this time fear of relapse was common. This appeared to result from the uncertainty as to whether the cancer will recur and when. In a similar way to the treatment routines, some of the participants found comfort in the routine of follow-up appointments. These appointments made some participants feel as though they were in control of their health. However for other participants follow-up routines were a reminder that their cancer could recur and they reported that they worried prior to follow-up appointments. In a similar way to the physical effects of cancer, the participants became more confident, and their psychological health was felt to improve, as time passed. This concurs with the findings of Stam et al. (2001) and Newby et al. (2000), namely that as time passes adolescents become more adjusted as they accept their status as a cancer survivor.

Another key finding of this study was that the cancer experience results in a shift in perspective that correlates to a “new normal,” causing the participants to feel different from their peers. This “new normal” results from acceptance of their cancer survivorship experience and adjustment to changing physical needs and perspectives. The shifts in perspective that the participants incorporated into their identities exemplifies the conclusions made by Zebrack (2011) and Zebrack and Isaacson (2012) that identity is influenced during cancer survivorship and manifests in a new perspective on what is considered to be “normal” from diagnosis onward.

This is further exemplified in data from this study that explored how the cancer experience shaped career aspirations for the participants. The majority of the participants in this study expressed a desire to seek out jobs that had a greater meaning, for example that would enable them to help people and to use their experiences of dealing with cancer to influence others in a positive way. The cancer experience was found to contribute to the formation of identity as the adolescents in this study progressed into adulthood.

Lastly, social reintegration into school is more challenging depending on the length of absence and the severity of treatment effects. As outlined in the previous section, physical effects can have an impact on self-concept, which can in turn have an impact on social reintegration into school. This is due to the changes in self-concept that occur as a result of changing physical appearance. Woodgate (2005) refers to this as the “alien” persona for adolescents in post-treatment. This persona is adopted when the adolescent feels as though they are not themselves due to hair loss, puffy face, weight loss or gain, and general strangeness (Woodgate, 2005). In this study, the female participants expressed more concerns regarding their changing physical appearance than males.

However, length of absence can also influence the social interactions of adolescents in post-treatment. Being separated from peers for a long period of time can promote the feeling of difference between adolescents and their healthy peers. Feeling different in high school can influence the desire for adolescents to engage in social interactions. These conclusions support those made by Stam et al. (2001) that challenges in social functioning increase during the Post-treatment stage.

This study was particularly focused on how adolescent cancer survivors coped with their experiences. As assessed by the Adolescent Coping Scale – Short Form school achievement was a common concern for participants. This result confirms the findings reported by Sullivan et al. (2001) that participants exhibited concerns regarding their academic progress during treatment, and were looking forward to their return to school. With regard to illness, relapse and the worsening of physical side effects were common concerns for participants, which confirms the findings reported by Zebrack and Isaacson (2012) that adolescents in cancer survivorship exhibit fears of relapse and concerns for future health problems. Lastly, feeling different and being treated differently by peers were social concerns shared by the participants. As shown in the previous paragraph, these results confirm the conclusions drawn by Stam et al. (2001) that adolescents in cancer survivorship experience challenges in social functioning.

The majority of the participants appeared to use productive coping strategies, suggesting positive adjustment in post-treatment and it might be assumed low incidence of PTSD as found by Pelcovitz et al., 1998; Stuber et al., 1997. Zebrack and Chesler (2002) reported that productive coping strategies can be used an indicator of high quality of life. Therefore, the use of productive coping strategies in this study also suggests that the participants' quality of life in cancer survivorship increased during the post-treatment stage.

Participants' Experiences with Educational Policy

What role does school play in cancer survivorship for adolescents?

a. How do participants define a successful school experience during and after cancer treatment?
b. How does United States policy shape the school experience of adolescents in cancer survivorship?

The findings from this study indicate that participants view supplemental education as successful if it meets the following criteria:

- Supplemental education should be flexible to meet the personal academic and physical needs of the student.
- Once the personal academic and physical needs of the student are agreed, supplemental education should be implemented consistently.
- Supplemental education should be available to all students who are deemed to be physically able to continue education while in cancer survivorship and have a desire to do so.
- Supplemental education should make the student feel emotionally supported and socially connected to their school and their peers.

In the instances in this thesis where supplemental education was viewed negatively, it resulted in the participants feeling as though they were facing additional academic challenges compared to their healthy peers. The aim of supplemental education is to maintain educational engagement, as well as provide a sense of normalcy, for students missing out in schooling because of health problems. In the case of adolescents in cancer survivorship implementation of supplemental education should enable schools to assist the adolescent in maintaining his or her education during survivorship. It should also help them to feel connected to their peers and the school community as a whole. This structure of supplemental education is expected to allow the adolescent in cancer survivorship to receive the support that they need as they progress through the stages of cancer. Despite any physical and psychological changes that adolescents in cancer survivorship experience, supplemental education should be there to maintain academic progress, providing them with much needed consistency at a time when many daily routines have changed. As noted by Prevatt et al. (2000) when an adolescent in cancer survivorship has been absent from the school setting for an extended period of time, their physical return to the school environment acts as a symbol of their health.

This study found evidence of limitations in the way United States supplemental education policy is being implemented. Federal policy Section 504 is intended to serve students with a physical or medical disability so that they can receive the same or similar education experiences as their healthy peers. This policy is available to all United States students who meet eligibility criteria. However, the limitations occur at the state and district levels. States and districts are allowed to create their own eligibility guidelines as long as they meet the general federal guideline to provide services for students in need. This study has shown that several adolescents in cancer survivorship missed out in support because they were deemed ineligible for supplemental education services, or services when provided, were found to be inadequate in terms of meeting their physical and academic needs. More research is needed that focuses on the implementation of this supplemental education policy at the state and district levels to discern whether this is a common challenge unique to this population of students with a physical or medical disability.

Research Limitations

There were two main limitations with regard to this research study. Firstly the limited sample size makes generalization to the broader population of adolescents in cancer survivorship difficult. Out of a total population of 73.6 million children and adolescents in the United States (U.S. Census Bureau, 2014), approximately 15,000 of them are diagnosed with cancer each year, according to the Cancer in Children and Adolescents Fact Sheet from the National Institute of Health (2014). As a result, the sample available for this research topic is not only limited to an extremely small population, but they are also a highly guarded population, making access to them challenging. "Their participation is controlled by a hierarchy of gatekeepers including ethics committees, organizations, professionals, parents, caregivers and teachers," according to Powell and Smith (2009). Using personal connections from the American Cancer Society – Great West Division I was able to gain access to the population; however I was not able to contact the participants directly. This made recruitment to this study challenging and resulted in a much smaller sample size than initially planned.

Having a small sample size for this doctoral study makes generalization to the rest of the population difficult. However, this study is valuable in that it throws some light on how the physical and psychological effects, plus schooling challenges, are experienced from the first person perspective of adolescents during cancer survivorship. Furthermore the evidence collected on their experiences during and after treatment provide valuable data on aspects of supplemental education implementation needs that may be overlooked, namely in relation to addressing satisfactorily the physical, psychological and social integration needs of these adolescents.

Recommendations for Future Research

This research project focuses on a number of factors associated with adolescents' experiences in cancer survivorship, which provide the basis for further in-depth research into this field.

Firstly, this doctoral study has found that more research is needed into the transition from cancer treatment into post-treatment with regard to educational engagement of adolescents during and after cancer treatment. While literature in this field focuses on implementation at a school level, first person accounts of experiences are limited. Since adolescents are responsible for their academic achievement at this age, their first-person accounts regarding their educational experiences during cancer survivorship can be very insightful. Furthermore, while limited in scale, this study has demonstrated that as an approach involving adolescent cancer survivors in reflecting on their own experiences is feasible, plus helps to avoid the biases involved in focusing on third party views on coping strategies adopted by such adolescents during the process of making the transition from treatment to post-treatment

Secondly, more research is needed into the implementation of special education policies targeting this population in the United States. This study has shown that not all adolescents in cancer survivorship are receiving access to supplemental education accommodations that meet their needs. In addition more research is needed that includes the adolescent, his or her parents, schools, and social workers or school counselors, to understand in some depth where the specific gaps in provision exist and how accommodations can be inadvertently overlooked. Several research studies have outlined models, themes, and educator responsibilities for addressing the special education needs of this population

(Harris, 2009; Harris & Farrell, 2004; Gartin & Murdick, 2009; Shaw & McCabe, 2008). However there has been limited research into the implementation of these recommendations, and whether adolescents facing all the physical and psychological challenges of cancer treatments feel as though they are well supported and are able to achieve academically with minimum disadvantages in comparison to their peers.

APPENDIX

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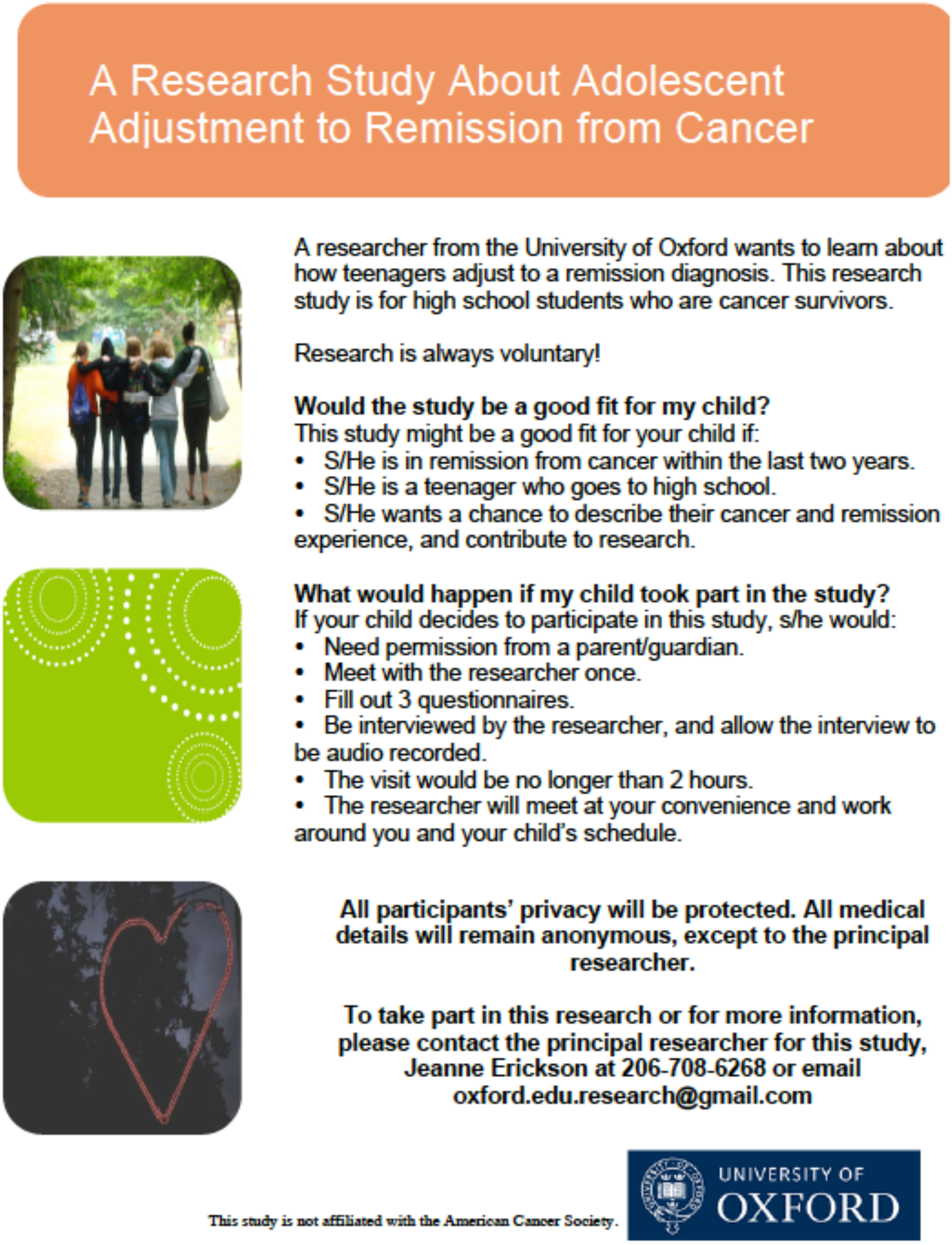
Documents for Fieldwork

Recruitment Flyer



A Research Study About Adolescent Adjustment to Remission from Cancer

A researcher from the University of Oxford wants to learn about how teenagers adjust to a remission diagnosis. This research study is for high school students who are cancer survivors.

Research is always voluntary!

Would the study be a good fit for my child?
This study might be a good fit for your child if:
- S/He is in remission from cancer within the last two years.
- S/He is a teenager who goes to high school.
- S/He wants a chance to describe their cancer and remission experience, and contribute to research.

What would happen if my child took part in the study?
If your child decides to participate in this study, s/he would:
- Need permission from a parent/guardian.
- Meet with the researcher once.
- Fill out 3 questionnaires.
- Be interviewed by the researcher, and allow the interview to be audio recorded.
- The visit would be no longer than 2 hours.
- The researcher will meet at your convenience and work around you and your child's schedule.

All participants' privacy will be protected. All medical details will remain anonymous, except to the principal researcher.

To take part in this research or for more information, please contact the principal researcher for this study, Jeanne Erickson at 206-708-6268 or email oxford.edu.research@gmail.com

This study is not affiliated with the American Cancer Society.

UNIVERSITY OF
OXFORD

CUREC 1

University of Oxford
CENTRAL UNIVERSITY RESEARCH ETHICS COMMITTEE (CUREC)
IDREC Checklist

Principal investigator/supervisor/student researcher (title and name):	D.Phil Student Researcher, Jeanne Erickson
FOR STUDENT RESEARCH PROJECTS ONLY ***Name of Supervisor:***	Terezinha Nunes
Department or institute:	Department of Education
Address for correspondence:	Linacre College, St. Cross Road Oxford, Oxfordshire OX1 3JA
E-mail and telephone contact:	Jeanne.erickson@education.ox.ac.uk 07751 061 275 mobile

Before completing this checklist, please ensure you have consulted the following CUREC guidance documents available on the CUREC website at http://www.admin.ox.ac.uk/curec/resrchapp/index.shtml:

- Guidance on approval process
- Glossary
- FAQs

This checklist is the first stage of the University of Oxford's scrutiny procedure for *research involving *human participants. (Definitions of terms marked with an asterisk are to be found in CUREC's glossary and guidance).

The University aims to ensure that all research is subject to *appropriate* ethical scrutiny. This form is designed to identify those projects which fall outside CUREC's remit; those which fall within CUREC's remit but which pose low risks to participants and so need scrutiny only through this checklist; and those which fall within CUREC's remit and which pose greater risk to participants and so need more scrutiny. If you need further advice or if you have comments about this form, please consult the relevant IDREC officer (please see: http://www.admin.ox.ac.uk/curec/oxonly/contact.shtml).

The checklist should be completed by the *principal investigator/supervisor/student researcher (under the guidance of his/her supervisor) undertaking or supervising research which comes under CUREC's responsibility. Please carry out a risk assessment of the project, in consultation with all researchers involved, using the checklist and CUREC's other documentation.

This form does not cover research governance, satisfactory methodology, or the health and safety of employees and students. As principal investigator, it is your responsibility to ensure that requirements in these areas are met.

Office use only:

IDREC Ref. No. ________________
Date of confirmation that checklist accepted on behalf of IDREC: // //

Section A

Title and brief lay description of *research (about 150 words), plus description (about 200 words) of the nature of participants (including the criteria for inclusion/exclusion, method of recruitment, attaching samples of participant information and consent forms), purpose of the research, methods to be used, how professional guidelines are being applied (if applicable) and use to which the results/data will be put.
Title: Adjustment of American High School Students in Remission from Cancer The research design for this project investigates the adjustment of high school students who are in remission from cancer. It focuses on the students' quality of life, physical effects, adjustment, and coping abilities since the remission diagnosis. The participants will be a small sample of the population of high school students in remission from cancer in Seattle. The methods used in this study will follow a mixed-method design, including semi-structured interviews of a minimum of 20 adolescent cancer survivors, at two time-points. It will also include three questionnaires given at three time points: the Quality of Life Questionnaire C-30, the Piers-Harris Children's Self-Concept Scale, and the Adolescent Coping Scale. The researcher will recruit participants for this study from the Seattle office of the American Cancer Society. Thematic analysis of the transcripts will be paired with quantitative questionnaires to discern the extent of adjustment to the remission diagnosis. The researcher's primary concern during the course of this research is to protect the participants and their health privacy by adhering to the Health Insurance Portability and Accountability Act of 1996 (HIPAA), a United States law that protects all patient privacy. Please see the attached consent forms, privacy protection forms, interview questions, and questionnaires. The results of this study will be used primarily for a doctorate thesis. It is possible that the results will also be published and presented at research conferences and meetings.

List all *sites where project will be conducted:	Seattle and outlying areas, participant's choice of venue.		
Anticipated duration of project:	_24_ months		
Anticipated start and end dates:	From 01/ 01 /2011 until 30/ 12 / 2012		
Name and status (e.g. 3rd year undergraduate; post-doctoral research assistant) of others taking part in the project:	n/a		
External organisation funding the research (if applicable - see also Section D):	n/a		
	Does the funding body require some form of monitoring of the conduct of the research until completion (eg. annual ethical re-approval of the study)?	**YES**	**NO**
Please indicate what training on research ethics you have received,	I have received training in research ethics through Oxford University's department of education. I have also received		

e.g. online training in ethics/human subject protection etc.	ethical training in the US in working with students as an elementary school teacher and 6 years of training in working with children and adolescents with cancer as a volunteer.

Section B

(Please put a tick in the yes/no column as appropriate to indicate your response).

1). Does your study primarily aim to monitor and/or improve the performance of a particular service provider?	**YES**	**NO**
		X
2) Will your conclusions be applicable wholly or primarily to that service provider?	**YES**	**NO**
		X
3) Are you conducting your study on behalf of or at the request of a service provider?	**YES**	**NO**
		X

If you have answered 'yes' to any question in section B it is likely that your study is *audit, not *research. Please check the CUREC glossary and if your study is audit you need not submit your proposal for ethical scrutiny. If you have answered 'no' to all questions please proceed to section C.

Section C

(Please put a tick in the yes/no column as appropriate to indicate your response).

1) Will the research involve *human participants recruited by means of their status as present or past NHS *patients or their relatives or carers or present or past NHS staff?	**YES**	**NO**
		X
2) Will the research involve *personal data of any of the people listed in question C 1 above ?	**YES**	**NO**
		X
3) Will the research in whole or part be carried out on NHS premises or using NHS facilities?	**YES**	**NO**
		X
4) Does the research involve administering any drug, placebo, or other substances to participants in the European Union (EU)?	**YES**	**NO**
		X
5) Does the research involve ionising radiation in the EU?	**YES**	**NO**
		X
6) Does the research involve human genetic research in the EU?	**YES**	**NO**
		X

7) Does the research involve magnetic resonance imaging in the EU?	**YES**	**NO**
		X
8) Does the research involve use of organs or other bodily material of past and present NHS patients?	**YES**	**NO**
		X
*9) Does the research involve any other *invasive procedure (Class A) not described above?*	**YES**	**NO**
		X
*10) Does the research involve *human participants aged 16 and over who do not have *capacity to consent for themselves?* *[Please note that the definition of *capacity has been altered by the Mental Capacity Act 2005; see the Glossary on the CUREC website for further information]*	**YES**	**NO**
		X

If you have answered 'yes' to any question in section C please stop work on this checklist as you will need to submit your proposal to the appropriate NHS ethics committee. Further details may be obtained from the website http://www.nres.npsa.nhs.uk. Please submit the NHS Ethics Committee approval to the relevant IDREC officer for information when received.
If your research involves any of the above procedures but will be carried out by University of Oxford staff wholly outside the EU, your research will be reviewed by OXTREC (http://www.tropicalmedicine.ox.ac.uk/oxtrecframeset.htm). **If you have answered 'no' to all questions so far, please proceed to section D.**

Section D

(Please put a tick in the yes/no column as appropriate to indicate your response).

1) Is the study to be funded by the US National Institutes of Health or another US federal funding agency?	**YES**	**NO**
		X

If you have answered 'yes' to the question in section D please stop work on this checklist as you will need to submit your proposal to OXTREC which uses separate documentation (http://www.tropicalmedicine.ox.ac.uk/oxtrecframeset.htm).
If you have answered 'no' to all questions so far, please proceed to section E.

Section E

(Please put a tick in the yes/no column as appropriate to indicate your response).

*1) Are all the data about people to be used in your study previously collected anonymised data which neither you nor anyone else involved in your study can trace back to the individuals who provided them (e.g. census data, administrative data, secondary analysis)? Please refer to the definition of *personal data in the glossary and FAQ no. 6 for further guidance.*	**YES**	**NO**
		X

FAQ 6

If you have answered ‘yes’ to the question in section E please stop work on this checklist as you do not need to secure ethical approval for your study. There is no need to submit any details to IDREC as such research does not constitute research involving human participants for review purposes.
If you have answered ‘no’ to all questions so far, please proceed to section F.

Section F

Methods to be used in the study (**tick** as many as apply: this information will help the committee understand the nature of your research and may be used for audit).

METHOD USED	**PLEASE TICK**
Unstructured interview	
Semi-structured interview	X
Structured interview	
Questionnaire	X
Analysis of existing records	
Participant performs verbal/paper and pencil/computer based task	
Measurement/recording of motor behaviour	
Audio recording of participant	X
Video recording or phtotography of participant	
Physiological recording from participant	
Participant observation	
Systematic observation	
Observation of specific organisational practices	
Other (please specify)	

Section G

See protocols

(Please put a tick in the yes/no column as appropriate to indicate your response).

1). Have you made arrangements to obtain written *informed consent from participants?	**YES**	**NO**
	X	
2) Have you made arrangements to ensure that *personal data collected from participants will be held in compliance with the requirements of the Data Protection Act?	**YES**	**NO**
	X	

3) If your research involves any use of *personal data obtained from a *third party, have you checked to ensure that the *third party has arrangements in place to permit disclosure?	**YES**	**N/A**	**NO**
		X	
4) Does the research involve as participants *people whose ability to give free and informed consent is in question?	**YES**		**NO**
	X		
5) Does the research involve any alteration of participants' normal patterns of sleeping, eating, or drinking?	**YES**		**NO**
			X
6) Is there a significant risk that the research will expose participants to visual, auditory, or other environmental stimuli of a level or type that could have short- or long-term harmful physical effects?	**YES**		**NO**
			X
7) Is there a significant risk that the research will induce anxiety, stress or other harmful psychological states in participants that might persist beyond the duration of the test/interview?	**YES**		**NO**
			X
8) Does the research involve exposing participants to any physical or psychological hazard, beyond those of their usual everyday life, not covered by questions 6 and 7?	**YES**		**NO**
			X
9) Does the research involve any *invasive procedure (Class B)?	**YES**		**NO**
			X
10) Will the research elicit information from participants that might render them liable to criminal proceedings (e.g. information on drug abuse or child abuse)?	**YES**		**NO**
			X
11) Does the research involve the *deception of participants?	**YES**		**NO**
			X
12) Will the research require a participant to spend more than 2 hours in any single session on activities designed by the researcher (NB this time restriction does not refer to situations where participants are observed going	**YES**		**NO**
			X

about activities not devised by the researchers e.g. observation of lessons in schools)?	▨	

13) Will the research involve a significant risk of any harm of any kind to any participant not covered above?	**YES**	**NO**
	▨	**X**

If any of your answers in section G are in a shaded box, please complete section H. If all your answers in section G are in the unshaded boxes, please complete section I.

Section H

FAQ
s 19-

One or more aspect(s) of your research project suggest(s) that it may pose risks to participants (see shaded box(es) ticked in section G).

FA
Q

Are all the aspects of your project which caused you to tick a shaded box in section G fully covered by research protocol(s) which has/ve received IDREC/CUREC approval?	**YES**	**NO**
	Please give IDREC protocol number (s). Please proceed to section I.	Please complete this form AND form CUREC/2 and submit both to the relevant Inter Divisional Research Ethics Committee.
If you answered NO to question 1) in Section G concerning informed consent but a section of the Code of Practice governing your research activity is relevant, are you going to apply the standard set out in the Code of Practice?	Name of Code of Practice and section number: Please ensure that the description in section A indicates how the Code is applied and proceed to section I.	Please complete this form AND form CUREC/2 and submit both to the relevant Inter Divisional Research Ethics Committee.

Section I

FAQ
s

Complete this section only if you do not need to submit form CUREC/2.

I understand my responsibilities as principal researcher/supervisor/student researcher as outlined on p.1 of this form and in the CUREC glossary and guidance.

FAQ
s

I declare that the answers above accurately describe my research as presently designed and that I will submit a new checklist should the design of my research change in a way which would alter any of the above responses so as to require completion of CUREC 2/full scrutiny by an IDREC. I will inform the relevant IDREC if I cease to be the principal researcher on this project and supply the name and contact details of my successor if appropriate.

Signed by principal researcher/supervisor/student researcher:……………………………………
Date:………………………..
Print name (block capitals)…………………………………………………………………………
Signed by supervisor:………………………………………………………(for student projects)

Date:……………………..
Print name (block capitals)…………………………………………………………………………

I understand the questions and answers that have been entered above describing the research, and I will ensure that my practice in this research complies with these answers.

Signed by associate/other researcher: ……………………………………………………………….
Print name (block capitals)……………………………………………………………………………
Date ………………

I have read the research project application named above. On the basis of the information available to me, I:
(i) consider the principal researcher/supervisor/student researcher to be aware of her/his ethical responsibilities in regard to this research;

(ii) consider that any ethical issues raised have been satisfactorily resolved or are covered by CUREC approved protocols, and that it is appropriate for the research to proceed without further formal ethical scrutiny at this stage (noting the principal researcher's obligation to report should the design of the research change in a way which would alter any of the above responses);

(iii) am satisfied that the proposed project has been/will be subject to appropriate *peer review and is likely to contribute something useful to existing knowledge and/or to the education and training of the researcher(s) and that it is in the *public interest.

(iv) [FOR DEPARTMENTS/FACULTIES WITH A DEPARTMENTAL RESEARCH ETHICS COMMITTEE (DREC) OR EQUIVALENT BODY - PLEASE DELETE IF NOT APPLICABLE] confirm that this checklist (and associated research outline) has been reviewed by the Department's Research Ethics Committee (DREC)/equivalent body, and attach the associated report from that body.

Signed:……………………………………….**(Head of department or nominee e.g Chair of DREC, Director of Graduate Studies for student projects)**
Print name (block capitals)………INGRID LUNT…………………………………………………
Date:……………………

Please send an electronic copy and a paper copy of this completed checklist to whichever of the IDRECs is more suitable (Social Sciences or Medical Sciences), keeping a copy for yourself.

Forms may be sent by email (without signature), where both the note of submission from the researcher and the note of endorsement from the supervisor/Head of Department are sent from a University of Oxford email address.

IDRECs and/or CUREC will review a sample of completed checklists and may ask for further details of any project.

FINAL CHECK

To prevent delay please check each of the following before submitting the application.

Have you completed Section A and answered all relevant questions in Sections B-H? ☐

Have you defined all technical terms and abbreviations used? ☐

Have you included all questionnaires and participant information, consent forms, advertisements, and surveys to be used? ☐

Have you included all relevant approvals and supporting letters? ☐

Have you declared all potential conflicts of interest? ☐

Are all pages (including appendices and attachments) numbered? ☐

Are all relevant declarations in Section I complete and any necessary authorisations obtained (by email or by signing the form)? ☐

Revised May 2009

CUREC 2

University of Oxford
CENTRAL UNIVERSITY RESEARCH ETHICS COMMITTEE (CUREC)

Not all research project leaders need to fill in this form. **Before starting work on this form**, please fill in CUREC's checklist (CUREC/1), which will show if you need to complete this form. Please also ensure you have consulted the following CUREC guidance documents available on the CUREC website (http://www.admin.ox.ac.uk/curec/resrchapp/index.shtml):

FAQs 14-

- Guidance on approval process
- Glossary
- FAQs

Definitions of terms marked with an asterisk are to be found in CUREC's glossary and guidance.

SECTION 1: PROJECT TITLE, RESEARCHERS, AND CONTACT DETAILS

1. Person to whom IDREC/CUREC should direct correspondence.

***Principal investigator/supervisor/student researcher**

FAQ

Title and name: Ms. Jeanne Erickson

Appointment: Doctoral Student

Department: Education

Institution: University of Oxford

Address: Linacre College, St. Cross Road,
Oxford, Oxfordshire OX1 3JA

Phone:07751 061 275

Fax:

e-mail: jeanne.erickson@education.ox.ac.uk

Will you need training to participate in this project?
☐ Yes ☐ No

FOR STUDENT RESEARCH PROJECTS ONLY

Name of Supervisor: Terezinha Nunes

2. Full project title and proposed starting date:

FAQs 13&2

Adjustment of American High School Students in Remission from Cancer
1/1/2011

Office use only: **IDREC Ref. No.**____________
Date of Approval: / /
Application date: / /
Approval Period: from / / to / /

Signature of IDREC approver: ______________________________

Name (printed) and position of approver: ________________________

Date applicant informed of approval: / /

3. Are you submitting this project to another ethics committee or has it been previously submitted to an ethics committee?

☐ Yes - provide details.

☐ No

If other relevant approvals for this research are required (e.g. from other universities' ethics committees) please attach them.

4. Have you made use of professional/CUREC guidelines in framing your research project and preparing documentation?

Note: the CUREC guidelines are available online (http://www.admin.ox.ac.uk/curec/oxonly/protocols/guidelines.shmtl) or by emailing curec@admin.ox.ac.uk

☐ Yes - provide details.

☐ No – explain why not.

Given the nature of this project in working with adolescents under the age of 18, the principal researcher wanted to ensure the research is ethically appropriate for participants by using the CUREC guidelines and recommendations to frame the parameters for the study.

5. Researchers involved in this project

Please supply one completed copy of this box for each researcher.

*For each researcher who requires training to participate in this project, describe training on a **separate page** and include the name of the trainer(s).*

***Associate researcher/student researcher** Title and name:	
Appointment:	
Department:	
Institution:	
Address: Phone:	Fax:
e-mail:	
Role in this project:	

Qualifications and relevant experience for this project:
Degree course (if relevant):

Will this researcher be approved by the principal researcher as competent to obtain *informed consent from participants?

Will this researcher need training to participate in this project? ☐ Yes ☐ No

SECTION 2: PROJECT DESCRIPTION

6. Description of project

Please give a description (300-800 words) of your project to supplement the information already provided in Section A of the checklist (CUREC/1), detailing those aspects of the project which involve *human participants, particularly any aspect which is beyond already established and accepted techniques. Please attach all other documents (e.g. questionnaire, recruitment advertisements, participant information, and consent forms) that you plan to use in the study. **Please note that detailed scientific background is not required unless directly relevant to ethical issues.**

The research design for this project investigates the adjustment of high school students who are in remission from cancer. It focuses on the students' quality of life, physical effects, adjustment, and coping abilities since the remission diagnosis. The participants will be a small sample of the population of high school students in remission from cancer in Seattle. The methods used in this study will follow a mixed-method design, including semi-structured interviews of a minimum of 20 adolescent cancer survivors, at two time-points. It will also include three questionnaires given at three time points: the Quality of Life Questionnaire C-30, the Piers-Harris Children's Self-Concept Scale, and the Adolescent Coping Scale. The researcher will recruit participants for this study from the Seattle office of the American Cancer Society and if necessary, Seattle Children's Hospital. Participants will be adolescents in high school, who have received a remission diagnosis from cancer that does not include any form of brain cancer or tumors. A HIPAA consent form from Columbia University in New York City has been used as a template HIPAA consent form for this research project. Participants will be mailed the recruiting documents from the American Cancer Society office in order to protect patient privacy. The first five participants to respond to the study will be used in a pilot study to ensure efficacy of the measures. If applicable, adjustments will be made to the measures. A minimum of twenty participants will be included in the field study. Participants will continue to be recruited until qualitative saturation has occurred. Thematic analysis of the transcripts will be paired with quantitative questionnaires to discern the extent of adjustment to the remission diagnosis. The researcher's primary concern during the course of this research is to protect the participants and their health privacy by adhering to the Health Insurance Portability and Accountability Act of 1996 (HIPAA), a United States law that protects all patient privacy. Please see the attached consent forms, privacy protection forms, interview questions, and questionnaires.

7. Literature search

If the research involves significant risk to the human participants please describe what literature searches have been undertaken to obtain information to aid risk reduction/management.

This research does not involve significant risk to the participants; however, the principal researcher has completed extensive literature searches on the research topic, as well as on ethical consent for research involving medical information and minors under the age of 18.

SECTION 3: RESEARCH INVOLVING CONTACT WITH *HUMAN PARTICIPANTS

If the project does NOT involve contact with*human participants, but only use of data about them, do NOT complete this section, but go to Section 4. If you are not completing Section 3 please delete it from your application to save paper.

8. Description of participants

How many participants will be involved in the project?

A minimum of 25 adolescents.

9. Details of participants

(a) What types of people will be recruited e.g. students,* children, people with learning disabilities? [Please see the Glossary on the CUREC website for information on how the meaning of *capacity to consent has been altered by the Mental Capacity Act 2005]

American high school students who have had cancer (excluding brain cancers) and received a remission diagnosis from their oncologist.

(b) What will be the age range of participants?

Approximately 13-19 years old, enrolled in high school.

(c) How will the competence of participants to give *informed consent be determined?

Both the adolescent participants and their parent/guardian will give informed consent, provided they have no altered mental ability from their cancer, which is why participants with brain cancer will be excluded from this study.

(d) What are the *defining criteria for participation in the study?

The participants must have been diagnosed with childhood cancer and have received a remission diagnosis within two years of their participation in this study. They must also be enrolled in a mainstream American high school.

10. Recruitment of participants

(a) Describe how, where, and by whom participants will be identified, approached, and recruited.

The American Cancer Society has agreed to send out recruiting documents to their contacts on behalf of the researcher. If further participants are needed, the researchers will contact Seattle Children's Hospital.

(b) If your research involves any use of *personal data obtained from a *third party, describe the steps you have taken to ensure that the *third party has arrangements in place to permit disclosure.

The American Cancer Society will not provide the principal researcher with any information to protect the medical privacy of their contacts. It will be up to the participants to contact the principal researcher, based on the recruitment documents sent out by the American Cancer Society.

(c) Will any *unequal relationships exist between anyone involved in the recruitment and the potential participants?

☐ Yes

☐ No

If yes:

(i) Describe the nature of the unequal relationship.

The principal researcher is an adult, who will be interviewing the participants, who are minors under the age of 18 about private medical information and personal adjustment.

(ii) Explain how ethical problems arising from the unequal relationship will be resolved.

The principal researcher is a former teacher and has experience as well as has been trained on working with minors under the age of 18. The principal researcher also has experience volunteering with children and adolescents with cancer. So the training used for that experience would also help make the participants feel more comfortable during their participation in the study.

(d) Describe any *financial or other rewards which will be offered to participants.

N/A

11. *Participant information

It is essential that written information is easily understandable by participants. Failure to provide this information in appropriate lay language is the most frequent reason for delays in ethical approval.

(a) Will participants receive **written** information about the project before giving their consent?

☐ Yes - please attach.

☐ No - give reasons.

Please see attached consent forms, HIPAA forms, and recruitment documents.

(b) Who will give the participants the information and how?

The recruitment documents will be mailed to participants from the American Cancer Society. The other forms will be completed in person with a verbal explanation of the

research by the principal researcher.

(c) Does the research involve deliberate *deception of participants?

☐ Yes- explain why the real purpose of the research needs to be concealed and how and when participants will be told of the deception.

☐ No

(d) Please describe the basis on which you have decided how long participants will have to think about the information provided before giving consent.

Participants will receive the documents in the mail. If they are willing to participant, they will contact the principal researcher. They have from the time they read the recruitment pamphlet to the time of the in-person meeting to decide on their consent.

12. *Informed consent

(a) Will you obtain written consent?

☐ Yes - please attach *consent form.

☐ No - explain how consent will be obtained and recorded and why this method is used.

(b) If participants are unable to give valid consent, how and from whom will you obtain consent? [Please see the Glossary on the CUREC website for information on how the meaning of *capacity to consent has been altered by the Mental Capacity Act 2005]

Both the participants and their parent/guardian will give consent after meeting with the principal researcher and asking any questions or addressed any concerns they may have.

(c) List those researchers who will, with the authorisation of the principal researcher (or supervisor in the case of student researchers), secure the consent of participants.

N/A

13. Consequences of participation

(a) What are the potential risks or actual ill effects of participation (if any) e.g. invasive procedures, distress, deception etc, and what will be done to minimise these risks

(i) to the participants?

N/A

(ii) to the researchers?

N/A

(iii) to others (e.g. the university, family)?

N/A

(b) Is there a need for support or counselling?

☐ Yes - describe the form of support or counselling and how, when, and by whom it will be conducted.

☐ No

(c) Is there a need for debriefing or follow-up discussion?

☐ Yes - describe the form of debriefing or follow-up discussion and how, when, and by whom it will be conducted.

☐ No

The participants and their parent/guardian will be given a full verbal explanation of the study along with the written explanation by the principal researcher. At this time they can address any concerns they have or have any of their questions answered.

(d) Are there any potential benefits to the participants?

☐ Yes - describe them below

☐ No

14. *Adverse events

How will adverse events be monitored and reported?

Should an adolescent discover that their cancer is no longer in remission during this study, they will be offered resources for counselling as made available by the American Cancer Society.

15. Monitoring

Explain how and by whom (e.g. supervisor in the case of student research projects) the ethical aspects of the project will be monitored to ensure that they conform to the procedures set out in this application.

The supervisor will monitor this study research project to ensure that it conforms to all procedures and guidelines.

SECTION 4: RESEARCH INVOLVING COLLECTION, USE, OR *DISCLOSURE OF *PERSONAL DATA

Your project must meet the standards laid down in the Data Protection Act (1998) with respect to the collection, use, and storage of *personal data about *human participants.

Please delete questions or parts of questions that you are not required to answer to save paper.

16. Need I complete this section?

Does the project involve the collection, use or disclosure of personal information including sensitive and/or genetic information?

☐ No – you need not complete this section. **Go to Section 5.**

☐ Yes – you must answer questions in this section. **Go to Question 17.**

17. Type of activity proposed

Does the research involve:

(a) disclosure of personal information?

☐ Yes

☐ No

(b) collection of personal information?

☐ Yes – **go to Question 18**

☐ No – **go to Question 20**

18. Collection of information directly from individuals

(a) Does the project involve collection of information directly from individuals about themselves?

☐ No – **go to Question 19.**

☐ Yes – answer the following questions:

(b) Do the *participant information and the *consent form include the following:

the name of the study?	☐Yes ☐No
the name and status (e.g. doctoral student) of the researcher collecting the information and how to contact him/her?	☐Yes ☐No
the purpose of the study?	☐Yes ☐No
declarations that the participant has read the participant information sheet?	☐Yes ☐No
has had the opportunity to ask questions about the study and has received satisfactory answers to questions, and any additional details requested?	☐Yes ☐No
understands that s/he may withdraw from the study without penalty at any time by advising the researchers of this decision?	☐Yes ☐No
understands that this project has been reviewed by, and received ethics clearance through, the University of Oxford Central University Research Ethics Committee?	☐Yes ☐No

understands who will have access to personal data provided, how the data will be stored; and what will happen to the data at the end of the project?	☐Yes ☐No
agrees to participate in this study?	☐Yes ☐No
understands how to raise a concern and make a complaint?	☐Yes ☐No

(c) Are the consent form and participant information on headed letter paper which bears the name of the University and the name and address of the department to which the principal researcher is attached?

☐ Yes

☐ No - explain why not.

(d) Are the participant and the researcher who secures the consent required to sign, print and date their names?

☐ Yes

☐ No -explain why not.

19. Collection of information from a third party

(a) Does the project involve collection of information about an individual from a source other than the individual?

☐ No – **Go to Question 20.**

☐ Yes – complete the following sections.

20. Form in which data are to be stored

Are the data to be kept

(a)	with an open identifier i.e. in non-anonymised form	☐Yes ☐No
(b)	as anonymised but potentially identifiable data	☐Yes ☐No
(c)	as anonymised, non identifiable data	☐Yes ☐No

21. Use or disclosure of information about individuals

(a) Does the project involve the use or disclosure of information potentially or actually ascribed to an individual?

☐ No – **go to Question 22.**

☐ Yes – answer the following questions

22. Data collection, storage, and disposal

(a) How many records will be collected, used or disclosed? Specify the information that will be collected, used, or disclosed e.g. date of birth, medical history, number of convictions.

Number of records: Minimum of 25

Type of information: Medical history/private health information, and behavioral information

(b) How, where, and under what security arrangements will electronic and paper data be stored? Who will have and control access to the information?

Audio and electronic data will be password protected on an individual laptop belonging to the principal researcher. Paper data will be entered into the computer and disposed of.

(c) When, how and by whom will the information be disposed of?

Paper data will be shredded after being entered into the computer by the principal researcher. Digital data will be deleted at the end of the study.

(d) How will the privacy of individuals be respected in any publication arising from this project?

If the publication of any individual names is necessary, the names will be changed. However, for the purposes of this study and not for publication, all participants will be given a number as their identification.

(e) Have you explained in the *participant information and *consent form that maintenance of confidentiality of information is subject to normal legal requirements?

☐ Yes

☐ No – explain why not.

23. Adverse and unforeseen events

How will adverse and unforeseen events relating to the collection, use, or disclosure of information be managed, monitored and reported?

Should adverse and unforeseen events occur, they will be managed by the principal researcher and the supervisor, as well as the American Cancer Society staff. The principal researcher will report any necessary information to all involved parties.

SECTION 5: MISCELLANEOUS ISSUES

24. *Conflict of interest

(a) Do researchers on this project have a financial or other interest in its conduct or outcomes?

☐ Yes – give details.

☐ No

(b) If there is a conflict of interest, have you declared it in your *participant information and *consent form?

☐ Yes

☐ No – explain why not.

N/A

(c) Are there any other potential conflicts of interest e.g. research findings that could compromise the researcher's relationship with the university?

N/A

25. *Peer review

Has this project been peer reviewed?

☐ Yes – explain by whom (e.g. by a, tutor, supervisor, funding body etc) and with what outcome

☐ No – explain why not.

This project has been peer reviewed by fellow doctoral students, as well as the research supervisor. It has been recommended for submission for transfer of status.

26. Funding

List all bodies and individuals from whom funding has been or will be sought.

Source	Amount in £	**Status of Funds** Available	Applied for
N/A		Yes ☐ No ☐	Yes ☐ No ☐

27. Reporting of results

(a) Will the project outcomes be made public at the end of the project?

☐ Yes – describe the intended report and how and to whom it will be made available.

☐ No – explain why not

It is a possibility that this project may be presented at a conference or published, but it will not be made otherwise public.

(b) Will a report(s) of the project outcomes (for example, individual or group data) be made available to participants at the end of the project?

☐ Yes – describe report and how it will be made available.

☐ No – explain why not.

☐ N/A

28. Declaration by researchers

Full project title: Adjustment of American High School Students in Remission from Cancer

I/We, the researcher(s) agree:

- To start this research project only after obtaining approval from IDREC/CUREC;
- To carry out this research project only if funding is adequate to enable it to be carried out according to good research practice and in an ethical manner;
- To provide additional information as requested by IDREC/CUREC before approval is secured and as research progresses;
- To maintain the confidentiality of all data collected from or about project participants;
- To notify IDREC in writing immediately of any proposed change which would increase the risks that any participant is exposed to and await approval before proceeding with the proposed change;
- To notify IDREC if the principal researcher on the project changes and supply the name of the successor;
- To notify IDREC in writing within seven days if any serious *adverse event occurs in the course of research;
- To use data collected only for the study for which approval has been given;
- To grant access to data only to authorised persons; and
- To maintain security procedures for the protection of personal data, including (but not restricted to): removal of identifying information from data collection forms and computer files, storage of linkage codes in a locked cabinet and password control for access to identified data on computer files.

FAQs 28&3
FA

Signed by principal researcher/supervisor/student researcher:…………………… ……
Date:…………………
Print name (block capitals)……JEANNE ERICKSON……………………………………

Signed by supervisor:…………………………………………………(for student projects)
Date:…………………
Print name (block capitals)……TEREZINHA NUNES……………………………………

Signed by associate/other researcher: ……………………………………………………
Print name (block capitals)…………………………………………………………………
Date ……………..

29. Certification by *principal researcher/supervisor/student researcher and head of department

Full project title: Adjustment of American High School Students in Remission from Cancer

Certification by *principal researcher/supervisor/student researcher

I accept responsibility for the conduct of this research project.

I certify that all researchers and other personnel involved in this project are appropriately qualified and experienced or will undergo appropriate training to fulfil their role in this project.

Signed by principal researcher/supervisor/student researcher:……………………………..
Date:…………………
Print name (block capitals)…JEANNE ERICKSON………………………………………

Acceptance by head of department/other senior member of the department if the principal researcher is the head of department

I have read the research project application named above.

On the basis of the information available to me, I judge the principal researcher/supervisor/student researcher to be award of her/his ethical responsibilities in regard to this research. I am satisfied that the proposed project has been/will be subject to appropriate peer review and is likely to contribute to existing knowledge and/or to the education and training of the researcher(s) and that it is in the public interest.

Name of head of department/other senior member of the department (e.g Chair of DREC, Director of Graduate Studies for student projects):………INGRID LUNT……………………

Signature ………………………………………………… Date……………….

FINAL CHECK

To prevent delay please check each of the following before submitting the application.

Have you answered all relevant questions in Sections 1-5? ☐

Have you defined all technical terms and abbreviations used? ☐

Have you included all questionnaires and participant information, consent forms, advertisements, and surveys to be used? ☐

Have you included all relevant approvals and supporting letters? ☐

Have you declared all potential conflicts of interest? ☐

Are all pages (including appendices and attachments) numbered? ☐

Have you completed the declaration by researcher(s)? ☐

Have you completed the certification by principal researcher and head of department? ☐

Revised July 2008

Consent Forms

HIPAA RESEARCH AUTHORIZATION[·]

Authorization for the Creation, Use, and Disclosure of Protected Health Information for Institutional Review Board Approved Research

Instructions: This authorization should be attached to each Consent Form. Investigators please complete information fields below and questions 2-8. Leave the name of research subject and signature areas blank.

Study Title: Flexibility in the Adjustment of American High School Students in Remission from Cancer

Name of Investigator: __Jeanne Erickson________________________________

Phone Number: _____312-315-3774 mobile______________________________

Sponsor: ________University of Oxford________________________________

IRB Number: _________N/A______________________________________

Protocol Approval Date: ___Jan. 2011________________________________

Consent Form Approval Date: ___Jan. 2011_____________________________

This form authorizes Department of Education, University of Oxford to use and disclose certain protected health information about ______________________________ that we will collect and create in this research study. (Name of research subject)

This authorization is voluntary. You may refuse to sign this authorization. If you refuse to sign this form, your health care will not be affected; however, you will not be able to enter this research study.

1. If you sign this form, you are agreeing that University of Oxford may use and disclose protected health information collected and created in this research study.
2. The specific health information and purpose of each use and disclosure are:

Health Information (Check as applicable)	**Purpose(s)**

[·] Research Authorization form revised from the Teachers College, University of Columbia Research Authorization form to adhere to University of Oxford ethical review board standards for the intention of field work conducted in the United States.

_____ Medical records ____________________

_____ X-ray/MRI/CT/Diagnostic Images ____________________

_____ Photographs, videotapes, or digital or other images ____________________

_____ Questionnaires, interview results, focus group survey,
psychology survey, behavioral performance tests
(e.g., memory & attention) ____________________

_____ Other: (please describe) ____________________

____

____

3. If the information to be used or disclosed contains any of the types of records or information listed just below, additional laws relating to use and disclosures of the information may apply. You understand and agree that this information will be used and disclosed only if you place your initials in the applicable space next to the type of information. *(Investigators please type N/A in irrelevant fields).*

_N/A__ Acquired immunodeficiency syndrome (AIDS) or human immunodeficiency virus (HIV) infection information
_N/A__ Drug/alcohol diagnosis, treatment, or referral information
_N/A__ Mental or behavioral health or psychiatric care
_N/A__ Genetic testing information

4. The persons who are authorized to use and disclose this information are:

___ All the investigators listed on page one of the Research Consent Form
___ Others at University of Oxford who are participating in the conduct of this research protocol:
___ The Department of Education Institutional Review Board

<u>Note: We will use this information for research purposes only. Any information we get from you or your health records will be identified by a number only, not by your name</u>.

5. The persons who are authorized to receive this information are:

______ The sponsor of this study: University of Oxford
_N/A__ Federal or other governmental agencies responsible for research oversight: NIH/NEI
______ Others:

<u>Note: We will use this information for research purposes only. Any information we get from you or your health records will be identified by a number only, not by your name.</u>

6. Protected health information that we collect from you in this study will be kept by us until:

______ The study is completed
_N/A__ Indefinitely
_N/A__ Other:

7. You have the right to revoke this authorization and can withdraw your permission for us to use your information for this research by sending a written request to the Principal Investigator listed on page one of the research consent form. If you do send a letter to the Principal Investigator, the use and disclosure of your protected health information will stop as of the date he/she receives your request. However, the Principal Investigator is allowed to use information collected before the date of the letter or collected in good faith before your letter arrives. Revoking this authorization will not affect your health care or your relationship with University of Oxford.

   ______ (please initial)

8. If we have disclosed your protected health information outside of University of Oxford, to persons or agencies identified in item #5 above, it is possible that this information could be released again without your permission. The Principal Investigator tries to protect against this by being very careful in releasing your information. The ways in which we will limit the further release of your protected health information are:

_N/A__ Contractual agreements with those who may not receive the information
______ Not releasing your information in a way that could identify you
______ Other: We will use this information for research purposes only. Any information we get from you or your health records will be identified by a number only, not by your name.

You will receive a copy of this authorization form after you sign it.

____
Printed name of research subject

____ ________________________
Signature of subject Date

-AND/OR-

____
Printed name of subject's parent/guardian

Signature of subject’s parent/guardian Date

Description of Relationship to subject:

Department of Education, University of Oxford

Student Consent for Participation in Doctoral Research Project

Research Description

You are invited to participate in a research study on the adjustment of students in remission from cancer. The purpose of this study is to investigate the perspectives of students who are cancer survivors. You will be asked to participate in an interview. The interview is designed to get feedback regarding your needs, and how having cancer and surviving cancer has affected your life. The interview will last a maximum of one-hour. The interviews will be audio recorded. Audio recording is necessary for transcription during research analysis. The second part of the research is to complete three questionnaires. The questionnaires focus on quality of life, self-perception, and coping abilities. They will each take approximately 15 minutes to complete. Anonymity will be preserved throughout the research process.

This research will be conducted by the Principal Investigator, Jeanne Erickson, D.Phil Student, University of Oxford. All participation will take place at the participant's choice of venue within the greater Seattle and outlying areas with permission from both the participant and his or her guardian.

The risks and possible benefits associated with this study are that the participant may feel ostracized due to the focus on their illness and how it has affected their life. However, this research is expected to have the same amount of risk that participants would have already encountered during the cancer treatment process and recovery. Other risks may include violation of confidentiality of HIPAA laws. Please see the attached HIPAA consent form to ensure these risks are avoided. Maintaining the privacy of all participants is subject to legal requirements as a part of HIPAA. The goal of this study is to gain insight into the adjustment of adolescents to a diagnosis of remission from cancer. The benefits to the participants involved in the study include creating a better overall adjustment experience for the student who has survived cancer, and contributing to a study that can make future recommendations to the research community. There are no other direct benefits to the participant.

There will be no reimbursement for participating in this study. However, those participants who wish to have the results of this study relayed to them for possible application in their daily life should notify the Principal Researcher to make arrangements. Debriefing notices will be sent out throughout the study to keep participants informed of the study's progress at the request of the participant.

Participant confidentiality will be kept by assigning all participants with an identification number. Any information with Protected Health Information that is collected during this research will also be kept confidential in accordance with HIPAA guidelines. All computer files that link the participant's identification number with their name will be kept in a password-protected, locked file. These files will be deleted upon completion of the research.

Your participation will take place periodically over the 2011 year. Specifically, you will take part in one maximum one-hour interview, plus any follow-up questions that the Principal Investigator may have, and the completion of three questionnaires. Actual participation time is expected to be a maximum of two hours. The duration of the field study is a maximum of one year.

The results of this study will be used primarily for a doctorate thesis. It is possible that the results will also be published and presented at research conferences and meetings.

Department of Education, University of Oxford

PARTICIPANT'S RIGHTS

Principal Investigator: Jeanne Erickson, D.Phil Student, University of Oxford

Research Title: Flexibility in the Adjustment of American High School Students in Remission from Cancer

- I have read and discussed the Research Description with the researcher. I have had the opportunity to ask questions about the purposes and procedures regarding this study.
- My participation in research is voluntary. I may refuse to participate or withdraw from participation at any time without jeopardy to future medical care, employment, student status or other entitlements.
- The researcher may withdraw me from the research at his/her professional discretion.
- If, during the course of the study, significant new information that has been developed becomes available which may relate to my willingness to continue to participate, the investigator will provide this information to me.
- Any information derived from the research project that personally identifies me will not be voluntarily released or disclosed without my separate consent, except as specifically required by law.
- If at any time I have any questions regarding the research or my participation, I can contact the investigator, who will answer my questions. The investigator's phone number is (312) 315-3774.
- If at any time I have comments, or concerns regarding the conduct of the research or questions about my rights as a research subject, I should contact ______________________________.
- I should receive a copy of the Research Description and this Participant's Rights document.
- If video and/or audio taping is part of this research, I ( ) consent to be audio/video taped. I ( ) do NOT consent to being video/audio taped. The written, video and/or audio taped materials will be viewed only by the principal investigator and members of the research team.
- Written, video and/or audio taped materials:

  ( ) may be viewed in an educational setting outside the research

  ( ) may NOT be viewed in an educational setting outside the research.

- My signature means that I agree to participate in this study.

Participant's signature: ________________________ Date:___/___/_____

Name: ____

Guardian's Signature/consent: ____________________ Date:___/___/_____

Name: ____

Department of Education, University of Oxford

Assent Form for Minors (8-17 years-old)

I ____________________________ (child's name) agree to participate in the study entitled: *Flexibility in the Adjustment of American High School Students in Remission from Cancer*. The purpose and nature of the study has been fully explained to me by Jeanne Erickson (Principal Investigator). I understand what is being asked of me, and should I have any questions, I know that I can contact the Principal Investigator at any time.

I also understand that I can to quit the study any time I want to.

Name of Participant: ____

Signature of Participant: ____

Witness: ____

Date: ___________________________

Investigator's Verification of Explanation

I certify that I have carefully explained the purpose and nature of this research to __________________________________ (participant's name) in age-appropriate language. He/She has had the opportunity to discuss it with me in detail. I have answered all his/her questions and he/she provided the affirmative agreement (i.e. assent) to participate in this research.

Investigator's Signature: ____

Date: ___________________________

Interview Questions

The researcher will first ask the participant for their verbal consent in audio recording the conversation.

The researcher will conduct a short introduction in a sensitive tone of voice. The goal of this introduction is to acknowledge to the participant that the researcher is aware of how cancer can affect your daily life, and to ensure through observation that the participant is visibly comfortable with the researcher.

Help me to understand what it was like when you were first diagnosed with cancer. What were you thinking about it? How did your feelings change throughout the treatment process? Help me to understand what it was like when you found out that your cancer had gone into remission.

Questions that focus on participant emotions:

- We all know that it is not pleasant to have cancer, but let's first look at it from the positive side. Can you think of any good things that have come from your experience?
- What are some of the more difficult things you've faced in having cancer?
- Do you feel different from your peers? How?
- Do you mind when people ask or talk to you about your cancer experience?

Questions that focus on participant family:

- Do you have any siblings?
- Has your relationship with them changed since you were diagnosed? How?
- Has your relationship with your parents changed since you were diagnosed? How?
- Has your relationship with your siblings changed since you found out you were in remission? How?
- Has your relationship with your parents changed since you found out you were in remission? How?
- Do you think that your parents treated you differently (from your siblings) because you had cancer?

Questions that focus on participant school life:

- Let's talk about school. How are you doing in school?
- Do you feel supported by your school? By your friends?
- What sort of things do you do with your friends?
- Do you find that when you had cancer it kept you from doing those things with your friends? How has that changed since your cancer went into remission?
- How many different teachers do you see in a day?
- Are they accommodating with regard to your schoolwork?
- Is there any special education that you receive?
- (If so) Do you think that it's helpful?

Questions that focus on participant treatment during cancer:

- Can you tell me what you had to do everyday for your treatment?
- How much medicine did you take?
- Did you take medicine at school?
- How often did you go to the hospital for your treatment?
- How long were you receiving that treatment?
- How did the treatment make you feel physically?
- Did your reaction to the treatment change each time you went, or did you feel the same way after each treatment?

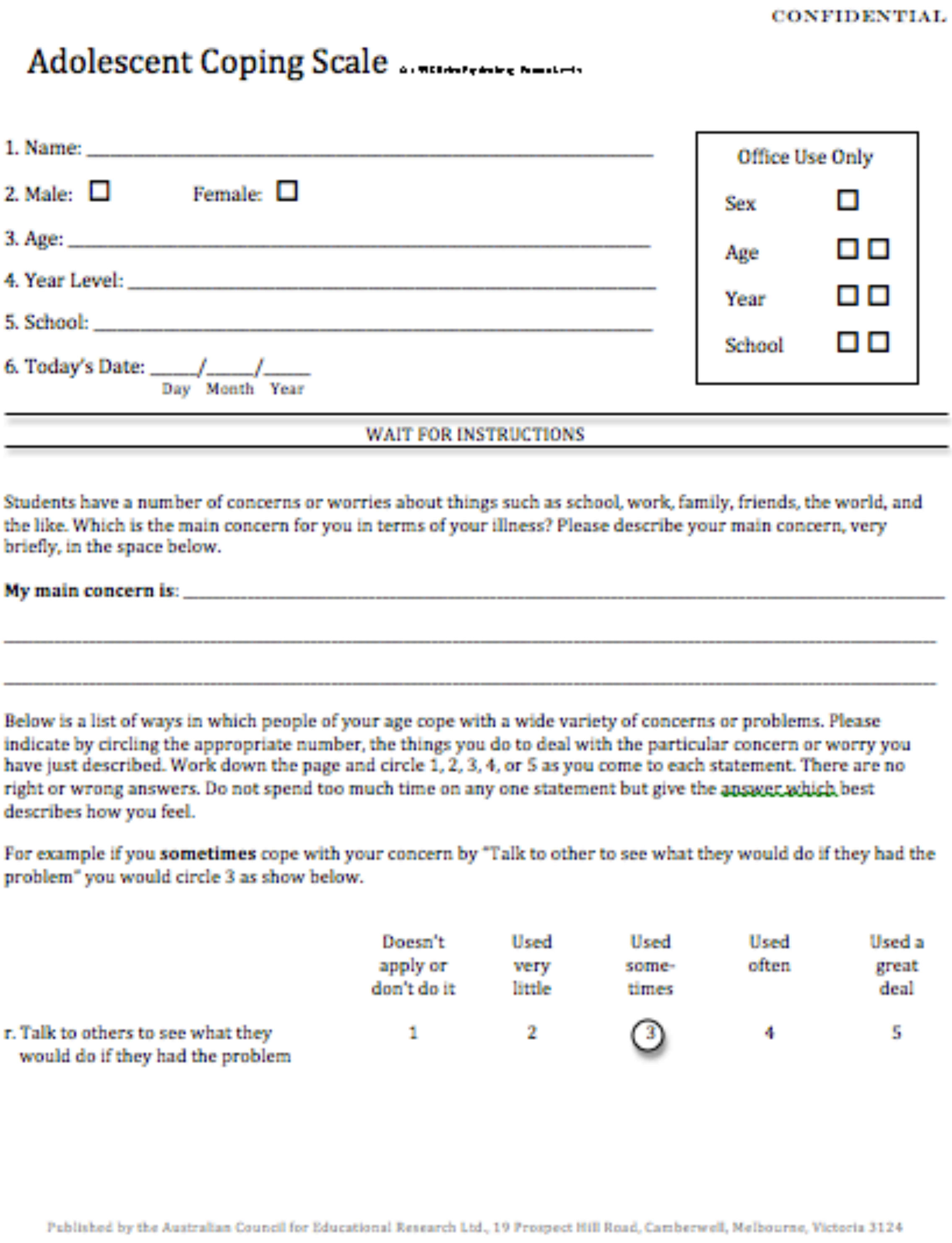
Questions that focus on remission:

- How long has your cancer been in remission?
- Do you remember the date?
- Was that when your treatment stopped as well?
- How did your family and friends react?
- Was there any reaction at the school?
- Do you still receive any treatments for the cancer?
- How often do you go for check-ups?
- How do you feel about the idea that your cancer may return one day?

Researcher will conduct a short conclusion in a sensitive tone of voice that will express gratitude to the survivor for their participation. The researcher will also express admiration for what the survivor has gone through, and make the survivor aware that they can contact the researcher if they have anything more to add, questions or concerns.

Adolescent Coping Scale – Short, Sample

This scale sample is specific to Illness. The other scales are specific to school and social interactions, but are in the same wording and format.



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Adolescent Coping Scale [illegible]

1. Name: ______________________

2. Male: ☐ Female: ☐

3. Age: ______________________

4. Year Level: ______________________

5. School: ______________________

6. Today's Date: ____/____/____
Day Month Year

Office Use Only	
Sex	☐
Age	☐ ☐
Year	☐ ☐
School	☐ ☐

WAIT FOR INSTRUCTIONS

Students have a number of concerns or worries about things such as school, work, family, friends, the world, and the like. Which is the main concern for you in terms of your illness? Please describe your main concern, very briefly, in the space below.

My main concern is: ______________________

____

____

Below is a list of ways in which people of your age cope with a wide variety of concerns or problems. Please indicate by circling the appropriate number, the things you do to deal with the particular concern or worry you have just described. Work down the page and circle 1, 2, 3, 4, or 5 as you come to each statement. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which best describes how you feel.

For example if you **sometimes** cope with your concern by "Talk to other to see what they would do if they had the problem" you would circle 3 as show below.

	Doesn't apply or don't do it	Used very little	Used some-times	Used often	Used a great deal
r. Talk to others to see what they would do if they had the problem	1	2	[✓ 3]	4	5

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REMEMBER: YOU ARE THINKING ABOUT A SPECIFIC ILLNESS CONCERN

		Doesn't apply or don't do it	Used very little	Used some-times	Used often	Used a great deal
1.	Talk to other people about my concern to help me sort it out	1	2	3	4	5
2.	Work at solving the problem to the best of my ability	1	2	3	4	5
3.	Work hard	1	2	3	4	5
4.	Worry about what will happen to me	1	2	3	4	5
5.	Spend more time with boy/girl friend	1	2	3	4	5
6.	Improve my relationship with others	1	2	3	4	5
7.	Wish a miracle would happen	1	2	3	4	5
8.	I have no way of dealing with the situation	1	2	3	4	5
9.	Find a way to let off steam; for example cry, scream, drink, take drugs etc.	1	2	3	4	5
10.	Join with people who have the same concern	1	2	3	4	5
11.	Shut myself off from the problem so that I can avoid it	1	2	3	4	5
12.	See myself as being at fault	1	2	3	4	5
13.	Don't let others know how I am feeling	1	2	3	4	5
14.	Pray for help and guidance so that everything will be all right	1	2	3	4	5
15.	Look on the bright side of things and think of all that is good	1	2	3	4	5
16.	Ask a professional person for help	1	2	3	4	5
17.	Make time for leisure activities	1	2	3	4	5
18.	Keep fit and healthy	1	2	3	4	5
19.	List any *other* things you do to cope with your main concern	1	2	3	4	5

Interview Transcripts

Jamie

17-year-old African American female
Diagnosed: October 2008 – ALL
Treatment Stopped: November 2010 – chemotherapy
First Interview: September 2011 – in person

Interviewer: You know that I have never had cancer.

Jamie: Yes.

Interviewer: So, I would really appreciate it if you could help me understand what it was like when you got your cancer diagnosis.

Jamie: At first, I thought I had the flu at first and that I why I came into the emergency room. So, before I was sick I was like… I always thought of myself of being like the pretty girl in school. I wanted to be a cheerleader. Everybody liked me. I was skinny and had a cute shape. My first concern was like, "oh my gosh, I am going to be so ugly." My hair is going to fall out. So, it was never my concern of like this is a situation where I can die. That was never my first concern but as I got into my treatment, then that started to be a concern.

Interviewer: So, as you were going through treatment, how did your feelings change? You mentioned shifting from a cosmetic concern to more of a life concern. Over what kind of time span did that happen?

Jamie: I guess when I started to receive my heavy doses of chemo and I was always throwing up. I would throw up so much and I was like, oh, my gosh, I don't think people should be throwing up this much. I was always in the hospital. That is when it started getting real. I could really die. They started off like the next days, so two months maybe.

Interviewer: Talk to me when you found out that you were going to stop treatment and that things were going well for you. You were… I hate to use the phrase, in remission, because you know that is such a grey term. But, when you got the news that things were stable, what went through your mind?

Jamie: To be honest, I wouldn't say that I was upset. I was kind of used to everybody doing stuff for me and I wasn't in school. I missed school, but I was having fun not going to school. So, it's like, what do I do now? This is what I have been doing for two and a half years. I don't even know how to start back my life.

Interviewer: What kind of cancer were you diagnosed with?

Jamie: Acute lymphoblastic lymphoma.

Interviewer: When did you get that diagnosis?

Jamie: October 31, 2008.

Interviewer: What kind of daily treatment did you have to do?

Jamie: I took pills daily, a lot of them. Along with my cancer I got diabetes. I had everything. There was something wrong with my kidney or something. They always measured my pee. It just came with like a lot of things. I forgot the question. I am talking about everything else.

Interviewer: I was just wondering what you had to do every day for your treatment.

Jamie: I was taking a lot of pills. I had to take my insulin. I had to make sure I was eating good. My mom, some regiments of chemo my mom had to actually give them to me, like stick them. Sometimes when I got sick I would have to carry around this ball. It was a ball of – what is it called – antibiotics. It would like go away, like the ball would like get smaller. I can't go to school because I had my port in all the time, so I couldn't do like daily activities. It was mostly just me in my room by myself most of the time.

Interviewer: Did you have to take these meds and things? Did you have to do that while at school? When did you stop attending school?

Jamie: They told me that I couldn't go back to school… it was a Friday. So, I was in the hospital for a month. After that month they told me I couldn't go back to school because they didn't want kids breathing on me and getting sick. It was not a logical thing that I was going to be back at school. I was taking heavy doses of chemo every day, so I was always sick. They took me out and I had a tutor, but that fell through. I didn't go back to school… I tried to go back sophomore year, but I stayed in for like a month because my dad had passed away during that time. I was just a mess. I was dealing with my chemo, then my dad passed away. After my dad passed away, like a week after that, my mom took me back out because it was a lot on me to do both. I didn't go back to school until last year. Last year was my first year to complete the whole year of school.

Interviewer: Wow.

Jamie: Yes.

Interviewer: That is a lot to deal with in one family. How often did you have to go to the hospital for treatment?

Jamie: Just to go in to get treatment?

Interviewer: Just throughout your process, how often were you in the hospital?

Jamie: It sounds crazy, but I want to say almost every day. I would get out. I would be in for a week, then I would get out, then I would go back like the next day. I want to say in and out the hospital, not just to go visit for like every day it felt like. Out of a month, I would be in the hospital… if it was 28 days, I was probably in the hospital 19 days out of that 28.

Interviewer: So, how long did you have to go through treatment?

Jamie: I was in treatment two and a half years.

Interviewer: Two and a half years of exactly what you are describing to me?

Jamie: Maybe a year and a half. Then, like the other year was like kind of… I was sick, but not as sick. I would probably go to the hospital maybe two weeks out of a month. It got…

Interviewer: So, it started to dwindle over time?

Jamie: Yes ma'am.

Interviewer: Okay. What made you feel worse, cancer itself or the treatment?

Jamie: The treatment.

Interviewer: How so?

Jamie: It just felt like I had the flu all the time. I was so happy. I was always out with my friends. The treatment just stopped me from doing all that with me being sick. Then, of course I didn't want to go out. I was bald headed. I was just awful. The treatment was worse.

Interviewer: As you were returning to the hospital so frequently, 19 out of 28 days is your estimate. Every time you went to the hospital, did you have the same feelings upon going there, or did your feelings change after going every single time?

Jamie: The first couple of times it was like, oh Lord, what are they going to do to me? Poking me with needles. After a while, I got used to it. I know they going to do the same thing. They want to measure my pee. They want to know whenever I use the bathroom. They're going to wake me up in the middle of the night to take blood. I just kind of got used to it. After a while, I could start doing my own vital signs. I would just write them down for them and give them to them. I can do it myself after a while.

Interviewer: Makes the nurses' job a little bit easier. Were you attending school before you were diagnosed, or was it summertime?

Jamie: I was in school. I didn't finish first semester. It was my first year in junior high, well it was supposed to be high school, but in [my] school district, ninth grade is junior high. So, it was my first year in high school or junior high. I didn't really get to experience… I never got to experience really my high school years. I am not even experiencing now because I am busting butt trying to make up for the credits that I missed. They didn't give me any leeway on my credits. I have to still get 22.5.

Interviewer: We are going to talk about school in just a second. I want to talk to you about being in remission real quick. How long have you been in remission?

Jamie: It will be a year on November 8th.

Interviewer: Let's talk more about your first thoughts. When the doctor gave you the news, what was going through your head?

Jamie: I was like… I wanted it to be gone, but at the same time I didn't want it to be gone because it became like a habit. Not a habit, but something that I was used to. I was kind of like oh. It wasn't that I like being sick, because of course I don't like being sick. But, it was just like I didn't know what to do with my life. It was like cancer was all that I knew. I never did anything else other than treatment so that was all that I knew all the time.

Interviewer: When you received that news, did you stop treatment right away? How did that work with your treatments?

Jamie: They told me months before that I was going to finish treatment. So, they had a specific date of when I was going to finish my treatment. My cancer had went away like maybe a year after I started receiving my treatment. But, with the cancer I had if they stopped my treatment right then, it could come back and it would come back worse. So, I had to finish it. I knew that I was going to go into remission. If anything bad had happened, if it didn't get worse over night.

Interviewer: How did it make you feel knowing that your cancer was gone but still having to go through the treatments and the vomiting and all the side effects? What was that like?

Jamie: It kind of made me mad. I didn't understand. I was 16. I didn't understand why I was being sick if there was nothing wrong. I used to not even try to take my medicines. I used to be on pills and I used to put them down the bed. I was so sick of being sick. I try to throw them down the drains and my mom used to have to keep my medicine. I was crazy. I am surprised I am even alive right now. I never took my medicine.

Interviewer: You are very lucky. Did you guys do anything to celebrate?

Jamie: We are actually… I had a party at the hospital. They threw me a little party. We never did anything to like officially celebrate because we are going to do my graduation party and my chemo party all at the same time. It's going to be really big. So, we are just going to do all that at the same time.

Interviewer: When you graduate high school?

Jamie: Yes ma'am, this year.

Interviewer: Sounds like a good way to celebrate.

Jamie: Yes ma'am.

Interviewer: How did your family and friends react when they heard your remission news?

Jamie: They were happy. They kind of all knew. My family is like really Christian and strong. So, they all knew I was going to be well. They were happy. They were really thankful. My church as all like running around, like oh my gosh. My pastor would always make me stand up and testify every Sunday. I am like oh my gosh, I do not what to do this. Yeah, everybody was happy.

Interviewer: So, your pastor would make you stand up and testify even though you didn't want to?

Jamie: Yes. It's not like he used to make me. My pastor is funny. If I didn't, he would. Like somebody was going to hear about this.

Interviewer: Was there any reaction that you received from the school when you returned?

Jamie: When I tried to come back my sophomore year; a lot of people were surprised. When I went back for my sophomore year I was still doing my heavy dose of treatments. So, a lot of people were surprised. "Oh my gosh, what is she doing here?" They were always so careful. I used to get out of class a few minutes early because I had my port and they didn't want anybody to bump it. They were really protective and surprised like I was some big thing or something. It was hard to do.

Interviewer: By they, you mean the teachers?

Jamie: Yes ma'am. The teachers, my nurses, my principle, everybody. Everybody knew me. People I didn't even know knew me.

Interviewer: You did receive some treatments while you were attending school?

Jamie: Yes ma'am.

Interviewer: Was that pill treatments or did they do port?

Jamie: They did stuff in port. Like twice a month I would go in and get chemo in my port. It would make me sick so I would probably miss the next few days even if I didn't feel that hot. I didn't want to miss a lot of school.

Interviewer: Are you still receiving treatment in any way?

Jamie: No ma'am. Well, I guess. It's not chemo treatment, but they still make me come in once a month to get blood taken.

Interviewer: Okay, so you are still getting regular checkups once a month.

Jamie: Yes ma'am.

Interviewer: Will that change over time?

Jamie: Yes ma'am. I think it's one year after you go every other month to give blood. I am kind of like iffy about that because I am scared. Two months? That is like a lot can happen in that time. I am nervous about that. My friend just passed away. She had the same cancer as me. That kind of threw me for a big scare because when I was coming onto my treatment she was going into remission. She just passed away. I am scared. We had similar types of cancer and she was going to the month. I don't know. I am kind of scared of that. I will check my own blood. I don't want it to come back. I think I have made so much progress in this time, that if it comes back I am going to be so messed up.

Interviewer: Mentally?

Jamie: Yes ma'am. Physically, everything. It comes back. They told me it's harder to get rid of the second time when it comes back. I don't know if I can be as strong as I was the first time if it comes back a second time.

Interviewer: Your friend who passed away, at what point in her remission was she at? Was she at the two months?

Jamie: Yes ma'am.

Interviewer: So, she was in her second year of remission and it came back?

Jamie: Yes ma'am.

Interviewer: How often do you think about your cancer returning?

Jamie: I guess, I feel normal every day until that one-month check up when I realize that I am not like any other girl. So, I guess the one-month checkup or when I am like watching TV or something and the little happy birthday commercial from the Cancer Society comes on. I am like oh my gosh, and then I think about it. When I get overwhelmed with my homework my mom is like, okay, you had cancer. You have to slow down. Everything is not going to be easy like it's for all of your other friends. So, I guess the month where I go in and if somebody brings it up, but other than that I am not like always constantly thinking about it.

Interviewer: When you think about it returning, what kind of emotion would you associate with that?

Jamie: Scared, scared, oh so scared. Even though I didn't do my treatments like I was supposed to, I just really don't want it to come back. So, mostly scared and like failure. Man, that is failure. If it comes back, what did I do that made it come back? Obviously I did something. It's not supposed to come back. There is like 70% chance that it's not supposed to come back or something like that.

Interviewer: So, you feel responsible for whether or not your cancer returns?

Jamie: Yes ma'am.

Interviewer: Obviously there are a lot of negative things associated with cancer and treatments. What would you say is something positive that came from that experience?

Jamie: I became a lot stronger than I was before. I didn't know that I could even take on that much responsibility or I didn't even know I had it in me because a lot of people don't. A lot of people just give up. I feel stronger than I was. Other people look at me as strong. I get a lot of… the lady that goes to my church, she just got diagnosed. She is in remission now, but she got diagnosed with cancer a while back. When she finished her treatment she was like, you were the person I always thought about when I went into my treatments and you are my inspiration. So, that makes me happy that people look up to me, even older people look up to me even though I am young.

Interviewer: What would you say is the most difficult thing you have had to face in the last few years of treatment battling cancer?

Jamie: The most difficult thing, I guess… I don't know. Falling back in school. I am behind all my friends. My friends have cars and they have jobs. I just got a job, but my friends have a job and they are all like ahead of me. I feel like dang. I am so behind everybody and we are all the same age. I feel like I have a lot of catching up to do.

Interviewer: Do you feel different from your peers then?

Jamie: Yes ma'am. When we go to school, I feel like they know everybody. I am kind of like at least know them because they have been in school like the whole time and I have been like off and on. So, I feel like I am left out. I don't feel as pretty as they do. Oh my gosh! I guess it's something…

Interviewer: I want to go back to something you had mentioned just a few moments ago. You were talking about one of the positive things that came from your experience is that you feel stronger. Just before that you were talking about if your cancer relapses that you don't think that you would have the strength to do it. I am kind of interested in how that works because you are telling me that you feel stronger, but you also said that you don't think you would be strong enough to go through it again.

Jamie: I feel like I have exhausted as much strength. Nothing could be worse than that I guess. If it comes back, it's coming back worse than that. I don't know if I have enough strength to go through all of that again because that takes a lot out of you. Maybe I do have enough strength, but I just don't want to go back through it again. It doesn't have anything to do with my strength. Maybe I could do it, but emotionally I just don't want to go through it again.

Interviewer: I don't think anybody does. Are you bothered when people ask you about your experience?

Jamie: No ma'am.

Interviewer: So, if you have friends at school asking you about it, you are happy to discuss it?

Jamie: It depends on what kind of things they want to know. Sometimes they take it as a joking matter. I will tell them… because I make jokes about it. When I first started losing my hair I said I was like fire marshal Bill. Then I said when I shaved it all off I looked like Mini Me. Some people take that and run with it. I am like, okay. I said that as a joke, but don’t keep saying it. So, I guess it depends on how much they ask.

Interviewer: So, would you say to an extent you feel it's okay to joke about it because it's your experience, but you don’t like when other people joke about it?

Jamie: Yes.

Interviewer: Let’s talk about school a little bit. How are you doing in school right now?

Jamie: I think I am doing pretty good. I wouldn’t say I am doing the best. Of course my transcript doesn’t look as good as somebody else’s would. But, I plan on graduating with my class after missing two years of school. I took nine classes last year the whole semester and I took two classes online. This year, I have to work a job and I have to take an exam to get a credit. So, I feel that I am doing the best that I can do with what I have been through. So, I think I am doing pretty good. A lot of people would drop out already.

Interviewer: True, very true. You are still on time with your class?

Jamie: Yes ma’am. I wasn’t last year.

Interviewer: So, you missed two years of school and after last year, you are now caught up?

Jamie: Yes ma’am.

Interviewer: To your class?

Jamie: Yes ma’am.

Interviewer: That is really impressive.

Jamie: Thank you.

Interviewer: Does the school support you?

Jamie: I think they get tired of seeing my face. I come in there ever day to make sure… is there anything else I do to get a credit here or anything. My counselor, I think is tired of seeing my face because I come in every day. But, my principal, she always tells me I am doing a good job.

Interviewer: Have they done anything academically to help you besides just accommodate requests? Do they do any accommodations during tests or anything like that?

Jamie: No.

Interviewer: So, they are accommodating you in the sense of letting you sign up for all these classes, but they are not helping you get through them?

Jamie: She signed me up for a Brigham Young class. She never checked on me to see how I was doing. I actually kind of fell off my class last year because I was too busy worried about the other eight. I still had to take my final exam and tests with everybody else. Actually, at the end of the year I had told her I missed a week when I got sick and the final exam was the following week. So, I came in and told her I don't know if I am going to be able to pass my test. If I don't pass my final exam I am not going to pass the class and I need this credit to graduate. She was just kind of like, you know what you have to do. You have to study and it's up to you if you pass the test or not. I was like okay. I don't know what to do.

Interviewer: So, they didn't make any arrangement to take the exam a week later or anything like that to give you extra time?

Jamie: No ma'am. My sophomore year they tried to help me out a little bit when I was real sick. But, now this year that I am off of treatment they think I am supposed to jump right back into it.

Interviewer: Do you feel that you would benefit from having extra accommodation in the classrooms?

Jamie: I feel like if they do that people would be giving me a grade because they knew that I had cancer. I don't ever want people to feel sorry for me. If I get a grade I want to be able to earn it. I would benefit from accommodations, but I would rather do it the way everybody else is doing it. Does that make sense?

Interviewer: It makes perfect sense. Do you feel that the treatment you went through has affected the way you are able to take in information or study?

Jamie: I can't see the board sometimes and they say that could be from my treatment. Is that what you are talking about?

Interviewer: Yeah, anything like that. Physical responses that are different now that you have gone through treatment.

Jamie: It's hard for me to see some things. They told me that I could take junior ROTC to get a credit. I know that's strenuous exercise - I would not be able to do that. I haven't been active for two years, so I am trying to get back. It's kind of like my body is kind of like slowly but surely getting back to a normal 17-year-old.

Interviewer: You are not getting any kind of special education?

Jamie: No ma'am.

Interviewer: You are taking how many credits this year?

Jamie: I took a summer school class and that is a half of credit. I have work-based learning that I am taking throughout the whole year. That is a full credit. My other class is a full credit. So, two and a half.

Interviewer: You are planning on graduating this spring with your class?

Jamie: Yes ma'am.

Interviewer: And, having a big graduation/chemo party?

Jamie: Yes ma'am. You are invited.

Interviewer: Thank you. If I am in town, I will definitely be there. Let's talk a little bit about your family now. Is that okay with you?

Jamie: Uh, huh.

Interviewer: Do you have any brothers or sisters?

Jamie: Yes, I have an older brother. I have two older sisters and a younger brother. And, I have God family and they stay with me right now.

Interviewer: How did your relationships with your siblings shift and change once you were diagnosed?

Jamie: My sister hated me. When I say hated me, she hated my guts.

Interviewer: Which sister is this?

Jamie: My sister that is with me at my house. She is 19 now. She hated me so much. I was like, oh my gosh. At a time when I needed you the most, you were the one that talked about me the worst. She used to call me all kinds of stuff. She used to tell me I was faking my cancer. You ain't really sick. She used to come in there, my mom used to have to come because I used to get sick in the night. So, I would call my mom of course so she can bring me some medicine. She would come in there, why you keep waking up mommy? You ain't really sick. You can handle it yourself. I didn't want to keep bothering her, but it was just stuff that I couldn't do by myself. I just felt like she wasn't there.

Interviewer: She wasn't supportive?

Jamie: Not at all.

Interviewer: Why do you think she reacted that way?

Jamie: She felt left out. I can understand where she is coming from. She felt left out. All the attention was of course on me. I was sick and she felt like nobody was paying attention to her. I used to try to include her in everything. My make a wish, I got that. She came, I wanted to go on a cruise and include the whole family, but at the time when I was one my treatment, I had my four nieces and nephews. They were there with me in the summer. They spent the whole school year with us. It was unreasonable for them to try to send my five and their four. So, they couldn't afford it. So, I just asked for a computer. She was all mad. She sat at the back of the table. She was rolling her eyes. It was awful. She was so mean to me. Words can't describe how mean she was to me.

Interviewer: Has that relationship changed since you have gone into remission?

Jamie: She tries to change it. She expects us to just jump back. Our relationship has never been… of course we are sisters. We fight all the time. But, when I was going through my treatment that like really broke up our relationship. Now, she tries to do little stuff to bring us back. Of course we have a falling out sometimes. But, when we do start to get close I always take a step back because I am still hurt and mad that she was like that. Now, she expects everything to just jump back to normal. I have always been supportive of her and whatever she has done. When she is sick, I am always there to take care of her. But, I am like, it's kind of hard for me to jump back to trying to be like sisters after she hurt me the way that she did.

Interviewer: Do you share that with your mom or anyone?

Jamie: Yes ma'am. She knows.

Interviewer: They are aware of it?

Jamie: My mom does. I tell my sister and she is like that is the past. Let it be in the past. I am like, that is a big thing in the past that you can't just brush underneath the carpet and say that is okay. So, we never have a discussion because whenever we do it all gets heated. I am just at the point I am so tired of talking about the same thing. So, I don't care anymore.

Interviewer: You just let it be and deal with it on your own.

Jamie: Yes ma'am.

Interviewer: How did your relationship with your parents change when you were diagnosed?

Jamie: My mom used to do a lot of things for me. I got to a point where I wasn't always respectful. I am trying to get back to a point where that is my mom and not my slave. I need to be respectful. They said that it was the treatment that made me cranky. I used to be like really snappy. Now, I am trying to get back to being respectful. When I look back and I think about what I say when I go to my room and have a discussion. I would go to my room and be like wow! I am like one of those bad kids on Maury or something. I need to go to an Army school. I am trying to work on that.

Interviewer: Do you find yourself kind of making up for some of the things you say when you are irritable? Do you go to your mom and…

Jamie: Apologize? Yes ma'am. I always try to. Sometimes I am like, apologies are getting played out. I need to stop because I am getting too old to disrespect my mom. She has done so much for me and I kind of get sad when I think about the way I treat her because she is the best mom anybody could have. I love my mom to death. She is always so supportive. Anything I want, she would get it for me, my dad too. I love my dad. He worked… he busted his butt when I was sick to pay the bills. Even though it wasn't that expensive, it was still like we had four other kids with us and I was on medicines that made me so hungry. I used to wake up… he used to wake up and make me stuff to eat. I was like so spoiled. So, now I am trying to get back to handling things on my own and being normal. Not being so disrespectful to my mom and things like that.

Interviewer: When did your dad pass away?

Jamie: My real dad passed away. I stay with my step dad now. My real dad passed away February 6th, a week before Valentine's Day.

Interviewer: What about since remission now with your parents? You said that now that you are in remission you are trying to be more respectful with your mom. How has their behavior towards you shifted?

Jamie: They used to take good care of me. Now they are like, you can do that by yourself. So, I think they are trying to give me that extra push to help me get back. Nobody is going to hand this stuff to me. After a year, nobody is going to care that I had cancer anymore. They ask you in the past year if you had cancer. So, they are not even going to care anymore. They are trying to get me used to doing stuff on my own. They are still the best.

Interviewer: So, come November, you are not allowed to say, "I had cancer?"

Jamie: My friends are like… I got sick… this is a side note. Sorry. I was mad at the time, but now I am like heck yeah. I had got sick. They were like you already sick. I probably was because I was trying to do too much. I was like, I just got off of chemo. My friends were like, when are you going to stop using that as an excuse. You have been using it for six months. So, I do find myself using that as an excuse sometimes. But, now I have gotten to a point where I don't want people to know. It's not relevant anymore because there is no need for me not to do things. I think I had enough time for my body to get back to normal. I can do things by myself now.

Interviewer: We call it playing the "c" card. You are pretty much almost done playing the "c" card. You're not going to be able to play it much longer.

Jamie: No, I am not. (laughs)

Interviewer: Let's hope you never have to play that again. I want to talk to you a little bit about the hospital. So, when you go back for your treatments monthly, have they provided you with any support or anything pertaining to adjusting to remission?

Jamie: They try to give me a counselor or psychiatrist. He was just kind of weird to me. I don't think I am crazy. They try to say a lot of my sick… I used to get sick and they are like there is no reason why you should be sick. It's probably mental. So, they tried to make me talk to this guy. I felt like they were just trying to make it seem like I was faking when I was like no. I know when I am sick obviously. They try to make it seem like it was mental. So, they had me talk to this guy.

Interviewer: When you say when you were sick, so during remission?

Jamie: Yes ma'am.

Jamie: Or like the flu. I would throw up. I don't see how you can fake throwing up. They said it was mental. I guess… I don't know. I am not psychiatrist or anything.

Interviewer: So, how long did you visit with the counselor?

Jamie: I just visited him once. He was not my cup of tea. He was so weird.

Interviewer: How so?

Jamie: He was asking me like retarded questions and stuff that I didn't feel was relevant. He was asking me… I don't know. I just kind of had an attitude because I didn't want to be there. So, maybe it was my fault. He wasn't getting the information that he needed. I blocked him out kind of.

Interviewer: What kind of questions did he ask that were irrelevant?

Jamie: He would ask me about school and stuff. He asked me if I had a boyfriend. Of course I don't have a boyfriend! I don't have any hair. He was asking me stuff that obviously you know the answers. So, why are you asking me? I felt like he was trying to play me. Don't ask me questions that you already know the answers to. I know they already told you, so why you asking me the same questions? That is what I felt like. Maybe it was my fault. Maybe I shouldn't of had an attitude. Maybe I should have came in there with a different mindset, but that was why I was like that. Don't ask me questions.

Interviewer: I think that was your mindset at the time, he should still be able to adapt to whatever mindset you are in whenever you walk into his office, right?

Jamie: I didn't like it.

Interviewer: You never thought about going to someone else? Or, you never felt you needed it?

Jamie: When I was in treatment, I had this lady. She reminded me of you. Her name was Dr. Smith.[5] She was the best. I love her so much. When I used to be in the hospital she used to write me little notes when I was asleep and leave them on my little machines. We used to always joke. I can take a joke with her. She always called me Mini Me, but I can take that from her. She came the first night when I first got diagnosed and she always came to visit me. Then, she left. I don't know. I felt like she kind of kicked me to the curb too because she was a cancer person that dealt with people that was going through cancer. I felt like she kind of kicked me to the curb. I wanted to talk to her. I would be able to talk to her because I feel like I can be real with her. I didn't feel like I had to front or like yeah.

Interviewer: So, you feel since her specialty is with people who are currently battling cancer, that you couldn't talk to her once you are in remission?

Jamie: Yes ma'am.

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[5] Names have been changed to protect participant privacy.

Interviewer: Was that per her, or was that just your feeling?

Jamie: That was just my feelings. I didn't want to ask them and they be like, well she is a chemo doctor so I can ask her but I don't know for sure. After I got out of treatment she just kind of stopped seeing me. So, I thought she didn't want to be near. But, maybe she moved or something. I haven't heard anything from her.

Interviewer: Did you ever feel that you needed to talk to a counselor about things?

Jamie: I think it would have been beneficial and maybe I wouldn't be so angry at my sister now or trying… it would help to talk to somebody other than my mom or my God-mom. Sometimes I do need a medical answer to why I am feeling the way I do. So, maybe, but now I don't think it's beneficial because I am handling everything myself. I learn how to handle everything myself because I haven't had anybody to talk to. Now, I can just cope or deal with things my own way.

Interviewer: Do you feel like it's too late?

Jamie: Yes ma'am, for anybody to try and help.

Interviewer: Do you talk to friends about it?

Jamie: No. They don't understand. They are like, I've been short more than they have I think because of what I have been through, but they are still stuck in this, "Oh my gosh, I hit my knee on the door. I am going to die. I need to miss a week of school." I am like, "Seriously?" You can push through that kind of stuff. I feel like… not that they are beneath me, but I feel like we are on different levels in that perspective that I can't even go talk to them about things that I am dealing with like that.

Interviewer: Is there anything else you want to talk about? About your experience with remission, your experience during treatment, experience in the hospital or at school?

Jamie: It's hard to remember anything with treatment because they used to give me medicine. I used to take lumbar punctures. They would make me like, not forget like amnesia stuff, but like kind of boggled my memory. That seemed to work. So, I can't remember much about my treatments. I can't remember even half the times I went in for regular treatments.

End of interview.

17-year-old African American female
Diagnosed: October 2008 – ALL
Treatment Stopped: November 2010 – chemotherapy
Second Interview: June 2012 – video interview

Interviewer: How are you? What is going on?

Jamie: Nothing really. Trying to finish school. I did not get to walk. That is what you said about graduation. I was like, well it going to be too hard and try to finish and everything, so…

Interviewer: Ok.

Jamie: I did not get to walk. I ended up at the end of the semester. I needed one more credit. They said that could not let me walk unless I had all 22.5. So, I had to do another semester at the high school.

Interviewer: Ok.

Jamie: I – well, I do not know when we supposed to; I had my job or not. I had got hired at [the grocery store].

Interviewer: Yeah. You were actually going for your first shift when I met with you last time.

Jamie: Ok, well I quit that job.

Interviewer: Ok.

Jamie: But now I am not working. Because I really feel like I need to focus on school and just only school where I can get my credits and do what I need to do. I am now looking for another job because – where I can do the work based learning. You remember I was telling you about that?

Interviewer: Yes.

Jamie: It ended up that my job was not giving me enough hours for my other work based – for to get the credit for work based learning. And second semester so I ended up not being able to get that credit. That was one of the reasons why I did not get to walk. I was kind of frustrated. I probably should not quit it because of that reason. But I was really just frustrated. I was like, "I quit, and you guys got to get out here pushing carts in a hundred degree weather." Yes, we were done with that. Now, I am looking for a new job. [A clothing store], get the clothes in the store. That should be more fun than pushing cart in the rain, hopefully.

Interviewer: Hopefully.

Jamie: Yes, ma'am, hopefully. I – well, my sister said she worked in retail. She said it was not really all of that. I do not know.

Interviewer: Well, I do not think…

[Crosstalk]

Jamie: I just need extra money coming in.

Interviewer: I don't think people work because it is fun.

Jamie: Yeah, that's true.

Interviewer: Most work because they have to.

[Crosstalk]

Jamie: That is why I think I need to get a job.

Interviewer: Exactly.

Jamie: Yes, ma'am.

Interviewer: Exactly. So, anything else going on before I jump into questions?

Jamie: Umm. No, ma'am not really. Just that is basically it. I got my license.

Interviewer: Congratulations!

Jamie: (laughs) Thank you. That is pretty much it.

Interviewer: The world look out, you are driving on the road!

Jamie: Yes, sure. (laughs)

Interviewer: All right, well, I just think I wanted to talk to you. I was going through our last interview from – gosh, it was like almost a year ago already. It was in September wasn't it?

Jamie: Yes, ma'am.

Interviewer: I just kind of wanted to fill in some holes and clarify some things that I had understood at the time. But then when I started to really look into it, I had a few questions. Let us start actually with talking about graduation and school. What was the name of the school that you attended?

Jamie: ___________ high school.[6]

Interviewer: Will you be done with your credit at the end of the summer, or do you have to go to December?

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[6] High School name redacted for participant privacy.

Jamie: I am going to do until December. But I am going to still be able to be considered the Class of 2012. As long as I get it finished by the end of December. But I will not be finished by summer.

Interviewer: Ok. What is your last credit?

Jamie: Just electives. No – I have all my –

[Crosstalk]

Interviewer: Just electives?

Jamie: – Core classes, I just need electives.

Interviewer: Ok. What are you taking?

Jamie: I am not taking anything now. But I am probably just going to take – do the work base learning. And if I get hired at [Clothing Store]. That – and I think I need a math elective. I will probably do accounting two again. Because I did not pass accounting two when I did it this semester, or last semester.

Interviewer: Ok. That will help you get that credit.

Jamie: Yes, ma'am and then that will be all of them.

Interviewer: What are you thinking about for college?

Jamie: I really want to do. Well, I was talking to the lady. This counselor lady that helped with school. She said the career that I want to go into, they usually do not require college. Because I wanted to do firefighter. But, I do not know, I have not checked on it or anything. Because she said they kind of see and do like – kind of like the police academy. But, I do not know, I have not really checked into it that much. But that is what I want to do. That is my final decision. I know I was talking about nursing and all of that kind of stuff. But, that is my final.

Interviewer: Yes, I think you would be great at that.

Jamie: Yes, ma'am. Thank you.

Interviewer: Well, have you thought about doing your work based learning with something having to do with the fire department?

Jamie: The work based learning, you have to have like pay stubs, and like all that kind of stuff. I do not know if I would be able to do with. Well, I do not know. If I get… I never thought about that. If I get enrolled into like the academy. I guess they saying that. But, I do not know, I have not really thought about that. I am kind of like I have not been on my - a game with school and stuff. No…

Interviewer: Why is that?

Jamie: I do not know, it is just kind of. It is kind of frustrating. It really is frustrating. Because I feel like I had no control over what happened to me in being out of school.

I felt like nobody kind of did not make any exceptions. They did not try to help me. It was just like this is what you need to do. If you do not do it, you – that you are not graduating. So, I do not know, I just kind of feel like it is unfair the way everything played out. Even though I should not take that out on like everybody. Like and I get my diploma because only her and me in the – in the future. But, I do not know, I am going to get it together.

Interviewer: Well, let's talk a little bit more about this. I mean, you say a lot when you are saying that you think it is really unfair. But you mentioned having the counselor at high school. I mean, have you talked to the counselors?

Jamie: No, we have – we have a lot. We have had a lot of altercations with that. Because at the end of the year, she was telling me that I was graduating. Then later on last year that I was in then. It is like off and on, off and on. And I just really did not have like a set of what. Like a set, a list of what was happening or what was the plan. She was supposed to. My mom had called her like a few minutes before school got out to figure out if I could take summer school class where I can be finished by the end of summer.

Interviewer: Yeah.

Jamie: She was like, well, I am going to get back to you guys. She never called us back. Now, I have to wait until school starts, so.

Interviewer: Ok.

Jamie: Yes.

Interviewer: That is unfortunate. It sounds like you just had a bad counselor.

Jamie: Yes, horrible.

Interviewer: Well, as for the whole firefighter thing for your work based learning credit, you would not necessarily. I do not know a whole lot about this, but you would not necessarily be able to do like the academy. Then jump into your work based learning. But what you might be able to do is you might be able to work at like the part-time as a secretary or something within the city office. Then they would kind of help and be able to guide you right into that career. But what – the work you would be doing and the part of your work base learning would be mostly like administrative. It would be mostly like secretary office stuff.

Jamie: Yes, ma'am. Ok.

Interviewer: You should look into that. I mean, it might – it might be a good way for you to jumpstart.

Jamie: Yes, ma'am.

Interviewer: Just something to consider. When we were talking last you mentioned that the school was not very helpful. You just mentioned it now that you just did not have a counselor that was really helpful. I guess I am wondering, what did they tell you when you came back?

Jamie: My counselor actually... I told her that – about how I wanted to graduate. Like what classes I needed. My counselor actually told me the first meeting I had. She is like, it is very unrealistic to think. No, what'd she say? She did not say unrealistic. She – well, maybe she did. She said something like it is very unrealistic to think that you are going to be able to walk with your class. That is just not possible for you.

Interviewer: Ok.

Jamie: So, she was not very… She was not very nice. She was not a very nice at all.

Interviewer: She was pretty blunt about it?

Jamie: Yes, ma'am. But she was telling me that I was not going to be like graduating until 2014 because I missed two years of school. But, she said that I was not going to be able to graduate until 2014. I kind of proved her wrong. I am still graduating with my class, but just not walking with my class.

Interviewer: You are just not walking with them. Well, I mean, and I think that is commendable. Because you were absent you said for two years, right?

Jamie: Yes, ma'am.

Interviewer: Ok. But, this is one of the things I wanted to clarify. I am wondering if you can just walk me through it again. You got your cancer diagnosis. You were out of school. You got your diagnosis in October, right? I have October 2008 is when you –

Jamie: Yes, ma'am.

Interviewer: – Got your diagnosis. You were absent.

Jamie: Yes, ma'am.

Interviewer: You were absent then for the rest of the school year.

Jamie: Yes, ma'am.

Interviewer: Correct?

Jamie: Yes.

Interviewer: And then what happened?

Jamie: I tried; I did not go back to school for that whole year.

Interviewer: Right.

Jamie: Then tenth grade year, because I got diagnosed in ninth grade year. Tenth grade year, I tried to go back, but without doing like not really harsh chemo, but still chemo. That I was like doing inpatient and stuff like that. They put me on a half-day of school so I did one through fourth. Then like I was just missing a whole bunch of days because I was really sick. My mom just took me out then.

Interviewer: Ok. When you went back in the tenth grade you were doing a half-day of school from 1:00 p.m. to 4:00?

Jamie: No. I did first through fourth period.

Interviewer: Ok. First through fourth period.

Jamie: Then I left fifth and sixth.

Interviewer: All right.

Jamie: Yes, ma'am.

Interviewer: What about it being there for the half day did not work for you?

Jamie: I do not know. I guess I really just – I was just tired a lot. And after being out of the school that whole year, I guess I really did not have motivation to do it. I do not know, I was just tired with being sick in bed. That it was hard… I mean, it had just been me alone. Everybody coughing and stuff. I got sick a lot. I was just missing a whole bunch of days. My counselor thought it was like it would be best for me not to – just to go home and get dropped out after the second – after first semester.

Interviewer: Ok. You were tired a lot. You were getting sick a lot. It just – you and your mom decided that it just did not. It was not worth it for you to stay in school.

Jamie: Yes.

Interviewer: How long when you went back in tenth grade, how long did you try this before your mom took you back out again?

Jamie: The whole semester. I finished the whole first semester.

Interviewer: Ok. When you were going to the hospital for your treatment, you are in your outpatient treatment, did the hospital have a social worker that came to talk to you about school at all?

Jamie: No, ma'am.

Interviewer: Really?

Jamie: Yes, ma'am.

Interviewer: They did not say anything to you about doing any kind of education through the hospital?

Jamie: No, ma'am.

Interviewer: Hmm. But you mentioned in our last conversation that – that you had a tutor but it “fell through.” When did you have the tutor?

Jamie: He came my freshman year. When I first started chemo. But it didn’t work out.

Interviewer: It just didn’t work out?

Jamie: No, ma’am.

Interviewer: When you returned back to school, both times. The first time just for that semester. Then the second time at the start of your junior year. Did the school do anything to help you kind of reintegrate?

Jamie: No, ma’am. They gave my classes and that is it.

Interviewer: They gave you your classes and that is it?

Jamie: Yes, ma’am. They sent out e-mails to my teachers telling them my situation. They had me on like a 504 plan. A 504 plan is like for a student. You know what a 504 plan is?

Interviewer: I do, but I would like to hear you explain it.

Jamie: Ok. Well, what I was told, a 504 plan is for students that like miss school or whatever. It is supposed to help you stay current, but not get you ahead of anybody. My 504 plan, it fell through because even when I was not in school. I had not been sick. I had never got any of my work. When I used to try to come back to school and get my work, it was like stacks of like homework that was just like ridiculous. My 504 plan really did not work, so.

Interviewer: Nobody at the school tried to keep you in the loop for your 504 plan?

Jamie: No, ma’am.

Interviewer: Ok. They sent out e-mails to the teachers. Did they say anything to your classmates? Did they give any presentations about your experience or anything?

Jamie: No, ma’am, they were just... They would speak on it if I wanted them to speak on it. But, at that point it was like I was tired of getting… I was tired of getting things because… Well, not…I wouldn’t say that I explained it. I was tired of people feeling sorry for me for what I have been through. I kind of just wanted to be on the – like nobody needed to know type thing.

Interviewer: Ok.

Jamie: Because my teacher needed to know. Because if I am missing school, of course. But, like students, I did not feel like they needed to know.

Interviewer: Ok. Did they – did they ask you if you wanted to let the students know? And then you said no?

Jamie: No, ma'am, they never asked.

Interviewer: They never asked?

Jamie: No, ma'am.

Interviewer: Ok. Did you tell them that from the – from the very beginning that you did not want them to know?

Jamie: No, ma'am.

Interviewer: Ok. So, it is just trying to – they did not pursue it, and you did not want them to.

Jamie: Yes, ma'am.

Interviewer: Ok. All right, I appreciate that. I was just trying to kind of understand exactly how much involvement the school tried to help you with getting back into it.

Jamie: Yes, ma'am.

Interviewer: How are things with your friends? You mentioned that sometimes they joke about your experience and it bothers you. I just kind of wanted to see how things were going with that.

Jamie: Pretty good. I have – I have a whole – like from starting my treatment and then going off. I have like a whole different set of friends. I guess that is just high school experience. You, like, grow apart from your friends. Yeah, my – like, my friends I have now. I only think I have one friend that would look at me different through like the whole cancer experience. We – it was kind of… It is kind of over now. I kind of let it be over. I kind of do not bring it up anymore. I forget, that is why. I forgot, you did not. It is because I went through that, so.

Interviewer: Really?

Jamie: Yes, ma'am.

Interviewer: That is quite a change from last year when you mentioned that you still think of it pretty much everyday.

Jamie: No, not anymore. I – because I am like surrounded in my – like my – like in remission. Like I do not even go into the hospital every month or like I used to. I go in every two months.

Interviewer: Ok.

Jamie: Then I have – I have bigger problems to worry about now. Boys… All I got are different. I wonder why… (laughs)

Interviewer: You've got problems with boys?

Jamie: Actually I am talking to somebody right now. Yeah, I would not say he is my boyfriend, but we are almost there, small strides.

Interviewer: How long has that been going on?

Jamie: Almost a year now.

Interviewer: Almost a year?

Jamie: Yes, ma'am, almost.

[Crosstalk]

Interviewer: No kidding? I am glad to hear that is going well.

Jamie: Yes, ma'am.

Interviewer: What about your relationship with your sister?

Jamie: We have – I guess we have our sister arguments. But, it is not – it is not nearly as bad as it used to be. We are – we are older now, so we just kind of learn to go our separate ways and cool off. Then tomorrow we will do fine, so.

[Crosstalk]

Interviewer: Do you still resent her for saying that you were faking?

Jamie: Umm, I kind of do. But not anything that I am letting it hinder our relationship..

Interviewer: Ok. That is good. Ok, so now I am going to get into some of the more difficult questions in terms of emotional questions. These are some of the things. I am just going to read you –

Jamie: Yeah.

Interviewer: – Some of the things you said the last time we spoke. I would like to get an idea of how you feel about them now, if that is ok. When I asked if you felt –

Jamie: Yeah.

Interviewer: – Different from your peers, you said that you feel left out. And you do not feel as pretty as they do.

Jamie: Yes.

Interviewer: Do you still feel that way?

Jamie: Kind of, not really. I feel like I am getting back into like the swing of things. I do feel you never know. Not really, I mean, break some thinking. You asked me a question that made me think. No, ma'am. I am fine now.

Interviewer: Good.

Jamie: They will include me. We do not… Even though I do not do like some of the stuff that they do. Like stuff that I do, they call me, and we go out. I go out a lot now. I am hardly ever at home.

Interviewer: Ok. Especially now that you can drive, right?

Jamie: Yes, ma'am. My sister lets use her car and stuff.

Interviewer: Another thing that you had said was when you started getting your heavy doses of chemo. You were always throwing up. You suddenly felt that your experience was real. That you felt that you could really die. Can we talk a little bit more about that?

Jamie: Yes, ma'am.

Interviewer: Explain that just a little bit more to me. What does that mean to you to hear that sentence come out of your mouth? "I can really die."

Jamie: I do not know. I do not know, I guess like anything to like make you die. But knowing that I am dealing with life, a life threatening disease that can really take my life. It is just like instantly. That my chances of dying is like way more higher than anybody else's. Or, just the average person is. It is scary to know that I was like so close to like being gone or being… You know.

Interviewer: Well, given the fact that is how you felt as you were just starting your heavy doses of chemo. Already based on how you had mentioned that you do not even think about it some days. It seems like you feel pretty great about your experience now.

Jamie: Yes, ma'am. I… If, like looking back on it, what they say, do not. Or, what does not kill you, makes you stronger. I do feel way more stronger than when I did. Just know that I overcame something that a lot of people do not. In that, I am here, which I can tell people about my experience. Like somebody that is going through what I am going through. If they are feeling like giving up. Or like I can help them. Just tell her what I have been through. I do feel a lot stronger and being so – being at such a low point. Then down looking back over and being able to conquer it. Yes, it was a good feeling.

Interviewer: I think it sounds like you are in a really good place, especially in comparison to when we were talking last September.

Jamie: Yes.

Interviewer: You should be really proud of that.

Jamie: I do.

Interviewer: One more thing I want to talk about with regard to our last conversation. Is that you had talked to me about how you did have an opportunity to talk to a counselor, and it didn't go well.

Jamie: Yes, ma'am. I think of it. But I was in the hospital.

[Crosstalk]

Interviewer: Yeah.

Jamie: If you think, it was ages ago. It is like still some comfort. Because I felt like – I felt like the reason that I was talking to him was not on – for the reasons that I should have been talking to him. I know when I got because they forcing me to talk to him. Because I felt like they think – thought that I would, like making myself sick or something. I don't know, I just did not. I just did not – was not on good terms with him. I had one counselor that I talked to. She was really – she was really nice.

Interviewer: Yeah. You had mentioned.

[Crosstalk]

Jamie: But she just up and left one day. Then I do not know where she went.

Interviewer: Yeah. You mentioned that you really liked talking with her. But you felt like talking with her was more you had to still be in treatment to talk to her.

Jamie: Yes, ma'am.

Interviewer: Ok. Then you said it was a guy that you spoke with when you started to stop treatment. Or, when your treatment stopped.

Jamie: Yes, ma'am.

Interviewer: What about him that you were saying? You said that the doctors wanted you to go because they thought you were making yourself sick?

Jamie: Yes, and they thought that because I was like weaned – like getting off of treatment. They thought that it was of like a mindset that what- Because I was on treatments for so long that I am supposed to be sick. I am supposed to be sick. I am supposed to be sick. Like I was just getting myself into that mindset. I was making myself like sick, so they made me talk to him.

Interviewer: Do you think that they were wrong?

Jamie: Looking back on it, no. Because I was not really. I was not really was not taking any heavy doses of treatment. But if you are in that – if you are in that situation for so long. Where you are used to waking up. You are just used to running to the bathroom and throwing up, you know if you wake up one morning. You are like, ok, well, maybe there is something wrong. Or, because I am not feeling sick. I do not know, maybe I was psyching myself out a little bit, but not that much.

Interviewer: Ok.

Jamie: To where I can just talk to a guy at eight o'clock in the morning. Maybe that is really why I did not like him. It was like seven o'clock in the morning. I was like, my gosh. I was a little tired.

Interviewer: It was the crack of dawn?

Jamie: Yes, it was.

Interviewer: You also mentioned the last time we spoke. That you think even last year when we were talking that it would be helpful to have someone to talk to.

Jamie: Yes, ma'am.

Interviewer: But you also had mentioned that you thought it was too late for anyone to try and help.

Jamie: Yes, ma'am.

Interviewer: Do you still feel that way?

Jamie: Yes, ma'am. I feel like it is over now. There is really nothing to talk about. I do not want to re-experience. Like having to talk to somebody. Then have to re – in my mind have to go through all that. I just feel like it is done now. It is over, so there is really nothing more to talk about.

Interviewer: I mean, I would say that there is a kind of balance there between being ready to move on from it and trying to ignore it.

Jamie: Yes, ma'am.

Interviewer: Which one would you say you are doing?

Jamie: I think I am trying to move for a minute. Because I do not ever want to be back into a place where I am feeling like I have to. Like I was telling you before, like having to use my cancer as an excuse for everything.

Interviewer: Yeah.

Jamie: Like, I do not want to say that I did not graduate because I was sick. That part, I have to read this? That is all the reason why I did not graduate. I did not graduate because I did not try as hard as I could have tried.

Interviewer: Ok.

Jamie: I just… I am glad that I had come to that point where I could recognize that. Because at the beginning of the New Year, that was not. It was everybody else's fault that I would not graduate. It is the doctor's fault for giving me all of these treatments, and making me sick. It was my mom's fault for taking me out of school. But now that I am at a place where I can recognize that was almost four years ago. That I have to move on. I do not want to go back to that.

Interviewer: Do you think your age has something to do with that change about school?

Jamie: No, ma'am, not really.

Interviewer: But it is still very grown up.

Jamie: Thank you. No, ma'am, I just. I do not know. It is… I do not know. It really just – it took a lot of – a lot of… I guess it is growing up. I guess you can say that. But I felt like the whole experience makes me have to grow up a lot anyway.

Interviewer: True.

Jamie: So, I do not know. I cannot really put my finger on it.

Interviewer: That is one of the things that you really I guess did not have a whole lot of control over.

Jamie: Yes, ma'am.

Interviewer: You kind of had to grow up. You had to face the music and realize that you were essentially facing death.

Jamie: Yes.

Interviewer: If you were facing life, you were facing a different kind of life from other people your age.

Jamie: Yes.

Interviewer: Yeah, I mean, I think it is a very grown up way to look at it, if I may say so.

Jamie: Thank you.

Interviewer: You're very welcome. You feel like you would not be able to talk to anybody now?

Jamie: No, ma'am.

Interviewer: Ok. Definitely over and done with on that? (she nods her head) When you go in to the hospital every two months, you said?

Jamie: Yes, ma'am.

Interviewer: How do you feel going in there, now.

Jamie: I feel like it is hard to… Well, I would not say it is a waste of time. It is we have drive like 15 minutes and get blood taken. It always comes out the same way. Sometimes they feel like extra fluid. Well, we go check and take x-rays… I just feel like it is stressful for no reason. I think it is unnecessary stress. I think – but honestly, I hope you know I got… Well, I hope you do not think I am crazy for doing this. I feel like it is just going to come back. I obviously just feel like I cannot go be that strong a second time around. But if it does come back, I just want to just live my life peacefully without treatments and all that. Do I honestly…? I do not know. It will keep coming back, obviously. My time is up, right.

Interviewer: No.

Jamie: If they are just trying to keep trying to fight something. But, as long as you keep coming back.

[Crosstalk]

Interviewer: I think this… You had mentioned that last year, too, that you did not think you would be strong enough to face it again. But the difference is that the last time we spoke, you said that you would still be ready to fight it. You would probably find the strength somewhere. But now, what I am hearing is that if you are saying that if you were diagnosed with – If your cancer had come back and you had relapsed. You are saying you would not go – undergo any treatment?

Jamie: No, ma'am. I would not want to.

Interviewer: Even if the doctors told you, "Well, it might be another year or two years of this. But you would probably get better."?

Jamie: No, ma'am. I would not want to. I do not know if I told you about my friend.

Interviewer: I'm not sure if you did.

Jamie: Yes, ma'am. I just do not. I do not want to be in the hospital and then still end up dying. Then I, the time I was in the hospital I could have been doing something else.

Interviewer: Your friend… I think you did mention her to me. She relapsed at the same stage you are at? She relapsed when she was over two month check ups, right?

Jamie: No, ma'am, she was a little further along than I was, I think. Maybe by like a year. Maybe, or three months…

Interviewer: Hers was similar to yours?

Jamie: But, I… Yes, but I do not think she was as soon as I was.

Interviewer: Ok.

Jamie: Because she got into remission when I was just going off to treatment. That was two years. And I am only on one year.

Interviewer: Ok.

Jamie: Light remission.

Interviewer: Ok. She was at her three-month part?

Jamie: Yes.

Interviewer: Ok. Yeah, now I remember you telling me her story. I can understand how that would ring very true for you. But you know, everyone is different.

Jamie: Yes, ma'am.

Interviewer: Ok. Well, I am just kind of looking through what I have got in front of me between my notes and our conversation from last year. How are things in your family aside from your sister. How are things with your step dad and your mom?

Jamie: Everything is pretty good. I think I am at the stage now where I am trying to do – experience stuff that – parties and all that kind of stuff. My mom doesn't like that. Most of the time at the house, I am usually out doing things. I just do not know why I am thinking I am doing way worse stuff than I really am. She holds me at a very high expectation. Because us with being a Godly church, our family. She feels like God delivered me from cancer, so I should not be piercing my face. I do not know if you have seen any of my piercings. Because I have, like, I had like three piercings on my face… I had my lip, my nose, and I had my tongue; I think I have both my lips and tongue. I took out my lip one yesterday.

Interviewer: Ok.

Jamie: I still have my nose (ring) in though. I do not know, I just feel like she holds me at a very high standard that she didn't hold any of my other siblings, any of my other three siblings at. But I –I am just trying to make up for the time that I lost. It is like when I was going through treatment. It was like everybody else like already got out of there. If there is somebody, no I am just trying to experience it now.

Interviewer: Yeah. Why do you think she holds you to a different standard than your siblings?

Jamie: Because of what I have been through. She thinks that I should not have to experience that because – or, I shouldn't have to go through all of that because of mainly of what I see my siblings do. [sentence omitted to preserve anonymity] My sister is staying in the house. My other sister has 20,000 kids. But I guess she thinks that I should not. Being them, I should not have to do that. Then what I have went through. That should just be out of the question.

Interviewer: Do you think it comes from…?

Jamie: I do not know.

Interviewer: Do you think she has that idea from a place of discipline or from a place of pride?

Jamie: Discipline.

Interviewer: More discipline?

Jamie: Discipline problems, but yes, ma’am.

Interviewer: I can see that.

Jamie: Yes, ma’am. But I do not know. I do not do anything crazy. I am not having kids, or drinking, or any of that kind of stuff. I just like men. So, I just go out.

Interviewer: Yeah. Dancing is fun.

Jamie: Yes, ma’am.

Interviewer: How old are you now?

Jamie: Eighteen.

Interviewer: You are 18 years old.

Jamie: Yes, ma’am.

Interviewer: You know that by next summer you can be a staff member at camp.

Jamie: Yes. Oh! I can, can’t I? I was thinking... I was really sad. I missed like the last two years, but. Will you go to camp this summer?

Interviewer: I am not able to.

Jamie: Work?

Interviewer: I am up to my ears in work. I am taking this year off, but I already have the date set up for next year. Hopefully I will be able to make it back for next summer.

Jamie: Yes, ma’am. Actually, it was fun!

Interviewer: But, you should keep it in mind. Because you have experienced it. I think you have a lot of… I think you have learned a lot from your experience. You have an outlook that would be really beneficial to other kids that are going through similar things that you have gone through.

Jamie: Yes, ma’am.

Interviewer: Plus you will be… A lot of the kids that you were with in the cabins will be returning next year as staff members, too.

Jamie: Yes, ma’am. That would be cool.

[Crosstalk]

Interviewer: You would get to see some old friends.

Jamie: Yes, ma'am.

Interviewer: All right, well do you have any questions for me?

Jamie: No, ma'am.

Interviewer: No? None?

Jamie: No, ma'am.

Interviewer: All right. Well is it ok if I contact you again just in case I have more questions?

Jamie: Yes, ma'am. That is fine.

Interviewer: I really appreciate it. I think I am good. I have got all of the information that I was curious about. I got the name of your school, which I want to look into a little bit more in terms of how they operate. Like reintegration and their 504 plans and things like that. But other than that, I think I am doing pretty well. And I just – I want to wish you good luck with the job-hunt.

Jamie: Yes, thank you.

Interviewer: Definitely look in to see if you can get your work based learning credit from doing something pertaining to the fire department.

Jamie: Yes, ma'am.

Interviewer: It might really just be that jump-start that you needed. Then you might actually really love your work this time

Jamie: Yes, ma'am. Ok. (laughs)

Interviewer: All right?

Jamie: Well, thank you!

Interviewer: You are very welcome. I will talk to you soon! Have a great summer!

Jamie: Ok, you too. Bye.

Interviewer: Ok. Bye.

End of Interview.

Tracy

Tracy: 17-year-old Caucasian female
Diagnosed: August 2010 – Metastatic Capillary Thyroid Carcinoma
Treatment Stopped: November 2010 – Surgery (continues thyroid management)
First interview: October 2011 - Phone with mother present

Interviewer: So, I have never had cancer, so I would really appreciate it if we could start by – if you could help me to understand what it was like when you were first diagnosed.

Tracy: It was more of a relief rather than, what's the word?

Interviewer: A relief rather than a concern?

Tracy: Yes, because we had been dealing with it for four years.

Interviewer: Okay. Well, let's talk about your cancer diagnosis; what were you feeling when you were told by the doctors that you had cancer?

Tracy: I wasn't scared of it. I wasn't scared. I don't know, I guess, nervous because I knew I had to have surgery and I was going to be alone in surgery.

Interviewer: Okay. But you said that you were not scared?

Tracy: No, not really.

Interviewer: Why do you think that is?

Tracy: Because we were just looking for a diagnosis, didn't really care what it was or anything. We just wanted to find out what was wrong.

Interviewer: Okay. And when did you have your cancer diagnosis?

Tracy: August 30th of 2010.

Interviewer: What specifically, what kind of cancer did you have.

Tracy: It is called metastatic capillary thyroid carcinoma

Interviewer: That is quite a mouthful. I am glad I was recording that. So what kinds of things were you doing every day for your treatment?

Tracy: Up until the surgery we really didn't do anything we just went to doctor's appointments and biopsies or anything. And then we just went to surgery; it wasn't like you had to eat special foods or anything.

Interviewer: And how long was the time between your cancer diagnosis and your surgery?

Tracy: About two, two and a half months. Between two months; I was diagnosed August 30th and the surgery was November 2nd of 2010.

Interviewer: Talk to me about the surgery. How long did it take?

Tracy: It took four and a half hours from the time I went back to the time I was in recovery. It took two and a half hours longer than it was supposed to because my tumors were actually in my vocal cord nerves and then they had to get all the lymph nodes out that were cancerous.

Interviewer: The lymph nodes they had to take out, were they also in your neck and your throat?

Tracy: Yes.

Interviewer: So it was localized to your neck and your head?

Tracy: Yes.

Interviewer: Okay. And how, so what was your – what was your recovery time?

Tracy: It was more than a year or so dealing with it.

Interviewer: And how is that – you say more than a year you are still dealing with it – describe that to me.

Tracy: How many months? In November? In November, so we are at 11 months right now that I am still recovering. My neck is still numb and we are still trying to figure out medications and I am still extremely sleepy.

Interviewer: Okay. And so how often do you find yourself going to the hospital?

Tracy: I haven't gone to the hospital since I got out.

Interviewer: Oh great, okay. What kinds of treatment are you doing at home?

Tracy: Oh yea, I did radioactive iodine for a week and then I had –I started taking (medications) they just kept upping my level until it got regulated. Then I started getting sleepy again, so they put me on a different medicine than the stentorian and that is what I am on right now.

Interviewer: And you are still on those to this day?

Tracy: Yea.

Interviewer: Do you think that your feelings changed at all from before going into surgery to after you had recovered and were back at home?

Tracy: In relation to how I felt about the cancer?

Interviewer: Yea. In relation to all of the emotions floating around; you said that you weren't scared, you were a little nervous going into surgery, but mostly you were relieved that you got a diagnosis. I am trying – wonder did you have different feelings once they had removed the tumor and were going through the process of the iodine, radioactive iodine treatment and just taking your medication at home?

Tracy: I thought I'd feel better like right away and I still to this day have not felt better, I don't know what feeling better is like. It is hard for me to figure out when my medicine is right and stuff. I have no idea what I'm supposed to feel like.

Interviewer: I would imagine that would be kind of frustrating that you don't know what feeling better is supposed to feel like…

Tracy: Yes.

Interviewer: How is that? I am trying to wrap my mind around it; how long were you sick before you were diagnosed?

Tracy: Probably three, four years they can't tell us exactly, but that is when all the symptoms started happening, three or four years.

Interviewer: What kind of symptoms did you have?

Tracy: I gained 40 pounds in a year. In a year, I was sleeping. I wasn't eating very much at all. I was eating like a six year old, yea six year old portions and I was 12, 13, 14, 15 and 16. We have always eaten really healthy, so there was no explanation for the weight gain. I threw out both my feet within, not even a year of each other.

Interviewer: Wow, okay.

Tracy Mother: And then later stages probably before the diagnosis, her hair started falling out in a large quantity.

Tracy: I had a really bad headache. I would wake up with a headache and I would go to sleep with a migraine and it would happen every single day. There was not a day that did not happen. My hormones were crazy. I would be on a week off a week with my menstrual cycle and it was so heavy and it was a pain in the butt.

Interviewer: I bet. Now that – what kind of symptoms are you having now?

Tracy: I am just sleepy right now.

Interviewer: Okay, so you – so since you've had surgery you just kind of feel a little bit tired all the time. Do you feel weak from time to time?

Tracy: Yes. Sometimes I get really weak to just where it is hard to even get myself off the couch or out of bed. My muscles just don't want to do anything.

Interviewer: And what about the weight gain?

Tracy: It's still an issue. I lost 10 pounds, but I gained it all back.

Interviewer: When you gained it back did it have to do with the cancer that you gained it back or did it have to do with?

Tracy: I have no idea, but people keep saying that I look thinner than I have but I gained the 10 pounds back.

Interviewer: Interesting. Let's go back to when you were feeling symptoms before the surgery. What was the school reaction at that time? Was your school supportive? When you were at school and you were saying that you had migraines and that you weren't feeling well, were your teachers supportive? Were they understanding?

Tracy: I would never really complain about it to my teachers just because they couldn't do anything. My mom was at work. I couldn't drive at the time, so she couldn't come get me. It's not going to get me anywhere if I complain about it and go to the nurse, so I just didn't.

Interviewer: So you kept it to yourself?

Tracy: Yea. I carried ibuprofen with me and stuff and if I really needed some ibuprofen or Tylenol or whatever, I would just take it. I knew how much doses and stuff to give myself, so.

Interviewer: Great, okay. You were talking to me about how you are still feeling symptoms and it has been 11 months. It will be a year soon, is that right?

Tracy: Yes.

Interviewer: As a family, did you do anything to celebrate when the doctors told you they had removed it all?

Tracy: I was in the hospital bed.

Tracy Mother: You mean immediately after the surgery?

Interviewer: Well, in the last 11 months have you done anything to celebrate that you are cancer free?

Tracy: We went out to dinner.

Tracy Mother: We went out to dinner. Well, once she did her radioactive iodine she was in isolation for three or four days so I couldn't be near her. So she had to stay upstairs in her room and family room upstairs area. I had to stay away from her downstairs. We really couldn't do anything. Then after that we kind of celebrated a little bit once she could come out of isolation. Then coming up November 2nd will be her one year surgery and we haven't had specific plans yet. We are intending to do something at this point.

Interviewer: Great. Now, you had mentioned to me that you have concerns about cancer returning in other places of your body. How often would you say you think about that?

Tracy: Every day.

Interviewer: Every day.

Tracy: When I don't feel good and my stomach starts to hurt or I can't breathe. My doctors think I got asthma or something, whatever. When I can't breathe I always think the thyroid cancer likes to go to your lungs and liver and I think that maybe there is cancer in my lungs and maybe that is why I can't breathe. Not a day passes that I don't think about it.

Interviewer: Did the doctors say that there was a chance that it could end up somewhere else in your body?

Tracy: I have a greater risk now to have cancer come back somewhere else in their body than most people do.

Tracy Mother: That was a result of the radioactive iodine treatment.

Interviewer: So your increased risk in cancer is more because of the treatment than the tumor itself?

Tracy: Yes.

Interviewer: Interesting. How often do you go back to the doctor?

Tracy: Every three months, but I have different doctors that I go to different increments. I have like three different doctors that follow up with me. My actual doctor that prescribes my medicine every three months. I go to my ear, nose and throat doctor that diagnosed me with it in the first place every six months. I go to my nurse practitioner, which is a doctor that discovered that there was a lump in my thyroid in the first place, I go back to her every three months, two months, four months whenever I need more medicine, headache medicine or whatever.

Interviewer: Is it now just really normal for you when you walk into that doctor's office or do you feel any kind of nerves or worry or apprehension?

Tracy: Yea. It's just the biopsy guy that I get nervous with because I do not like that place. Every other doctor I'm like, "Hey, what's up?"

Interviewer: Does the biopsy, when you get things any time you visit that doctor, does it make you nervous because you are afraid you are going to find something? Or does it make you nervous because it is painful?

Tracy: Well, it's not painful anymore because they have nothing to biopsy. They do an ultrasound on my neck and it just makes me nervous that he is verifying something else or.

Interviewer: Okay. So whenever you are thinking about the fact that your cancer is gone, what kind of thoughts do you have when you think about your future?

Tracy: I want to have kids, so. We thought at first that it was going to impact that, but it won't. I don't know.

Tracy Mother: Worried about school at all?

Tracy: I don't have any worries about that.

Interviewer: Do you worry about your ability to be successful later in life and this getting in the way of that?

Tracy: No.

Interviewer: No. Okay.

Tracy Mother: I think for her too, from the conversations she and I have had it is just I think it has pulled her more towards a health services, medical type of field that she looks towards what to do after high school and college. Just kind of driven from her thought process was to maybe want to be a physical therapist, but focusing on cancer patients and rehabilitation things like that.

Interviewer: So it seems like you have kind of found something positive from the situation. You have a little bit more of a passion towards the medical field.

Tracy: Yes.

Interviewer: Obviously, having cancer is not pleasant. Not feeling well, the treatments, you had to be in isolation, but besides what you just mentioned, looking to your future and having now a greater passion for the medical services field, can you think of anything else that is good that has come from your experience?

Tracy: I think it was a good learning experience for new people that I meet. They are like, "what's that scar on your neck?" I say, "Oh I had thyroid cancer last year," and they just like they never stop asking questions. They always come up with new questions every day. People were like, infatuated with touching my neck because it feels so different from everybody else's because there is nothing protecting my muscle and stuff right there. Whereas, everybody else has a thyroid there protecting it so they feel that squishy thing right there and mine is hard muscle and my bones and stuff. It is like – people are like intrigued with what happened and everything and that I am still in school and not depressed about it or anything.

Interviewer: So you take other people's interest as a compliment?

Tracy: Uh-huh.

Interviewer: That is a good way to look at it. What would you say is the most difficult thing you have had to face throughout your entire cancer process? From the moment you first didn't feel well until now, what would you say is the most difficult thing you have had to deal with?

Tracy: Probably just the headaches. That was the most annoying thing ever. There was no getting ready for it. I just woke up and would go to school for maybe an hour and then after that I would be back to the regular headache, migraine.

Interviewer: And you said that you still have those?

Tracy: Not as much – I don't have them every day. I get them maybe once a week. It has been worse now I think maybe because it got cold last week and it has been extremely hot here. I think it is just like – and my allergies are bugging me right now.

I think it is the temperature drop and change and everything that has caused it the past couple of days, but I mean usually it is only like once a week and I have medicine to take for it, so.

Interviewer: Okay, and medicine helps?

Tracy: Yea. And another one was just getting back in school. I couldn't keep myself in last year after I got back and after fifth period I was like hey, I'm done. I'm leaving. And I would just leave school. I am still having trouble just being in class. I want to leave and just do something else, but I need to stay in school.

Interviewer: That is actually a perfect segway; let's talk about school a little bit. How often would you say you are missing class?

Tracy: Last year I left early probably one, two, three times a week. And this year I probably leave early like once a week or I come to school late or –

Interviewer: Is that because of the headaches or because of other reasons?

Tracy: I don't want to go. And I just want more time to sleep in.

Interviewer: Okay. Has your school given you – you said last year you were absent about three times a week; did the school help you at all to make sure you didn't fall behind?

Tracy: Yea. I have been on 504 since I was in elementary school for ADD, ADHD and then learning disabilities so they just added it to my 504. One of my teachers would collect all of my work from my other teachers and bring it to my house so I could do it at my house. They were really –

Tracy Mother: They eliminated some of it for her to do – she was out of school for almost two months. She missed the whole second quarter. So they put her on a completely different schedule for mid-term exams and then they just went back in the grade book and modified everything for second quarter and semester. So she went back to school the middle of January and was still kind of in and out. And then I think it took her until the middle or end of February until she was completely caught up with assignments and mid-term exams, end of semester exams and was kind of in a regular routine at school.

Interviewer: So was it, you said that teachers were bringing assignments to your house?

Tracy: Yea, I had one teacher that it is called home bound services, and I don't know if they do it in other states, but they do it here and one teacher will pick up this job and they go around to all my teachers, I think once it was or every day that I missed the teacher could tutor me up until an hour. Well, if I missed five days of school that week the teacher could come tutor me –

Tracy Mother: It was every two days that she missed at school she was eligible for one hour of tutoring through supplemental home services as an attachment on her 504 plan. The science teacher picked up the job and wasn't able to help with her math, so I had a friend of mine who is a middle school, high school math teacher come to my office and then this gal got her all caught up in math. Little 20/30-minute tutoring sessions at a time.

Interviewer: Great. So the home bound services, is that something that the county puts together as a part of the school district?

Tracy Mother: Yes. They have got multiple entry points. There are home bound services for students that cannot physically over an extended period of time attend school. And they come from their home and teachers at school a few times a week. And then there is the supplemental education services or supplemental home services that come for people that we know that are going to be back in school… They put her on that supplemental home services as an attachment to her 504 because they knew she was coming back.

Interviewer: But you said it was the science teacher. Do they make a request that it is a teacher from her school?

Tracy Mother: Yes. Any of her teachers of record could pick up the job assignment. And the school system paid for them to come out and tutor.

Interviewer: That is fantastic. I have heard of this service in other states and other counties. I have also heard of some school districts that just won't do it.

Tracy Mother: We were just extremely fortunate with Tracy's counselor. She orchestrated everything. And we met multiple times with the teachers and because her proficiency exams were last year as well, which was another pick up. They just were extremely patient and workable with us and I even offered to take Tracy off of their roster because of yearly progress for the school and put her into virtual high school or something like that. They said absolutely not. She belongs here. She is part of our campus. They just wouldn't do it. They said no. This is where she needs to be. This is where her friends are and this is her school.

Interviewer: That's fantastic. As a former teacher it makes me happy to see that keeping kids in the general education setting as often as possible is actually being pursued.

Tracy Mother: Yes. It was wonderful.

Interviewer: Especially after going through the cancer and everything you don't want school to be a problem as well.

Tracy Mother: Yea. It kept her in with her group of friends. You know, I know going back after two months was a little challenging but at least it was familiar.

Interviewer: Well, let's talk about your friends at school. Were they also supportive?

Tracy: Yes. They would always text me and tell me what is going on at school. And one of them would come over and I didn't get – I didn't have them come over a lot, just because I was never feeling good or I was sleeping or we had family company or my mom's friends would come over that she had known for years just to say hi and see how I was doing. So I never had my friends come over because they wanted to go do something and I couldn’t do it then.

Interviewer: Do you think that support has changed since you started to feel better and better?

Tracy: You mean the support being different or the focus?

Interviewer: You were saying that your friends were so attentive and that they were always checking up on you. You know, if you miss a day of school now do they check up on you the same amount or?

Tracy: Yea, my closest friends are like are you okay? What’s going on? They will text me like right when I’m missing in class or if they don’t see my car in the parking lot or whatever, they will text me.

Interviewer: That’s great.

Tracy: They will be like, are you okay, what’s going on, do you need anything.

Interviewer: Do you feel different from them?

Tracy: What?

Interviewer: Do you feel different from them?

Tracy: No. Not anymore. They don’t treat me any differently. They just treat me like a normal kid.

Interviewer: Do they have a lot of questions about your cancer?

Tracy: They did at the beginning. Some of them still ask questions because they know it is getting close to a year. One of my friends yesterday, we were walking to gym, and she asked me when is the year, what are you guys doing. She asked me if I was cancer free. I said I don’t know until November 2nd and that is when I can say that I actually am. They know it is getting time that I should be a year out they are starting to ask more questions now but usually they don’t say anything.

Interviewer: Do you mind when people ask you about it?

Tracy: No. It doesn’t bug me.

Interviewer: So you’re open to discussing it?

Tracy: Mm-hmmm.

Interviewer: So when you had returned back to school after two and a half months of recovering; what did it feel like walking through the hallways again?

Tracy: It was weird. Everybody was staring at my neck because it was super red at that time. Usually my friends would just, I always had friends to walk to class with. One of my friends would try to come up and hug me and one of my best friends would put their arm around me and be like stay off her neck. They were making jokes out of it and yea, they protect me. So they if they saw people staring they would say let's walk this way or they would turn me and try to have me walk a different way and stuff.

Interviewer: Did – once you were back at school regularly, what kinds of things were you doing with your friends for fun?

Tracy: I didn't really do a lot at that point because I was so extremely tired I would come home and sleep until my mom made dinner. She would wake me up, make me eat dinner and I would go back to sleep. I wouldn't even do my homework so I didn't have any time or it's not I didn't have any time – I didn't have any energy to do anything.

Interviewer: And what about now?

Tracy: I do a lot, I do more things with my friends now. I was out until 11 last night and yea. I do a lot more things now, I am not as tired. I am still trying to get back up to being not tired anymore.

Tracy Mother: Or just to be able to function at the same energy level that her peers do.

Interviewer: Yea. Now, you had mentioned that you got a 504 for ADD and learning disability. Do you still have the 504 plan pertaining to the cancer at all?

Tracy: Yea, I do because I have to take medicine at school. It was just more of a- to cover my back if I needed to get out of class to call my mom, if I had a problem, if I didn't feel good. You need to be able to call my doctor or she knows more about my medicine than I do and she can kind of tell me if I'm like if I forgot to take my medicine in the morning and I needed it third period because I completely had forgotten and I needed to call her to see if I could take my second dose, I needed to be able to do that. Some teachers will be like no you can call at lunch, but I needed to call right then it's not something you can wait like that. It is something you need to take care of right then when you remember. So I did it to cover my back so I wouldn't get in trouble with my teachers if I have to call my mom or whatever.

Interviewer: In a way, having that 504 still in place gives you a little more freedom to take care of yourself.

Tracy: Yes.

Interviewer: Does that give you kind of piece of mind as well? Like if you didn't have that 504 would you worry that you wouldn't be able to get out of class to call the doctor if you needed or so on and so forth?

Tracy: Yea, because some teachers in our school we have the no cell phone policy and some teachers are really strict about it because they just are. Some of them wouldn't even let you go talk to your counselor which would be my counselor lets me come down whenever I want to just to sit in her office if I don't want to be in class anymore if I just can't like focus or something she will let me go down to her office and some teachers won't let you do that. Some teachers won't let you go down and talk to your counselor, so if I remembered, say in third period that I needed to go take my medicine my third period teacher would not let me leave to even go to the bathroom, I would be up a creek because I would need my medicine right then and I would need to call my mom or my doctor to figure out what to do.

Interviewer: So in a lot of ways that 504 plan keeps you calm and relaxed as well.

Tracy Mother: Yea, because there were days where just the nausea and vomiting were huge issues, that is tapering off as well but she needed to be able to just leave if she you know, felt that sick. She was needing to run to the bathroom because she was going to throw up. It is more facing that for us.

Interviewer: Like I said, it is so great to see that you are attending a school in a district that has been so supportive and so helpful.

Tracy Mother: I don't think all the schools are in the district. We have a friend of ours whose daughter, 15 years old as well, this summer was diagnosed with an inoperable rare brain tumor and her high school across town is just giving them shit. We have been trying to be supportive of them and talk to them about what Tracy's school has done and giving them people's names of what can be done – a lot of times it is just whether the school will actually be supportive and compassionate versus put the breaks on, so. It is a personnel issue too about who is going to be willing to help you. We just happened to be at a school that was.

Interviewer: Which is great. I am going to ask you a little bit about your family. Before I do I am going to ask you one difficult question about school. The reason I say difficult is because your mom is with you while I'm asking this, but did you ever find yourself going to your counselor when you felt fine, but you just needed to be out of class because you didn't want to be there?

Tracy: Yea, I do it now too.

Interviewer: Okay. Well, thank you for being honest about it.

Tracy: My mom knows that I do it. Sometimes people just get to my head and I can't deal with people who are asking so many questions about my thyroid or anything. I can't deal with people asking like five questions in a row that is when I just freak out and I just leave. So I just go sit in my counselor's office and she has me do stuff for her.

Interviewer: I am a little curious because you mentioned you don't mind talking about your cancer experience. But now you are saying that you get frustrated when people ask too many questions.

Tracy: It is just like when people ask like ten different questions in a row. When people ask me like one or two questions here and there I am completely fine. When people ask me why did this happen, what did you do, why did this happen, what did you it is just that is when I'm like oh my God, just be quiet. I can't do it. My head can't process that fast.

Interviewer: Do you have people that almost accuse you of causing cancer on yourself?

Tracy: No.

Interviewer: So when you say "what did you do…"

Tracy Mother: Even when I ask her many questions and then and then she gets frustrated with me. I will just ask what do you think about this, what do you think about that, what are your grades, what about this, did you study, when I start throwing a lot of stuff at her comments or questions it doesn't even necessarily have to be about school, she gets frustrated. I don't know if she gets overwhelmed but I can sense the frustration. And same with school if people just keep harping about the same thing over and over and over and multiple questions it gets frustrating for her.

Interviewer: Okay. So it gets a little overwhelming.

Tracy Mother: Information overload. Like, okay, I can't think about that many things at one time. And she will tell me you are asking me too many questions, I can't think straight anymore stop talking. I'm like okay.

Interviewer: Do you think that is something that maybe pertains to your cancer and remission experience or do you think that is something that is more associated with your learning disability?

Tracy: I think it is something that is more associated with my head. I have done it before I even got diagnosed with cancer. That I can remember.

Interviewer: Okay. Understandable. So let's talk a little bit about your family. Do you have any brothers or sisters?

Tracy: No.

Interviewer: And has your relationship with your parents changed at all since your diagnosis?

Tracy: It's only – I only live with my mom I don't speak to my dad. I don't even know him. I haven't seen him since I was five.

Interviewer: Okay. So it's just you and your mom.

Tracy: Yes. We have grown a lot closer I think since I have been diagnosed because she practically did everything for me when I was in the hospital, literally everything. And she has done all the research for everything. I think it has brought us a lot closer rather than grown apart. She has just had to take on so much more responsibility since then. Monitoring my medicine if she is noticing something I am doing weird, she has to get on it and call my doctor and make sure that it is okay. If it's not okay we have to get an appointment with some doctor right away and it is just so I mean she has kind of been my personal nurse.

Interviewer: Yea, moms go by many different titles. So, those are all things that made you guys stronger; your mom being able to just be there for you and just to take really good care of you. Now that you are heading into remission and you are starting to feel better and better do you feel like maybe you guys are getting less close or do you think that relationship is continuing to get stronger?

Tracy: I think it's continuing to get stronger because we still have to go to doctor's appointments together. I mean, we are always going to have to go to doctor's appointments together or at least until I move out and go to college. So for instance, when I do go to college I'm still going to have doctor's appointments and even after that I want to talk to her and find out what is going on and stuff. I don't think it is ever going to go backwards.

Interviewer: Aside from taking care of you, do you think that your mom has treated you any differently now then she did before you got sick? Does she go easier on you when you are misbehaving, anything like that?

Tracy: She has never been hard on me when I have misbehaved anyway, so it is kind of hard to say if she has been easier or harder.

Interviewer: Okay, so you would say it is maybe about the same?

Tracy: Yea. I've never really been like actually grounded. When I was little, but I have never really been like grounded, grounded. She has always been like don't do it again.

Tracy Mother: She has always been a really good kid and just I don't know she has always been really responsible. Little things we get into tiffs about laundry I kind of have to harp on, but for the most part I think there's normal give and take and you know, she just tends to be really responsible. I know she is busy with band, marching band, work and school I kind of ease off because I am sensitive to her time schedule, things like that.

Interviewer: And you understand that Tracy can get tired easily as well.

Tracy Mother: Yea, but I can kind of sense too when she is playing a little bit of the "oh, I'm tired I don't want to do anything" card because then 30 minutes later oh, I am going to go do this with my friend.

Interviewer: Yea, at the American Cancer Society office here we call it playing the C card.

Tracy Mother: Ah. (laughs)

Interviewer: Well, that's mostly all the questions I have for you. Is there anything that you really want me to take note of while we are talking right now about your entire experience or about the way you feel?

Tracy Mother: I think one thing that we were both impressed about is we just have so many people from everywhere. My parents came here from Arizona and they just at our house while we traveled to [the hospital]. My sister flew out and came with us so (Tracy) and I wouldn't be by ourselves and we took turns in her hospital room so she wasn't by herself, ever. So we just had my neighbors packaged up things, the charity that (Tracy) and I belong to, they brought over things. My neighbors brought over food and it was just an incredible outpouring of just people form everywhere just cards and letters and emails and just all kinds of stuff and my people put us on prayer chains all over the United States. It was cool, but just kind of different I am not used to that kind of attention so it was a little awkward. But it was neat. It was really refreshing.

Interviewer: Do you find that having that kind of support from everyone surrounding you did it help your situation?

Tracy Mother: I think so. It just gave an outlet so that I didn't just sit here. With it just being her and I at the house there was a lot of times it just you know, oh my God factor. How could this be, she is only 15 and it happened we got the diagnosis the day before her 16th birthday. First day of school, day before her 16th birthday. Just kind of a smoosh of just it was just a difficult time. So coming home and not really having anybody here, because I have to be strong for her it just was tough. Having that outlet of other people coming by and calling and emails and things like that kind of balanced it out.

Interviewer: Do you think that you would have been able to be as strong for her if they were not there?

Tracy Mother: Probably not. I just – I was on the phone with my mother who was just devastated and my dad too and because they couldn't do anything, they couldn't fix it. That's what moms and dads and grandparents do, they fix things and they were just devastated but she is the baby grandchild and there was nothing they could do to fix things. So it was nice to have them and just friends to just call and like oh my god what am I going to do. It was overwhelming. My family had offered what can we do, what can we do. They couldn't take her to the doctor's appointments, they couldn't do all the phone calls. Our insurance didn't cover the surgery for the most part because it was out of network they wanted it done here and I wouldn't allow that. It was just a lot of phone calls and a lot of stress.

Tracy: A lot of money.

Tracy Mother: One appointment to the next, and how are we going to pay for this and stuff like that. Plus, I just started a new job with the district as well.

Interviewer: Yea, a lot to happen with one plate.

Tracy Mother: Keep piling more on the haystack and hope it doesn't, somebody doesn't move a piece of straw and it all crumbles.

Interviewer: So, Tracy, do you think you are closer with your grandparents than you were before?

Tracy Mother: She has always been super, super close to them because I got divorced when she was a newborn baby, so they that was her family. Whenever she drew pictures of family at preschool it was always my mother and dad, their dog and Tracy and I. That is who the family was.

Tracy: My grandma and grandpa.

Tracy Mother: My mother and father, your grandparents. So it was always that was her family pictures that is what she knew who her family was. So they have always been very close to her.

Interviewer: That's great. Well, I am all out of questions. I would love to be able to contact you in the future if I have any further questions. Would that be all right with you?

Tracy: Absolutely.

End of interview.

17-year-old Caucasian female
Diagnosed: August 2010 – Metastatic Capillary Thyroid Carcinoma
Treatment Stopped: November 2010 – Surgery (continues maintenance treatment)
Second interview: June 2012 – Phone with mother present

Interviewer: We'll just jump right into it. How are you feeling?

Tracy: I guess okay.

Interviewer: Well, the last time we spoke, you were having trouble with fatigue and a little bit of weakness. Does that still persist?

Tracy: That's probably gotten better. I'm trying to remember when we… When did we speak last the first time?

Interviewer: It was October.

Tracy: Oh, okay. So we were already on this medication regimen. It is just a long road, you know, messing with medications and things like that. I've been on this medication for a year or so, and that's really helped. I'm not as tired. I'm not sleeping as much and things like that.

Interviewer: So, how's school? You graduated, right?

Tracy: Yeah.

Interviewer: Congratulations!

Tracy: Thank you!

Interviewer: So what's next for you?

Tracy: I'm going to college.[7]

Interviewer: That sounds exciting. Are you looking forward to it?

Tracy: Yeah.

Interviewer: So what are you most excited about in going to college?

Tracy: No idea.

Interviewer: Oh, there has to be something.

Tracy: I'm ready to leave [this town].

Interviewer: Any particular reason why?

Tracy: I hate it here.

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[7] University name omitted to protect anonymity.

Interviewer: Why?

Tracy: It's boring.

Interviewer: Oh, okay. Fair enough. So you're just ready to start the next chapter then?

Tracy: Yeah.

Interviewer: So I'm really glad to hear that the fatigue has kind of let up a little bit. What about – because I did talk to you in October – how was the second half of your school year?

Tracy: It was good.

Interviewer: You mentioned that you had trouble staying in class. Did that become easier, as well?

Tracy: No.

Interviewer: Okay, so you were still having focusing problems?

Tracy: Not with focusing. I just didn't go to school.

Interviewer: Okay…

Tracy's Mom (to Tracy): You should tell her about your academics, how you felt like you could focus better and you could listen to the teachers.

Tracy: Yeah.

Tracy's Mom: She had told me that she just felt more – I know you want to hear this from her…

Interviewer: No problem.

Tracy's Mom: …but that she could focus better and just when the teachers were talking, she actually could listen and comprehend what was happening and follow more closely what was going on and stay on top of things better.

Interviewer: Got it. Is that, do you think, because of the new medication?

Tracy: No, because the cancer isn't there anymore.

Interviewer: So just knowing that it's gone has given you that extra confidence boost?

Tracy: Well, no, it affected everything.

Tracy's Mom: Yeah, it affected that she had in the sense that… it affected how your brain processes information. It can cause cognitive fogginess and things like that. So the combination of the surgery and the medication being balanced now is helping a great deal.

Interviewer: Yeah, it sounds like it. Now, Tracy, you were already on a 504 Plan for ADHD, correct?

Tracy: Yes.

Interviewer: And then when you went back to school after the surgery, they added some more things to your 504 Plan?

Tracy: Mm hmm.

Interviewer: Does that carry over to college?

Tracy: No.

Interviewer: It doesn't.

Tracy: Uh uh.

Interviewer: Well, that's got to be a little scary for you. You had mentioned in our last interview that having it was a source of comfort for you.

Tracy: Yeah.

Interviewer: How do you feel about that?

Tracy: I didn't really use it that much.

Interviewer: Okay, so you think you'll be all right without it?

Tracy: Yeah.

Interviewer: Okay. And you also do get a little bit more of that freedom in your college classes, which is what you said you had needed before in your classes.

Tracy: Yeah.

Interviewer: So if you do have to get up and leave, it's not like you're going to get yelled at or anything.

Tracy: Yeah, exactly.

Interviewer: So mentally, you're feeling much better?

Tracy: Right.

Interviewer: Okay. And another thing you had mentioned when we last spoke is that you tend to get really overwhelmed when you get asked a strong series of questions in a row. Does that still happen?

Tracy: Uh huh.

Interviewer: Okay. Well, let me know if I overwhelm you at all as we're talking.

Tracy: Okay.

Tracy's Mom: Or you can direct it at me.

Interviewer: Fair enough, that works for me. Now, one of the things I remember you explained to me, Tracy, about your process from beginning to end – from diagnosis to now – you were explaining to me that your school was extremely helpful.

Tracy: Mm hmm.

Interviewer: What was the name of your high school?

Tracy: ______ High School[8]

Interviewer: And were they helpful just in getting you back on track?

Tracy: They were helpful the whole time… When I got back – up until I graduated.

Interviewer: Oh, that is great! And one thing I forgot to ask you last time which I meant to is when they had reintegrated you back into the school after taking that quarter off and they updated your 504 plan and everything, did they do any other sort of reintegration for you? Did they give a presentation? Did they talk to your teachers or your peers at all about you returning?

Tracy: I don't know. My mom does, though.

Tracy's Mom: She didn't want anybody to make any big deal about having her been gone. She was really concerned about people coming up like, "oh my gosh, where have you been, what happened?" She just wanted to slide in under the radar. So I had sent… I had addressed that with her counselor, who was beyond fabulous and instrumental in organizing everything, keeping everything on track. And so I emailed her teachers and just said, you know, Tracy kind of wants to slide back in under the radar. You know, she doesn't want kids bugging her or asking a bunch of questions. And so they just… So what Tracy told me is she kind of walked back into class – she only attended like half days at the very beginning or she'd go a couple periods and then come home. She didn't go back full time until after winter break. But her teachers just kind of… She said they just went about their business. They didn't oh my gosh, are you okay, are you feeling… They didn't, they just let her slide back in the door and nothing really was said, which is how Tracy wanted it.

Interviewer: Okay. And Tracy, that worked out well for you?

Tracy: Yeah.

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[8] Name of high school was omitted to protect anonymity.

Interviewer: Okay. Because I do remember you telling me that you were a little uncomfortable with people staring at your neck…

Tracy: Mm hmm.

Interviewer: …and that your friends were really protective.

Tracy: Yeah.

Interviewer: How does your neck look now? Is it still quite red?

Tracy: No, it's almost gone.

Interviewer: Oh, great. So would you say that it's almost not even noticeable?

Tracy: Yeah.

Interviewer: Oh, fantastic. Does that give you an extra boost in confidence, as well?

Tracy: Yeah.

Interviewer: And how's your relationship with your friends?

Tracy: Good.

Interviewer: Are any of them also going to [the same college as you]?

Tracy: No.

Interviewer: Okay, so you're going to have a whole new set of friends to make when you get there.

Tracy: Yup.

Interviewer: That's going to be really exciting. I remember that, it's a good time. When did you graduate?

Tracy: June.

Interviewer: June. And when do you head off to college?

Tracy: Like the middle of August.

Interviewer: So you must be doing all that college prep and shopping and sheets and bedding and all of that stuff right now.

Tracy: Yup.

Interviewer: That's always so fun. What are you hoping to study at college?

Tracy: Exercise science.

Interviewer: Really?

Tracy: Mm hmm.

Interviewer: And why is that?

Tracy: Because I want to do occupational therapy for kids who are diagnosed with cancer.

Interviewer: Excellent. And is that because of your experience?

Tracy: Yup.

Interviewer: Now, you had also mentioned to me that you were struggling a lot with your weight.

Tracy: Mm hmm.

Interviewer: Is that still true?

Tracy: Yeah.

Interviewer: Can you explain a little bit more? I mean, how are you feeling? How often do you try and adjust it?

Tracy: Well, I don't really know an answer for that.

Interviewer: Well, some of the things you had told me previously is that you felt really uncomfortable because people would come up to you and say that it looked like you lost weight and you hadn't. And you mentioned that it felt as though you were being put out there for all to see and so on and so forth. Is that still true?

Tracy: No.

Interviewer: Okay. How comfortable do you feel in your own body right now?

Tracy: Whatever. It doesn't really bother me.

Interviewer: It doesn't really bother you?

Tracy: Uh uh.

Interviewer: Okay. Do you think by majoring in this, you'll get to kind of apply some of it to yourself?

Tracy: Yeah.

Interviewer: Okay, good. So it's a learning experience for you, as well as you can share it with others one day.

Tracy: Mm hmm.

Interviewer: Excellent. I'm going to ask you a personal question if it's all right with you.

Tracy: Yes.

Interviewer: Are you dating anyone, Tracy?

Tracy: No.

Interviewer: Were you dating anyone in the last year?

Tracy: No.

Interviewer: All right. So I wanted to ask you also if you have any questions for me about the way that the study's going or if you have anything specific you want to ask me, as well.

Tracy's Mom: We have been interested just in the, like the goals behind the research.

Interviewer: Uh huh.

Tracy's Mom: As far as – and I know you're not trying to, like I hope this outcome comes out – but the purpose behind the research and how is it going to be shared with others. Not like as far as I know you'll keep her name private and stuff, but as far as what is it going to do to help other kids like her going through this to… You know, then that they're told that there's light at the other end of the tunnel or something to share with counselors or things to help kids for this.

Interviewer: For each participant that I speak with, I compile all of the information together and then, I see what patterns emerge when I do the analysis. And something that I've noticed – and Tracy, this is actually not the case with you – but a couple of the participants have struggled with the school not following through with their educational promises to the participant. And so as you say, you had a wonderful experience with your school within your district and they immediately added things to your 504 and you told me numerous times that you felt really supported. You're very fortunate for that. Unfortunately, a lot of the other participants haven't had that.

Tracy's Mom: Tracy's got a friend – actually, I knew this gal's dad for the past few years – who was diagnosed with an inoperable brain stem tumor a year ago so she and Tracy had gotten to be friends and stuff and seemed healthy. She was in the north side of [the city]. Obviously, we live in [the south side of the city]. Totally different experiences – same school system, everything, and totally different experiences.

Interviewer: Wow. Yeah, you had mentioned that the last time we spoke.

Tracy's Mom: There's a school that's just bent over backwards for us and wanted to make sure… Because I offered to pull her out of school and they just said absolutely not. This is her school, this is where she belongs. You know, kind of like this is her home and we want to make sure that it remains her home, something that's stable for her. And the school where this friend of Tracy's goes to, they just kind of butted heads. They haven't wanted to accommodate her. They now have a 504 plan, I kind of helped send them some information about some statutes in the 504 that they should bring up to the school in regard to her needing services. And I don't know how that's going now. The gal's going to be a senior this year.

Interviewer: Is she still undergoing cancer treatment? Or is she in remission?

Tracy's Mom: She's on experimental treatment.

Interviewer: She's on experimental treatment. Yeah, and so that's basically almost exactly what the research I've done so far has showed is that one participant has a wonderful experience and usually another participant – as you say, within the same city, within the same district – they'll have a completely different experience. And so what I'm starting to realize is that it seems difficult for these programs to implement the provisions across cases, which is really a shame because it's a national policy that it should be implemented for all students.

Tracy's Mom: Right. That's our thought, exactly.

Interviewer: So that's one thing that I've been noticing and that's kind of the direction that the data has sort of taken me in, which I think is extremely fascinating.

Tracy's Mom: Mm hmm. Is that something that you would then share with school districts, potentially?

Interviewer: Well, this is still a doctorate thesis, and it mostly for my educational purposes.

Tracy's Mom: Mm hmm.

Interviewer: And so it will gain recognition as I present it at conferences and publish papers about it, and I do plan on doing that. But beyond that, what a doctorate thesis does is basically, the purpose of – you know, besides just helping somebody to get their degree – the research purpose of a doctorate thesis is to notice where there is a discrepancy in research and try to fill the hole. And in instances where it can't fill the hole on its own, it'll point the direction for how best to do it in future research. So I think it would probably be safe to say that in terms of this exact study, the biggest way it'll contribute to the research field is by making it a little bit more well known that this is an area that requires attention. And it'll pave the way for other researchers to go from there.

Tracy's Mom: Mm hmm. Good.

Interviewer: Beyond that, it becomes a little bit more personal for me and it's just a matter of me trying to personally broadcast this as an area that needs more attention as often as possible.

Tracy's Mom: Okay, good. Well, we appreciate all you're doing.

Interviewer: Oh, absolutely. And thank you as well. I hope that answers your question?

Tracy's Mom: Yes, it does.

Interviewer: Okay. So yeah, in terms of specifically, will I be broadcasting this immediately to your local school district? That's highly unlikely. But one of the reasons why I did want to find out the name of the school that you attended, Tracy, is because I really want to start looking very specifically at the school districts and to look at the different ways that they are implementing these national policies.

Tracy's Mom: Unless a parent is involved and monitoring it… And we just happened to luck out, fortunately, with a really good high school counselor that was kind of Tracy's mom away from home…

Interviewer: That's fantastic.

Tracy's Mom: Made sure that Tracy was just well taken care of and had every opportunity. And I don't know that that would be truly said of all counselors. I don't know, that's just the one we fortunately have.

Interviewer: Absolutely. Now Tracy, did you ever feel that you needed to speak to the counselor about personal or emotional issues regarding your cancer?

Tracy: No.

Interviewer: Okay. So you didn't really kind of use her in that capacity. It was mostly just academic?

Tracy: Yeah.

Interviewer: Okay. Did you ever talk to anybody about it in that capacity?

Tracy: Unfortunately, not by choice.

Interviewer: Okay, so you did, but not by choice?

Tracy: Right.

Interviewer: Okay. So I'm curious. Why do you say unfortunately and not by choice?

Tracy: It was my mom's fault for making me do it.

Interviewer: Okay. What was so bad about it?

Tracy: Huh?

Interviewer: What was so bad about talking to a counselor?

Tracy: I don't like talking to people.

Interviewer: You seem to like talking to me just fine.

Tracy: Well, I don't know…

Interviewer: Does it have to do maybe with opening up about your experience? Or was it the person? Did you not trust them?

Tracy: I don't know what it was, I just didn't like it. (long pause)

Interviewer: Okay.

Tracy's Mom: …And she delved into other things, which got Tracy frustrated, I think. And she delved into other things that weren't directly related to the cancer. My intent was to make sure that Tracy felt she had a foundation, that she wasn't doing this alone, that if there were any fears or concerns that they were brought out into the open. And she felt she had some avenues to release some of the anxiety and things like that. But then, the counselor kind of went off in a different direction and started talking about other stuff.

Interviewer: What kinds of other things were they talking about?

Tracy: "It's your problem, it's your fault."

Tracy's Mom: My ex and I – Tracy's biological other parent – divorced when she was a newborn so he didn't have a relationship with her, like his choice. And so last summer, Tracy was wanting to get to know him possibly and so there were issues revolving around that. So it was stuff like that – how do you feel about that, Tracy, what about this?

Interviewer: Which really didn't have anything to do with her medical situation.

Tracy's Mom: …go away and I know it kind of got sidetracked and stuff. So it created… Like Tracy had told me, she's like whenever we go, it almost creates more animosity and brings up more issues that we were dealing with, her and I together on our own in our own way.

Interviewer: Got it.

Tracy's Mom: So that was the main frustration.

Interviewer: So Tracy, do you think you would've been better off had you not gone?

Tracy: Yeah.

Interviewer: Okay. I think that's fair. I mean, if it really wasn't helpful for you. How long did you go for?

Tracy: A year.

Tracy's Mom: No, we didn't go that long. No, I think we probably went for a few months, probably less than six months.

Interviewer: All right. Are we in agreement that it was less than six months?

Tracy's Mom: Yes.

Interviewer: Okay. But as you say, Tracy, it felt a lot longer than that?

Tracy's Mom: Why? (long pause)

Interviewer: Well, the reason I was asking about the counselor is because I'm also looking into how much a counselor plays into your cancer experience. As you said, your mom made you go to it. I wasn't sure if maybe the hospital had recommended it or if the school had recommended it, but your mom took the initiative on that one, right?

Tracy's Mom: She did see a social worker when we were at [the] Medical Center. Did she come like twice? She was a young gal, she was in training. I think she came by twice but Tracy was just kind of… She had calcium and magnesium imbalance just because they wiggled and jiggled around with her parathyroid gland, which controls your electrolytes.

Interviewer: Uh huh.

Tracy's Mom: And so she was having like calcium depletion seizures where she wouldn't seize – like you would think like a grand mal seizure – but she would just zone out.

Interviewer: Oh yeah, the smaller ones.

Tracy's Mom: Become emotionless and would just stare off, might become fixated on something. And she doesn't remember a whole lot of all the nitpicky particulars of being in the hospital because she was kind of in an out of these phases, depending upon her electrolytes.

Interviewer: Well, Tracy, that's actually quite common.

Tracy: Really?

Interviewer: Not the condition of the seizures being quite common but it's very normal for – at least from my experience with kids with cancer – it's common for them to not remember a whole lot about their experience in the hospital.

Tracy: Huh.

Interviewer: There's so much going on and you're not feeling well and you're usually on a great deal of medication. And so a lot of times, a lot of the memories of actually sitting in the hospital bed and being in the hospital can be difficult to find and to remember.

Tracy's Mom: Yeah, so the social worker gal came by a couple times – maybe twice over the course of the eight days just to see how she felt, if she was doing okay. There was no referral or recommendation beyond that.

Interviewer: Okay, so she just was checking in on your guys and then went on her way?

Tracy: Mm hmm.

Interviewer: Okay, all right. Well, that's also good to know. Now Tracy, I know that you don't particularly like to open up to especially strangers about your experience.

But if I may give you a little bit of advice, your time at college and being away from home, it might not be but it might be a little bit more difficult on you than someone who didn't have cancer. And so I would just encourage you – even though I know you don't' like opening up – if you do feel the need to talk to a counselor while you're at school, please do that. Because they're not going to all be like the one that you spoke to. They're not all going to delve into personal things. They're probably going to ask you about your classes and ask you why you're stressed and then go from there.

Tracy: Okay.

Tracy's Mom: I almost wished there was some counselor – I don't even know – maybe they exist and I didn't know where to look. And I went to this lady because her daughter, I'd known her for several years, and her daughter had knee cancer. So I thought she knows from a parent perspective and having a child previously having had cancer treatment, she would kind of be more understanding, sympathetic, and kind of understand where we were coming from. And then delving into other things that weren't pertinent to what we wanted to be there for. I don't know if there are counselors out there that specifically deal with people that have a health crisis.

Interviewer: To my knowledge, they do exist. But they can be hard to find because you won't find anyone, that I'm aware of, that would *only* specialize in that. That might be a branch of their specialty. But honestly, the best place to look would've been in the hospital and to ask the hospital [where Tracy was admitted]. They can do the research for you [in your hometown]. And so what the social worker should have done is given you guys a "just in case, here's so and so's" phone number if you need anything.

Tracy's Mom: Oh, okay.

Interviewer: That's what some social workers do, but not all. Some do, some don't. They do make their own assessments and they try and see if it's necessary. They probably saw that you were a very capable mother and figured that you guys would be just fine. But yeah, what I'm seeing more and more is that that's what the social workers are supposed to do. But it's not a matter of them doing it or not doing it because they do make their own assessment. And it's not for me to way whether or not you guys needed it at that time.

Tracy's Mom: Okay, yeah.

Interviewer: So I'm sure the person that came by to visit you guys was extremely capable and made her assessment for her reason. So I wouldn't feel like ripped off or anything like that. Because [Tracy's hospital] is almost as good as you can get. So yeah, it's been really interesting on my part seeing the different cases. And Tracy, I've spoken, actually, with several other girls – three off the top of my head, aside from you – that were seniors in high school, they're now going off to college. And it's amazing to me the similarities that occur between you girls. So I just wanted to tell you that. There are other people that understand what you're going through out there.

Tracy’s Mom: Cool. So we’re in the normal range.

Interviewer: Yeah, you’re absolutely in the normal range from what I can tell with my sample size. But I’m not kidding. If you need to talk to somebody at [college], you know, they have those resources available. And especially, like I said, somebody with your experience, it might just be that extra boost. And the great thing is that it won't be – and this is no offense to you, Tracy’s Mom – it won't be your mom doing it. It’ll be your choice and you can go one time and make your assessment of whether or not it’s working, and never go back if you don’t want to.

Tracy: Mm hmm.

Interviewer: So you know, you get to embrace all of that fun independence of being off at college!

Tracy: Mm hmm.

Tracy’s Mom: She’s excited. Her grandparents are up there and one of my sisters is there. My niece is going to school at [that college] right now and I was there years and years ago. And so the layout of the city and…

Interviewer: Oh, great.

Tracy’s Mom: …buildings are on campus. So I thought it’s a lot less transition than figuring out living arrangements and getting to class and what’s the rigor of the whole organization would look like.

Interviewer: Exactly. And plus you have family nearby just in case you need anything.

Tracy’s Mom: Yup, that’s what she said today. If she needs a home-cooked meal, just to call Grandma.

Interviewer: Oh, absolutely. Grandmas are the best for that.

Tracy’s Mom: Yeah, so it gives her a good level of independence and making choices on her own but yet still having that safety net.

Interviewer: Well, great! You know, I’m just about out of questions but Tracy, would it be all right if just in case I did have any more I could still contact you in the future?

Tracy: Yeah. Sure.

Interviewer: Okay, excellent. Thank you. And you know, before we wrap this up, do you guys have any other questions I can answer for you?

Tracy: I don’t think so.

Interviewer: Okay, all right. Well, I really appreciate you guys taking the time today. You know, I know it’s right in the middle of the day. But good luck going off to college. I’m so excited for you. That’s going to be awesome.

Tracy: Thank you!

Interviewer: And don’t hesitate to give me a call if you need anything.

Tracy’s Mom: All right, I appreciate your time. Thank you.

Interviewer: Thanks, have a good day.

Tracy’s Mom: You too. Bye bye.

Interviewer: Bye bye.

End of Interview.

Caleb

Caleb: 15-year-old Native American/White male
Diagnosed: November 2010 – Hodgkin's Lymphoma
Treatment Stopped: June 2011 – 3 months chemotherapy/6 months radiation
First Interview: October, 2011 – Phone Interview

Interviewer: Okay, so let's start by – if you could help me to understand what it was like when you were first diagnosed with cancer.

Caleb: Well, at the very beginning like I really didn't know what to think. Like, you're like okay and you're like this just didn't happen to me and that goes on for a few days actually until like you're like, okay, this is actually going to happen. Then, you have to go meet your doctors and everything, your whole team of doctors and like, okay, this is actually going to happen, okay. And, you kind of just like break down a little, and really think about everything.

Interviewer: And, did you have any kind of worry that was associated with it or were you just in this mind of shock?

Caleb: It was actually mainly a lot of shock in the beginning but like towards like the very beginning I'm like you got to do what you got to do just to get through it.

Interviewer: And, what kind of cancer were you diagnosed with?

Caleb: Hodgkin's Lymphoma

Interviewer: And, when were you diagnosed?

Caleb: November of 2010, last November.

Interviewer: And, what kind of treatment did you get?

Caleb: I went through chemo and radiation.

Interviewer: Chemo and radiation – how long did you undergo chemo?

Caleb: Chemo I had – let me think. I had to go down to [major local city] for five days at a time for three times and I had chemo every day. So I guess fifteen treatments overall.

Interviewer: So fifteen treatments and that was over you said five days at a time. Was that over three months, was that over a month?

Caleb: Probably about three months because I'd go there for – yeah, probably about three months.

Interviewer: Okay. And, so did you just kind of start to get used to going there for treatment or did you have that same kind of shocking feeling every single time?

Caleb: Actually, you pretty much get used to it. It's just really the first time because like you don't know what to expect so you're kind of just like a guinea pig and they just like – you just got to go through it, but the second and third time was just routine. Everybody, everything was just normal.

Interviewer: Uh-huh. And, so how did the chemo make you feel?

Caleb: Oh, the first time was horrible because they don't really know what to do because mean like they never really worked with you before. So they kind of got to let you go and like see what happens. And, I got really sick that night throwing up and like a couple days after I was like really weak and I had to go to the emergency room just because I couldn't do anything. And, like that whole time was just bad.

Interviewer: I would imagine that – I mean I don't know, I would be so worried that I would feel that way every day.

Caleb: Yeah, well, like you really are, like you really don't feel great but like compared to the other times that were worse it's like a lot better so you think you feel okay.

Interviewer: Okay.

Caleb: It's mainly just like sick, not feeling good and just kind of got to hang out because you're always tired.

Interviewer: And, when did you find out that your cancer was in remission?

Caleb: Probably about three months ago. Oh actually, let me think – yeah, June, middle of June.

Interviewer: What was going through your mind when you were hearing the doctor tell you the good news?

Caleb: I was extremely happy like because I was thinking this was going to be it because it was kind of the plan like if you get a PET scan and you see where you're at. So it could be impossible and you had to continue treatment or you're fine and we just go to radiation or actually you're just done. And, after they told me I was done with chemo I was thrilled.

Interviewer: I bet.

Caleb: But then like after that you had to continue with the radiation but that's a set, like they have those planned out to where you know when it's going to end.

Interviewer: Okay and so are you still undergoing radiation treatments?

Caleb: No, that ended June, middle of June.

Interviewer: Oh, okay. So when did you stop the chemo?

Caleb: I'm not sure. You want me to go and ask my dad real fast?

Interviewer: No, no, it's okay. I mean I can do the math because you said you were diagnosed about last year and then you did chemo for about three months because you had the – so I mean I can kind of figure that it was probably January.

Caleb: It was two like fifteen-day treatments.

Interviewer: Okay.

Caleb: And, three weeks in between so nine weeks total.

Interviewer: Nine weeks total.

Caleb: Yes.

Interviewer: Great, thank you. And, how did your family react when you told them that you're – you know when the doctor told them that your cancer was gone?

Caleb: Yeah, oh, they were so like – they kind of like looked – let's not get too happy before anything happened but like me – because my grandma was down here. Me and my grandma were thrilled when it happened but my dad just wanted to make sure like everything was perfect like we knew for a fact that we were just going to go to radiation.

Interviewer: That's great. Yeah, was he being extra protective, I guess?

Caleb: Yeah.

Interviewer: And, have you guys done anything to celebrate?

Caleb: Yeah, I mean like we went to – we just like went to dinner like that night and we planned a trip to – actually this weekend we're going to Disneyland.

Interviewer: Oh fun!

Caleb: Yeah and we're going to Mexico for Christmas and stuff, so. We got quite a bit planned.

Interviewer: Did you guys used to travel a lot before you got sick?

Caleb: We traveled. Like, we would go the normal vacation like once a year as a family but now we're just like might as well.

Interviewer: Enjoy life a little bit more now…

Caleb: Yeah, yeah, exactly.

Interviewer: So how often do you see your doctor?

Caleb: Now, it's just every three months. I just have to go every three months for like blood work, PET scan, and that's it.

Interviewer: Okay, do you take any oral medication?

Caleb: Not right now, none at all.

Interviewer: Oh, that's good. And, when you think about the fact that your cancer is in remission what kind of thoughts do you have in terms of your future?

Caleb: Just really like my future's just going to do whatever I can to make it what I want. I'm just going to go with the flow like nothing ever happened.

Interviewer: Do you have any thoughts on whether you're going to go to college or what want to do?

Caleb: Oh yeah. Yes, I'm going to go to college for sure but for a career I want to go into music production.

Interviewer: Wow, that's very specific.

Caleb: Yeah.

Interviewer: Do you…

Caleb: I've wanted to do it for a while.

Interviewer: Do you play an instrument?

Caleb: I play piano, guitar, trumpet, drums.

Interviewer: So you're a one-man band.

Caleb: Yeah, you could say that. (laughs)

Interviewer: Well, were you able to kind of find some, I guess, relief from treatment in your hobby of music?

Caleb: Oh yeah, definitely. I would like – piano is like – I play piano whenever I'm stressed or just like not having a good day. It just like takes you to a whole other place like, yeah, it just releases.

Interviewer: That's great. Everyone knows that having cancer is nothing that anyone would actually wish for but can you see anything good that came from this experience?

Caleb: Just the way you think of life afterwards and the way you appreciate it more.

Interviewer: Can you give me an example?

Caleb: Just like I appreciate like everything – just like I just make sure I have fun every day, just live life, have fun, do good, like get good grades, just do everything I always wanted to do.

Interviewer: Yeah. And, what would you say was the most difficult thing that you had to face in going through this whole process from start to finish?

Caleb: Like, the hardest thing actually was just dealing with the fact that I actually had cancer.

Interviewer: Uh-huh.

Caleb: That was really like the hardest part like just thinking about everything because it was a lot – actually, because my mom had cancer and she passed away from it. So it was kind of the thought that like I got it too and just – I mean that was really it.

Interviewer: When did your mom pass?

Caleb: Five years ago.

Interviewer: Five years ago so you were definitely old enough to remember it.

Caleb: Yeah.

Interviewer: Did that experience have any kind of bearing on your own emotions when you were diagnosed?

Caleb: Like, what do you mean, like…?

Interviewer: Well, I mean knowing that anyone who's passed away from cancer and on top of that have it be your mother I would imagine that once you were diagnosed there might be kind of an automatic fear that that might be your fate as well.

Caleb: Oh yeah, there was definitely like the thought of it but like you just have to like keep in mind that that's completely different than what you had and it's not like – it doesn't run in the family and everything. And, the doctors would tell me that over and over and over, so.

Interviewer: So it was kind of helpful to have that reassurance.

Caleb: Yeah, definitely.

Interviewer: Great. It sounds like you had some really good doctors.

Caleb: Oh yeah, I did, definitely.

Interviewer: Do you mind when people ask you about your cancer experience?

Caleb: Oh, not at all. Like a lot of people like whenever people ask me they're like you don't have to answer if you don't want to. I don't care at all. I'll talk all day about it.

Interviewer: That's good. Is there any particular reason why you are so comfortable discussing it?

Caleb: I don't really know why.

Interviewer: You just are? You're just happy to…

Caleb: I mean if they ask, yeah, I'll let you know what's going on.

Interviewer: Do you feel different from your friends in any way?

Caleb: I think – I might appreciate life more than they do, not in like the sense that a different or a better way, just different.

Interviewer: Uh-huh. How much support did you receive from your friends throughout this process?

Caleb: Oh, I got a ton of support. Like, I'd get calls daily and like it got to the point where like I had Facebook posts about me and all my friends, like every one of my friends posted something about me on Facebook. And, it got spread out throughout like all of the school and I got like posters from all of my friends. And, I got like calls and just prayers from everybody around…

Interviewer: That sounds great.

Caleb: …from like everybody, yeah.

Interviewer: I would imagine that that would give you a little extra strength.

Caleb: Oh yeah, it actually really does. Like, I had like my posters up in my room and stuff and I just looked at the all the time. Yeah, it definitely does.

Interviewer: So, were you absent from school quite a bit?

Caleb: I was. It was just over a quarter.

Interviewer: Just over a full quarter of school?

Caleb: Yeah, like it was supposed to be actually like over a half a year. As things turned out good and I managed to make it only a quarter.

Interviewer: That's fantastic.

Caleb: Yes.

Interviewer: Was the school supportive?

Caleb: Oh yeah, definitely. Like, I'm a lot closer with my counselors because they know the whole, like, everything that's going on so they just – my only concern was to make it through ninth grade without having to repeat it and that happened so everything worked out.

Interviewer: So did they give you kind of like any supplementary help as far as like an IEP or anything?

Caleb: They gave me a school tutor.

Interviewer: Okay.

Caleb: Like, someone that works in the district and he'd come over every day, well, Monday through Friday for an hour each day. So it wasn't much time but it was enough to help me with what I needed.

Interviewer: And, were you – you were with the tutor for an hour everyday but were you doing schoolwork outside of that hour as well?

Caleb: Yeah, not much but as much as I could that night. Like, he'd give me a few papers to do and like I'd try to stay with what they were doing in class but it was hard just knowing that I wasn't in class and I couldn't learn with them. But, I'd just try to like kind of keep up with everything that's going on.

Interviewer: Yeah. What was it like after that quarter that you had off from school? What was it like walking back into school and getting back into the routine?

Caleb: Yeah, it was definitely like crazy, like surreal like, you just look at everybody and everybody's like freaking out because you're back. And, I mean just – I couldn't wait to get back to my old routine and everything. Like, you think its fun to be away from school but definitely not that long.

Interviewer: Definitely not that long. So it was kind of fun at first maybe?

Caleb: Yeah and it was just good to be back with friends and be able to be around them anyways without getting sick.

Interviewer: Uh-huh. And, when you were back at school has the school done anything for you now that you're – when you were first returning?

Caleb: They definitely worked with me. Like, I'd have to – I just had to go in a lot and learn extra stuff but they were fine with everything. They would just let me kind of slide through with what I had to but I'd do a lot of work. But, the things that they knew I couldn't like handle like that they learned prior to when I was there they would be fine with.

Interviewer: Can you give me an example?

Caleb: Like, my Spanish teacher last year she would just like – because I missed like the main part that I had to learn and she just helped me with it. Like, if they were doing something in class like she let me just kind of go with the flow until she could get one-on-one with me and then we'd learn it together then.

Interviewer: Oh nice! That's great. And, before you got sick what kinds of things did you do with your friends for fun?

Caleb: Just really hang out, go to movies, parties, not that much, but just snowboarding, skateboarding, music, all that.

Interviewer: Uh-huh and how did that change once you got sick?

Caleb: Like to now or during?

Interviewer: During when you were actually undergoing treatment.

Caleb: During was really hard. Like most of the time I was sick and just like – well, actually not most of the time I wasn't sick, just tired and couldn't really do much. Like, I'd want to do a lot of stuff so I'd go out and I'd just get tired really fast and burnt out. So I'd have to come back. But, I'd hang out with friends as much as I possibly could.

Interviewer: Okay and has that – since you've gotten better again would you say you're – the things you do with your friends is completely back to normal?

Caleb: It's back to normal but the things we do are like we're a lot crazier now I guess you could say.

Interviewer: How so?

Caleb: Like, we just do anything that we think is fun like the stupidest things possible.

Interviewer: And, this goes back to your desire to make sure you live every day to its fullest.

Caleb: Pretty much, yeah.

Interviewer: Okay, well, at least you're doing it with friends.

Caleb: Yeah, exactly and hopefully maybe teaching them to live life to its fullest as well.

Interviewer: Yeah. And, so – I'm sorry I just lost my place.

Caleb: Take your time.

Interviewer: How many different teachers would you say you see in a day?

Caleb: Like my teachers or just teachers like – what do you mean?

Interviewer: Like your teachers, like how many classes, different classes, do you go to?

Caleb: Oh, I have six classes a day.

Interviewer: Six classes a day – and they were – they're all as helpful and responsive as your Spanish teacher has been?

Caleb: Uh, like now they like really don't have to be anymore just because the whole routine's fine now and everything's back to normal.

Interviewer: So as you've started your sophomore year it's almost as if nothing's happened.

Caleb: Yeah, pretty much. Like, half my teachers really don't even know what happened to me.

Interviewer: Oh wow! Okay.

Caleb: Yeah, unless it like actually comes up and like in an essay or something then they'll find out that way.

Interviewer: Do you have any physical differences from the cancer or the chemo?

Caleb: Not really physical but like I can't do heavy lifting weights anymore.

Interviewer: Because you get tired easily?

Caleb: No, not that. It's just like I'm actually better than I used to be like with – I'm actually a lot less tired now than I used to be. It's just like okay with the sickness I had and the treatments I went through some other person like a long time ago had the same exact treatments and he died while lifting weights. So it's like just precaution. Like its nothing really but if something happened to someone – you know what I mean. It's nothing really but it's just precaution so nothing can happen.

Interviewer: Okay, so it not as though you're physically unable to do it. It's just that you've been asked to avoid it.

Caleb: Yes.

Interviewer: Got it. So let's talk a little bit about your family. Do you have any brothers or sisters?

Caleb: No.

Interviewer: So it's just you and your dad?

Caleb: Yeah.

Interviewer: What kind of family support did you have during treatment, grandparents, aunts, uncles, anything?

Caleb: Yeah, my grandma came down from where she lives to come here for like five, six months to help out.

Interviewer: And, this is your dad's mom?

Caleb: Yes.

Interviewer: Okay. Do you still stay in touch with your mom's side of the family?

Caleb: I try to as much as I can because a lot of them live here. Yeah, so I mean I stay in touch with my cousins a lot and my aunts.

Interviewer: And, were they supportive?

Caleb: Oh yeah, definitely. They were extremely supportive.

Interviewer: That's good. I would imagine that it would be difficult for them as well having lost her.

Caleb: Yeah.

Interviewer: And, then seeing you go through cancer.

Caleb: Like, at times, it seemed like it was harder for them than it did for me. Like, it's weird to understand but… (pause)

Interviewer: No, I think that makes sense. I can see that. Did you feel this need to kind of any time they were around or on the phone checking up with you, did you feel any need to kind of make yourself seem healthier than you were for their sake?

Caleb: At times. It just depends who I was talking to really like whether it be my aunt or my cousins because my aunt would probably worry more than my cousin would. But, usually actually most of the time when they called I was feeling fine so that's what I'd tell them.

Interviewer: Okay, so you didn't actually have to cover for yourself.

Caleb: Not really that much.

Interviewer: How is – well, I should say how has the relationship changed between you and your dad?

Caleb: Oh like we've been extremely close. I mean like we've always been close but even more so since my mother passed away but ever since I've had (cancer) we've been a hundred times that closer.

Interviewer: Yeah, I just – I'm trying to think about what your dad must have gone through when you were diagnosed…

Caleb: Yeah, he was definitely a lot more worried than I was like by a hundred percent.

Interviewer: Well, he's your dad.

Caleb: Yeah.

Interviewer: And, so would you say that it's the same – like your relationship with him is just as strong as it was before you were diagnosed?

Caleb: Oh yeah, if not way more than that.

Interviewer: And, how was he during your treatment?

Caleb: He was always really nervous just like you could tell. Like, he would say he wasn't but he was always tense and you could just tell like the whole time. And, like I kind of felt bad because I didn't – I mean I had nothing to do.

Interviewer: Uh-huh, yeah, I mean I'm sure you, of course, wanted to make it easier for him but you can't help what's going on inside yourself.

Caleb: Exactly.

Interviewer: Do you think he treats you any differently now?

Caleb: Yeah, I'm probably more spoiled now.

Interviewer: More spoiled now. Can you give me an example?

Caleb: Just I mean like me and my dad always have fun with anything we do but now like we're going on trips and all that kind of stuff.

Interviewer: So when you guys go to Disneyland, is it just you and him?

Caleb: No, actually it's going to be me, him, and my dad's girlfriend who's been living with us for a few years. So I'm like really close with her because she was with me through all my treatments and everything and she helped like a ton. And, so she's coming down and my cousin's coming down.

Interviewer: That's going to be – it sounds like it'll be a fun group of people.

Caleb: Yeah, it'll definitely be fun and a few friends are going to be down at the same time so it'll be good.

Interviewer: So do you think as you mentioned your dad's girlfriend was really there for you during treatment, would you say that your relationship with her has strengthened through this process?

Caleb: Oh yeah, like a million percent. It's like we've always been really close but she's helped a ton through everything.

Interviewer: So would you say she's kind of maybe stepped into a more maternal role with you?

Caleb: Yeah, definitely.

Interviewer: Interesting. So you actually breezed through my questions which normally take much longer than this so I just want to ask you, I mean is there anything else that you'd like to add to the conversation?

Caleb: Uh…

Interviewer: Anything about how life has been since you've been in remission?

Caleb: Just I've been making it a lot more fun than it usually is, just having fun with everything I do.

Interviewer: Now, you had mentioned to me earlier that one of your concerns is that you have too much fun.

Caleb: Yeah, I mean I do but I mean if I really think about it I mean life's short, have fun.

Interviewer: So it's worth it.

Caleb: Yeah. I mean I always get my work done. I have straight A's and everything but I always make sure I have fun during the day, too.

Interviewer: Great, yeah. I think that's a good way to look at it.

Caleb: Yeah.

End of interview.

15-year-old Native American/White male
Diagnosed: November 2010 – Hodgkin's Lymphoma
Treatment Stopped: June 2011 – 3 months chemotherapy/6 months radiation
Second Interview: June, 2012 – Phone Interview

Interviewer: All right, so you were telling me that you just got a job. What have you been doing?

Caleb: I've just been working all summer like that's really all I've been doing. I just work up at the water park that we have as a lifeguard.

Interviewer: Oh, very cool.

Caleb: Yeah.

Interviewer: Do you like it?

Caleb: Yeah, it's a fun job. I mean it's a good summer job.

Interviewer: Yeah.

Caleb: So…

Interviewer: And remind me, what year are you in school?

Caleb: What do you mean? Oh. I'm going into junior year this year.

Interviewer: You're going into junior year. Okay, I couldn't remember if you were going in as junior or senior. Okay. And what's the name of your school?

Caleb: ______ High School.[9]

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[9] Name of school omitted to protect anonymity.

Interviewer: It's kind of funny because a friend of mine was actually just talking to me about Hot August Nights coming up.

Caleb: Oh yeah?

Interviewer: Yeah, I used to live there when I was younger and I loved it.

Caleb: Oh yeah. I mean I love it. I mean I honestly would think about going somewhere else and then I'm like I couldn't do it.

Interviewer: Yeah. Well, it's tradition. You just get used to it.

Caleb: Yeah, exactly.

Interviewer: So how are things? How are you feeling? How's school?

Caleb: Everything's good. I mean honestly just I'm just trying to get everything together now after everything. So I'm working, getting money, just getting ready for school.

Interviewer: So what do you mean when you say get everything together after everything?

Caleb: Just like trying to do my best with everything like I'm trying to like – I already have a job so I'm like trying to stay on that. I'm just like doing like all my schoolwork and stuff, just trying to keep on top of everything.

Interviewer: Yeah. Do you have any residual anything from your cancer experience?

Caleb: No.

Interviewer: So it really is as if nothing ever happened?

Caleb: Yeah, pretty much.

Interviewer: And you're not feeling any nervousness or anything about it coming back?

Caleb: Not at all, no.

Interviewer: Not at all?

Caleb: No.

Interviewer: Okay. Do you still go for regular checkups?

Caleb: Yeah, I just actually – I had mine yesterday.

Interviewer: And it went well?

Caleb: Yeah, everything was good. I got to get a PET – not a PET scan, but a CAT scan and a CT scan and just blood work.

Interviewer: And do you find out about that stuff right away or do you have to wait for it?

Caleb: Well, I had those two days ago and then I had my meeting yesterday with them.

Interviewer: Okay. And everything is all good?

Caleb: Yeah, the only they said is like thymus gland in my neck was like – it looked slightly enlarged so they're going to look at it but they said it's nothing to worry about at all.

Interviewer: Are you feeling any weirdness or worry about that?

Caleb: Not at all, no.

Interviewer: Okay. So I mean pretty much if they tell you it's nothing to worry about you don't worry about it.

Caleb: Yeah, exactly. Like I mean if they're not worried I'm not worried.

Interviewer: Okay. Well, the last time we spoke you were talking to me a lot about your friends. How are things going with them?

Caleb: Different. It's like, I don't know, like because I like, it's only like me and two other friends that have cars.

Interviewer: Okay.

Caleb: So it's kind of hard to get coordinated on that, but a lot of my friends are very motivated.

Interviewer: Very motivated to find a way out of the house…

Caleb: Or to find a way to do anything. Hang out.

Interviewer: Yeah.

Caleb: Well, I mean, like, I still hang out with them all but I'm starting to hang out with some different people, too.

Interviewer: Well, that must be nice though, and refreshing.

Caleb: It is, definitely.

Interviewer: So but I mean you would say that you're friendships are all in good graces and everything?

Caleb: Yeah, definitely.

Interviewer: All right, excellent! Well, there was something I wanted to ask you the last time we spoke and it had just slipped my mind. When you were talking to me about the time you were absent you had mentioned that you were absent for about a quarter of school.

Caleb: Yes.

Interviewer: Okay. And during that time you got home schooling, right?

Caleb: Uh-huh

Interviewer: And they had a tutor from the district come to your house?

Caleb: Yeah.

Interviewer: How often did they come?

Caleb: They came every morning from – oh God... I want to say every morning to read. No, I think they came five times a week for an hour every day.

Interviewer: Okay, so Monday through Friday?

Caleb: Yeah, an hour a day.

Interviewer: Excellent! Thank you. And when you got back to school, did the school do anything like a presentation for the other kids or talk to the teachers for you? Was there any sort of reintegration?

Caleb: They talked to every teacher like just to let them know what was going on just so they could help me out. Like, it was like kind of like everybody has to do this. It was kind of like when you talk to the teachers they like – each teacher has like a different plan for you.

Interviewer: Okay.

Caleb: Yeah, so they all helped out extremely.

Interviewer: So what was their different plan?

Caleb: Well, like my Spanish teacher, because I had to switch Spanish teachers, so she kind of like just let me like kind of go under the radar a little.

Interviewer: Uh-huh…

Caleb: And like biology, she let me skip some of the tests and stuff. So it was just kind of different like that.

Interviewer: Okay, so they really kind of left it up to the teachers to decide how best to reintegrate you.

Caleb: Yeah, exactly.

Interviewer: Great! Okay. That’s a pretty flexible way to go about it.

Caleb: Yeah, it was nice. It was definitely nice. Like, it was definitely a lot less stressful.

Interviewer: So it wasn't stressful on you?

Caleb: No.

Interviewer: And did you feel like you had a really smooth transition?

Caleb: Yeah, everything… Yeah, it was like I just got there and it was just normal again.

Interviewer: Great!

Caleb: Uh-huh.

Interviewer: You know I have to admit not everybody has been fortunate enough that I've spoken with to have an experience like that.

Caleb: Yeah.

Interviewer: So you must feel pretty lucky.

Caleb: Yeah, I'm happy.

Interviewer: I bet, especially after what you went through.

Caleb: Uh-huh

Interviewer: So how else are things? Was that your step mom that I spoke to?

Caleb: Yeah, that was her.

Interviewer: And when I spoke to you guys last you were about to head off to Disney World, I think.

Caleb: Yeah, we got to go to Disneyland down in LA.

Interviewer: How was that?

Caleb: Oh, it was great! Like because it's usually just like the family that goes down but it was me and like three of my friends, too

Interviewer: Great! That sounds fun.

Caleb: Yeah, it was so much fun.

Interviewer: That's always fun when you can bring friends along with you.

Caleb: Yeah, exactly.

Interviewer: So you were also telling me that you and your dad were really careful about trying to kind of embrace life.

Caleb: Yeah.

Interviewer: And you mentioned that after your experience you kind of felt almost a responsibility to be really positive.

Caleb: Yeah, like I was always just that way but just way more so after everything. Like, I'm still that way definitely. Like I always think of everything and I like just look at the big picture of everything. Like, I try to stress so much that I'm still alive.

Interviewer: Yeah, exactly. Well, I was wondering, do you – has that tapered off at all or do you still feel exactly that kind of positivity that you had they day you found out your cancer was gone?

Caleb: I don't think about it as much. Like I don't think about it but I always feel the same exact way.

Interviewer: Okay. So you really don't – how often would you say you think about your cancer experience?

Caleb: I think about it all the time just because a lot of people ask about it.

Interviewer: Okay

Caleb: Just because they wonder about it but yeah, I talk about it all the time and think about it.

Interviewer: But when you do, you feel positive?

Caleb: Yeah, I mean I feel – like, they're always like are you okay talking about it? I'm like yeah. I don't care. Like, I talk about it all the time and yeah, everything's good about it because I mean everything went smoothly so I have nothing to hide about it.

Interviewer: Yeah. And it's not as though you're still walking around with scars and things like that, right?

Caleb: Yeah, I mean even if I was, I wouldn't really care. That's the least of my worries.

Interviewer: What's the most of your worries?

Caleb: Nothing really, just really most of my worries I have is school.

Interviewer: And what's going on with school?

Caleb: Oh no, I'm just trying to like stay on top of it and like get good grades with everything.

Interviewer: Yeah. Well, you had mentioned to that you were so busy having fun with your friends last year that you might have been letting school slip a little bit.

Caleb: Yeah, it like – my grades went up and went down slightly, nothing that was crazy, but they went down slightly and I was like okay, that's enough.

Interviewer: And now you're getting back on top of it.

Caleb: Yeah.

Interviewer: So you're not taking any summer school or anything?

Caleb: No, I'm just – all I'm doing this summer is working.

Interviewer: Okay. That's good. And how often do you work at the water park?

Caleb: It kind of depends because they send you a new schedule every two weeks. But it's usually about five days a week, five to six days a week.

Interviewer: Oh, that's great for a summer job.

Caleb: Yeah.

Interviewer: Excellent! And that, I'm assuming, will stop just before school starts?

Caleb: Yeah, I'm assuming it'll just end.

Interviewer: Yeah, so you won't have to do school and work or do you think you'll get a job while you're in school?

Caleb: No, probably not.

Interviewer: Okay. Just focus on school.

Caleb: Yeah, exactly.

Interviewer: So we talked a little bit last time about what you were hoping to do after high school.

Caleb: Uh-huh

Interviewer: And I just wanted to see if your thoughts have changed at all?

Caleb: Well, I was thinking about music production.

Interviewer: Yeah.

Caleb: And we actually went down to [the college] because we were going to – we like [unclear talking]

Interviewer: Oh, I'm sorry. Can you hold on just a second? I don't know what just happened with this phone. Can you hear me? Let me try to put you back on speaker again. All right, can you hear me?

Caleb: Yeah, we're good.

Interviewer: Okay, so say that again. You went down to [the college]…

Caleb: Yeah, because we were in Boston so we were like – I was like let’s stop by [the college] because that was the college I wanted to go to. And it was amazing. Like it was intense, like it was crazy so but I always think about like that was always just my number choice but then I would think about like just going into – what do you call it – just as like a childhood cancer doctor.

Interviewer: An oncologist?

Caleb: Yeah, like kind of just like my doctors, like Dr. Smith and Dr. Jones.[10] They’re like the specialists so they’re like the doctor that like tells you like what you’re like – what’s going to happen and like they were like the doctors that like gave me my game plan. Like, this is like the chemo you’re going on and like they help you through everything and talk with you through everything.

Interviewer: Uh-huh.

Caleb: So like I always think about that stuff.

Interviewer: So you’re actually starting to think about something more medical then.

Caleb: Yeah, just because I like the music industry is like really sketchy just and everything like it's never really set in stone.

Interviewer: Uh-huh

Caleb: So I always think about that stuff because I don’t know. I just think it would be cool like actually being after everything and going back in the same field that I got treated from.

Interviewer: Yeah. Well, I mean you’d be able to give your patients a little bit more perspective.

Caleb: Yeah, exactly, yeah.

Interviewer: Because you know exactly what it was like to go through it.

Caleb: Yeah, that’s why I thought it’d be like – and it's a really rewarding like area.

Interviewer: Uh-huh. You know it's difficult too.

Caleb: Oh yeah.

Interviewer: I mean you’re talking about a medical field and then on top of that I mean it's emotionally difficult being – having to deliver bad news.

Caleb: Uh-huh

Interviewer: Do you think you’d be able to handle that?

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[10] The names of both doctors have been omitted to protect participant anonymity.

Caleb: I think I would just because of like… I connect with them just because I've been through it too.

Interviewer: Uh huh. I understand.

Caleb: So I think I could make them feel better at the same time.

Interviewer: Yeah. I think that's great and I think it's fantastic to hear that, not only that you've taken so many positive outlooks away from your experience, but that you actually want to put it to a good use as well.

Caleb: Uh-huh, yeah.

Interviewer: And of course, that's if you decide to go that direction.

Caleb: Yeah, like I was trying to donate like – like I would try to donate like blood or bone marrow to them but they just – I tried doing it during school and they wouldn't let me either.

Interviewer: Why is that?

Caleb: Yeah, because we had like a blood drive. Just, I guess like the type of cancer I had it's not allowed.

Interviewer: Oh, okay.

Caleb: Yeah.

Interviewer: Well, I'm sure there are plenty of other ways you can find to donate. You can volunteer and help out other ways, too. Well, I wanted to ask you Caleb, did you have any questions for me about what I've been up to or what I've been doing?

Caleb: No, I mean like – well, my only question is like how many people have you talked to like this?

Interviewer: Well, with regard to the study I had eight participants including you.

Caleb: Okay.

Interviewer: So it's just a handful of people and I've been talking to you guys a couple of times and I get really in depth about emotions and feelings and experiences, and then I put it all together and I look at the similarities and the differences. And then I also look at from a business perspective almost, how could the school or a social worker have made your school experience better?

Caleb: Yeah, exactly.

Interviewer: And it's interesting with you because you've had such a positive experience overall.

Caleb: Yes, I know I have.

Interviewer: So it's really fascinating for me because as I look at some of the other participants who may not have had as positive an experience as you've had I like to actually kind of use you as the baseline of what these kids needed to get but didn't that you got.

Caleb: Yeah.

Interviewer: And so I find that really interesting, and in that regard, your story and your participation has been absolutely monumental.

Caleb: Thank you.

Interviewer: No, thank you. I can't even tell you how much I appreciate that.

Caleb: Oh, no problem.

Interviewer: So then beyond that basically I've already spoken with everyone and I've spoken with everyone twice. You're the last one for me to talk to a second time. And basically, yeah, I just keep putting it all together with the intention of putting it out there for researchers to do more with it in the future.

Caleb: Uh-huh

Interviewer: And in terms of how many kids I work with this project has eight participants but I've been a regular volunteer at Children's Hospitals and the American Cancer Society for the last eight years.

Caleb: Oh, okay.

Interviewer: So I work with all ages of kids who've experienced cancer and survived it and, unfortunately, I've also been around some kids who haven't survived it.

Caleb: Yeah.

Interviewer: But, I mean, similar to your situation it was just something that I knew I wanted to spend time focusing on and helping out with.

Caleb: So how did like these eight people get chosen though exactly?

Interviewer: Well, the same way you did. Essentially with the help of the American Cancer Society I had sent out the flyers that you and your dad got. And then from there because I was not allowed to contact any of you directly...

Caleb: Yeah, exactly.

Interviewer: …so from there was the ones that chose to participate.

Caleb: Uh-huh, okay.

Interviewer: So basically what I've started looking at is I have noticed that there are a lot of kids that, unlike you, have not received the services that they feel they should have.

Caleb: Yeah

Interviewer: So that's essentially where this is going and it's – I find it really fascinating because I never expected it to go into that direction but you guys…

Caleb: No, I wouldn't have either.

Interviewer: Exactly and you guys and your stories have just kind of shown me that some people that have cancer aren't getting what they feel they need to keep up with their school.

Caleb: Yeah, I agree.

Interviewer: So you agree. Have you experienced that with friends or anything?

Caleb: Well, like I can see it like for sure because like when I was going through it there was like one teacher that just wouldn't do anything.

Interviewer: Oh really?

Caleb: Yeah, it was my biology teacher and she like – well, it wasn't anything. Like she tried to do it in a nice way but she like she wouldn't give me any less work to do at home.

Interviewer: Okay.

Caleb: She's like this is what you have to do to pass the ninth grade.

Interviewer: Yeah.

Caleb: And it was everything everybody else had to do so like they had like everybody talking to her and yeah.

Interviewer: And she wouldn't budge…?

Caleb: No, not really until she – until like one of the higher end people at the school came down and said she had to.

Interviewer: Wow! Okay. So it really went all the way up.

Caleb: Yeah.

Interviewer: Interesting. So yeah, I mean unfortunately where you had – in your situation where you had somebody fighting that battle for you within the school, unfortunately, not all of the participants I've spoken with haven't had that person there to fight on their behalf.

Caleb: That's so weird to me.

Interviewer: Yeah. So it's…

Caleb: I don't get why.

Interviewer: Honestly, I don't either and that's basically what I'm trying to figure out. So yeah, that's essentially what I'm trying to figure out and we're going to take it from there. Does that answer your question?

Caleb: Yeah, yeah, uh-huh.

Interviewer: Great! Well, any other questions…?

Caleb: No, I don't think so.

Interviewer: Okay, well, you've got my cell phone number.

Caleb: Yeah, I do.

Interviewer: So feel free to text me or call me if you have any further questions or if your dad or your stepmom wants to get in touch with me for any reason.

Caleb: All right.

Interviewer: Would it be okay if I gave you a call later if I have any more questions?

Caleb: Oh yeah, that's no problem.

Interviewer: Great! Caleb, I really appreciate it. And it sounds like you're doing great.

Caleb: Yeah, everything's going good.

Interviewer: So enjoy the rest of the summer and good luck with the start of school. And hopefully, I'll chat you again soon.

Caleb: Sounds good.

Interviewer: Take care.

Caleb: You too. Have a good summer.

Interviewer: You too. Bye-bye.

Caleb: All right, bye.

End of Interview.

Brandon

14-year-old Caucasian male
Diagnosed: September 2008 – Non-Hodgkin's Lymphoblastic Lymphoma
Treatment Stopped: November 2010 – chemotherapy (oral and intravenous)
First Interview: November 2011 – Phone

Interviewer: Great, so let us start by please explain to me what kind of cancer you were diagnosed with?

Brandon: Non-Hodgkin's lymphoblastic lymphoma.

Interviewer: Okay and when were you initially diagnosed?

Brandon: End of September '08.

Interviewer: How did you handle getting that diagnosis?

Brandon: It was hard to take, you hear about people getting it, it does not really affect you and then once you actually hear that you have it, it is like, it breaks your heart.

Interviewer: Can you describe to me what you had to do every day for treatment?

Brandon: I had to take pills most days, and I had to take [a combination antibiotic treatment][11] on the weekends so that I would not get infections, it would fight infections. I would have to get IV chemo not every day but you just want like every day stuff or just?

Interviewer: Well let us talk a little bit about the chemo, how much chemo did you get, how often?

Brandon: Every night I would have to take a pill, and then once or twice every week I would have to go in and get IV chemo. I would have to get it in the mediport; I would have to get lumbar punctures when I would go in for those treatments in my back.

Interviewer: How long did you have to do all this? I am sorry, say that again?

Brandon: I would have to get shots in my legs too.

Interviewer: How long did you have to do all of that?

Brandon: Two years, or like yeah two years.

Interviewer: Two years, so you have had two years of treatment.

Brandon: Yeah.

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[11] Medication name redacted to protect participant privacy.

Interviewer: That sounds like a lot to take for two years.

Brandon: Yeah.

Interviewer: So how often were you actually in a hospital?

Brandon: Probably like four times a week in a hospital.

Interviewer: Four times a week for two years?

Brandon: Well like a year and a half and then the last six months is maintenance. I would go in once a month for lumbar punctures in the back and you have to take pills every night over a couple weeks.

Interviewer: So did your reaction to treatment change each time you had to go back to the hospital or did you feel the same way every time you went?

Brandon: Well sometimes, they would give you different medications that make you feel different; they make you more tired sometimes. Sometimes they give you more energy like blood transfusions; you are energetic because you have an extra pint of blood. Some just make you super tired and really sick and you could not eat or you would just throw up like instantly.

Interviewer: How often did the treatment make you feel like that?

Brandon: Pretty much 24/7.

Interviewer: For the year and a half or even when you were doing maintenance treatments?

Brandon: Pretty much just the year and a half, it would go in two-week intervals where I would go four times a week for two weeks and I would have two weeks off and just take pills.

Interviewer: So what made you feel worse was it the cancer that made you feel worse or was it the treatment?

Brandon: The treatment.

Interviewer: Describe to me exactly, you said that you were tired a lot, what else were you feeling?

Brandon: Sick, no appetite at all, I would have to force myself to eat. Except when I got the lumbar punctures, I have to take steroids so make me heal up faster and it makes you super hungry. So you would be super full but you still felt like you were starving and you had not eaten for weeks.

Interviewer: Wow, how did you change physically? Did you lose your hair? Did you gain weight? Did you lose weight?

Brandon: During when I would take the steroid pills, I would gain 20 pounds in a week. Then when I was off those, I would just lose it all again because I would not eat. I lost my hair instantly.

Interviewer: So now how long have you been out of treatment?

Brandon: Just over a year.

Interviewer: Do you remember the date?

Brandon: 11/10/10.

Interviewer: How did you deal with the news that your cancer was stable and in remission?

Brandon: It was like a big weight taken off my shoulders, I know the big weight taken off my parents shoulders and everyone that knew me and stuff.

Interviewer: So did you stop treatment at 11/10 or did you stop treatment earlier than that and then you found out that your cancer was gone?

Brandon: I stopped treatment right on 11/10.

Interviewer: Did you know that your cancer was gone before then?

Brandon: Yeah, New Years Day actually, it was January 1st, 2009, they told me that there was nothing. The cancer was completely gone. So I just had to keep up with the treatments just to make sure that every single cell was gone and it would not come back.

Interviewer: How did that make you feel having to go through treatment that does not make you feel well, when you knew that the cancer was gone?

Brandon: I thought it was pointless because it was already gone. Then after they told me, we have to get rid of every cell so it does not go to your brainstem and other stuff.

Interviewer: So do you feel that the treatment was justified even though it was not making your feel well?

Brandon: Yes.

Interviewer: So how has your life changed since you stopped treatment?

Brandon: It is kind of a hard question, how has my life changed since I stopped treatment. I do not have to worry about taking pills every night, and with the chemo pills in maintenance, you could not drink or eat any dairy products for an hour before or after I took it.

Interviewer: Are you a big fan of milk?

Brandon: Yeah.

Interviewer: So how did your family react to your remission?

Brandon: Oh, they were so happy, because they knew that I was going to be fine and that someday I would be out of treatment and everything.

Interviewer: What about your friends?

Brandon: I do not really know because I could not really hang out with them because I had a low immune system. So if I got sick I would be in the hospital. So I could not really talk to them about it.

Interviewer: Well it is your one-year anniversary from being out of treatment; do you still receive any treatment of any kind?

Brandon: For the first year out of treatment, you have to go back to the hospital once a month and get blood draws once a month just to make sure that everything is going good. After that, it goes to every two months, and now I go every two months.

Interviewer: How long will you continue to go for every two months?

Brandon: How long will I continue to go every two months? The second year and then the third year will be three months. Fourth year four months, and then the fifth year, five months.

Interviewer: So they gradually wean you away from the hospital.

Brandon: Yeah.

Interviewer: Do you have any concerns about your cancer now?

Brandon: No not really.

Interviewer: So when you think about being in remission, what kinds of thought do you have about your future?

Brandon: I think I will be good and I will not have any health problems or anything.

Interviewer: You do not think you will have any more health problems?

Brandon: No, I know it will not come back and if it does, they will get on it right away.

Interviewer: You feel that way because you continue to go for treatments so regularly.

Brandon: Yeah.

Interviewer: Well they seem to be pretty on top of it, the checking it every month for the first year and every two months for the second year, so I would imagine that that would instill some confidence.

Brandon: Yeah.

Interviewer: So everybody knows it is unpleasant to have cancer, but can you think of any positive things that have come from your experience?

Brandon: It has brought my family closer; I have met really great people.

Interviewer: How has it brought your family closer?

Brandon: We spend more time together; we eat dinner together regularly every night. That is about it.

Interviewer: What would you say is the most difficult thing you have faced throughout your entire cancer journey?

Brandon: I would say not being able to eat, and being sick all the time.

Interviewer: Has your hair grown back?

Brandon: Oh yeah.

Interviewer: Did it make you feel, I mean how did you feel socially not having any hair?

Brandon: I did not like it.

Interviewer: Can you explain?

Brandon: That is kind of a hard question too. How did I feel not having hair? I would just wear a hat or a beanie or something.

Interviewer: So it was not that awkward for you?

Brandon: No, I do not think so.

Interviewer: Okay, do you feel different from your friends?

Brandon: No.

Interviewer: Not even a little bit?

Brandon: Nope.

Interviewer: Do you have any concerns about your friendships?

Brandon: No, not at all.

Interviewer: What kinds of things do you do for fun?

Brandon: I like to play guitar, play drums, play baseball, golf, being with friends, and stuff like that.

Interviewer: Excellent, do you mind when people ask you or talk to you about your cancer experience?

Brandon: No.

Interviewer: You are happy talking about it.

Brandon: Yeah, it does not bug me.

Interviewer: All right, well let's talk about school for a little bit. How are you doing in school right now?

Brandon: Good, oh speaking of I have to give my mom my report card I got today.

Interviewer: So what are the grades looking like?

Brandon: I have three A's, and a B, and two C's.

Interviewer: Are you concerned about the classes that you got C's in?

Brandon: Kind of, but I can bring it up.

Interviewer: Now, had you been absent from school a lot because of your cancer?

Brandon: In Middle School, I was because I would have to go and get the lumbar punctures and so I would have to miss a full day of school and maybe the next day if I was not feeling good.

Interviewer: So how often would you say you were absent?

Brandon: Like once or twice a month.

Interviewer: Once or twice a month so you still attended school while you were getting chemotherapy.

Brandon: During the main part of it, I missed that whole year of school in sixth grade.

Interviewer: So you missed all of sixth grade, did you end up staying back a year or how did you handle that?

Brandon: I just did home school on the computer.

Interviewer: Was that something that your parents sought out or was that something that your school put together for you?

Brandon: My parents thought of it.

Interviewer: Did the school help you at all?

Brandon: They had spaghetti feeds and stuff to raise money.

Interviewer: So the school helped you guys to raise money I am assuming to pay for your treatment, but did they do anything for you academically?

Brandon: No.

Interviewer: How did you manage to keep up with schoolwork then?

Brandon: On the computer it had all the stuff and I would just print it out and do it. Then I would just email it to the teacher and then I would just get the grade that way.

Interviewer: Okay, so you would email it to the teacher at your school.

Brandon: No, it was just a home school.

Interviewer: Oh, okay so it was completely separate from your regular class.

Brandon: Yeah.

Interviewer: The school had not offered to help you or anything like that.

Brandon: Not really. No.

Interviewer: So I do not know, I kind of find that shocking. Did they help you to get back into school again when you were back? I mean did your teachers give you any allowances for being gone for a year.

Brandon: I went back the last two weeks of sixth grade to just get the feel of it again and just see all my friends again. So that was kind of nice, and I did not really have to do the work because I was not there the rest of the year so I would not get it. I just sat there the whole time.

Interviewer: How did it feel being back?

Brandon: It was weird getting back into the routine of everything.

Interviewer: How so?

Brandon: Yes.

Interviewer: Well how is that so?

Brandon: Wait what?

Interviewer: How did it feel weird? What was weird about it?

Brandon: Because I would sleep in until about 11:30 every day, and I had to get up at 7:00, and just being around kids all day and not being my myself pretty much.

Interviewer: That must have been difficult after being by yourself for almost a year.

Brandon: Yeah.

Interviewer: Did you have a lot of the same friends?

Brandon: Yeah.

Interviewer: What was their reaction to your being back?

Brandon: They just kind of acted like everything was normal.

Interviewer: So they did not look at your like you were strange or weird or anything?

Brandon: No, they did not do that.

Interviewer: Good, it sounds like good friends then.

Brandon: Yeah.

Interviewer: So obviously when you were absent during that year of school you did not get to hang out with your friends as often. How has your social friendships changed since you have stopped treatment?

Brandon: I see them every day now, and I have really good friends, we have gotten closer. We hangout most weekends too… You know.

Interviewer: Awesome, do you receive any sort of special education?

Brandon: Nope.

Interviewer: Do you feel like you need any kind of special education?

Brandon: No.

Interviewer: So you do not have any delays leftover from your cancer or from your treatment.

Brandon: No.

Interviewer: Do you have any siblings?

Brandon: Yeah, an older brother.

Interviewer: How much older?

Brandon: Two years older.

Interviewer: How was the relationship with you guys since you were diagnosed?

Brandon: We got closer, and we, mom, how did John's[12] relationship and mine change? Yeah, besides that it has not really changed.

Interviewer: Just gotten closer.

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[12] Sibling name changed.

Brandon: Yeah.

Interviewer: Was the relationship shifted at all from being diagnosed to now being in remission, or has it pretty much remained the same the whole time?

Brandon: It pretty much remained the same.

Interviewer: Do you think your parents treated you any differently because you had cancer?

Brandon: No not really.

Interviewer: They did not make any allowances for you over your brother or anything like that.

Brandon: No.

Interviewer: Well I want to talk again a little bit more about the symptoms that you had felt and kind of going through all those symptoms. I mean you were in treatment for two years basically, I would imagine that that is a tough adjustment going through that for two years and then into being healthy again.

Brandon: Yeah, when you feel good, you just want to run and do everything because when you are down and feeling sick you just want to lie down and not do anything.

Interviewer: So it is almost as if maybe you want to take a bit more advantage of time being healthy.

Brandon: Yeah.

Interviewer: Do you try and do that as often as possible with your family?

Brandon: Yeah I think so.

Interviewer: And friends?

Brandon: Yeah.

Interviewer: So what is your favorite subject in school?

Brandon: Oh, that is a tough one. What is my favorite subject in school? Math I guess.

Interviewer: Yeah?

Brandon: Yeah.

Interviewer: Excellent, and you said for fun as hobbies you play instruments.

Brandon: Yeah.

Interviewer: What do you play?

Brandon: Huh?

Interviewer: What instruments do you play?

Brandon: Guitar and drums.

Interviewer: Guitar and drums, did you play guitar and drums when you were sick or is that a new hobby?

Brandon: I played guitar, but I just got a drum kit.

Interviewer: Okay, your mom must be thrilled about that.

Brandon: Yeah.

Interviewer: So were you playing a lot of guitar when you were by yourself?

Brandon: I would play at least eight hours a day.

Interviewer: Wow, so you must be pretty good by now.

Brandon: Yes.

Interviewer: Did you find that it gave you comfort or relief in any way?

Brandon: It sort of let me forget everything.

Interviewer: How did that work? How does playing the guitar make you forget?

Brandon: It would just take my mind off everything so I could just focus on guitar and not worry about anything else.

Interviewer: Almost kind of helps the pain go away too?

Brandon: Yeah kind of.

Interviewer: How often were you in pain from your treatment?

Brandon: When I would get lumbar punctures, sometimes my back would hurt maybe that night or the next day. Sometimes I would get a headache or something.

Interviewer: Now how did you know that you had cancer? What prompted you guys to go to the hospital?

Brandon: I was going on a fieldtrip with the school, you go to San Francisco for three days and stay the night there, stuff and I had a cough, and my mom was just worried about it. So we went over to this urgent care thing, to just check it out and get me on some medications so it could go away. They were slow so they just took and x-ray and there was a mass there so they just sent it over to the Children's Hospital and then the next day when my dad and me were on the bus there, the hospital called my dad and said, you have to get off the bus and come here right now.

Interviewer: That must have been kind of frightening.

Brandon: Yeah, I did not even know what was going on.

Interviewer: Did your dad tell you what was going on or did he wait until you got to the hospital?

Brandon: He waited.

Interviewer: So it might have been even a little bit more scary if you are wondering what is going on and why you have to stop your field trip to go to the hospital.

Brandon: Yeah.

Interviewer: So was the mass in your lungs?

Brandon: No, it was behind my lungs kind of, just in my chest.

Interviewer: Did you have to have that removed or was it just shrunk with treatment?

Brandon: It was just shrunk with treatment.

Interviewer: And now it is totally gone?

Brandon: Yeah.

Interviewer: Great, I am just trying to get an idea of what that experience was like to hear the doctors say you have this particular kind of cancer.

Brandon: They did not really say it, I asked my mom and she was like yeah, so they did not really say it to me they said it to my parents.

Interviewer: And then it was your parent’s choice to tell you.

Brandon: Yeah.

Interviewer: So in the same respect, I am also trying to get an idea of what it felt like to hear the opposite that your cancer is gone, and that treatment is working. Did they tell your parents that first as well?

Brandon: No, not really, because I had a CT scan and so I saw the images and then they just said oh, it is going away and that is about it.

Interviewer: Great, well I am just about all done, is there anything else that you want to tell me about anything pertaining to your entire cancer experience or your recovery?

Brandon: No, I think you have covered it all.

Interviewer: Well is it alright with you if I give you a call back if I have further questions?

Brandon: Yeah that is fine.

Interviewer: Excellent, well it was such a pleasure talking to you, and if you have any further questions, please don't hesitate to contact me.

Brandon: Sure.

End of interview.

14-year-old Caucasian male
Diagnosed: September 2008 – Non-Hodgkin's Lymphoblastic Lymphoma
Treatment Stopped: November 2010 – chemotherapy (oral and intravenous)
Second Interview: July 2012 – Phone

Interviewer: Well first, I just want to start by letting you know what's going on over on my end with my research since the last time we spoke. So I finished my first round of interviews speaking with various participants about their experiences and now, I am just going around and following up – seeing how you're doing, if there are any changes, and just to fill in any extra questions I might've had.

Brandon: All right.

Interviewer: And I also wanted to let you know that all of the participant rights that we discussed when we first spoke about changing your name to protect your identity and if you have any questions or complaints, please don't hesitate to contact me, all of that still stands, okay?

Brandon: Okay.

Interviewer: All right. So how have you been since we last spoke?

Brandon: Perfect.

Interviewer: Perfect?

Brandon: Yeah.

Interviewer: Are you out of school?

Brandon: Yeah.

Interviewer: Now you mentioned you had a summer job. What have you been working on?

Brandon: At a water park.

Interviewer: Oh, that's fun. Are you a lifeguard there?

Brandon: No, I'm like a kitchen runner.

Interviewer: Oh, great.

Brandon: I work in the kitchen all day.

Interviewer: Well, still better than having to be in the sun all day, I bet.

Brandon: Yeah.

Interviewer: So how are you feeling?

Brandon: Good.

Interviewer: Do you have any leftover effects from your cancer treatment since we last spoke?

Brandon: Nope.

Interviewer: Nothing?

Brandon: Nothing.

Interviewer: Okay, and school, and did well?

Brandon: Yeah, I got good grades.

Interviewer: Excellent. Well, I was wondering. When we last spoke, you had told me that you were absent from school in the sixth grade for basically the entire year except for two weeks at the end of the school year.

Brandon: Yeah.

Interviewer: Okay, so that's correct. I was wondering, do you remember the name of the school?

Brandon: My elementary school?[13]

Interviewer: Great. And I wanted to talk a little bit… Because you mentioned that they didn't offer you any sort of help with your education when you got sick. So I was hoping you could elaborate just a little bit based off of what you remember of interacting with the school. I mean, did they ask you to not come back for a year? How did that discussion go?

Brandon: I never was a part of that discussion.

Interviewer: Do you remember what your parents told you, how they explained it to you?

Brandon: They just said you're going to be home schooled for this amount of time and it's going to be an online home school.

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[13] School names have been omitted to protect anonymity.

Interviewer: Okay. Do you happen to know how they found it?

Brandon: I think just researching online.

Interviewer: Okay. So the school didn't really give them any leads or recommendations, they just kind of found it online themselves.

Brandon: Yeah.

Interviewer: Okay, well, that's one of the things I was curious about. And I also wanted to ask you… Now you had mentioned that you went back to school for the last two weeks of the school year.

Brandon: Yeah.

Interviewer: Can you elaborate just a little bit more on what that was like? Because you said that you didn't really have to do anything for the classes and that you were just back there to kind of help get used to being in school again.

Brandon: Yeah. Because I wasn't there all year, there was nothing for me to do for the class. And so I was just bringing my schoolwork that I got from home school and do it in class.

Interviewer: Okay. And did the teacher explain anything to the other kids about you being back?

Brandon: She never did when I was there. She might've when I got back or something.

Interviewer: But you don't know?

Brandon: Yeah, I don't know.

Interviewer: Okay, none of the other kids ever said anything?

Brandon: No.

Interviewer: Okay. And how was it just with your friends? Because I remember you were saying it was really weird and different to return.

Brandon: Yeah. It was something that was hard to get used to.

Interviewer: Why?

Brandon: Because I was used to being at home alone all day so yeah, it was kind of weird being with your friends and waking up early.

Interviewer: Hmm, yeah. Well, so you were there for two weeks and then you had summer vacation, right?

Brandon: Yeah.

Interviewer: Did you see your friends a lot over the summertime, too? Or were you pretty much sticking close to home?

Brandon: No, I saw my friends a lot in the summer.

Interviewer: Okay. So when you went back to school for the middle school, I assume, right? In seventh grade?

Brandon: Yeah.

Interviewer: So when you went back to school in seventh grade, did you feel more comfortable?

Brandon: Yeah.

Interviewer: How so?

Brandon: It was pretty weird.

Interviewer: Oh, it was still weird?

Brandon: No, well, it was a new school so everyone is nervous going in and so it was a little weird for everyone at first.

Interviewer: Uh huh.

Brandon: So it was like more normal.

Interviewer: So maybe because you had other people that were also kind of returning into this situation that's brand new it might've been a little bit easier?

Brandon: Yeah.

Interviewer: Did you ever have a feeling like you were different from your friends, given your experience?

Brandon: Sometimes.

Interviewer: Can you explain that?

Brandon: I don't really know but actually, sometimes I'd have to go and get LPs and I'd have to leave for that. And then sometimes the next day, too, or my friends would ask and I'd have to explain.

Interviewer: What was that like, trying to explain what an LP is to other kids at the age of thirteen, fourteen?

Brandon: It's really difficult. They don't get it really.

Interviewer: Well, that must've been difficult to have to go through something that none of your friends could identify with.

Brandon: Yeah. And it's very hard to explain anything to them.

Interviewer: Do you still try to explain to them?

Brandon: No, not really. They don't ask, so I don't know…

Interviewer: Okay, so you pretty much just keep it to yourself?

Brandon: Yeah.

Interviewer: Did you ever have the option of talking to a counselor or anything?

Brandon: I didn't really want to.

Interviewer: Okay, how come?

Brandon: (crosstalk)

Interviewer: Was there any…?

Brandon: …parents.

Interviewer: I'm sorry, say that one more time?

Brandon: I never really wanted to. My parents weren't really open, so I wasn't really brought up to…

Interviewer: Is there any particular reason why you didn't want to?

Brandon: I don't really know why.

Interviewer: Not at all? You don't have any idea why you just wouldn't want to?

Brandon: Uh uh.

Interviewer: Could it have something to do with always having to explain things to your friends and maybe not wanting to explain things to yet another person?

Brandon: Yeah, I think so.

Interviewer: Okay. Well, what grade are you in now again? I forget.

Brandon: I'm going to be a sophomore.

Interviewer: Going to be a sophomore. And are you excited?

Brandon: Yeah.

Interviewer: How come?

Brandon: I don't know, it's the beginning of the class and this year, I get to drive so…

Interviewer: Excellent, when do you start driver's ed?

Brandon: I don't know when the next driver's ed class is but I think my mom will sign me up for it.

Interviewer: Excellent. Drivers of the road, beware. So are you doing any… I mean, you mentioned that you're doing the summer job now. Does your school do any kind of vocational training? Like do they offer any sort of work program so that you can kind of start to get an idea of what you want to do?

Brandon: I don't think they do.

Interviewer: No? What about you? Have you given any thought on your own about what you want to do? Go to college? Or what do you want to do after college?

Brandon: Yeah.

Interviewer: And what are you thinking?

Brandon: SWAT or a cop.

Interviewer: Oh, very cool.

Brandon: Yeah.

Interviewer: What led you to want to go that direction?

Brandon: I don't know. Just ever since I was a kid, I just wanted to be a cop.

Interviewer: You can't think of what could've drawn you to that position?

Brandon: Just have a lot of power, too.

Interviewer: True. A lot of responsibility.

Brandon: Yeah.

Interviewer: Well, all right. I think I've basically filled in most of the blanks that I had from our last conversation. But Brandon, would it be all right if I gave you another call sometime soon if I have any further questions?

Brandon: Yeah. Sure.

Interviewer: Great, thank you.

Brandon: You're welcome.

Interviewer: Do you have any questions for me about the work I'm doing or anything like that?

Brandon: Not right now.

Interviewer: Okay, well, if you do think of any, you've got my cell phone number now so feel free to just give me a call or shoot me a text message if you are just wondering about anything, all right?

Brandon: All right.

Interviewer: Okay. Well, thanks so much and you have a great day at work today.

Brandon: Yeah, you're welcome. Thank you.

Interviewer: Bye bye.

Brandon: Bye.

End of Interview.

Aaron

17-year-old Caucasian male
Diagnosed: December 2009 – Mucoepidermoid Carcinoma
Treatment Stopped: Surgery (Dec. 2009)/Radiation (March 2010) –
July 2010 scans show no cancer.
First Interview: November 2011 - Phone

Interviewer: Okay, Aaron. Please tell me what kind of cancer were you diagnosed with?

Aaron: It is what is called mucoepidermoid carcinoma.

Interviewer: Okay.

Aaron: It is cancer of the salivary glands.

Interviewer: Okay. When were you diagnosed?

Aaron: December of 2010. I was 15, almost 16.

Interviewer: Okay. What was it like when you got that news from the doctor?

Aaron: It was pretty unbelievable. We have all heard stories about the kids who have gotten it and I was just hoping I would not have it. I do not want to be that person I guess. It was just unbelievable.

Interviewer: When you say unbelievable, what kinds of things were going through your mind?

Aaron: Part of it was why me and the other part was probably in shock, yeah.

Interviewer: What did you have to do for treatment?

Aaron: I had a surgery and then I did radiation treatments?

Interviewer: You did not go through any chemo?

Aaron: No, I did not.

Interviewer: Okay. How much time had passed from diagnosis to surgery?

Aaron: Probably about two/two and a half weeks.

Interviewer: Okay so it was fairly quick then.

Aaron: Yes.

Interviewer: Okay. You did radiation after the surgery.

Aaron: Yeah we started probably a month/six weeks after the surgery.

Interviewer: Okay. I am just trying to get an idea of how things went in to place. You had surgery, they let you heal up a bit and then they started radiation.

Aaron: Yes.

Interviewer: And how long did you do radiation for?

Aaron: I think it was about 30, how many treatments was it mom?

Aaron Mother: Thirty-one.

Aaron: Thirty-one-treatments. It went and they did them five days a week. It went six weeks.

Interviewer: Okay and you had it five days a week.

Aaron: Yes.

Interviewer: Oh, wow. How did the treatment make you feel?

Aaron: It did not hurt during it, it was just somewhat weird to just have to lie down on that table and be perfectly still. About two weeks, once treatment started, my neck started getting really red, like sunburn.

Interviewer: Okay.

Aaron: It shot the layers inside and then both layers came to the surface. For a couple weeks, it was just as if I had a big sunburn on my neck and it was peeling pretty bad and it hurt.

Interviewer: It hurt to touch?

Aaron: Yeah.

Interviewer: What about moving your neck around?

Aaron: I could move it pretty good, not the best, not all the way and sometimes it did hurt.

Interviewer: Okay, would you say that was the only kind of side effect of the radiation?

Aaron: I did actually get a bald spot in the back of my head.

Interviewer: Okay.

Aaron: Probably about an inch or two in diameter.

Interviewer: Okay. That’s not bad.

Aaron: Yeah.

Interviewer: Is that still there?

Aaron: Yeah it is not as noticeable but it is still there.

Interviewer: Okay. You said that you had gone in to treatment about five days a week over about five or six weeks. Did your reaction to the treatment change each time you went?

Aaron: The first time I was just wondering, I had never known about treatment stuff. I was just waiting for instructions I guess. After a while, after probably a week/a week and a half, it just became routine. I just went in, followed the doctor, and went back to the table and something like a routine.

Interviewer: What were you feeling that first time you went in when you were waiting for instructions?

Aaron: Kind of scared, but I was also appreciative of technology and how much they can do.

Interviewer: Maybe a little bit wowed by what was around you?

Aaron: Yeah, exactly.

Interviewer: How long have you been out of treatment now?

Aaron: Probably a year and a half.

Interviewer: When did you find out that your cancer was gone? Was it just because of the surgery it was gone?

Aaron: We had a scan, I finished treatments in March 2011, and then the end of July of that same year we had a scan and found out a couple days later that I was in remission and it was gone.

Interviewer: Just this past July you found out.

Aaron: What?

Interviewer: It was just this past July that you had found out that cancer was gone.

Aaron: Oh, sorry it was July of 2010.

Interviewer: Okay.

Aaron: Diagnosis was actually December of 2009, sorry.

Interviewer: No problem, especially towards the end of the year it gets difficult getting years right.

Aaron: Yeah.

Interviewer: You were diagnosed in December of 2009, March of 2010 you had one of your last scans and you found out in July of 2010 that it was gone.

Aaron: I finished treatments in March.

Interviewer: Okay.

Aaron: Then we waited until July to have the scans.

Interviewer: Got it, okay.

Aaron: Yeah.

Interviewer: How did you feel when you found out that cancer was gone?

Aaron: I was way excited.

Interviewer: Can you explain “way excited?”

Aaron: (laughs) Yeah sorry, just I felt like a huge burden had been lifted off my shoulders, I felt free. I do not know how else to describe it.

Interviewer: I can imagine that. Now have things changed for you since you stopped treatment? How has your life changed?

Aaron: I have a hard time swallowing sometimes. It has gotten better progressively, but bread is probably the worst just because it is so dry. I carry a water bottle around with me at school and I have to take a drink every once in a while.

Interviewer: Okay.

Aaron: My neck is not as movable but I can still move it almost all the way.

Interviewer: Okay. Do you have difficulty producing saliva?

Aaron: Yes.

Interviewer: You do not think it really impairs you besides just occasionally getting a little bit of dry mouth?

Aaron: Yes.

Interviewer: Okay. Do you still receive checkups or treatments in any way?

Aaron: Yeah I still receive checkups between the cancer doctor and the surgeon.

Interviewer: Okay. How often do you go in for checkups?

Aaron: When I first was in remission it was every six weeks, one time to the surgeon, one time to the cancer doctor.

Interviewer: Okay.

Aaron: This month they upped it to every three months going to the surgeon, then the next three months later going to the cancer doctor.

Interviewer: Okay, now that you are about a year and a half out of treatment, you see the surgeon every six months and you see the oncologist every six months but you alternate going to each every three.

Aaron: Uh-huh.

Interviewer: Okay, got it. That must be very difficult to keep straight sometimes.

Aaron: Yeah it is hard to remember sometimes.

Interviewer: Do you have any more concerns about having cancer?

Aaron: There is always the thought in the back of my mind that part of it does come back, but I feel really confident that it is gone.

Interviewer: How often would you say that thought crosses your mind?

Aaron: Probably every occasionally, maybe every once a month or so, sometimes twice a month. I try to stay positive though and just not think about that.

Interviewer: When you found out that, you were officially in remission and that doctor and the surgeon were setting you up for your check up appointments and everything, did they provide you with any kind of support to help you adjust to remission? Or did they just say here you go we will see you in a week.

Aaron: As far as I can remember, they just said here you go, we will see you in a week. They just said get back to your normal routine of life and just get back to the way things used to be.

Interviewer: Was it easy to get back to the way things used to be?

Aaron: Not really. The hardest part was probably my friends, maybe it was me or them, but I just felt like we both kind of acted different towards each other.

Interviewer: Okay.

Aaron: I just did not feel as close to them.

Interviewer: How so?

Aaron: I do not know, probably that I felt a little distance from them because I had been out of school for like two weeks and just because of what I had been through. I do not know if it was because they did not know what to say or whatever.

Interviewer: You feel pretty different from your peers?

Aaron: Sometimes, yeah.

Interviewer: Did you have any concerns that maybe you might have lost any friends over this?

Aaron: Yeah, maybe a couple, maybe one or two. I figured that and my parents said the same thing… the friends who distanced themselves from me are just not the friends to have. They are not worth being friends with if they are going to not support me if the distance themselves from me because of what I went through.

Interviewer: Yeah I think that is a really good way to look at it. I think if I were in your shoes, I would probably look at it similarly then you do. Now we all know that it is not pleasant having cancer, but I want to know is there anything positive that you have taken away from the whole experience.

Aaron: Yeah, my family became a lot, a lot closer. In addition, you would really be surprised at what you can go through because some people probably think I could never do that, but after going through that I feel like I can do a lot more now. I have a different perspective on things. Some things really are not as bad as they seem. Life is a gift and it is really precious.

Interviewer: Yeah I think a lot of people tend to overlook that message. It is fortunate that you have been able to see it even through such a difficult experience. What would you say is the most difficult thing you have had to deal with in having cancer?

Aaron: That is a tough one. Probably, the most difficult thing, probably just the physical challenges. As I said before, always having to have a water bottle and having a hard time swallowing sometimes. There are some candies that I like and completely stay away from because they just hurt my throat.

Interviewer: Let us talk about school for a little bit. You had mentioned that some of your friends, when you returned to school did not quite know how to talk to you or how to, I guess, approach you. Is that still true now?

Aaron: No, I feel like the situation has changed a lot and it is mostly back to where it used to be, I have different friends. I feel like people are more outgoing to me and I am more outgoing to other people.

Interviewer: Great. How are you doing in school right now?

Aaron: I have A’s and one B.

Interviewer: Excellent. Do you have any concerns about school at all, learning, falling behind, anything like that?

Aaron: No. I had it pretty good. I actually stayed in school when I was going through treatments and after the surgery, I missed almost two weeks.

Interviewer: Okay.

Aaron: It was the last week of the semester so I did not have to take a final on two of my classes, they just said do not worry about it, you have done well in class, just get better.

Interviewer: That was great.

Aaron: Yeah.

Interviewer: You feel pretty supported then?

Aaron: Yeah, oh yeah definitely.

Interviewer: You were absent for two weeks, but it was at the end of the semester and you were able to return to school by the start of the next semester?

Aaron: Yeah.

Interviewer: You did not really miss out on that much of actual schoolwork?

Aaron: Yeah.

Interviewer: Your teachers were all really supportive?

Aaron: Uh-huh.

Interviewer: Great. How did it feel coming back to school after being gone for surgery?

Aaron: Kind of weird because most of the people did not know and they were like oh what happened. Many people had heard and they just said hi to me and were just really nice to me.

Interviewer: Would you say you had a good support group?

Aaron: Yeah.

Interviewer: Except for the few friends that could not take it.

Aaron: Yeah, but there were not very many friends, who could not take it, most everyone was supportive.

Interviewer: That is good to hear. What kind of things do you do with your friends for fun?

Aaron: Sometimes we watch movies and play games and just talk and just hang out.

Interviewer: Has that changed at all since before you had cancer?

Aaron: Not really, it mostly has been the same.

Interviewer: Well that is good.

Aaron: Yeah.

Interviewer: I want to talk a little bit about your family. I spoke briefly with your brother who answered the phone. Is it just you and your brother or do you have any other siblings?

Aaron: I have four siblings including my bother – two brothers and two sisters.

Interviewer: Oh wow, okay cool. What was their reaction to your cancer experience?

Aaron: They were just as shocked as I was. We were actually on vacation in California as a family when they called, so it was kind of a bummer, but we were all there together and it was really nice, except my brother who was on a mission.

Interviewer: Okay.

Aaron: We were able to call him on Christmas day and we talked to him and just told him what it was about. I was really glad I was with my whole family when they told me.

Interviewer: I guess you could say that Christmas day kind of has a different meaning for your brother.

Aaron: Yeah, uh-huh.

Interviewer: How has your relationship with your parents changed?

Aaron: I have gotten closer to them. I fit in the category of most teenagers who when they are starting high school they distance themselves a little bit from their parents. As I went through cancer, I just got really close to them, talked to them a lot, and told them my concerns, worries, and just what I was feeling and they helped me. That was good.

Interviewer: Great. Would you say that you are a pretty good kid at home?

Aaron: Yeah, most of the time.

Interviewer: Most of the time. Do they still, this is a strange question, but I am just curious, do they still discipline you the same now that they would have three years ago?

Aaron: Probably not. I did not really break the rules much before, so they have been more lenient with me since then, because they trust me a lot more.

Interviewer: Okay, they are probably more lenient with you because you are older now.

Aaron: Exactly.

Interviewer: Do you think your having cancer has anything to do with that?

Aaron: It is kind of helped me mature faster. My mom said my older brother and older sister went through a point in their junior year of high school where they just changed a lot and matured a lot. It was my sophomore year for me, just because that is when I went through cancer. My mom said I seemed to have matured a lot and quicker than everybody else.

Interviewer: Do you think your parents treat you differently from your brothers and sisters?

Aaron: While I was going through treatments probably a little bit, but for the most part, no they treated me the same.

Interviewer: Well, I am just curious, what kind of hobbies do you do?

Aaron: I like to play the piano.

Interviewer: Okay.

Aaron: And I really am in to graphic arts, stuff, and graphic design. I also like running and just watching sports and watching TV.

Interviewer: Did you find relaxation in doing any of those hobbies while you were going through treatment?

Aaron: Yeah, most of the time after school I would come home, lie on the couch, and just flip on the TV and it was nice to get away. Sometimes I just went and played the piano and played whatever song I want and however fast I wanted and however loud I wanted. I was just able to let out my emotions and how I felt.

Interviewer: Did you find that to be really helpful?

Aaron: Yeah.

Interviewer: What kind of emotions would you need to let out at the end of the day?

Aaron: Probably just a little bit of anger still for having to go through treatments. Even though there is a whole support system at school, I just felt really different. It was nice to still just let that out. I did not want to feel really different from everybody else.

Interviewer: Did you ever think about speaking to a counselor about it at school, or telling your parents you need to speak to a counselor?

Aaron: Not really. It was not too bad of emotions I guess, just little feelings. I talked with my parents a lot though and they help.

Interviewer: Did you feel like speaking to someone would help?

Aaron: What?

Interviewer: Did you feel like speaking to someone would help?

Aaron: I feel like it would, I just never took the initiative.

Interviewer: Do you still have those feelings of difference from your peers and anger now?

Aaron: No.

Interviewer: Okay so it has pretty much passed.

Aaron: Yeah.

Interviewer: Okay, so you might say that it is too late to talk to a counselor.

Aaron: Yeah.

Interviewer: Okay, but it might have benefitted you to have it at the time, but now that you have gotten through it on your own, it is not a problem.

Aaron: Yeah.

Interviewer: Okay, I just want to make sure that I understand you properly. When you think about your future, are you thinking about college?

Aaron: Yeah I want to go to college. I am deciding between going in to dentistry, I want to be some kind of doctor and I want to help people in some way. I am also thinking about graphic design and graphic arts because that is something I really love to do.

Interviewer: Do you think your experience with cancer has pointed you towards something like a dentist, doctor, or anything like that?

Aaron: Yeah, before I wanted to be a doctor because they made a lot of money.

Interviewer: Okay.

Aaron: And are well off and after I went through treatments I realized that I would really want to do it because I really like to help people and just help them out and do what I can to make their lives better.

Interviewer: Interesting. I think you often see that where at a young age. You said had to mature faster than your siblings because of your cancer. If you were in a medical field it would make sense that, you want to provide something that someone had once provided for you.

Aaron: Yeah.

Interviewer: Makes sense. Well Aaron I am just about all out of questions, but is there anything else that you can think of that I should know about your experience.

Aaron: I did try to stay positive through the whole thing. I had a positive attitude. I told myself every day that it would end; I would be in remission some day. We counted down the treatments and my mom got me to finish the treatments.

Interviewer: That is great. Was it difficult for you to say positive?

Aaron: Not really because I have been a positive thinker my whole life.

Interviewer: Almost in preparation for this?

Aaron: Yeah.

Interviewer: Well great. Aaron is there anything else that I should know?

Aaron: I think that's it. I can't think of anything else.

Interviewer: Okay, is it all right with you if I have further questions to give you a ring back sometime?

Aaron: Yeah.

Interviewer: Great. I just want to thank you so much for participating.

Aaron: No problem.

End of interview.

17-year-old Caucasian male
Diagnosed: December 2009 – Mucoepidermoid Carcinoma
Treatment Stopped: Surgery (Dec. 2009)/Radiation (March 2010) –
July 2010 scans show no cancer.
Relapse: January 2012 – Surgery: March 2012
Second Interview: July 2012 – Phone

Interviewer: So before we get started, I just wanted to let you know how things are going on my end. I've talked to all the participants who were participating in the study and now I'm basically just revisiting with everybody several months later to see how things have changed, improved, gotten worse, and so on and so forth. Okay?

Aaron: Okay.

Interviewer: Do you have any questions for me off the bat?

Aaron: No.

Interviewer: Okay. Well, just as we're getting started here, how are you doing?

Aaron: I'm pretty good.

Interviewer: Yeah? How's summer going for you?

Aaron: It's great. It's nice to be graduated.

Interviewer: How was graduation?

Aaron: It was awesome.

Interviewer: Did you do anything special?

Aaron: We actually had our senior trip. We graduated on a Thursday and we left that night at like midnight and we went to Disneyland. We spent all day Friday at Disneyland and then came back that night.

Interviewer: A senior trip to Disneyland? That's awesome.

Aaron: Yeah. Yeah, it was fun.

Interviewer: I think like my senior trip was like overnighting at some amusement park.

Aaron: Yeah?

Interviewer: But Disneyland definitely takes the cake.

Aaron: Yeah.

Interviewer: And can you remind me – I don't know if I'd ever asked you this when we spoke previously – what was the name of your high school?

Aaron: ______ High School.[14]

Interviewer: So are you going off to college soon?

Aaron: Yeah, I'm going to college.[15]

Interviewer: Okay.

Aaron: It's just right in town.

Interviewer: Okay, so you'll still be close to home?

Aaron: Yeah, I'm living at home, actually.

Interviewer: Oh, great. Okay, well, that's nice and easy then.

Aaron: Yeah.

Interviewer: What are you thinking about majoring in?

Aaron: I think I want to go into communications.

Interviewer: Okay. You have any idea what you want to do with that?

Aaron: Not really. I kind of want to do something that involves like being in front of people.

Interviewer: Okay.

Aaron: Just because like I was a student body officer and I had fun with that.

Interviewer: Great. So do you like working kind of in politics and things like that?

Aaron: Not really as much politics but I kind of like, I think it would be cool to be a news reporter or something like that.

Interviewer: Oh, very cool.

Aaron: Yeah.

Interviewer: So I wanted to talk… Your mom had told me back in January that you had a little scare with relapse.

Aaron: Yeah, I did.

Interviewer: What happened?

Aaron: They actually found another lump because when I had radiation a couple years ago, they didn't do a spot right in the middle like right where my Adam's apple

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[14] Names have been redacted to protect participant privacy.

[15] University name has been redacted to protect participant privacy.

is, and this is where they actually found the lump. And so they took that out and I actually had another big surgery and they took out more and just got it really good, got a lot of it out. And they actually redid my old scar, too, so I had like a twenty-inch scar from the surgery.

Interviewer: Twenty inches?

Aaron: Yeah. Or I don't know if it was that much, but it was kind of like fifteen or so.

Interviewer: Wow, on your neck?

Aaron: Yeah.

Interviewer: My goodness. So when did you have the second surgery?

Aaron: I had it in March.

Interviewer: In March. So pretty recent. And they got all of it?

Aaron: Yes.

Interviewer: And so they know for a fact that you are cancer-free?

Aaron: We actually have follow-up scans. My first scan is like next week and they'll just do scans like every six weeks. But as far as I know, they got it all and they feel pretty confident about it.

Interviewer: What was that like?

Aaron: It's kind of scary. But this time, I knew that if they did it last time they could do it this time and get pretty much all of it out. Because they missed that spot and that's where it showed up, I felt like a little better that it wouldn't come back. But I knew it was going to be easier because I just had a surgery, I didn't have radiation or anything. And I didn't let it ruin my senior year, so I just had surgery, recovered, and went back to school.

Interviewer: How long was the recovery from surgery?

Aaron: Probably about two weeks.

Interviewer: About two weeks. Oh, okay, so because I remember when you told me when you had your first surgery in December of '09, that only took you out of school for two weeks.

Aaron: Yeah.

Interviewer: So I mean, you actually didn't have to miss a whole lot of school altogether.

Aaron: Yeah.

Interviewer: Okay. Did the school do anything this time around to help you out?

Aaron: Yeah, the student government – because I was in it – they actually gave me like some presents and stuff and each person was in charge of a present and I got to open one each day while I was out of school.

Interviewer: Oh, fun!

Aaron: And they went around and got like people I know that they'd just throw a simple little note and they rolled it up and tied it like one of those fake Christmas trees and they put that in and lit it up and it was pretty cool. I saw that when I came home.

Interviewer: That is amazing. Well, it must've made it also a little bit easier knowing that you had such support in your friends.

Aaron: Yeah.

Interviewer: Which is kind of different from what you had told me the last time we talked, which is when you initially diagnosed, you had said that you had lost a few friends who just didn't know how to take it.

Aaron: Yeah.

Interviewer: So you got a completely different response from your friends this time.

Aaron: Yeah.

Interviewer: Have you dealt with any of your peers that reacted like last time when they just couldn't handle it?

Aaron: No, because I didn't really talk to those kind of people. But I don't know.

Interviewer: So would it be safe for me to say that you just kind of knew to avoid that type of person?

Aaron: Yeah.

Interviewer: Okay. Yeah, sometimes it's hard that you have to… You know, you learn the hard way who your friends are and who you want to surround yourself with. And by the reaction of your friends during this surgery, the second surgery, it sounds like you've chosen to surround yourself with some pretty special people.

Aaron: Yeah.

Interviewer: So are any of your friends going to be going to [the same college as you]?

Aaron: A couple are. There's some that have already moved away and there's some that are going to schools up north. But there's probably a good five or six friends that are staying here and going to [a local college][16].

Interviewer: Well, that's good that you'll have them still around.

Aaron: Yeah.

Interviewer: Yeah. So was your decision to stay at home and go to [your local college] anything to do with your cancer?

Aaron: No, probably not.

Interviewer: Okay.

Aaron: All of my siblings that are older than me have actually gone to [the same college] and it just felt like the right school to go to, so I'm going, too.

Interviewer: Yeah, it's kind of like your family's alma mater.

Aaron: Yeah.

Interviewer: Yeah. Okay, good. So you don't feel as if you're being held back at all by what happened?

Aaron: No.

Interviewer: How do you feel now that you're approaching your first scan next week?

Aaron: I'm a little nervous, I guess, but I'm kind of, I guess, excited to just see if it's gone or if it's still there, just to kind of know.

Interviewer: Now what happens if it's still there?

Aaron: I don't know. I'll be pretty surprised.

Interviewer: Okay. Because they were so confident?

Aaron: Yeah.

Interviewer: Okay. Well, I think it's really interesting, too, that obviously, relapse is the last thing you want to experience after having already experienced cancer.

Aaron: Mm hmm.

Interviewer: So that, I would imagine, the minute that you noticed the lump or that the doctors noticed the lump, I would imagine that would be – for lack of a better phrase – your worst nightmare.

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[16] College name redacted to preserve participant privacy.

Aaron: Yeah.

Interviewer: So I find it really fascinating that you dealt with it so strongly and so positively.

Aaron: Well, thanks.

Interviewer: I think that's just really interesting. Did you just kind of… Now, I just want to elaborate a little bit more. You were explaining to me that because you knew that the radiation never got there. Was there part of you that maybe thought it would come back one day in that spot where they didn't radiate you the first time?

Aaron: No, I thought it would be all gone. But I never… Once it came back, I was like oh, you know, I can see now that it probably would've… Yeah.

Interviewer: Okay, and since they did surgery without any radiation, are your vocal cords affected at all?

Aaron: No, they didn't touch my vocal cords.

Interviewer: Oh good. So do you have any side effects from this surgery?

Aaron: My neck gets a little sore sometimes, but that's about it.

Interviewer: Sore around the incision or where the scar is? Or sore like muscular?

Aaron: Probably like a little bit of muscular like around where the scar is. Like sometimes when I wake up in the mornings I have to stretch it out because I haven't moved it for so long that it's still just sore.

Interviewer: Yeah. And how are you doing in terms of creating saliva? Do you still have to carry water with you all the time?

Aaron: Not as much.

Interviewer: Okay, that's good.

Aaron: But most of the time still.

Interviewer: Most of the time? Is that going to continue to improve over time?

Aaron: Yes.

Interviewer: Okay. So will there come a time where you may not need to carry around water?

Aaron: Yes.

Interviewer: Good. Did the doctors give you any kind of timeline as to how long that'll take?

Aaron: Just whenever I feel like I don't need it. Sometimes when I don't have water with me, I just have like a piece of gum or something.

Interviewer: Oh yeah, to help you kind of create saliva.

Aaron: Yeah.

Interviewer: Great.

Aaron: Yeah.

Interviewer: Actually, that was most of what I needed to get from you. I wanted to know mostly how the relapse had gone for you and it sounds to me like it actually went as well as it could've gone.

Aaron: Yeah.

Interviewer: So I'm thrilled to hear that. Would it be okay, Aaron, if I gave you a call in about two weeks just to see how the scans went?

Aaron: Sure.

Interviewer: Do you have any questions for me right now?

Aaron: I don't.

Interviewer: Okay. Your mom's okay? She doesn't have any questions either?

Aaron: No.

Interviewer: Okay. All right, well, that about wraps it up. I don't want to take up too much of your time today. But yeah, I will give you a call soon to find out, hopefully, good news about your scan.

Aaron: All right, thank you.

Interviewer: All right, have a good day.

Aaron: Okay, you too.

Interviewer: Bye bye.

Aaron: Bye.

* Note: Aaron's scans showed no current signs of cancer.

End of Interview.

Tim

14-year-old Caucasian male
Diagnosis: Neurofibromatosis (nerve tumors) – 8 years old at diagnosis
Treatment stopped: 18 months of chemotherapy – tumors still present but stable
(4 years since treatment stopped)
First Interview: November 2011 – In person, both parents present.

Interviewer: So let's start by you explaining to me what it was like when you were told that you had a brain tumor.

Tim: I didn't know what to think.

Interviewer: Can you explain that?

Tim: I didn't really know what was going on.

Interviewer: Do you remember what you were feeling?

Tim: No. I really don't.

Interviewer: How old were you?

Tim: Eight.

Interviewer: Okay, so what were you feeling before you ended up going to the hospital? What made you guys want to go into the hospital?

Tim: For the tumor to stop growing.

Interviewer: How did you know that you... there might be something wrong? Were you getting headaches, not feeling good?

Tim: It was hard for me to read things.

Interviewer: Okay, so it was getting more and more difficult to see?

Tim: Yes.

Interviewer: Did you go to an eye doctor first? Do you remember?

Tim: Yes.

Interviewer: Okay, and then the eye doctor led you to... told you guys to go to the hospital?

Tim Mother: He had paleness in his optic nerve.

Interviewer: Okay. And so that led you guys to end up going to see a doctor – did you go straight into oncology?

Tim Mother: We went in for an MRI.

Interviewer: Okay and then they found a brain tumor?

Tim Mother: They found brain tumors.

Interviewer: Okay, several?

Tim Mother: Two, one on each optic nerve. He has neurofibromatosis.

Interviewer: Okay and so, what did they explain to you? Now I understand you were eight, but what did they explain to you about what was going on?

Tim: I don't remember.

Interviewer: You don't really remember?

Tim: Nuh huh.

Interviewer: Did you have surgery?

Tim: No.

Interviewer: Okay, so no surgery, they... how did they want to treat the tumors?

Tim: Chemotherapy.

Interviewer: No radiation?

Tim: No.

Interviewer: Okay, so when did you find out that these tumors were not cancerous?

Tim Mother: Right away. They knew they were benign by the nature of the disease.

Interviewer: Okay.

Tim Mother: And they did not do radiation because the collateral damage would cause learning disabilities so we didn't want to go that route.

Interviewer: All right. Can you explain to me why they wanted to treat with chemotherapy knowing that it wasn't cancer?

Tim Mother: To arrest the growth of the tumors and possibly shrink them. They were inoperable because they're invasive in the optic nerves.

Interviewer: Okay, gotcha. So they thought chemotherapy would be the best way to progress.

Tim Mother: Yes, that's how they treat them.

Interviewer: Okay, interesting. And how long do you remember doing chemotherapy for?

Tim: Eighteen months.

Interviewer: Eighteen months. That's a long time at age eight. How did it make you feel?

Tim: Weak.

Interviewer: Did you lose your hair?

Tim: No.

Tim Mother: Some.

Interviewer: Some of it? But mostly just weak?

Tim: Yeah. And pale.

Tim Mother: Weight loss.

Interviewer: So you lost weight, were you nauseous, were you vomiting?

Tim: No.

Interviewer: Okay, what kinds of things... I actually want to get your perspective on this rather than your mom's. How did your family react when you were going through treatment?

Tim: Stressed.

Interviewer: Okay, why do you think that?

Tim: Because they didn't know what was going to happen.

Interviewer: Okay, so would you say they were worried?

Tim: Yeah.

Interviewer: And you were worried?

Tim: Yeah.

Interviewer: What did you do throughout treatment to kind of help you handle being scared or worried? What did you do for fun during that time?

Tim: Played video games, watch TV.

Interviewer: Did you have a big support group of friends?

Tim: No.

Interviewer: Were you in school?

Tim: Yes.

Interviewer: So you stayed in school through treatment?

Tim: Yes.

Interviewer: Interesting. Were you absent a lot?

Tim: Every Friday.

Interviewer: Every Friday to go get treatment?

Tim: And for a two-week period I was out sick.

Interviewer: Oh, okay. Other than that you didn't miss any school?

Tim: No.

Interviewer: Well that's good. How was the school reacting to what you were going through? Do you remember if they were helpful?

Tim: No, I don't remember.

Tim Mother: They were.

Interviewer: They were supportive?

Tim Mother: The teachers were supportive and a lot of the school parents provided meals for us so it was very good support. We go to a parochial school, so it was wonderful.

Interviewer: Oh great, excellent. And so those Fridays that you were absent, did your teachers help you accommodate homework, or...

Tim: They didn't give me any homework.

Interviewer: They just didn't give you any homework. Well, eight years old is third grade?

Tim: Third... fourth.

Interviewer: Fourth grade, so you were in fourth grade for this?

Tim: Yes.

Interviewer: Okay, so and what about now in school, do you... your mom mentioned that you are at a new school this year.

Tim: Yes.

Interviewer: So talk to me about that... last year you were at a parochial school, right?

Tim: Half the year.

Interviewer: Half the year, and this year where are you now?

Tim: The School for the Blind.[17]

Interviewer: And what is different about your experience at the Washington State School for the Blind?

Tim: It's easier, less homework, more accommodations for me.

Interviewer: More accommodations for you. Was the parochial school just not really able to help you out?

Tim: Yeah.

Interviewer: They just didn't know how to handle it?

Tim: Yeah.

Interviewer: Okay.

Tim Mother: We were relying on the public school systems to provide visual support and braille lessons and we weren't getting the support we needed and the... it just wasn't good enough. It wasn't adequate; he was falling behind.

Interviewer: Okay, so your schoolwork started to suffer a little bit at the Parochial school because they were unable to help you.

Tim: Yes.

Interviewer: Even though they were collaborating with the public school system?

Tim Mother: Yeah, we weren't getting the support of the public school system coming into the private school to teach our teachers. And they didn't have the technology that was needed, so yeah.

Interviewer: And would you say that you are happier at your new school?

Tim: Oh yeah.

Interviewer: It is the school for the blind so I'm assuming you're there with other children who also have...

Tim: About sixty-six of them.

Interviewer: Okay, so sixty-six other kids that also have visual impairments.

Tim: Yeah.

Interviewer: Do any of them have their impairments from brain tumors, or natural or both?

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[17] School name redacted to protect participant privacy.

Tim: Both.

Interviewer: Okay, have you talked with other kids about their experiences with their brain tumors?

Tim: All the time.

Interviewer: All the time, so it's pretty common to just be open about it?

Tim: Yes.

Interviewer: And you're okay with talking about it with your friends now?

Tim: Yes.

Interviewer: How did your friends react before you went to the school for the blind? How did your friends react at school with your blindness? Were they helpful?

Tim: Some were most weren't.

Interviewer: Most were not. What did it feel like for you being in a school where there probably were no other blind children?

Tim: I felt like the only one. Like I was different.

Interviewer: What was it like to feel different from everyone else?

Tim: Frustrating.

Interviewer: Were you able to easily get from one class to the next?

Tim: There... sometimes it was a challenge because everyone was around and the halls were so small.

Interviewer: Did you have any friends that helped you out?

Tim: No.

Interviewer: I'm trying to understand how your life has changed since chemo stopped. So, I know it was a while ago, but you were getting chemo for benign tumors, do you feel like it helped you?

Tim: Helped me... my tumors stopped growing, but not really.

Interviewer: But not really other than that?

Tim: Yeah.

Interviewer: Can you explain a little bit more what that felt like?

Tim: Like how should I pursue this when everyone else can see it?

Interviewer: What do you mean when you say, “pursue this”?

Tim: Just like… how should I do stuff when everyone else can see?

Interviewer: And you can’t?

Tim: Yeah.

Interviewer: And you still feel that way now?

Tim: Not at the school for the blind.

Interviewer: Not at the school for the blind, what about when you’re at home?

Tim: Once in a while.

Interviewer: And do you feel like your parents have been really supportive?

Tim: A great deal.

Interviewer: Are you open with your parents? Do you tell them when you get frustrated with things?

Tim: Yes.

Interviewer: And you feel like they hear you?

Tim: Yes.

Interviewer: And what about your sister?

Tim: Hmm, sometimes.

Interviewer: Is she helpful and supportive?

Tim: Yes.

Interviewer: But she’s also still a sister, right... so... I’m sure there’s some kind of sibling fun that goes on there.

Tim: Mmm hmm. Yeah.

Interviewer: So I want to talk a little bit more about your relationships with your friends. Do you still have a lot of friendships from your old school?

Tim: Some, since I’m gone now they want me back.

Interviewer: Oh, okay, so that’s interesting. Since you’ve left now they want you back. That almost sounds like maybe they didn’t appreciate it as much when you were there.

Tim: Yeah.

Interviewer: Do you talk to them often?

Tim: I try to.

Interviewer: I would imagine that being at a specialty school like the School for the Blind, that you probably have a lot of very close friends there, too?

Tim: Yes.

Interviewer: You mentioned that you live in a cottage?

Tim: Yes.

Interviewer: And how many other boys live there?

Tim: Thirteen, fourteen.

Interviewer: And do you live there seven days a week?

Tim: Five days a week.

Interviewer: So you're there for five days and then you're...

Tim: Sunday night through Friday I'm at school. I'm home Friday.

Interviewer: Oh great, okay. So you still get to see your family?

Tim: Yeah.

Interviewer: Are there girls that go to this school?

Tim: Yes.

Interviewer: Do you have classes with them?

Tim: Yes.

Interviewer: Okay. And the teachers there are accommodating?

Tim: A lot.

Interviewer: A lot, okay. Good. That's good to hear. Do you think that you're gonna apply for college?

Tim: Yes.

Interviewer: And do you have any idea what you want to do?

Tim: Architecture.

Interviewer: Interesting. Why architecture?

Tim: I just like sketching and drawing buildings, designing things.

Interviewer: And do you have any concerns about being able to do that with your visual impairments?

Tim: Maybe it'll be more difficult, but I don't really know.

Interviewer: Would it be accurate for me to say that you're still pretty confident that you could still do it and be successful?

Tim: Yes.

Interviewer: Would you agree if I say that you still feel like you can live a completely normal life?

Tim: Yes.

Interviewer: Okay, good. Do you have any side effects besides the visual impairments?

Tim: No.

Interviewer: Health wise?

Tim: Not that I know of.

Interviewer: Do you have any side effects from taking chemo for eighteen months?

Tim: Not that I know of.

Interviewer: (Turns to mother) Are you aware of anything?

Tim Mother: During the chemo is when he lost most of his eyesight.

Interviewer: Okay.

Tim Mother: Sleeping disorders when he was going through chemo he had sleeping disorders and that's continued. He has to take melatonin every night to fall asleep and they think it might be post-traumatic stress disorder. But as far as his personality, he's the same kid.

Interviewer: Okay.

Tim Mother: It hasn't really changed him as far as who he is - just a couple little things.

Interviewer: Okay. So Tim, do you still have tumors?

Tim: Yes.

Interviewer: Is there anything they can do to treat them?

Tim Mother: They're stable now for four years. We have MRIs to make sure.

Interviewer: Great, okay so they don’t continue to do anything as far as making sure the chemo stopped them from growing.

Tim Mother: Yeah. We monitor.

Interviewer: How often do you go to monitor them?

Tim: Every year.

Tim Mother: Once a year now.

Interviewer: And I’m assuming right after the chemo it was probably once every three months?

Tim Mother: Yes, every month at first. Then three months…

Interviewer: Okay, and then six months and now you’re up to once a year?

Tim: Yes.

Tim Mother: You asked about follow-up after the chemo... I remember that he had neuropathy on his hands and feet. We had to go through physical therapy for a bit because he was having trouble walking and functioning motor-skill wise.

Interviewer: Okay, so did you have to relearn to do a couple of things, Tim?

Tim Mother: Relearned motor skills, yeah... walking... just the placement of the foot because he was numb and didn’t have the feeling, so he had to just learn some... and re-learn kind of the balance because of all that.

Interviewer: How... can you explain what that was like for you to have to re learn things like walking and fine motor skills at nine and a half years old?

Tim: Different. None of my other friends have had that trouble.

Interviewer: But now you have other friends that can relate to that?

Tim: Oh yeah.

Interviewer: So at least it doesn’t feel so different now.

Tim: No, it doesn’t.

Interviewer: What about at the time? How did it feel having to relearn things?

Tim: Frustrating.

Interviewer: How did you deal with that frustration?

Tim: Kind of... just kind of blanked it out of my mind.

Interviewer: So just do it... just learn how to do it, don’t think about it too much?

Tim: Basically, yeah.

Interviewer: Okay. I think that's a good way to look at it. Do you have any concerns about the tumors starting to grow again?

Tim: I kind of wonder when will it happen? Will there be any signs?

Interviewer: Signs like what?

Tim: Well, when my sight... will it ever go... will it ever go again… will the tumors start growing again?

Interviewer: So when you see, can you describe to me what you see? How you see things?

Tim: Nothing in my left eye.

Interviewer: Nothing out of your left…

Tim: And tunnel vision on my right.

Interviewer: Okay.

Tim: I can't see very far. Probably twelve feet.

Interviewer: Okay, so tunnel vision, so you have kind of like you're looking through a straw maybe?

Tim: Yeah. Exactly.

Interviewer: Okay and what kind of visual devices do you use? You mom had mentioned you have things that help you.

Tim: Yeah, CCTV, Amigo, and short arm.

Interviewer: Okay, can you explain to me what those are?

Tim Mother: CCTV is a monitor that's basically like a projector he puts his book underneath and you hook it into a computer and it puts the words on the computer and he can magnify it to bigger or smaller fonts. And then Amigo is a portable CCTV basically a little smaller than that he lays on the book and it magnifies it. And then the acrobat short arm is...

Tim: It's almost exactly the same thing but you can look at things up...

Tim Mother: He can see the board, it's like a camera he can put on the board and then it would be transmitted into his laptop and he can see the board.

Interviewer: Excellent! That is pretty amazing that they have all that technology. So these devices that you use, I'm assuming are not something that you can just run to Target and pick up.

Tim: Uh uh. (shakes head no)

Interviewer: No, okay. But you find them really helpful?

Tim: Yes, a lot.

Interviewer: It must be kind of fun to play with them too. I mean everybody loves technology, right? So, are they difficult use? Is this one of them?

Tim: Yeah.

Interviewer: May I see it? (hands Amigo to interviewer) Oh that is great. So you just lay it on?

Tim: Yeah, lay it on the book or whatever you want to read. You can change the size of things. And change the colors too.

Interviewer: Wow. Do you find it helpful to change the colors?

Tim: On some things.

Interviewer: Okay. It just helps you see a little bit more clearly?

Tim: It all depends on the lighting.

Interviewer: Okay. Great... well that's pretty cool. How long have you had those devices for?

Tim: CCTV since fourth grade, Amigo since fifth and the short arm since sixth.

Interviewer: And this is the...

Tim: Amigo.

Interviewer: I like that name too.

Tim Mother: The CCTV, the Lion's Club provided for us. They've been wonderful as far as helpful financially.

Interviewer: Yeah, I can't imagine what an item like this would cost.

Tim: Two grand.

Tim Mother: Yeah, this was about fifteen hundred dollars; the acrobat was about twenty-five hundred.

Tim: I thought that was more.

Tim Mother: Was it more than that?

Tim: Like five grand.

Tim Mother: Yeah, and then we got some special glasses for him that were twenty-five hundred. So...

Interviewer: Do the glasses help?

Tim: Yeah. I use them to read graphs. This can only read so much, so I use those to read graphs.

Interviewer: So when you have let's say a full page as a graph...

Tim: Yeah, like bar graphs and everything, I just use those.

Interviewer: Great, okay so that's good for more visual type images?

Tim: Yes.

Interviewer: Gotcha. And how many other kids at your school have devices like these?

Tim: I'm the only one.

Interviewer: You're the only one? Well, what makes you so special?

[Laughter]

Tim: Just lucky I guess. And my parents are really helpful and supportive.

Interviewer: That's a very good answer, especially since they're in the room with us. (laughs) I would imagine that you're probably not the only one who would benefit from something like this.

Tim: No, this school has been asking for one of these for ten years.

Interviewer: Do you share it with friends?

Tim: Sometimes.

Interviewer: When you're able to.

Tim: Yeah, but I'm using it most of the time.

Interviewer: Well you should. It's yours, after all. And so... explain to me how the public school was a part of the shift before you guys decided to go to the school for the blind.

Tim Mother: Well, the public school provides the visual lessons in Braille and gives us access to large print books through the braille and auditory library... and there also were the ones... Tim had to go out of school after school to have his visual instruction and then he was receiving orientation mobility where he was learning to use the white cane and that teacher was the one who recommended we go to this school for the blind because we were having so many meetings on why he was falling behind academically. His braille skills were inadequate. I had gone to a camp in Seattle for independent living skills for the blind and there were other visual teachers there and these kids were way ahead of him so that's how the transition happened.

Interviewer: I see.

Tim Mother: And so we went for a... what was it, just a six-week kind of evaluation period and then they found that he really needed some special instruction and then we decided to make the school change.

Interviewer: And it's been a good change?

Tim: Mm hmm. (Nods yes)

Tim Mother: Oh he's confident.

Interviewer: I was just going to say that you seem pretty happy about being there.

Tim: Mm hmm.

Interviewer: Well great. I don't really have any more questions for you, Tim. Is there anything that you think I should know about your whole experience that I should definitely be aware of?

Tim: Not that I can think of.

Tim Mother: As far as?

Interviewer: Just anything that pertains to his adjustment and how he's been coping and things like that.

Tim Mother: He's a strong kid. (Father), you can jump in here too.

Tim Father: Well, you know I can't help but think that some of those answers to some of those yes/no questions on the survey might be different if he was in public or back in his private school because his current situation now... I mean he's with the kids that are similar and so he's developed really different bonds and friendships than what he had with his classmates at his previous school. As I listen to some of those questions, I just think his answers would be more negative if he was still at his old school. And now all were pretty positive and pretty... I guess just positive responses; I think it'd be a lot different if he was back in the old school.

Interviewer: Tim would you agree with that?

Tim: Yes.

Interviewer: There was bullying at your old school?

Tim: Mmm hmm. (nods head)

Interviewer: Can you talk to me about that? What kinds of things? I know it can be difficult to talk about.

Tim: They were calling me names, pushing me around. One kid said, "I'll kill you."

Interviewer: Wow.

Tim Mother: Well, one of the biggest issues was in the lunchroom. Since he can't see he uses his hands a lot, and somebody threw... at the boys' table... somebody threw a bag of some food in Tim's direction. He picks it up and the boy became upset and basically choked... tried to choke him and pushed him against the wall and just because he couldn't see it, "don't touch my food" and there was... he was just excluded... he had really no boy friends; he was excluded from basically any play or activities regarding boys. Wouldn't you say? (turns to Father)

Tim Father: Yes.

Tim Mother: The girls are the ones who miss him.

Tim Father: Yes.

Tim: Mostly the girls… and Billy miss me.

Tim Mother: But he wasn't really... (pause)

Interviewer: What was that like for you before you got to go to a school where other kids could relate to you? I mean, I can imagine that felt... (pause)

Tim: Stressful.

Interviewer: Stressful?

Tim: Yeah. Because I didn't know what was going to happen to me that day.

Interviewer: It's interesting that you use the word stressful... can you explain what you mean by stressful?

Tim: Yeah, I didn't know what kids were thinking that day or what they were feeling and they usually took all their anger out on me.

Interviewer: I'd imagine that it can be really difficult when they don't understand.

Tim: Mm hmm.

Interviewer: But you feel better now that you're at this other school?

Tim: Yes.

Interviewer: Yeah, and safer maybe?

Tim: Yes. A lot safer.

Interviewer: A lot safer.

Tim Mother: Yeah, they'd get mad at him if he bumped into them because he couldn't see them (at his old school).

Interviewer: Was there ever any attempt at talking to the other kids in your class, having the teacher maybe discuss your impairments with the other kids so that they were more aware?

Tim: Yes.

Interviewer: There were attempts at that?

Tim Mother: Yes, we brought in someone from the Department for the Blind and she came and spoke in Tim's class about blindness.

Tim: In Middle School.

Tim Mother: In Middle School and gave an assembly... we brought in Magnifier glasses that distorted vision to try to duplicate what he saw and...

Interviewer: Showed the other kids so they can understand?

Tim Mother: It was short lived.

Interviewer: So it worked for a little while.

Tim: Maybe a week.

Interviewer: Only a week?

Tim Mother: So we tried to educate them and it just didn't work.

Interviewer: Well then it sounds like it's a really good thing that you're in a place that can not only accommodate your learning abilities, but can also just make you feel comfortable and safe.

Tim: Yes.

Interviewer: What about your sister? Where does she go?

Tim: The school I used to go to.

Interviewer: Do you miss going to school with her?

Tim: I miss coming home every night.

Interviewer: Mmm, I'm sure.

Tim: Yeah.

Interviewer: So you've only been at this new school for a year, right?

Tim: Almost a year.

Interviewer: Okay, so you started in I'm guessing January?

Tim: February.

Interviewer: February. Okay. Great, well I'm glad to hear that you're much happier at your new school and that you're safer and more protected. Bullying is a big issue even when you don't have any physical impairments, but especially so when you do.

Tim Mother: That was our issue. He can't even defend himself.

Interviewer: Uh huh.

Tim Mother: And the principal was trying to... you know anti bullying and all that, but kids are kids.

Interviewer: Yeah, it's difficult. (long pause) Well, that is all the questions I have for you today. Tim, would it be alright for me to contact you later if I have more questions?

Tim: Sure.

End of interview.

14-year-old Caucasian male
Diagnosis: Neurofibromatosis (nerve tumors) – 8 years old at diagnosis
Treatment stopped: 18 months of chemotherapy – tumors still present but stable
(4+ years since treatment stopped)
Second Interview: June 2011 – phone

Interviewer: So as we're getting started, how are things? How's your eyesight, how's school?

Tim: My eyesight's improved a little.

Interviewer: Great!

Tim: Yeah.

Interviewer: So, how is it that you see now? How do you notice the improvements?

Tim: My left eye used to always see shadows and things and now I can count fingers sort of.

Interviewer: Well, great! Is that something that you're expecting to continue to get better?

Tim: Yes.

Interviewer: Fabulous! Okay, so you were kind of anticipating that it would get better soon.

Tim: Yes.

Interviewer: Great! That's such good news. Have they looked at the tumor size or anything like that?

Tim: We do an MRI every year.

Interviewer: Okay and have you done that at all this year since we last talked?

Tim: No.

Interviewer: Okay. And how's school going?

Tim: It's going good.

Interviewer: Do you have the summer off or do you still attend during the summertime?

Tim: I have the summer off.

Interviewer: Oh, great. Did you go to camp this year?

Tim: Two camps so far this year, one's in August.

Interviewer: Which camps have you gone to?

Tim: Cancer camp[18], a camp at my school, and a camp for the blind…

Interviewer: Wow! That's a lot of camps.

Tim: Yes, it is.

Interviewer: It must be fun though.

Tim: Yes.

Interviewer: So when we last talked we talked quite a bit about your old school, and it was a Parochial school, right?

Tim: Yes.

Interviewer: And I remember you telling me that there was a lot of bullying that was going on there…

Tim: Yeah.

Interviewer: How do you feel at your new school?

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[18] Name of camp redacted to protect participant privacy.

Tim: Much happier, it's a state school for the blind.

Interviewer: Uh-huh…

Tim: So much happier, everyone there feels how everyone feels, and sees.

Interviewer: Is there any bullying that goes on there?

Tim: Very little, they deal with it right before it gets out of hand.

Interviewer: So have you experienced any bullying?

Tim: Very little.

Interviewer: Okay. Well, that's good. So you feel a lot safer now that you've been there for, you know, over a year.

Tim: Yeah.

Interviewer: Great! Well, that's good news. I wanted to make sure I followed up with you on that because I remember that you were pretty stressed about that when we spoke.

Tim: Yeah.

Interviewer: Do you still talk to anyone from your old school?

Tim: Yeah.

Interviewer: Who?

Tim: Mostly the kids that just helped me through and didn't give me a bad time.

Interviewer: The ones that were your friends.

Tim: Yeah

Interviewer: Great! Do you get to see them?

Tim: I saw them in June-ish…

Interviewer: Oh good. Okay, so you do get to see them from time to time.

Tim: Yeah.

Interviewer: Especially now that you're not in school I would assume…

Tim: Yeah.

Interviewer: Great! And how's your family?

Tim: They're doing good.

Interviewer: Yeah, everybody's happy…?

Tim: Yeah.

Interviewer: Did your sister go with you to camp?

Tim: Yes.

Interviewer: Tell me about that. I couldn't be there this year so I'd love to hear about it.

Tim: It was the radio station [theme this] year.

Interviewer: Oh yeah?

Tim: And it was a lot of fun this year! I had probably the best counselors ever.

Interviewer: Very cool.

Tim: Yeah

Interviewer: Which cabin were you in this year?

Tim: Two.

Interviewer: Excellent! Gosh, you're so grown up now.

Tim: Yeah. Our cabin was like one of the loudest cabins.

Interviewer: Yeah, it usually is. (laughs)

Tim: Yeah. (laughs)

Interviewer: Well, that's awesome.

Tim: Yeah

Interviewer: Like I said, you're so grown up. Before I know it you're going to be cabin one or you might be even be on staff one day and I'm just not even going to know where the time went.

Tim: I can't wait to be on staff.

Interviewer: So with your eyesight improving did you notice that school was getting a little bit easier with your eyesight improving or have things been pretty much the same, would you say?

Tim: The same.

Interviewer: Okay.

Tim: The same…

Interviewer: So you’ve been using the same, like the CCTV and everything…?

Tim: I don’t use the CCTV as much as I used to. I use the Amigo’s more…

Interviewer: Okay.

Tim: …and my math book and stuff.

Interviewer: How come you’re not really using the CCTV much anymore?

Tim: Because the Amigo’s they’re like a CCTV but portable and handheld.

Interviewer: Okay, so it's just easier.

Tim: Yeah.

Interviewer: Okay. But you still use the Amigo more often than not.

Tim: I use it all the time.

Interviewer: Great! Okay. So you are pretty dependent on it?

Tim: Yeah.

Interviewer: Okay, so I wanted to ask you, this is something I kind of forgot to talk about when we first met. What kind of things do you do? I mean do you do anything after school like extracurricular activities?

Tim: Our school down there offers a lot of stuff like tandem golf and archery and stuff.

Interviewer: Cool.

Tim: I do all of it.

Interviewer: Oh really? Okay. So is that like a program where they kind of alternate what they do everyday? Is it one program or is it completely separate groups and you just do all of them?

Tim: It's a program all throughout the school year and day-to-day.

Interviewer: Okay, so it's kind of a little bit more like an intramural program and…

Tim: Yeah.

Interviewer: Okay, so the goal in that, I would imagine is to help you experience lots of different things.

Tim: Yeah.

Interviewer: Okay. I got it. And how do you like that?

Tim: I love it. I have so many classes I sometimes can't do them.

Interviewer: Yeah. Is it maybe too many classes?

Tim: No, it's just real busy trying to get everything I need.

Interviewer: Yeah. What grade are you going to go into?

Tim: Sophomore.

Interviewer: Excellent! Good for you.

Tim: Uh-huh.

Interviewer: So you're not quite thinking about college or anything just yet.

Tim: Not yet.

Interviewer: Have you given any thought to what you want to do when you're older?

Tim: Architecture.

Interviewer: Okay, so that's what you had mentioned last time. You're still interested in architecture?

Tim: Yeah.

Interviewer: And have you done any drafting classes or anything?

Tim: I haven't taken any drafting.

Interviewer: Okay, so what made you warm up to architecture, I forget?

Tim: Just watching buildings get built and seeing how they look at the end.

Interviewer: Seeing the work of art that you can walk around in?

Tim: Yeah.

Interviewer: I can see you doing that. I think you'd be very good.

Tim: Thanks.

Interviewer: So academically, how did you do by the end of the year?

Tim: Well, this year I couldn't finish off the school year…

Interviewer: How come?

Tim: …because I had a tumor that had to get removed.

Interviewer: Okay.

Tim: But with the way I did it I got all A’s and B’s.

Interviewer: That’s great! So talk to me about the tumor removal.

Tim: One day I was at home and I said to my parents, “my knee hurts.” Well, they thought I just did something stupid over the weekend. Well, throughout the week it just kept getting worse. So I went to the doctor and the doctor said there’s nothing that indicates that it's bad so just give it time. So we went to a leg specialist and he said go get an x-ray. We got an x-ray…

Interviewer: Okay.

Tim: Nothing showed up. Then we got an MRI, the MRI showed I had a bruised bone and he said it looks like you have a tumor.

Interviewer: Okay.

Tim: So I had to go get another MRI with contrast and there was a tumor the size of a deck of cards.

Interviewer: Wow!

Tim: Yeah, right behind the knee.

Interviewer: And so, I mean, do you expect to kind of see tumors show up throughout your body like that?

Tim: Yeah, I could have them pop up throughout my whole life.

Interviewer: Wow! That’s got to be kind of scary.

Tim: A little.

Interviewer: What where you thinking when you found out that you had a tumor in your knee?

Tim: Well, when did this happen? How long has it been there? Why hadn’t I felt it before?

Interviewer: Yeah, especially at that size.

Tim: Yeah.

Interviewer: So you kind of have a lot of, I guess, unknown and doubt not knowing when it started growing or where it came from.

Tim: Yeah.

Interviewer: And I suppose, I mean, if I were in your situation I would start thinking, well, what if it didn’t hurt. I never would have known about it.

Tim: Yeah. Exactly.

Interviewer: So yeah, that – I guess for me that would be really scary.

Tim: Yeah.

Interviewer: You seem to be dealing with it okay though.

Tim: Yeah. It's just a lot of nerve pain now.

Interviewer: So you still have some pain?

Tim: Yeah but not as bad as it was.

Interviewer: Well, that’s good that it's not as bad.

Tim: Yeah.

Interviewer: Do you think that going through that helps you to kind of prepare yourself for it if it should happen again?

Tim: Yeah. If it did, so I would know what nerve pain feels like and what it feels like when you have a tumor.

Interviewer: So you feel more physically prepared and you know what signs to look for?

Tim: Yeah.

Interviewer: But does it help you feel like emotionally ready? Are you…?

Tim: I wasn’t really emotional during this process.

Interviewer: Do you know why?

Tim: No. It just kind of didn’t really impact me until right before my surgery.

Interviewer: And then what were you feeling?

Tim: Nervous, a little scared.

Interviewer: Uh-huh.

Tim: Because we had to sign like a blood transfusion and an artery reconstruction paper.

Interviewer: Okay and just reading about how that works was a little scary…?

Tim: Yeah, but the surgery went better than they thought it was going to go.

Interviewer: That’s always good news.

Tim: Yes.

Interviewer: So yeah. I just would think that – I think it's fantastic that you are able to – and I remember you telling me that you were dealing with, from what you can remember, when you were having the chemotherapy on your eyes. I remember you explaining how you very positive about the situation.

Tim: Yes.

Interviewer: And I think that really helps you because you're able to not get overly emotional or, I guess, hysterical and it seems like you're able to keep really level headed during that, I guess, process.

Tim: Yeah.

Interviewer: So that's pretty good. I'm really impressed with you Tim just because you were just having this tumor in your knee removed and you seem to be really level headed about it.

Tim: It was about six weeks ago.

Interviewer: So it was still pretty recent.

Tim: Yeah, May 23rd.

Interviewer: May 23rd was the surgery?

Tim: Yeah.

Interviewer: And do you remember about when you found out about it?

Tim: The beginning of the month.

Interviewer: Okay, so the beginning of May.

Tim: Of May…

Interviewer: So wow! Have you been able to walk?

Tim: Before the surgery I was in a wheelchair basically to just help relieve pain. And after surgery I was probably in the wheelchair for three or four weeks.

Interviewer: Okay.

Tim: Then I started using a walker, then a cane, and now I'm not using anything.

Interviewer: That's great! So when you were at camp in late June you weren't using anything?

Tim: I was using a wheelchair then.

Interviewer: Oh, you were, okay. I was going to say going up and down those big hills must, you know…

Tim: It was a disaster.

Interviewer: How so?

Tim: Because those trails had no gravel. There wasn’t gravel left and the wheelchair had no traction.

Interviewer: Oh, that’s no good. Well, did you have the cart pick you up a lot of times?

Tim: No, I just usually powered through it. Everyone in the cabin helped me out.

Interviewer: Yeah, I think it always helps to make good friends too when you’ve got everyone working to give you a hand.

Tim: Yeah.

Interviewer: So did you make any new friends this year at camp?

Tim: It was basically everyone was the same from the past few years.

Interviewer: Yeah, so you knew who your friends were and you knew who you were going back to see.

Tim: Yeah.

Interviewer: That’s great. And what about the camp that you were going to that’s associated with your school?

Tim: Yeah, that was – it just ended last week.

Interviewer: Okay. And what’s that camp like?

Tim: It's a camp for blind people to see what kind of jobs are out there to offer them.

Interviewer: Super cool.

Tim: Yeah.

Interviewer: And what kind of jobs are out there?

Tim: Working in factories, inventory, and capital stuff.

Interviewer: Did you enjoy it?

Tim: Kind of, not really. It was kind of boring.

Interviewer: Okay.

Tim: Most of the camp was just like for, I think, friends. Free to make new friends.

Interviewer: Yeah. So I’m assuming that you also made new friends there too?

Tim: Yeah, and a big chunk of them, their classmates are in school.

Interviewer: Great! So you did know a few people there.

Tim: Yeah.

Interviewer: Excellent! Well, it sounds to me like you're in a much more comfortable social circle than you were a year ago….

Tim: Yes.

Interviewer: …which is always great. So how does it feel – I remember when we talked last you were a little bit nervous and – not nervous necessarily, but you were a little bit sad that you weren't around your family as much because you were boarding at school. Did that feeling improve at all?

Tim: Yeah, that was like the first two weeks I was at the school and this is going to be my third year going there.

Interviewer: Uh-huh. That's really great.

Tim: You kind of lean more on your friends and people you share the college with. So that's your family for the week.

Interviewer: So you do get used to it…

Tim: Yeah.

Interviewer: And you do see your family every weekend?

Tim: Yes.

Interviewer: Okay, so that helps and then you got the whole summer with your family too.

Tim: Yeah.

Interviewer: Excellent! Okay, so you still feel like they're there for you.

Tim: Yeah.

Interviewer: Great! That's good to hear. Well, Tim I wanted to ask you, do you have any questions for me about the work I've been doing or anything like that?

Tim: No.

Interviewer: Okay, your parents don't have any questions?

Tim: Neither of them are home right now.

Interviewer: Okay. Well, I think I've got just about everything I need from you right now. Would it be okay if I had to call another time?

Tim: Yeah.

Interviewer: Excellent! Well, do me a favor and just let both your mom and your dad know that they can call me if they have any questions.

Tim: Okay.

Interviewer: And the number I called you, this is your cellphone, right?

Tim: Yeah.

Interviewer: The number I called you on is my home number so if you have any questions don't hesitate to just give me a call back.

Tim: Okay.

Interviewer: All right?

Tim: When are you going to be at camp again?

Interviewer: I am hoping to be back there next year.

Tim: In June?

Interviewer: Yeah.

Tim: Sweet!

Interviewer: Yeah, I am actually going to try and do both again next year.

Tim: Cool!

Interviewer: Yeah. So it'll be really great to see you.

Tim: Yeah.

Interviewer: So all right well yeah. I will talk to you soon and if I don't talk to you before school starts up again good luck with your freshman year. That's pretty exciting.

Tim: Yep. And John and Jane[19] are coming down my school.

Interviewer: Oh really?

Tim: Yeah.

Interviewer: That's going to be awesome. So you'll have some friends from camp there too.

Tim: Yeah.

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[19] Names have been changed to protect participant privacy.

Interviewer: Excellent! That's great to hear.

Tim: So I gave George[20] my cell number and said if you have any questions give me a holler.

Interviewer: Oh, that's great for you to be there for him.

Tim: Yeah, I saw him at sports camp last week too.

Interviewer: Wow! So you've already got friends coming to join you.

Tim: Yep.

Interviewer: Excellent! That's such good news. Well, it sounds like you're just doing great Tim and I'm so glad to hear that that tumor was caught and that you're feeling good and that you're eyesight's improving. It sounds like life is going pretty well on your end.

Tim: Yes, it is.

Interviewer: Excellent! Well, enjoy every minute of it and, yeah, hopefully I'll talk to you soon.

Tim: Thanks.

Interviewer: Have a good day!

Tim: You too.

Interviewer: Bye-bye.

Tim: Bye.

End of Interview.

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[20] Peer name has been changed to protect participant privacy.

Kevin

14-year-old White male
Diagnosed: May 2009 – Anaplastic Astrocytoma (brain tumor)
Treatment stopped: Surgery (eye and optic nerve removed)/Radiation (6 weeks)/Chemotherapy (10 cycles/approx. 10 months) March/April 2010
First Interview: January 2012 – in person, parent present

Interviewer: All right, can you start by telling me what kind of cancer you had?

Kevin: I had anaplastic astrocytoma.

Interviewer: Okay. What is that in layman's terms?

Kevin: It is a cancerous brain tumor. It is grade three. That is pretty much it.

Interviewer: What are the grades, what does grade three mean?

Kevin: Grade three means it is a fast growing tumor.

Interviewer: Okay. And when were you diagnosed?

Kevin: I was 11 when I was diagnosed.

Kevin Mother: May of '09.

Interviewer: And what was your reaction when you found out that that is what the problem was?

Kevin: I was very calm about it. I wasn't really, really scared. I was, you know, scared because I knew what I was going to have to go through and what I didn't know I had to go through and I wasn't that – I wasn't really scared about it, I was pretty calm about it.

Interviewer: Interesting. Okay. And what was your feeling?

Kevin Mother: We were terrified of course… My husband and I.

Interviewer: Do you think maybe you were so calm because you saw your parents so worried?

Kevin: I wouldn't say that. That is not at all what I thought. I knew I had to be calm and if I didn't I would just not be able to handle it well, so I just stayed calm.

Interviewer: Great. What kind of treatment did you get?

Kevin: I had – well, before they knew it was cancer they put me on steroids and that – that didn't help at all, right? And so I gained about 20 pounds when I had the steroids and after that I had –

Kevin Mother: That was with a different hospital.

Kevin: Then they did the biopsy and found out I had cancer. I started on chemotherapy.

Kevin Mother: First they removed your eye.

Kevin: Oh yea, first they removed my eye.

Kevin Mother: And your optic nerve.

Kevin: And my optic nerve, and started on chemotherapy and radiation.

Interviewer: And how long did your treatment last?

Kevin: My chemotherapy was for one year and the radiation was for almost two months. Right, mom?

Kevin Mother: Yea, it was for six weeks. And you actually did the radiation first. You did chemo along with it, then after the radiation you had a year of – of 10 cycles of chemotherapy.

Interviewer: Ten cycles of chemo.

Kevin Mother: Yea.

Interviewer: Do you still take medicine?

Kevin: I don't except – well, I am not growing how I should grow so a doctor gives me a little pill and I have to take it before I eat anything, half an hour before I eat anything. It helps me or we think it will help me start growing some more.

Interviewer: How often, going back to the treatment itself, how often were you in the hospital?

Kevin: Well, we didn't go to the hospital for chemotherapy. Luckily we got it by pill so. We went of course for regular checkups.

Kevin Mother: Couple of times a week.

Kevin: Yea, couple times a week.

Kevin Mother: And how often were you taking the chemotherapy pills?

Kevin: Every night.

Interviewer: Okay.

Kevin Mother: It was five nights in a row – the cycle was five nights in a row and then three weeks off. And then five nights –

Interviewer: And you did 10 cycles of that? Okay. So how did the chemotherapy and the radiation make you feel physically?

Kevin: I hated taking the chemotherapy. Before I heard I had to take it in pills I was terrified. I could not take pills back then; I was terrified of taking them. And so what my mom did is she opened capsules and put it in – first we tried applesauce, which was terrible, the worst thing I have ever tasted. Then we tried pudding, which was maybe just the taddest bit better.

Kevin Mother: The hardest part was he had to take it on a completely empty stomach. So he could only have one tablespoon of whatever it was he had to mix it in it was just –

Interviewer: Not good.

Kevin Mother: Needless to say he learned how to swallow pills within a couple of weeks.

Interviewer: So you could take it with water and things.

Kevin: I'm still scared, but I manage to take the pills. What did you ask me again?

Interviewer: About how did it make you feel?

Kevin: I was tired when I took it. Of course, I was also tired from the radiation which was just terrible because I went in every morning – the ray went through my nasal glands and made a terrible smell when I was in there having the radiation. I can't describe it but I guess it smells almost like burning flesh. I don't know, it was terrible.

Interviewer: So how long would that last when you were going for the –

Kevin: Just as long as it was – just as long as I was being radiated on.

Interviewer: Okay, and how long were you being radiated?

Kevin: It was two minutes, right, mom?

Kevin Mother: I think it was a three and a half. They would do a CT scan real quick and then they would adjust the table that he was on.

Interviewer: So they did it as fast as possible.

Kevin Mother: And we tried – they would put, we would put oil scents or something on nothing.

Interviewer: The scent didn't linger beyond that?

Kevin: I would smell cinnamon – that is what they tried. It worked better than anything else and now I don't like the smell as much.

Kevin Mother: So she is asking if you – after the actual radiation was finished did you keep continue to smell that smell?

Kevin: No. I thought I did. But it was just in my head and I like whenever I went to go get a drink of water from a public fountain it just reminded me of that smell somehow, but I never really smelled it again.

Interviewer: Okay. So maybe like the metallic of the public fountain or something kind of triggered it. (Kevin nods his head) Interesting. So that was during the actual treatment. What about, let's say an hour after treatment how did you feel?

Kevin: I was tired.

Interviewer: Just tired.

Kevin: And the first day I had my when I had radiation I got a really bad headache and unfortunately, we were going to a musical that night so it was very loud and –

Kevin Mother: There were a few times you had headaches; not every time though. A few times he vomited, but only a few times. That was all during radiation, not during chemo.

Interviewer: You didn't have too many side effects then from the chemotherapy?

Kevin: I just lost some hair around here and –

Kevin Mother: That was radiation too, not chemo.

Interviewer: Oh, okay.

Kevin: So chemotherapy really wasn't that bad compared to other kids.

Interviewer: Now how long have you been out of treatment?

Kevin: About two years now.

Kevin Mother: A year and a half so June of 10 of 2010, it was his last treatment.

Interviewer: Okay. Now you had mentioned that you knew that you had to stay calm when you received the cancer diagnosis. What was your reaction when you were told your cancer was under control and gone?

Kevin: The same when I learned, of course I was very happy when I learned that it was gone and I knew that it would end, so I was very, very happy. When I heard that I had cancer I was surprised that I had cancer, but I still tried to stay as calm as I could.

Kevin Mother: He never – he never asked why me, he never cried about it, he never was scared about it.

Interviewer: That's interesting. Why do you think that is?

Kevin Mother: I don't know if it goes back to the – my husband and I were pretty upset about it, of course and he just is a very calm person anyway and I don't know. I think divine intervention.

Kevin: I don't know either.

Kevin Mother: Because he is great today.

Interviewer: So how have things changed since you stopped treatment?

Kevin: Of course, I am not going to as many doctor's appointments which is nice. When I had a whole bunch of appointments and I was going through treatment my mom sent my brother and sister[21] to public school because there was so much stuff to have to do and she couldn't handle it all, so they went to public school for a while and my brother, my other brother and I stayed home. We didn't school as much because it was so much, it was just really hard to focus, especially when I was having my treatments. Now I can – all of us home school and now I am better at focusing on it. Of course, when I have my treatment. When I had my treatment I was tired and it was very hard, but, we didn't do too much school because it was very hard to do.

Interviewer: You were diagnosed in May of 09, you stopped treatment in June of 10 so you had about 13 months of treatment, regular treatment. Are you a year behind in school then based on home schooling?

Kevin: I wonder that myself. Am I? (Asks mother)

Kevin Mother: No. You are doing the same stuff that your brothers are doing.

Interviewer: So you were able to make up time?

Kevin Mother: He did. When the two – when we sent the two to public school they had to test into public school and they tested two grades ahead, so we just put them in one grade ahead. So when it didn't last very long, they were in public school for about four months. They just didn't want to do it. When we brought them back home it was like spring break time, about that time, so we just stopped. We just didn't do anymore school after that until after the summer. Because they tested ahead we didn't worry about it. We actually kind of skipped ahead because we just quite school.

Interviewer: And jumped to the next.

Kevin Mother: Yea. And he has been fine with it.

Interviewer: Great. You must be very smart. What was, in your point of view, what was your family's reaction to when you were – you found out that your cancer was under control?

Kevin: Of course, my parents were very stressed about it and my brother's and sisters were – I'm not sure how they felt. They didn't act very stressed or they just kind of went – went along with it and didn't really get I mean they are, of course, wowed. When they heard I got cancer and they went to visit me in the hospital sometimes. I am not exactly sure.

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[21] Siblings' names have been changed to protect participant privacy.

Interviewer: So would you say that that stress kind of faded out when you found out that you were going to be healthy?

Kevin: I would. Of course, I think everyone's stress would be like that.

Interviewer: How often do you still go for check ups?

Kevin: Usually after I had my MRI and that is now every six months. I have some eye checks during the year.

Kevin Mother: Yea, so this is the first time we have gone six months between MRIs. He just went two weeks ago and we are going today for the results. He goes twice for the year – his good eye checked because it was in the optic nerve.

Interviewer: And they connect.

Kevin Mother: Yea. There is a chance that it could go, but so far so good. He sees an endocrinologist for growth and hormone, again, about twice a year now. And that's about it.

Interviewer: Do you have any concerns anymore about your cancer?

Kevin: It kind of affects my job a little bit. I would like to be when I get older, I considered being a policeman or a firefighter, but unfortunately, my dad talked to me about that and said that to qualify for one you need to have you know, good muscle – you need to be in fit and he said I probably wouldn't be able to get in with just one eye.

Interviewer: Okay. How did that feel when your dad told you?

Kevin: A little disappointed, my brother wants to be a firefighter and I was thinking I could maybe be in the same house as he was, you know, and we could both do that.

Interviewer: Do it together.

Kevin: It would be nice to be able to talk to him. He's fun.

Interviewer: What are you thinking you might do now if that doesn't work out?

Kevin: I don't know. I was thinking about being a lawyer or yea, I don't know. Before when I played piano a lot more I liked it more. Now, I don't like it as much. I considered being a pianist on the piano, but now I just don't think that is how it is going to go.

Interviewer: Why don't you like it anymore?

Kevin: Piano just kind of gets in the way of having a normal life. I don't know how to read the notes. I can only memorize songs. I can't read a single note without having to remember the phrases that my teacher gives me to remember them, the little rhymes or something. So I just don't think I am going to.

Interviewer: Do you think it is because of your eye?

Kevin: No.

Interviewer: You think it's because of your focus?

Kevin: No. I just don't think I like it is not – it is just not in my heart that I want to do piano. It just bores me.

Interviewer: Okay. So you just kind of grew out of it? (nods) Okay. What when you think about your future and you mentioned about how you may not be able to be a fireman do you have any other concerns about your future in respect to your experience with cancer?

Kevin: I would say being able to drive with one eye, I would say that is a big concern for me because I don't want to be – I mean I would have to look everywhere around me, which is bad, you know.

Interviewer: How are you with distance?

Kevin: It is harder for me to catch things than it was before. I have never been good at catching balls and stuff. Sometimes when I go to grab something I grab something like that and I don't know how far it is and it is harder to tell distance with my one eye.

Interviewer: I would imagine that would make driving much more difficult as well. So everybody knows cancer is not a pleasant experience. Is there anything you can think of you have gotten from this experience that is positive?

Kevin: I would say my attitude has changed and made me a better person.

Interviewer: What was your attitude like before?

Kevin: I am not sure. I don't think I would be as good of a person. I don't think I would be as calm as I am now. As in if something happened and I would be all mad about it. Now, I just try to stay calm and just go with it.

Interviewer: Keep things in perspective?

Kevin Mother: You told me a few other things about having cancer you were actually glad for it at one point you said.

Kevin: It just kind of changed me and I think it made me a better person.

Kevin Mother: And all the people that you have gotten to meet and –

Kevin: I have a great friend now from the [the cancer camp], we do science together every week it is very nice. If I hadn't had cancer I would have never met him. He is a great guy.

Interviewer: Yea, cancer camps are great in that respect. I have actually volunteered with one in Seattle for the last seven summers and I thought I might not be able to go to it this year because I was so busy with this work and I am doing everything I can to go back to it because it is just one of those situations, like you say, you wouldn't get to be involved otherwise. Hopefully, one day, you can be on the staff side. What would you say is or are some of the more difficult things you have to face in having cancer? Thinking about your whole experience.

Kevin: Let's see, definitely radiation and chemo are probably the most difficult things I have had to deal with.

Interviewer: Because of the discomfort of having to take it and deal with it?

Kevin: Yes. And let's see –

Interviewer: Anything outside of treatment? Friendships, school, family relationships?

Kevin: School, just not as good as it used to be before I had cancer. I can't focus that well now. That is pretty much it. I don't have too many other concerns.

Kevin Mother: The only other one you said that I know of is growing. That you wished you could be taller, but looks like he is probably close to being about done.

Interviewer: Okay. You will have to forgive me, I meant to ask this question at the start; how old are you?

Kevin: I'm 14 now.

Interviewer: Fourteen, when is your birthday?

Kevin: August[22].

Interviewer: Based on your home schooling, what year are you in school?

Kevin Mother: You are ninth grade.

Interviewer: Ninth grade. Okay. So obviously, we already talked about that you are doing very well at school and you don't seem to have any concerns aside from the fact that it is very difficult for you to focus now. Is your mom your homeschool teacher?

Kevin: Yea. She is.

Interviewer: I have never actually been homeschooled so can you describe for me how homeschooling works? What a typical day like for you in homeschooling?

Kevin: Well, first when we get up we usually come out and eat breakfast and then when we are done with that we get started on math. We just have the book and get the math and instead of having to buy four math books, one for each of us, we have one math book and two plus, what we do is all three of us boys are in the same math. Two of us read from the same book and we copy the page or the pages and give the

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[22] Date omitted to protect participant privacy.

other one the pages so they can read. We write them down on a piece of note or in our little notebooks. So we do that and then we usually do grammar. And that takes about as long as math.

Interviewer: Okay. About how long?

Kevin: About an hour. It just takes a really long time. And let's see, then we usually do language arts, well that is part of grammar. We do Wordsmith it is called.

Kevin Mother: Writing.

Kevin: Yea, writing. Then we do yea, vocabulary. That is very easy. They are called vocabulary comics almost. So they say what the word is and they draw they make a picture and it says like if the word is bite and then it says this fish bites or something, just a little phrase. Then we read all the phrases with that word. We do one lesson of those, keep reading them all week and then take a test at the end of each week.

Interviewer: Great. Okay. And do you do lunch after that?

Kevin: No, usually we do math, have a snack, do grammar, have lunch, then do language arts.

Interviewer: And do you stop after language arts?

Kevin Mother: Science.

Kevin: Yea, we have science and government, which we both do around the same time.

Interviewer: Both?

Kevin: Yea, well we do sometimes don't we do what every each like every other day we do science or?

Kevin Mother: Four days a week we do science.

Interviewer: Okay.

Kevin: And then four days a week for grammar too?

Kevin Mother: Because we have coop on Friday with another family.

Kevin: And then government. When do we do that?

Kevin Mother: That is four days a week too.

Interviewer: Okay, so you have a pretty full day then. I imagine you are done with home school in the afternoon same time around regular school, 3:00 or so?

Kevin: Yea, probably.

Interviewer: Okay. Oh, but no homework. Interesting.

Kevin: That's the best part.

Interviewer: Yea, I'm sure. So how does homeschooling work with friendships?

Kevin: I don't have as many friends as I would going to the public school because most of my friends are here on the street that we live on. I do have some friends, my friend Matthew who was at Camp Rainbow that I met that I told you about. Meet him about every week when we do science.

Interviewer: You mentioned, so does he get homeschooling as well?

Kevin: Yes, he does.

Interviewer: And he lives nearby?

Kevin: Yes.

Interviewer: Oh, great.

Kevin Mother: And then, you do Scouts too.

Kevin: Oh yea, I have some friends in Scouts. We just moved to a new Troop in Scouts because our other troop didn't live up to our expectations. So I have some friends, well they are just more in our – we have different patrols and we are in the Scorpion patrol and we are in Falcons. And I am friends with the ones in Scorpions.

Interviewer: Did you do Scouts before you got a diagnosis as well?

Kevin: I did. I went through Cub Scouts and I am almost done with Boy Scouts.

Interviewer: How did your friends that you had before cancer react to your diagnosis with cancer?

Kevin: Well, they were surprised. They were happy when they heard that I was done with – that it was gone and one time when I came home from Camp Rainbow, I think the first time, they actually waited outside for me with a banner and just the kids came over and made a banner for me. It was really nice.

Interviewer: Oh, that is nice.

Kevin: Yea, they have been great since I had cancer.

Interviewer: Have you lost any friends over it?

Kevin: No.

Interviewer: Has just the relationship you had with them changed at all?

Kevin: Not very much.

Interviewer: So they have been real tolerant about it and you know, no bullying or anything like that?

Kevin: I have never been bullied my whole life.

Interviewer: That's good. So what kinds of things when you are not being homeschooled, when your friend comes here and is homeschooling with you what kinds of things do you do with your friends for fun?

Kevin: Go outside, or play on the computer games. When we go outside we usually swing or we don't go on bike rides they can't bring their bikes over here like we do with our other friends. Usually we just go outside and play outside or be in here and play on the Wii or the computer or something.

Interviewer: Just hang out?

Kevin: Yes. Just something fun.

Interviewer: Excuse me. So you mentioned that you have how many brothers?

Kevin: I have four brothers. One of them is older.

Kevin Mother: Three.

Kevin: Yea, I'm sorry three brothers.

Interviewer: So there is four boys – you have three brothers. There are four boys in the family.

Kevin: One lives in, he is much older than us. He is about 30 and he lives in Texas. And then my other two brothers that were triplets, of course here. What was the question?

Interviewer: I was just seeing – and you have a sister?

Kevin: I do. We are 14 she is 11 now.

Kevin Mother: Twelve. The is 12.

Interviewer: Okay, great. And your sister gets home schooled with you guys?

Kevin: Yes.

Interviewer: But she is on a different level.

Kevin: Only in math. She and science, but she follows along with? And grammar, she is different in grammar. She follows along with –

Kevin Mother: She is seventh grade, but she does all of Bible and history and just Bible and history now, she is pretty much in seventh grade now.

Kevin: She used to do a different type of grammar with us, but she doesn't do that anymore.

Kevin Mother: It's too much for her.

Interviewer: And I wonder does she get homeschooled at the same time as you and your brothers?

Kevin: Yes.

Interviewer: So I wonder if maybe that is part of the thing – you know, like she is several grades ahead when she went to public school. So you and your two brothers are triplets. Earlier you had mentioned that you and one of your brothers did not go to public school, but one did. Was it just given as a choice or?

Kevin: Well, my brother and sister, Jessica and Robert, wanted to go to school, but Thomas didn't want to. He tried going to school for a little, but he really didn't like it. He got to stay home and my brother and sister wanted to see how public school was so they went.

Kevin Mother: So we decided it was just crazy at that time; trying to meet all of his appointments and school them at the same time. So we actually put all three of them in a charter school, but nobody was happy with it. Within a week we knew it wasn't the right place for them to be.

Interviewer: Okay.

Kevin Mother: And he really had a hard time with it because all of a sudden all three of them are gone and he is home by himself now. That was hard too. We decided just to put the two of them wanted to go. They wanted to go to public school. We put the two of them in the local public school here, Thomas stayed home with him.

Interviewer: I just want to make sure that I understand this. Okay, so when things were getting difficult with treatment your other siblings were initially put into a charter school and that didn't work out and so then Thomas was given the option to stay at home if he wanted to, which he chose to do. And then Robert and Jessica wanted to try out public school. And that didn't – you mentioned that didn't work out.

Kevin Mother: It didn't. That only lasted about four months and that was you know, we told them we needed them to go ahead and finish out the rest of the semester. They cried every day on the way to school, I don't want to go. I want to be home schooled again.

Interviewer: Did they say why?

Kevin Mother: Robert just really missed how we did school and being with the family and being home with Kevin I think. That was his main thing. They both did fine in school. Jessica had a really hard time with trying to connect with other girls – because we went in in the middle of the year girls are harder, it was fifth grade. They were all very cliquey already and had all their little groups they hung out with. It was a shock for her, I think.

Interviewer: When all of your siblings had gone off initially to the charter school, what was that like for you being kind of left here?

Kevin: I did not like it. I was very alone. Of course, I had had all three of them every day here and then it was just me here. And I was – I was very bored. I just had nothing because we play around all the time and I – I just didn't like it at all.

Interviewer: Okay. That also now makes sense when you say you want to be with your brother as the fire house. I imagine that you and your siblings are all very close. Especially you with your brothers being triplets. Has your relationship with your parents changed at all from before you had cancer until now? Feel free to answer honestly.

Kevin: I would say they are a little softer than they are with the other ones to me, which of course, I like.

Interviewer: So maybe the discipline has changed a little bit.

Kevin: A little more. Yea, a little bit.

Interviewer: Does that bother your siblings at all, that you get special treatment?

Kevin: I don't think it just that much – just a little bit. They have never said.

Interviewer: They have never said and they have never shown any behavior that would change that.

Kevin Mother: They never have. Not to us either.

Interviewer: Oh, okay. Good.

Kevin Mother: They have never.

Interviewer: Well, I'm sure they have been really understanding.

Kevin Mother: They have.

Interviewer: And your friends – you said they haven't treated you any differently. Now, I just wanted to ask you a couple of questions about the camp you go to. How long do you go for?

Kevin: A week.

Interviewer: Do you sleep there?

Kevin: I do.

Interviewer: Okay. I'm assuming it is in the summer time at some point.

Kevin: It is.

Interviewer: What kind of things do you do there?

Kevin: It is almost like classes, except it is fun things. We do, let's see there is art, which is pottery making and necklace making, something like that. I will show you something.

Interviewer: Okay.

Kevin Mother: He has been to a few different ones. Camp Rainbow is the one he is talking about that is done through Phoenix Children's Hospital. He did, there is a one time in your life kind of camp that you can go to in Colorado, in Aspen. He did that for a week.

Kevin: We actually made these. They are so much fun to make.

Interviewer: Very pretty.

Kevin: We did a centerpiece. These are fish bones that we carved. They are very fun to make. Have you ever gone to a pottery store and painted them? We made one of those.

Interviewer: What other activities do you guys do? Do you do like archery or swimming or anything like that?

Kevin: Yes, we do. We do archery and swimming. They are both really fun. What we do when we do archery is we set up some targets and they put balloons on the target and we shoot the balloons.

Interviewer: Very fun. It is like being at a carnival.

Kevin: Yes, canoeing was my favorite one. You could just go wherever you wanted to and it was just really nice and calm and. When we went swimming we had a whole bunch of stuff play with. It was really fun.

Interviewer: Excellent. Do you find that you have kind of a camp set of friends?

Kevin: I have one friend from camp that I told you about. I met him there.

Interviewer: Do you stay in touch with anybody else that is from camp?

Kevin: Not really. I just went there. I just pretty much stay in touch with my friend.

Interviewer: So do you not connect with the other kids? I am just curious. How many kids, I am assuming you stay in a cabin of some kind.

Kevin: I have a picture of them. Probably seven kids and three counselors.

Interviewer: So you have actually got a great ratio there of kids to counselors. You basically only connected with one other boy.

Kevin: Of course, I talked with the other ones and they are fun. We just hung out when we were doing activities. I just really got along with him and we talked a lot and he was really fun to talk with and he loved Star Trek and he talks about that.

Interviewer: Great. Is it a coed camp?

Kevin: I don't know what that means.

Interviewer: Is it boys and girls?

Kevin: Yes. It is. Of course, the boys stay in one cabin and one section of cabins. The girls are in another set of cabins.

Interviewer: Yes. We wouldn't want things to get out of hand.

Kevin: What is really fun to do is we would raid each other's cabins. That is what we used to do my friend told me about, last time he was at camp, I didn't go to that camp, but what they did is they actually got the mattresses and spelled out aha on the roof of their cabin with the mattresses.

Interviewer: Oh, I'm sure the girls must have loved coming back to that. So is that something you are going to come back to?

Kevin: I would like to go back this year. Because I didn't like it as much because I chose to be in the one with my friend and that is where the counselor's are a little tougher because the kids are younger and more annoying.

Kevin Mother: But your friend is younger.

Kevin: Of course, but he is not annoying. Some of the kids are public schooled and some that need I feel like they need attention, more attention. And the counselor was just more –

Interviewer: Strict?

Kevin: Yes. More strict with the rules because they are younger. And I think this time if I go with an older group they would be more mature.

Interviewer: Then you wouldn't get to be with your friend anymore.

Kevin: That is what I am mad about or upset about, but at least I will be able to see him.

Kevin Mother: Same camp just – (pauses)

Interviewer: So you will still be able to see him and you never know, maybe you will make a new friend that is as good as your other friendship?

Kevin: Yea.

Interviewer: Okay, great. Well, I have pretty much asked all the questions I have here. I just wanted to ask you if there is anything else you want to add that you think it is important for me to know about your cancer experience? Emotions, the way you have handled things, anything?

Kevin: Nothing I really need to get off my chest or anything.

Interviewer: Would it be all right if I ask you follow-up questions if I have any later on?

Kevin: Yeah, sure.

End of interview.

Diagnosed: May 2009 – Anaplastic Astrocytoma (brain tumor)
Treatment stopped: Surgery (eye and optic nerve removed)/Radiation (6 weeks)/Chemotherapy (10 cycles/approx. 10 months)
Second Interview: July 2012 – phone

Interviewer: Your kids for home schooling. Where do you go from there?

Kevin's Mother: Well, in Arizona, and it is different in every state. But in the Arizona, you have to file an affidavit of intent to home school.

Interviewer: Ok.

Kevin's Mother: With the – through the – like a home school liaison.

Interviewer: Ok.

Kevin's Mother: Then that has to be done by the age of eight.

Interviewer: All right.

Kevin's Mother: In Arizona, I just asked. Then they do not have any. It is very lenient here with home schooling. They do not have… You do not have to show them any records of anything. You do not have to keep track of your days, or…

Interviewer: Really.

Kevin's Mother: You don't have to test every year. It's none of that to do file an affidavit of intent to home school.

Interviewer: Ok.

[Crosstalk]

Interviewer: How did they? How did they actually keep track of whether or not the children are being home schooled?

Kevin's Mother: They do not. They have the right to come and check. And look at if they think there is a need. They have the right to come and look at the records so they keep for them. I keep – I have keep all of their records until they got to high school. Then I got rid of their elementary stuff.

Interviewer: Ok.

Kevin's Mother: But now I have to keep all of their high school records for college purposes.

Interviewer: Yeah.

Kevin's Mother: Not through the state purposes.

Interviewer: Yeah. Wow, ok. Being a part of home school, I mean, do you affiliate with any kind of government based agency?

Kevin's Mother: No.

Interviewer: No, so it is completely private within your family?

Kevin's Mother: Yes.

Interviewer: Wow, ok. That would be why he did not. I guess Kevin was not eligible for any kind of educational assistance during his treatment?

Kevin's Mother: He can be.

Interviewer: Ok. How would that work?

Kevin's Mother: He still is. In the state of Arizona, they also have to allow. Because they still pay taxes, we have to pay taxes. Part of those taxes go for home schooling.

Interviewer: Yeah.

Kevin's Mother: I mean, for schooling, home schooling.

Interviewer: Yeah.

Kevin's Mother: Even when he was younger, he and his brother both needed speech therapy. We were able to get that through the – through the school district.

Interviewer: Ok.

Kevin's Mother: Yeah. We just have to apply for what we want to. If they – if they decide they want to be in band with the school; or play a sport with the school, they can do that.

Interviewer: Ok. I did not realize that. You just have to make an application to the school?

Kevin's Mother: Right.

Interviewer: Or to the district?

Kevin’s Mother: No, just to the school.

Interviewer: Ok.

Kevin’s Mother: Talk to the school about it. Yes.

Interviewer: Do any of your kids do any extracurriculars affiliated with the school?

Kevin’s Mother: Not with the schools, not yet. Next year, they are… For their 11th and 12th grade years, there is a program, [which is] kind of an offshoot of a [university] thing. Where they… It is kind of like a vocational class that they can take depending on what they want. For instance, one of my sons wants to, or is interested in graphic arts. He can go to this [program] in the morning. Appellate schools offer it too. You have to actually be in the – within the school district and go. Like the public schools bus them back and forth to this place. Where I would – he is not in public school with just driving back and forth. But we are… He is able to do that kind of thing, too.

Interviewer: Great.

Kevin’s Mother: Yeah. We have that in mind for eleventh and twelfth. But they are just going to be in tenth grade this year, so.

Interviewer: Ok. I forget, I think you had already told me this. But do you do any teaching over the summertime?

Kevin’s Mother: Yeah. We do. They have been doing math the whole time. They do a little bit of government.

Interviewer: All right, well, I hope I am not interrupting school this morning.

Kevin’s Mother: No, you are not.

Interviewer: Ok. Good.

Kevin’s Mother: Not yet, because we have not started that yet.

Interviewer: If, because you can apply to the school for extracurricular [activities], with regard to Kevin, and when he was undergoing treatment. Would you also apply to let us say the school’s social worker if you needed another teacher to come in to teach him?

Kevin’s Mother: I could, yes.

Interviewer: Ok. That would also go through the school?

Kevin’s Mother: Yes.

Interviewer: May I ask what school you affiliate with?

Kevin’s Mother: Well, we are in the [local] school district.

Interviewer: Ok.

Kevin’s Mother: Our – there are two high schools that are near us. [Sentence omitted to protect anonymity.]

Interviewer: Ok. I have been trying to get a better idea of specifically what Kevin was eligible for.

Kevin’s Mother: Ok.

Interviewer: And what you guys have specifically chosen to embrace or deny.

Kevin’s Mother: Right.

Interviewer: I – that actually leads me to my next question.

Kevin’s Mother: Ok.

Interviewer: Did you guys ever consider going with a home-school teacher with the school? Or, did you just figure that you could handle it?

Kevin’s Mother: We have not at this point. I mean, I – not with Kevin. I have another son and a daughter who did go to public school for a short period of time.

Interviewer: Yeah. You had mentioned that.

Kevin’s Mother: Yeah. But Kevin has not ever, and has not ever wanted to.

Interviewer: Ok.

Kevin’s Mother: We are so far, we are able to do everything just fine, just us.

Interviewer: Great.

Kevin’s Mother: I do have him in… It is in the works to have a neuropsych. evaluation done.

Interviewer: Ok.

Kevin’s Mother: In– house, but if he does need some tutoring help that I can get it.

Interviewer: Ok.

Kevin’s Mother: That way – through… Because he is – he is struggling a little bit in the math area, which may just be because he struggles in math. It may not and most likely does not have anything to do with his illness. But…

Interviewer: Yeah.

Kevin’s Mother: I still wanted to have it done just so I could get those resources if I needed them.

Interviewer: Exactly, ok.

Kevin’s Mother: Yeah.

Interviewer: You do still feel like you have resources available to you and your children if you – if you think that they need them.

Kevin’s Mother: I do, yes.

Interviewer: Ok. Great, and before I start to talk with Kevin, I just wanted to also hear from you. How do you feel like he’s been doing?

Kevin’s Mother: He is doing really well. We just had another MRI and appointment with his oncologist. There are no signs of *it* coming back.

Interviewer: Great.

Kevin’s Mother: – At this stage, so yeah, everything is going really well.

Interviewer: Fantastic, that’s great news.

Kevin’s Mother: Yeah, thanks.

Interviewer: Well, great, I would love to talk to Kevin, if he is available?

Kevin’s Mother: Ok, he is. Let me get him.

Interviewer: Thank you.

Kevin’s Mother: Good luck with your research.

Interviewer: I appreciate it. Thank you.

Kevin’s Mother: It’s really helpful. Down the line I am sure it will be very helpful for… (pause)

Interviewer: I hope so. Yeah, it is at least good to make sure that everyone is getting the resources they deserve.

Kevin’s Mother: Yeah. I agree. Ok. Let me grab them. Hang on a just a second.

Interviewer: Thank you so much!

Kevin’s Mother: Do you remember that when we had that lady come to the house? It is kind of a research project for her column. You just – like she is just asking you questions about your illness and your experience. She wants to talk to you a little bit more. Could I ask you to come in for ten minutes for me?

Kevin: Sure.

Kevin’s Mother: Can you come and get the phone?

Kevin’s Mother: Yep.

Kevin: Hello?

Interviewer: Hi, Kevin. How are you?

Kevin: Pretty good. How are you?

Interviewer: I am doing great. Thanks for asking. If it is all right, I wanted to talk to you a little bit more, and just kind of follow-up and see how you have been doing.

Kevin’s Mother: Ok.

Interviewer: Because I think. When was the last time we spoke? I think it was January, right?

Kevin: Yeah, I think so.

Interviewer: How are things?

Kevin: Pretty good.

Interviewer: Yeah?

Kevin: Yeah, I am doing pretty good.

Interviewer: How are you feeling?

Kevin: I feel ok.

Interviewer: Your mom was telling me that you just had an MRI recently?

Kevin: I did.

Interviewer: And?

Kevin: It is – it is pretty clean. They said it looks good.

Interviewer: Great.

Kevin: Yeah.

Interviewer: That must be a great relief every time you get to hear that news.

Kevin: It is.

Interviewer: Can you explain that?

Kevin: Well, I just know that I am going to hopefully be ok. It is kind of a regular thing now. Because I have had so many MRIs.

Interviewer: Yeah.

Kevin: I just kind of expect it to be that way.

Interviewer: Yeah.

Kevin: I try to prepare myself for if it is not as clean as it should be. That it could come back.

Interviewer: How do you prepare yourself for that?

Kevin: I just mentally tell myself that it could happen. If it does, I just need to try to get through it the best I can.

Interviewer: I think that is pretty normal way of looking at it. How is that – everything going with school with your siblings?

Kevin: School is – it is a little hard for me to focus.

Interviewer: Ok.

Kevin: Like it almost seems like I am focused on school now. I just kind of drift away. I just cannot help drifting away.

Interviewer: Ok.

Kevin: It – especially math.

Interviewer: Ok. Yeah, your mom had mentioned that to me just now.

Kevin: Yeah.

Interviewer: What do you think it is specifically about math that is not holding your attention? I mean, do you – do you like the subject?

Kevin: I hate it.

Interviewer: Ok. That could have something to do with it.

Kevin: Yeah, probably.

Interviewer: Do you have a favorite subject?

Kevin: I like reading a lot.

Interviewer: Ok.

Kevin: Yeah, let us see. Besides reading, I do not. I kind of like taking Spanish classes.

Interviewer: Very cool.

Kevin: Like we do Spanish on Rosetta Stone. Have you heard of that program?

Interviewer: Absolutely. Yeah, that’s great.

Kevin: Yeah, and I kind of like that because I like being able to speak another language. It is interesting.

Interviewer: Yeah. It is pretty cool.

Kevin: Let us see, what else do I do? That is pretty much it for school. Because like, doing grammar, it is just kind of boring. Well, actually science is pretty interesting.

Interviewer: Yeah. What are you guys doing in science now?

Kevin: We are on a summer break, but we were doing. Let us see, we were talking about cells and a lot of things about cells. Like, the insides of them and what they do. How – what different types of cells, and stuff like that.

Interviewer: Very cool. Well, that must have a little bit more meaning for you, especially going through what you have gone through medically.

Kevin: Yeah.

Interviewer: Your mom tells me that you are going to be in tenth grade?

Kevin: I am, soon.

Interviewer: That is pretty cool.

Kevin: Yeah.

Interviewer: When does that start?

Kevin: I assume at the end of our summer break. But, I am not. I am really not that sure.

Interviewer: Ok. How long do you guys do summer break for?

Kevin: Usually about two months.

Interviewer: Ok. Pretty much the same as kids that go to school, like an actual school?

Kevin: Yeah, we used to not do summer break. The second year we have done it. Yeah, but we were a little late, though with getting our stuff done. We are still not done with math. But we have got all our… We have gotten all of our other stuff done.

Interviewer: That is good. Is there any reason why that one subject is behind?

Kevin: We just kept on taking days off of it.

Interviewer: Ok.

Kevin: Like we have… We do piano lessons. I have, not a million doctors appointments, but a few doctors appointments sometime. Or sometimes we go to places. Like we have scouts.

Interviewer: Yeah. You mentioned that you were in Boy Scouts?

Kevin: We go there sometimes. We did have a program that I was doing before summer break.

Interviewer: Ok. Tell me about it.

Kevin: It is just a program where you go to workout three days a week.

Interviewer: Fun!

Kevin: That probably hinders our school a little more.

Interviewer: Yeah. But, I mean, it is kind of a different sort of school. I mean, you are doing physical education instead of mental. Yeah, so you like doing that?

Kevin: I think that like physical you mean? You are talking about school, right?

Interviewer: Yeah.

Kevin: I think it is more mental than physical, I would say.

Interviewer: Really?

Kevin: Yeah, because I just have a very hard time focusing –

Interviewer: Yeah.

Kevin: – With it, basically.

Interviewer: What about this will power program?

Kevin: That would have just like if we did not have enough time before we had to go there, that we would have stopped to. It would have had to have stopped doing that if we were doing it that time.

Interviewer: Yeah.

Kevin: And [that workout program] actually works really good. It was a good experience for us. Now we know how to work out better and eat better. It had a nutritionist. I think it was a very good program.

Interviewer: Excellent.

Kevin: Yeah.

Interviewer: Well, I remember when we last spoke, you had mentioned to me about wanting to be a firefighter. Is that still true?

Kevin: I think that I would love to be one. I think it would be a really interesting job. But I cannot think of a few things that would really hinder that. Like having my – on my… My dad talked to me about… Well, before I wanted to be a police officer even more than a fireman. He said that there was a physical that they had to go through. Me not only having one eye might be – might not get me through. He said there is a very good chance that I will not be able to go through with just having one eye. Yeah.

Interviewer: Did you have any problems doing any of the physical stuff in the program?

Kevin: I did not, actually.

Interviewer: Well, that is great!

Kevin: I, at first running was hard. Just – but just because I had gained a lot of weight during my hospital stays and all of that stuff. But I got used – much more used to it. It was a very good thing.

Interviewer: Great, that is good to hear. Now, your mom had mentioned something to me about not this year, but in your eleventh and twelfth grade years. You guys might be doing a kind of vocational type program at a local high school?

Kevin: I cannot remember…

Interviewer: Was she…

Kevin: … Exactly what she said about that, but… like where we… Did she say that we would go at like at three times a week?

Interviewer: Yeah.

Kevin: Yeah, ok.

Interviewer: She mentioned that one of your brothers wants to do like graphic design.

Kevin: Yeah.

Interviewer: Is there any particular vocation that you are interested in doing? Have you given any thought to that?

Kevin: I thought graphic design might be a little interesting. I had not really made up my mind about that kind of stuff. Like what job I want to do.

Interviewer: Yeah.

Kevin: I do not have to take this one thing. It is called a, like, I cannot remember what it is called. But jobs or something like jobs.com, or something like that. I am not sure.

Interviewer: Ok.

Kevin: But, we… It asks questions and we type in our answers. It comes up with a few jobs that we like to. That our – that we might be interested in.

Interviewer: Great.

Kevin: I am thinking about. I am going to do that sometime this week. I am going to hopefully try. If you can call me back then for that question, that would be awesome.

Interviewer: Sure, yeah, I can give you a call back next week and see what the results are.

Kevin: Because I am going to try to get to that this week. Hopefully I will remember. That would be awesome.

Interviewer: Yeah. No, I can definitely do that. I would love to hear your results as well. What about in terms of friends and things. You had mentioned back in January that you – given that you are home schooled, you had a few friends from extracurricular things. You had a friend that came over; I think his name was Matthew, for science. How are you feeling now about the number of friends you have? And the time you get to spend being social?

Kevin: I feel that I do not have enough time with other kids my age.

Interviewer: Ok…

Kevin: I feel that I need to be getting in more activities.

Interviewer: Ok…

Kevin: So, I can be more social. I am going to a Sunday night get together with a [religious] group.

Interviewer: Neat.

Kevin: Youth – and I just actually went yesterday to try it. See what it was like. I plan on going to the other groups. I think it will be a good way to interact with other kids.

Interviewer: Yeah. It sounds like it. How was it yesterday?

Kevin: It was fun. It was really fun. Like what we did was we played games for 45 minutes, I think. They have some video games. They have air hockey. Well, not air hockey; they had Ping-Pong, and Foosball, and games like that. We played some games. They had some pizza and soda. Then we all went into a one room and talked about Christian stuff. Like Jesus, and God, and that stuff. That was – it was really good. They had band and they sang a few songs.

Interviewer: That sounds great.

Kevin: Yeah, I think they were going to plan some things. Every week to do something different. But I think it will be really fun.

Interviewer: It sounds kind of like a mixer.

Kevin: Well, I think basically what it is – is we talked early. We hang out for 45 minutes and do whatever we want. Then we just go into one room and talk about

Jesus and all of that kind of stuff. I am not exactly sure how it is going to go. I only heard it from my friend, who lives across the street. I am going to – but, I am going to keep on trying and see how it is. We are also doing the Scouts and all that. We are that… I am interested more of Boys and that.

Interviewer: That is always great. Yeah, and scouts help you, too, with the physical things as well.

Kevin: Yeah, that we do fun games, and activities, and stuff like that.

Interviewer: Do you feel like? You said last night was your first night at this [religious] group. Do you feel like you made some new friends?

Kevin: Not exactly; it was. The first time for everything, you get all. You are kind of looking at everyone and figuring out who looks nice. Like at that program I told you about. We did not really talk too much the first time. We just gradually went together. Now, we are… I feel very comfortable speaking with my friends [there]. It is really good.

Interviewer: Great.

Kevin: I think it will get much better.

Interviewer: Yeah. You think you will kind of slowly start to feel a little bit more comfortable?

Kevin: Yes.

Interviewer: Do you go with your brothers?

Kevin: Yes, I do. Just [my brothers]; and my sister does not come. But it was just my friend [across the street], and [my brothers], and I.

Interviewer: Great.

Kevin: Yeah, and then all of the other kids that go to that place.

Interviewer: Great.

Kevin: Yeah.

Interviewer: But the kids that you have met. Even though you have not become instant friends just yet. Have they been friendly?

Kevin: They are pretty friendly.

Interviewer: Excellent.

Kevin: Yeah.

Interviewer: It is nice that you have your neighbor there, too.

Kevin: Yeah. She can kind of show us around.

Interviewer: Absolutely.

Kevin: Yeah.

Interviewer: All right, well, I am sure your brothers are pretty happy being back from… You had mentioned that they were at a school when you were undergoing some treatment.

Kevin: Yeah.

Interviewer: Is everybody really happy to be back at home schooling?

Kevin: Yeah, they think they really are.

Interviewer: Do you? Why do you think that is?

Kevin: They said that they just did not like it. It just was completely different from what we did. It is just kind of interrupted with our homework stuff.

Interviewer: Yeah.

Kevin: Like how our lives were.

Interviewer: Exactly. Well, I think when you are used to something, too, it is just difficult to change.

Kevin: Yeah, you can.

Interviewer: Well, as I was telling your mom, I wanted to give you a little bit of an update as to how things were going on my end as well. It has been really interesting. I have gotten the chance to interview all of the kids that have volunteered. It has been wonderful, I think, from my end to get to hear stories that are very similar to yours… To get an idea of where and how at each individual person likes to deal with different things. One thing that I have found very interesting is that I have been looking a little bit more into how schools have helped kids continue to get an education and support them during the emotional struggle of having cancer.

Kevin: Yeah.

Interviewer: But it sounds to me like, what you have always told me. What you told me in January is that you did not struggle too much emotionally.

Kevin: I – well, I think it was more like I had to get through all my cancer stuff. Then like the aftermath was a little more. Like not now as much, but let – before I thought about not having one eye. I was big and heavy at that time. Food was kind of my comfort, something that just comforted me. That is the family. I just felt that I was. I felt like a person who had completely changed.

Interviewer: Ok.

Kevin: Like I felt that I thought differently. I did different things from before. I just completely felt different so I was scared of that. But, I realize that I think it made me a better person than I was before.

Interviewer: Ok.

Kevin: Things, like you know how the things that do not kill you make you stronger.

Interviewer: Exactly.

Kevin: I think that is kind of how it helps me.

Interviewer: Absolutely.

Kevin: Yeah.

Interviewer: You were talking a lot about feeling so much different from before you were diagnosed. Do you feel alone?

Kevin: I do not feel alone. I have met plenty of people who also had cancer. Even some people who have lost eyes like me. I met a boy who was with a prosthetic leg. I don't feel alone at all with having cancer. I just feel like I am different basically.

Interviewer: But as you say, you think that is a good thing?

Kevin: I do, and in different ways. Some are good. Some are bad.

Interviewer: Yeah.

Kevin: Yeah, that is basically it.

Interviewer: You had mentioned that you do not necessarily feel that way now?

Kevin: I feel it less. Like I realize that I was. That it was good. It was a better good than bad change. And that it was more positive than negative, and that stuff. I just needed to keep on going and keep on focusing on doing better things. Doing the right thing, and making good decisions.

Interviewer: Absolutely.

Kevin: It was like eating right and exercising more, which I am going to start doing even more than I have.

Interviewer: Yeah. I mean, especially with your situation. You said you were taking comfort in food. I am sure that program was very interesting for you.

Kevin: Yeah, it was very interesting.

Interviewer: Good way to help you get back on track.

Kevin: Yeah, it was.

Interviewer: Now, also when we talked in January, you mentioned, I think it was [a cancer camp]?

Kevin: Yeah, I think, yeah.

Interviewer: Are you going to go back there this summer?

Kevin: Not this summer, but I am going to [a different camp] this summer.

Interviewer: Ok.

Kevin: We had planned to go to both camps this summer. But we were going to the beach. Then we – I would have to go to that plan – that camp. Then a few days later I would have to go to [the camp]. It was just too much of a hassle.

Interviewer: Yeah.

Kevin: We decided not to. But next year, I definitely want to go.

Interviewer: Are you excited?

Kevin: I am. They said they are going to have this one thing. Like you have to make your costume. It is a… I do not know why, but they call it the wacky tacky dance. I do not know, but it. You are supposed to go completely unmatched. Like just completely wacky, like different shoes, different socks. Weird, like wearing a tuxedo with a biker's suit or something. Something like that –

Interviewer: Yeah.

Kevin: – Just something funny.

Interviewer: Well, that is going to be fun. Do you make it there or do you bring it with you from home?

Kevin: I bring it from home.

Interviewer: That's awesome!

Kevin: Yeah, but I am also having a – they call it a white house. Because you are not supposed to wear anything with white. Because we… It is like mess night basically.

Interviewer: Ok.

Kevin: We make these swine stuff. We throw it at each other and play games. Like they have slip and slides with slime. It is just – you basically get really dirty.

Interviewer: I was going to say that sounds gross, but a lot of fun.

Kevin: It is definitely a lot of fun.

Interviewer: Well, that is fantastic. I mean, of course, you are going to make a lot of friends doing that as well.

Kevin: Exactly. That is how I met [my friend I told you about].

Interviewer: That is right, yeah. You mentioned that. You and [he] are still good friends?

Kevin: Yeah.

Interviewer: I see.

Kevin: We are definitely good friends, really good friends.

Interviewer: Excellent, that is great to hear.

Kevin: Yeah, we get... We try to get together about almost every Friday. We do things together. During summer break, we just kind of like to hang out.

Interviewer: Perfect.

Kevin: He has a brother. We are also really good friends with him. It is really fun.

Interviewer: That is great.

Kevin: Yeah.

Interviewer: Well, it sounds like because you were saying that you would like to have more social activities in your life. I mean, it sounds like you have got a lot lined up for this summer.

Kevin: I was saying that I… I think I was saying that before. Now I feel like I have more to do.

Interviewer: From January to now you feel like you have got a lot more available to you? Do you think that is just because of summer? Or do you think it is because maybe you are a little bit more ready to hang out?

Kevin: I think I am more ready to hang out. Being – and not just summer, but we have always. Well, forever since I went to [the cancer camp], we had been doing that thing with [my friend]. I just – I just heard about this Sunday night church thing. I decided that I wanted to do that because it would help me more. It would be fun and I would be able to interact. Scouts, we have always done.

Interviewer: Yeah.

Kevin: I think that is good, too. I love going to these camps.

Interviewer: Absolutely, yeah.

Kevin: Yeah, I try – I tried to go to that camp almost every year. It is really fun.

Interviewer: It sounds like it. Well, and it is also really nice I think that you have got so many different things going on.

Kevin: Yeah.

Interviewer: It is not just one thing with one group of friends.

Kevin: Yeah, me too.

Interviewer: It is, you are really casting out a wide net. Great, well, I mean, I think that is just about it. If I would let you know when I am – I have been doing. Do you have any other questions about what I am working on or anything like that?

Kevin: Is this supposed to help other kids?

Interviewer: Yeah, well, I mean, it is. Because it is not a very large-scale study, you will not see it taking place in the hospitals tomorrow.

Kevin: Ok.

Interviewer: But what it will do is that it will gain some recognition that there is a need for even more research in this area with kids like you.

Kevin: I see.

Interviewer: Then other people will see that as well. I will continue it myself as I am done with my – with this project – with another project. People will start to look into it more and more until we can do something about it with actions.

Kevin: Ok. I see.

Interviewer: Instead of just research. Research is kind of weird like that. Where it is – it is very… It kind of works like a spiral. For each project that one person does, another person can build on it in a different way.

Kevin: Yes.

Interviewer: Then you all of a sudden have this great pool of knowledge available. That is when people can actually start to make some real good changes. Does that answer your question?

Kevin: Yes, it does.

Interviewer: Ok. Good. Well, I really cannot thank you enough for wanting to participate Kevin. I mean, your input has just been absolutely fantastic. I really appreciate it.

Kevin: Thank you for doing that. I love helping other kids.

Interviewer: Right! I can see that.

[Crosstalk]

Kevin: Going to walks and stuff like that for them. Because I know what they are going through. I like to comfort them.

Interviewer: Absolutely. Maybe you should – maybe you should volunteer back at the hospital? You can help out kids that are going through it.

Kevin: Yeah, I should do that.

Interviewer: Also meet some new people, too. It is something to think about.

Kevin: Yeah.

Interviewer: All right, well, I might give you another call later on. But, it depends on how things go.

Kevin: No problem.

End of Interview.

Allison

17-year-old Caucasian female
Diagnosis: October 2008 – Pilocytic Astrocytoma (brain tumor on spinal cord)
Treatment Stopped: October 2008 (surgery)/September 2010 (intravenous chemotherapy)
First Interview: January 2012 - Phone

Interviewer: All right, I have never had cancer so I would really appreciate it if can explain to me what kind of cancer you had and what you felt like when you heard your diagnosis.

Allison: I had Pilocytic Astrocytoma and it was a brain tumor on my spinal cord. My MRI that I got at first showed my spinal cord was pushed almost to a ninety-degree angle so they do not really understand why I am alive. I am really lucky about that, but when I first found I felt like my whole life was being taken away like I did something wrong that I got it. I just did not understand why, why me.

Interviewer: Uh-huh. When were you diagnosed?

Allison: When I was 14.

Interviewer: When you were 14. Do you remember the date?

Allison: What was the date mom?

Allison Mother: (inaudible)

Allison: October seventh.

Interviewer: October seventh, and what year was that?

Allison: I think it was 2008.

Interviewer: You were talking about how when the doctor told you you felt like your life had been taken away from you. Can you elaborate on that a little bit more?

Allison Mother: It was October 20, 2008.

Allison: It was October 20, 2008. There was, I do not know, I found out from an eye exam because ever since I was younger I suffered from migraines, really bad migraines to the point where half my body would be paralyzed and I could not see, talk, or anything. My pediatrician just kept saying that I had complicated migraines. He never thought to give me an MRI, even though my mom asked him.

Interviewer: Okay...

Allison: Then I had an eye exam and he put some pressure on my eyes and he made me get an MRI. The MRI doctor, the neurologist said that I had a brain tumor and he took us back in to the room and I saw it. I did not believe it because he said he 99% sure that I did not have one and have no problem so I just felt like it was not real.

Interviewer: Up until that point, the only symptom you had was migraines.

Allison: Uh-huh. In addition, I was really, really small.

Interviewer: Okay.

Allison: I had always been thin when I was little so I always thought that was just what it was. Now that I look at pictures, I looked really sick.

Interviewer: Okay, so looking back you began to wonder.

Allison: I'm amazed that no one really noticed.

Interviewer: Okay. What kind of treatment did you do for your tumor?

Allison: I had brain surgery October 28th, and then I turned to therapy.

Interviewer: You were diagnosed on October 20th and you had brain surgery eight days later?

Allison: Yeah I did, they said if I waited two more months I would have been completely blind.

Interviewer: Wow, okay so they really were rushing for it.

Allison: Yes.

Interviewer: That must have been difficult to realize that things had to be dealt with so quickly.

Allison: It was scary. I got out of school and I went back to school after my MRI and I was lying because I could not focus and I had to take a test and I just left and I had to get all my stuff from school. I did not tell any of my friends what was happening until I was in the hospital then I called my best friend. She did not even know what was going on. I did not even know what was going on, because I did not really talk about it.

Interviewer: Yeah, yeah I imagine it was pretty shocking. You said you had ten rounds of chemotherapy?

Allison: Uh-huh. I was supposed to get 12 rounds of carboplatin, but on my eighth round I was starting to get an allergic reaction, which they told me was a panic attack. I was just sitting in a room with an IV hooked up, I started freaking out, and trying to rip it out, trying to rip my clothes off and I had all these hives all over my body. I felt like I was dying. They said I had an allergic reaction, or a panic attack, but it happened again. They found out I was allergic to the carboplatin so they had to stop.

Interviewer: Okay. What is carboplatin?

Allison: It is an intravenous type of chemo.

Interviewer: Got it. How often did you receive chemo?

Allison: It was every month.

Interviewer: So once a month you were going to the hospital and were you taking oral chemo medicine or were you getting it through IV?

Allison: It was all intravenous.

Interviewer: Okay, all intravenous.

Allison: …because sometimes my blood count was not high enough so I would have to go a little bit longer.

Interviewer: Pretty much once a month, right?

Allison: Yeah, just depends basically.

Interviewer: Did you go to the hospital in between your chemo treatments or you only went to the hospital for chemo?

Allison: No, I went to the hospital, we would go to the primary children's get chemo, but I needed to get blood and platelets and stuff like that. I would have to go to the blood clinic every week and get blood drawn sometimes once a week up to four times a week.

Interviewer: How far away were these places to your house?

Allison: About 15 minutes.

Interviewer: Okay, so it wasn't terribly inconvenient.

Allison: No.

Interviewer: Okay. How did the treatment make you feel physically?

Allison: Disgusting. It warms your blood – they have to actually push it in a syringe and it burns. I used to get hives and then I would get really sick afterwards, and they would give me a pill to knock me out for three days and I would not even remember because I would be really sick.

Interviewer: When you say you were really sick was it just like you were nauseous?

Allison: I would get nauseous; I would get the hiccups a lot for some reason, really, really bad hiccups that were painful.

Interviewer: What about after the three days, let us say we are right in between you having chemo treatment let us say two weeks ago and how were you feeling in between then?

Allison: I would get really tired. Once your blood count gets low, you feel really heavy, like you cannot do anything, you are just really weak. I would feel nauseous and I would have a lot of drugs and pain too. I had a lot of drugs and my mom would make me go out and go shopping with her sometimes, like one thing per day.

Interviewer: How many pills were you taking in a day?

Allison: Only eight to ten.

Interviewer: Wow, okay. Let us talk about your very first time you went in for chemo. What was going through your mind? You had already had surgery, right?

Allison: Uh-huh.

Interviewer: You are out of surgery and you are going in to chemo.

Allison: I was pretty healthy going in to it. After my surgery, 10 days after my surgery and the doctor actually asked if I wanted to do my first round of chemo while I was at the hospital, but I said no I wanted to come back so that I could go home for a little bit. I went back and I cut my hair really, really short just in case it was going to fall out but it did not.

Interviewer: Okay.

Allison: We went and it was a big room of chairs. At first it did not hurt, that first one did not even hurt it was it was progressing. They did not really do anything to me. I got sick and puked but it was not anything compared to the other ones. I felt pretty healthy.

Interviewer: I am sorry say that one more time?

Allison: I always felt pretty healthy when I got the first one.

Interviewer: Then you go for the second one and you knew what to expect the second time because you had been there before. What was going through your mind then?

Allison: I do not know… I was sad. I did not like it. I hated it. I would go to sleep and I would not even get ready. I would say growing my hair but that is what you had to do.

Interviewer: Yeah. What was your feeling about; you had said that it got worse at one point. How many rounds did you do before it really was uncomfortable for you?

Allison: It was about the third round was when I started getting really, really sick from it and having to get more blood. I do not know.

Interviewer: Okay. You said that you never lost your hair.

Allison: No, I didn’t lose a lot, but I have really, really thick hair so it got thin.

Interviewer: Okay, so your hair thinned out.

Allison: It was really hard thing to go through because I have blonde really pretty hair and I wish I did not cut it off.

Interviewer: Has it thickened up since you stopped treatment?

Allison: Yes, I have long hair now and it has thickened.

Interviewer: Good. Let us talk about what happens after treatment. You found out that your cancer was under control and was stable. What was going through your mind?

Allison: I would worry a lot about it coming back. All that was in the back of your mind because there is still a piece left. The tumor was too close to my spinal cord that the surgeon could not get it out. It is always back in your mind, but it has been stable now for a year.

Interviewer: About a year. Do you happen to remember that date that you stopped treatment?

Allison: I think it was September. Mom, when was that? September of 2010.

Interviewer: You went, I just want to make sure I understand you correctly; you went from being diagnosed in October of 2008 to almost two years of treatment stopping in September of 2010.

Allison: Yes.

Interviewer: That is a great deal of treatment that you had to go through.

Allison: Yeah, it was long.

Interviewer: That must have been exhausting.

Allison: Yeah I was pretty sick of it.

Interviewer: How did things change because as we said, two years is a long time to be going through that kind of treatment? How did things change when you stopped treatment? How did your life continue from there?

Allison: It was really weird, I was home schooled for that whole period and I got myself through all of that which was my main concern. I did not mind it after school. I was scared; I cried the first thing I came home. It is like really different going from having these tons of problems to worry about your life to going to school and hearing people complaining about their hair. Or you are lucky your hair did not fall out!

Interviewer: Yeah.

Allison: I am really angry for a good two months at everyone just because I did not understand why they did not get it, that people had their problems.

Interviewer: How was it when you did return to school, did you feel like an outsider?

Allison: I did a lot. I only had a little group of friends, but I just had like one best friend and she was my only friend throughout the whole time that I had treatment. She was the only person that I talked to.

Interviewer: When you came back to school, did people, your classmates that were into your close friends, did they know about your experience with cancer?

Allison: Yeah. A lot of people knew because my school did a fundraiser for me, it was on the radio. Everyone kind of stared at me.

Interviewer: Was it strange to have people that you did not even really know that well who knew about you? Was that a strange feeling for you?

Allison: That was really, really weird.

Interviewer: Can you elaborate on that a little bit?

Allison: I do not know, just knowing people are looking at you and [thinking] 'oh, they have cancer.' In one of my classes when I first went, back a kid that I did not know very well was talking to me. He goes 'I thought you were retarded' and I just looked at him and was like – what??? I had no brain damage from that. I have some damage in my nerves and the back of my leg. I do not have any brain damage from it. I have a 4.0 and this kid was not the brightest kid in the world and I was like are you kidding me. Just having people judge you.

Interviewer: Just from hearing your story.

Allison: Yeah.

Interviewer: Do you like to talk about your cancer?

Allison: Yeah I do not mind.

Interviewer: If kids at school were to ask you about it you would be okay.

Allison: Yeah, definitely.

Interviewer: Did the school do anything or did the hospital do anything to help you get back in to school?

Allison: No, my school really screwed me over actually. They were supposed to send a home schoolteacher to me and I once had not heard. She did not even know how to teach AP classes so my mom had to teach me them.

Interviewer: Wow.

Allison: I was in all AP and she was like I cannot help you with that. My mom went to a meeting with all of my teachers. My teachers did help, they gave my mom all the work, but she said no I cannot help you with basically.

Interviewer: You met her one time.

Allison: She met with my parents one time, but she never met me.

Interviewer: You never even talked to her yourself.

Allison: No. at the very end she wanted to come and be my proctor, my test proctor to watch me take my finals and my mom said no.

Interviewer: Yeah well, I can understand that.

Allison: She would do it.

Interviewer: What about then going back in to school again. Was there anything to help you get acclimated to school again?

Allison: My counselor actually helped a lot once I was back in school he made sure my classes were all really close so I did not have to walk very far. I do not know, he made sure I had the classes that I needed to graduate.

Interviewer: When you were getting home schooled, how often did you work on schoolwork?

Allison: Probably every day, but not for very long every day, sometimes longer. Most of my classes I would do one for a couple of weeks straight to get it done.

Interviewer: Okay, you would…

Allison: …around to different subjects.

Interviewer: Instead of doing English, Math and Science every day, you might focus just on math for a month and then move on to English for a month, and so on...

Allison: Yeah, exactly.

Interviewer: That was working out pretty well for you?

Allison: I got everything done, I had to stop some of my courses and they did not grant me any elective courses, they said okay you do not have to do this. I have to do summer school. So I am taking finals for that.

Interviewer: How old are you?

Allison: I am 17, I will be 18 in two months.

Interviewer: Well happy early birthday!

Allison: Thank you.

Interviewer: Are you a senior?

Allison: I am.

Interviewer: Are you considered to be behind your other classmates because of this?

Allison: I am right now, I have a credit that I am going to get done, but I already have my finals sent to my counselor right now.

Interviewer: Okay.

Allison: I was junior year behind a lot because I had to take two classes or I had to take three and I am just finishing up my last one.

Interviewer: You were a little bit behind and you said you took some summer school to help catch up a little bit.

Allison: Yeah.

Interviewer: What was the reaction of your friends when you came back to school, the ones that you are close with?

Allison: My best friend who was always with me, when I first came home, her and my other friends came over, I showed them my scar, and she started bawling. She could not handle the fact that it was real and I actually went through that. She was crying and she did not think it was that serious. She came over probably every week that I felt good. She was really the only close person I have.

Interviewer: What was your reaction when you saw her cry like that?

Allison: I did not know what to do, I was – why are you crying. I was confused, I wanted to make her feel better and not sad, and she told me what was wrong and then we laughed.

Interviewer: I do not know. Did you feel like you should have done something?

Allison: No, I did not know. She thought it was going to be a little scratch with a band-aid, not a scar. I said I had brain surgery, and then we laughed about it.

Interviewer: It is good that you are able to see a positive side of it.

Allison: Yeah.

Interviewer: What else do you think that you have gained from the whole experience that has been positive for you?

Allison: My friend and I, I met her when I was 14, we were both going through the same thing, but she had a really rare type of bone marrow cancer and she passed away when we were 16, that was really hard. She fought so hard, she had it so much worse than me, she was on a ventilator. I think it was good to see. I think it was good to see you have these people that have it 20 times worse than you and she fought and gave me a reason to…I think getting a really good value on life that I was not to waste my time on people that do not deserve it. I fought so hard. Whenever I had a problem my mom was really, "it was really worse fighting for her life. Is this really, what you want to spend your time on?"

Interviewer: That keeps it in perspective for you?

Allison: Yeah definitely.

Interviewer: I wanted to ask you about your family. Do you have any brothers or sisters?

Allison: I do. I have one brother.

Interviewer: You have one brother. Is he older or younger?

Allison: He is a year older than me.

Interviewer: Was he supportive?

Allison: He was, I love him so much. He is like medicine.

Interviewer: Like medicine?

Allison: He makes me feel better.

Interviewer: That's nice. Do you remember your parent's reaction when you were diagnosed? Do you remember seeing them?

Allison: When I was first diagnosed, my mom did not, when they first went down there, she knew something was wrong. She would be crying and I was so confused because I thought she did not care. She was crying but she did not want to show me that she was scared. Ever since that point after I told her I thought she did not care, she never tried to hold back, we were all bawling in the car. I do not know, just a wreck.

Interviewer: Do you think that made you closer?

Allison: Yeah, definitely. It made our whole family closer.

Interviewer: Has your relationship changed? Were you close with your brother before all this happened?

Allison: We were pretty close, but we were not as close as we are now. I think it really helped.

Interviewer: Can we say that is another positive thing that has come from this experience?

Allison: Definitely.

Interviewer: I want to jump back to school for a minute. I was curious about you said you were still taking one more credit to help catch up.

Allison: Uh-huh.

Interviewer: Is the school currently doing anything to help you out? Are you receiving any kind of special education?

Allison: No.

Interviewer: Do you have any sight problems anymore?

Allison: Sight problems, no, nothing that would have been a result of my papilledema.

Interviewer: I am just curious, when you had your brain tumor and you started having difficulty seeing things, they did the surgery and you said they got most of it, but not all of it. Did your sight improve after surgery?

Allison: I never had problems with my sight at all. It was just pressure behind my optic nerve, it was a routine eye check.

Interviewer: Oh, okay.

Allison: I had no problems at all that would have made them think. It was the doctor who saw the pressure behind the optic nerve that was the buildup of the fluid.

Interviewer: Got it. That would be why if they had waited two months you would have lost your sight because it would have kept building.

Allison: Yeah.

Interviewer: Just wanted to make sure I had that clear. When you think about your future, and the experience you have had what kinds of things do you think about. What do you want to be when you grow up?

Allison: I want to go to school to be a mortician or pathologist.

Interviewer: That’s interesting.

Allison: I thought I would be a nurse, but nurses still hurt people, they want to help you but I do not want to hurt anyone and I think being a mortician or being a pathologist is going to be the best profession for me because I will be helping people without physically hurting anyone. The person that passed away you can only help them, like their family or help find the reason why they died to help another person.

Interviewer: You had mentioned earlier that it is always in the back of your mind that there is still a little bit of the tumor there.

Allison: Yeah.

Interviewer: Do you worry that it is going to return?

Allison: I do not think it will. If it does I do not think it will for a really long time, but yeah I do worry about it.

Interviewer: How often would you say that you think of that?

Allison: Usually only when I am really, really happy.

Interviewer: That's interesting...

Allison: I was for a long time when I went to school I did not talk to anyone, I did not try to make any friends because I felt like if I am happy again, that it would be taken away.

Interviewer: Very interesting. When you are upset about it, you do not really think of it that much?

Allison: No.

Interviewer: Very interesting. That is pretty much all the questions I have for you. Is there anything you can think of that I should know about your experience, your feelings, your family's feelings, anything like that?

Allison: Not really.

Interviewer: Would it be all right with you if I contacted you again if I have any follow up questions?

Allison: Sure.

End of interview.

17-year-old Caucasian female
Diagnosis: October 2008 – Pilocytic Astrocytoma (brain tumor on spinal cord)
Treatment Stopped: October 2008 (surgery)/September 2010 (intravenous chemotherapy)
Second Interview: July 2012 - Phone

Interviewer: So let's get started. How are you doing?

Allison: I'm doing well, thank you.

Interviewer: So your mom tells me that you've moved out.

Allison: I have. I live in [the city][23] now.

Interviewer: How do you like it?

Allison: I love it so much. I'm so glad to be away.

Interviewer: What's so great about it?

Allison: I love having like a fresh start. I didn't like living in Pocatello, it wasn't my type of town. And I love my new job, I work at _______ and I really love it.[24]

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[23] City name has been redacted to protect participant privacy.

Interviewer: Oh, great.

Allison: Yeah.

Interviewer: So what about [your home town][25] is not your style?

Allison: The people there are very judgmental, I guess, and kind of close-minded. I never really fit in there, didn't really ever feel like I belonged.

Interviewer: Have you always felt that way? Or did that feeling get stronger after you were diagnosed?

Allison: Yeah, it did get stronger after that.

Interviewer: Okay. So just kind of feeling so different from everyone else?

Allison: Yeah.

Interviewer: Yeah, because I remember the last time we spoke in January, you were telling me that you had to deal with a lot of feedback from people your age at school that you barely knew.

Allison: Yeah, definitely.

Interviewer: And they just didn't quite get it.

Allison: No, never.

Interviewer: So having this fresh start, are you planning on telling anyone about your experience?

Allison: Yeah, I actually have told a lot of people but I like it, just I get to tell them in my own words instead of them hearing it from random people. You know, I've told most of my coworkers when they ask about like where I was living and it kind of just gets brought up because of it. And you know, I saw like they more understand where I'm coming from when I'm actually telling them, like instead of just hearing it around.

Interviewer: Exactly. So you are in control of how much information they get and what information they get.

Allison: Yeah, exactly.

Interviewer: Okay, so that must give you a lot of actual relief.

Allison: Yeah, I love it.

Interviewer: That is great. I'm so glad to hear that. So how was graduation?

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[24] Name has been redacted to protect participant privacy.

[25] Town name has been redacted to protect participant privacy.

Allison: It was so good. I was so happy. It was a good day.

Interviewer: Good. So how long have you been in Boise now?

Allison: I moved here June 6, I believe.

Interviewer: Okay, so like right after graduation.

Allison: I did. I moved like eleven days after, I'm pretty sure.

Interviewer: You couldn't wait to get out of there.

Allison: Oh, no. I don't want to spend one more minute there.

Interviewer: Understandable. So can you remind me – I don't remember if I asked you this in January – what was the name of your high school?

Allison: __________ High School.[26]

Interviewer: And I wanted to ask you something that when I was reviewing our last interview, I didn't get quite a clear answer about. When you returned to school after being gone for two years, I know that you didn't get along with the caseworker or anything and that your mom ended up home schooling you for a while.

Allison: Yeah.

Interviewer: Did they talk to you at all about like a reintegration to help you ease back into school?

Allison: Yeah, after the whole mix-up with, like, the home schoolteacher. I had a counselor. And he actually doesn't work there anymore but when I came back, he really helped me out. It was kind of like he was trying to right the wrong.

Interviewer: Oh, great!

Allison: Yeah, actually he made sure like all my classes were close to my locker so I wouldn't have to walk far and he really helped. He was a good counselor.

Interviewer: Oh, great. Okay, so that's good to hear.

Allison: Yeah.

Interviewer: So you had more of a problem with the education you had to receive while you were undergoing treatment.

Allison: Yeah, definitely.

Interviewer: And then when you returned to school – because you mentioned that you didn't actually enjoy being in school, being back – but this guy made it easier? So this guy made it a little bit easier for you?

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[26] High school name redacted to protect participant privacy.

Allison: He did. He just made sure that I wasn't walking too far just because I was having problems with my energy levels at that time. He was a very good person.

Interviewer: Did he talk to you at all about like just emotional stuff? Did you ever confide in him?

Allison: No, I'm not really like that. My mom tried to actually get me in therapy when I was going through treatment and I don't know, I'm not one to talk to people about it. I don't know… I'd rather talk to my family about it.

Interviewer: Okay. So your mom did try and push for some kind of therapy or counseling and you chose…

Allison: Yeah, she did.

Interviewer: Okay, so it was your choice not to do it.

Allison: Yeah.

Interviewer: Okay. Do you feel like it would've helped you?

Allison: No, I don't think so.

Interviewer: Okay, so it was just a matter… You had support in your family.

Allison: I did, and it wasn't like… At that point in time, I just wasn't wanting to talk to people about it, especially strangers.

Interviewer: Yeah. Well, how do you feel talking to me about it?

Allison: I don't mind.

Interviewer: Okay.

Allison: Especially now, since it's over. So… (pause)

Interviewer: Okay, you're much more comfortable, kind of, rehashing it as opposed to explaining…

Allison: Yeah, exactly. I would talk to anyone who has a question about it. I don't feel uncomfortable.

Interviewer: Great.

Allison: Yeah.

Interviewer: Well, that's good to know because I was a little unclear about whether or not you had any help reintegrating into school. But it sounds like you had a really good counselor.

Allison: Yeah, he was amazing.

Interviewer: Did he talk to your teachers, as well?

Allison: He did. He let them all know. My teachers, I kind of… I don't know, I would kind of tell them. I had a lot of the same teachers throughout the whole entire time, so they all kind of just knew.

Interviewer: Okay.

Allison: Yeah.

Interviewer: But the teachers were supportive.

Allison: Yes, most of them.

Interviewer: Okay. So would it be okay for me to say that when it came down to classes and your actual academics, you had a decent experience getting back into school? But when it was the peers, it was difficult.

Allison: Yeah, and I mean, I struggled with some teachers. I would sleep a lot in my classes and they would yell at me for it.

Interviewer: Okay.

Allison: And I mean, it was extremely frustrating because I had a 4.0 and there was no reason for them to be yelling at me. But I had a hard time sleeping at nighttime after chemo just because my dose was all wrong and I didn't have a regular sleep schedule, so I would be sleeping in class but I would do my work. They would still yell at me, though, for sleeping.

Interviewer: Yeah, so they weren't very understanding.

Allison: No, not about that.

Interviewer: Okay. Well, that's nice to know. So what are you doing for college?

Allison: I'll be going to [college][27] and I just declared my major as Premedical Studies with emphasis in Biology. So I'm really excited.

Interviewer: Wow, that's quite a course load to start out.

Allison: Yeah, and I got a full ride for my academics.

Interviewer: Congratulations.

Allison: Thank you, yeah. I'm very excited.

Interviewer: So you're doing pre-med with an emphasis in biology?

Allison: Yes.

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[27] University name redacted to protect participant privacy.

Interviewer: And what are you hoping to do with that?

Allison: I'm kind of deciding between pathology and radiology. I'm not quite sure.

Interviewer: Okay.

Allison: I'm sure I'll figure it out when I do my residency.

Interviewer: Yeah. Yeah, I think you've got a little bit of time to figure that out.

Allison: Oh yeah. (laughs)

Interviewer: So your experience in being sick and getting well again has made you kind of lean towards the medical field?

Allison: It definitely has. When I got sick, I kind of wanted to be a nurse and then I just found it's really hard for me to watch people in pain, especially when I was at primaries. Like I'm not going back to primaries anymore. I'm actually going to be doing my MRIs in Boise [interruption] memory, just be like all those children being sick. So I kind of want to be more behind the scenes or dealing with the disease just because I don't actually want to, like to inflict any pain on anyone.

Interviewer: Okay. So you kind of took that away from your own experience.

Allison: I did, yeah.

Interviewer: And you remember the people who were poking and prodding you.

Allison: Yeah, I mean, not to say that they didn't help you in the long run. I just don't want to see the pain on people's faces.

Interviewer: Yeah. Do you feel if you were to see that kind of pain on their faces, do you feel like it would make you automatically remember what you went through?

Allison: It does, definitely. It's really hard to go… Like I had my last MRI a few months ago before I left and that was probably a really hard decision. My life was so good at that point. You know, I was getting ready to move and I'm going to college and I see all these people. And I'm a rarity in that kind of situation to come out so well when so many people are damaged for the rest of their lives.

Interviewer: Yeah. How often do you have to still go back?

Allison: I'll go back once a year now.

Interviewer: Oh, great. Okay, so now you're up to once year.

Allison: Yeah, it's very nice. I love it.

Interviewer: So every time you return for an MRI, does it just kind of bring it all back?

Allison: Yeah, in some ways. I mean, I get kind of nervous, I guess, internally about it. Because there's always like that worry in the back of your mind. But I don't know, I'm kind of over it.

Interviewer: Okay. Well, as you said, it helps having a fresh start.

Allison: Yeah it does.

Interviewer: And it kind of gives you this feeling of, "all right, that was then." I'm feeling good now, let's start…

Allison: Yeah. It's like in the past, I'm not that sick kid anymore.

Interviewer: That's true, you're not. You're living on your own already.

Allison: Yeah.

Interviewer: I can't believe it's been like a year already just since I've spoken to you.

Allison: Yeah.

Interviewer: Well, that's great. Do you have any friends from high school that will be at college?

Allison: No, I actually kind of have lost contact with all of my friends in high school. I kind of had a falling out with my best friend. We were really good friends and when I got sick, she was basically the only one that was there for me. And then when I got back to school, we just kind of stopped being friends because she did not like that I wanted to go out and live my life. She just wanted to stay at home, like how I was when I was sick. And I didn't want to do that anymore. And she started hanging out with a lot of people who are extremely judgmental who I don't like, and she kind of just turned into one of them. And I went to her party after graduation and she didn't talk to me and no one talked to me either. She told me we were going to hang out before I left and we didn't. And actually, when I was driving home I called her and I was bawling and I don't know, I haven't talked to her since.

Interviewer: What did she say during the phone call?

Allison: She really didn't say much. I just told her like I thought I was… She actually did this to another friend of ours, kind of just stopped talking to them because of the people that she was hanging out with didn't like him because he is gay.

Interviewer: Oh, okay.

Allison: So she didn't hang out with him anymore because they were judging her for it, even though we've all been friends since we were kids.

Interviewer: Yeah.

Allison: I told her like I was upset she'd just throw us away and she just said I don't know what to tell you. And I said well, I guess it just boils down to the fact that you don't care anymore. And I haven't talked to her since.

Interviewer: So you're really kind of looking to not really look back at [your home town].

Allison: No, I don't want any part of it.

Interviewer: Well, what about the friends that were there for you?

Allison: She was basically the only one that really knew me when I was sick and I think that's why I have such a connection to her. Because she was like my only friend from real life that still treated me normal. And after I went back to school, I kind of got mixed up with some people that weren't really my friends. And I started thinking about what's the girl after that going to say for my work but it was more out of convenience just because we were in the same place. And I don't talk to her anymore but there was no harsh feelings.

Interviewer: Yeah, of course, you just kind of lose touch.

Allison: Yeah. She was [at home] and I was here.

Interviewer: Okay. Well, you know, I mean, that's all part of your experience and it gives you a lot to take away from it.

Allison: Yeah.

Interviewer: And you kind of have this ability now, I would think, that you can really know how to choose your friends in the future.

Allison: I do, I really do. I don't surround myself with anyone I don't want to be around anymore.

Interviewer: Yeah, and I think that's good. And as you say, you know, since you were starting to feel better and better, you wanted to go out, you wanted to live your life. And you know, it's good that hopefully, I assume now you've got some people you can do that with.

Allison: Yeah, I'm starting to make friends and really like better friends that I have a lot of things in common with.

Interviewer: Oh, great.

Allison: Yeah.

Interviewer: And you don't feel as if they're judging you.

Allison: No, not at all. I think it's more, too, like they're a little bit older.

Interviewer: And that helps, too, because you've got that maturity level there.

Allison: It's nice.

Interviewer: And I think, given your experience, you went through something that almost forced you to be more mature than your age.

Allison: Yeah, definitely.

Interviewer: Yeah, and it's difficult when your friends haven't gotten that experience. They don't understand and they don't have that maturity. Well, I hope you weren't necessarily taking any of that judgment personally.

Allison: Oh, I did for a while but it's all in the past.

Interviewer: Okay. So you feel pretty good about it now.

Allison: Oh yeah, I don't ever think back to those times. I don't care. I have a good life now.

Interviewer: That's a really good way to look at it, I think.

Allison: Yeah.

Interviewer: Yeah. Because I mean, when somebody's that judgmental, you have to understand it's more likely a problem with them than with you.

Allison: Yeah, definitely.

Interviewer: And I'm sure, given when I've talked to your mom before that she would've told you the same thing.

Allison: Yeah, definitely.

Interviewer: Yeah. So how often do you get to talk to your mom now?

Allison: Well, I'm actually with her right now. She came down here for the week to…

Interviewer: Oh, great.

Allison: …visit me. But yeah, I call her probably every day.

Interviewer: Oh, good. So you guys are still really close.

Allison: Yeah.

Interviewer: Excellent.

Allison: I talk to her all the time.

Interviewer: Great. So you're not feeling lonely or anything living…

Allison: No, not at all.

Interviewer: Great, excellent. Well, I actually don't have a whole lot more to ask you. Do you have any questions for me?

Allison: No, not really.

Interviewer: Well, like I said, you've got my cell phone number and that's the 312 number. So if you have any questions or if your mom has any questions, don't hesitate to call me. I'm actually not in England anymore, so I'm back stateside. You can call me any time.

Allison: All right, sounds great.

Interviewer: All right? Well, take care, Allison. I might give you another call later on just to check in on how you're doing but good luck.

Allison: Thank you.

Interviewer: And enjoy school. You're going to love every minute of it.

Allison: Thank you.

Interviewer: All right, take care.

Allison: All right, you too.

Interviewer: Thanks, bye bye.

Allison: Bye.

End of Interview.

Coding Tree

- Stages of Cancer
    - Pre-diagnosis
        - Symptoms of Cancer
            - Flu
            - weight gain
            - appetite changes
            - weakness
            - headache
            - hormone changes
            - fatigue
            - hair loss
            - weight changes
            - cough
            - vision impairment
            - sick-looking
        - appointments
    - Treatment stopped
    - Post-treatment
        - support stopped
        - follow up appointments
            - stress
            - nervous
            - routine
            - confidence
        - don't have to worry about medication
        - Lingering Effects
            - greater risk of future cancer
            - allergies
            - precaution
                - weight lifting
            - can't donate blood
            - hard time swallowing
            - avoid bread
            - carry around water
            - avoid candy
            - growth supplement
            - piece of tumor left
        - Improvements Over Time
            - fear of relapse has diminished over time
            - less different from peers as time goes by
            - more social as time goes on
            - less fatigue over time
            - focus better over time
            - think about cancer less as time goes on
            - less anger over time
            - vision has improved over time

            - stress goes down as health improves
            - feel less different over time
            - hair improved over time
            - more comfortable talking about cancer now
            - Fewer problems in creating saliva over time
            - feel more normal as time goes on
        - Reactions to Being Cancer-free
            - happy
            - thrilled
            - cautious
            - relief
            - excited
            - celebration of being cancer-free
            - community's reaction to hearing participant is cancer-free
        - Social Interactions in Post-Treatment
            - closer to friends
            - ready to be social
    - Transition from Treatment to Post-treatment
        - hopelessness
        - lack of guidance
        - recovery from surgery
            - isolation
        - cancer is gone but treatment continues
    - Cancer Treatment
        - treatment adherence
        - Location for Medical Treatment
            - ER
            - hospital
        - procedures and methods of treatment
            - antibiotics
            - port
            - chemo
                - IV
            - lumbar punctures
            - pills
                - scared to take pills
            - surgery
                - removed eye
            - medication
                - self-management of medication
                - parent administers medication
            - radioactive iodine
            - ibuprofen
            - biopsy
            - ultrasound
            - radiation
            - PET scan

    - blood work
        - needles
    - CT scan
    - CAT scan
    - shots
    - blood transfusion
        - more energy
    - steroids
    - X-Ray
    - MRI
    - check vital signs
- expectations of treatment
    - understanding the severity of treatment
    - confident that an end would come
    - cut hair in anticipation of hair loss
- Mental Side Effects of Treatment
    - cranky
    - memory problems
    - lack of motivation
    - learning delays from radiation
    - relive experience every MRI
    - think he's smells radiation burn when it's not there

- Physical Side Effects of Treatment
    - vomit
    - diabetes
    - compromised immune system
    - sick
    - vision impairment
    - strenuous exercise
    - hungry
    - hair loss
        - not awkward
        - cover up hair loss
        - regret cutting it
    - fatigue
    - hindrance of daily activities
    - numb
    - weak
    - headache
    - nausea
    - minor seizures
    - no appetite
    - weight changes
    - no dairy
    - sunburn
    - limited mobility

      - wheelchair
      - walker
      - cane
    - scar
    - pain
    - pale
    - sleeping disorder
    - neuropathy on hands and feet
      - relearn motor skills
      - relearn walking/balance
    - depth perception
    - allergic reaction to treatment
    - hiccups
    - burning sensation
    - burning smell
    - growth concerns
  - Descriptions of Treatment
    - horrible
    - impressed
    - hated treatment
    - disgusting
    - feel like you're facing death
  - adjustment to treatment
    - routine
    - normal
  - Social Interactions During Treatment
    - joking about hair loss
    - can't go out with friends
    - can't talk to friends
    - met new people
      - shared experience
    - friends would keep her connected during absence

  - Emotions about Treatment
    - anger
    - scared
    - sadness
    - frustration
- Relapse
  - enlarged gland
  - thinking about relapse
  - lump
  - surgery
  - did not affect school
  - expectations for future tumor growth
  - Emotions Relating to Relapse
    - no fear of relapse
    - stay positive

      - scary
      - shock
      - understanding
      - fear of relapse
      - afraid to be happy
  - Doctors
    - felt supported
    - meeting doctors helps understand the reality of the situation

    - trust doctors
    - Type of Doctor
      - eye doctor
      - endocrinologist
      - pediatrician
      - neurologist
  - Diagnosis
    - coping with diagnosis
    - just get through it
    - tumor
      - pain
    - brain tumor
    - Neurofibromatosis
    - Participant Reactions to Diagnosis
      - relief
      - not scared
      - wanted answers
      - denial
      - break down
      - shock
      - breaks your heart
      - hard to understand
      - why me?
      - calm
      - surprised
      - didn't cry
      - felt like whole life was taken away
      - I did something wrong
      - disbelief
      - scary
      - didn't tell friends right away
      - all happened so fast
      - nervous
      - coundn't focus on test at school after diagnosis
    - Peer Reactions to Diagnosis
      - friends sad
- Family
  - family's reaction to remission
  - siblings

        - sibling rivalry
        - lack of sibling support
        - sibling felt left out
        - hesitant to trust sibling again
        - tired of fighting with sibling
        - sibling reaction to diagnosis
        - sibling support
        - mature faster than siblings
        - follow in sibling footsteps
        - siblings sent to public school
        - sibling reaction to remission
        - hard being separated from siblings
        - sibling makes feel better
    - parents
        - dependency on parent
        - appreciative of parent
        - parents push for independent behavior
        - treated different from siblings
        - confide in parent
        - parent keeps things in perspective
        - parent interacts with school
        - parent does things for me
        - parent expectations
        - parent finds supplemental tutor
        - parent insisted on psychiatrist/counselor
            - not alone
            - discuss fears
        - parent overwhlemed
        - parent cautious
        - parent is protective
        - mom had cancer
        - closer to parent
        - parent worry
        - parent nervous
        - parent relief
        - parents told diagnosis
        - parents signs him up for driver's education
        - parents trust more
        - parent support
        - parent finds better school
        - parent scared
        - parent stressed
        - parent encourages daily activity
        - parent sad
        - thought parent didn't care
        - disrespectful to parents
        - parent feels helpless
        - respectful towards parents
    - extended family

  - family dynamic
  - travel
  - family support
  - hard for family
  - lessen symptoms to protect family
  - family worry
  - closer to family
  - treatment interrupted family life
- School
  - Pressure to Catch Up
    - concern
    - making up missed schoolwork
    - graduation
    - falling behind academically
    - school credits
    - overwhlemed with schoolwork
    - making up missed experience
    - academic standing
    - repeat a grade
    - keep up with classes
    - maintain school and job
    - desire to do well in school
    - good grades
  - School Reintegration
    - routine
    - differences between schools
    - normal
    - being around peers
    - different
    - difficult
    - Presentations
      - reintegration presentation
      - visual impairment presentation
    - Social Interactions at School
      - popularity
      - Alone
      - protective
      - well-known throughout school
      - different
      - comparison to peers
      - joking about scar
      - peer response to return to school
        - peer surprise
        - peer questions
        - peers staring
      - friends don't understand
      - not as close to friends anymore
      - friends don't know what to say

            - bullying
                - stressed
            - feeling judged by peers
            - no judgement from peers
            - treated normally
        - Emotions about Reintegration to School
            - frustration
            - scared
            - angry
    - Attendence
        - attempted to return to school
        - desire to attend school
        - Absence From School
            - enjoy absence at first
            - Missed being at school
        - expectations of how attendance would be affected by treatment
    - School Activity
        - Extra-curricular activity
            - more opportunities available
        - homework
        - job
        - senior trip
        - school subjects
    - new school
        - safer
        - happy
    - homeschool
        - ahead a grade in mainstream school
        - less friends with homeschool
        - play outside
        - parent keeps records
    - Accommodations
        - tutor
        - school counselor
        - unfair
        - 504 Plan
            - learning disability
            - security of the 504 plan
            - no cell phones in school
        - half-day school
        - wouldn't complain if there wasn't anything that could be done about it
        - school support
        - teacher plans vary from one to the next
        - teacher is not willing to accommodate
            - scolded for sleeping in class
        - supplemental education

            - school wants to keep her connected
            - stay connected to peers
            - digital home school
            - alone
            - learning delay
            - supplemental education inadequate
        - no accommodations
        - no exams
        - accommodations aren't enough
        - can't get around school easily
        - visual devices
            - CCTV
            - Amigo
            - Short Arm
        - Braille Instruction
        - did supplemental homeschool work in class
- Social Interactions
    - spending time with friends
        - hang out
        - watch movies
    - peer support
    - community support
    - summer camp
        - camp counselor
            - strict
- Psychological Experience
    - uncertainty
    - control
    - psychiatrist/counselor
        - unwilling to work with psychiatrist/counselor
        - attitude
        - defensive
        - anxiety
        - fault
        - looking for a cancer-specific psychologist/counselor
        - frustration
    - Identity
        - Self-concept
            - appearance
            - boyfriend
            - initially rebellious teenager
            - different
            - feel similar to peers
            - well behaved
            - not athletic
        - normal
            - homework as a reminder of normalcy
            - desire to be normal

    - return to life before diagnosis
    - feel no different from friends
  - gaining independence
    - responsibility
      - failure
      - summer job
    - driving
  - understand that your experience is specific to you
  - control how story is told
  - the person with cancer and beyond
    - encourages pride in experience
    - Incorporation of cancer experience into post-treatment life
      - using cancer experience to teach friends to appreciate life
      - use experience to help others
    - special treatment
      - being catered to
      - Enjoying being special
      - make-a-wish
      - doesn't want special treatment
      - spoiled
      - no special treatment
      - only during treatment
    - cancer as an excuse
    - don't want people to know about cancer
    - exaggerating cancer effects
    - shift in perspective
      - embrace life
      - optimistic
      - fun
      - thankful
      - life is a gift
      - life is precious
      - better person
      - scared
    - gain/loss of friends
    - start a new chapter
    - happy to talk about cancer experience
    - mature faster
    - not a sick kid anymore
- acceptance
  - reality of the situation
- mental processing
  - ADHD
  - ability to focus
  - zone out
  - hard to focus

        - neuropsychological evaluation
        - frustration
    - social worker
    - coping with stress
        - emotional strength
        - play instrument
            - bored
            - gets in the way of a normal life
        - play sports
        - take mind off of cancer
        - not worry about other things
        - play games
        - running
        - watch TV
        - let out emotions through hobby
        - can't remember
        - PTSD
        - blanked out of mind
- Life After High School
    - job
        - health services
        - graphic design
        - architect
        - firefighter
            - disappointed
        - policeman
        - lawyer
        - pianist
        - mortician
        - pathologist
        - don't want to hurt people
        - radiology
        - pathologist
    - college
        - leave town
        - scholarship

State-by-State Implementation of Section 504

STATE	STATE HOMEBOUND DEFINITION	STATE ELIGIBILITY STANDARDS [1]	MINIMUM NUMBER OF HOURS OF INSTRUCTION	HOMEBOUND CERTIFICATION STANDARDS [2]
Alabama	Same as Federal Definition [3]	Special Education or 504 Eligibility	No minimum or maximum hours specified	Same as Special Education or Related Services Personnel
Alaska	None	Inability to Attend and Determination Made by IEP Team	No minimum or maximum hours specified	Same as Special Education or Related Services Personnel
Arizona	Students with Chronic Health Problems Unable to Attend School	Certification by a Doctor of Inability to Attend School	At Least 4 Hours as a Full-time Homebound Student	Same as Classroom Teachers
Arkansas	Any student three (3) to 21 years of age who, because of the severity or nature and/or extent of the disability, requires homebound or hospital instruction	Medical Opinion Student will be Absent for 4 or More Consecutive Weeks	Amount of instruction determined by school personnel in relation to each student's educational needs, physical and mental health, and the availability of teachers for the program.	Same as Special Education or Related Services Personnel
California	Special education and related services provided in the home or hospital for school-age pupils	IEP Team decides based on report from attending physician or psychologist, certifying severity of the condition prevents the pupil from attending less restrictive placement. Report must include a projected return to school.	No minimum or maximum hours specified determined by IEP Team with respect to previous program received in school	Shall be provided by a regular class teacher, the special class teacher or the resource specialist teacher.
Colorado	Individual tutoring shall be provided for students who have a physical disability or illness, which could cause them to be out of school.	Student is unable to spend full time in school. Verification of absence due to illness or disability shall be made by a physician who is licensed to practice medicine in Colorado.	A teacher shall be assigned to tutor the student up to five hours per week. Amount depends on the student's ability to keep up with his class.	Colorado Teacher's Certificate

Connecticut	Homebound and hospitalized instruction shall be as specified in the child's individual ized education program.	Absence will be at least three weeks and: (1) Physician certifies child unable to attend school for medical reasons along with projected date of return; or (2) Student has disability of such severity it prevents child from safely learning in a school setting; or (3) Special Ed. program recommendation is pending and the child was home at the time of referral; or (4) The child is pregnant or has given birth and a physician certifies homebound is in the child's best interest for a specified period of time.	One hour per day or five hours per week in grades K-6 and at least two hours per day or ten hours per week for grades 7-12. Where evaluative data indicates that these time requirements are too great for the child, the Planning Team may decrease instruction time.	Same as Special Education or Related Services Personnel
Delaware	Supportive instruction in an alternative program provided at home, hospital or related site for children suffering from an illness or injury Students must be identified as disabled and in need of special education	1. IEP Team may provide homebound in lieu of present placement if child with a disability is a danger to self or is so disruptive that behavior substantially interferes with learning of other children; or (2) absence due to medical condition requires documentation by a physician, absence will be for two weeks or longer; or (3) absence due to severe adjustment problem requires documentation IEP team, that includes a	IEP Team Determines. Amount of services necessary for FAPE. (Delaware DOE Note: Special education is not a location but is services and supports provided to the child in order to meet the IEP goals. Settings do not determine the intensity of services.)	Teacher Certification

		licensed or certified school psychologist or psychiatrist, that such placement is necessary and temporary; or (4) for transitional in-school program, IEP team must document necessity for an orderly return to the educational program.		
District of Columbia	Same as Federal Definition	Special Education or 504 Eligibility	Determined by IEP Team	Same as Special Education or Related Services Personnel
Florida	A homebound or hospitalized student is a student who has a medically diagnosed physical or mental condition that confines the student to home or hospital and whose activities are restricted for an extended period of time.	(a) Certification by a licensed physician that the student is expected to be absent from school due to a physical or mental condition for at least 15 consecutive school days, or due to a chronic condition for at least 15 school days, which need not run consecutively, and will be able to participate in and benefit from an instructional program; and (b) student is under medical care for illness or injury, which is acute or catastrophic in nature; and (c) certification by a licensed physician that the student can receive an	Determined by IEP Team. For special education eligible students at time of assignment to homebound, IEP must be developed prior to assignment. For students not previously eligible, may be assigned to homebound/hospital program prior to IEP development and formal IEP meeting is not required.	Same as Special Education or Related Services Personnel

		instructional program without endangering the health of the instructor or other students with whom the instructor may come in contact; and (d) student is enrolled in a public school prior to the referral for the homebound or hospitalized program, unless the student meets criteria for (special education) eligibility; (e) a parent, guardian or primary caregiver signs parental agreement concerning homebound or hospitalized policies and parental cooperation.		
Georgia	Students with disabilities who are enrolled in a special education program and have a medically diagnosed physical condition that restricts them to their home or a hospital for a period of time that will significantly interfere with their education.	Referral form shall be completed and signed by a physician, who shall project that the student will be absent a minimum of 10 consecutive school days and is physically able to participate in educational instruction, unless the physician certifies that the student has a chronic health condition causing the student to be absent for intermittent periods of time, i.e., of greater than, equal to or less than 10 days on each occasion,	The student is counted present each day if served a minimum of three hours per week	Same as Special Education or Related Services Personnel

		during the school year. In case of the latter situation, re-documentation of the chronic or recurring condition is not required upon each period of absence.		
Hawaii	Not specified state regulations but would be part of continuum of placements	No specific eligibility criteria other than those for special education or 504 eligibility	No minimum or maximum specified	Same as Special Education or Related Services Personnel
Idaho	Special education and related services provided at home, in a convalescent home, or in a hospital by special education personnel	No specific eligibility criteria other than those for special education or 504 eligibility	No minimum or maximum specified	Same as Special Education or Related Services Personnel
Illinois	Services at home or in a hospital or other setting because student is unable to attend school elsewhere due to a medical condition	When an eligible student has a medical condition that will cause an absence for two or more consecutive weeks of school or ongoing intermittent absences, the IEP Team for that child shall consider the need for home or hospital services. Such consideration shall be based upon a written statement from a physician which specifies:A) the child's	Amount of instructional or related service time determined in relation to the child's educational needs and physical and mental health needs. Amount of instructional time shall not be less than five hours per week unless physician has certified in writing the child should not receive as many as five hours of instruction in a school week. A child whose home or hospital instruction	Same as Special Education or Related Services Personnel

		condition; B) the impact on the child's ability to participate in education; and C) the anticipated duration of the child’s absence from school.	is being provided via telephone or other device shall receive not less than two hours per week of direct instruction services.	
Indiana	Homebound instruction means instruction provided to students, including students without disabilities, who are unable to attend school.	No specific eligibility criteria other than those for special education or 504 eligibility.	No minimum or maximum specified.	Same as Special Education or Related Services Personnel
Iowa	Special education provided to eligible individuals whose condition precludes their participation in the general and special education provided in schools or related facilities.	No specific eligibility criteria other than those for special education or 504 eligibility along with a condition that precludes participation in general and special education provided in schools or related facilities	No minimum or maximum specified	Same as Special Education or Related Services Personnel
Kansas	Homebound instruction means the delivery of special education and related services in the home of a child with a disability. Hospital	No specific eligibility criteria other than those for special education or 504 eligibility	No minimum or maximum specified	Same as Special Education or Related Services Personnel

	instruction means the delivery of special education and related services to a child with a disability who is confined to a hospital for psychiatric or medical treatment.			
Kentucky	Homebound and Hospital Settings specified as part of the continuum of placements	No specific eligibility criteria other than those for special education or 504 eligibility	No minimum or maximum hours specified	Same as Special Education or Related Services Personnel
Louisiana	Home or hospital instruction – refers to alternative education placements on the continuum for the provision of special education to a student with a disability in the student's home environment or in a hospital, based on an IEP	No specific eligibility criteria other than those for special education or 504 eligibility	No minimum or maximum hours specified, however, itinerant teacher may serve no more than 10 students and on-site teacher may serve no more than 17 students	Same as Special Education or Related Services Personnel
Maine	A Homebound/Hospital Placement is a placement where a student with a disability receives special education and supportive services at home or in a medical treatment facility.	Home instruction is usually appropriate for only a limited number of students, such as students who are medically fragile and are not able to participate in a school setting with other students	No minimum or maximum specified	Same as Special Education or Related Services Personnel

Maryland	Student who receives special education instruction at home	Initial service need is determined by: 1) Verification of the physical condition, including drug and alcohol dependency, by a licensed physician, or verification of emotional condition by a certified school, or licensed psychologist or licensed psychiatrist; and (2) A statement by the physician or psychologist verifying that the current physical or emotional condition prevents the student from participating in the student's school of enrollment. Service need is subject to review: (1) 60 calendar days after the initial determination of eligibility; or (2) Sooner at the request of either the parent, guardian, or local school system. (3). Continuation of this service beyond 60 calendar days requires reverification of service need.	No minimum or maximum specified, however, full-time instruction is considered to be a minimum of 6 hours per week. Half-day instruction is considered to be a minimum of 3 hours per week. Level of services is determined by IEP Team.	Beginning July 1, 2001, instructional services shall be delivered by an individual possessing a minimum of a bachelor's degree from an institution of higher education as defined in state regulations. The requirement does not apply to an individual who demonstrated satisfactory performance as a home and hospital teacher in a local school system before July 1, 2001. For students eligible for special education, teachers must meet same certification standards as special education teachers.

Massachusetts	For students of ages (3-21), the special education includes programs provided by the district in a home or hospital setting if required by the student's physician	Upon physician's written order verifying any student enrolled in a public school must remain at home or in a hospital for medical reasons for a period of not less than 14 school days in any school year, the principal shall arrange for provision of educational services in the home or hospital. If physician certifies student will be absent more than 60 days during the school year, referral will be made to special education for evaluation and IEP development	No minimum or maximum specified	Same as Special Education or Related Services Personnel
Michigan	Homebound/Hospital services provided for eligible special education students who cannot attend school because of physical or medical impairment	Homebound services shall be initiated within 15 school days after verification, by a licensed physician, of a medical handicap that requires the eligible special education student to be confined to the home. Such verification shall indicate the anticipated duration of the required confinement. Hospital service shall be provided for eligible special education students who cannot attend school because of hospitalization for a physical or medical impairment.	Students receiving homebound or hospital services shall receive a minimum of 2 nonconsecutive hours of instruction per week. Related services personnel may supplement, but not substitute for, the teacher's instruction.	Same as Special Education or Related Services Personnel

		Services shall be initiated when determined medically feasible.		
Minnesota	Home and Hospital settings defined as part of the continuum of placements	Education services must be provided to a pupil or regular education student who is: A. prevented from attending the pupil's normal school site for 15 consecutive school days; or B. predicted to be absent from the normal school site for 15 consecutive school days according to the placing authority, such as a medical doctor, psychologist, psychiatrist, judge, or other court-appointed authority; or C. health-impaired and in need of special education and predicted by the team to be absent from the normal school site for 15 intermittent school days.	Absence greater than 170 days, exclusive of summer school, district shall make available: A. instruction necessary for the student to make progress to successfully complete the courses, programs, or classes the student would have been enrolled in if the student were not placed for care and treatment; B. preferably a normal school day in accordance with the pupil's IEP; C. an average of at least two hours a day of one-to-one instruction; or D. a minimum of individualized instruction for one-half of the normal school day if it is justified in the pupil's IEP. If the predicted absence is fewer than 171 school days, exclusive of summer school, the district shall provide either small group instruction	Same as Special Education or Related Services Personnel

			for one-half of the normal school day or at least an average of one hour a day of one-to-one instruction Extended year services are optional unless the pupil has an extended year IEP.	
Mississippi	Included in definition of special education and included in continuum of placements	Special Education or 504 Eligibility. Additionally, Mississippi Code provides that when (5) or more between the ages of (6) and (21) years who are capable of pursuing courses of instruction at secondary school level or below shall be confined in a hospital for an extended period of time, such children shall be eligible for and shall be provided with a program of education, instruction and training within such hospital, provided that the need for hospitalization for	Determined by IEP Team	Same as Special Education or Related Services Personnel

		an extended period of time shall be certified by the chief of staff of such hospital and that the ability of such children to do school work shall be certified by qualified psychologists and/or educators approved by the State Board of Education.		
Missouri	Follows federal definition of special education.	Homebound services may be provided to both disabled and nondisabled students. Application must be submitted to State DOE for: 1. Students with disabilities who require homebound services for over nine (9) weeks with a diagnosed medical condition, (except in the case of a normal pregnancy which allows for six (6) weeks pre- and six (6) weeks post-partum); 2. Students requiring homebound services for the purpose of a reevaluation; 3. Students receiving homebound services who were long-term suspended or expelled; 4.	Five hours of instruction must be given each week in order to be counted for full attendance The total length of homebound instruction must not exceed the number of instructional days the district provides for all students or 36 weeks.	Same as Special Education or Related Services Personnel

		Students who require homebound services when a court injunction has been issued. For all other students, with the exception of those listed above, the school district must still complete a homebound application form and maintain it in their files for a minimum of five (5) years.		
Montana	No specific definition in state regulations	Montana Code requires provision of a FAPE to students placed in residential treatment facilities or children's psychiatric hospitals. District of residence is responsible for coordination of services	No minimum or maximum specified.	A teacher of homebound or hospitalized students must hold a current Montana teaching certificate.
Nebraska	Follows federal definition of special education and included in continuum of placements	No specific eligibility criteria other than those for special education or 504 eligibility.	No minimum or maximum hours specified.	Same as Special Education or Related Services Personnel
Nevada	Follows federal definition of special education and included in continuum of placements.	No specific eligibility criteria other than those for special education or 504 eligibility.	No minimum or maximum hours specified, however, teachers of pupils with orthopedic impairments and health impairments receiving special education services in a home or	Same as Special Education or Related Services Personnel.

			hospital may have no more than 10 students.	
New Hampshire	Home/Hospital Instruction defined when a child with a disability receives all or a portion of her/his special education program at home or in a hospital or institution	Preschool children with disabilities may receive all or a portion of their special education program at home depending upon need as specified in the IEP; Home instruction for children at least 6 years of age but less than 21 years of age shall not include parent-designed home education programs.	Provided for same period as regular school year. Minimally includes 10 hours per week of specially designed instruction as specified in the child's IEP to allow progress in the general curriculum and meet all IEP goals; and Includes related services in addition to the 10 hours of specially designed instruction required.	Same as Special Education or Related Services Personnel.
New Jersey	Home instruction due to temporary illness or injury for students with or without disabilities	Parent shall submit a written determination from a physician documenting the need for confinement at the student's residence for at least a two-week period of time. When the provision of home instruction will exceed 30 consecutive school days in a school year, the IEP team shall convene a meeting to review and, if appropriate, revise the student's IEP. When a nondisabled student is confined at home or to a hospital by a physician for more than 60	Minimum of five hours per week provided on three separate visits on three separate days. When instruction is provided in a small group, the number of hours of instruction per week for the group shall be determined by multiplying the number of students in the group by five hours.	The teacher providing instruction shall be appropriately certified as teacher of the handicapped or for the subject or level in which the instruction is given.

		calendar days, the school physician shall refer the student to the child study team.		
New Mexico	No specific definition in state regulations	New Mexico School Health Manual requires a doctor's statement explaining medical condition and expected dates of school absences.	No minimum or maximum specified.	Same as Special Education or Related Services Personnel.
New York	Students with disabilities recommended for home and/or hospital instruction by the instruction by the special education committee shall be provided instruction and appropriate related services as determined by the committee in consideration of the student's unique needs.	Eligibility determined by Committee of the student's unique needs and based upon a determination the placement is the least restrictive environment.	Minimum of five hours per week at the elementary level, preferably one hour daily; or a minimum of 10 hours per week at the secondary level, preferably two hours daily.	Same as Special Education or Related Services Personnel

North Carolina	Children with disabilities who receive special education in homebound or hospital placements including children who are served as: in-patients, out-patients, out-patients served in clinics; homebound programs.	No specific eligibility criteria other than those for special education or 504 eligibility, however, Homebound placement shall be temporary with a goal in the IEP for returning the child to a less restrictive environment within the school year, unless there is medical information that would require extended homebound instruction.	No minimum or maximum hours specified.	Same as Special Education or Related Services Personnel
North Dakota	None	No specific eligibility criteria other than those for special education or 504 eligibility	No minimum or maximum hours specified	Same as Special Education or Related Services Personnel
Ohio	Follows federal definition of special education and included in continuum of placements.	No specific eligibility criteria other than those for special education or 504 eligibility	No minimum or maximum hours specified	Same as Special Education or Related Services Personnel
Oklahoma	Follows federal definition of special education and included in continuum of placements.	Determined by IEP Team, when needs of student require IEP to be implemented in the home, hospital or other out of school setting, based upon the individual needs of the child.	Frequency and duration of services are determined by the IEP team on an individual basis.	Same as Special Education or Related Services Personnel

Oregon	School districts may provide home, hospital, institutional, or other regularly scheduled instruction to any eligible student with a disability.	Criteria for Placement: School districts that propose to place a student with a disability in a home, hospital, institutional, or other regularly scheduled program shall ensure that the following criteria are met: The student must be enrolled as a resident student of the school district; The home, hospital, institutional, or other regularly scheduled program shall be appropriate to the unique educational needs of the student; The student shall meet the minimum criteria established by the State Board of Education for determining eligibility to receive special education. Students are expected to be hospitalized for 5 days or more.	No minimum or maximum hours specified.	Same as Special Education or Related Services Personnel.
Pennsylvania	Instruction in the home is governed by federal regulations and an October 2001 Basic Education Circular (BEC) issued by the(BEC) issued by the Department of Education.	Request must be made in writing by the parent and supported by a statement of the physician attending the child, indicating the nature of the disability and the length of time the child will be homebound.	No minimum or maximum hours specified, however, each school district may have a policy that addresses these issues.	Same as Special Education or Related Services Personnel

Rhode Island	Follows federal definition of special education and included in continuum of placements.	Eligibility criteria same as for special education and is based upon an assessment of the student's needs and a determination that the homebound/hospital setting is the LRE.	Minimum number of hours of instruction shall be five (5) hours per school week at the elementary level of education and six (6) hours at the secondary level of education unless physician recommends fewer hours Depending on the physical condition of the child, a number of instructional hours greater than the minimum number of hours required per week are permissible.	Teachers of homebound instruction shall hold Rhode Island teaching certificates in the area appropriate to educate and provide related services to the student with a health impairment, a physical disability or to the student's disability condition.
South Carolina	Home/hospital setting included as part of the continuum of alterna-tive placements	No specific eligibility criteria other than those for special education or 504 eligibility	No minimum or maximum hours specified	Same as Special Education or Related Services Personnel
South Dakota	Follows federal definition of special education and included in continuum of placements.	No specific eligibility criteria other than those for special education or 504 eligibility	No minimum or maximum hours specified	Same as Special Education or Related Services Personnel
Tennessee	Home/hospital setting included as part of the continuum of alternative placements.	No specific eligibility criteria other than those for special education or 504 eligibility	No minimum or maximum hours specified	Same as Special Education or Related Services Personnel

Texas	Homebound Instructional arrangement/setting is for providing special education and related services to students who are served at home or hospital bedside.	Students served on a homebound or hospital bedside basis are expected to be confined for a minimum of four consecutive weeks as documented by a physician licensed to practice in the United States. Homebound or hospital instruction may, as provided by local district policy, also be provided to chronically ill students who are expected to be confined for any period of time totaling at least four weeks throughout the school year as documented by a physician licensed to practice in the United States.	The student's ARD committee shall determine the amount of services to be provided to the student in this instructional arrangement/setting in accordance with federal and state laws, rules, and regulations.	Same as Special Education or Related Services Personnel.
Utah	Follows federal definition of special education and included in continuum of placements. Instruction designed for identified students with disabilities permanently or temporarily homebound or hospitalized, the primary purpose of which is something other than the student's educational needs.	Students served as homebound or hospitalized must be evaluated and classified according to one of the disability conditions as described in the special education rules. Classification of the student as eligible under one of the disability categories must follow the approved regulations for evaluating and determining special education eligibility. The services can begin as soon as possible, although	Amount of instruction determined by the IEP team.	Utah Professional Educator License in the area in which they provide services.

		the student must have an expected absence of at least two weeks Educational services for the homebound or hospitalized student with disabilities must be approved by the student’s health professional contingent upon the student’s health and ability to receive instruction.		
Vermont	Follows federal definition of special education and included in continuum of placements	(a) Children who are eligible for essential early education services who are homebound or hospitalized due to a medical condition and are unable to access the services outlined in their current IEP shall receive direct instruction. (b) Homebound or hospitalized elementary special education students and elementary special education students whose IEPs call for tutorial services outside school shall receive instruction. (c) Homebound or hospitalized secondary special education students and secondary special education students whose	(a) Children who are eligible for essential early education services instruction as determined by the child’s IEP team. (b) Elementary special education students-instruction sufficient to provide a FAPE pursuant to their IEPs, for no less than six hours per week unless inconsistent with medical recommendations. (c) Secondary special education students-instruction sufficient to provide a FAPE pursuant to their IEPs for no less than an average of two hours per subject per week unless inconsistent with medical recommendations.	Same as Special Education or Related Services Personnel

		IEPs call for tutorial services outside school, shall receive instruction.		
Virginia	Academic instruction provided to students who are confined at home or in a health care facility for periods that would prevent normal school attendance.	Homebound instruction eligibility requires certification of need by a licensed physician or licensed clinical psychologist.	For a child with a disability, the IEP determines the delivery of services, including the number of hours of services.	Same as Special Education or Related Services Personnel.
Washington	Home or hospital instruction shall be provided to both special education students and other students who are unable to attend school for an estimated period of four weeks or more because of physical disability or illness.	Requires the parent(s) of a student or the adult student to request the services and provide a written statement to the school district or other public agency from a qualified medical practitioner that states the student will not be able to attend school for an estimated period of at least four weeks, however, school district or other public agency is prohibited from paying the cost of the statement	No minimum or maximum hours specified	Same as Special Education or Related Services Personnel

		from a qualified medical practitioner for the purposes of qualifying an otherwise non-disabled student for home/hospital instructional services.		
West Virginia	Follows federal definition of special education and included in continuum of placements	Special Education or 504 Eligibility	No minimum or maximum hours specified	Same as Special Education or Related Services Personnel
Wisconsin	None	Special Education or 504 Eligibility	No minimum or maximum hours specified	Same as Special Education or Related Services Personnel. Non-special education students do not require instruction by certified personnel.
Wyoming	Included in the continuum of placements	Special Education or 504 Eligibility	No minimum or maximum hours specified	Same as Special Education or Related Services Personnel
1. States may provide homebound services to students who are not eligible disabled students. To the extent state regulations contain a lower standard than that necessary to provide a FAPE under Section 504 or IDEA, it is assumed that the lower standard is applicable to non-disabled students provided services under the state homebound provisions. In most cases, however, the eligibility standards should be viewed in the context of Section 504 or IDEA eligibility.				
2.The regulation implementing Section 504 at 34 C.F.R. Section 104.4(a) and (b)(1)(iii) states that a recipient may not provide a qualified person with a disability with an aid, benefit, or service that is not as effective as that provided to others. The Appendix to the regulation states that the quality of the educational services provided to students with disabilities must equal that of the services provided to students without disabilities; thus, teachers with disabilities must be trained in the instruction of persons with the disability in question and appropriate materials and equipment must be available. Accordingly, it is assumed that if there is a lower standard for homebound certification standards, they are applicable to students served in a homebound setting who have not been determined eligible under Section 504 or Special Education.				
3. 34 C.F.R. Sec. 300.26(a)(I) defines special education as specially designed instruction, at no cost to the parents, to meet the unique needs of a child with a disability, including instruction conducted in the classroom, in the home, in hospitals and institutions, and in other settings.				

TACA. (2012) *Homebound Education State-by-State Comparison*. Retrieved on January 11, 2013 from http://www.tacanow.org/family-resources/homebound-education-state-by-state-comparison/

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