More than Medical Records: Uncovering how Childhood Cancer Survivors learn about and interact with their Cancer Histories.

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Abstract

From 1971 to 2010 the combined 5-year childhood cancer survival rate has increased from 40 percent to 82 percent (Cancer Research UK, 2015). With more children surviving cancer, more adults will live with the long-term effects of cancer treatments. 70 percent of childhood cancer survivors (CCS) are at risk of physical, psychological, and social late effects of treatment and 66 percent reported living with at least one chronic health condition 30 years post diagnosis (Hewitt, Weiner, & Simone, 2003). Amplifying the likelihood of poor health outcomes, CCS with limited access to their health histories have greater risk for poor health outcomes (Hóven, Lannering, Gustaffson, & Bownman, 2018). To limit some of this risk for poor health outcomes and to properly manage their healthcare, CCS need access to their health histories. Despite the importance for survivors to understand their health histories, research neglects to explore how CCS learn about and interact with their cancer histories as young adults. To fill this gap in the literature I interviewed 9 CCS between the ages of 18 and 29 that were treated for cancer at 10 years of age or younger. With these interviews I conducted a content analysis to identify common themes. I present how CCS learned about and continue to learn about their cancer histories. CCS reported using the following resources to learn about their cancer histories: parents, healthcare professionals knowledgeable of their cancer histories, scientific literature, summer camps for CCS, and survivor clinics. Although participants each reported using some of these resources, many of them still have questions about their cancer histories and relevant long-term effects. CCS interact with their cancer histories through feelings of uncertainty, fearing long-term side effects, feeling fortunate for good health, and feeling guilty for their limited knowledge of their cancer histories. The research reveals needed improvements in health education programs for CCS.

Keywords: Childhood cancer survivor, cancer, survivor, cancer histories, cancer narratives
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Introduction

From the 1950s to today survival rates of childhood cancer have increased significantly with some childhood cancer survival rates above 80 percent (“Key Statistics for Childhood Cancers”, 2018). When children undergo cancer treatment, depending on their age, it is likely that they are not fully aware of the treatments they receive and the procedures their bodies go through. As childhood cancer survivors (CCS) develop and move past cancer, short-term and long-term impacts combined with curiosity about their cancer pull them back to their cancer histories.

A survivor is a person who remains alive after an experience that others die from (“Survive”, n.d.). The label, childhood cancer survivor, requires that some children pass away from cancer (Jain, 2013). Although this label rests on children that have died and are dying from cancer, I use it throughout my thesis to align with existing literature and popular nonprofits targeting childhood cancer. In presenting the implications of this label I acknowledge childhood cancer patients that have passed away from the disease.

While there is some research on CCS and the impacts cancer treatments have over time, existing research neglects to explore how CCS learn about their cancer histories and interact with these histories as young adults. This is a significant oversight. Cancer treatments can have long-term impacts that manifest years after treatments conclude (Hewitt, Weiner, & Simone, 2003). In order to seek appropriate care for long-term impacts, CCS require access to or knowledge of their cancer histories. Limited access to health histories puts CCS at higher risks for poor health outcomes (Hóven, Lannerling, Gustaffson, & Bownman, 2018). In addition to physical risks,
restricted accessibility to healthcare history may have psychological effects (2018). My thesis aims to assess these impacts by answering the following questions: How do childhood cancer survivors learn about their cancer narratives and interact with their cancer narratives as young adults?

To present the narratives of childhood cancer survivors, how they learn about and interact with their health histories, I interviewed 9 CCS between the ages of 18 and 29. I then conducted a content analysis of the interviews to assess themes and the frequency of these themes in the narratives.

With these findings I reveal narratives that are not present in the existing literature. In analyzing the themes, I expose how parents and healthcare providers influence the relationships CCS have with their cancer histories. These relationships, in fact, do have psychological impacts on participants and their relationships with their bodies.

My thesis includes five chapters. My first chapter provides a review of cancer treatments, the impacts of these treatments, and narratives relevant to childhood cancer survivors. With this review I reveal the need for my research. I then present my research methods such as interview and analyses strategies. In my third and fourth chapters I discuss my data and the implications of this data. I conclude my thesis in chapter five with a review of the themes found in the narratives and an outline of criteria that should be considered when designing and implementing health education programs for CCS.

**Motivation**

My doctors declared me cancer free at the age of five. For nine or ten years after I was declared cancer free I attended follow up visits at the hospital where I was treated. At first I went in every month, then every three months, every six months, every year, and finally every other
year. By the time I wanted to learn about my cancer history and potential long-term impacts I had aged out of these appointments. Without these appointments, my resources to learn about my cancer history and potential long-term impacts included family members, medical records, and the Internet. I avoided discussing my cancer history with family members cognizant of my cancer history because I anticipated that their responses would be biased by their experiences and emotions. I did not want to learn my story through their perspectives. I wanted to understand the facts of my treatment and the science behind it. Since I was younger than eighteen at the time when I began questioning my cancer history, I could not request a copy of my medical records. This left me with the Internet as my primary resource.

Throughout middle school, high school, and the beginning of college I would occasionally Google the type of cancer I had and the few words I recalled doctors mentioning at appointments. Prior to these Googling sessions I reminded myself that most of the information I found would not apply to my unique health profile and that I should not take the research too seriously. Despite these reminders, many of these Googling sessions ended with the abrupt closing of my laptop when I felt myself getting overwhelmed. While these Googling sessions left me frustrated and a little frightened, they allowed me to uncover a part of history that I could not learn about on my own terms in any other way.

During my sophomore year of college, due to a combination of factors, I became increasingly uncomfortable with the limited information I had about my cancer history. To address my questions I got access to my medical records. For a week or so I studied my medical records – taking notes and looking up terms online and in my biology textbook. I met with a physician to discuss my chance of experiencing specific long-term effects. I took control of my health history. Now, a few years later, I still do not know everything about my cancer history.
but, at the moment, I am satisfied with the information I have learned. My motivation for this thesis stems from my experience searching for ways to learn about my cancer history.

My personal connection with pediatric cancer provides me with a unique perspective that I am motivated to use to help others. In writing this thesis I kept the following groups in mind and hope each group gains the following out of this research.

For childhood cancer survivors - I wrote this thesis primarily for you. I hope you can connect with some of the experiences described in the narratives presented here.

For family members and friends of childhood cancer survivors – Through the themes presented in this thesis, I aim to help you better understand what survivors experience years after their treatments end.

For health care providers – In this thesis I present the impacts healthcare providers have on CCS years after their cancer treatments conclude. In revealing these impacts I outline improvements that will allow CCS to feel more in control of their health and healthcare.
In second grade I attended a school for children with learning disabilities. On the way to school my mom and I picked up my schoolmate and friend James. During our commute to school James and I played videogames on our Gameboys. To pull us out of our games my mom often tried to engage us in conversations. During one of these attempts James mentioned that someone in his family had cancer. Today, 14 years later, I clearly remember my response. Without looking up from my Gameboy I told him, “I had cancer and I’m actually really lucky that I already had it because now I can never get it again. Cancer is like the chickenpox, once you have it you can’t get it again.”

Once I finished this remark my mom replied in a serious tone “that is not how cancer works.” I looked up from my Gameboy into the rearview mirror so I could see her face. She locked eyes with me briefly before returning her stare to the road.

I do not know when I constructed this similarity between cancer and the chickenpox or when I realized that relapse was a possible outcome of cancer treatment. I do recall the feeling this comparison gave me. With cancer like the chickenpox I was protected from a disease that many people feared.
Chapter One - Literature Review

Cancer throws individuals and their support systems into a new world consisting of medical jargon, procedures, hospital stays and hospital cafeteria food. Pediatric cancer adds a twist to this new world in that the patient is not the primary decision maker of her care as she is “just a kid.” In this type of cancer, the child takes on the sick role. The sick role has specific obligations that exempt ill people from social expectations set for healthy individuals (Varul, 2010). In the sick role patients “accept violations of personal and bodily integrity, treatments that come with discomfort and sometimes even considerable pain” (Parsons, 1951, 442). When a child takes on the sick role, her parents or caregivers are subjected to this role as well (Parsons, 1951). During treatment, parents make decisions for their child and are very involved in supporting their child. Mark Unger, the parent of a child diagnosed with a rare form of cancer describes in his novel, First Survivor, his experience:

At any time, night or day, we were inundated with information that felt alien in words and meaning. Learning and remembering so much information all at once was near impossible and I soon realized that if we were to survive, we had to understand the new world we had been thrown into very quickly (Unger, 2017, 7).

While I cannot assume Mark Unger’s experience is representative of all parents with a child undergoing treatment for cancer, it provides a perspective illuminating the roles parents play in managing their sick child’s care.
In Lucy Grealy’s *Autobiography of a Face* she shares her battle with a malignant tumor located in her jaw. Lucy unveils that her experience with cancer was greatly influenced by her healthcare providers and family. Lucy and her family immigrated to the United States from Dublin, Ireland in 1967 (Lehmann-Haupt, 2002). At the age of nine Lucy was operated on for a seemed dental cyst. During surgery the innocuous cyst was found to be much more. Lucy was diagnosed with Ewing’s sarcoma, a rare and deadly form of cancer at the time. Lucy’s treatment included surgery, chemotherapy, and radiation. The initial surgery left Lucy with a significant facial deformity that she spent the rest of her life seeking treatment for. While undergoing surgeries to correct the deformity, Lucy attended high school and college. After college Lucy wrote her memoir, which received literary praise. In 2002, at the age of 39 Lucy passed away. Her family did not announce a cause of death (2002).

Since the 1970s when Lucy was treated, hospital care has evolved significantly with more psychological services and anti-nausea medications available. While hospital procedures have evolved, cancer treatments have remained somewhat consistent. Given the similarities between treatments administered almost 50 years ago and treatments provided today, Lucy’s cancer narrative continues to describe a relevant experience.

Lucy received chemotherapy and radiation for two and a half years (Grealy, 1994). Throughout Lucy’s narrative she reveals how little she understood what was being done to her body. While preparing Lucy for the removal of her tumor and the neighboring part of her jaw, a nurse asked if she had any questions about the surgery. Lucy responded that she “understood everything perfectly” although she “hadn’t a clue how sick [she] was or what was going to happen to [her]” (Grealy, 1994, 23). Although Lucy received many tests during her hospitalizations she never questioned “what was going on, what the tests were for, [or] what the
results were” (Grealy, 1994, 30). In addition to Lucy’s naivety, healthcare professionals often withheld information from her. A healthcare provider described chemotherapy to Lucy as “simply another drug, another injection, maybe one that would make [her] a little flushed, no more” (Grealy, 1994, 34). The combination of Lucy’s dissociation from her cancer experience and the limited information explained to Lucy by either her parents or her care team, left Lucy uninformed about her diagnosis and her treatment. Lucy illustrates her minimal knowledge in the passage below:

Some years later, I don’t remember how many, as my family was milling about the kitchen and I was leafing through the paper at the table, someone dated an event as something that had happened “before Lucy had cancer.” Shocked, I look up.

“I had cancer?”

“Of course you did, fool, what did you think you had?”

“I thought I had Ewing’s sarcoma.”

“And what on earth do you think that is?”

In all that time, not one person ever said the word cancer to me, at least not in a way that registered as pertaining to me (Grealy, 1994, 48).

Similar to Lucy’s discovery that she had cancer, a study assessing the unmet needs of childhood cancer survivors found that fifty percent of CCS were unaware of the treatments they received (White et al., 2018). Many were also unaware of their diagnoses (2018). As CCS age into adulthood questions about their cancer histories persist and questions about their health futures arise. For example, 59 percent of survivors reported uncertainty regarding fertility status (Cherven et al., 2016). In research conducted by White et al. a survivor interviewed at age 28
noted “I don’t know if I will be able to have children or not because of the chemotherapy that I had” (2018).

The number of childhood cancer survivors unaware of their cancer histories presents two issues. First, without knowledge of their health histories, CCS cannot responsibly manage their health, which may be influenced by their cancer treatments. Second, cancer treatment is a significant life event and without sufficient information about this life event, survivors may struggle to integrate their cancer histories into their personal narratives. In the following passage Lucy reveals her curiosity to learn about her cancer:

_I found myself in the medical section, where a book on pediatric oncology caught my eye. Pulling the heavy thing out, I laid it on the table, opened to the index, and looked up my cancer, Ewing’s sarcoma. I turned to the given page and read a brief description of the various manifestations of it, followed by a table of mortality rates. A reasonable chance of survival was given at five percent_ (Grealy,1994, 58).

Lucy was not alone in searching for information about her cancer history. Unmet information needs are present among 75 percent of survivors and parents of survivors and stem from a combination of time lapse since cancer and a lack of accessible resources (Vetch et al., 2017). In a study assessing the unmet needs of adult childhood cancer survivors (ACCS) White et al. analyzed surveys from 94 ACCS (2018). In a survey an ACCS, 44 years old at the time he completed the survey, noted “as I grew up, I had lots of questions and no answers or help trying to understand my cancer/treatment or what to expect” (2018). Similarly, a study focusing on adult survivors of childhood malignant lymphoma found that 66 percent were unaware of their heightened risk for long-term side effects (Jacobs & Pucci, 2013). Many CCS would like to
receive more information regarding fertility, survivorship, and cancer recurrence (Gianinazzi et al., 2013).

It is important to highlight that while many CCS request more information, some childhood cancer survivors feel overwhelmed with the amount of information they have received and report no need for additional information (Vetch et al., 2017). Given the variable needs of CCS, long-term follow up care and health education will need to be customizable for specific patients.

The lack of personal cancer history awareness among childhood cancer survivors has cascading impacts. Unmet information needs have been associated with lower overall health, secondary co-morbidities, psychological distress, worry about the future, and lower health-related quality of life (Hóven, Lannering, Gustaffson, & Bowman, 2018). Although research highlights the need for CCS to comprehend their cancer treatments, the literature does not address how CCS learn about their cancer histories. My research aims to address this gap.

In the remainder of this chapter I first present the progression of a childhood cancer journey, the prevalence of childhood cancer, treatments, side effects, and long-term follow up care. This review of the cancer journey provides information needed to empathize with the narratives of CCS presented in this document. In part II I review how cancer treatment has evolved over time. I then present the short-term and long-term effects cancer treatments may have on survivors. I conclude with a discussion of published cancer narratives. These narratives highlight how uncertainty impacts survivors and their families supporting the need for research assessing how CCS learn about their cancer narratives and interact with their survivor statuses.
Part I - The nuts and bolts of cancer treatment: from diagnosis to remission

Cancer is the growth of abnormal cells that no longer undergo normal cellular regulatory processes (Tian et al., 2011). In 2018 the American Cancer Society reported that 10,590 children between the ages of 0 to 14 were diagnosed with a type of cancer (Howlader et al., 2018). With the 5-year survival rate for childhood cancer at 83 percent, approximately 8,790 of these children will survive five years after their diagnoses (2018). Today there are more than 420,000 childhood cancer survivors in the United States (Fish, 2018). By 2020 this number will increase to 500,000 (2018).

After a child is diagnosed with cancer, the first step in ridding the child’s body of cancer is to determine a treatment plan. Commonly used cancer treatments include chemotherapy, radiation, and surgery. Chemotherapy is generally used when cancer has spread all over the body while radiation and surgery target cancer in a specific part of the body.

Chemotherapy utilizes drugs to kill cancerous cells in the body. Such drugs spread through the body and kill healthy cells in addition to cancerous cells. In a growing child, whose cells divide quickly, the destruction of healthy cells amplifies the harmful effects of chemotherapy (Bornstein et al., 2012). After receiving chemotherapy many patients experience intense nausea. Fortunately, with anti-nausea medications available today, nausea is mitigated. Lucy, who received chemotherapy prior to the development of anti-nausea medications, intensely felt the short-term side effects. She describes:

*My body, wanting to turn itself inside out, made wave after wave of attempts to rid itself of this unseeable intruder, this overwhelming and noxious poison. I shook with heaves so strong they...*
felt more like convulsions. Someone lifted a metal basin to my face, and I quickly deposited in it everything my digestive system owned… (Grealy, 1994, 66).

Some long-term impacts of chemotherapy include learning disabilities, delayed development, and infertility. The impacts of chemotherapy vary according to each patient, type of chemotherapy, dosage, and age of the child when exposed to such drugs. (“Late Effects of Childhood Treatment”, 2017).

In radiation, x-rays target cancer cells to shrink tumors. Similar to chemotherapy, radiation harms normal cells as well as cancerous cells (“Side effects of radiation”, 2018). Radiation and chemotherapy have similar side effects but target the body differently. Radiation targets a part of the body while chemotherapy spreads to all parts of the body. Despite the negative side effects of chemotherapy and radiation, these treatments are successful in eliminating cancerous cells as indicated by the high 5-year survival rate for childhood cancers. Lucy received chemotherapy and radiation. In comparison to chemotherapy Lucy reflects that:

* Radiation treatment itself was a breeze, about as complicated as an x-ray. I’d get up on the table, and Chris would don her lead smock and turn out the lights. Bulbs inside the clunky machine hanging from tracks on the ceiling would shine down on my face, waiting to be aligned with the Magic Marker x’s drawn on my neck and face (Grealy, 1994, 64).

The duration of treatment depends on the form of cancer. Some cancer treatments last for a couple months while others last for multiple years. After surviving this treatment, if a patient’s body is cancer free she is considered to be in remission. When a patient reaches five years of remission the chances of cancer relapse reduce significantly. At this time point some healthcare
professionals consider the patient to be cured of the cancer she was originally treated for (Tralongo et al., 2015). Other healthcare professionals avoid using this term because relapse and development of another form of cancer are still possible outcomes (2015).

In this section thus far I have presented cancer as a linear process: diagnosis to treatment to remission. While this is the ideal progression of cancer treatment, many variables may disrupt this sequence. As mentioned, chemotherapy kills cancer cells as well as healthy cells. When chemotherapy eliminates healthy cells some complications may arise. For example, white blood cells are crucial in a body’s immune response and can be thought of as the manager of the immune system. When something foreign enters the body, white blood cells attack the foreign invader and protect the body. Chemotherapy often depletes the body’s supply of white blood cells and makes the body vulnerable to infection. Infection derailstreatment and makes treatment much more complicated than the linear process I have presented.

New methods for cancer treatment are being developed and administered today. Immunotherapy is becoming a popular treatment option. To understand how immunotherapy is used in cancer treatment, one first must abstractly understand how the immune system protects the body from foreign invaders.

The immune system is comprised of two defense systems, the innate response and the adaptive response. The adaptive immune system detects foreign cells in the body by distinguishing between self versus non-self antigens that act as markers (Garcia et al., 2014). T cells and B cells are the main proponents of the adaptive immune system and go through similar non-self versus self-testing. The Major Histocompatibility complex (MHC) is a section of the genome that codes for surface proteins found on cells that present antigens to T cells. Within the thymus (a gland located behind the breastbone) the body produces T cells that are tested with
self-antigens and self-surface proteins. T cells that recognize self-antigens and self-surface proteins are destroyed while T cells that do not recognize self-antigens and self-surface proteins are released into the body. When T cells recognize non-self antigens they amplify the production of such T cells and launch an attack to kill any cells presenting with the same non-self antigen.

Cancerous cells present non-self antigens (Boon et al., 1994). A specific type of T cell, known as cytotoxic T cells, recognizes cancerous cells through non-self antigen detection (1994). Although these T cells detect cancerous cells they rarely provide protective immunity as cancerous cells have ways to evade detection (Chen & Mellman, 2013). Immunotherapy aids the body in creating T cells that may recognize cancerous cells. If this treatment is successful the growth of cancer can be reduced. Like radiation, immunotherapy is a targeted approach (2013). Immunotherapy has less severe side effects when compared to the side effects of radiation and chemotherapy (“Side Effects of Immunotherapy”, 2018). Since immunotherapy is a newer form of treatment, the side effects of it have not been studied as extensively as the side effects of other forms of cancer treatment (2018).

**Part II: How the treatment experience has changed over time**

Prior to the 1960s, cancers stemming from tumors were treated with surgery and radiotherapy (DeVitra & Chu, 2008). Long-term remission rates with these treatments were low due the inability for treatments to eliminate all of the cancerous cells from individuals’ bodies. Additionally, these treatments were only useful in regional specific cancers. The rise of chemotherapies in the early 1950s and the acceptance of this treatment method in the 1960s improved long-term remission rates across many types of cancer (2008).
Scientific research leading to chemotherapies came out of chemical warfare research (2008). During World War I the accidental spill of sulfur mustards on troops revealed that the chemical depleted bone marrow and lymph nodes (2008). The documented impact of sulfur mustard on men in World War I suggested that the chemical could reduce cancer cells in the body. After testing with animals, nitrogen mustard seemed to be a promising treatment for cancer patients (2008). In 1946 it was used in people with lymphomas and was successful in eradicating cancer cells from the body for brief periods of time (2008).

The failure of nitrogen mustard as a cancer cure was a setback for researchers and the public that had become invested in the groundbreaking medicine (2008). Turning away from war related chemicals, Sidney Farber, a pediatric pathologist, found that Aminopterin, a compound related to vitamin folic acid, resulted in remissions among children with leukemia (2008). This compound was a predecessor of methotrexate, a chemotherapy used today (2008). The breakthrough of Aminopterin in the early 1950s marks a change in cancer treatment (2008).

Chemotherapy was not successful in getting patients to remission initially. It took time for researchers and doctors to find dosages that balanced ridding the body of cancer and limiting damage to the body’s noncancerous cells (2008). As more and more drugs like Aminopterin were produced, patients received mixtures of drugs. Utilizing multiple drug combinations proved to be more successful than ingesting a single drug (2008).

Chemotherapy was initially tested and used in patients suffering from cancers not local to one area of the body. These cancers include leukemias and lymphomas. In the 1970s chemotherapy became a treatment option for location specific cancers (2008). After surgery and radiation, chemotherapy ensured that all of the cancerous cells were eliminated from the body. Utilizing multiple forms of treatment such as chemotherapy after surgery is known as adjuvant
therapy (2008). Today adjuvant therapy is used to treat location specific cancers like breast cancer and colon cancer.

Since the 1960s to today, nausea and vomiting have been severe symptoms felt by patients receiving chemotherapy. In the 1980s antiemetics, which are pharmacological treatments for chemotherapy induced nausea and vomiting, were developed and administered to cancer patients (Tonato, Rolia, Del, & Ballatori, 1994). By the late 1990s antiemetics became a standard part of chemotherapy treatment and have been reported to significantly reduce chemotherapy induced nausea and vomiting (1994).

As mentioned, Lucy received treatment in the 70s for a tumor located in her jaw. Lucy’s treatment included surgery, radiation, and chemotherapy. Combining treatments at this time was still a relatively new form of cancer treatment. Unfortunately for Lucy antiemetics were not available when she was treated and she experienced the full symptoms of chemotherapy. Lucy’s descriptions of her cancer treatment and how she learned about her cancer history illustrate the physiological and psychological repercussions of treatment. While Lucy’s narrative is limited in that it is specific to a certain time period, the themes she present match the themes found in research conducted more recently.

**Part III: Potential impacts of cancer treatment**

Most of the short-term and long-term impacts of cancer treatment are negative. In the literature I reviewed, chemotherapy especially is viewed as a poison that harms the body. While this is true, chemotherapy is often successful in ridding the body of cancer, which is the main purpose of cancer treatment.
**Short-term impacts**

As briefly mentioned while reviewing types of cancer treatments, chemotherapy and radiation have short-term and long-term impacts. It is important to note that short-term and long-term impacts of childhood cancer treatment vary for each child and depend on many factors specific to the child and her treatment.

Children undergoing treatment for cancer are at heightened risk for infections due to the destruction of cells important to the immune system. With a weakened immune system the patient is susceptible to infections. To limit the chance of infection and additional illness, the patient is isolated from any person that could expose her to germs such as classmates, friends, and siblings. This social isolation may hinder social development as well as mental development since the patient cannot attend school (Kim, Lee, & Koh, 2018). The duration of social isolation is specific to each patient and impacts each participant differently. Radiation and chemotherapy also may result in physical and cognitive deficits such as memory impairments that hinder academic progress (2018).

**Long-term follow up care**

The long-term impacts of childhood cancer treatment include physical, psychological, and social effects. The American Cancer Society published that “70 percent of childhood cancer survivors are at risk of physical, psychological, and social late effects of treatment, 66 percent were found to have at least one chronic physical health condition 30 years post diagnosis, and 42 percent had a severe, life-threatening, or disabling health condition or suffered from premature death” (Hewitt, Weiner, & Simone, 2003). Physical side effects are more likely to be addressed by a healthcare professional than psychological and social effects. Psychological effects include the uncertainty of cancer relapse in survivors, which may make it difficult for survivors to plan
their futures (2003). Some survivors are hesitant to engage in relationships due to the uncertainty of cancer relapse, underscoring long-term social effects.

Many CCS appear “normal” a few years after completing treatment. Since many CCS pass as “normal” they must decide if and how they share their cancer histories with others. Passing as “normal” or as another race is often studied in sociology (Lonardi, 2007). Typically passing as “normal” pertains to individuals with invisible chronic illnesses or invisible disabilities. Individuals passing as “normal” report feeling conflicted in deciding whether or not to disclose their illnesses or disabilities to others (2007). In sharing their invisible illnesses or disabilities with others, individuals put themselves at risk of suffering from stigmas associated with such illnesses or disabilities. While surviving cancer is not stigmatized to the same degree as chronic illness and mental illness, CCS may feel conflicted when determining if they will share their cancer histories with others.

The importance of CCS engaging in follow up care is crucial in monitoring long-term health impacts. Supporting this, cancer patients that are knowledgeable of their medical histories are better decision makers, adhere more to the prescribed care-plan, show lower levels of distress and higher quality of life, have a greater sense of control and fewer information needs (Gianinazzi et al., 2013). Despite the benefits, only 42 percent of childhood cancer survivors regularly attend cancer related follow up appointments (Howard et al., 2017). Reported variables associated with the low attendance rate include living a greater distance from the treating hospital, non-white ethnicity, not having medical insurance, longer time off treatment, younger age at diagnosis, older age, and poorer health status (2017).

Existing long-term follow up care programs for CCS provide ongoing multidisciplinary follow up care that can be individualized for each survivor (2017). While these existing
programs may benefit CCS, they do not follow set guidelines supported by research (2017). Additionally, these programs are limited and many CCS do not have access to long-term follow up care. Barriers that limit long-term follow up care include lack of guidelines regulating care, financial constraints, and few providers trained in and experienced in caring for young cancer survivors.

**Part IV: A review of existing childhood cancer narratives**

In *Life is never the same: childhood cancer narratives*, 39 children with a variety of cancer diagnoses and their families participated in formal and informal interviews (Woodgate, 2005). 21 participants identified as female and 18 identified as male. 95 percent of participants were white and the age of children surveyed ranged from 4.5 to 18 with 10 years as the mean age. The three narratives identified through this research include collective and individual losses, moving forward, and the feeling that the cancer journey is never over (2005). Throughout the interviews it became apparent that parents’ (especially mothers’) and their sick child’s sense of self merged through the frequent use of the pronoun ‘we’ in their narratives (2005). As the parents’ and child navigate cancer treatment, siblings of the cancer patient reported feeling like outsiders that watched their parents and sibling battle cancer from a distance. Supporting this sentiment, parents felt it was difficult to keep their families together and to maintain a household during treatment (2005).

The theme that cancer never ends, stems from uncertainty that accompanies cancer treatments. There are two main causes that elevate uncertainty as a significant theme in childhood cancer survivors’ lives. First, uncertainty results from the significant yet unknowable impacts cancer may have on one’s future. For example, some survivors may suffer from infertility while other survivors may suffer from learning disabilities. There are no set long-term
side effects and former patients, by surviving cancer, are experiments testing how their genetics and lifestyles interact with long-term effects over time. Participants reported that their awareness of uncertainty increases when they experience important life events or deaths of relatives and friends (Parry, 2003). Interestingly, some participants stated that as time in remission increases, their awareness of uncertainty decreases. For others, their awareness of uncertainty has remained consistent over time (2003). The second cause of uncertainty, as outlined by Lucy’s experiences in learning about her cancer, emerge from childhood cancer survivors not understanding their cancer narratives. While uncertainty due to the unknowingness of the future cannot be alleviated, uncertainty resulting from survivors questioning their health histories is preventable. Lastly, as described, although uncertainty has many negative impacts, many survivors note it as a force that motivates growth, increases appreciation for life, awareness of life purpose, confidence, resilience, and optimism (2003).
The human ear detects sound waves with frequencies between 20 Hz and 20,000 Hz. As people age or suffer from hearing damage, they lose the ability to hear sounds with higher frequencies. To illustrate the connection between hearing and sound wave frequency my high school physics teacher led our class in an activity. For this activity my teacher instructed the class to stand up and for individuals to sit down when they could hear pitches played from his computer.

The first pitch played had a frequency of 20,000 Hz and everyone in the class remained standing. As my teacher decreased the pitch, chunks of the class sat down. I became confused and felt my cheeks turn warm – I couldn’t hear anything. Quickly after we started the exercise I was the only person standing in the classroom and my peers sitting in front of me had turned around in their chairs to look at me. My teacher seemed surprised that I was still standing and continued to play pitches with lower frequencies. I pretended I could hear the noise and quickly sat down. Later in class my teacher approached my desk and asked if I listened to music loudly, a common activity that harms one’s ability to hear sounds with high frequencies. The attention from my peers made me uncomfortable and I tersely responded that I was unaware of any unhearing damage.

For the rest of the class period I thought about why my hearing, according to the exercise, was worse than my peers’ and my teacher’s. As I was packing up my backpack to go to the library I hypothesized that stereocilia, which are hair cells in the inner ear that vibrate at specific frequencies corresponding to sounds, are impacted by chemotherapy just like hair on the body. On a library computer I quickly confirmed my hypothesis. Unlike hair on the body, stereocilia do not grow back after chemotherapy ends. When was anyone going to tell me that my hearing was
impacted by the chemotherapy? When would have been the right time to tell me this? Perhaps a health professional informed me of this long-term impact and I neglected to remember it.
Chapter Two – Methods

Since this research includes interviewing human subjects I submitted my research protocols to Stanford University’s institutional review board (IRB). To protect the anonymity of participants, I omitted all personal information stated during interviews while transcribing the interviews. The interviews were recorded on my phone and then immediately transferred to my computer and deleted off of my phone. The audio recordings will be deleted with the termination of this project.

Participants

All of the participants in this study met the following requirements:

1. Diagnosed with cancer between the ages of 0 and 10.
2. All participants interviewed were between the ages of 18 and 29.

In total, I interviewed nine participants: five male participants and four female participants. Six interviews were conducted over the phone, two were completed in person, and one participant responded to my questions in writing. Eight of the participants were treated in the United States. One participant was treated in the United Kingdom.

Recruitment

To recruit for this study I shared my thesis proposal with peers and asked if they knew of anyone that fit the participant requirements. Through a peer I was put in contact with the St. Baldrick’s foundation. The St. Baldrick’s foundation raises money for childhood cancer research. With the help of a contact at St. Baldrick’s, my participant request was shared with people in the
organization’s network. I also recruited participants by posting in Facebook groups specific to cancer survivors and childhood cancer survivors.

**Interviews**

In preparing for interviews I wrote a set of questions to guide conversations with participants. The questions are listed below. Interviews lasted between 15 minutes and 45 minutes.

**Set 1**
- Can you tell me about your cancer story?
- What type of cancer did you have?
- At what age were you diagnosed with cancer?
- What was the duration of your treatment?
- How old are you now? / How long have you been cancer free?

**Set 2**
- Are you curious about your cancer history?
- How much do you know about your cancer history?
- Do you have questions about your cancer treatment?
  - How have you learned about your cancer history?
  - What prevents you from learning about your cancer history?
- If you had the chance to talk to your cancer care team today what questions would you ask them?
- Do you get asked questions about your cancer treatment that you cannot answer?
  - Can you describe a time when this happened? How did that encounter make you feel?

**Set 3**
- How often do you think about your cancer history? (Ex: Daily, monthly, yearly, rarely?)
- How has this changed over time?
- What occasions or experiences remind you of your cancer history? Can you describe any of these experiences?
- How has being a cancer survivor affected your life?
- Think back to the last time you told someone about your cancer history. What was that like?
Set 4

- What resources have you used to learn about your health history?
- What resources would you recommend to CCS? What resources would you not recommend to CCS?
- How could long-term care for CCS improve?

Each set of questions targets a different part of my research question. Set 1 assesses the “facts” of participants’ cancer diagnoses and treatments. Set 1 and set 2 focus on their cancer histories and how much they know about their experiences. Set 3 questions how cancer has impacted their lives. Set 4 investigates the resources participants utilized to learn about their cancer histories and questions how long-term care including health education could be improved. In Appendix A I include excerpts from two interviews.

Analysis

Each interview was transcribed by hand. With these transcripts I conducted a content analysis to organize themes present in the narratives. For my content analysis I first developed a codebook. In creating my codebook I listed all of the themes I expected to find in the transcripts. I then listed all of the opposing themes. For example I expected to find the theme: survivor wants to learn about her/his cancer history. I included that theme as well as the following theme in my codebook: survivor does not want to learn about her/his cancer history. Through this process I attempted to eliminate personal bias. With this preliminary codebook I read through all of the interviews and added themes to the codebook as they came up. I repeated this process three times. My final codebook can be found in Appendix B.

Limitations

Participants recruited from St. Baldrick’s and Facebook groups specific to cancer survivors may be biased since they have opted to continue interacting with cancer through social
media and fundraising campaigns. By interacting with cancer survivors and people working in fields related to cancer research, it is possible that these participants are more or less aware of their cancer histories than CCS that do not interact with such platforms. During interviews participants sometimes contradicted themselves. In my analysis I note these contradictions. While interviewing is a useful strategy for this type of research, how participants respond depends on factors that cannot be controlled.

**Improvements**

Due to the short timeframe I had for recruitment it was most efficient for me to recruit through Facebook and St. Baldrick’s. With this recruitment strategy many of my participants were not local to me and I had to conduct interviews over the phone. I found that interviewing participants in person resulted in longer conversations with more information shared by the participants. For people interested in collecting health narratives I recommend interviewing in person if possible.
Interlude

I have a faint scar on the right side of my neck. One day, while getting ready for middle school and scrutinizing my appearance in the mirror I noticed the scar and realized that I had no recollection of how I got it. At breakfast I asked my mom while pointing to my neck, “what is this scar from?” My mom replied “that is from your breathing tube, don’t you remember?” I was upset that my mom thought I remembered this and ended the conversation by questioning “I was three, how would I remember that?”

In high school, while at practice a coach noticed the scar on my neck and asked if it was hickey. With a sarcastic laugh I told her it was a scar. I didn’t mention that it was from my breathing tube. Sharing that information quickly changes a light-hearted conversation to a serious one.
Chapter Three – Data

I identified 36 themes in the interviews. The following two tables present the themes identified as well as the frequency at which they were mentioned. Table 1 presents themes that were mentioned in four or more interviews. Table 2 includes themes that were mentioned in one to three interviews. In the next chapter I discuss the nuances of each theme listed in Table 1 and some listed in Table 2.

<table>
<thead>
<tr>
<th>Themes</th>
<th>Frequency (n=9)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aware of cancer history and potential impacts</td>
<td>9</td>
</tr>
<tr>
<td>Unsure about cancer history / potential cancer impacts</td>
<td>9</td>
</tr>
<tr>
<td>Dealing with long-term impacts</td>
<td>8</td>
</tr>
<tr>
<td>Comfortable with cancer</td>
<td>7</td>
</tr>
<tr>
<td>Learning about cancer from parents</td>
<td>6</td>
</tr>
<tr>
<td>CCS does not want to know more about cancer treatment</td>
<td>5</td>
</tr>
<tr>
<td>Feeling fortunate for good health</td>
<td>5</td>
</tr>
<tr>
<td>Fear of long-term impacts</td>
<td>5</td>
</tr>
<tr>
<td>Comfortable asking to learn more about cancer</td>
<td>5</td>
</tr>
<tr>
<td>Personal connection with healthcare providers after treatment</td>
<td>4</td>
</tr>
<tr>
<td>Involvement with health education</td>
<td>4</td>
</tr>
<tr>
<td>Medical interest</td>
<td>4</td>
</tr>
<tr>
<td>Cancer impacted/impacts family dynamic</td>
<td>4</td>
</tr>
<tr>
<td>Survivor wants to know more about cancer treatment</td>
<td>4</td>
</tr>
</tbody>
</table>
Surviving cancer is part of identity  4
How people respond to survivor’s cancer history  4

**Table 1.** Themes presented in four or more interviews.

<table>
<thead>
<tr>
<th>Themes</th>
<th>Frequency (n=9)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attitude towards cancer history changes over time</td>
<td>3</td>
</tr>
<tr>
<td>Motivation from cancer experience</td>
<td>3</td>
</tr>
<tr>
<td>Doctors question cancer history</td>
<td>3</td>
</tr>
<tr>
<td>Young age limiting awareness of cancer treatment is a benefit</td>
<td>3</td>
</tr>
<tr>
<td>Learning about cancer from information available on the Internet</td>
<td>3</td>
</tr>
<tr>
<td>Attended a camp related to cancer</td>
<td>3</td>
</tr>
<tr>
<td>Cancer history impacted relationship with body</td>
<td>2</td>
</tr>
<tr>
<td>Learning about cancer through classes</td>
<td>2</td>
</tr>
<tr>
<td>Supplementing cancer treatment with other forms of care</td>
<td>2</td>
</tr>
<tr>
<td>Limited knowledge of cancer history elicits guilt</td>
<td>2</td>
</tr>
<tr>
<td>Feeling guilty for good health</td>
<td>2</td>
</tr>
<tr>
<td>Talking about cancer history made survivor uncomfortable at some point during childhood</td>
<td>2</td>
</tr>
<tr>
<td>Uncomfortable asking to learn more about his/her cancer history</td>
<td>2</td>
</tr>
<tr>
<td>Questions about fertility status</td>
<td>2</td>
</tr>
<tr>
<td>Does not fear long-term impacts</td>
<td>1</td>
</tr>
<tr>
<td>Family member still involved in managing healthcare</td>
<td>1</td>
</tr>
<tr>
<td>Desires more awareness about long-term impacts of cancer</td>
<td>1</td>
</tr>
<tr>
<td>Passing</td>
<td>1</td>
</tr>
<tr>
<td>Wants to move on</td>
<td>1</td>
</tr>
<tr>
<td>Language barrier prevents discussing care</td>
<td>1</td>
</tr>
</tbody>
</table>

**Table 2.** Themes presented in one to three interviews.
Interlude

After passing my driver’s license test I was directed to a counter at the DMV to complete forms. One of the forms required my hair color, eye color, weight, height and donor status. The first four questions were easy - just facts about myself. The last question pertaining to donor status, however, caused me to pause.

When I was younger, because I am comfortable with needles and blood draws, I wanted to donate blood. In researching the blood donation process I quickly discovered that donors must pass a health screening. The health screening criteria provided online listed my cancer as an ailment that often excludes individuals from donating blood. Given that my cancer survivor status may bar me from donating blood, I realized at the counter of the DMV that my organs could be denied as well. While I completely understood the rationale behind donor criteria, at the time I interpreted being denied as a donor as an insinuation that my body was not healthy and that my organs and blood were not “good” enough for people. With these thoughts running through my mind I opted out of being an organ donor.

Recently, I renewed my license and changed my donor status. If it comes to that, (and hopefully it doesn’t) I’ll let health professionals determine how my organs can benefit others.
Chapter Four – Analysis

In this section I provide context for the themes listed in my data section and discuss the implications of these themes. To provide context I present quotes from participants. I edited these quotes for clarity. Many quotes reference multiple identified themes. To address this I list related themes in brackets. The implications of themes unveil how participants’ limited knowledge of their health histories impacts their daily lives. By contextualizing the barriers survivors’ face, I support the need for individualized health education for childhood cancer survivors.

Part I: Context and implications of frequent themes

1. Aware of cancer history and potential impacts

Participants presented their cancer histories and impacts of their treatments through three themes – 1) facts about their cancer histories, 2) medical testing for potential long-term impacts, 3) awareness of potential long-term impacts. All of the participants stated the type of cancer they had while only some participants shared that they undergo long-term testing to monitor potential impacts of their treatments. Other participants recognized potential long-term impacts but reported that they do not receive testing for these potential impacts. Participant 2 knew the duration of her chemotherapy, where she was treated, and when she was diagnosed. She listed these facts about her cancer history readily. Participant 2 is not representative of the participant
pool. In fact, with the exception of participant 2, participants disclosed that they were less aware of their cancer histories. [Dealing with long-term impacts]

2. Unsure about cancer history / potential cancer impacts

Similar to research presented in Chapter 2, uncertainty was a significant theme in participants’ narratives. Participants reported two main sources of uncertainty: 1) uncertainty originating from a lack of education specific to cancer history and 2) uncertainty inherent to cancer and cancer treatments.

Most participants expressed uncertainty caused by a lack of education specific to their cancer histories. Participants shared this uncertainty when discussing dates and durations of treatments. Participants answered questions targeting their cancer timelines with general responses such as “since I was diagnosed in 2005 or whatever year that was…” Additionally, many participants were unaware of treatment specifics including type of chemotherapy, type of radiation, duration of radiation treatment, duration of chemotherapy treatment, and dosages of cancer related medications. Participant 3 noted “If doctors ask me ‘what kind of chemo did you have? How much radiation did you receive?’ I don’t know. I don’t have the answers to that.”

Many participants realize their uncertainties at appointments with healthcare providers unfamiliar with their medical histories. One participant shared, “Basically every time I see new doctors they ask me questions I can’t answer. They are usually pretty surprised that I do not know the answers to their questions.” Likewise, a participant said:

“I don’t remember what drug names I was using or whatever because I was little. In terms of how it has impacted my life since then, I’ve really not had that many side effects luckily. I’m always texting my mom like what was the name of the chemo I was on? Did I take this drug? I think my questions are mostly around that, treatment regimen.”

Realizing uncertainties has emotional impacts on participants. Participant 9 shared:
“She was asking me about my aspirations for research and why I want to go into medical school. I told her about my cancer. She asked me questions about it and I felt kind of flustered. I know I didn’t have radiation treatment but that was all I could offer her. I felt kind of guilty. This is irrational but I didn’t want her to think I was making this up for some reason. Obviously this is something significant I had and the fact that I don’t know much about it kind of invalidates it.”

Participant 9 highlights that lack of knowledge about personal cancer treatment elicits guilt. Guilt originating from minimal knowledge was reported by multiple participants. A participant illustrated the connection between minimal knowledge of cancer history and guilt:

“a lot of people don’t have that luxury. They are still very impacted by the cancer. They don’t have the option to live in the world, like ‘what cancer? I don’t know what you are talking about.’” [Limited knowledge of cancer history elicits guilt]

These findings suggest that childhood cancer survivors need support learning about their cancer histories. Healthcare providers should not assume that CCS understand their cancer histories and realize that questioning CCS about their cancer histories may elicit feelings of guilt and frustration.

The second source of uncertainty is inherent to cancer and cancer treatments. As presented, long-term side effects vary significantly among CCS depending on their type of cancer, type of treatments, genetic predispositions, and lifestyles. Some survivors are at higher risks for specific side effects and cancer relapse. Unfortunately healthcare professionals cannot predict these outcomes with certainty leaving CCS with uncertainty about their health futures. While everyone experiences uncertainty about their future health, CCS are at higher risks for poor health outcomes.

Participants share how this form of uncertainty impacts their lives. Participant 2 noted that she takes medication to combat a long-term impact. She stated:

“I know from the chemo and everything that my spleen doesn’t work. [I wonder if] there is any scenario in which the medicine I’m taking for it, stops working. Will they ever have to actually remove it?”
This participant also noted “my friends who had childhood cancer have been relapsing so I keeping thinking about cancer. Sometimes I wonder if I am going to the next friend to relapse.”

This type of uncertainty manifests as fear in some participants. Two female participants reported uncertainty when discussing fertility. A participant remarked:

“The biggest question that I’m still concerned about is fertility. Because that is something I obviously want in the future. I’ve talked to my gynecologist about it and she hasn’t been concerned. It hasn’t been brought up as something I should be concerned with. We didn’t freeze my eggs as fair as I know.” [Fear of long-term impacts, Unsure about cancer history / cancer impacts, Desires more awareness about long-term impacts of cancer]

Fertility status provides an example of how health education can alleviate uncertainty inherent to cancer treatment. Scientific research reveals that specific types of chemotherapy and cancer treatments impact fertility (“How Cancer Treatments Can Affect Fertility in Women”, 2019). Providing CCS with information about the types of treatments and drugs they received will allow them to more accurately assess how their fertility may have been impacted.

It is important to consider how CCS should learn about serious long-term side effects. Multiple participants reported that they search terms related to their cancer histories on the Internet. Discovering the likelihood of serious long-term impacts through the Internet without support from healthcare professionals, family, or friends could be emotionally stressful and isolating for CCS. While it is a right of CCS to have access to their health histories, they should not have to carry the emotional burden of researching potential long-term impacts. Rather, CCS should be assisted in a way that is comfortable for them and empowers them to learn about potential long-term impacts on their own terms.

3. Dealing with long-term impacts

Due to the uncertainty inherent to cancer treatments, many participants undergo testing to monitor possible physiological effects. Participant 1 noted “I had cisplatin which can kind of
damage your heart in some cases. So I’ve had ultrasounds for that.” Participant 1 also commented “My leg was really affected. When I work out and stuff I have to be careful. If I’m just playing pickup basketball with my friends I have to be careful.” Similarly, another participant reported:

“Because of the chemotherapy I do need vitamin D supplements because my bones are weaker. I’ve had a lot of dental issues because of it. I know I have an increase risk of others cancer like skin cancer. I’m always careful with my skin. It’s something that is always in the background.”

Another participant is missing vaccines because she did not receive vaccines when she was immuno-compromised. This has made her more susceptible to infections and diseases that vaccinated individuals are protected from. This participant shared that a few years ago she tested positive for Human papillomavirus virus (HPV). She shared:

“I’m missing a lot of vaccines because I didn’t get any when I was immuno-compromised. And it sucks because I tested positive. It turns out that I had some abnormal cervical cells. And it was bad. I got the phone call from the nurse and had a melt down. She said abnormal cells which is a huge red flag for someone that had cancer. I was sobbing and having a melt down. I called my dad and told him what the nurse said and I will never forget his tone of voice when he responded. After the scare my parents and I did some research. It is unclear if I’m more predisposed to HPV because of my cancer treatment. I had to go in and have a surgery where they take this hot knife and scrape it around your cervix. Since the cervix lining is always regenerating the hope is that killing all of the cells will allow healthy ones to replace them. Afterwards you have to get pap smears really regularly. That seemed to clear it out for me. That was a really scary experience. It might have been completely unrelated to my cancer. The feeling of touching that again though. My mom said that when I was in the hospital bed with the bracelet on she had flashbacks to when I was sick.”

In addition to physiological impacts, some participants experience long-term psychological impacts. A participant disclosed:

“…long term effects remind me about my cancer history. So like my hair being thin or my hearing being impacted, not being as tall as I should be. Very vain things in the grand scheme of things. But they remind that I’m not a normal typical person living in the world, that I’m damaged in some way.”

It is important to acknowledge the variability I found regarding this theme. Some participants experience physiological impacts, psychological impacts, or no impacts. The
severity of these impacts also varied significantly among the participants interviewed. Each participant that acknowledged negative long-term impacts also commented how fortunate they are to be alive and healthy. [Feeling fortunate for good health]

4. Comfortable with cancer

Most participants, including those experiencing long-term impacts, are comfortable with their cancer histories. One participant shared “it is not a big deal because I was so young.” Another participant stated, “For me it is a casual thing. It’s just a part of my life.” When participants share their cancer histories with people they bring it up casually to reflect that it is not a big deal for them. Often times, when participants share their cancer histories with others, they pay more attention to it than the participants anticipated. To avoid follow up questions, a participant expressed that he avoids the topic unless he is with close friends. Other participants, however, share it freely because they consider their survivor status a part of their identity. A participant described “I’m taking a class and the instructor asked ‘what makes you, you?’ I raised my hand and said cancer survivor.”

5. Learning about cancer from parents

Interestingly, there was little variability in this theme. Either participants learned about their cancer histories from their parents or felt that their parents were not an available resource to them. A participant referenced that “My mom will tell me stories sometimes and I’m like yeah I don’t remember any of that.” While this participant feels comfortable discussing his cancer history with his parents, not all participants shared this sentiment. Participant 3 commented, “I know that especially for my family or the people that were closely involved, they don’t like to
talk about that time. That was a horrible awful time and they don’t want to talk about it anymore. So I can’t really ask my parents about it.”

Parents play an important role in communicating cancer health histories to their child. Parents may require support in how to share cancer histories with their child. Parents and CCS must realize that in their attempts to protect each other from rehashing a difficult experience, CCS suffer because they do not have access to a resource aware of their cancer histories. As discussed in later themes, CCS want to learn the facts about their health histories and to avoid uncovering the emotional impacts their care had on their parents and their younger selves. Since watching their child undergo cancer treatment was likely very emotional and stressful for parents they may not be the best resource for CCS that only want to learn the facts about their treatments.

6. CCS does not want to know more about their cancer treatment

Five out of nine participants remarked that they did not want to know more about their cancer histories. This finding is contradictory, however, as some of the participants that noted this also reported that they would be interested in receiving a summary of their treatments and potential long-term effects. To address this contradiction participants remarked that they would like to understand the facts about their treatments and avoid uncovering the more emotional parts of their treatments. A participant remarked “that was a part of my life that wasn’t that great so I don’t care to ask. I guess that is why I’ve never looked into it.” [Survivor wants to know more about cancer treatment]

7. Personal connection with healthcare providers after treatment
Roughly half of participants have a personal connection with a healthcare provider that was on their care team. A participant noted “I’m actually good friends with my oncologist to the point where we’ve been golfing together so I have his number.” Another participant shared that “I’m still pretty good friends with my nurse practitioner. I often ask her a lot of questions [about my cancer history]”. Through these relationships CCS feel that they can learn about their cancer histories from someone knowledgeable of their care. Between personal connections with former healthcare professionals and their parents, 5 out of 9 participants feels that they have access to resources that allow them to learn about their cancer histories. [Comfortable asking to learn more about cancer]

While these connections are useful for some CCS, what happens when CCS no longer have these connections? Later in life, if a survivor’s health deteriorates and the healthcare provider knowledgeable of his cancer treatment is no longer available to provide insights, how will he receive treatment appropriate for his symptoms? How will CCS learn about their care if they relocate or their health providers relocate? Rather than relying on others for information about themselves, CCS need access to their cancer histories. With access to their cancer histories, personal relationships with healthcare providers can supplement survivors’ understanding of their cancer histories.

8. Involvement with health education

4 out of 9 participants received some type of health education. The main resources for health education include discussions with oncologists at checkups, attending camps for children with cancer or chronic illnesses, or visiting survivorship clinics. Participant 2 describes her experience at a camp:
“I used to go to this camp. When we graduated they gave us all of this information about the survivor clinic. If you go to the survivor clinic they will give you a zip file with all of your pertinent health history so you can take it to new doctors.”

Each participant that mentioned attending camps for children inflicted by serious ailments, mentioned on how positive the experience was for them.

Unlike camps that benefited CCS, half of participants that visited survivorship clinics had negative experiences. A participant stated “I’ve been to a survivorship meeting at a cancer clinic. It was overwhelming, the amount of things I should be doing. I should get a bone scan every year and make an appointment with this person and do this.” This participant no longer visits the survivorship clinic and, at the time of the interview, did not intend to seek recommended appointments. Similarly, a participant shared, “I was trying to schedule an appointment with the survivor clinic. I guess it is not a big program though because I couldn’t schedule the appointment. They never called me back. So that was kind of irritating.”

Overall, in comparison to survivor clinics, camps have been beneficial for CCS. Incorporating peer support is an important criteria that should be considered when designing health education programs for CCS.

Conversely, survivor clinics require improvements. First and foremost, survivorship clinics must be accessible to survivors. Second, as mentioned in Chapter 2, there are no guidelines supported by research for survivorship clinics. Research analyzing long-term impacts of cancer treatment in children should investigate treatments to mitigate such impacts. Lastly, survivorship clinics should be intentional in how information is presented to survivors. As revealed through narratives, navigating follow up care is stressful and frustrating for survivors. Providers that are insensitive to this may psychologically harm participants.
9. Medical interest

Many participants plan to work in medical fields or in fields related to medicine and healthcare. Of these participants, each of them noted that their interest for medicine stems from their experience with healthcare as a child. One participant noted “you don’t want to attribute every life choice and thing to cancer. But then again I’m sitting here at a health company so it has guided my choices.” Another participant admitted that it “has made me want to help people with cancer, hence my work right now, and I’ve always volunteered and worked in hospitals as much as I can.”

10. Cancer impacted/impacts family dynamic

While undergoing treatment, some participants recall how their illnesses impacted their family members. During treatment they acknowledged that their parents’ attention shifted to them. Participant 9 notes:

“When I had cancer my entire family’s attention shifted towards me and I think that I was uncomfortable with so much attention. I had extended family flying in. My two older brothers were taken care of by family friends. They obviously needed to be taken care of by family friends because my parents were sleeping at the hospital with me. I think this made me feel a little guilty.”

Some participants mentioned how their cancer histories continue to influence their families years later. For example, one participant’s family acknowledges diagnosis day and remission day. She describes:

“We recognized diagnosis, d day. There is always some sort of somber moment in the house. We always recognize and respect it. My parents would tell me the story of what happened on that day and how they found out. We always celebrate remission day - it’s actually the fourth of July. The day represents freedom in a lot of ways for my family.”
While acknowledging diagnosis day and remission day is an overall positive experience for this family, another participant shared how her family’s relationship with her cancer history makes her feel isolated.

“Due to the kind of family I have who are always so positive and upbeat I’ve always felt like I can’t express my true feelings about my cancer experience so I have always pretended that it’s had a great positive impact on my life.”

Two participants expressed that they avoid asking their parents questions about their cancer treatments to protect their parents. One of them said:

“It is really difficult for me to talk about with my parents. I think for them it was extremely difficult to see their third son go through that. It’s not something we know how to bring up in a conversation.”

This theme reveals that family members’ attitudes toward the survivors’ cancer influence how survivors interact with their cancer histories and their families. When a family is overly positive about its family member’s cancer experience the CCS may feel isolated in dealing with negative long-term impacts. Conversely, when family members avoid discussing the family member’s childhood cancer, the survivor feels shameful and isolated in learning about their cancer histories. To protect their family members from discomfort, CCS avoid discussing their cancer histories with family members.

To aid childhood cancer survivors in learning about their cancer histories, family members may require support in understanding how their actions influence their childhood cancer survivor’s relationship with her cancer history. Since managing their child’s cancer treatment was likely a stressful experience for parents it is understandable that discussing their child’s care may make them uncomfortable. While children are undergoing treatment, healthcare professionals could advise parents on record keeping strategies so that information can be easily passed to CCS. Once CCS reach a certain age or express interest in learning about their cancer
histories, these files could be shared. Additionally, it is likely that parents fear long-term impacts that their child may experience. Parents may benefit from reviewing their child’s cancer history and deciphering which long-term impacts are more likely than others. Regardless of how the parents feel, CCS deserve information about their cancer histories and should be able to learn about them in ways that are comfortable for them.

11. Survivor wants to know more about cancer treatment

A few participants acknowledged that they do not know much about their cancer histories and that they would like to learn more. A participant shared:

“I don’t know what chemotherapy drugs I had or the progression of my care. I don’t even know what type of lymphocytic leukemia I had. I know it was B cell but that is it. These are questions I want to ask my parents but don’t know how to ask. I don’t want them to relive any of the trauma they may have endured during that time.” [Cancer impacted / impacts family dynamic].

Another participant stressed that she only wants to learn the facts of her treatment. She stated, “I don’t think I would want to know – did you think I was going to die? I don’t see the purpose of that.” In terms of designing an intervention this finding supports that CCS want to learn the facts of their cancer histories rather than the emotional aspects of their treatments.

12. Surviving cancer is part of identity

Multiple participants recounted how cancer has shaped their identities. Participants indicated that they consider surviving cancer as a part of their identities like being female or a specific ethnicity. Some participants shared that cancer has positively impacted their identities. One participant commented that cancer “has taught me to see a lot more…I can compare how my sister’s look at life and how I look at life. I think I take life more seriously sometimes more than
them. I think about budgeting and being thankful. I’m always telling my dad or anyone that I’m always thankful.” Similarly, participant 8 said:

“maybe it is over-attributing but I feel like I attribute a lot of my personality to surviving cancer. My drive and my tenacity come from that experience. I tend to be very practical about things and can deal with difficult situations really well. I see it as a point of pride and a badge of success.”

While these two participants note surviving cancer as a catalyst for favorable behaviors, another participant remarked how cancer has made him more reserved the participant remarks:

“I’ve never really liked attention on me. It is hard to parse out how much was the cancer and how much it is just my personality. Compared to my brothers I’m the quietest. I don’t like garnering a lot of attention at the dinner table. In that sense, by attributing it to cancer I think it has formed my identity as someone who is a bit more reserved, quieter, and doesn’t take up much space.”

For CCS that consider surviving cancer an experience that has shaped their identities, limited access to health histories evokes frustration in CCS because it prevents them from learning about themselves.

13. How people respond to survivor’s cancer history

In discussing their cancer histories, CCS are cognizant of how this information may impact others. A participant shared:

“Usually I bring it up as a casual thing. It is not like I want to tell you about this big dark secret from my past. Usually when I bring it up the other person doesn’t really know what to say. They say something like ‘oh my gosh I’m so sorry.’ I’m like ‘no no, I’m not trying to have a pity party about this. I just want to let you know that is why I want to be on your left side, so I can hear you better. I don’t need to give you my whole life story about cancer right now.’ Usually, I would say people are surprised that I would share something that deep and dark about my life. But I never intend to share something deep and dark about my life, it’s just a part of my life.”

Another participant with a limp due to his cancer expressed:

“If someone says ‘why do you limp’, like someone in class, I don’t want to get into any deep conversation. Not that it’s deep for me but for other people it is. I usually say I had leg surgery. If they press on, I’ll say I had bone cancer when I was younger. Usually I don’t say that because it leads to a lot more questions. I think my friends are aware of it. Just the other day, a kid in my pledge class in my fraternity, who I’ve known for a long time and have done this St. Baldrick’s
event with asked me while we were walking ‘why are you limping?’ And I was like ‘are you serious, I had bone cancer.’ And he responded ‘oh yeah. I don’t think I knew that.’ So I guess maybe I haven’t told as many people as I assume I have. It is kind of hard to keep track. I would say that most of the time, unless they are a good friend, I’ll say I’m sore or I had surgery and I’ll just leave it that.”

Peoples’ reactions toward childhood cancer survivors’ histories oppose how some CCS feel about their cancers as revealed in the examples above. The examples portray that people often respond with concern and sympathy, which put CCS in the position of consoling others. Many of the CCS interviewed revealed that, although their cancer histories have impacted their lives and their identities, many of them do not see the experience in a negative light. Instead, they use it as source of strength and motivation. When people react to their cancer histories in a way that underscores the gravity of childhood cancer it makes CCS uncomfortable.

As supported by prior themes, there is variability among survivors. While most CCS interviewed are comfortable with their cancer histories and do not want people to pay much attention to them, one survivor feels that her cancer history plays a prominent role in her life through long-term impacts and would like people to understand how significantly she is affected. She noted:

“I told my colleagues at work very recently. I rarely tell people about my cancer history unless it comes up from their side. I would never bring it up myself because of the fear of looking like I’m attention seeking. This most recent time, as always, I felt very uncomfortable and nervous talking about it and felt very tense and awkward. My colleagues were very shocked and I tried to make it out that it wasn’t a big deal when that’s not really how I feel. It’s never a fun experience so I tend to try and avoid telling people.”

Like the narratives from the two CCS previously mentioned, this survivor downplays her cancer history so that people do not feel that she seeks pity. Although she downplays her cancer history it is significant to her. Rather than sharing her cancer experience in a way that is true to how she feels, she adjusts it for the people around her.
To improve communication among CCS and people that they disclose their cancer histories to, people should explicitly ask CCS how they feel about their cancer histories. Rather than responding with sympathy, a person could ask, “How do you feel about that (referring to cancer history)?” Depending on how CCS respond, individuals can modify their responses accordingly. This will allow CCS to share how they feel about their cancer histories and receive a response that is comfortable for them. Evaluating how people feel about their experiences before responding in a specific way allows people to have more honest conversations.

14. **Young age limiting awareness of cancer treatment is a benefit**

CCS reported that receiving treatment at young ages protected them from the harsh and frightening realities of cancer. A participant shared:

“People tell me how inspiring I was and how positive I was and how they wish they could be like that. I accept the compliment but I was nine and really stupid and I didn’t understand anything. I just kinda went off what the other adults were doing and saying. I didn’t even know I had cancer until like 6 months into my treatment when we went to the cancer department of the hospital and I was like ‘I don’t have cancer, I just have a brain tumor.’ I didn’t understand that I had cancer. I think it was a great age to have cancer. I wouldn’t trade it for another age by any means.”

This survivor’s realization that he had cancer reflects Lucy’s realization presented in Chapter 2 and shows that her narrative is relevant to survivors today. Another participant said:

“I remember how I felt about my illness. I was always positive of it all. I also was too young to understand the fatality of my illness. I just thought I had a bad cold. I knew I had a tumor in my brain but I didn’t fully understand that I had a fatal disease. I just thought it was going to be a long time before I was cured. I never had doubt that I wouldn’t be cured.”

This quote illustrates that with holding information from young cancer patients is beneficial to them. While it is important that children are protected from the harsh realities of cancer, this dissociation from reality cannot be long-term as survivors will eventually discover their cancer histories. How CCS uncover these realities needs to be addressed.
Part II: Context for and implications of themes presented in Table 2.

3 out of 9 participants shared that their feelings toward their cancer histories evolved as they aged [Attitude towards cancer history changes over time]. When participants were younger they did not engage in learning about their cancer histories and recall acting very uncomfortable when their parents, family members, or healthcare providers discussed it.

Participant 9 recounted:

“...growing up it was a source of shame because I didn’t understand what it was. I thought I had a reason to be embarrassed about it. So whenever my parents brought it up I would not want them to talk about it. I would get really flustered. It felt like a personal defect. Something I did wrong. It was a sign that something was wrong with me.”

This shame influenced how the participant presented his body as disclosed in the quote below:

“...I have a scar on my chest and I was on the swim team while growing up. I always wanted to cover it at all costs. You know stand in a way so that it is covered. I didn’t want people to ask questions about it.”

Similar to this participant, another participant said:

“From freshman or sophomore year of high school to around sophomore year of college I was bulimic. I think it relates to cancer. There are a lot of studies relating eating disorders to cancer. Because if you think about it you’ve been taught for a number of years that your body is bad, your body is trying to kill you, your body is malignant. So many people spent time controlling your body. It’s like your body is not your own.” [Cancer history impacted relationship with body, Dealing with long-term impacts]

A third of CCS interviewed attended summer camps for children in remission from cancer or living with chronic illnesses. Each participant that attended these camps reported that it was a positive experience for them because the camps provided them with a community of people they could relate to. In addition to finding community at these camps, participants were also provided with health education. One participant mentioned that she received information
about a survivor clinic while at camp and was encouraged to attend the clinic by camp staff members. [Attended a camp related to cancer, Involvement with health education]

A few participants revealed that they feel uncomfortable asking their parents about their cancer histories. Participants feel this way because they are aware that their cancer treatments were emotionally difficult for their parents to navigate and fear that asking them questions will make their parents relive those difficult moments. In addition to protecting their parents, one participant noted a language barrier. This participant has learned about his cancer predominantly through college classes in English but speaks with his parents exclusively in another language. The participant does not have the vocabulary to ask his parents questions about his cancer history in the language they speak at home. He shared that his parents “rarely bring up cancer, they usually reference it as your illness in their native language. I think they use that phrasing because cancer has many connotations. They don’t want to label it as that.” [Language barrier]

In discussing how participants would ideally like to learn about their cancer histories, a participant said:

“I would like it to be approached as something like adoption. I think talking about cancer more and not being afraid to bring up those experiences makes it less of a big deal. I think it is hard. I don’t even know when I would have wished that my parents talked to me about it. I do wish it was something that was talked about once I was in a better place. If they had sat me down and said ‘hey this is what you had, doesn’t mean you’re not normal.’ That would have started the conversation I think. My parents do not have scientific backgrounds. Had it been an ongoing conversation maybe my discomfort would not have been so severe. I don’t blame them by any means.”

Later in his interview, this participant expressed that in comparison to other childhood ailments, childhood cancer seems to be more difficult to talk about. Equating childhood cancer with adoption may make people more comfortable when sharing their experiences with childhood cancer.
Overall, many of the themes presented in this section relate to each other. The themes align with and add to previous research. Specifically, this research contributes the resources CCS use to learn about their cancer histories.
Chapter Five – Conclusion

Through my research I set out to answer the following questions:

How do childhood cancer survivors learn about their cancer narratives and interact with their cancer narratives as young adults?

In this section I revisit these questions, present my main findings, and suggest criteria for health education programs.

Main findings

My interviews support that CCS predominantly learned and continue to learn about their cancer histories from their parents. Other resources include healthcare professionals, science classes focusing on cancer, personal research, summer camps for CCS, and survivor clinics. Participants that feel uncomfortable discussing their cancer histories with their parents knew less about their histories when compared with participants who reported their parents as a resource. All of the participants that feel uncomfortable discussing their cancer histories with their parents, expressed that they do not blame their parents for avoiding the topic.

Through my interviews I uncovered that childhood cancer survivors interact with their cancer narratives predominantly through feelings of uncertainty. CCS are uncertain of their cancer histories and of potential long-term impacts. Beyond uncertainty, CCS interact with their cancer histories by including cancer survivorship as a part of their identities, engaging with health education, attending long-term follow up appointments, experiencing guilt, fearing long-term impacts, and feeling appreciative for good health. For a few participants, their cancer
histories influence how they interact with their bodies. Regardless of how participants interact with their cancer histories, most do not harbor negative emotions toward their cancer histories.

**Limitations**

As mentioned in Chapter 2, my recruitment process may have organized a biased participant population since most participants were recruited through organizations or platforms related to cancer. By opting to engage with platforms related to cancer, participants may think about or interact with their cancer histories more than CCS that are not involved with such organizations. The subjective nature of this research is an additional limitation. To minimize this, researchers conducting thematic analyzes should have multiple readers categorizing the interviews. Due to time constraints this was not a possible procedure for this thesis.

The small number of participants interviewed questions the generalizability of this research. Although the sample size is small, the findings expand upon prior research on childhood cancer survivors, suggesting that the research is generalizable. Future research could target interviewing larger sample sizes of childhood cancer survivors.

**Criteria for health education programs and future implications**

Healthcare providers influence how CCS interact with their cancer histories. Healthcare providers may incite guilt or frustration in CCS when they ask questions about their cancer histories. While providers must ask questions to provide the most informed care possible, they should be aware that CCS face barriers in accessing their health histories. When treating a survivor, healthcare providers may need to spend extra time reviewing the patient’s medical charts.
Given that parents are the primary resource for a majority of participants in learning about their health histories, parents could benefit from advice focusing on how to communicate health information with their survivor. Future research could explore how parents have navigated discussing their child’s cancer history with their child and the barriers they faced in doing so.

Most participants reported that they would benefit from a summary of their cancer treatments including the types and dosages of the medications they received. This summary would allow participants to be more autonomous in managing their healthcare as adults. Overall, health education for CCS should include the following criteria:

1. Specific to each CCS
   a. While learning about their cancer histories, CCS should have control over the type of information presented to them.
   b. Information presented to CCS must be specific to their cancer histories. CCS should only learn about potential long-term side effects that are specific to their cancer treatments.

2. Accessible to CCS
   a. Throughout their lives CCS may have questions about their cancer histories. Information about their histories should be accessible to survivors regardless of location and how much time has passed since treatment.

3. Comply with HIPAA and data privacy regulations

To collect data on long-term impacts of cancer treatment, CCS could consent for their medical histories to be organized and updated in a database. With sufficient data, patterns of
long-term impacts may be revealed. Utilizing big data to analyze long-term impacts may be more efficient than conducting scientific research on long-term impacts of cancer treatment.

Overall, childhood cancer survivors learn about their cancer histories through multiple resources. Some of these resources are more educational than others. There is variation in how CCS interact with their cancer narratives as young adults. Presently, CCS must seek information about their cancer histories. To mitigate stress when CCS learn about their cancer histories and potential long-term impacts, health education programs should target connecting survivors with their health histories. Making health education more accessible to and beneficial for CCS may increase their participation in long-term health monitoring and, in doing so, improve their long-term quality of health.
Appendix A

Below I include two interview transcripts. These transcripts have been edited for clarity and to protect the identities of participants. In these transcripts I include stories and moments described by participants.

Example transcript 1

By filtering through a 3 year old child’s memory I have constructed what I believe to be my cancer story. There are a lot of missing pieces but I’ve parsed them together as best as I can. I recall a lot of small details like the tricycle I had at the hospital and the Mario arcade game I played in the waiting room. I remember my friend, Steven, who had a brain tumor. Unfortunately, I think he passed away. Beyond people and toys in my surroundings, internally I recall feeling different. I had a lot of questions. Why was I hooked up to an IV pole in the hospital while my brothers lived at home and went to school. Why were my parents sleeping on the couch in my hospital room? Why did I have to wear a hospital gown? Why couldn’t I go home? Why was everyone treating me differently than my brothers? All of these questions illustrate that I was unaware that I had cancer. I heard people say “cancer” when referring to me but I didn’t know what that meant. It was not until pretty late in the game that I learned about cancer and that there are many types of cancers that are treated differently.

After completing cancer treatment my questions did not subside. Rather than subsiding the questions influenced my actions as well as my identity. For example, I have a scar on my chest. Over time it has faded but to me it has always been obvious. When I was younger I was on
a swim team. While at practice I always wanted to cover my scar. I would stand and fold my arms in a specific way to hide it from others. I was concerned that if the other kids saw my scar they would ask me how I got it. Although I knew the scar was from my cancer treatment I still did not understand what that meant. This made me feel shameful.

Fast forward to college and I still experience shame and guilt from my limited knowledge about my cancer treatment. At University I’ve studied cancer in depth. Through my classes I’ve learned about specific cases that are clinically interesting. For me it is ironic because I know more about strangers’ cancers than I know about my own. Similarly, I work in a lab at my University. While working in the lab, one of my supervisors asked me why I want to attend medical school. I told her that my history with cancer plays a central role in my motivation to attend medical school. In response to this she asked some standard questions about my cancer history. I couldn’t answer her questions. I didn’t have answers for her questions. I felt shame just like the kid at swim practice. This time I felt guilt as well. I should know more about my personal health history.

Cancer also influences my identity. Compared to my brothers I’m the quietest. I don’t like garnering a lot of attention at the dinner table. When I was sick I had all of the attention on me and now I prefer to not have attention directed at me. By attributing this part of my personality to my cancer it has made me more reserved and quieter. Sometimes I internally struggle when I attribute parts of my identity to my cancer history. This part of my identity could stem from my cancer experience or it could just be who I am.

There are other parts of my identity that I can more easily trace back to my cancer experience. I think that for better or worse cancer has contributed to my sense of being different. There are some health side effects that I have to deal with that my brothers have not had to deal
with. While cancer makes me feel different from my brothers, I’m also the only gay brother so this definitely strengthens my sentiment that I am unique. In middle school and high school being the gay brother and the one that had cancer made me feel like I was defective. I’ve learned since then that I’m not defective and accepted my differences but it was hard to accept myself for a period of my life.

In college I’ve been able to connect with my cancer treatment. During my freshman year I received a scholarship for people that had a hematology disorder. After receiving the scholarship I was invited to a conference where I was presented with the award. After the award presentation three of the nurses that had taken care of me approached me to introduce themselves. Speaking to them was bizarre for me because I have very limited memory of my treatment. Once they started talking I immediately knew who they were. It was an odd form of deja vu. These nurses had spent so much time with me and I had forgotten them. I realized that one of my nurses had a speech impediment. When I was younger I thought she had an accent.

When you reached out to interview me, I began to reflect on childhood cancer in general as well as my cancer history. I think speaking about childhood cancer is seen as somewhat of a taboo especially in comparison to how freely people speak about adult cancer. I know people today who had various chronic childhood ailments and they discuss their ailments much more freely than I do. I think society’s perceptions of children and cancer make it more difficult to talk about childhood cancer. Children are seen as innocent and a population that requires protection while cancer is seen as one of the worse diseases people can experience because there is still so much about the disease and treatment we do not know.
Example transcript 2

During high school, as I was in the midst of taking my SATs and applying to colleges my mom took me to a vintage fair. In one of the booths we ran into a roommate I had while receiving treatment at the hospital. This roommate and I were very similar - we had the same type of cancer, we were the same age, we received similar treatments, and shared the same ethnicity. The day my mom and I reconnected with her at the vintage fair the differences between us were striking. She had a negative reaction to the treatment we received and was cognitively impaired. She could not read or write and would not be able to live on her own. While she and her family navigated those long-term impacts I was stressing about my SAT score and college applications. After this encounter my parents shared that the prognosis given to me was more similar to her long-term outcomes. The doctors told my parents that they were unsure if I would ever be able to process at grade level or run a mile. My parents did not tell me any of this. I’ve gone on to attend a top university and win a National Championship.

This encounter set off an identity crisis and if it had not happened my relationship with cancer would be pretty different than it is now. Between high school and college I suffered from bulimia nervosa for a few years. Growing up I had been told and inferred that my body was bad because it had tried to kill me. So many people spent time controlling my body that it did not feel like my own. If I could control my body perhaps it would feel more like my own.

Meeting my former roommate made me realize that I’m not only really lucky to be alive but also to be smart and physically able. Sometimes I feel that I’m not worthy of the odds working out in my favor if I’m not professionally successful and personally perfect. I know a lot of my strengths and insecurities stem from this mindset. My drive and my fears of not being
good enough both come out of this feeling that I’ve been exceptionally fortunate in comparison to others.
Appendix B

Themes coded in interviews:

Aware of cancer history and potential impacts
Unsure about cancer history/potential cancer impacts
Dealing with long-term impacts
Comfortable with cancer
Learning about cancer from parents
CCS does not want to know more about cancer treatment
Feeling fortunate for good health
Fear of long-term impacts
Comfortable asking to learn more about cancer history
Personal connection with healthcare providers after treatment
Involvement with health education
Medical interest
Cancer impacted/impacts family dynamic
Survivor wants to know more about cancer treatment
Surviving cancer is part of identity
How people respond to survivor’s cancer history
Attitude towards cancer history changes over time
Motivation from cancer experience
Doctors question cancer history
Young age limiting awareness of cancer treatment is a benefit
Learning about cancer from information available on the Internet
Attended a camp related to cancer
Cancer history impacts relationship with body
Learning about cancer through classes
Supplementing cancer treatment with other forms of care
Limited knowledge of cancer history elicits guilt
Feeling guilty for good health
Talking about cancer history made survivor uncomfortable at some point during childhood
Uncomfortable asking to learn more about his/her cancer history
Questions about fertility status
Does not fear long-term impacts
Family member still involved in managing healthcare
Desires more awareness about long-term impacts of cancer treatment
Passing
Wants to move on
Language barrier prevents discussing care
Work Cited


