The Impact of Childhood Cancer on Young Adult Survivors: A Life Course Perspective

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THE IMPACT OF CHILDHOOD CANCER ON YOUNG ADULT SURVIVORS:

A LIFE COURSE PERSPECTIVE

by

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ABSTRACT

This thesis investigated the impact that cancer has on young adult survivors of childhood malignancies. Existing studies explore varying physical, psychosocial, and psychological, late effects experienced by survivors of childhood cancer. However, there exists a gap in survivorship literature; young adults, and young adult survivors of childhood cancer in particular, are understudied compared to adult and pediatric survivors. Moreover, most studies address objective, clinical, aspects of cancer survivorship. They rarely focus on survivors' subjective experiences. Yet, previous research suggests that positive cognitive appraisals of adverse life events such as cancer mitigate detrimental psychosocial and psychological symptomologies later in life.

This study adopted the life course perspective to investigate the subjective experiences of young adult survivors of childhood cancer. It examined how events such as cancer diagnoses and transitions back to school are interconnected throughout one's entire life history, rather than analyzing these specific occurrences as isolated events. Participants were invited to fill out two existing quality of life surveys and take part in an interview to explore areas of survivorship previously identified as being specific to young adult survivors. An analysis of interview transcripts and survey data revealed three major events that occur after being diagnosed with a pediatric malignancy. Furthermore, each participant not only recalled positive subjective experiences over the course of these checkpoints, but ultimately found positive meaning from their cancer experience. This thesis suggests that positive subjective experiences soon after a cancer diagnosis are critical in ensuring that patients have favorable conceptions of their journeys and their aftermath.

ACKNOWLEDGEMENTS

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CHAPTER 1. **INTRODUCTION**

“What happened to you? You look like you got chewed up!” the bartender asked Participant 8. She laughed and shook off the question, all-too-familiar with stares and questions she receives from strangers when they see the scars over her chest, abdomen, and legs. Participant 8 had stage 4 rhabdomyosarcoma cancer as a teenager, twice. She is one of the 429,000 survivors of childhood cancer in the United States, and though childhood cancer 5-year survival rates are well over 80 percent, research on young adult survivors and the long-term effects of their cancer is minimal (Siegel et al., 2020).

This study aims to discover the impact that childhood cancer has on young adult survivors’ perceived quality of life. It focuses on their subjective experiences, as research shows that the *interpretation* of how an experience impacts an individual has a larger influence on a person’s attitudes regarding the experience than the objective clinical effects (Zebrack & Landier, 2011; Juth et al., 2015). There is extensive research on childhood cancer survivors that assess psychological outcomes, psychosocial functioning, physical implications, and more (Zebrack et al., 2010; Wengenroth et al., 2015; Stuber et al., 2010; Quinn et al., 2013). However, many studies are not comprehensive; they fail to address quality of life issues of particular concern to the young adult survivor community. Instead of exploring issues such as fertility complications and sense of self, most studies measure pediatric cancer patients’ quality of life during or immediately following treatment (Zebrack et al., 2010; Wengenroth et al., 2015). A number of studies assess older adult survivors of pediatric cancer, but primarily focus on the presence and incidence of late health effects (ACS, 2020f).

Moreover, a majority of current quality of life scales lack the ability to elucidate how a diagnosis of cancer in childhood continues to affect survivors later in life. As a result, studies report varying impacts of childhood cancer on young adult quality of life (Zebrack et al., 2010; Stuber et al., 2010; Wengenroth et al., 2015; Quinn et al., 2013). Having cancer as a child is unique, as it has significant impacts on the individual's development and experiences later in life (American Cancer Society [ACS], 2020f). Cancer interferes with the patient's livelihood, affecting the individual's view of the world, the role they assume, and how they draw meaning from their experiences.

Existing research, medical advancements to lessen treatment intensity, and increased accessibility of support groups, make it both timely and necessary to focus attention on young adult survivors of childhood cancer. Investigating their subjective experiences suggests how to best support survivors as they navigate life after cancer. The researcher conducted interviews and administered quality of life surveys to young adult survivors of childhood cancer, identifying domains of life most affected by cancer. She also identified three events at the onset of a patient's journey that greatly affected the patient's ability to cope with their diagnosis and adjust to life after cancer. These three checkpoints ultimately impacted participants' feelings and attitudes towards each survivorship domain.

There is no blanket statement to describe the experiences and perceived quality of life for young adult survivors of childhood cancer because each journey is different, and each individual is different. As such, the way in which the cancer experience impacts a person's life differs. The research conducted in this study provides critical insight on how to deliver the most comprehensive and patient-centered continuum of care.

Purpose of the Study

There are several purposes to this study. First, the researcher aims to identify long-term impacts cancer has on the lives of young adult survivors of childhood cancer. Then, pertinent elements of survivorship will be analyzed in congruence with responses to the Impact of Cancer - Childhood Survivor scale (IOC-CS) to test whether the scale is valid and addresses all relevant aspects of survivorship. Third, the study intends to discover important stages along an individual's cancer journey that influences the attitudes regarding certain facets of long-term survivorship. The study finally sets out to propose specific strategies for community members, healthcare workers, parents, and young adult survivors, that when implemented, will reduce the potential for adverse psychosocial outcomes later in life.

Research Questions and Hypotheses

There are three main questions that guide this study. They are as follows:

I. What areas of young adult life does a childhood cancer diagnosis impact the most?
    A. Do survivors' attitudes and feelings about these domains vary by age when first diagnosed and age when undergoing treatment? Do support networks buffer any potentially adverse effects of childhood cancer on subsequent perceptions of these domains?

II. Do existing quality of life surveys accurately address topics that pertain to the lives of young adult survivors of childhood cancer? If not, what is missing in current quality of life surveys?

   A. Is the Impact of Cancer - Childhood Survivor scale reliable and accurate, measuring distinct and relevant topics relating to the lives of young adult survivors of childhood cancer? If not, what can be added to this scale to better capture the lives of young adult survivors of childhood cancer?

III. Is there a typical life course for young adult survivors of childhood cancer? If so, are there events along the way whose outcomes shape the meanings survivors draw from their cancer? Do the events impact the attitudes survivors have regarding key aspects of survivorship?

The researcher's general expectation is that the ways in which the cancer experience impacts a person's life differs from person to person. For example, some long-term effects of treatment impair an individual's physical abilities, and thus may drastically alter their lives. Therefore:

> *Hypothesis 1: Individuals who do not have many long-term effects from treatment will have a better subjective quality of life.*

Similarly, after treatment, some individuals have larger support networks of friends and family, thereby having stronger coping mechanisms to prevent the development of negative attitudes or overcome relapses. Therefore:

> *Hypothesis 2: Individuals who have stronger support networks will have more positive interpretations and feelings when reflecting on how cancer influenced their lives than individuals who do not have strong support networks.*

The age at which one is diagnosed and the subsequent journey may also play a larger role in one's psychosocial development. Therefore:

> *Hypothesis 3: Individuals diagnosed during teenage years will experience more identity strain than individuals diagnosed during early childhood. As such, as the age of diagnosis increases, so does the likelihood of adverse psychosocial development.*

Additionally, based on existing studies, the researcher expects that:

Hypothesis 4: The Impact of Cancer - Childhood Cancer Survivors scale will be more thorough than other scales in both identifying relevant aspects of survivorship and measuring young adult survivors' attitudes about such factors.

Organization of Thesis

The thesis is divided into six chapters. The first two chapters provide an overview of the project and the gap which it is aiming to fill in existing research. Chapter 1 introduces the purpose of the study, research questions, and organization of the thesis. Chapter 2 provides an overview of relevant literature to the subject area, and introduces thematic lenses through which the researcher analyzed the data.

Chapter 3 presents common methodological issues associated with research studies and the rationale behind the chosen methodology for this study. It also discusses the goals of this research, research design, the process of data collection and analysis, and role of the researcher.

Chapters 4 and 5 present the findings of the study. Chapter 4 consists of brief biographies for each individual to provide context for their interview responses. Chapter 5 highlights the findings of participant surveys and interviews.

Chapter 6 synthesizes the main findings of the study and discusses their relevance in the context of broader cancer research. The thesis concludes with implications of the study for various groups, limitations of the study, and recommendations for future research.

CHAPTER 2. **LITERATURE REVIEW**

Introduction

This chapter contains a review of literature relevant to the subject area of this study and a description of theoretical concepts used to create this study and analyze results. It begins with an overview of what cancer is, common treatment and side effects, and its prevalence in the United States. Then, it discusses existing long-term survivorship research on young adult survivors of childhood cancer. Next, the researcher discusses the effects of adverse life events, *trauma*, on children later in life. She explains common coping mechanisms for such events, and explores common tools for measuring the impacts of such stressors on perceived quality of life years after trauma. The chapter concludes with theoretical frameworks used to design this study and analyze its results.

What is Cancer?

Cells in the human body have certain functions; some relay information in the brain and nervous system, some carry oxygen and other gasses to tissues, some contract to make muscle movement, some ossify to make bone, and more (Weinberg, 2014; ACS, 2020h). Cells communicate with each other, relaying signals about what is happening inside the body and outside of the body. They make energy, clear waste, engulf pathogens, make proteins, replicate DNA, and divide (Weinberg, 2014). The numerous complex processes occurring inside cells necessitates a strict monitoring system; if a process is not working properly, it must be repaired, or else the cell must die. Normal cells grow and divide in an orderly fashion, and die when they become damaged or worn out (Weinberg, 2014). The ratio of new cell growth to old cell death is usually steady. But, when the rate of new cell growth becomes out of control, cancer develops (Weinberg, 2014; ACS, 2020h).

The cancer cells continue to grow and divide until they crowd out normal cells. This impairs normal cell function and creates problems where the cancer started (ACS, 2020h). Cancer can originate in any place in the body; brain, blood, digestive organs, skin, etc. Eventually, the cancer cells can spread to other parts of the body, creating problems for tissues in other parts of the body, too. Metastasis occurs when cancer cells spread from their original location. If left unmanaged, cancer cells eventually overtake vital organ function and lead to organ system failure, and ultimately, death (Weinberg, 2014).

What are Cancer Treatments?

The most common treatments for cancer are surgery, chemotherapy, and radiation. Other therapies include hormone therapy, targeted therapy, immunotherapy, or a stem cell or bone marrow transplant (ACS, 2020g). Patients may receive one of these treatments, or in combination with each other. Length of treatment also varies depending on cancer type, disease progression, and treatment schedule. From one surgery to multiple years of therapy, cancer treatment is highly specific to each patient.

Patients may undergo surgery to completely remove a tumor, or to take a small piece of the tumor out for diagnostic testing (ACS, 2020a; ACS, 2020h). In extreme cases, doctors must remove the tissue that the tumor affects, such as the breast during a mastectomy, or part of a limb.

Chemotherapy, or as it is colloquially called “chemo,” is a complex group of medicines that the patient takes to kill cancer cells and slow their progression (ACS, 2020c; ACS, 2020h).

Some chemotherapy drugs are intravenous, and others are pills. Chemotherapy is considered systemic, as the drugs travel throughout the body to kill not only the original site of tumorigenesis, but any other tumors that may have metastasized away from the primary tumor. Chemotherapy dosage depends on the type and stage of the cancer, patient’s weight, age, overall health and current medications, and any other serious health problems (ACS, 2020c). Chemotherapy drugs are also administered at specific intervals called cycles, such as a dose of drugs for a few days, then several days or weeks without treatment, to give the body time to rest and recover. A patient’s chemotherapy schedule and cycle is created to maximize the anti-cancer properties of the drugs, while minimizing their side effects (ACS, 2020c).

Since many chemotherapy drugs are systemic and not specific to cancer cells, there can be multiple side effects from treatment. For instance, many drugs attack rapidly dividing cells because cancer cells grow and divide fast. Other cells in the body that normally grow and divide fast include hair follicles, nails, blood-forming cells in the bone marrow, and cells in the mouth, digestive tract, and reproductive system (ACS, 2020b). Therefore, these cells are often damaged by chemo, contributing to common chemotherapy side effects such as hair loss. Other common side effects of chemo are intense nausea, fatigue, easy bruising, anemia, appetite changes, constipation or diarrhea, nerve and muscle problems such as numbness and tingling, mood changes, fertility problems, and susceptibility to infection (ACS, 2020b). Chemotherapy drugs also place stress on the heart, so regular heart check-ups are often part of a patient’s long-term treatment and follow-up regimen (ACS, 2020b).

Radiation therapy is one of the most common treatments for cancer (ACS, 2020d; ACS, 2020g). There are several different types of radiation therapy, including external beam radiation therapy, internal radiation therapy (brachytherapy), oral or systemic radiation therapy, and photodynamic therapy (Taghian, 2020; ACS, 2020d). Radiation therapy uses high-energy particles and waves, such as x-rays, gamma rays, electron beams, or photons, to target, damage, and kill cancer cells (Taghian, 2020). These high-energy waves and particles damage the DNA inside cells, preventing cancer from growing and dividing, ultimately leading to cell death (ACS, 2020d).

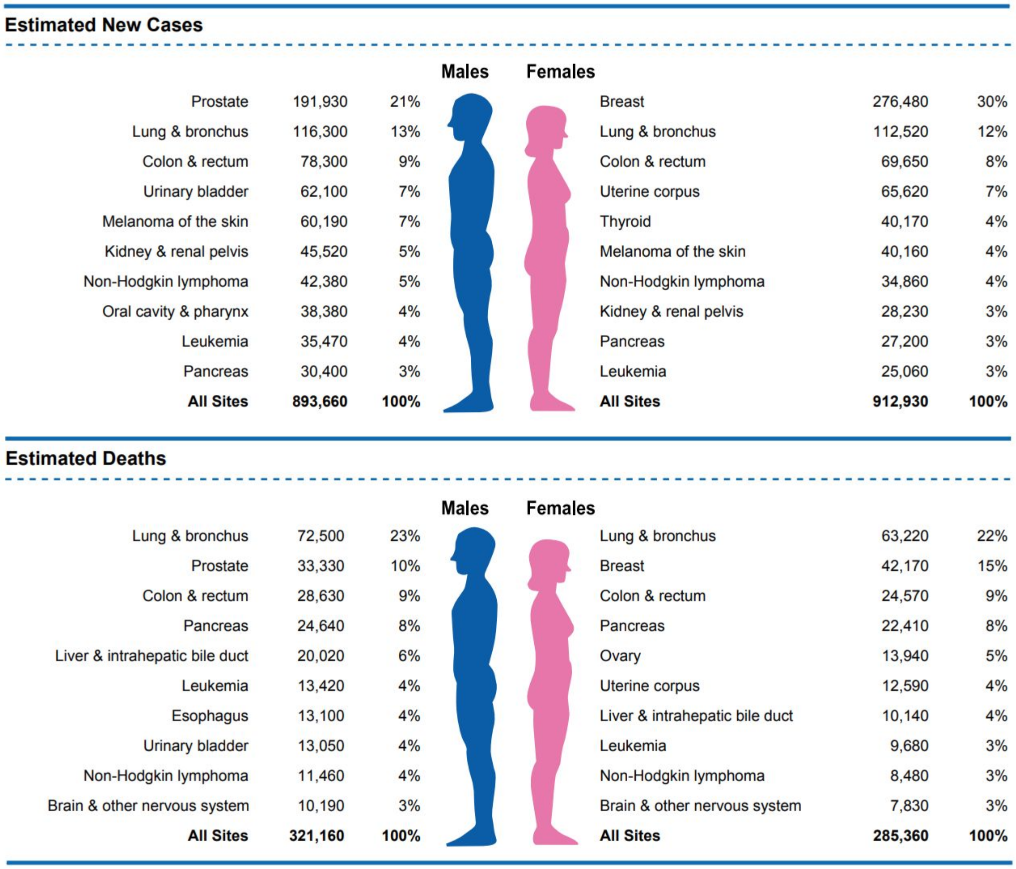
Radiation therapy is primarily localized to the site of the tumor, whether by external beam radiation targeting specific areas in the body, or by systemic therapies, where radioactive substances collect in the area of the tumor (ACS, 2020d). As such, there is little effect on the rest of the body. Short term side effects include fatigue and skin discoloration, such as having the appearance of a sunburn or a tan (Taghian, 2020; ACS, 2020e). These side effects are often temporary. Long-term effects from radiation on surrounding tissues often take months or years to develop (Taghian, 2020;ACS, 2020e). They vary depending on the site that received radiation.

Cancer Incidence

Each year, the American Cancer Society estimates the number of new cancer cases and deaths that will occur in the United States (Siegel et al., 2020). These projections are based on the most recent data compiled from various groups, including the North American Association of Central Cancer Registries, National Program of Cancer Registries, and the National Center for Health Statistics. As such, they lag two to four years behind the current year (Siegel et al., 2020). Because these models are projections based on retrospective data, they must be interpreted with caution. Novel drugs, revised treatment regimens, and screening processes may affect the numbers. Regardless, trends in the data still demonstrate important patterns and bring to light important considerations.

Based on these models, the American Cancer Society predicts that there will be 1,806,590 new cancer diagnoses in 2020; 893,660 new male cases and 912,930 new female cases (Siegel et al., 2020). This is approximately 4,950 new cases per day. They project that prostate, lung, and colorectal cancers will be the most commonly diagnosed for men, and that breast, lung, and colorectal cancers will be the most commonly diagnosed for women, see Figure 1 (Siegel et al., 2020).

Figure 1. Ten Leading Cancer Types for the Estimated New Cancer Cases and Deaths by Sex, United States, 2020 (Adapted from Seigel et al., 2020)



Estimated New Cases

Males			Females		
Prostate	191,930	21%	Breast	276,480	30%
Lung & bronchus	116,300	13%	Lung & bronchus	112,520	12%
Colon & rectum	78,300	9%	Colon & rectum	69,650	8%
Urinary bladder	62,100	7%	Uterine corpus	65,620	7%
Melanoma of the skin	60,190	7%	Thyroid	40,170	4%
Kidney & renal pelvis	45,520	5%	Melanoma of the skin	40,160	4%
Non-Hodgkin lymphoma	42,380	5%	Non-Hodgkin lymphoma	34,860	4%
Oral cavity & pharynx	38,380	4%	Kidney & renal pelvis	28,230	3%
Leukemia	35,470	4%	Pancreas	27,200	3%
Pancreas	30,400	3%	Leukemia	25,060	3%
All Sites	**893,660**	**100%**	**All Sites**	**912,930**	**100%**

Estimated Deaths

Males			Females		
Lung & bronchus	72,500	23%	Lung & bronchus	63,220	22%
Prostate	33,330	10%	Breast	42,170	15%
Colon & rectum	28,630	9%	Colon & rectum	24,570	9%
Pancreas	24,640	8%	Pancreas	22,410	8%
Liver & intrahepatic bile duct	20,020	6%	Ovary	13,940	5%
Leukemia	13,420	4%	Uterine corpus	12,590	4%
Esophagus	13,100	4%	Liver & intrahepatic bile duct	10,140	4%
Urinary bladder	13,050	4%	Leukemia	9,680	3%
Non-Hodgkin lymphoma	11,460	4%	Non-Hodgkin lymphoma	8,480	3%
Brain & other nervous system	10,190	3%	Brain & other nervous system	7,830	3%
All Sites	**321,160**	**100%**	**All Sites**	**285,360**	**100%**

The lifetime risk of being diagnosed with invasive cancer is 1 in 2 for men (40.1%) and 1 in 3 for women (38.7%) (Siegel et al., 2020). Experts do not know for sure why there is an increased risk for men, but they believe it may be due to environmental exposure, hormones, or perhaps sex differences in immune function (Siegel et al., 2020).

As an individual ages, the risk of developing a cancer increases due to the accumulation of environmental factors and agents external to the body that somehow enter the body and attack and corrupt its tissues (Weinberg, 2014). In addition to age, cancer risk also varies based on sex (Siegel et al., 2020). Cancer incidence during childhood (ages 0-14) is 10% higher in males than females (18.2 vs 16.4 per 100,000 people). During early adulthood (ages 20-49), cancer incidence is 77% higher in females than males (203.4 vs 114.9 per 100,000) (Siegel et al., 2020). The sharp increase in female cancer incidence is largely due to breast cancer. Among individuals ages 0-49, males have a relative risk of 1 in 29 for developing cancer, females have a risk of 1 in 17. Among individuals ages 50-59, both males and females have a risk of 1 in 16. Among individuals ages 60-69, males have a risk of 1 in 8, females 1 in 10, for developing a cancer. And for those above 70 years of age, the risk for developing cancer among males is 1 in 3, and for males 1 in 4 (Siegel et al., 2020).

Since 2004, there has been a slight increase (0.3%) in the incidence of breast cancer, which the American Cancer Society attributes in part to declining fertility and increased obesity (Siegel et al., 2020) Liver cancer diagnoses have risen relatively quickly from 2007 to 2016, about 2% to 3% per year (Siegel et al., 2020). The American Cancer society predicts that this rapid increase is due largely in part to lifestyle factors. They estimate that 71% of liver cancer cases are potentially preventable because many risk factors are modifiable, such as obesity, excess alcohol consumption, cigarette smoking, and hepatitis B and C virus infections (Siegel et al., 2020). For instance, chronic hepatitis C virus is the most common chronic blood-borne infection in the United States, and "confers the largest relative risk for liver cancer, accounting for 1 in 4 cases" (Siegel et al., 2020, p. 12).

On the other hand, lung cancer incidences have been declining rapidly, reflecting changes in tobacco product usage (Siegel et al., 2020). Likewise, despite an overall increase in the incidence of melanoma, the incidence of melanoma is declining in more recent birth cohorts (Siegel et al., 2020). This reflects increased practicing of cancer-preventing habits in younger generations (Siegel et al., 2020).

Cancer Demographics

In addition to cancer occurrence and outcomes differing by gender, cancer occurrence and outcomes also differ by race/ethnicity (Siegel et al., 2020). Such differences are largely due to socioeconomic inequality, which lead to differential risk factor exposure and barriers to cancer prevention (Siegel et al., 2020). The overall cancer incidence among non-Hispanic whites (NHW) is the highest (464.6 per 100,000 compared to 448.4 per 100,000 across all races combined). However, non-Hispanic black men (NHB) have the highest incidence of cancer compared to all men (540.0 per 100,000 vs 489.4 per 100,000), and NHW females have the highest incidence of cancer compared to all females (440.7 per 100,000 vs 421.1 per 100,000) (Siegel et al., 2020). The overall cancer incidence among Asian/Pacific Islanders is the lowest, at 288.4 per 100,000 (Siegel et al., 2020).

Cancer prevalence varies by state due to differences in medical detection practices and the prevalence of cancer-related lifestyle factors, such as smoking, obesity, and other behaviors and habits (Siegel et al., 2020). Siegel et al. (2020) points out that the cancers whose prevalences by state are most variable, such as lung, cervical, and melanoma of the skin, are also potentially most preventable (Siegel et al., 2020). For example, lung cancer incidence and mortality are highest in Kentucky, but smoking tobacco has been historically widespread there for decades (Siegel et al., 2020).

From a sociological standpoint, advancements in cancer prevention and treatment further exacerbate healthcare disparities. Siegel et al. (2020) predict that state gaps for cervical and other HPV-associated cancers may widen due to unequal uptake of the HPV vaccine (Siegel et al., 2020). The HPV vaccine has been shown to prevent cervical cancer, therefore unequal administration will exacerbate differences in cervical cancer incidence (Siegel et et al., 2020).

Survival Rates

For all cancers diagnosed between 2009 and 2015, the five-year survival rate was 67% overall (Siegel et al., 2020). The survival rate was highest for prostate cancer (98%), melanoma of the skin (92%) and female breast cancer (90%), while it was lowest for cancers of the pancreas (9%), liver (18%), and lung (19%) (Siegel et al., 2020).

There was also a race disparity; while survival rate was 67% overall, it varied from 68% among Non-Hispanic Whites (NHW), to 62% among Non-Hispanic Blacks (NHB) (Siegel et al., 2020). Stratified by cancer type, survival rate remained lower for NHB patients than NHW patients for every cancer except those of the kidney and pancreas (Siegel et al., 2020).

These disparities partly reflect later stages of disease at diagnosis, but also social determinants of health, such as access to healthcare, insurance coverage, etc. Siegel et al. (2020) found that after adjusting for sex, age, and stage at diagnosis, the relative risk of death after a cancer diagnosis is 33% higher in black patients than white patients. Furthermore, socioeconomic inequalities lead to differences in early detection and high quality treatments, influencing mortality rate (Siegel et al., 2020).

Survival rates have improved for all of the most common cancers except uterine, cervix, and uterine corpus, since the 1970's (Siegel et al., 2020). Uterine, cervix, and uterine corpus cancer survival rates have remained stagnant because there have not been successful treatment advances (Siegel et al., 2020).

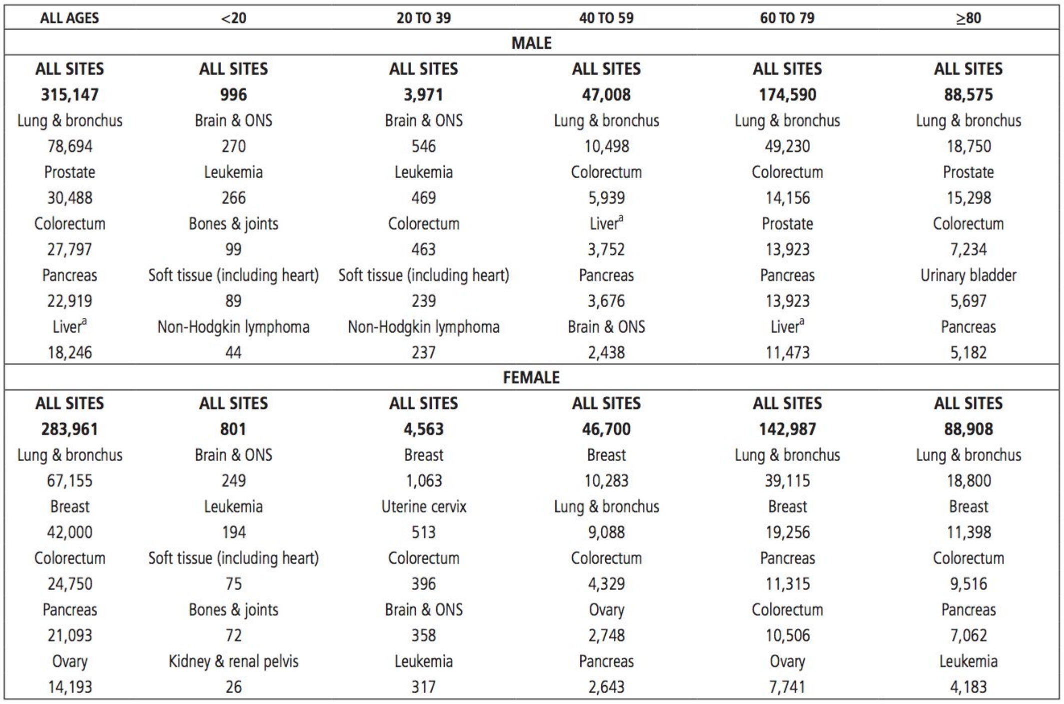
Conversely, there have been dramatic improvements in treatment protocols and medicinal advancements for hematopoietic and lymphoid malignancies since the 1970s (Siegel et al., 2020). As such, the five-year survival rate for chronic myelogenous leukemia increased from 22% in the mid-1970s to 70% for those diagnosed between 2009 and 2015 (Siegel et al., 2020). Novel drugs, such as tyrosine kinase inhibitors that target specific CML tumor proteins, allow most patients to experience a nearly normal life expectancy (Taghian, 2020; Siegel et al., 2020).

Cancer Deaths

Cancer is the second leading cause of death after heart disease for both men and women in the United States (Siegel et al., 2020). Among females, cancer is the first or second leading cause of death across the lifespan, see Table 1 (Siegel et al., 2020). Among males, however, intentional self-harm and accidents are the leading cause of death before age 40 (Siegel et al., 2020).

Out of all cancer deaths, brain and nervous system cancers and leukemias are the first and second leading causes of death among men less than 40 years and women less than 20 years (Siegel et al., 2020). Breast cancer leads cancer-related deaths among women ages 20-59 years old, with cervical cancer as the second leading cause of cancer-related deaths, see Table 1 (Siegel et al., 2020). Siegel et al. (2020) explain that the high mortality rate among cervical cancer patients, combined with the fact that cervical adenocarcinoma are often undetected by PAP smears, there is an increased need for HPV vaccinations (Siegel et al., 2020). However, roughly 50% of adolescent girls have not been fully vaccinated for HPV. Moreover, HPV vaccination status largely varies by state, requiring differing public health initiatives in different geographic areas (Siegel et al., 2020).

Table 1. Five Leading Causes of Cancer Deaths by Age and Sex, United States, 2017 (Adapted from Siegel et al., 2020)



ALL AGES	<20	20 TO 39	40 TO 59	60 TO 79	≥80
			MALE		
ALL SITES	**ALL SITES**	**ALL SITES**	**ALL SITES**	**ALL SITES**	**ALL SITES**
315,147	**996**	**3,971**	**47,008**	**174,590**	**88,575**
Lung & bronchus	Brain & ONS	Brain & ONS	Lung & bronchus	Lung & bronchus	Lung & bronchus
78,694	270	546	10,498	49,230	18,750
Prostate	Leukemia	Leukemia	Colorectum	Colorectum	Prostate
30,488	266	469	5,939	14,156	15,298
Colorectum	Bones & joints	Colorectum	Liver[a]	Prostate	Colorectum
27,797	99	463	3,752	13,923	7,234
Pancreas	Soft tissue (including heart)	Soft tissue (including heart)	Pancreas	Pancreas	Urinary bladder
22,919	89	239	3,676	13,923	5,697
Liver[a]	Non-Hodgkin lymphoma	Non-Hodgkin lymphoma	Brain & ONS	Liver[a]	Pancreas
18,246	44	237	2,438	11,473	5,182
			FEMALE		
ALL SITES	**ALL SITES**	**ALL SITES**	**ALL SITES**	**ALL SITES**	**ALL SITES**
283,961	**801**	**4,563**	**46,700**	**142,987**	**88,908**
Lung & bronchus	Brain & ONS	Breast	Breast	Lung & bronchus	Lung & bronchus
67,155	249	1,063	10,283	39,115	18,800
Breast	Leukemia	Uterine cervix	Lung & bronchus	Breast	Breast
42,000	194	513	9,088	19,256	11,398
Colorectum	Soft tissue (including heart)	Colorectum	Colorectum	Pancreas	Colorectum
24,750	75	396	4,329	11,315	9,516
Pancreas	Bones & joints	Brain & ONS	Ovary	Colorectum	Pancreas
21,093	72	358	2,748	10,506	7,062
Ovary	Kidney & renal pelvis	Leukemia	Pancreas	Ovary	Leukemia
14,193	26	317	2,643	7,741	4,183

Abbreviation: ONS, other nervous system.
Note: Ranking order excludes category titles that begin with the word "Other."
[a]Includes intrahepatic bile duct.

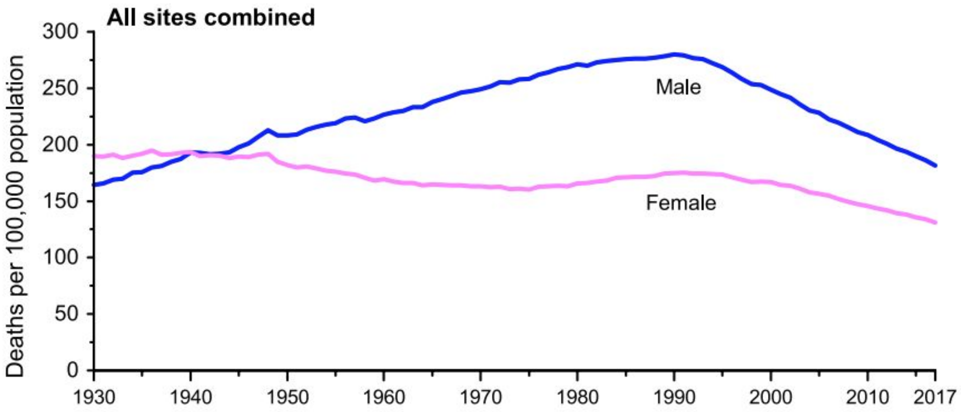
The American Cancer Society estimates that there will be 606,520 deaths due to cancer in 2020; 321,160 male deaths and 285,360 female deaths (Siegel et al., 2020). This is roughly 1,600 per day. They project that greatest number of deaths for males will be due to lung, prostate, and colorectal, cancers, and the greatest number of deaths for women will be breast, lung, and colorectal (Siegel et al., 2020)

Mortality Rates

Siegel et al. (2020) explain that mortality rates are better indicators of progress against cancer than incidence or survival rates. This is because mortality rates are less affected by biases such as changes in detection practices (Siegel et al., 2020).

Throughout most of the 1900s, cancer mortality rate rose due to increased lung cancer deaths among males. The tobacco industry primarily drove this trend (Siegel et al., 2020). There has been a continuous decline in the cancer mortality rate since its peak in 1992, consequential to declining tobacco use and improvements in treatment (Siegel et al., 2020). The peak mortality rate dropped 29% since 1992, from 215.1 deaths per 100,00 to 152.4 deaths per 100,000 as of 2017, see Figure 2 (Siegel et al., 2020).

Figure 2. Trends in Cancer Mortality Rates, United States, 1930 to 2017 (Adapted from Siegel et al. 2020).



Siegel et al. (2020) estimate that the rate corresponds to 2,902,200 fewer cancer deaths. In fact, since 2008, the mortality rate for cancer has been the only declining cause of death factor (by 1.5% per year), while all other causes have been stable or even increased (Siegel et al., 2020). From 2016 to 2017, the cancer death rate declined by 2.2%, the largest single-year drop since 1992 (Siegel et al., 2020). The most current data shows 2,820,034 recorded deaths in the United States 2017, 21% of which were due to cancer (Siegel et al., 2020).

Cancer in Children and Adolescents

Each year 15,780 children ages birth to nineteen are diagnosed with cancer (American Childhood Cancer Organization (ACCO), 2020a). This means that every three minutes, a parent hears that their child has cancer. Globally, more than 300,000 children are diagnosed with cancer each year, and 1 in 285 children will be diagnosed with cancer before their twentieth birthday (ACCO, 2020a).

Research is ongoing to describe complex interactions between environmental exposures, health behaviors, and genetic susceptibility underlie young adult cancer development (ACS, 2020f). Interestingly, increasing evidence shows that several types of young adult cancers are molecularly distinct from those that occur in other adults (ACS, 2020f). This suggests that there may be differences in how cancers develop in adolescents and young adults, and how they are most effectively treated (ACS, 2020f). For example, studies suggest that melanoma of the skin in adolescents and young adults is linked to genetic interactions in susceptible individuals with early-life UV exposure, whereas melanoma in older adults likely reflects cumulative lifetime UV exposure among those with less susceptibility (ACS, 2020f).

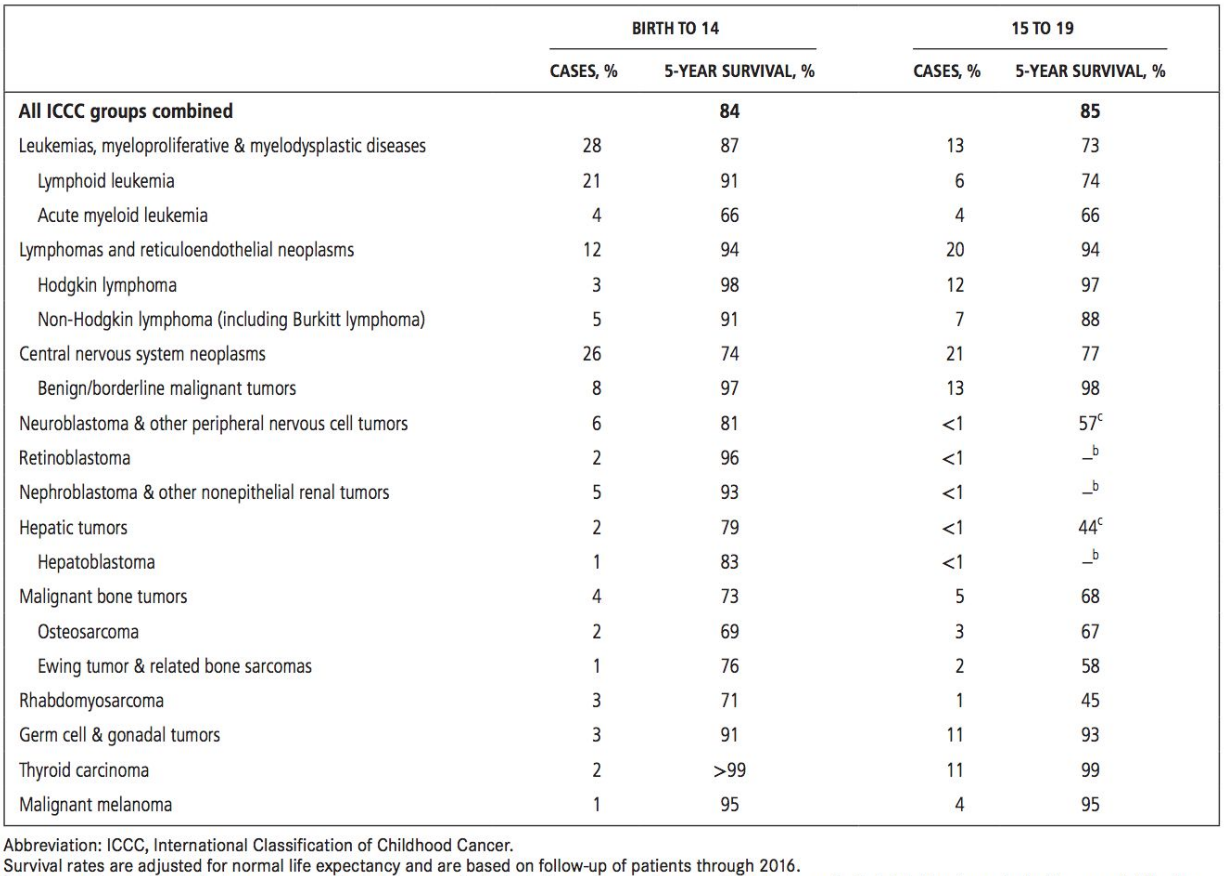
In 2020, the American Cancer Society estimates that 11,050 children (ages 0-14) and 5,800 adolescents (ages 15-19) will be diagnosed with cancer. They also estimate that 1,190 children and 540 adolescents will die from cancer (Siegel et al., 2020). Pediatric cancer is the most common cause of death among children ages birth to fourteen in the United States, surpassed only by accidents (Siegel et al., 2020).

Leukemias are the most common childhood (ages 0-14) cancers, comprising 28% of all cases, see Table 2 (Siegel et al., 2020). Brain and other nervous system (ONS) tumors are the second most common type of pediatric cancer, making up 26% of all cancer cases. Of these, more than 25% are benign or borderline malignant (Siegel et al., 2020).

The most prevalent cancers among adolescents are different, see Table 2. Brain and ONS tumors are the most common at 21%, followed by lymphomas at 20% (Siegel et al., 2020). Interestingly, there are twice as many cases of Hodgkin's lymphoma cancer than non-Hodgkin's lymphoma cancer among adolescents, whereas among children, the reverse is true (Siegel et al., 2020). Thyroid carcinoma and melanoma of skin have a similar peculiar relationship; their prevalence among adolescents is 11% and 4%, respectively, but only 2% and 1% among children (Siegel et al., 2020).

The overall cancer incidence rate in children and adolescents has been increasing each year since 1975 (Siegel et al., 2020). Reasons behind the 0.7% per year increase are unclear, however, pediatric mortality rates have declined continuously for decades (Siegel et al., 2020). In 1970, death rates for children and adolescents were 6.3 per 100,000 and 7.1 per 100,000, respectively. By 2017, mortality rates dropped to 2.0 per 100,000 in children (68% decrease), and 2.7 per 100,000 in adolescents (63% decrease) (Siegel et al., 2020).

Table 2. Case Distribution (2012 - 2016) and 5-Year Relative Survival (2009 - 2015) by Age and Cancer Type, Ages Birth to 19 Years, United States (Adapted from Siegel et al., 2020)



	BIRTH TO 14		15 TO 19	
	CASES, %	5-YEAR SURVIVAL, %	CASES, %	5-YEAR SURVIVAL, %
All ICCC groups combined		**84**		**85**
Leukemias, myeloproliferative & myelodysplastic diseases	28	87	13	73
Lymphoid leukemia	21	91	6	74
Acute myeloid leukemia	4	66	4	66
Lymphomas and reticuloendothelial neoplasms	12	94	20	94
Hodgkin lymphoma	3	98	12	97
Non-Hodgkin lymphoma (including Burkitt lymphoma)	5	91	7	88
Central nervous system neoplasms	26	74	21	77
Benign/borderline malignant tumors	8	97	13	98
Neuroblastoma & other peripheral nervous cell tumors	6	81	<1	57[c]
Retinoblastoma	2	96	<1	–[b]
Nephroblastoma & other nonepithelial renal tumors	5	93	<1	–[b]
Hepatic tumors	2	79	<1	44[c]
Hepatoblastoma	1	83	<1	–[b]
Malignant bone tumors	4	73	5	68
Osteosarcoma	2	69	3	67
Ewing tumor & related bone sarcomas	1	76	2	58
Rhabdomyosarcoma	3	71	1	45
Germ cell & gonadal tumors	3	91	11	93
Thyroid carcinoma	2	>99	11	99
Malignant melanoma	1	95	4	95

Abbreviation: ICCC, International Classification of Childhood Cancer.
Survival rates are adjusted for normal life expectancy and are based on follow-up of patients through 2016.

Decreasing leukemia death rates drove down the mortality rate for all pediatric cancer patients; remission rates for acute lymphocytic leukemia rose to between 90% and 100% over the past few decades (Siegel et al., 2020). Higher survival rates were due to optimization of established chemotherapies, not the development of new therapies (Siegel et al., 2020). Pediatric lymphomas also have reduced mortality rates from 1970 to 2017, decreasing 80% in children and 82% in adolescents (Siegel et al., 2020). Most promising, the 5 year survival rate for all cancers combined improved from 58% during the mid 1970's to 84% during 2009-2015 for children, and increased from 68% to 85% for adolescents (Siegel et al., 2020). Like adult cancers, pediatric cancer survival rates vary by cancer type and age at diagnosis (Siegel et al., 2020).

Long-term and Late Effects of Childhood Cancer

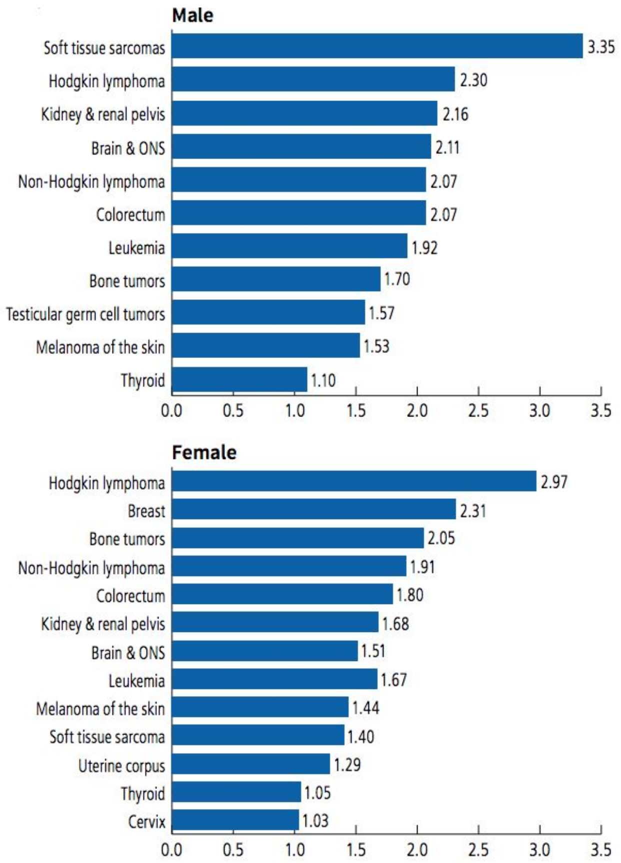
Childhood cancer 5-year survival rates are well over 80 percent (Siegel et al., 2020; ACCO, 2020c). As of January 1, 2019, there 678,420 adolescents and young adults (47,760 adolescents ages 20-39 years old, and 630,660 young adults ages 20-39 years old, living in the United States with a history of cancer, some of whom were diagnosed as children (ACS, 2020f). Of these survivors, 66% will develop at least one chronic health condition, and 25% will face a long-term effect classified as life-threatening or severe (ACCO 2020c). Financial concerns in young adult survivors, for example student loan debt and medical bills, exacerbate late-effects. High cost-of-care and limited financial resources lead to young adult survivors more frequently forgoing needed medical care compared to older survivors (ACS, 2020f). As such, there is extensive research on young adult survivors of childhood cancer, assessing psychological outcomes such as indicators of post-traumatic stress disorder (PTSD), social impacts like peer relationships, physical implications, and more (Haase & Phillips, 2004; Zeltzer et al., 2008; Zebrack et al., 2010; Zebrack, 2011; Wengenroth et al., 2015; Stuber et al., 2010; Quinn et al., 2013; Juth et al., 2015).

Physical Late Effects

Physical late effects from cancer treatment include heart damage, lung damage, infertility, cognitive impairment, growth deficits, and hearing loss (ACCO 2020c; ACS, 2020f). Other late effects include a compromised immune system, neurocognitive delays, and permanent visible physical disabilities and impairments (Quinn et al., 2013; Zebrack et al., 2011). Among women, problems with fertility and sexual dysfunction are also common (ACS, 2020f, source 8, 82). Moreover, young adult survivors have an increased risk of death at an early age (Zebrack et al., 2010).

Cancer survivors are also at an increased risk for developing secondary cancers (ACS, 2020f). Underlying genetic predispositions, adverse health behaviors, and type of cancer treatment received, contribute to increased risk for developing a subsequent cancer. The American Cancer Society estimated the risk of developing subsequent cancers by comparing the number of new cancers in the survivor population to the number expected in the general population, see Figure 3.

Figure 3. Observed-to-expected (O/E) Ratios for Subsequent Cancers by Primary Site, Ages 15-39, US, 1975-2016 (Adapted from ACS, 2020f)



They found that risk varies by original cancer and sex; the risk for secondary cancer development is highest for males who had a soft tissue sarcomas (3.35 O/E ratio), and for females who had Hodgkin's lymphoma (2.97 O/E ratio). Males who had Hodgkin's lymphoma have the second highest male O/E ratio at 2.3, and females who had breast cancer have the second highest female O/E ratio at 2.31 (ACS, 2020f).

Psychological and Psychosocial Late Effects

Research also shows that young adult survivors of childhood cancer are at risk for developing neuropsychosocial problems (Stuber et al., 2010; Zebrack 2011; Zebrack et al., 2010; Barnett et al., 2016). In fact, they report worse overall psychosocial functioning than other cancer survivors, as well as their cancer-free peers (Haase & Phillips, 2004; ACS, 2020f). Cancer may force a child or teen to unexpectedly confront drastic physical changes, the increased need to rely on parents, and the idea of death (Quinn et al., 2013). These stressors take a toll on an individual's sense of self, and can lead to low self-esteem, low self-efficacy, difficulties in socialization, and disruptions in the development of the self (Quinn et al., 2013).

For instance, Schulte et al. (2018) found that central nervous system (CNS) tumor survivors are at an increased risk of adverse social adjustment post treatment, with nearly seven times as many CNS tumor survivors (15.3%) reporting zero friends compared to solid tumor survivors (2.9%) and siblings (2.3%). These issues may reflect challenges patients face in coping with treatment and their transition to life after cancer (ACS, 2020f).

Cancer diagnosis and treatment can also cause substantial disruptions in school; children with cancer have more absences than those with other chronic conditions, and have more absences than healthy controls (ACS, 2020f; Vance & Eiser, 2002). While these absences decline with time, they remain a problem long past the initial diagnosis due to transition hardships (Vance & Eiser, 2002). Since cancer treatment can also lead to an altered physical appearance, some survivors develop feelings of shame and embarrassment; among women, body image problems are common (Bellizzi et al., 2012; ACS, 2020f). These feelings can also lead to isolation, aggravating challenges experienced by survivors when resuming daily life activities (ACS, 2020f).

According to teachers who filled out the Revised Class Play assessment (RCP), the most popular method of assessing social relationships, children with cancer differ from healthy children in key areas of social functioning, and have restricted leadership and social skills (Vance & Eiser, 2002). When children filled out the same assessment, children with cancer were more often nominated by their peers for sensitive-isolated roles. This suggests that the peers viewed the child with cancer as someone who is often left out, whose feelings get hurt easily, and as someone who is usually sad (Vance & Eiser, 2002). However, there were no differences in popularity ratings or number of friends (Vance & Eiser, 2002). Therefore, difficulties that children with cancer face during the transition back to school likely stem from a lack of understanding and misinterpretation, not ill intentions and bullying by peers.

Disrupting the Sense of Self

Having cancer at a young age also "intertwines itself with survivors' sense of self, impacting self-esteem, self-efficacy, self-awareness, and overall identity formation," (Quinn et al., 2013, p. 116). Damon and Hart (1982) created a model to demonstrate how a child actualizes their sense of self (as cited in Quinn et al., 2013, p. 116):

1. *Initial awareness of self based on competencies while engaging in a variety of activities*
2. *Awareness of physical characteristics such as gender*

3. *Shifting into defining themselves by internal qualities*
4. *Age-related integration of self into the world around them*

Cancer disrupts these sequential stages, interfering not only with their physical development, but also "psychologically with the survivor's view of the world and the role they assume, and how they interpret their own quality of life (Quinn et al., 2013, p.116).

The years transitioning from childhood to adulthood are critical, as young adults are in the midst of establishing their identity, "developing a positive body image and sexual identity, separating from parents, increasing involvement with peers and dating, and beginning to make decisions about careers or employment, higher education, and/or family" (Zebrack, 2011, p.2289). As such, impacts a cancer diagnosis has on life can be particularly distressing for adolescents and young adults. Rowland (1990) categorized a universal set of cancer-related disruptions occurring across all life stages, including "altered interpersonal relationships, issues of dependence/independence, achievement of life goals, concerns about body-sexual image, and existential issues (as cited in Zebrack, 2011, p.2290). For children and young adults in particular, cancer-related concerns that coincide with critical developments include premature confrontation with mortality, changes in physical appearance, disruptions in social life and school/employment because of treatment, loss of reproductive capacity, and health-related concerns about the future.

For example, the "experience and meaning of intimacy, a significant factor affecting well-being, will be different for young, single survivors, trying to figure out if, and when, to disclose the effects of cancer treatment to a potential partner, when compared with older adults in established relationships" (Zebrack, 2011, p.2290). Likewise, typical concerns such as establishing independence from parents and making decisions about careers and higher education are disrupted with a cancer diagnosis, as the patient must balance their sense of autonomy with the need for relying on others during treatment and beyond. Furthermore, successful achievement of life stages and personal development rely on healthy peer relationships, as identity development occurs through social interactions (Schulte et al., 2018). However, isolation due to medical reasons, such as lengthy stays for treatment in the hospital and neutropenia, is commonly reported among cancer patients. As Schulte et al. (2018) found, this can even lead to a lower number of friends. Absence may cause patients to miss out on experiences that their peers enjoy, such as dating and attending college, further isolating the patient from their peers and disrupting development.

However, many studies do not address the full scope of late effects for young adult survivors of childhood cancer. Many focus either on pediatric cancer patients during or immediately following treatment, or on adult, long-term, childhood cancer survivors, with little to no attention on young adult survivors of childhood cancer (Zebrack et al., 2010; Wengenroth et al., 2015). Furthermore, adolescents and young adults ages 15 to 39 years in the United States are often grouped with younger or older patients in studies and in treatment strategy (Haase & Phillipa, 2004; ACS, 2020f). This masks important differences in cancer distribution, tumor biology, and survivorship. Haase and Phillips (2004) even suggest that young adults are ‘invisible’ because of this lack of distinction, establishing a need for further young adult research. A high proportion of young adult survivors also report a variety of unmet needs within a year of their diagnosis. These include access to mental health professionals (56%), cancer rehabilitation (58%), and pain management services (63%) (ACS, 2020f). These factors necessitate further research on young adult survivors of childhood cancer, specifically on how late effects impact their development, experiences, and perceptions of their quality of life.

Childhood Trauma

It is estimated that over 4 million children in the United States are exposed to traumatic, stressful, and adverse, experiences each year (Perry et al., 1995). Lazarus & Folkman (1984) further refine the definition of life stressors, categorizing them into three major types; major changes, often affecting large numbers of persons; major changes affecting one or a few persons, and daily hassles. The four types of stressors are acute, time-limited stressors, such as going skydiving, stressor sequences, such as the sequence of events following an initiating stressful event, chronic intermittent stressors, such as conflict-filled visits with ex-spouses, and chronic stressors, such as permanent disabilities (Lazarus & Folkman, 1984). In terms of common childhood traumatic events, Perry et al. (1995) describe two generic categories; sustained and chronic, such as abuse; or acute, such as a natural disaster. Pertaining to this study, cancer can be qualified as a traumatic stressor in any of the three categories: a stressor sequence, over the period of diagnosis, treatment, and short term effects; a chronic intermittent stressor, during stressful follow-up testing and visits to the doctor; and a chronic stressor, concerning late effects that impact the survivor across his or her lifespan (Luther et al., 2000). Perry et al. (1995) explain that at least half of all children exposed to adverse events develop significant neuropsychiatric symptoms later in life, depending on the severity, frequency, nature, and pattern of the trauma.

Developmental experiences, whether positive or negative, determine the organizational and functional status of an adult brain. As such, the impact of traumatic experiences on development and function of the brain has multiple effects that persist into adulthood (Perry et al., 1995). While there have been billions of dollars poured into research on how trauma affects adults, few resources have been dedicated to research and treatment for childhood trauma (Perry et al., 1995). However, childhood trauma has profound impacts on emotional, behavioral, cognitive, social, physical functioning of children, therein necessitating research in this field (Perry et al., 1995; Luthar et al., 2000).

The human experience is filtered by senses; sight, sound, taste, and touch. These senses are reflected in the brain and their transduction pathway alters neuron architecture, neurochemistry, and brain structure (Perry et al., 1995). The pattern, intensity, and frequency of neuronal action in response to sensory information creates 'templates' that the brain uses the next time a similar sensation occurs. Thus, the brain organizes and internalizes information in a *use-dependent* fashion; the more often a similar pathway is used, the easier it is for the brain to access that pathway in the future (Perry et al., 1995). Traumatic events are often so intense that the brain becomes sensitized to the experience. Once sensitized, the same degree of neuronal activation can be elicited by a lower-intensity stimulus (Perry et al., 1995). In other terms, children who have experienced trauma exhibit sensitization of the neural response patterns associated with the traumatic experience. As a result, minor stressors have the power to elicit strong traumatic-response patterns such as hyperarousal or dissociation (Rutter, 1985; Perry et al., 1995).

This use-dependent trauma response creates a constant mental state that can be built into a mature, adult brain (such as in combat-related PTSD). In developing brains, however, undifferentiated neural systems *depend* on environmental cues to organize appropriately (Perry et al., 1995). Simply put, pediatric brains are more malleable to experiences than adult brains. Adverse mental states resulting from traumatic experiences can therefore influence how these neural systems grow and create personality traits (Perry et al., 1995; Luthar et al., 2000). While adverse experiences may alter the behavior of an adult, adverse experiences literally influence the organization and formation of a child's brain (Perry et al., 1995).

Long-Term Effects of Childhood Trauma

While adults often respond to stressful stimuli through the hyperarousal pathway, research shows that the younger a person is at the time of sustaining trauma, the more likely he or she is to use dissociative adaptations in response to trauma (Perry et al., 1995). Also, the more helpless and powerless the individual feels in the situation, the more likely they are to utilize dissociative responses (Perry et al., 1995). The dissociative response to stress is nicknamed the "freeze or surrender" response. This is in contrast to the hyperarousal response to stress that adults primarily use, nicknamed the "fight or flight" response. The hyperarousal pathway is a defensive response mechanism characterized by an increased heart rate, blood pressure, respiration rate, and muscle tone (Perry et al., 1995). This prepares the individual to fight the stressor, or escape. A concurrent theory to explain a child's response to childhood trauma is the stress-inoculation theory, where physiological and psychological 'toughtening' occurs through chronic exposure to stressors (Campbell-Sills et al., 2006). Evolutionarily speaking, children evolved to primarily employ the dissociative response because when faced with a threat, they are not biologically equipped to fight or flee (Perry et al., 1995).

A child employing the dissociative response will first cry or use other means to inform the caretaker that they are threatened, in hopes that the caretaker will remove the threat. But in traumatic events, a caretaker cannot remove the threat; it is either out of the caretaker's control, or the caretaker is the source of the threat (Perry et al., 1995). After prolonged and repeated exposure to the threat, the child learns that crying and other attention-seeking means will not stop the threat. Further along the dissociative spectrum, the child will freeze and feel anxiety in response to the stressor because the child senses that he or she is out of control of the situation. Eventually, the child will completely disengage from the stimulus and retreat into an 'internal world' (Perry et al., 1995). Child experiencing chronic trauma become sensitized and habituate to this response, often reporting "'going to a different place,' assuming the persona of heroes, or a sense of 'just floating'," in response to stressors, while observers report that the child seems "numb and robotic," (Perry et al., 1995, p. 281).

Perry et al. (1995) followed 50 young children for the six months that directly followed a traumatic event. They observed a clear relationship between the type of adaptive response utilized in the situation and the symptoms that children expressed six months later (Perry et al., 1995). As the time following a traumatic event increases, and the frequency that a child is in a state of hyperarousal or dissociation increases, the more likely they are to persistently exhibit a hyper-aroused or dissociative symptomatology (Perry et al., 1995). Acute adaptive states in response to stress, when they persist, can become maladaptive later in life, contributing to the development of neuropsychiatric disorders (Luther et al., 2000).

The long-term impact of a stressor is very dependent on the timing of the event. Whether beneficial or adverse, the outcome is dependent on the child's ability to understand the event (Haase & Phillips, 2004). This is why very young infants are relatively protected from the ill-effects of adverse events (Rutter, 1985). The persistence of the trauma not only influences the cognitive response pathway, but also impacts the extent to which the child attaches meaning to the threat and incorporates the meaning into his or her set of self-concepts (Rutter, 1985; Perry et al., 1995; Haase & Phillips, 2004). As a child's brain is more malleable than an adult's in respect to the impact stressors can have on character traits, a child's stress response is highly modified by the cognitive ideation he or she has about the event (Rutter, 1985; Perry et al., 1995).

Coping Mechanisms for Trauma and Stress

Even though experts have recognized that negative life experiences and stressful happenings may precipitate mental disorders for nearly 200 years, the systematic study of such effects is recent (Rutter, 1985). Interestingly, even with the most severe stressors and most glaring adversities, less than half of children exposed to such events develop neuropsychiatric symptoms later in life (Rutter, 1985). In fact, following personal losses and other disturbing life events, it is common for most people to *not* become depressed (Rutter, 1985). What factors allow an individual exposed to trauma to evade developing adverse traits later in life?

Rutter (1985) explains that one's ability to respond to stressors is not solely dependent on individual characteristics such as genetics. Rather, people shape their environment, and the environment in turn shapes them. This results in both genetic factors and environmental factors influencing a person, a combination of nature versus nurture (Lazarus & Folkman, 1984; Rutter, 1985; Campbell-Sills et al., 2006). Specifically, Rutter (1985) lists age, temperamental characteristics, social support, prior experiences, and patterns of parent-child interaction as main determinants of a person's stress-response. Lazarus & Folkman (1984) also describe cognitive appraisal, in which a person's reaction to a stressor relies on the individual's understanding, interpretations, and reactions to the event. The appraisal, or understanding, of a situation defines whether or not it is seen as positive or threatening to the individual (Rutter, 1985). This tradition that the subjective meaning of an experience shapes the emotional and behavioral response has been present in Western thought for hundreds of years, even appearing in Shakespeare's *Hamlet* (Lazarus & Folkman, 1984). Factors such as these are called coping mechanisms. While stress and adverse events are inevitable aspects of being human, "it is coping that makes the big difference in adaptational outcome," (Lazarus & Folkman, 1984, p. 6).

Coping is defined as "constantly changing cognitive and behavioral efforts to manage specific external/internal demands appraised as taxing or exceeding the resources of the person," (Lazarus & Folkman, 1984, p. 141). Rutter (1985) explained that the mere presence of a coping process was more predictive of eventual well-being than the specific method of coping. In fact, Rutter (1985) found that factors likely to foster a positive cognition about an experience, such as resilience, self-esteem, belief in self-efficacy, and the ability to adapt and adjust to change, were built on secure and stable relationships, and experiences of achievement in areas central to the individual's interests. Below are two mechanisms that have been demonstrated to have a positive impact on the cognitive appraisals of young adult survivors of childhood cancer.

Social Support Networks

Social support is the mechanism through which interpersonal relationships exhibit a protective effect against adverse outcomes of chronic stress (Kessler et al., 1985). During the mid-1970's, research flourished around the effects of social support on well-being. These studies show associations between psychiatric disorders and social disintegration, and demonstrated that social networks were important predictors of emotional adjustment following life crises (Kessler et al., 1985). Furthermore, studies on adult depression following adverse life events found the absence or presence of social support networks to be vital in terms of both vulnerability factors that increase the susceptibility of stressors, as well as buffers that serve as protection against the same stressors (Rutter, 1985; Coyne & Downey, 1991). Moreover, it was not the mere number and availability of these supports, but the quality of the relationships that impacted the role of the social network (Rutter, 1985; Coyne & Downey, 1991; Decker, 2007).

Coyne & Downey (1991) also found that negative features of social relationships, rather than positive features, associated more strongly with measures of perceived support and psychological symptoms. For example, the positive effect of having a marriage and a support partner as opposed to not being married is less strong than the negative impact that being married and not being able to talk to one's spouse has on an individual (Coyne & Downey, 1991).

Uncertainty and inability to make sense of adverse-related events negatively influences outcomes such as resilience and quality of life (Haase & Phillips, 2004). This uncertainty may be alleviated through social support and opportunities to express feelings with those who share similar experiences (Haase & Phillips, 2004; Decker 2007; Goffman, 1963).

Resilience

Coping and resilience are two related terms that experts use to describe the response to traumatic events. While coping is the set of cognitive and behavioral strategies used by an individual to manage the demands of adverse and stressful situations, resilience refers to the individual's adaptive outcomes that follow the adverse event (Haase & Phillips, 2004; Campbell-Sills et al., 2006). More specifically, resilience is "a dynamic process wherein individuals display positive adaptation despite experiences of significant adversity or trauma"

(Luthar et al., 2000, p. 543). Resilience studies are thus geared towards understanding how individuals not only recover, but how they "bounce back" and experience growth and positive adaptation following periods of intense stress (Campbell-Sills et al., 2006). In fact, studies show that resilience is common among children and adolescents who experience disadvantage, trauma and adversity (Luthar et al., 2003; Campbell-Sills et al., 2006; Zeltzer et al., 2008).

What factors influence resilience? Positive affect and strong social support networks have been linked to resilience (Luthar et al., 2000; Campbell-Sills et al., 2006). Campbell-Sills et al., 2006 measured the resilience and coping skills of 132 college undergraduates exposed to trauma and other psychological distress as children. They found that resilience demonstrated a strong negative relationship with neuroticism (a trait describing individuals prone to negative emotions, poor coping, and have difficulty controlling impulses) (Campbell-Sills et al., 2006). This finding is in congruence with other studies, which suggest that people who express neuroticism are more vulnerable to emotional distress (Campbell-Sills et al., 2006). Furthermore, research also demonstrates that individuals with low neuroticism are well adjusted, emotionally stable, and better able to cope with stress (Campbell-Sills et al., 2006).

Campbell-Sills et al. (2006) also found that resilience was positively related to extraversion. They believe that extroversion plays a beneficial role in resilience because of the positive affective style, capacity for interpersonal closeness, and high levels of social interaction demonstrated by many extroverts. Rutter (1985) similarly demonstrated that the ability of extraverted individuals to build strong social networks was a strong protective factor during stressful situations. Moreover, studies suggest that positive affect helps individuals rebound both subjectively and physiologically from stressful situations (Luthar et al., 2000; Campbell-Sills et al., 2006). Also, positive affect broadens the “thought-action” repertoires available to individuals under stress. These thought-action repertoires increase a person’s “coping toolkit” and enable the individual to have more flexible thinking and react with a wider variety of behaviors (Campbell-Sills et al., 2006)

Ultimately, Campbell-Sills et al. (2006) found that individuals who reported higher levels of emotional neglect during childhood exhibited higher levels of current psychiatric symptoms *only* if they scored low on resilience. This phenomenon is also shown in monkey studies on the effects of separation during infancy; maternal separation at a young age (trauma) created a predisposition to depression. However, depression and other adverse neuropsychological symptoms would only manifest if the monkeys were later exposed to stressful social situations (Rutter, 1985). Likewise, individuals who experienced trauma as young children, but who scored high on resilience measures, were able to manage stressful events as a young adult better than their low-resilience counterparts. In fact, individuals who experienced adverse childhood stressors but who scored high on resilience reported the lowest neuropsychiatric symptoms of all study participants (Campbell-Sills et al., 2006).

These findings strengthen the theory that resilient individuals grow and become stronger through adversity (Luthar et al., 2000; Zeltzer et al., 2008). They are not only able to recover from trauma, but their coping strategies and resilience enable them to experience growth beyond that which characterizes young adults who come from less traumatic environments (Luthar et al., 2000; Campbell-Sills et al., 2006).

Positive factors such as social networks and resilience have the ability to modify, ameliorate, or alter an individual’s response to a stressor with a potentially maladaptive outcome.

Thus, the long term effects of adverse effects can be viewed as an equation; the sum of the accumulated risk factors minus the sum of accumulated positive experiences equals the net effect of the stressor on the person. Those who do not have negative outcomes later in life either have fewer stressors and/or less severe adversities, or they were counterbalanced by sufficient compensatory protective coping strategies and positive affect (Rutter, 1985).

Coping with Cancer as a Traumatic Event

As stated, some childhood survivors exhibit symptoms of depression and post-traumatic stress disorder, as well as social and behavioral challenges (ACS, 2020f; Schulte et al., 2018; Stuber et al., 2010; Juth et al., 2015). However, studies suggest that risk factors contributing to distress are not objective characteristics of a patient's cancer or treatment (Haase & Phillips, 2004; Zebrack et al., 2008; Juth et al., 2015). Several demonstrate that the effects of objective cancer-related factors, such as time since diagnosis, type, or severity of treatment, on psychosocial outcomes is mixed or weak at best (Juth et al., 2015; Zebrack & Landier, 2011).

Rather, research shows that significant risk factors for developing adverse outcomes later in life include involvement in educational or employment opportunities, social life disruptions, and exposures to social prejudice, discrimination, or stigmatization occurring at critical developmental life stages (Zebrack & Landier, 2011). Decker (2007) reported in their review of adolescent survivorship literature that social support was effective in decreasing stress and enhancing coping. In fact, adolescents with higher levels of perceived support also reported fewer health complaints, lower depression, higher optimism and self esteem, and better adjustment to illness (Decker, 2007)

Studies also suggest that survivors who report subjective experiences and perceptions of how cancer has negatively affected their lives also experience more distress, and worse quality of life (Juth et al., 2015; Zebrack & Landier, 2011). Moreover, the inability to understand and make sense of illness-related events negatively influences outcomes such as hope, psychological distress, resilience, and quality of life (Haase & Phillips, 2004). Therefore, subjective assessments of cancer's impact on one's life may be larger contributors to psychosocial and quality of life outcomes than objective clinical factors (Haase & Phillips, 2004; Zebrack et al., 2008; Zebrack & Landier, 2011).

Zebrack & Landier (2011) administered three common quality of life scales to young adult survivors of childhood cancer. These scales were the Medical Outcomes Study Short Form (MOS SF-36), a widely-used and well-validated instrument that assesses quality of life aspects across 8 dimensions, the Brief Symptom Inventory (BSI-18), an 18-item self report scale to assess psychological distress, and the Impact of Cancer - Childhood Survivor scale, which tests 45 items across 8 subscales (Zebrack & Landier, 2011). They found that the influence of reporting objective late-effect health problems was not a significant predictor of survivors' mental health scores. Furthermore, objective measures of health conditions had no significant impact on psychological distress measures. In fact, results suggested that subjective perceptions of how cancer has affected a survivor is a critical predictor of distress and quality of life for young adult survivors of child cancer (Zebrack & Landier, 2011). Haase & Phillips (2004) also explain that the derived meaning of illness-related experiences are tightly linked with acceptance of an illness. These findings demonstrate that the *perception* of how much a health problem impacts one’s life in either positive or negative ways is more important than the actual existence of the health problem (Zebrack & Landier, 2011).

Also, survivors were less likely to report strongly positive or strongly negative impacts of cancer and distress symptoms as they moved further in time from their cancer experience (Zebrack & Landier, 2011). Therefore, the time during and immediately after treatment may be the period of greatest risk for developing distress, and also the period of greatest potential for creating positive experiences and attitudes towards cancer.

Measuring the Effect of Cancer on Young Adult Survivors

Researchers commonly assess the impact of childhood life events on adult life through survey scales (Zebrack & Landier, 2011; Vance & Eiser, 2002; Wengenroth et al., 2015, Quinn et al., 2013). Scales are used abundantly across various fields of research, measuring topics ranging from depression, to progression of neurodegenerative diseases, and general perceptions about life (Beck et al., 1961; Mlinac & Feng, 2016; Zebrack et al., 2010). Quality of life scales measure the attitudes a person has about specific life domains, and are often used in combination with other scales to determine the effect an event has on a person’s perceived quality of life (Zebrack & Landier, 2013; Quinn et al., 2013; Wengenroth et al., 2015).

In the cancer survivorship community, many studies use quality of life scales to measure the impact cancer has on a survivor’s long-term quality of life (Zebrack et al., 2010; Wengenroth et al., 2015). Studies also attempt to assess psychiatric symptoms such as depression, anxiety, and PTSD, and health-related quality of life (HRQoL) measures (Stuber et al., 2010; Zebrack & Landier, 2011; Wengenroth et al., 2015; Juth et al., 2015). However, few studies assess “issues of particular concern to [young adult survivors], such as the effects of cancer and treatment on sexuality and fertility, future health, school and work performance, ability to achieve life goals, relationships with family, friends, and intimate partners, and spirituality" (Zebrack et al., 2010, p. 208).

For instance, in concurrence with Zebrack & Landier (2011), Juth et al. (2015) found that patients' reports of subjective illness severity were not associated with objective illness severity. Rather, patients' subjective illness severity was the strongest predictor of their own post-traumatic stress symptoms, suggesting a greater need for in-treatment coping strategies. Juth et al. (2015)'s research addressed common psychiatric struggles associated with stressful life experiences, but did not tap aforementioned issues pertaining to the unique population of young adult cancer survivors.

And of studies and surveys designed to specifically research young adult survivors of childhood cancer, many standardized health-related quality of life instruments do not tap into pertinent information that relates to the every-day lives of young adult survivors of childhood cancer. The Childhood Cancer Survivor Study (CCSS) is the largest and most comprehensive cohort study of childhood cancer survivors, assessing over 14,000 survivors, and their siblings for a comparison group, in North America (Zebrack et al., 2010). However, this study does not report how participants feel cancer affected, or continues to affect, their life in specific and meaningful ways (Zebrack et al., 2010).

Quinn et al.'s team (2013) administered three common quality of life surveys to young adult survivors of childhood cancer; the Quality of Life in Adult Cancer Survivors (QLACS), MOS SF-36, and Quality of Life – Cancer Survivors Survey (QL-CSS). After follow-up interviews with 30 participants, expanding on missing content from each of the three surveys, they found over ten content areas that fell into three main categories of missing information; perceived sense of self, relationships, and parenthood (Quinn et al., 2013). Missing content from all three assessed standardized scales include maturing faster, feeling an obligation to be valuable, survivor guilt, changed outlook on death, making efforts to hide one's cancer, fear of burdening others, specific concerns related to scars, worried children will get cancer, and worried about fertility status (Quinn et al., 2013). While studies discussed in this introduction identify these concerns, they fail to relate how the cancer experience, the life after cancer experience, and late effects, affect a survivor's life in meaningful ways.

Moreover, a majority of current quality of life scales lack the ability to elucidate how a diagnosis of cancer in childhood continues to affect survivors later in life (Zebrack et al., 2010; Quinn et al., 2013). Some studies suggest that portions of childhood cancer survivors are troubled psychologically, with a worse health-related quality of life compared to peers, while others suggest that most survivors score within normal ranges on HRQoL and measures of psychological well-being (Zebrack et al., 2010; Quinn et al., 2013). Still other studies find that young adult survivors of childhood cancer score higher on HRQoL and psychological scales when compared to the normal population (Stuber et al., 2010; Wengenroth et al., 2015). This may be an outcome of inaccurate and incomprehensive scales, as Quinn et al. (2013) suggests, failing to tap into aspects of survivorship that specifically pertain to young adult survivors. Zebrack et al. (2010) aimed to develop and evaluate a new instrument to measure aspects of childhood cancer survivorship not captured by existing tools. They created a tool named the Impact of Cancer for Childhood Cancer Survivors Scale (IOC-CS), which specifically targets childhood cancer survivors ages 18-39 who were 21 or younger when diagnosed with cancer (Zebrack et al., 2010).

The scale was found to be reliable, highlighting eight specific subscales that measure distinct and relevant constructs for young adult survivors of childhood cancer (Zebrack et al., 2010). It tapped into additional content areas that Quinn et al. (2013) found missing in existing instruments, including life challenges, talking with parents, personal growth, thinking/memory problems, health literacy, socializing, and financial problems (Zebrack et al., 2010). The IOS-CS scale was more closely related to survivors' "psychological and subjective experience, and perhaps reflects survivors' perceptions (as opposed to objective realities) of the way cancer affected them and continues to affect them" (Zebrack et al., 2010, p. 214). This is relevant because perceptions of one's experiences have been shown to be better predictors of health-related quality of life outcomes than objective measures (Zebrack et al., 2008; Zebrack & Landier, 2011; Juth et al., 2015). This suggests a need for not only more qualitative assessments of young adult survivors of childhood cancer experiences, but also a need to focus specifically on their perceptions of experiences, and not objective realities.

Role of This Study

This study aims to bridge the gap between cancer as an acute experience; the diagnosis, treatment, and short-term effects, and cancer as a chronic experience; transitions later in life, late effects of childhood cancer, and attitudes and perceptions of the world. The researcher will evaluate the subjective interpretations of experiences that young adult survivors of pediatric cancer face throughout their lives in order to determine how and why certain factors significantly impact long-term survivorship. She hypothesizes that stronger social networks and coping mechanisms will lead to positive feelings about the cancer experience and a better subjective quality of life. Furthermore, she predicts that examining the paths of participants' survivorship will reveal a "Trail of Survivorship" that can be used to predict the trajectories and quality of life outcomes of young adult survivors of childhood cancer.

The researcher administered common quality of life surveys for cancer survivors and interviewed participants about domains of life that are important to them as survivors. Interviews explored participants' lives shortly after cancer, their transition to life after cancer, and opinions and attitudes towards specific topics of survivorship, such as identity, current and future health, and perspectives on the world.

The researcher then analyzed survey responses to test the construct validity of the IOC-CS scale. Interview responses about domains of survivorship that are meaningful to survivors substantiated the efficacy of the scale. She also identified three major events that occur early in the timeline of cancer survivorship. The outcomes of these key checkpoints greatly impact the individual's sense of self in relation to cancer, as well as their attitudes and feelings about their cancer experience. They culminate together to impact attitudes and feelings about late domains of childhood cancer survivorship. The study ultimately demonstrates the importance of identifying key turning points in the lives of childhood survivors and mitigating adverse occurrences at each checkpoint to ensure that young adult survivors of childhood cancer have positive subjective qualities of life.

Theoretical Framework

Theoretical frameworks guide social research by providing "a framework for studying phenomena at the nexus of social pathways, developmental trajectories, and social change," (Elder et al., 2003, p. 10). Theory offers models of conceptualization for describing and explaining the data, enabling the researcher to make predictions and explanations about behavior, (Glaser & Strauss, 1967; Elder et al., 2003). The basic beliefs held by each paradigm also influence the questions asked, and provide operationalized hypotheses, rationale for variable selection, and strategies for research design and data analysis (Glaser & Strauss, 1967; Elder et al., 2003). Several theoretical perspectives that guide this study are described below.

Life Course Theory

The life course theory, or life course perspective, holds that the life course consists of age-related patterns that are embedded in a social and historical context (Elder et al., 2003). Proponents of the life course theory argue that events in a person's life cannot simply be analyzed as individual and isolated occurrences. Rather, the entire lifetime of events and social-historical happenings accumulate and influence the trajectories, attitudes, and lives of individuals.

The life course approach was first proposed in the early 1900's by W. I. Thomas (Elder et al., 2003). He explained that cultural histories and individual life trajectories must be studied in a longitudinal fashion, as opposed to a series of unrelated events. C. Wright Mills similarly suggested in the 1950's that people should aim to "understand what is happening in themselves as minute points of the intersections of biography and history in society," (Mills, 1959, p. 7). He argued that the human experience is a social construct, and as such, the social pathways of human lives depend on historical time, social place, and individual experience (Mills, 1959). The Great Depression, two World Wars, the Cold War, the Civil Rights Movement, the Women's Movement, and other unforeseen events that had profound influences on life trajectories further contributed to a growing interest in how the paths of human lives relate to interpersonal, structural, and historical forces (Elder et al., 2003). Meanwhile, racial and ethnic diversity, socioeconomic differences, gender, rural versus urban living, and other domains were quickly rising as prominent factors in the social landscape (Elder et al., 2003). These topics demonstrated how lives are intersectional; life trajectories differ across social groups and the changing social-historical conditions.

This new wave of thought challenged conventional aging theories of the time. Early models of aging and development were cyclical; a child grows into an adult, marries, has children of their own, and so the story continues (Elder et al., 2003). However, this set of ordered stages is extremely limited to Western, white, heterosexual, families. Similar rigid social pathways existed for careers and education, inherently labeling anyone who did not follow the paths as deviant. The emergence of the life course theory, however, introduced the concept of the social clock (Elder et al., 2003). The social clock offers a less rigid perspective on the life course. It connects individual lives with socio-historical timelines by describing *normative timetables* for appropriate times of life transitions, rather than objective checkpoints (Elder et al., 2003).

The life course theory views that individuals follow trajectories. Trajectories are sequences of roles and experiences, composed of transitions (Elder et al., 2003). Transitions are a change in state or role, such as becoming a parent, beginning a new occupation, or retiring (Elder et al., 2003). As such, transitions also often involve changes in status and identity, which create opportunities for behavioral change (Elder et al., 2003). Research shows that multiple transitions early in life, which cancer may cause, can have lifelong trajectory implications by shaping later events, experiences, and transitions (Elder et al., 2003; Decker, 2007; ACS, 2020f). Trajectories are also modulated by turning points. Turning points are substantial changes in one's life (Elder et al., 2003). They may be objective, such as moving to a new city and getting married, or subjective, such as regaining a positive self-image and achieving satisfaction in interpersonal relationships.

Transitions and turning points mark various stages of life, such as childhood and adolescence. These stages are socially constructed, as they are governed by age expectations and informal sanctions, rather than objective landmarks (Elder et al., 2003). Elder et al. (2003) explains that the "normative concept of social time specifies an appropriate age for transitions such as entry into school, marriage, and retirement, leading to relatively 'early' and 'late' transitions," (p. 10). A cancer diagnosis disrupts life course transitions, often forcing survivors to confront issues such as mortality at an earlier age than their peers (ACS, 2020f)

Viewing life stages as social norm stages gives flexibility in analyzing how social norms give meaning to, and direct, individual trajectories (Elder et al., 2003). Instead of seeing life trajectories as rigid, the new perspective allowed researchers to investigate how social institutions and historical forces shape the normative paths that individuals follow. Through this lens, researchers understand that individuals are not completely autonomous; they are constrained by opportunities structured by previous life choices, social institutions, and culture (Elder et al., 2003). For example, although birth cohorts link individuals of similar ages, members of birth cohorts are not uniformly exposed to life changes. Therefore, cohort groups (such as young adult cancer survivors) better describe collections of individuals with similar exposures (Elder et al., 2003)

Elder et al. (2003) describe five key principles of the life course perspective. These principles guide research away from age-specific studies and towards the recognition of lifelong development shaped by individual choice and decision making within personal constraints (Elder et al., 2003).

1. The Principle of Life-Span Development: human development and aging are lifelong processes (Elder et al., 2003, p. 11). Development does not end once a person is 18 and no longer a minor. Rather, adults can and do experience meaningful fundamental changes throughout life. (Elder et al., 2003). Many studies on young adult survivors of childhood cancer fail to consider how cancer continues to affect survivors years after their experience (Zebrack et al., 2010; Quinn et al., 2013). In this study, participants described how they have continued to grow and develop as a result of their cancer history long after they turned 18.
2. The Principle of Agency: individuals construct their own life course through choices and actions they take within the opportunities and constraints of history and social circumstance (Elder et al., 2003, p. 11). People are not passive in the lifecourse; they make choices based on the unique subsets of constraints that impact their lives. Research shows that cancer survivors who have favorable cancer-related experiences have a more positive attitude and interpretation of their cancer (Zebrack et al., 2008; Zebrack & Landier, 2011; Juth et al., 2015). Survivors are faced with many choices during their cancer journey, from partaking in support groups to interacting with peers. They therefore have many opportunities to make choices and act in a way that impacts their future perceptions of their journey. Furthermore, individuals can shape how an adverse

experience impacts them later in life through conscious cognitive restructuring (Lazarus & Folkman, 1984; Hase & Phillips, 2004; Campbell-Sills et al., 2006). In this study, participants voiced that they make conscious choices to be optimistic, find positive meaning in adverse experiences, and make the most out of what they have been given.

3. The Principle of Time and Place: the life course of individuals is embedded and shaped by the historical times and places they experience over their lifetime (Edler et al., 2003, p. 12). The same event, such as a war or cancer diagnosis, may change in substance and meanings across different regions and nations (Elder et al., 2003). In this study, participants were from similar historical times and different regions. Their overall experiences did not depend as much on time and place, but rather, social interactions within certain time periods and at certain places.
4. The Principle of Timing: developmental antecedents and consequences of life transitions, events, and behavioral patterns, vary according to the timing in a person's life (Elder et al., 2003, p. 12). The same event may affect individuals differently depending on when they occur in the life course. Studies show that the age at which a patient is diagnosed determines how well the patient is able to understand their cancer (Rutter, 1985; Haase & Phillips, 2004). This ultimately impacts the eventual outcome the event has on a survivor. Furthermore, the meaning of the event can change at different developmental stages, depending on the subjective interpretation of the event, and if cognitive restructuring occurred (Zebrack & Landier, 2011; Juth et al., 2013). Early transitions may also have detrimental effects on mental health, as the 'pileup' of transitions does not allow for adequate adjustment (Elder et al., 2003). Decker (2007) similarly found that

cancer diagnoses impact typical adolescent development tracts, forcing children to both mature faster as well as have an increased dependence on others during treatment.

5. The Principle of Linked Lives: linked lives are interdependently and socio-historical influences are expressed through this network of shared relationships (Elder et al., 2003, p. 13). Transitions and events in one person’s life often entail transitions for other people, too. For example, large social changes such as economic hardship affect interpersonal relationships, such as parent-child relationships being strained due to increased anxiety of parents (Elder et al., 2003). Vance and Eiser (2002) explored how the behaviors and attitudes of other school children change in response to a child's cancer diagnosis, and participants in this study described how health outcomes of other patients shaped their personal attitudes and actions. Also, the creation of new social relationships may influence lives by fostering turning points that lead to changes in behavior or attitudes (Elder et al., 2003). Participants in this study explained how they formed new social relationships as a result of cancer-related experiences, and described how these relationships continue to affect them today.

The life course perspective enhances the understanding that human lives cannot be adequately studied when removed from other social relationships, and that specific life events cannot be fully understood without taking into account the person’s entire life course, historical circumstances, and social constraints. Social changes, and in the context of this study, a cancer diagnosis, has the capacity to alter life trajectories, thereby changing the developmental course of a person (Elder et al., 2013).

Presentation of the Self

Erving Goffman (1959) presented the concept of dramaturgy in his book *The Presentation of the Self in Everyday Life.* The theory describes the practice of impression management in the social world. He describes social establishments as “stages,” where individuals who participate in interaction are called “actors” (Goffman, 1959).

Within the boundaries of social establishments, particular activities regularly take place. There is a certain fundamental dialectic, and actors cooperate within these establishments to present a given definition of the situation (Goffman, 1959). For example, within hospitals, actors cooperate to create a normative healthcare setting, with individuals performing roles such as doctors, nurses, patients, and family members. There are also assumptions in social settings, such as in schools, religious settings, and public coffee shops, that guide actors’ behaviors to maintain certain “rules of politeness and decorum,” (Goffman, 1959, p. 152).

When an individual enters a social establishment, he or she projects a particular presentation of themself to fit what is required in the situation (Goffman, 1959). Individuals act certain ways in the presence of others in order to avoid disrupting informal or formal social rules. Furthermore, acting in particular ways also allows an individual to control how others perceive and interact with them. Goffman (1959) calls this theatrically presented persona the “front stage,” where the actors perform routines of normative interaction.

The front self may be displayed through insignia of rank, clothing, age, looks, posture, speech patterns, facial expressions, bodily gestures, and more (Goffman, 1959). Some of these vehicles, such as speech patterns and facial expressions, may vary from one performance to the next. For example, the same individual will present different “roles” of himself when he is at work as an attending physician versus when he is at his daughter's parent-teacher conference. In both social settings there are sets of expected social cues, and the same individual changes his behavior to meet those standards in each setting. At the same time the actor presents one role in a given situation, he keeps other details and roles on the "back stage," away from the other actors.

In addition to the front self striving to perform acceptable interactions, the individual presenting also tends to "incorporate and exemplify the officially accredited values of the society," (Goffman, 1959, p. 23). That is, the actor attempts not only adequately perform the role, but he or she will aim to perform the perfect and ideal representation of that role. In today's society, this action is most commonly demonstrated by individuals performing gender. Males attempting to portray the ideal 'masculine' image often refer to the hegemonic masculinity image; white, heterosexual, physically strong (Connell & Messerschmidt, 2005). Therefore, events such as a cancer diagnosis that impact a male's ability to perform his conceived 'ideal role' may lead to distress and embarrassment (ACS, 2020f, Goffman, 1963). Goffman (1959) further explains that members of a group do not typically strive to perform the ideal role in all social situations.

> *They tend to invest their egos primarily in certain routines, giving less stress to the other ones which they perform. Thus a professional man may be willing to take a very modest role in the street, in a shop, or in his home, but in the social sphere which encompasses his display of professional competency, he will be much concerned to make an effective showing.*
>
> (Goffman, 1953, p. 22)

There are several consequences when an event occurs that is incompatible with the structured situation. Goffman (1959) provides a healthcare example; if all of the healthcare professionals in an operating turn their backs to the patient during a surgery and the patient falls off the table, not only is the actual flow of events disrupted, but the reputation of the doctor and of the community he represents (the hospital) may be weakened. In relation to this study, when a person informs another person that they are a cancer survivor, the conversation flow and relationship may be disrupted. The participants may sense awkwardness and confusion at how to continue in the moment, which may ultimately shape the way that person views and interacts with the survivor in the future. Participants in this study recounted experiences of such nature, where other individuals treated them differently once knowing the cancer history of the participant.

Disruptions in social encounters also create long-lasting individual consequences which may shape the actor's sense of identity (Goffman, 1959). The actor may identify with a particular role or group, such as that of an athlete. When a disruption occurs, such as a cancer diagnosis, that individual's connection to the role may be impaired.

Stigma

Goffman (1963) also explained stigma and the impact it has on a person's identity in his book *Stigma: Notes on the Management of Spoiled Identity.* He introduces the topic by explaining how normative expectations are created. Goffman (1963) writes that society establishes categories into which individuals may fall, and that there are also socially determined attributes that are considered normal and natural for the individuals within each category. Social settings also dictate which categories of people are likely to be encountered in each setting. As such, there are routines of social interaction that allow individuals to go through their daily lives with general assumptions and expectations regarding who they will meet (Goffman, 1963).

Assumptions individuals hold about qualities of individuals in particular categories soon turn into expectations, and eventually, demands (Goffman, 1963). When a person encounters another who does not meet preconceived demands, such as having an attribute that others in the category do not, the original person may view the other as a less desirable person of that category. The other is quickly reduced in the minds of others from a whole person to a tainted one (Goffman, 1963). This reduction in status in the minds of others is called stigma, especially when the "attribute is deeply discrediting," (Goffman, 1963, p. 3). People also tend to assume a variety of imperfections based on the one original deviation from the norm (Goffman, 1963). Thus, those who have a stigma are assumed to be not fully human. They are therefore frequently the recipeints of discrimination, which reduce life chances (Goffman, 1963).

There are three types of stigma. First, there are "abominations of the body, physical deformities," such as scars and amputated limbs (Goffman, 1963, p. 4). There are also "blemishes of individual character perceived as weak will, domineering or unnatural passions, treacherous beliefs, and dishonesty," and these blemishes are inferred from conditions such as imprisonment, addiction, unemployment, and illness (Goffman, 1963, p. 4). The stigma associated with cancer patients may be that of being sensitive and weak, leading others to be patronizing towards the survivor. The third type is "tribal stigma of race, nation, and religion," (Goffman, 1963, p. 4).

Stigmatized individuals recognize that others may not fully "accept" them based on these assumptions, inevitably causing those who are stigmatized to feel that they fall short of what they ought to be (Goffman, 1963). In this case, shame and embarrassment are likely. As such, a person with a stigma may attempt to 'correct' the attribute; in the case of cancer survivors, they may wear shirts to cover and hide scars, and may refrain from sharing their health history. These individuals may also see the adversity they faced due to stigma as an opportunity for personal growth (Goffman, 1963).

Stigma and Identity

One's personal identity is the "unique combinations of life history items that come to be attached to the individual," (Goffman, 1963, p. 57). In the case of this study, life history items such as son, daughter, student, friend, athlete, and eventually, cancer survivor, combine to create participants' identities. However, an illness such as cancer may be a stigma and lead others to treat the survivor differently (Zebrack & Landier, 2011). Individuals with a stigma may be unsure about how those without the stigma will perceive them (Goffman, 1963). Therefore, people with a stigma may consciously keep their stigmatized status private.

The perceptiveness of a particular sigma and degree to which it interferes with the flow of social interaction also shapes how the stigma impacts the individual. For example, the experience of someone in a wheelchair giving a presentation will likely be different than the experience of someone with a speech impediment giving that same presentation (Goffman, 1963). Stigmatized individuals likely feel as though they have to be "on," constantly self-conscious about how they present themselves to others (Goffman, 1963). There are social rewards in being considered "normal," and almost all individuals with a stigma who are able to pass as normal choose to do so (Goffman, 1963). Individuals with stigmas present themselves in particular ways and disclose their attributes to select people in an attempt to control the perceptions others hold of them. Goffman (1959) calls this practice impression management, controlling a person's front stage. Individuals with a stigma often display a different image to the public than the image they project to closer friends (Goffman, 1963).

Individuals with stigmas may feel comfort by being with those who share the same stigma (Goffman, 1963). These communities can provide support and acceptance to an individual with a stigma, as members of these groups share similar learning experiences and experience similar struggles (Goffman, 1963). Studies show that cancer survivors and others who face adversity also feel solace by being with others who share their experience (Rutter, 1985; Coyne & Downey, 1991; Decker, 2007). Members of stigmatized groups likewise experience similar changes in the conception of the self because of the shared adversities they face. In this study, participants who belonged to survivorship communities expressed similar feelings of comfort and support. However, members of stigmatized groups do not always identify and participate in the group. They have affiliation cycles, where attachment varies based on their identification with the group at a given time (Goffman, 1963).

Summary

Cancer knows no boundaries; it is a disease that affects individuals of all ages, genders, socioeconomic classes, and ethnicities. The cancer itself, as well as therapies to treat the cancer, have varying short-term and long-term effects on individuals. There is a rich body of literature exploring physical, psychological, and psychosocial effects of cancer on childhood survivors. There is also a rich body of literature that examines trauma, effects of childhood trauma later in life, and coping mechanisms that prevent the development of maladaptive traits. However, the literature fails to consider the life course of a survivor and relate it to why survivors draw certain meanings from their experiences. There is no link that relates cancer as a childhood trauma, the coping mechanisms that childhood survivors employ to manage distress experienced as a result of the trauma, and the subsequent perceptions of late effects. Filling this gap will provide health professionals, community members, and patients, strategies to best support survivors of childhood cancer across the span of survivorship.

CHAPTER 3. **METHODOLOGY**

Introduction

This study used the life course theory to understand the long term effects that childhood cancer has on young adult survivors and the meanings survivors draw from their experiences. This chapter describes several analytic strategies and a rationale for the paradigm adopted in this study. An outline of the research approach and design that were used to achieve the purposes of the study will follow. The chapter will conclude with details regarding procedural limitations and the role of the researcher.

Research Aims and Objectives

The goals of this research were:

I. To investigate the impact childhood cancer has on young adult survivors perceived quality of life.

II. To identify key factors that influence the meaning young adult survivors draw from their cancer experience.

III. To create a "Trail of Survivorship" that suggests how certain factors in cancer journeys shape the lives of young adult survivors.

Research Methodology

All research is "guided by a set of beliefs and feelings about the world and how it should be understood and studied," and as such is structured by an interpretive framework called a paradigm (Denzin & Lincoln, 2011, p. 13). Research paradigms provide a lens through which the researcher observes and analyzes the world. They provide models of conceptualization for describing and explaining the data, enable the researcher to make predictions and explanations about behavior, and are useful in real-world applications (Glaser & Strauss, 1967). The basic beliefs held by each paradigm also influence the questions asked and provide operationalized hypotheses (Glaser & Strauss, 1967; Denzin & Lincoln, 2011).

The types of research questions asked lead a researcher to take a research approach that falls within the scope of two main research methodologies; quantitative research and qualitative research. There are significant differences between quantitative and qualitative research, and the methods address the same set of issues in different ways (Denzin & Lincoln, 2011). Each has its strengths and limitations, requiring the researcher to decide which approach best provides a framework to investigate that which they are looking to answer (Creswell & Poth, 2018).

Positivism and Quantitative Research

For almost 200 years, the positivism research paradigm dominated social research (Denzin & Lincoln, 2011). Positivism posits that the world is measurable, and that there is a reality to be studied (Creswell & Creswell, 2018). There are laws and theories that govern the world, and research tests, verifies, and refines these laws (Creswell & Creswell, 2018). Therefore, the positivist paradigm is best suited for answering questions of causality, addressing the “Who,” “What,” “Where,” and “When,” of processes. These questions often result in quantitative studies. Quantitative studies aim to measure in terms of quantity, amount, intensity, and frequency. They seek to emphasise measurement and analysis of “causal relationships between variables, not processes” (Denzin & Lincoln, 2011). However, positivism fails to account for the influence of subjective experience and human complexity that also governs the social world.

Relativism and Qualitative Research

During the 1980's, a different paradigm rose in popularity; relativism (Denzin & Lincoln, 2011). In contrast to positivists, relativists believe that reality can never be fully understood (Denzin & Lincoln, 2011; Creswell & Creswell, 2018). Relativists seek to understand the world in which they live and work, and are interested in the meanings directed towards certain objects or drawn from experiences (Creswell & Poth, 2018). These subjective meanings are modulated by interactions with others and historical and cultural norms that shape people's lives. Lincoln & Guba (1986) describe how relativism takes into account the diversity and uncertainties of the human experience, addressing complexities for which positivism fails to account:

> *There is no single reality on which inquiry may converge, but rather there are multiple realities that are socially constructed, and that, when known more fully, tend to produce diverging inquiry. These multiple and constructed realities cannot be studied in pieces (as variables, for example), but only holistically, since the pieces are interrelated in such a way as to influence all other pieces. Moreover, the pieces are themselves sharply influenced by the nature of the immediate context. (p. 75)*

Therefore, the relativist paradigm is best suited for research that aims to address how social experience is created and given meaning, the "Why" and "How" to social processes. Qualitative research methods utilize these interpretive practices, emphasizing "processes and meanings that are not experimentally examined or measured (if measured at all) in terms of quantity, amount, intensity, or frequency" (Denzin & Lincoln, 2011, p. 8). There are numerous definitions of qualitative research, representative of the complexities that qualitative research aims to address (Creswell & Poth, 2018). For this research project, the following definition of qualitative research best applies:

> *Qualitative research is a situated activity that locates the observer in the world. Qualitative research consists of a set of interpretive, material practices that make the*

> *world visible. These practices transform the world. They turn the world into a series of representations, including field notes, interviews, conversations, photographs, recordings, and memos to the self. At this level, qualitative research involves an interpretive, naturalistic approach to the world. This means that qualitative researchers study things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them.*
>
> (Denzin & Lincoln, 2011, p. 3)

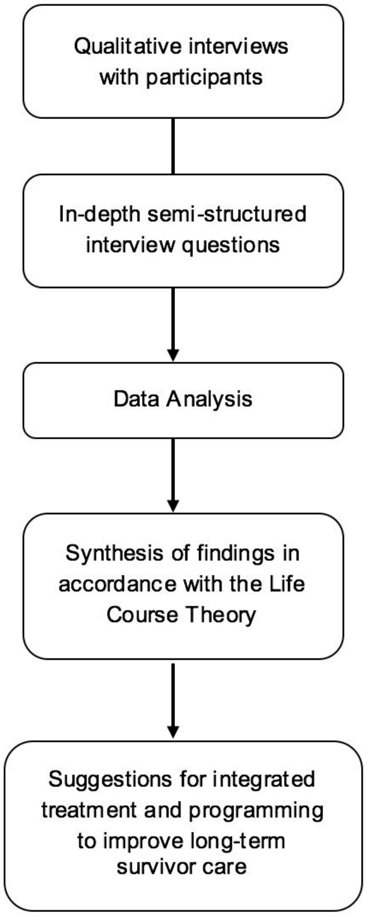
Methodology Adopted Within this Study

Given the nature of this project, to explore the impact that childhood cancer has over the life course and investigate factors that modulate the meaning that survivors draw from their experiences, a qualitative methodology was most the most rational choice (Creswell & Creswell, 2018). This investigation focused on the complexities of the human lived experience, necessitating a constructivist paradigm. The constructivist paradigm holds that the social world is unique to each individual and is shaped by the unique life experiences of that individual (Elder et al., 2003; Denzin & Lincoln, 2011). The researcher aimed to discover *why* and *how* participants draw certain meanings from experiences. It is rooted in the life course theory, positing that the timing of life events leads to differential experiences: Occurance A does not necessarily lead to, or mean, the same thing for individuals who experienced the occurrence at different stages of life (Elder et al., 2003). Despite each participant sharing the same experience as going through cancer treatment, how does the timing of the event, life experiences, and social structures, shape the unique experience of survivorship for each participant (Elder et al., 2003)?

Research Design

Figure 4 provides an outline of the study flow employed in order to investigate the questions described above.

Figure 4. Research Design



Participants

The nature of the research project is an advanced independent study, so the researcher was the sole person interviewing, transcribing, and analyzing data. Due to timing constraints and available resources for the research project, the researcher chose to set the maximum sample size thirty participants. Furthermore, the researcher predicted that she would reach saturation before reaching 30 participants. Saturation is reached when the addition of more participants does not bring about new themes or surprising findings (Creswell & Creswell, 2018). According to the

ACS, young adults are individuals ages 20-39 (ACS 2020f). The researcher therefore chose the age range 21-30 to narrow the sample to individuals who faced pediatric cancer more recently.

Recruitment

Eligibility criteria were as follows: the researcher sought young adults, ages 21-30 years old, who were diagnosed with cancer prior to age 18, and off active treatments and therapy for at least two years. To recruit participants, she created a Boston College Institutional Review Board (IRB) approved Facebook announcement containing eligibility information (Appendix A). The researcher posted the announcement flier in several survivorship groups, in a mid-size New England university's Facebook group, and on my personal Facebook page. Posts in the survivorship Facebook groups reached approximately 1,000 individuals. Of these individuals, all were diagnosed with cancer prior to age 18, and roughly half were under the age of 30. Posts in the mid-size New England university's Facebook group reached approximately 10,000 individuals. Every individual was over 21-years-old, but there is no available data on how many met cancer diagnosis criteria. Twenty-eight individuals contacted the researcher indicating interest in participating in my study. Of those, she interviewed nineteen individuals. Seven individuals chose not to participate after contacting the researcher, and two individuals did not meet selection criteria. The individuals who ended participation early did not provide reasons for doing so.

Participant Characteristics

The study sample ranged from 21-30 years old (M = 25.4 years ; Median = 23 years), and comprised twelve females (63%) and seven males (37%). Six (32%) participants were diagnosed with cancer when they were less than five years old. These participants have no memory of their cancer experience. Three (16%) participants were diagnosed with cancer as a child between 6-12, and ten (53%) participants were diagnosed with cancer as a teenager ages 13-18. Sixteen (84%) participants are from the northeast United States, one (5%) participant is from Europe, one (5%) participant is from the southeast United States, and one (5%) participant is from the southwest United States. Twelve (63%) participants have earned a bachelor's degree or higher, five (26%) participants are currently pursuing a bachelor's degree, and two (11%) participants have earned a high school diploma.

Data Collection

For this study, sixteen (84%) interviews were conducted over Facetime and Facebook Video Chat. The remaining three interviews (16%) were conducted in-person. Video chat interviews were most efficient for many participants, because it was the only practical way for the researcher to connect with individuals across the country. In-person interviews were convenient for several participants because they met with the researcher at central dining halls on the university's campus in-between classes. It is for this reason that the researcher did not conduct focus-group interviews.

Participants were given an electronic consent form and a hybrid survey of the QLACS, MOS SF-36, and QL-CSS scales (Appendix B, C) approximately one week before their scheduled interview. The survey was created by piecing together portions of the three existing quality of life surveys (Avis et al., 2005; Ware & Sherbourne, 1992; Ferrell et al.,1995). The timeframe primed the participants, granting them time to think about their responses to the questions prior to the interview. Before the interview began, the researcher reminded respondents of the purpose of the study, research procedures, their right to withdraw from the study at any time, and protection of confidentiality. The researcher identified herself as an undergraduate student at Boston College and a cancer survivor. She did so in order to demonstrate familiarity with the research topic and establish good rapport with participants (Lincoln & Guba 1986; Rubin & Rubin, 2005). Interviews were audio-recorded with participant approval to ensure complete and accurate transcription.

Interviews were conducted with a semi-structured approach described by Rubin and Rubin (2005) (Appendix D). Interviews began with, "Please tell me a little bit about yourself, your family, life growing up, before cancer if you can remember it, and please describe your cancer journey; how you found it and what treatment was like." The question gave participants time to get comfortable sharing about themselves, and the freedom to go as in-depth as they would like with their cancer story (Rubin & Rubin, 2005). The rest of the interview consisted of open-ended questions to give respondents space to talk freely about topics and go deeper into areas that resonated with their experiences (Mishler, 1986; Rubin & Rubin, 2005). The open-ended interview questions were developed based on the missing elements that Quinn et al. (2013) identified.

The researcher emphasized to each participant that they were welcome to talk as much or as little as they felt comfortable, and she replied back to answers to establish the essence of conversation. The interactive nature of the interview allowed the researcher and respondent to "fruitfully learn together," (Lincoln & Guba, 1986, p.76). Probing questions such as "Why? How so? Tell me more about that," were used to encourage participants to elaborate on or clarify a response, as well as give the respondent time to fully think about their experience

(Rubin & Rubin, 2005). Interviews lasted approximately 45 minutes to ensure that all aspects of cancer survivorship were explored in-depth.

After each interview, the researcher emailed participants the Impact of Cancer - Childhood Survivor Scale (Appendix E) and a copy of the informed consent document.

Transcription

The researcher later transcribed interviews verbatim in a server-secured Microsoft Word document according to the principles put forth by Mergenthaler and Stinson (1992). Transcribed interviews are integral to a complete analysis, and are key to "demonstrating variations in how social phenomena are framed, articulated, and experienced," (McLellan et al., 2003, p. 67; Rubin & Rubin, 2005). Transcription documents were verbatim, keeping the pauses, use of slang, and notations of emotional content [crying, laughing, whispering, sarcasm] to reflect true views of participants (Mishler, 1986; McLellan et al., 2003). During transcription, the transcriber removed all personal identifiers to ensure participant confidentiality (McLellan et. al., 2003).

Analytic Strategy

There are many different theoretical frameworks in qualitative research that have been developed over the past several decades (Creswell & Poth, 2018). The characteristics of this study indicated a hybrid between the grounded theory approach and narrative theory approach as the best analytic strategy.

There were four stages of data analysis. First, the researcher made a list of recurring concepts while transcribing interviews (Rubin & Rubin, 2005; Corbin & Strauss, 2012). She also highlighted quotes and typologies from the interviews that were particularly salient. This method of analysis is known as the grounded theory approach, where coding, recognizing key themes and concepts, theory development, is a simultaneous and integrated process (Glaser & Strauss, 1967; Rubin & Rubin, 2005). The grounded theory emerges from rigorous data analysis, rather than looking for data to fit into preconceived theories. Each interview was initially coded, and the researcher generated lists of recurrent themes (Glaser & Strauss, 1967; Creswell & Creswell, 2018).

Next, using the narrative analysis method, the researcher created narrative memos for each transcript. The narrative theory is focused on stories, rather than dissecting the whole into its individual pieces and parts (Riessman, 2008). Narrative analysis interprets data that has a common storied form, such a cancer patient's story of their diagnosis, transition to life after cancer, and long-term survivorship. It takes the histories of individuals in collective groups, such as individual survivors within the young adult survivor community, and assembles their stories together to provide a fuller picture of the larger group (Riessman, 2008). Narrative analysis theory connects isolated events into a sequence, imposing a meaningful pattern that links events and ideas beyond what otherwise would be considered random and disconnected (Riessman, 2008). Researchers that utilize narrative analysis focus on particular actors in particular social settings at particular times. They are interested in how the participant "assembles and sequences events and uses language to communicate meaning," (Riessman, 2008, p. 11). Investigators want to know how and why particular events are described in unique ways, they are not simply interested in the content of the story.

The researcher aimed to learn the attitudes and interpretations survivors have about their experiences, demonstrating that long-term survivorship is impacted by the entire life course, rather than a group of single events. She explored what creates particular subjective experiences from objective occurrences such as cancer. This rendered the narrative analysis method practical for interpreting participants' interviews. She also treated participants' narratives as analytic units, rather than fragmented pieces of separate themes (Riessman, 2008). Therefore, the grounded theory - narrative analysis hybrid strategy was appropriate for this study; analyzing common themes while keeping in mind the narrative units of each participant.

The narrative memos began with a short description about the participant and their cancer story, followed by sections for particularly resonant themes and quotes (Corbin & Strauss, 2012). Memo-writing is also a key intermediate analysis strategy for grounded theory (Charmaz & Belgrave, 2015). Since the grounded theory relies on cycles of vigorous analysis and testing plausible theories against the data, memos are instrumental in helping the researcher remember key points, questions, and critiques, as they continue data collection (Charmaz & Belgrave, 2015).

Third, the researcher brought together the narrative memos and looked for commonalities and patterns between the data sources (Rubin & Rubin, 2005). She grouped data by consistent themes and common domains across the lifecourse, and made an initial "Life Trajectory Model" (Elder et al., 2003).

Fourth, she tested the tentative model against data. The researcher integrated and refined categories until clear checkpoints and categories solidified (Glaser & Strauss, 1967; Corbin & Strauss, 2012). The researcher adopted the constructivist division of grounded theory adopted for this analysis. Constructivist grounded theory combines the ideals of rigorous analysis without preconceived notions as well as the interpretivist framework of constructivism (Charmaz

& Belgrave, 2015). It sees the researcher and participant as key research instruments, as they produce data through social interaction, thereby rendering the data a social construct (Charmaz & Belgrave, 2015). Constructivist grounded theory:

1. *Gives priority to the studied phenomenon rather than techniques of studying it*
2. *Takes reflexivity and research relationships into account*
3. *Assumes that both data and analyses are social constructions*
4. *Studies how participants create meanings and actions*
5. *Seeks an insider's view to the extent possible*
6. *Acknowledges that analyses are contextually situated in time, place, culture, and situation*

(Charmaz & Belgrave, 2015, p.3-4)

Since the nature of this study is to understand the meanings cancer survivors give their experiences, given each participant's unique life course, the constructivist grounded approach to data analysis is most appropriate (Elder et al., 2003; Charmaz & Belgrave, 2015).

Establishing Credibility

Qualitative data strays from quantitative data in that data are often not measurable in the same sense that quantitative data are measured. Therefore, the quality criteria used in quantitative research (internal validity, generalizability, reliability, and objectivity) are not suitable for judging the quality of qualitative research (Lincoln & Guba, 1986; Korstjens & Mosher, 2018). Qualitative research is judged on its trustworthiness, defined by Lincoln and Guba (1986) as the degree of credibility, transferability, dependability, and confirmability, research findings possess. *Credibility* refers to the extent to which the interpretations drawn from participants' original data is a correct interpretation of the participants' original views (Korstjens & Mosher, 2018). *Transferability* refers to the degree to which the findings of the study are applicable to other contexts with different respondents (Korstjens & Mosher, 2018).

Dependability is the extent to which the research was conducted and analyzed in line with the accepted standards for that study design, and whether the participants agree with the conclusions presented (Korstjens & Mosher, 2018). *Confirmability* is the degree to which other researchers agree with the findings and the original researcher's interpretations (Korstjens & Mosher, 2018).

To increase credibility, the researcher triangulated data (Lincoln & Guba, 1986). She gathered data from individuals across the country, who had different types of cancers, varying lengths of treatment, and been in remission for a wide range of years. She also employed persistent observation by constantly reading and rereading interview transcripts and narrative memos, revising key concepts and themes accordingly. Upon completion of preliminary drafts, the researcher sent the findings and conclusions to participants. This allowed members to check the interpretations and conclusions that the researcher made, and ensure that they were accurate. The researcher increased transferability by providing a thick description of the research process and of the participants themselves (Lincoln & Guba, 1986). She provides biographies of each participant so that the context of each participant's lived experiences is meaningful to outsiders. To increase dependability and confirmability, the researcher kept an audit trail (Korstjens & Mosher, 2018). She has records of each step of the research path; Institutional Review Board documents, interview transcripts, note sheets, narrative memos, etc., secured on a university-controlled server.

Role of the Researcher

Since qualitative research is rooted in observations and interpretations of the lived experience, there lies a large caveat; "there is no clear window into the inner life of an individual. Any gaze is always filtered through the lenses of language, gender, social class, race, and ethnicity" (Denzin & Lincoln, 2011, p. 12). The researcher's own life experiences, identities, beliefs, and assumptions, can intrude into the analysis of data (Denzin & Lincoln, 2011; Rubin & Rubin 2005). Lincoln and Guba (1985) therefore urge researchers to neutralize these natural biases, ensuring transparency and quality of the findings, through reflexivity. Korstjens & Mosher (2018) instruct the researcher to examine "one's own conceptual lens, explicit and implicit assumptions, preconceptions and values, and how these affect research decisions in all phases of qualitative studies" (p. 121).

The researcher acknowledges that her position as a young adult survivor of childhood cancer may bias her interpretation of research results. She was diagnosed with stage 4 Hodgkin's lymphoma cancer as an eleven year old, and finished treatment with few late-effects. Her experience with the medical field, organizations related to cancer, and people she has met through being a patient and a survivor influenced her career choice to attend medical school and pursue pediatric oncology. She has been involved with a summer camp for children affected by cancer for over ten years, and her experience at the camp shaped her perceptions of cancer and being a survivor. She knows ten participants from this study (53%) through the camp. Her own experiences, struggles, and questions, elicit a desire to find patterns and themes in the data.

To minimize personal bias on the results of the study, the researcher utilized member checks during interviews to increase credibility and dependability of the data (Lincoln & Guba, 1985). During each interview, the researcher summarized information and repeated it back to the participant, asking the participant to clarify or augment the researcher's initial interpretations. Meetings with the faculty advisor helped the researcher identify sociological theories through which to interpret the data, and focus on relevant themes that emerged from the data. She also included relevant quotes from participants to substantiate findings of the study.

Ethics and Governance Approval

The study protocol was approved by the Boston College Institutional Review Board in August 2019 (protocol number 20.041.01).

Summary

This chapter explained common research methodologies and provided the rationale behind the current study's design. It presented the study design, participant characteristics, and described the analytic strategy. The chapter concluded with credibility concerns and the role of the researcher. The following chapters will present the findings and conclusions of the study.

CHAPTER 4. **MEET THE PARTICIPANTS**

Introduction

The life course approach necessitates evaluating events, experiences, and meanings that participants draw from these, in the broader context of their life (Elder et al., 2003). It is therefore important to understand the narratives for each participant to analyze the results in a greater context (Reissman, 2008). As such, this chapter provides a brief narrative of each participant. Table 3 provides a summary of relevant participant characteristics.

Table 3: Participant Demographics

Participant	Current Gender and Age (years)	Age at Diagnosis	Type of Cancer	Treatment Characteristics	Years in Remission	Involved in Support Group
1	F:29	1 years	Neuroblastoma	Chemotherapy, radiation, 1 year outpatient	20+ years	Yes
2	F:21	3 years	Neuroblastoma stage 3+	Chemotherapy, radiation, surgery, stem cell transplant, 1 year outpatient	18 years	Yes
3	F:23	<1 years	Neuroblastoma stage 4	Chemotherapy, radiation, bone marrow transplant, few months outpatient	20+ years	Yes
4	F:23	21 months	Neuroblastoma	Chemotherapy, surgery, 6 months outpatient	20+ years	Yes
5	F:22	4.5 months	Neuroblastoma stage 4	Chemotherapy, radiation, 5 months, inpatient	20+ years	No
6	F:30	5 years, 24 years	Glioblastoma, meningioma	Chemotherapy, radiation, 6 months inpatient	6 years	Yes
7	F:23	9 years	Malignant melanoma	2 Surgeries outpatient	14 years	Yes
8	F:23	14 years, 17 years	Rhabdomyosarcoma	Chemotherapy, radiation, >30 surgeries inpatient and outpatient	6 years	Yes

9	F:28	18 years	Acute myelogenous leukemia (AML)	Chemotherapy, bone marrow transplant, 6 weeks inpatient, few months outpatient	10 years	Yes
10	F:24	12 years	Hodgkin's lymphoma	Chemotherapy, radiation, 6 months outpatient	12 years	Yes
11	F:24	15 years	Hodgkin's lymphoma	Chemotherapy, radiation	9 years	Yes
12	F:26	14 years, 17 years	Osteosarcoma	Chemotherapy, surgery, 9 months outpatient & 5 months outpatient	8 years	Yes
13	M:25	13 years	Leukemia	Chemotherapy, 3 weeks inpatient, 3 years outpatient	8 years	Yes
14	M:23	12 years	Osteosarcoma	Surgeries, 1 year outpatient	10 years	Yes
15	M:25	18 years	Undisclosed	Chemotherapy, radiation, 9 months outpatient	7 years	Yes
16	M:25	14 years	Osteosarcoma stage 4	Chemotherapy, surgeries, 1 year inpatient, 2 years outpatient	11 years	Yes
17	M:21	15 years	Leukemia	Chemotherapy, bone marrow transplant, 1 month inpatient, 3 months outpatient	6 years	No
18	M:22	14 years	AML	Chemotherapy, bone marrow transplant, 8 weeks at a time inpatient, 1 year outpatient	6 years	No
19	M:23	17 years	Synovial sarcoma	Chemotherapy, surgery, radiation, 3 years outpatient	5 years	No

Participant 1

Participant 1 is a 29-year-old female who lives in the northeast United States. She was diagnosed with neuroblastoma when she was about one year old, and after a year of chemotherapy and radiation, was pronounced in remission. She and her family have remained very involved in the cancer community; she currently works at an organization that runs summer camps and other programs for children and families affected by cancer. Since she was so young when she was diagnosed, Participant 1 does not have specific memories of her experience. She will have deja vu moments from time to time with certain smells and places, and she sometimes wishes she had those memories to feel more connected to her cancer past.

Participant 1 attended a summer camp for children with cancer, and remarks that it helped her connect to that portion of her biography. It was also comforting to be with children who understood what she had been through. She struggles sometimes with survivor guilt, because she sometimes feels like she did not earn the label 'survivor.' Because she does not remember her fight, it is occasionally difficult for her to accept her status. But being involved with the summer camp, and now working there, has helped her come to terms with her identity as a survivor and has given her an outlet to help others. Participant 1 feels that she views the world in a different light because of her cancer, that it is easier for her to put small problems into perspective. But at the same time, she says that it is not fair to compare every issue to having cancer, that it is important to still acknowledge daily struggles and pain.

Participant 1 has multiple post-treatment effects. She has visible scars, but they are usually covered. She has a small chest scar where her portacath, a surgically implanted central line, was placed, and a large abdominal one. She also experiences hearing loss and has had five surgeries related to ear problems. Participant 1's largest late-effect from her experience is her fear about developing a secondary cancer. She worries that since she does not remember her first experience, a second diagnosis would feel as if she were going through everything for the first time.

> *I think there's a part of me that's like "well you didn't experience that the first time around," so like it was kind of almost be like karma to have to experience it as an adult, it's such a backwards thought process, but sometimes I like go to the doctor with a problem, and I'm just waiting for that shoe to fall sort of thing.*

Participant 1 is grateful to live near a hospital with a long-term survivor program, and she attends regular follow-up appointments. She completely trusts her team, but the fear of a second diagnosis is still something in the back of her mind. During a health scare last year, she had a pit in her stomach that felt like ‘this is it.’ There was nothing serious, and she is healthy, but that worry was still there. She is also nervous for her family members and future family members, because cancer is common in her family. And since none of the cancers have been the same, she believes they were environmentally triggered, therefore everyone is at risk. She thinks about her sister and her future nieces and nephews, as her sister is engaged and wants to start a family, “especially just knowing how easy it is for doctors to dismiss childhood symptoms as like growing pains, or kids just being sick.”

Participant 2

Participant 2 is a 21-year-old female living in the northeast United States. When she was three years old, her mother noticed that she was developing differently than her twin brother. Her parents brought her to the doctor’s office, and the physicians prescribed flu medications. However, the medicines did not help her condition. When they arrived at the Emergency Room, the attending provider sent Participant 2 for specific testing because he recognized her symptoms as being indicative of cancer. She was admitted immediately, they found a three-pound tumor in her abdomen, and she was diagnosed with stage 3 neuroblastoma.

Her treatment journey was long, it took about five years until she was pronounced to have no evidence of disease. She had several rounds of chemotherapy and radiation to the abdomen and pelvis. While the majority of cancer was around her left kidney area, radiologists radiated both sides evenly so that during later development she would not have delays and appear hunched to one side. Participant 2 also had an autologous stem-cell transplant (with her own cells) so that her body would not reject the cells. Her earliest memories are of many doctor's appointments; "yeah it was difficult, but it was kind of like my 'normal.'" She will occasionally have 'déjà vu moments of her treatment. "I'll have this feeling in a dream, and I'll be like 'I just had this weird dream,' and my mom is like 'yeah, that happened years ago, you probably just repressed it, or are reliving it unconsciously.'"

Participant 2 has numerous late effects from both her treatment and her cancer. She has hearing difficulties, and she is in the process of learning sign language. She can lip read, and she has had hearing aids, but she does not particularly like them. Participant 2 describes that hearing aids make it seem as if she's "underwater and people are just yelling at [her]." She remarks that while some survivors benefit from hearing aids, they are not the best choice for her. When wearing them, she says that all of the small sounds she hears daily, such as the buzzing of the fridge, become overwhelming.

This was part of Participant 2's decision to start homeschooling in middle school, because it was so difficult to focus and hear in a classroom. Doctors predicted learning and developmental delays for Participant 2; she remarks "thankfully, I don't think that's true." She puts large amounts of effort into her studies, and earned her GED and associate's degree online. She also has severe gastrointestinal (GI) dysfunction, which has been one of her more impactful late effects. Doctors told her for a long time that she would grow out of her symptoms, "but then it came to where I was finishing high school and I was like "I can't go to college like this, and I'm not going to grow out of it at this point." Participant 2 started seeing different pediatric gastroenterologists, but they had trouble treating the issues that caused her distress. "And it's very difficult because a lot of GI disorders in children are like, common. Like you've heard of Kurd and an eating disorder, and that wasn't the case for me."

After seemingly exhausting the options, her primary care provider (PCP) referred her to an adult gastroenterologist. By this time, in three months, she lost 35 pounds and was down to 80 pounds, but lack of eating was not the issue. After trying many different regimens, powders, and diets, they were at a loss. Doctors found that one medication, in addition to eating heavy carbohydrates, worked to subdue Participant 2's symptoms. "People are always like 'oh, I'm so jealous that you get to eat carbs and carbs and carbs' and I'm like I don't have any choice." Fruits and vegetables are difficult to digest, which was an issue her body had. Participant 2 has since returned to her healthy weight, but still has stomach aches, nausea, and heartburn. Her doctor predicts that during the surgery to remove the tumor, surgeons may have nicked a nerve that plays a role in digestion.

Participant 2's late effects played a large role in her decision to begin homeschooling in middle school, and she has nearly completed her degree as a child life therapist. Her experience has helped her develop an attitude of advocacy, because she notices that there is so much yet to learn and understand about long-term cancer survivorship. "Because awareness with inaction isn't doing anything…, knowing and doing something about it are two very different, and both important, things." Since many young children are unable to advocate for themselves or fully comprehend their health situation, Participant 2 wants to spread childhood cancer awareness to the adult population. She sees many gaps in the survivorship world, such as gaps in survivorship literature, gaps in long-term care for pediatric survivors, gaps in understanding late effects, and she aspires to fill those voids. "I want to make sure that people don't think this is contagious or shameful to talk about… I wish more people would not be ashamed or afraid to ask about it." She is writing her own research project on how survivors cope with cancer and its long term effects, looking at different coping mechanisms and evaluating how they affect a person's perceived quality of life, depression, and more.

Participant 3

Participant 3 is a 23-year-old female living in the northeast United States. When she was less than a year old, her pediatrician found a mass in her abdomen. The physician sent her for scans, and she was diagnosed with stage 4 neuroblastoma. Participant 3 does not have memories from her treatment, looking at baby pictures of herself as a bald baby is the closest she gets to remembering. Her extended family was extremely supportive throughout her treatment, as her parents tell her that grandparent, aunts, and uncles, visited the hospital frequently. Since then, her family and grandparents have stayed extremely close.

Since her treatment was completed by the time she entered school, Participant 3 does not remember a 'transition period.' She found ways to circumvent the limitations her foot surgery created, such as tapping her foot a different way in band class, and investing in academics as opposed to sports. Gym class was difficult, however, because her disability singled her out. "You kind of know the people that are good at gym, and the people that are bad at gym, and I always got picked last. Gym is kind of awful because it does single people out like that." She spoke about high school kids and how they often do not understand the spectrum of ability and disability. Participant 3 continues to see a physical therapist for her balance, and has begun to wonder if her limitations will impact her career. A recent experience at her workplace was the first time where she felt her disability affecting her in a serious, potentially negative, way, and she is thankful that her workplace is accomodating, but she wonders how many other employers will be as receptive. Other long-term effects include a large scar on her abdomen from surgery, “I don't really walk around with my stomach out on a regular basis [chuckle] so it’s not a huge deal.” She is also unable to hear high-pitch noises, and takes thyroid medicine to compensate for the damage done to the organ from treatment. However, she works overnight shifts at her job, which alters the efficacy of the medicine. The medicine is meant to be taken in the morning to kick-start her body’s metabolism, but overnight shifts constantly switch her body’s internal ‘clock.’

Participant 3 has future health concerns, which also stem from a deep-rooted fear of secondary cancers. She is vigilant about her body, and does not partake in risky behavior that increases the likelihood of developing cancer, like smoking cigarettes, but she is nervous because “at the end of the day, there’s just some things you can’t prevent, predict, or control.” And although she attends her yearly follow-up appointments, “a lot can happen in a year, and that’s the scary thing."

> *I don't really know if I really want to know. If I go to the doctor and they tell me something… I can’t ever unhear [that]. So I’m like “okay well this is kind of hurting, what if I have cancer again?” I think that fear is always there. And I think that people that have had cancer and tell you that they don't have that are just lying, because I don't know how you can ever… it’s always in the back of your mind, how can you forget? Especially knowing people who have passed away, how can you say, “oh yeah, I’ve had some kind of pain but I never thought it could be cancer” like oh come on, who are you kidding.*

At the same time, Participant 3 is appreciative of her experiences, and the people she has met through cancer. She has a greater appreciation for life, especially after being involved with a camp for children with cancer. She tries to remind herself on bad days that she is lucky to be alive and have bad days, because some people do not have that chance.

Participant 4

Participant 4 is a 23-year-old female living in the northeast United States. After her mother noticed blood in her diaper and a large mass in her abdomen, she took Participant 4 to the physician's office. The provider did not think anything was wrong, but her mom was adamant. Participant 4's mom kept taking her to different offices, "kept pushing in order for them to even look at me." Eventually, they got an appointment with her primary care physician, who sent them to the hospital right away. There was a large tumor on her kidney, and she was diagnosed with neuroblastoma at the age of 21 months. "If it wasn't for my mom pushing and advocating for me, I don't know if they would have ever found it." She had surgery to take out that whole kidney, two lymphnodes, and adrenal gland, then she had 6 months of chemo. She has been in remission and attending yearly follow-up appointments ever since.

During early school years, Participant 4 always covered her scars and markers of her cancer. She did not want to be labeled as 'different' by her peers, and did not want people to ask her questions about it. But as time passed, she embraced her scars with pride. They are a symbol of her strength, and they give her confidence.

> *It's shaped me, it's not that I think about it on a daily basis, like "oh I had cancer, I'm different," sometimes I kind of stop and think about my life, I think about how lucky I am to be able to be here… I think sometimes you stop and you look back, like "I'm so lucky I am able to do the things I do." So I went to my grandma's for dinner the other night, and she was talking about all my accomplishments and how proud she was of me, and I think that's the first moment where I was like "I did this, I went to college, I graduated with my two degrees, I passed my boards, this like the next step." And I guess I'm never proud of myself, I never really look back and I'm like "okay like I did this," and I think I need to stop more and do that. And I'm just so lucky to be able to do stuff, and that cancer hasn't*

> *stopped me, and it's just given me a better outlook on life. Because some people unfortunately don't survive this, and they don't get to go on and live their life. So it gives me more of a drive to be able to go out and do stuff.*

Participant 4 occasionally feels as though she is not doing enough with her life. She feels that she was given a second chance, so she questions whether or not she is living up to the expectations she has set for herself. She became involved with a camp for children who have been affected by cancer, and serving there relieves her survivor's guilt. The people she met through camp also helped her feel less alone, and realize how lucky they all are to be healthy and pursuing their dreams. Participant 4 does not ever question why she got cancer, because having had cancer has always been her 'normal.' In fact, she appreciates the 'seize the moment' mentality she developed from the experience, as she finds life more enriching.

She has some future health concerns, and Participant 4 feels that the concerns will become more prominent as she ages. "I think I might be a little bit more worried with an ache or pain, and I might be more [inclined to have it examined] even if it is nothing. Because I'd rather be safe than sorry, especially with my history." She is also worried about passing cancerous genes down to future children, because she does not want to subject her child to pain that she does not remember experiencing herself. "I feel like it's going to be kind of my fault. Even though we know there's no way I can prevent it, I'm worried that they're going to have to go through it."

Participant 5

Participant 5 is a 22-year-old female from western Europe. When she was four-and-a-half months old, her mother noticed a lump in her abdomen, and took her to the doctor. They found a kidney tumor so large that she went into septic shock, and she was later diagnosed with stage 4 neuroblastoma. Participant 5 commented that pictures of her as a baby show a football-like lump on her stomach. She then had chemotherapy and radiation for five months, and had regular check-ups until she was about seven years old. Growing up, she never had a realization moment where she learned that what happened to her was not normal. She remembers a lot of anxiety surrounding her doctor appointments, and that her appointments were different than those that other children went to. Her parents often called her a miracle baby, and Participant 5 can tell that she was sick when looking at pictures of herself as a baby. “I don’t really like to see the pictures, because it’s kind of weird seeing yourself as a baby, sick.”

She does not have any visible markers of her cancer, and Participant 5 now attends a mid-size private university in New England. She does not see cancer as a large part of her identity, because it happened when she was so young and it does not impact her now. The only late-effect that she experiences is a concern about fertility. She is partly grateful for having cancer when she was so young, now being able to understand the gravity of her condition, but also wishes that she remembers some of it in order to have a greater appreciation for things.

Participant 6

Participant 6 is a 30-year-old female from the northeast United States. She was diagnosed with glioblastoma at age five after the school nurse noticed something blocking her corneas in a routine kindergarten exam. Scans at the hospital revealed spider-like projections throughout her brain, and initial survival predictions were lower than 20%. After a surgery to remove the tumor, the surgeon found that the tumor was actually balled up like a little golf ball instead of the spidery pattern the scan showed. They then gave her a 10% chance of life, saying she was likely going to be blind, deaf, and paralyzed. Today, she is not any of those three.

After surgery, Participant 6 underwent six months of inpatient chemo, and radiation on both sides of her head. She attributes her remission to her uncle's tragedy; he also had glioblastoma, and they only radiated one side of his head. His cancer came back on the other side and he eventually passed, so they radiated both sides of her head. Five years later they announced her in remission, but in 2014 relapsed with a different brain cancer; meningioma. They did not do radiation for the second cancer because of how much her brain had already sustained. After relapsing, she realized that living in fear was a waste of energy.

> *When something did come back, it boggled my mind. I just kind of lost it. Like I cried for like days… but I'm not afraid of it anymore. Like it's there, it's always going to be something in the back of my mind, and I have an 'it is what it is attitude' right now. Like, I'll take it as it comes.*

Growing up, she had difficulties making friends because there was a lack of understanding about pediatric cancer. People treated her like an outcast because of her bald spots and other physical indicators of her cancer experience, because they often thought it was contagious, or were ignorant. But as she has grown older, people have grown more accepting. She is also more confident, and frankly, the older she gets, "the less [she] gives a crap." When she was 18 she came down with epilepsy due to scar tissue from the first surgery.

Participant 6 always wanted to be a teacher, and during college began working towards that goal, but her epilepsy diagnosis slowed things down. Though unable to become a teacher, she does not feel that cancer has prevented her from finding fulfilment and joy. She finds other ways to pursue her passion for being with kids, such as through volunteering for hospitals, babysitting, and working with children at a camp for cancer survivors. She loves working with childhood cancer survivors, because she is able to show them what life after cancer and treatment will be, what moving on is actually like.

Participant 7

Participant 7 is a 23-year-old-female from New England. When she was in third grade, her family moved, and soon after her mom noticed a freckle on her head. Her pediatrician recommended they visit a dermatologist because Participant 7 would itch the freckle until it bled. They went to the local hospital to get it examined, and the examining provider suggested they visited a larger hospital. The attending dermatologist at the larger hospital took photographs of the freckle and suggested monitoring the freckle for any changes. At a three-month follow up with the local dermatologist, the doctor insisted they remove the freckle to be safe. Participant 7 then had the freckle removed under local anesthetic at a local outpatient clinic.

> *I was awake. I remember my vision going blue, kind of going in and out of it… I remember listening to the radio and singing along because that was the only thing that was keeping me with it and taking my mind off of what was happening.*

She describes her head feeling like a cinder block right after the procedure. When Participant 7 and her mother returned to have the stitches checked, she had a feeling of dread; it was there that the physicians informed her that she had cancer. The physicians spoke with her mom, but barely addressed her.

> *This was a theme during the whole situation, that I was just too young to understand, and nobody was telling me as it was happening. It was more like I was there in the room because it was about me, but I didn't know what was happening until I left the room.*

Participant 7 was diagnosed with malignant melanoma, the most serious form of skin cancer, especially for such a young child. She didn't understand the gravity of the whole situation and her diagnosis until afterwards. Doctors did not remove all of the cancerous cells, so she had to go back for a second surgery. "That was the worst recovery I remember, I was lying on the couch… the Gatorade juice boxes, that's what I lived on for like, two weeks" She ended up needing a third surgery, and after that went back every six months to the dermatologist for a check-up.

Participant 7 did not receive chemotherapy or radiation therapy for treatment, and she was able to go back to school once her surgery wounds healed. It was difficult to fully transition into her new school, because her wounds had bandages and gauze. She wore bandanas to cover the bandages, and kids would ask her why she covered her head. At first, she was embarrassed to be different, and just wanted to “fit in and be normal” at her new school. Throughout the process, Participant 7 remembers wanting to move back to their old home, almost as if it would fix everything. She associated the old home with safety, a strong sense of community, and neighborly love: “It was that preserved ‘everything's great, life is good,’ and then I moved and this traumatic thing happened to me, so I associate [my old home] with being in, like, heaven.”

Participant 7 lived in a type of denial and resentment of the cancer for years. She also felt isolated from the healthy children because of her bandages, and also from cancer patients, because she did not undergo chemotherapy. She attributes her feeling of isolation throughout childhood to the lack of representation, that she did not know anyone else who had a similar experience. “Maybe it’s because we’re so ingrained to see certain things, and assuming, as opposed to understanding that different types of cancer look differently.” Cancer became an issue that was “pushed under the rug,” by her family and her, and it took until she was a freshman in college to fully understand, accept, and embrace her cancer journey. Meeting other survivors who validated her fight and who encouraged her to reflect on her experience enabled her to come to terms with her health history. She sees her current role as being both an ear for those who need to share their story, and an advocate to show that cancer and its treatment takes many different shapes and forms. She even got a tattoo in honor of her cancer, and it serves as a conversation starter.

> *[The tattoo] became a talking point for it. It's a way to bring it up without people feeling like 'oh I am so sorry that you had cancer,' and they get uncomfortable. I'm able to be like 'no I'm fine, I have a sun tattoo and I had skin cancer, I'm okay with it. And I think I got that tattoo at a point where I was at peace with what happened, and what I went through. And someone will be like 'oh, I like your tattoo," and I'll be like 'thanks! I actually got it cuz I had skin cancer' and then they're a little bit less weird when it's a tattoo, because then they can talk about that.*

Participant 8

Participant 8 is a 23-year-old female living in the northeast United States. She began to notice back pain the summer before her freshman year of high school. An avid dancer, she welcomed the soreness as 'getting into shape' pains. "I wasn't really like a sissy really when it came to pain. If I was sore from dance I was happy about it. So I just thought I'd stretch it out and ignore it." Stretching alleviated her pain at first, but it progressively grew worse. Doctors originally thought she injured her back through dance, and suggested physical therapy. After a few weeks, Participant 8's physical therapist noticed her ribs protruding and felt a lump around the kidneys. Despite muscle relaxers and pain reducers, there was no pain relief. Participant 8 also began fatiguing easily; the flights of stairs at school she could climb with ease had her huffing and puffing after one little section. And more strange symptoms arose; she began to get a metallic taste in her mouth after eating frozen pizzas, a food she used to eat weekly, now made her gag.

She returned to the doctor's office, and on that same day found out that her cousin was diagnosed with cancer. Participant 8 was terrified, suspecting that she, too, had cancer. Doctors told her not to worry. "But lo and behold, I go to the emergency room the next day, and yeah, I had [rhabdomyosarcoma].” Following a surgery where doctors found one of her tumors wrapped around her aorta, Participant 8 underwent several rounds of aggressive chemotherapy and radiation. She experienced horrible side effects, throwing up anywhere from 20 to 50 times a day. She needed feeding tubes as a result.

> *I’ve had them down my nose, I've had like three different kinds in my stomach, I've had some through IVs. My esophagus swelled shut at one point, so then I had a huge nose tube down through there. And then outside of that there was like a baggie that took everything out of my stomach.*

One large tube in her abdomen began pushing itself out, so she had to have another surgery to reconstruct her stomach. She also had her esophagus reconnected to her stomach, surgeries to stretch it, and countless other surgeries, not from the cancer itself but effects of treatment. “Most of my surgeries are not from cancer, just from really bad crazy side effects I’ve had,” Participant 8 says. During this time, her weight dropped to just 67 pounds because of hyperemesis caused by chemotherapy. After two years of treatment, Participant 8 showed no evidence of disease and returned to school. It took a long time for Participant 8 to build up her strength following treatment, and she kept her feeding tubes in for a few weeks.

The spring of her junior year of high school, Participant 8 noticed a hard mass in her leg. Just two weeks later, the hard mass grew into a noticeable bump, and she immediately knew her cancer returned. She quickly had scans to confirm, “and even when I was getting them I was crying because I knew, and everyone else knew, too.” Participant 8 had surgery to remove the tumor, part of the muscle in her leg, and the nerve. She was afraid to start chemo again, but the chemotherapy did not have as intense side effects as her first treatment.

Returning to school was difficult for Participant 8 because she received so much unwanted attention, and felt that people were disingenuine towards her. She also felt disconnected from her friends. It was hard to relate to problems they faced, such as breakups with significant others, when she was experiencing friends passing away from their cancers. One place where Participant 8 did not feel different was at a summer camp for children who have been affected by cancer. She also worked at Camp for the whole summer after she graduated high school.

> *It was just so awesome to be with people that I could laugh and joke around with, and not care, and no one was looking at me like "She's so skinny, her hair is so short, oh that's the girl who had cancer."*

For a long time after she was sick, Participant 8 overworked herself to "make up for everything that I missed… because as cliché as 'you never know what's gonna happen or when your last day is,' it's so true." She powered through feeling aches and pains, because she had the mindset that nothing was as bad as her chemotherapy experience. She has since learned to give herself rest time, and to feel tired, but it has been hard to find a balance between seizing each moment and giving herself space to rest. She has also come to accept her cancer and find the positives in it, because for a long time she resented her missed opportunities; her truncated high school experience, shortened dance career, and more. But she says that the people she has met, organizations she has learned about, and overall personal growth she has experienced are silver linings to her challenging health journey.

Participant 9

Participant 9 is a 28-year-old female living in the northeast United States. The schools she attended as a child were small enough that by the time she was in high school, she knew just about everyone. Before cancer, she was extremely involved in extracurriculars; class president, performed in musicals, played on sports teams, "president of everything basically." When she displayed symptoms of cancer, Participant 9 attributed them to fatigue from being so involved. Looking back, there are a lot of symptoms linked to the disease that she didn't even notice.

> *It was the weekend that my musical was finishing, I was at a cast party, and I was getting scrappy with all the guys. I was playing basketball and I got elbowed pretty hard in the face, and I got a bruise… that lasted a really long time. I also worked at a restaurant, and I remember having to go in late on two different occasions because I had really prolonged nosebleeds. I was like "well it's winter, it's probably just dry," and didn't really think much of it. And then I was on my senior trip, and I had this really weird chest pain that I've never had before. I remember calling my mom, and for me to complain about something was not really normal, I had a pretty high pain tolerance…*

She later fell asleep in the middle of a family party on Easter Sunday, which was very out of the ordinary for her. Her mother took her to the physician's office, and tests results came back saying that she was slightly anemic. As a Family Nurse Practitioner (FNP), her mother thought there was more to the story than that. Further tests came back negative, and they made the decision to go to the hospital because something was not right. She was admitted to the hospital immediately, and was diagnosed with acute myelogenous leukemia (AML). Participant 9 then spent six weeks inpatient, and went to an outpatient clinic for the remainder of treatment. She also received a bone marrow transplant from her sister. She did not finish out her senior year of high school, but graduated on time. She then took her first semester of college off to prevent infections after the bone marrow transplant; she even had all her immunizations readministered. She attended college second semester, but found it difficult to transition because other freshmen had been together for an entire semester. Participant 9 was shy to share her story with her college friends, even though no one knew her background. Over time, she became more comfortable sharing her story. Becoming involved in a survivorship group where she was surrounded by others who understood her experience also helped her come to terms with her cancer diagnosis.

She always wanted to do something in the healthcare field, and her experience as a cancer patient solidified the desire to become a nurse. Participant 9 enjoys connecting with her patients through their shared experience. As a patient, one of her nurses shared her survivor story with her, and she remembers thinking "this is so cool, I can get past this, and I can do this." Now having patients of her own, she will share her cancer story and encouraging words with patients after building trust with them. Participant 9 feels her cancer experience helps her be a better nurse and have a better bond with her patients, "it really does mold and shape who you are in the healthcare profession, and how you treat other people and patients."

Participant 9 works to always have a positive perspective in life, and does not live in fear of secondary cancers. She leads a well-balanced life, but does not obsess about every habit. She feels that a secondary cancer could develop regardless of practicing healthy habits 24/7.

> *I mean it might not be the best attitude to have, I probably should be a little bit better about it, but even people who strictly eat vegan, no gluten, and don't have sugar in their diets, are still getting diagnosed with cancer, and it's no fun. So I'd rather have cake I guess [chuckles].*

The most impactful late-effect of her treatment related to fertility concerns, but her husband and her have adopted two baby girls. She is extremely appreciative of the life she has been able to lead, and feels that her cancer experience has helped her develop that thankful perspective.

Participant 10

Participant 10 is a 24-year-old female living in the northeast United States. She was always involved in theater and academics growing up, and participates in theater productions to this day. Right before Thanksgiving, she remembers very vividly going to a doctor's appointment to examine a lump she found in her neck after theater practice. She also had bad itching in her legs, and for months physicians didn't know what the cause of the sensation was. At a follow-up for the itching, they found a second lump. Since it was the day before the holiday, Participant 10's mother and her went to get a chest x-ray to settle their nerves. From there she went to the hospital, and underwent multiple tests with the oncologist and his team. She was diagnosed with stage 4 Hodgkin's lymphoma at 12 years old, and was out of school for treatment for about four months. She returned in the spring while she received radiation therapy, and had her central line removed in early June.

Participant 10 kept the same friend group throughout her journey because her treatment process was over a few months, and commented how pleasantly surprised she was by the outpouring of support and kindness her community gave to her. She was also one of the first individuals involved in a local young adult survivorship program. Participant 10 became incredibly connected to other participants in the group because everyone related to struggles that the other members were facing. It gave her a strong sense of community, but hand-in-hand with that came the difficulties of seeing some friends lose their fight. The cycle of loss became very taxing, and she has since taken a step back in involvement.

Cancer shaped Participant 10's faith, and the experiences she had throughout her journey led her to believe that everything happened for a reason. But events after cancer challenged that mindset, so now she is unsure of the path she is on. But Participant 10 is choosing to live each day in the moment. For instance, she went to college for art history, because she preferred to dedicate her time doing something that brought her joy as opposed to what was most ‘employable.’

Participant 10 knows that she will have late effects from her cancer and her treatment, but she keeps it in perspective by telling herself that life could always get worse. With that, she is on the lookout for signs of secondary cancer. The fear of relapse and other future health concerns is less now than when she first ended treatment, and she chooses to not let that fear weigh down on her each day.

> *If it becomes a secondary cancer, it's going to happen, I'm not going to be able to do anything until it happens. So [the fear] there and it’s always there, but it’s not my first priority. I’m just like, “I’ll be worried about something else today.” And it is one of those things where even though it's always hanging over me, in some ways it's a good thing, because it keeps me from doing stupid things. Like, I'll be getting bogged down, and then I can be like “I don't need to worry about this.” Or like, thinking about, this is really just a second of my life that I don't need to spend this much emotion on. It does put things in perspective a little bit.*

She realizes that she can’t necessarily prevent it, but she can catch things. Participant 10 makes sure to stay up to date with follow-up appointments and trusts her medical team to notice anything out of the ordinary. Her team treated her cancer very aggressively, and she appreciates that they were so open with her about treatment options and their decision about her course of treatment.

> *The fact that there are doctors willing to try things, I feel very confident about that. And also having people like [her radiologist] in my corner, who are following up with me, and I trust him to a T. So I feel like enough people are watching it that, if something does happen, I'm going to be ready. It's something that's always in the back of my mind, but I'm kind of just expecting that… it’s more of a question of when for me. I feel like I'm going to have to deal with it again at some point, so the best thing I can do is catch it early.*

Participant 11

Participant 11 is a 24-year-old female living in the northeast United States. Throughout high school, she was involved in track and field, rigorous academics, and was a pretty "basic, normal, teenager." In the late fall of her sophomore year of high school, she noticed an itch on her legs. "I would itch, and it would open small scabs all over my lower leg. Kind of like, I don't have psoriasis, but kind of looking like that - small little patches like from my knee to my toes." She went to a dermatologist for a few months and received treatment for the rash, but the condition didn't go away. "And they were kind of like 'we don't think it's actually itchy, we think you are having a compulsory tick or something.' And I was like, 'no, it's just super, super itchy.'" Then one day, she found a little bump near her collar bone. "I thought 'That's kind of weird,' maybe I slept weird, but then within like two weeks, both of my collar bones were huge. It wasn't painful, but it looked like I had huge muscles on my neck." They went to her pediatrician and had some testing done. Everything came back negative, but her pediatrician still had a feeling that something was off. The physician sent her to the oncology unit at the hospital, "and I honestly don't think I really knew the term oncology" The oncologist, after seeing her legs and feeling her neck, predicted cancer. "In my head I was kind of like 'this guy is really on one … there's no way.'" He recognized her leg itching as a symptom of Hodgkin's lymphoma, and feeling the swollen lymph nodes in her neck, he ordered tests to confirm his suspicions.

Participant 11 underwent chemotherapy and radiation for about a year, and was able to attend school for a majority of treatment. Despite being with her peers, she still felt disconnected from them. She attributes the separation to her not fully processing her diagnosis, and as a result being unable to help her friends understand it. Halfway through treatment, her friends introduced her to a survivorship group. Though hesitant at first, she was pleasantly surprised at how helpful she found the group. She found the deep level of understanding and unspoken connection between everyone there comforting as well as inspiring, showing that there is a life after cancer.

One life event that cancer took from her was a special sweet sixteen birthday party. She was able to celebrate with her friends by suppressing her exhaustion with medicine, but the day was not what she had expected, or hoped for, growing up. Overall, Participant 11 does not feel as though she has missed opportunities because of cancer, everything has worked itself out and she feels secure in life. She returns to the doctor for follow-ups once a year. Even years later, she appreciates the warmth with which the unit treats her.

> *I just go [to appointments] alone at this point. So it's me, and a bunch of kids in the waiting room. Like "hi, I can barely fit on the bed, my legs just hang off." [chuckles] And it's so nice they all remember everyone, it's been years and I haven't changed that much in appearance, but I'm surprised they all still remember us and our names. I'm like you have enough people coming in here every day, like how? Maybe they see the good stories and like seeing us, normal as ever.*

Participant 12

Participant 12 is a 26-year-old female living in the northeast United States. After experiencing a bizarre shooting pain in her right leg when she was 14, she was diagnosed with osteosarcoma. She had nine months of chemotherapy and a surgery to remove several inches of bone. Before cancer, Participant 12 played softball, volleyball, karate, track, and other things; socially, sports were her outlet. However, the surgery left her unable to play sports, so she turned to art and architecture. She missed the end of her freshman year of high school and sophomore year due to her treatment schedule, so a tutor visited her in the hospital to keep her up-to-date with work. Three years later, her cancer came back in her lungs. Participant 12 underwent four more months of chemotherapy. She took the first year of college off to finish her second course of treatment, and afterwards attended college to pursue architecture. Since having cancer, Participant 12 keeps her health history private. Though she has a visible brace and people often ask questions regarding it, she refrains from telling people because "if I come out and say it was from cancer then people would freak out;" she wants to be seen as more than just a cancer patient.

Participant 12 was involved with a survivorship group, but being an older teen she did not feel strongly attached to the younger participants. However, she appreciates the connections and relationships she made with adults in the community. She says that it was comforting to be around people who truly understood what she went through. She spoke fondly of one girl she met during treatment; "we could commiserate together the fact that we were in the hospital all the time. We could share that hatred of being there, not wanting to be there, and we could understand what each other was going through."

She says that while she does not have regrets or resent her cancer, sometimes she does feel bitterness when thinking about how her "high school experience was kind of… crappy." But, when Participant 12 becomes frustrated with pains or limitations because of her leg, she reminds herself that she is lucky to be healthy, and is proud of the progress she has made.

Participant 13

Participant 13 is a 25-year-old male living in the northeast United States. He noticed bruises up and down his leg as well as bruises on his ribs after football practice when he was 13. He kept writing his many symptoms off to different things; he had a lymph node on his ear that they thought was from getting hit with a rubber band, they attributed the bruises to playing rough with his friends, etc. After coming back from a family trip in early January where stomach pains prevented him from eating for practically the entire trip, he finally went to the doctor. Participant 13 got bloodwork, thinking that he had mono. A few hours later, he got the call, and was diagnosed with leukemia. His first four months were in upstate NY, then after getting a second opinion on treatment, changed care to a larger city hospital a few hours away. He finished 35 months of treatment there. He thinks that it changed his life because the outlook of the physicians was much more positive than the first hospital. He says that he can never repay his parents for driving him to all of the appointments and treatments, he's so appreciative of their sacrifice for him.

Participant 13 comes from a very close-knit family, with an older sister and younger brother. The whole family was hit pretty hard when he was diagnosed, but everyone was very supportive throughout the process. It was a strong feeling of unity, like "we will beat this together." After treatment, he was told to stay away from contact sports for 40 months. To Participant 13's surprise, the providers gave him the go-ahead to start sports 15 months after he ended treatment. He attributes the fast recovery to the positive mindset that his family had.

He repeated the eighth grade due to missing half of the school year for treatment. Participant 13 said that it was difficult to see his friends move on to high school without him, especially on top of the fact that he was unable to play sports at that time. However, once he entered high school, the difficulties melted away because classes were intermixed. Participant 13 began volunteering for a camp for children affected by cancer shortly after treatment ended, and found that volunteering there helped him heal wounds that his survivor's guilt had created.

It helped him see that he was able to make a positive impact on others, that he was not helpless against cancer. He sees his cancer experience as enabling him to see the world through a positive lense, and to work harder in everything because nothing is guaranteed.

Participant 14

Participant 14 is a 23-year-old male from the northeast United States. He had always been an active kid who was involved in many sports throughout grade school. After his 7th grade football season, his arm started hurting. He had the pain for about a month before deciding to take further action, because he and his mom thought the pain was due to a football injury. Participant 14 went to the physician, and found that the pain in his arm was due to osteosarcoma.

Participant 14 received chemotherapy for a whole year and underwent surgery before returning to school the first time. He found it difficult to return to school, and was not comfortable sharing his cancer with the other kids; he just wanted to "be a normal kid again." Participant 14 remarked that it was likely due to age and maturity, because as he aged he was more comfortable and better able to eloquently share his story. He also broke his arm twice in high school, and had several surgeries to fix it. Overall, he had upwards of six surgeries on his shoulder, ending with his rotator cuff being removed. The course of treatment was hard on Participant 14. From losing his hair and being tired, to not being able to play sports, he resented his cancer for years. Attending a summer camp for children with cancer, and eventually working at it, helped him move past the resentment. He saw that there was a life beyond sports after meeting other children who were in similar situations. Being around cancer survivors, and working with children who lost a sibling or parent to cancer, helped Participant 14 have an appreciation for his health, and he now sees being a cancer survivor as a major part of his identity.

Participant 15

Participant 15 is a 25-year-old male from the southeast United States. He was diagnosed with cancer right after his freshman year of college, and took a medical leave from a northeast university to attend the university in his home city. He lived at school throughout treatment, in a dorm right next to the treatment center. He began chemotherapy and surgery over the summer, and continued weekly chemotherapy and radiation therapy throughout the academic year. After one year of treatment, he returned to the northeastern university.

Participant 15 made the decision to keep his health private from peers because he is in a military program, and does not want to be seen as inferior. Beyond keeping his health private in order to be treated equally at school, Participant 15 says that physically adjusting back was extremely difficult. He says that he tried to pick up training and athletics quicker than he should have, and "ended up burning out."

Through his cancer experience, he joined a survivorship group that went on nature outings, such as white water rafting and hiking. He enjoys his involvement with this group, and it is a way to integrate his survivor status with his identity, given the rigidity and uniformity that his military life requires. He appreciates how lucky he was throughout his experience, from having a smooth treatment journey, to adjusting to 'normal' life quickly and having minimal late effects. He recognizes that it is not the case for many other patients, and tries to help the cancer community as much as he can.

Participant 16

Participant 16 is a 25-year-old male from the southwest United States who spent a majority of his childhood in boys homes or homeless shelters. He then moved in with his grandparents less than a year before he was diagnosed with cancer. In 2008, at 14 years old, he was diagnosed with stage 4 osteosarcoma after an injury he sustained in gym class. He had treatment three out of his four years in high school, and missed all of his freshman year of high school due to 18 rounds of chemotherapy; 5 days inpatient, 2 days at home, with surgeries intermixed. A home-tutor came to his home to help him stay on top of his school work. Transitioning back to school after missing his entire freshman year due to treatment was very difficult. Most of his friends from school disappeared, and he found it hard to relate to the one true friend he kept throughout that process. His friend told him after the fact that she did not know how to best relate to him and support him, and she feared saying the "wrong thing."

He comments that overall, he had a very positive treatment experience because of his medical team: "[They] played such a huge positive role in my quality of life, and they knew how to create community for other kids that were currently under treatment." Part of this positive experience was due to being connected to other young adult survivors of cancer. He participated in a camp for survivors, and there met some of his best friends. Due to the nature of his treatment and cancer, Participant 16 does have physical long-term effects. He has an endoprosthesis, a very visible scar on his leg, and a slight limp. He fears some aspects of the future, not about cancer coming back, but about the inevitable end of his prosthetic. When asked if it worries him in the sense of physically not having a leg, Participant 16 said it's more of a fear about finding a romantic partner. He fully embraces his identity as a cancer survivor as helping him find his purpose, but fears that an amputation will make it that much harder to find someone who loves him. But being involved in the camp and meeting other survivors enabled him to envision a life after cancer, easing his fears about finding love later in life.

A counselor Participant 16 met at the summer camp became one of his closest mentors throughout high school and college; “it was the first time I ever had a fatherly figure, a big brotherly figure in my life.” Participant 16 lost his grandparents soon after high school, and this camp counselor brought Participant 16 under his wing, playing a large positive role in his life. The camp counselor connected him with a fraternity at college. The fraternity “really embraced who [he] was,” helping him make the college transition and embrace his identity as a cancer survivor. He became involved in the Dance Marathon movement while in college, and now works with Dance Marathons across the country. Ultimately, Participant 16 feels that the opportunities he’s had since his diagnosis outweigh the few missed opportunities.

Participant 17

Participant 17 is a 21-year-old male attending a private university in New England. He is from the northeast United States, and grew up being very active in academics and sports. The summer going into his sophomore year of high school, he noticed severe hip pain. Doctors originally believed it was a bone infection, but after a biopsy found that it was leukemia. Participant 17 says that at the time, he did not have a perfect understanding of the diagnosis because so much was happening at once. Over the first two weeks, chemotherapy was not working effectively. They began looking for a bone marrow donor, and found his brother to be a perfect match. “It was unbelievable. Just like really, really, emotional for everybody involved” After the transplant, he stayed in the hospital for 30 days, went through radiation, and a 100-day at home recovery to prevent infections. He returned back to school in January, and within six months of his diagnosis was pronounced in remission. Tutors came to the hospital to keep him up to speed with school work, and as a result he did not have to repeat a grade. Everyone gave him a warm welcome when he returned to school, and he recalls how supported he felt by the community.

During treatment, Participant 17 said that he “was not himself.” The fear of dying took over, and he got “stuck in his own head.” He was able to get out of that “dark place” once he found out that his brother was a perfect bone marrow match. Throughout the rest of high school after treatment, Participant 17 saw survivorship as a large part of his identity. He viewed college as an opportunity to break away from the label ‘the kid with cancer’ that he bore in high school. and was excited to be seen as everything else he is in addition to being a survivor.

Whenever possible, Participant 17 tries not to think about his cancer history. He does not necessarily think that is a good thing, and feels that he should take initiative to talk to a person or have an outlet to share his thoughts and feelings. Limitations he has due to late effects, such as fatigue and the inability to play sports, weigh down on him from time to time. He is frustrated that he still experiences these effects years after treatment, but tries to keep his problems in perspective and appreciate each day. There was a time where he wanted to be a doctor, however he does not see himself working on an oncology floor. He would love to be involved with volunteering for cancer patients in the future, and wants to show them that they have the strength to beat their cancer.

Participant 18

Participant 18 is a 22-year-old male from the northeast United States, currently attending school at a mid-size private university in New England. During the spring of eighth grade, he began noticing a pain in his side that he attributed to indigestion. The pain continued to progress, until he was physically unable to run during a baseball game. The same day, he had a very high fever, so his family took him into the emergency room. The physicians saw that he had an enlarged spleen, and after running tests, diagnosed him with acute myelogenous leukemia (AML). Following his diagnosis, he had four rounds of very intense chemotherapy. During each round, he was in the hospital for six to eight weeks at a time, with one week off in-between rounds. He relapsed about two months after his last round of chemotherapy. Participant 18 received more inpatient chemotherapy and a bone marrow transplant during his second fight. Friends came to the hospital to visit him during his treatments, but after his bone marrow transplant,visitation was strictly limited. Participant 18 did not return to school for about a year because he had to be cautious about being in public areas during the flu season after his transplant.

Before cancer, Participant 18 was extremely involved in sports. However, cancer treatment and time off made it difficult to return. He turned to other activities and sports to fill his time, such as throwing javelin, but mostly he joined those to be with his friends. Participant 18's friend group was extremely close-knit throughout his journey; he even says that his sickness helped keep the group together when they transitioned from middle school to high school.

He has some late-effects of treatment. Participant 18 admits that he should probably be more mindful of the stress his body went through, and watch some of the foods and drinks he consumes. He refers to his medical team as family, and trusts to keep him healthy and always practice patient-centered care.

Participant 18 says that his cancer experience helped him become a more empathetic and positive person. He has learned to live each day as it comes, because he can not always control what the future holds. This mindset has enabled him to find the good in some of his late-effects. One of his most serious effects is that he is unlikely to have children, which was very hard to accept as a freshman in high school. But he does not see it as a negative anymore, because he says that there are other ways to have children and be a parent. "You can do a lot of good by not having your own kids and helping out someone who might need a home." Career-wise, cancer has directed his interests, because "some things speak to me more than they probably would have if I [did not have cancer]." He is interested in working for the American Cancer Society one day, or other similar organizations, and is excited to see where his career path takes him

Participant 19

Participant 19 is a 23-year-old male from the northeast United States, who currently lives in the south. He was active in sports and theater throughout high school, and challenged himself in academics. In the early summer of 2014, he noticed that one calf was far larger than the other after rugby practice. He thought that was strange, so he went to the physician's to get it looked at. He had a CT scan and MRI, a biopsy, and was later diagnosed with synovial sarcoma in the right lower extremity.

> *It was kind of just pure luck that I looked down one day and noticed that my calf was just severely bigger than the other, and then that we took the right steps to kind of follow up on that observation.*

Participant 19 started treatment two weeks later; he had three rounds of chemotherapy, a month of radiation, and surgery in mid-December. After surgery, he had more chemotherapy, and was completely done with treatment by March 2015. During treatment, he went to school for a majority of the time. He took days off when he was physically in the hospital and during surgery, but tried to line up his treatment schedule with school breaks so that he would not miss too many school days.

During treatment, Participant 19 appreciated how his friends treated him normally, and didn't focus on his sickness. He does not see being a cancer survivor as a main aspect of his identity, he wants people to see him for everything else that he is. This desire played into his decision to not participate in survivorship groups, because he wanted to finish the 'cancer' chapter of his life as quickly as possible.

In December 2019 he was pronounced officially in remission, and now continues with yearly follow-up appointments. After treatment, he did have a renewed appreciation for life, but he notes that it faded with time. He also acknowledges that the experience was very formative and that in the long run, it will help him to become a better person and medical professional. He went to college in the midwest, is teaching in the south, and preparing his medical school applications. He feels like he is exactly where he is supposed to be, and that "there's not much of anything that I would change, given the chance."

Summary

This chapter listed relevant participant characteristics in terms of current age, age at diagnosis, cancer, and characteristic details about their treatment. In accordance with the life course perspective and narrative analysis strategy, it also described a brief narrative of each respondent (Elder et al., 2003; Riessman, 2008). These brief biographies create context for the results provided in the following chapter.

CHAPTER 5. **RESULTS**

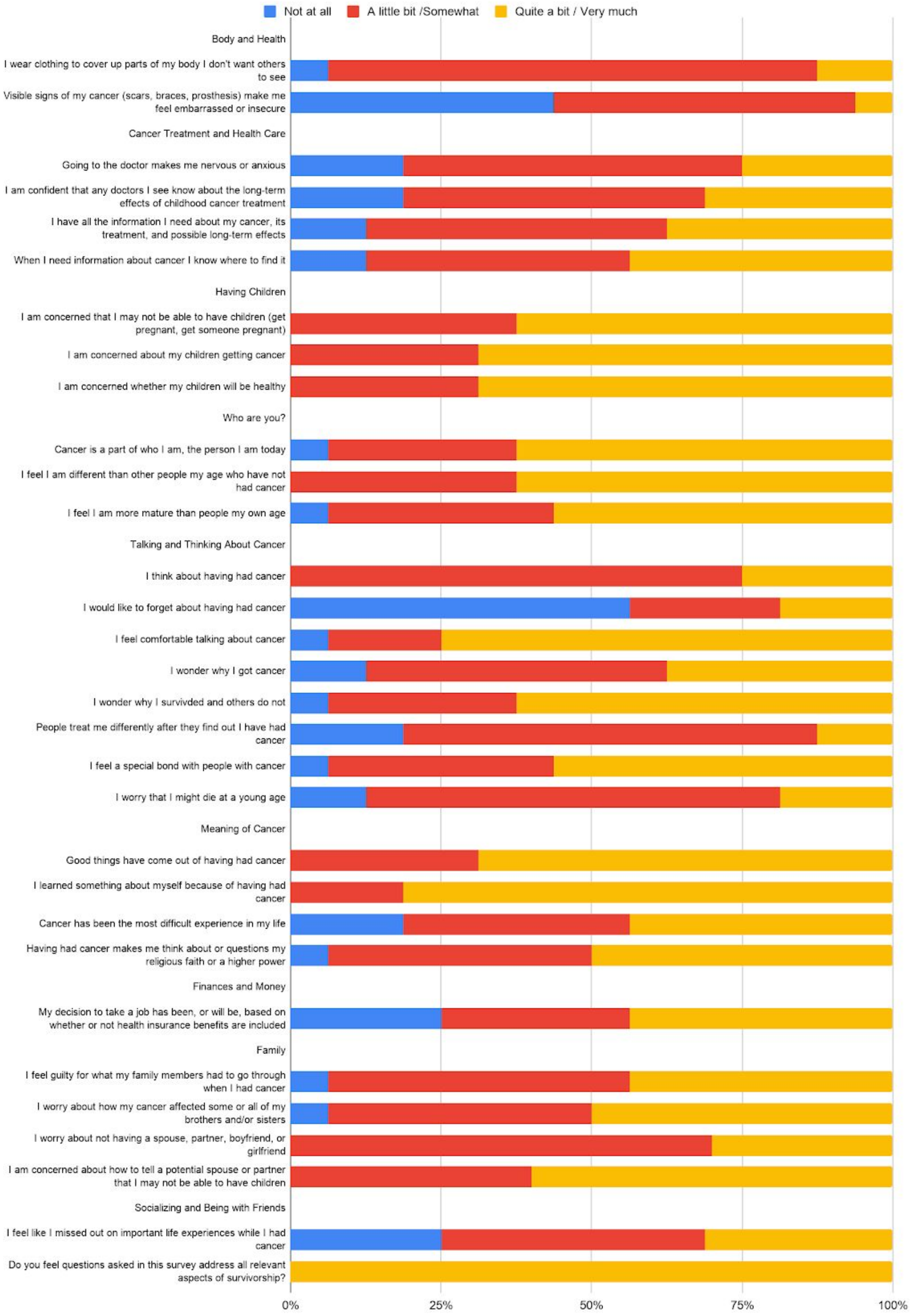
Introduction

Chapter 3 explained the rationale behind the chosen study procedures. Chapter 4 provided biographies about each participant, allowing the reader to conceptualize each participant and understand their interview responses in the larger context of their life. This chapter presents the results of the hybrid quality of life survey, the Impact of Cancer - Childhood Survivor (IOC-CS) scale, and interviews.

Quality of Life Scales

Before interviewing respondents, the researcher emailed them a hybrid quality of life survey, combining the Medical Outcomes Study Short Form-36, Quality of Life in Adult Cancer Survivors, and Quality of Life - Cancer Survivors scale. After interviewing each participant, the researcher sent the IOC-CS survey to each respondent. Sixteen respondents (84%) completed the survey (Appendix E). Of the 12 thematic categories, several questions had noteworthy answers, as well as answers in line with what one would predict someone who had cancer to say. Also, many questions were answered in accordance with what interviews revealed. Notable responses are shown in Table 4. The particular questions and answers were chosen because they reflect the topics and themes discussed in the interviews. As such, they are presented in the interview response sections.

Table 4: Impact of Cancer - Childhood Survivor Scale



Overall, participants preferred the IOC-CS survey to the first hybrid survey. Seven (44%) of participants responded with an increased satisfaction rate to the question "Do you feel that these questions accurately address all relevant aspects of survivorship?" and the remaining nine (56%) participants answered the same satisfaction rate. When asked to explain their answer, respondents described that they felt it to be more thorough, addressing topics that the first survey failed to measure. Participant 9, 16, and 19 critiqued elements of the first survey:

> *Questions could've pertained more to survivorship and what that looks like as well as relationships affected by cancer.*
>
> (Participant 9)

> *I think there should have been more questions regarding social settings and transitioning into friend groups again right after or during cancer treatment.*
>
> (Participant 16)

> *I feel that these questions miss the possibility of cancer affecting future actions, i.e. "Do you exercise more because of your medical history?" "Do you drink less?" etc.*
>
> (Participant 19)

Participant 19 then responded that he felt the second survey to be more encompassing. Participant 15 also felt that the first survey missed important topics of survivorship:

> *Although it touches on how social life is affected, it doesn't talk about social development as much. A lot of pediatric cancer patients experience issues with staying in touch with friends or keeping up with their social development during or after treatment. Additionally, many pediatric cancer survivors face issues with health or reduced life expectancy later on in life or impacts from anxiety surrounding follow up treatment and surveillance. Otherwise, touching on social, financial, lifestyle, and health impacts seems to be pretty comprehensive.*

She then described the IOC-CS scale as "a lot more clear than the first survey." Other participants also commented on the comprehensiveness of the IOC-CS scale:

> *This survey seems to have been written by those who have had similar experiences as me. The survey targets the anxiety that cancer creates when you are still trying to understand being a young adult. It considers relationships with peers and family. The impacts on*

> *the body become a point of anxiety when you still need your body for work, having a family, participating in social events. The questions about health insurance and the impacts on the body were particularly specific and should produce an accurate representation. The questions in the beginning about feeling comfortable with doctors who spoke to me - I only trust my cancer doctors to understand what I have been through and the true impacts on my body. My general practitioner often finds things out long after it has been discussed between me and my cancer doctor. No fault to them, but there's many variables they don't have experience with. The survey targets the right issues and pries into them more directly than the previous survey.*
>
> (Participant 12)

> *The emphasis on how it affects relationships with others is incredibly important and rarely seen in surveys like this.*
>
> (Participant 10)

> *These questions made me really think about the future and how cancer affects my future, many other QoL surveys that I have taken do not ask me about this*
>
> (Participant 4)

> *I think this survey addresses most of all the relevant aspects of survivorship, certainly the main ones, but it would be hard to address them all as survivorship is a vast experience and is unique to everyone.*
>
> (Participant 2)

> *It's tough to cover EVERYTHING, but this survey covers so much, including some things I've never really been asked about that really hit home.*
>
> (Participant 18)

Some participants wrote that the survey also sparked curiosity about other survivors. Participant 7 wrote in the first survey that she would like to learn how other people grew to identify as survivors:

> *I find it interesting as to how and if people identify as survivors. It took me 10 years to come to terms with the fact that I was a survivor. I never had chemo or lost my hair so I always felt that I didn't fit the description of what a cancer patient was.*

She continued in the IOC-CS survey:

> *I would be curious to know how many people seek professional help to overcome the mental challenges that came with cancer later down the line. I feel like I didn't have the*

> *psychological help I needed during and after cancer and I wonder how that would have affected my own quality of life.*

Participant 17 also wrote that he was interested in learning how other survivors felt about the life domains addressed in the IOC-CS scale:

> *The questions touched on things that I didn't even realize bothered me about my survivorship. They are all things that I would like to discuss more with those who have had cancer. The only thing that I am also interested in is how private others are compared to me in discussing their health history, and the way in which time passed affects that level of privacy, if at all. It touched on a lot of things I didn't even realize I felt.*
>
> (Participant 17)

Ultimately, participants felt that the IOC-CS scale appropriately addressed relevant aspects of survivorship, even concerning topics some that respondents had not previously considered as relating to their cancer.

Tracing the Trail of Survivorship

Following lives of young adult survivors of childhood cancer reveals three landmarks that alter the future trajectory of that survivor. These three checkpoints occur early in the journey of survivorship, and influence the domains of life that the Impact of Cancer - Childhood Survivor scale aims to measure.

1) <u>Age at diagnosis:</u> The age of a child when they are diagnosed separates cancer patients into two main categories; those who were younger and the diagnosis came before a majority of their identity formation, and those who were older, and the cancer diagnosis interrupted identity formation. Studies show that the age at which a person faces adversity impacts their eventual perception of and attitudes towards the event (Rutter, 1985; Elder et al., 2003). Did cancer shake an older child's sense of security and sense of

self, or has cancer been all they have really known? The impact of cancer depends on the ability of the patient to make sense of illness-related events, and age is a large determinant of that (Haase & Phillips, 2004).

2) <u>Transitioning to life after cancer</u>: The transition process the child undergoes after treatment further separates survivors into different tracts. Did the child feel isolated by their peers (Vance & Eiser, 2002)? Did they experience a major friend-group shift (Elder et al., 2003)? Did people perceive them differently after finding out the person had cancer (Goffman, 1963)? Young adults who felt disconnected from peers when transitioning back to 'normal' life had more negative experiences than those who reported strong friendship support networks. Research shows that social support networks may provide an important buffer in mitigating potential adverse outcomes of difficult experiences, as they create positive experiences that can restructure cognitive conceptions of cancer (Lazarus & Folkman, 1984; Rutter, 1985; Coyne & Downy, 1991; Decker, 2007).
3) <u>Knowing other childhood survivors</u>: For any given life experience, there is a difference between feeling supported and feeling understood. Not knowing or connecting to others who share a certain experience may exacerbate feelings of isolation (Goffman, 1963; Haase & Phillips, 2004; Decker, 2007). Young adults who feel understood because of knowing other childhood cancer survivors reflect on their journey and lessons learned differently than young adults who do not know other survivors.

These three key checkpoints in a childhood cancer survivor's life drastically impact the late effects they experience, how they cope with stressors, and the meaning they draw from life experiences. After presenting the results of the three landmarks, the chapter will conclude with the attitudes concerning IOC-CS survey domains.

1. Age at Diagnosis

The first checkpoint that childhood cancer patients pass is the age at which they were diagnosed. Some patients have no recollection of their diagnosis and treatment. For them, cancer has been a part of their entire life, they know nothing different. For other patients, their cancer diagnosis interrupted memorable times in their life. They distinctly remember a "before" and an "after." This distinction separates cancer survivors into two main categories.

No Memory of Diagnosis or Treatment

Participants 1-6 (32% of the sample) were diagnosed when they were less than five years old, and do not remember life before treatment, during treatment, or immediately after treatment. Therefore, life as a cancer survivor is all they know. Each participant has early memories of doctor's appointments and hospitals. Participant 3 said that the hospital was always her "normal" and did not realize that other children did not have as many appointments until later in life. Participant 5 spoke about the anxiety she sensed from her mother before follow-up appointments. The aura surrounding the doctor was an indicator to her that the appointments were "different" than her siblings, but it was years before she understood why her mother was nervous. Some participants even recalled their families making special occasions out of appointments. Participant 4 explained how her mother made trips to the doctor a positive experience; the whole family joined, they would go out to lunch afterwards, and even bring stuffed animals to the hospital. "[My mom] didn't want me to be scared or anything," Participant

4 said, “she tried to make it a good experience. She is grateful that her family put so much effort towards preventing her from developing a fear surrounding the doctor.

Despite knowing from an early age that they were cancer survivors, that term was an abstract concept to these participants. Participant 1 talked about her early experience at a camp with other childhood cancer survivors, and how it was difficult to comprehend.

> *I definitely understood cancer, and I understood chemotherapy, and stuff that we know 9 year olds should not know. I just didn’t quite... I had a hard time understanding as a kid that that was also me. Looking at pictures of myself going through treatment, it doesn’t feel like me at times, because I don’t have those memories. Now I get it because I’m older as an adult, but as a kid I didn’t.*

It took years before many of these participants fully understood what had happened to them. Participant 1 says that it was not until her teenage years that she “started to do research, look into it, and really get to understand what I had been through and what I can expect as an adult, having had gone through treatment.”

Cancer Interrupted Life As They Knew It

Participants 7-19 (68% of the sample) remember both life before cancer, and life after cancer. They each have vivid memories from points along their journey, and several participants commented that they believed remembering specific dates and moments bonds survivors together in a special manner. For example, Participant 16 said “I find it really fascinating in the pediatric cancer world that we remember dates very explicitly through our journey, I think it’s really cool…” Similarly, Participant 7 remakred “weird things [like dates and details] stick in your mind when you’re going through this whole process.”

Several participants spoke about their cancer diagnoses as a turning point, the beginning of a ‘new chapter’ in their life. Participant 7 remembered her diagnosis at age nine because it directly followed her family move to a new area. Her adjustment to the new school was difficult, and the struggles were exacerbated by the trauma and isolation she experienced when she was diagnosed and going through treatment. These two major life events occurring back-to-back left Participant 7 resenting her new home, and viewing her old home as an Eden-like oasis. Participant 10 likewise viewed cancer as the beginning of a new chapter of her life, one centered around cancer.

Participant 16 saw his cancer diagnosis as interrupting a chapter in life that he was excited to begin. He grew up with an unstable childhood and remarked that the uncertainty “played a huge factor in not really knowing who [he was].” After moving in with his grandparents and entering high school, he thought he was entering a new stage of life, a new beginning. All he wanted to do his freshman year was try out for the high school baseball team and be involved in student council. But just as he was beginning to focus on those goals, to build solid friendships and “trying to figure out who he was and trying to fit into the social dynamic that is so confusing,” he was diagnosed with cancer.

> *Prior [to cancer], I moved so much that I never really knew who I was. And so cancer became my first identity, which is really an interesting experience… because before, I had a bunch of interests, but I never had true hobbies as a kid. I did little league, but had to be pulled out of it because of circumstances, I had soccer but had to be pulled out of that. So it wasn’t necessarily anything consistent, but the first consistent thing in my life was cancer, which is really interesting.*
>
> (Participant 16)

Participants 8, 12, 13, 14, 17, 18, (26% of the sample) further specified that their cancer interrupted exciting athletic phases of their life. Using words such as “heartbroken,” and "devastated," they saw their diagnosis as a negative experience that cut short activities that they loved. Participant 12 said that her "life really did revolve around sports and things of that nature," and that it has changed dramatically since then. Her treatment included a surgery that fused her right ankle, leaving her unable to play sports. She shifted her energies to focus on other activities, but it was still quite an adjustment. She also said that being diagnosed as a teenager "throws a whole another monkey wrench into things." She explained that the unique age combines the difficulties of childhood, where cancer consumes every hour of every day, and the difficulties of adulthood, where individuals have a better understanding of cancer and all that comes with it.

> *Kids are kind of in some ways more resilient. Teens are really when you're developing things… You're picking your career, learning how to interact with people your age, developing your personality - your adult personality starts to develop then. You're learning how to cope with adult things like driving or finding jobs. So it's like a different challenge I guess… And then when you're an adult… I don't know, treatment is so different when you're older I think, or that's what I've been told anyways, I don't know If it's true. But it seems like for the most part, from people that I know who are older that have gone through treatment that it's less intense, and might not impact your day to day life as much. Maybe that's a generalization, but I still feel like you do the same stuff everyday. So as a teen I feel like how you are perceived by peers is a lot of different cuz people are more aware of what cancer is, and they're kind of more aware of how it makes you and them different, maybe. Where in kids they just kind of embrace you no matter. I don't know, that's just my thought [laughs].*
>
> (Participant 12)

Young adult survivors of childhood cancer can be separated into two broad categories; those who do not remember their journey, who were diagnosed as young children, and those who do remember their journey, who were diagnosed as older children or teenagers. Those who do remember their journey also tend to describe cancer as interrupting important activities in their lives, laying the groundwork for some to drive separation between their cancer and themselves as they age.

2. Transitioning Back to Normal Life

Transitioning back to school and navigating life after cancer is the second checkpoint at which childhood survivors arrive. Factors such as conspicuousness of late effects, friend group cohesion, social support, and the desire to feel normal impacted how young adult survivors navigated the social landscape of school and beyond.

Late Effects Single Survivors Out

For Participants 1-6 (32%), adjusting back to school was easy, because they never had an extended absence due to treatment. Physical late effects, however, labeled them as different and posed challenges to 'fitting in' in subsequent years. Participant 2's late effects began to make school difficult; hearing loss made it near impossible to concentrate, and severe GI distress brought intense pain and discomfort. The effects impacted her life so significantly that she decided to leave middle school and finish her GED through home-schooling.

Her late-effects continue to affect her today; at her first job, a coworker found out about her cancer history and these late effects, and began to use them to discriminate against her. It resulted in a large issue that year, and while it was ultimately resolved, the experience has stuck with her. "There are people who for some reason they think this is a weakness or something that they can target, and I was doing the same job as everybody else, so that was unfortunate." She also has anxiety about how her conditions will impact her professional career as a child life specialist, but feels very supported by those she knows in the profession and they put her mind at ease.

Participant 3 wore a foot brace for a majority of her school age years as a result of her treatment. “It's definitely super ugly. I mean it's like this huge plastic thing,” she said. The physical marker of her illness, along with her limited mobility, made her stand out in school. Participant 3 also mentioned that she was singled out in gym class because of her limitations. So, she worked hard to improve her physical abilities and reduce the time she was required to wear her brace. Participant 3 said that once she was no longer required to wear the brace, kids at school did not draw attention to her limitations. Similar to Participant 2, she fears that her disability will negatively impact her career. Her treatment affected her balance, and as a result she cannot put on the personal protective equipment according to standard guidelines. She worries that management will not be tolerant of her accommodations request.

Participant 6 found it difficult to make friends growing up because of the visible indicators that she had cancer. She remembers going to public places when she was bald from treatment, and seeing other parents take their kids away. They acted as if her sickness was something contagious. She attributes the hurtful behavior to a general lack of understanding and unawareness about childhood cancer:

> *When I was growing up it wasn’t really as known, so the kids didn't know what was going on. Whereas nowadays, I think it's more present, so people, the kids, understand more, to not pick on that person, but I had nobody growing up. I was bald up until… I still have bald patches right here [motions to top of head], so I was bullied and whatnot growing up.*

Though Participant 16 was diagnosed when he was older, the timing of his diagnosis matched his transition into a new school. As such, people did not know his cancer story, but immediately recognized him as ‘different’ because of his late effects. “I was definitely labeled as the cancer kid” he said, because of his physical markers. “I have a brace because of having an endoprosthesis, I have an exterior visual of having cancer, a very apparent scar from the middle of my thigh down to my ankle, where the internal prosthetic is.” High school was already a large transition for him due to his unstable childhood, and being immediately labeled as the sick kid before fully settling in made matters even more difficult for him.

Survivors of childhood cancer who were diagnosed and treated as young children completed their journeys before entering school. While they were not absent for long periods of time due to treatment, late effects drew attention to their differences. These survivors report varieties of difficulties in school because of their late effects.

Friendships Provide a Buffer

Participants 10, 13, 18, and 19 (21%) said that strong friend networks both made treatments more bearable, and eased the transition back to school. Participant 13 commented that despite repeating eighth grade due to missing so much school, his friends were very proactive about hanging out with him. Some of his close friends even slept on the floor of the hospital when he was inpatient. Their dedication made Participant 13 feel supported during treatment. He said that it was difficult to return to school the next year, when his friends moved on to high school. The feeling was intensified because Participant 13 was unable to play sports at the time, so there was nothing to keep his mind off of things. However, future years erased those hardships because many classes were intermixed, and he was reunited with his friends.

Likewise, Participant 18 remarked that his cancer kept the friend group united as they transitioned from middle school to high school. The effort his friends made to visit the hospital and spend time with him while he was at home kept the group close-knit.

Participant 10 also did not find it tough to maintain her friend group during treatment. In fact, her friend group grew; during her absence, her friends grew close to other people, so when she returned to school, Participant 10 became close with the new individuals. “It was pretty cool because that could go a lot of different ways, but it went pretty well for me.” Participant 10 also reflected on how being sick really brought out the true colors of other people. She learned unexpected positive character traits about others through her experience:

> *It opened up my eyes to some people. There was a guy I was in theater with, I remember him sending me flowers in the hospital… and I was so surprised, and now whenever someone brings him up that's the one thing I remember very vividly. I’m like “he sent me flowers when I was in the hospital.” There was one girl who I remembered being really broken up about me being sick. And at first I was really surprised and thought it was an attention thing or something like that. But since then I got to know her more and realized what a sweet person she was. And so it’s really interesting, because you sort of learn from what happens to you how other people actually are. You know, people you might not have expected much from. And I still have a whole bunch of cards that people made me when I was sick, and there's a lot of them that are just lovely or said really kind things. And I'm just like I barely spoke to this person and they still came out of the woodwork to do this for me.*

Participant 19 appreciated how his friends treated him like his normal self throughout the process, and not as just a cancer patient. Some would even take days off of school to visit him in the hospital. It frustrated Participant 19 when people would ask him, while good-intentioned, how he was feeling. The conversations got repetitive, and at the end of the day he wanted to be treated like himself again.

> *The biggest thing that pissed me off was that no one ever had any other topic of conversation… it gets to the point where you have the same conversation 60, 70, times a*

> *day, and you're just so sick of it that you would literally rather talk about anything else. And so the best support was when [my friends] would just talk to me about what funny thing would happen at school, or what they were gonna do that weekend, or asking me where I wanted to go, and then we would go out and do something. That was just like what we would do any other time. Not letting the illness, or the effects, or the treatment, be the first thing that they saw, seeing you for who you were beyond all of that.*

He further elaborated that it was most helpful for friends to treat him 'normal' because constant gestures of "let us know what we can do for you" made him feel like a burden. Participant 19 explained that patients already feel like a burden to others by being sick and needing assistance at times. Someone telling them to 'reach out' puts a load on the patient, ostracizing them even more. He said that he wishes supportive friends and family would just do something, no matter how big or small, instead of putting the patient in a place where they have to accept being a burden to others.

> *I think the least effective thing was to say "just let me know if there is anything I can do." Because you don't want to be a burden, you don't want to impose on anyone else – at least I didn't. I kind of saw it as "this is my thing to do, and it shouldn't negatively impact you" Just being proactive and helping, not letting that person reach out because they're scared, they're in a situation that they have never been in before, and I would say 9 times out of 10 they are not going to reach out. You kind of have to make an executive decision and reach out in some way, whether it's just a card, gift card, coupon, whatever you want to do, don't just say "let me know if there's anything I can do" even if it comes from a really good place, just do something. Because anything is more appreciative than just making that person identify themselves as a burden. Because once you admit that you need help, it's like you are owning that burden, you're owning that you are dependent on somebody, and that's a tough pill to swallow.*

Cohesive friend networks helped participants keep high spirits both during treatment, when friends visited participants at home or in the hospital, and after treatment, when participants returned to school. Cancer brings much unwanted attention to pediatric patients, and participants explained that having friends who interacted with the participants as if they were not sick was a breath of fresh air.

Difficulty Connecting to Peers

Participants 8, 9, 11, 12, 14, 16, and 17, (37%) found the transition back to school challenging; it was difficult to relate to friends and peers, and they felt separation grow between themselves and their friends. Participant 16 remarked that he practically lost all his friends except for one during his treatment process. He reflected on how and why it was difficult to connect with that friend again:

> *She didn't know how to respond, she didn't know how to help me. And I think that is a common theme for a lot of kids who lose their friends, is that friends don't know how to support. And they hear those words, and they just don't know how to respond, that's really it, and they don't know how to be an active friend. Because I think when anyone that goes through tragedy, like it's really difficult – how do you respond? And I think it's so interesting, like they don't want to say the wrong thing, when saying the wrong thing is actually the right thing because they just know that you care.*

Participant 11 felt a similar disconnect between her peers and herself. Even though she was able to go to school throughout most of her treatment, treatment made her weak and limited her ability to participate in activities. The limbo between being sick and healthy put distance between her friends and her.

> *I think it was sort of the "I don't know how to be correct in asking you questions" so they didn't, and just kind of treated me the same. But you could tell there was that awkwardness, and I would joke about stuff, like with cancer, and they were kind of like "is it okay for me to laugh? I don't really know…" It was definitely much of a more distant relationship, mainly because I was sick all the time, so it wasn't like a "hey let's hang out" sort of thing... I didn't know how to help them too much, just because I didn't really know how to process it myself, so then to try and help someone else process it was sort of taxing, sort of frustrating, but I guess expected at that age.*
>
> (Participant 11)

Participant 8 recounted how it was difficult to not only connect with her friend group, but to decipher people's true intentions following her diagnosis. She remembers girls who were not kind to her in high school suddenly doting on her and posting their condolences on social media, albeit not actually checking in on her. "I didn't want to go back because all the attention was on me, but no one was actually there for me… Everyone was like 'I'm [Participant 8's] friend, I'm [Participant 8's] friend' but didn't want to be my actual friend." The unsolicited attention made it difficult for Participant 8 to settle back into her friend group, and it caused her severe anxiety. Furthermore, as a teenager she wanted to partake in typical teenage girl activities, but struggled to connect with girls her age on common ground.

> *I never had a boyfriend, none of the boys like me in high school, obviously, and I was so sad about that, and like I feel bad for myself. Because I'm like why did you care so much about boys, it doesn't matter… Everyone's problems were just so dumb to me. And I felt bad, my friend would try to vent to me, and I'd be like "I don't care that you and your boyfriend or your girlfriend are fighting over like you looked at somebody else, you liked someone else's Instagram picture. This is dumb shit like I have real issues [referencing a friend who had just passed away].*

She regrets that her high school self exerted so much energy to fit in during high school, and at the end of her senior year she even thought about not attending commencement.

Participant 12 thinks that her friend group remained small because "cancer" and all it encompassed was offsetting to some people. "Going through treatment, I don't want to say scares people away, but it's kind of intimidating for people to see that whole process." She said she felt intimidated having to "reintegrate into society;" people around her did not understand what she went through, they could only see that she was bald and on crutches. She felt distant, as though people just saw her as "the girl who was forever on crutches." The feeling of being ostracized and labeled as ‘different’ leads her to keep her survivorship status private when meeting new people.

Participant 17 said that his community was very supportive, but the mental toll of treatment was debilitating. Like Participant 12, he was concerned about the degree to which his cancer would impact his friendships. As such, he became intentionally withdrawn during treatment.

> *Participant 17: I didn't, I just didn't want to [see friends]. I was reserved, and I wasn’t me, so it would have been weird for me to be hanging out with my friends when I wasn’t myself.*

Interviewer: What makes you say that? Did you physically lose your hair?

> *Participant 17: That, but also it took a mental toll like nothing else. Like I’ve given speeches about it, at Relay for Life and stuff like that, about how the mental aspect of it was just so much worse than the physical aspect of it. The physical aspect was of course, awful. I just went into a dark place. I guess the fear of dying was so prevalent that like, I didn’t, I don’t know. It was just a really dark place that I hated… it was awful, it’s hard to put into words. I guess I didn’t cope with it in the proper ways, instead I got quiet, stuck in my own head. So that was a rough time for sure.*

Participant 14 said that his inability to fully process what was happening contributed to feeling separation grow between himself and his friends. He was diagnosed with cancer mid-way through seventh grade, and missed months of school at a time over the next several years due to treatment and multiple surgeries. Participant 14 remarked that initially returning to middle school was difficult, because he was not comfortable sharing why his arm was in a brace, or why he was absent for so long. “I feel like it’s harder to explain things to people when you’re younger.” However, returning to high school was easier. He said he cannot explain exactly why, but thinks it was because his high school was so much larger than middle school that attention was not centered on him.

Since Participant 9's diagnosis came at such a transition time in life - the spring before high school graduation - she felt a lack of support from peripheral friends. She said they may have thought "well at the end of the year, it's senior year, we don't really have to deal with it." Participant 9 remembered that she had a few close friends who stuck by her side, so she did not feel completely alone.

> *I was kind of able to fully process [after treatment] that they kind of abandoned me when I needed them. That was really hard for me. But I've forgiven them and I've moved on, I know that they were only 18, so you know they weren't mature enough. Like I was put in a position where I had to be mature enough to face what I was facing, but they had the rest of their lives ahead of them, and they were headed to school, too. So they were at a place where they had a right to enjoy that, and to enjoy just being 18, and I can't really blame them for that.*

She took her first semester of college off to prevent infection following a bone marrow transplant. She returned that winter, and had a challenging time making friends because the rest of the class had been together since September. Participant 9 was embarrassed to explain to others why she missed fall semester, and was nervous to share her cancer history. As time went on, she became more comfortable. But ultimately it was difficult for her to transition into the new environment, compounding on having short hair, being the 'new kid,' essentially really 'sticking out.'

For some participants, cancer drove a wedge between themselves and their friend group. They attributed the separation to a lack of understanding and effective communication on both ends. Participants reported difficulties explaining their experiences to their peers in a way that someone not experiencing cancer would understand, and they believed that a similar challenge faced their friends.

Hiding Cancer Out of Fear of Being Ostracized

Eleven IOC-CS scale respondents (69%) marked that people occasionally treat them differently, and two (13%) marked that people often treat them differently, after they found out the individual had cancer. The fear of being treated differently often impacts how survivors present themselves to others. Like Participant 9, Participants 4, 7, 8, 11, 14, and 15 (32%) said in their interviews that they hid their cancer from peers at some times in fear of being ostracized and pitied. Participant 4 was self-conscious about her scars as a young child. As such, she did not want people to notice them. Similarly, thirteen IOC-CS survey respondents (81%) indicated that they sometimes wear clothing to cover up parts of their body that they do not want others to see. Eight respondents (50%) marked in a follow-up question that visible signs of their cancer occasionally make them embarrassed or insecure.

Participant 4 always made sure to have clothes to cover her abdominal scar to prevent people from seeing it and asking questions. Once, a dance costume exposed her torso, and she became anxious.

> *I worried "is my scar going to show, is it going to be okay?" and I think now I kind of just have grown to love it and embrace it, because it's a part of me, it's part of my story, it's who I am, and it's made me stronger.*

Participant 4 has since come to embrace her scar. She will wear crop tops with pride, and welcomes questions about her scars. Hearing messages of support from other people is validating and helps her have the confidence to go out in a bathing suit.

> *I was telling [someone] about [my experience], and she was like 'oh, you're a badass, like I respect you so much more because you've been through this… you're so much stronger than I thought you were." And hearing stuff like that is so amazing, and it helps me with the confidence to go out in a bathing suit, or in a bikini… and not have to worry*

> *about it. So I think now that I'm older, I'm like "you know what, I don't care, it's my body. Ask me what I went through and I'll tell you." So I'm not really scared anymore.*

She thinks that accepting her scars was a 'coming of age' thing. Just as she grew to accept her scars, she believes that other kids matured with age, too. Today, no one pays as much attention to her differences, as opposed to the kids in middle school and high school who "were just so brutal."

Participant 8, on the other hand, did not hide her scars (from over 33 surgeries) while she was sick. Her journey was so publicized that her entire school knew what was occurring as it happened.

> *One thing is that I never really stopped wearing bikinis or anything. And I forget that I have so many scars sometimes, and people are probably like "Yo, what the f*** happened," and not even in a bad way, I just forget about it sometimes.*

Now, she is more aware of her scars. Not because she is self-conscious about how they look, but sometimes she is not in the mood for the questions that are bound to come up. Her bald head during treatment was a telltale sign of cancer, but today, it is harder for people to tell where her scars come from. "I don't need everyone all up in my business about it," she said. She prefers her current anonymity to the special attention she received during treatment, and her scars are distinct signs that something major happened to her.

Participant 7 was fearful of being even more of an outcast at her new school. Absent for several days due to surgeries, she quickly became "that weird kid that just moved to a new school." She said at first she was embarrassed, and would cover up the areas where they performed the surgery because there was still gauze on them. She wore bandanas of all colors, and she laughed when thinking of how ridiculous she must have looked. Her first day she wore a baseball hat, and a school employee had yelled at her to take it off. Participant 7 responded that she wore the hat because she had surgery, but it confused her why an adult was yelling at her for something that another adult told her to do.

> *After that point, I did not wear hats for probably another couple of years. Because hats to me became a way of covering up my head, it came like a marker that I was different, it became a marker that I was trying to hide something.*

It was hard to fit in because kids would ask why she wore hats and covered her head, and Participant 7 did not want to tell kids that she had cancer. She did not want to talk about her journey with anyone, "it was just something that I wanted to bury." She just wanted to "be as normal as possible".

Participant 11 also tried to hide her sickness when she first returned to school. She was able to attend school during chemotherapy. She explained that "at first I tried to hide it while I still had hair. Because when you don't have hair there's no hiding it." She also did not want to bring attention to herself and detract from her brother's senior year experience. But Participant 11 felt that people grew more comfortable with her cancer history over time.

> *[At the end of high school], people started to feel a little bit more comfortable asking me about stuff because they kind of thought "oh she didn't die, guess we can ask her things now…" I think it's just as time goes on people are a little bit more comfortable with asking me or talking to me about things.*

Participant 14 was out of school from mid-seventh to mid-eight grade due to treatment and surgeries. When he returned to school with his arm brace, he did not tell many people that he had cancer. His hair had grown back by that point, but he was nevertheless afraid of being seen as different:

> *When I was younger, I didn't want anybody feeling sorry for me, I didn't want anybody giving me pity. I don't accept pity from anybody. So the only way I could not get pity from people, especially at a young age, is to hide it.*

In the months immediately following treatment, Participant 14 wanted to return to 'normal' and his athletics as quickly as possible. As time went on, he grew more comfortable sharing his cancer story with people.

Since many people do not fully understand cancer and how to respond to those who have it led Participant 3 to keep her journey private. "I guess I don't like telling people because I don't like having that pity party." She says that people who do not have a similar experience:

> *[They] just can't have an intelligent conversation about it… they don't really have knowledge, but they also don't have context. So when you say you had cancer, people just picture you sitting alone in the hospital with no friends, like all the [sad things]… which wasn't my experience.*

She does not want people to picture her experience as gloomy and lonely, because her family was very present and supportive.

Participant 15 said that he found it easy to balance school during his treatment because he was taking a lighter course load. However, he chose to keep his cancer private, both at the university he attended while receiving treatment and once returned to his original university after completing treatment, because he did not want to be seen as different. "I wanted to be normal, and I felt like it was a burden to everyone else, so I tried very hard to keep everyone out of that…" Participant 15 even remarked that two of his best friends found out about his sickness only because they came to his house unexpectedly. After treatment, he returned to the university up north, where he was enrolled in a military program. He continues to keep his health private, because he does not want to have differential treatment or be seen as inferior because of his health history.

> *They expect everyone to do the same exact shit no matter what, and if people knew that I was sick, I think that they'd treat me differently but in a bad way. So right now, my current boss doesn't know, will not know, no one in my company knows except for one*

> *friend who I've had for a while, and that's intentional. I don't want to be thought of differently, or be seen as weaker because of it.*

Furthermore, in the IOC-CS survey, Participant 15 described another element that added to his decision to keep his cancer private:

> *Although [medical costs are] covered by Tricare (military medical insurance), I try to avoid telling as many people as possible about it because I'm worried that I will be separated from the military if I have to take time away to see my oncologist for follow-ups. I received a medical waiver of standards for cancer to commission and attend several training schools, but that does not mean that the next military provider I see will be willing to waive the same standards. So, I tread lightly.*

For many participants, hiding signs of their cancer was an escape from the unwanted attention, and in some cases, a form of protection. They no longer wanted to be marked as 'different' than their peers; from scars to physical limitations, to the sheer knowledge that the individual had cancer, participants keep their cancer private unless they know they are in a safe space for sharing.

Cancer Impacting Ability to Perform Gender

Cancer and its aftermath made it difficult for Participants 7, 13, 14, 16, and 17's (26%) to perform gender when adjusting back to regular life. Being a cancer patient impeded the ability for some participants to perform their idealized conception of their gender, leading to role strain and feelings of embarrassment (Goffman, 1963).

Participant 7 felt a large amount of distress immediately following cancer, because she thought that she would not meet society's standards of feminine beauty. She believed that she would have to hide her head, wear sun shirts and never swim suits, for the rest of her life.

> *There's still that "I think I can be tan, I think I can be like everyone else," even though I can't. I'm still working through that… I'm very aware of society's standards of what is considered to be beautiful, and sometimes it's not always pale.*

She resented her cancer, and now actively works to overcome those feelings of not measuring up to society's definitions of beauty.

Participant 16 faced difficulties performing masculinity since his cancer treatment because of his brace and endoprosthesis. He felt an added pressure to "prove" who he was because of his physical limitations. At the same time, he was navigating coming out about his sexuality, adding another element of difficulty to transitioning back after treatment.

> *I wasn't out until college, and that was because of cancer, probably the biggest reason why I didn't come out, and because of my leg, and the opinions of other people, what they would think, and would I find someone to love me? So those were some things that I was focusing on all throughout high school and the beginning of college.*

Another element of performing gender that cancer hinders for patients is participating in gendered activities, such as playing sports to reinforce masculinity. Participants 13, 14, and 17, were so invested in athletics that they felt an aspect of their identity being stripped away after cancer. It was difficult for the young men to come to terms with not being able to play sports, and they use words such as heartbreaking and devastating to describe how being prohibited from playing sports felt. Participant 13's identity in high school was that of an athlete, a football player. He said it was devastating when doctors told him at his diagnosis that they predicted he would never be able to play sports again.

> *More than anything else physically, mentally, that was super draining as a 13 year old. I played sports almost all-year round so that was pretty rough to hear… That sticks out to me more than anything. I remember it clear as day, when they came in and told me that sports are kind of off the table for the rest of my life.*

Regaining strength and getting healthy enough to return to sports was a huge motivator for him during his battle. When Participant 13 was able to play football again, it was a huge turning point for him, because he thought "I know I can do this, then there is really no other stronghold that cancer has over my life anymore."

Similarly, Participant 14's cancer diagnosis took a toll on him. Going through chemotherapy, losing his hair, feeling tired and sick a majority of the time, was taxing. Furthermore, athletics were taken off the table permanently after multiple surgeries throughout high school, and the eventual removal of his rotator cuff. "It was heartbreaking," he said. He would still play pick-up games with his friends, and hid injuries when they occurred. Participant 14 has since learned how to adapt games to his range of motion, but remembers how devastating high school was, and how he resented his cancer for years because of it.

Participant 18 was heavily involved with baseball before his diagnosis. He was out for two years due to treatment, and trying to return to the sport was difficult. Treatment had made him weak, and the time off dulled his skills, so he could not compete at the level of his peers. "If you don't swing a bat for two years and everyone else has been playing while you've been getting physically worse, you're just not good anymore."

Participant 17 played basketball and other sports prior to his diagnosis, and also had to end his athletics career due to cancer. Late effects from treatment affect him to this day, and he becomes frustrated when he is unable to keep up with his friends competitively. He fatigues faster than his peers, and feels the need to explain to friends why he cannot lift as much weight, or why he needs more rest days. "At this point yeah I definitely do wish it hadn't been me. I don't wish it was someone else, but it's frustrating, it's been holding me back." His energy levels are lower than friends, and it impacts the activities he can do. But he also pointed out that leaving athletics allowed him to focus more energy on music, and it is currently a huge part of his life.

Other Difficulties

Participants also mentioned other unforeseen hardships in transitioning to life after cancer. Participant 19 commented that adjusting back to high school was not difficult, because he had a strong network of friends and teachers cut him a lot of slack his senior spring. It was more challenging, he said, transitioning into college.

> *I don't want to say that it was a formality, but [high school teachers] definitely let me slide on a lot of things… But getting back to college that first semester was just a rude awakening, because I hadn't done school in a long time. Like just to put it bluntly, I'd had a lot of passes, and I haven't had to study as hard because of senioritis, and now on top of that they're giving me more breaks. so getting back into the mindset of really pushing yourself, and like just being on top of your stuff, I thought that was… it took me awhile to get back into that.*

Transitioning back into a very structured social environment posed challenges to many participants. Many cancer survivors are suddenly labeled as the sick kid, and work hard to prevent that identity from being the only thing that others see. Hegemonic able-bodiedness creates negative attitudes, whether conscious or unconscious, towards those who are sick and have any degree of disability (Goffman, 1963; Campbell, 2009). Some survivors see friend networks as aids in overcoming these challenges, while others feel separation grow between their friends as a result of their cancer.

3. Support Generated From Knowing Other Survivors

The third checkpoint childhood cancer survivors reach is connecting to other childhood cancer survivors. Whether through special camps and survivorship groups, or simply meeting others during treatment, survivors draw meaning through these experiences. Fifteen interview participants (79%) recounted positive outcomes from knowing other childhood cancer survivors growing up, or being involved in a survivorship program. Nine (56%) IOC-CS scale respondents marked that they “Very Much” agree that they share a special bond with people with cancer. Themes such as feeling supported versus feeling understood, embracing one’s survivor status, and being able to picture a life after cancer because of meeting other survivors were vibrant.

Groups Help Survivors Embrace Identity

Participant 16 expressed that he had a very positive treatment process, not only because of the kindness with which his medical team treated him, but because they pointed him towards survivorship groups “Because yes, [doctors] have a roadmap for medical protocol, but what about that other side of healing?” He attended a camp for cancer survivors, where survivors would spend one week in the mountains over the summer together, being ‘normal teenagers’ again. Through this program he met lifelong friends, because the individuals could relate to him on levels that his other friends could not. “Your best friends really become those that are along your journey because they understand exactly what you’ve gone through.” Furthermore, seeing people who have similar late effects, specifically amputations, going on to succeed in their profession and creating families, was incredibly inspiring. One of Participant 16’s greatest fears is breaking his prosthetic, because one more break would lead to a full amputation. He has this fear not for physically losing the limb, but because he fears that it will make finding love, a romantic partner, and starting a family, more difficult. But knowing survivors and seeing them leading the life that Participant 16 envisions for himself gives him hope.

> *What's really cool is seeing some of my friends that I did go through treatment with, that do have an amputation, they're married and having kids. which is such an important part because that reminds me that if you can see other people that have gone through what you're going through, and having to life that you hope to live, you see the hope, that it is going to be possible.*

He met one woman with osteosarcoma through a survivorship group, and she inspired him to set a goal to make the paralympic cycling team. At the time, she was the captain of an olympic team and held five gold medals, an EPSY Award recipient, was on the cover of Sports Illustrated Swimsuit Edition, and had a family. The motivation behind his goal came from being involved with the survivorship groups, participating in the activities, and being surrounded by other amputees. Participant 16 said about the older mentors' achievements: "that opportunity to find hope, to find an outlet of their cancer journey... It's badass."

Similar to Participant 16, Participant 7 joined a group in college that helped her fully come to terms with her health history and embrace her survivorship status. She went to a Colleges Against Cancer meeting on a whim her freshman year of college. She struck a connection with the members so fast that she attended every subsequent meeting until she graduated.

> *And even still, being there for the first year so, I didn't quite always know how I could talk to other people. Because there were people who had lost parents, people who had cancer but maybe had it for years and years, went through chemo, so I was feeling like an outsider. Then there was this one girl, and she was in the club the same time I was, and she just gave me this pep talk one day. She looked at me and she was like "you ARE a survivor, you through all of this stuff, like don't downplay that." She was like "it doesn't make you anything less," and it was just like a big wakeup call for me because I*

> *was like "oh, yeah you're right," that this whole experience really affected me as a person, and it definitely affected my health.*
>
> (Participant 7)

She said she felt truly validated as a survivor when the upperclassman encouraged her. "It was that validation from someone who I knew had it a lot worse than I did, and them telling me 'your story is so important, your story is still worth hearing,' it was a really come-together moment. Participant 7's time with Colleges Against Cancer enabled her to embrace her identity as a cancer survivor, and come to a better understanding about how it affected her, because before she did not think that anyone would want to hear her story.

> *I found my community there, I found my people… You don't have to tell your story, you don't have to talk, but you know that you're in a room full of people that you don't have to explain yourself to, you have their support.*

The groups were incredibly helpful and instrumental for Participant 7 because she felt isolated as a cancer survivor.

> *And it's just hard if you don't have someone, that support. I didn't feel like I had any support afterwards, and because [my cancer] was more short-lived, it was kind of like "okay, you're done with cancer, bye!" and that was kind of it… I feel like if I could have looked up another nine-year-old who had malignant melanoma, my experience would have been completely different.*

She remarked that she wishes she had talked to someone, been able to share what she was going through, and work through processing the information with a professional. Having lacked that support during her experience, Participant 7 made it a mission to be that listener and support for others. She also set out to create a safe space in the organization, since she felt she did not have that for so long. She continued involvement with Colleges Against Cancer, and returned to Relay for Life after graduating to show her support.

> *I went back to Relay [For Life] last April, even though I graduated, and I met these two girls at the Survivor dinner. They both didn't really have a support system. They were*

> *international, and one girl got cancer when she moved to go to school from India. Can you imagine starting school in a different country and then getting diagnosed? And her family was very similar [to mine] in that they didn't really want to talk about it, they didn't tell her [extended] family that she had cancer because it was almost like a shame. And so I was photographing at the event, I told her to find me at the Survivor Lap and we could walk together, and they did. So we started walking, and I look over like two seconds later, and she's bawling because she's never felt this sense of support and community, so then I started crying. And I'm tearing up right now telling the story, because it was such a powerful moment, me being able to give back so many years later, because someone did that for me, and being able to do that again for someone was very full circle*

Participant 7's experience of feeling isolated and alone during her cancer, disconnected from both the healthy kids and other cancer patients, led her to bottle up for many years. The survivorship groups that she became involved with allowed her to reconnect to that part of her identity, and help her process the experience in a healthy way. More than anything, she did not feel alone anymore.

Meaning found through Support Group for Young Adult Survivors

Participant 11 found the same solace and understanding through a local support group. About halfway through treatment, Participant 11's friends introduced her to a survivorship group for teens and young adults ages 13-30 that have been diagnosed with cancer. At first she was very hesitant to join the group because she was not entirely comfortable talking about her feelings. When she did go, she found that it was incredibly different than what she expected. Similar to Participant 16, Participant 11 appreciated how everyone there understood what others were going through, opening up the conversation to whatever the participants were feeling.

> *It was really great because it was a space where I knew that I didn't need to answer questions for them because they knew everything I was saying. So if I was like "oh I hate the contrast, it's so gross," people wouldn't ask "what's contrast, what do you need it for, what does it do?" They'd say "oh my god I know, it sucks…" So it was great, it was*

> *more so just having people who you didn't need to explain everything to, and you also didn't have to share if you don't want to. Because it was like "these are people exactly like me, they get it they get it." If I don't want to talk about it, they get why I won't want to talk about it.*

She thinks the group also helped her transition after treatment, because she felt that the "hospital was so quick to say 'you're done we'll see you in three months,'' and did not provide adequate support during her transition after treatment. But since there were people of all stages in the group, both undergoing treatment and post-treatment, they were able to provide that critical support and show her what life after cancer can look like. "I think it's nice to see people who are 2, 3, years out, and I was like 'wow, they seemed exactly how I did before this, so there is that hope that I'm going to be normal again.'"

Participant 10 joined the same group as Participant 11 when she finished treatment, and stayed consistently involved for about six years. She was one of the first members of the group, the youngest of six people. Small membership provided many one-on-one opportunities to bond with other participants, for instance game nights and pancake breakfasts. The group also did events beyond group support sessions; they completed service projects, wrote grants to fund activities, hosted a cancer book club to educate kids in the community about childhood cancer, and organized a gala dinner, showcasing a performance by the young adults and teens in the group. There was a lot of reflection time at the group events, and Participant 10 said journaling as well as meeting other people with shared experiences helped her "understand a lot more than I probably would have otherwise."

Participant 10 grew very close to the core group of participants, "but the problem with it is exactly what it sounds like; we're all cancer patients or cancer survivors… people are going to relapse, things are going to happen. And we all knew that." Two friends she met through the young survivor's group passed away within a year. One girl went through treatment with her, her cancer relapsed aggressively, and "she was gone before we even knew what was happening." When another one of her close friends passed away during college, it was the 'final straw.'

> *I think that was kind of it for me after that. I came back, I did a few more things, and I remember I went to the gala that October after he died, and I couldn't do it. I was like "this is too hard for me" and I've seen other people leave for that reason, but I didn't think it was going to happen to me. That was the last thing, I was like "yeah I can't, I can't keep doing this." So part of it is definitely, you know, the loss factors… what made it really difficult to stay. But at the same time it might have also had to do with the further out I got from it, the less I felt like it was helpful to me in some ways.*

Participant 9 joined the same group of young adult cancer survivors, and had many positive things to say about her experience. Above all, it was healing to be in a space where she was understood that impacted her:

> *It was really nice to kind of show up and get that like everyone else there understood, they had been through the same. So for me it was very like healing to be able to just have a place to go where you could vent about some of these things, and talk to other people who got it.*

But after losing a few friends, similar to Participant 10, she needed space. Several years have gone by since her friends passed, and Participant 9 is ready to return to the group. She wants to volunteer and provide the same support services for others who need them.

Meaning Found at a Summer Camp for Children with Cancer

Participant 4 attended a one-week summer camp program for children affected by cancer from the time she was eight until she aged out as a camper, at 17 years old. The camp provided the same sense of understanding and acceptance to her that the survivor support groups provided to Participants 9, 10, and 11. Participant 4 said that being surrounded by so many people who shared her experience made her feel less alone. She also finds it inspiring to stay in touch with those she has met through the camp, and enjoys watching what they accomplish with their lives.

> *Because it's like look at all these kids who have gone through the same thing as you and feel what you went through. I still keep in touch with people… and seeing them growing up and going out and doing stuff is so cool because I know their story. And seeing these kids that had the same [diagnosis], it's really inspiring to get up and go out and do stuff in the world. Because we all have this new opportunity, this new outlook on life, and even just getting away from home life and stuff like that… some people don't have the best home life at home, and some of the kids were even still going through treatment, so being able to go to camp and not have to worry about the stuff for 5 days or a week, I think a lot of people benefited from being able to be like "for a week we're going to go out on the water and we're going to have fun." And do stuff like that, so I think for me, it was a getaway, and it was an eye-opener to see that I'm not the only one who was affected by childhood cancer, and I think that's a cool effect to have.*

Participant 14 also attended the summer camp for children with cancer. He was twelve years old during his first camp experience, and it was "the best time of [his] life." It took Participant 14 a few years to really understand what he had been through, and attending camp helped him work through those challenges. "I was not appreciative of breaking my arm, not being able to do sports. I was feeling sorry for myself, but being around camp and watching other survivors made me appreciate what I have now." Knowing other survivors helped Participant 14 come to terms with his diagnosis and no longer resent his cancer. After attending camp as a child, he chose to work there as an adult. He said that being a staff member has been more impactful than being a camper, because he was surrounded by other staff members who consciously chose to dedicate their time to helping children with cancer.

Participant 8 called the first summer after her diagnosis the "summer [she] shouldn't have made it." This was her first summer at camp, and although she spent each night in the infirmary instead of the cabins, she made lifelong friends.

> *Honestly, and I know this because that summer I was so sick, camp is literally the only reason I'm alive, I'm positive. Because first of all there's no reason for me to be alive, there's no way I should be alive, and camp has always been there….*

Participant 8 also said that camp reminded her that she was not alone. While family and friends came to the hospital to visit Participant 8 during treatment, at the end of the day, she was alone. "You're alone in your thoughts, and yeah your mom could be sitting with you the whole entire time and watching everything, but she doesn't know how you feel." And that is why camp was so important for her, because she finally was with people who understood. "Not that I would ever want it to [happen to others], but it's nice to not feel so alone." Furthermore, camp was a space where she felt normal.

> *But camp was so nice cuz everyone else feels like they have to be like "I know someone who had cancer, blah blah blah," or say something, but at camp you just freaking stroll up, and you don't even have to talk about it, you just know you can talk about it… cuz me and my family would make really weird jokes about being sick, they were super morbid and bad, but that's how we coped with it as a family. I would have to catch myself talking to other people, like "oh I probably shouldn't say that, that's kind of weird," but then you go to camp and you're just like "oh hahah my leg scar just ripped open, how are you doing? Oh, you don't have a leg, that's cool, look at this scar." I felt like a normal person before being sick, and then I felt like an outsider, but then going to camp it's just like home.*

Participant 1 said that being involved with the camp helped her connect to that part of her biography that she was unable to remember. More than that, camp was a place where she deeply connected with people similar to her, because she felt beyond her years and distant from other kids her age.

> *I really attribute to camp feeling a little bit more mature, beyond our years, feeling as though you don't react the same to situations as other people do. And I think that going through camp, as far as making friends and losing friends, and making new friends that are for life, and being able to have conversations about what we've been through, and*

> *conversations about our fears of the future… I think that definitely camp helped shape that because otherwise I wouldn't have stayed connected to those kids.*

Participant 3 did not meet many survivors who were also diagnosed when they were babies at the summer camp, but found solidarity with survivors who experienced similar long-term effects. Simply being with people who could understand aspects of survivorship, such as financial burdens and future health concerns, helped her feel less alone.

> *I haven't really met anyone at camp to be honest that had a similar experience that I know of where they were so young. But, I mean, it doesn't really matter – everyone kind of understands at least a little more than anyone you're going to talk to in the outside world, even if you try to explain it to them… So even just to have those other people and be like, oh yeah, this is something that is not just you, that is always a good thing. You never want to feel like you're the only one that had to deal with this.*

Participant 12 also did not feel like she completely connected with campers, but for the opposite reason; she was older than most participants. She also did not want to give cancer more focus and energy in her life than necessary, and remarked that "I did not want to throw myself into the organization because cancer was a temporary thing in my mind. I was thinking that I wouldn't be in the cancer world forever." However, she was grateful for the adults she met through the camp and another teenager she met during treatment. Participant 12 says that it was comforting to be around others who understood what she was going through.

Other People Who Understand

Participant 6 found solace and support from a close friend who experienced similar trauma in her life. The friend did not have chemotherapy or go through the same adjustments that Participant 6 did during her school years, but she shared draining fatigue and other late effects. This friend was involved in a serious car accident, and as a result has brain fog similar to what Participant 6 experiences. The friend also has a health condition that does not allow her to have children, and Participant 6's radiation to her pituitary gland makes it very unlikely for her to have children. Many people do not understand why Participant 6 feels fatigue in the early afternoons, why some activities cause intense headaches that keep her bedridden, or why she has to rest for a long time after having a full day of activities, but this friend in particular does. Later in life, Participant 6 volunteered for the camp for children who have been touched by cancer, and she finds fulfilment in being a mentor for them.

Similarly, Participant 12 met a young girl who was also in the hospital for long periods of time. She remarked that she appreciated the solidarity she felt with the young woman, as they could "commiserate together the fact that [they] were in the hospital all the time."

Did Not Find Support From Other Survivors

Participants 5, 17, 18, and 19 (21%) did not build connections with other survivors through participation in survivorship groups or programs. Participant 5 was diagnosed as a baby in Europe, and moved to America as a young child. As such, she was not exposed to many opportunities to join groups.

Participant 18 declined to participate in summer camps and programs that reached out to him. As a young teenager and a self-proclaimed homebody, the activities did not interest him. He also felt in an awkward limbo; he did not connect with people he met who were diagnosed as young children, but he didn't meet many teens with cancer. He commented that people who did not have cancer, or who were diagnosed as young children, were missing an element of understanding the cancer experience of a teenager. He appreciated the conversation with the researcher about survivorship, and said it was the first time he has ever talked about some of his feelings and experiences.

> *I've got a buddy who had it when he was six, and it's just different. Speaking to you right now compared to speaking to him about it, it's just different, it is. It's nice. Like this [motions between us] has been really nice. Like some of these things I've never even voiced.*

Participant 17 likewise said that he did not really participate in survivorship groups:

> *I don't want to say [I felt] alone because I was so well supported, but it was, I guess, hard to be understood, because I wasn't really talking to any other patients. I definitely wasn't attending any support groups and stuff like that.*

He knew a childhood cancer survivor, like Participant 18, but it was difficult to relate to the person because the younger survivor had a different cancer experience. For him, listening to music was a therapeutic experience and it really lifted his spirit more than other things. He attended a summer program in Arizona, where he met kids from all over the country who had cancer. Participant 17 said that the group was not as helpful in the same capacity that other participants said their programs were, rather, the program was a fun 'break from reality.'

Participant 19 also declined invitations to participate in cancer survivorship groups. He did not want to see being a cancer survivor as a main identity, and as such did not want to give his cancer more mental time and energy than required to beat it. Ultimately, he wanted to return to his previous life as quickly as possible.

> *A lot of [groups] reached out, but I think it just wasn't for me. It was definitely more like I didn't want [survivor] to be my identity, I didn't want to, I guess, accept the fact that [cancer] was happening. The way I got through it was kind of pretending that it didn't exist, and letting it take up as little of my time and mental energy as I could. And so I think one of the ways that I made that happen was by just not giving it more time or energy that it required. So, kind of just not reaching out to those groups, letting it only be a thing when I was physically in treatment or in the doctors, and other than that, just trying to keep life normal. Because that's what I wanted, honestly, that's what everyone*

> *wanted, to just be normal and have a normal life, and so I really just went as best I could for normality than anything else.*

Participants 17, 18, and 19, did not connect with other young adult patients through special programs because they did not view themselves as people who would benefit from those programs, as they were already late teenagers. Furthermore, they chose not to do partake in programs because cancer was temporary, and it was important for them to return to 'normal life' as soon as possible. The who did connect with young adult survivors through programs all reported feeling understood, no longer alone, and building a stronger connection to their survivor identity. It was important for their healing to be with those who were experiencing similar struggles, and to meet older people who have "come out the other side," who are living lives they hope to lead one day.

4. Long Term Effects of Childhood Cancer on Young Adult Survivors

Throughout the lifecourse of childhood cancer survivorship, individuals pass three landmarks; the age they were diagnosed, transitioning back to "normal" life, and finding meaningful connections with other childhood survivors. The lived experience of survivors at each checkpoint modulate their long-term life path, and ultimately shape how they view the world and draw meaning from their life experiences. The next section of the chapter presents the views and attitudes of survivors on select topics explored in the Impact of Cancer - Childhood Survivor scale; identity, perspective on life, faith, survivor's guilt, maturity, fear of the future, and more.

Identifying as a Survivor

Goffman (1959) explained how individuals modulate how they present themselves to others based on what perceptions they want others to have about them. Often, individuals will place more emphasis on portraying certain roles to which they feel more connection, with which they identify strongly (Goffman, 1959). Turning points in life may affect the identities that individuals hold as central, possibly introducing new identities or solidifying older ones (Elder et al., 2003) Some participants hold being a cancer survivor as a large part of their identity, while others feel their identification as a survivor to oscillate depending on the circumstance.

Cancer as a Large Part of a Survivor's Identity

In the IOC-CS scale, ten participants (63%) marked that cancer is a large part of who they are today. In the interviews, Participants 1, 2, 7, 14, 16, and 18 (32%) said that they hold being a cancer survivor as a large and important part of their identity. Because of Participant 16's unique childhood experience, cancer was the first 'stable' identity he had. Over time, it shifted from being a label to a core part of his identity, and it shapes where he currently devotes his time and energy:

> *My cancer identity grew over time, where it was not a crutch... freshman year in high school I had no other identity because I wasn't really involved in other things. I didn't create hobbies as a kid because of the circumstances that I grew up in. So my first identity was cancer, and it was so cool because of the people I was surrounded by, and the experiences that I had throughout college, over college my identity shifted. Instead of being the kid with cancer, it shifted to the things I enjoy are how I treated people, how I interacted with people, just who I was as a person changed, but it's definitely still part of my life. It was easier just because I had a really positive influence in college from the men I was surrounded by, and the people I was surrounded by in college embraced my cancer history.*

In college, Participant 16 joined the Dance Marathon (DM) movement to raise awareness and funds for local children's hospitals, and he eventually started his university's chapter of DM. He is involved with DM today through his work, keeping cancer and childhood sickness a huge part of his life. The friends and mentors he had throughout college helped him embrace his identity, enabling him to become a person who has grown from cancer rather than the cancer kid. He embraces his cancer identity, and said "it's part of who I am and my purpose, I think I have a very outward persona of it and how people know me, because that's a part of my everyday life and what I do, whether it's my work or volunteering," He explained that his present work and extracurricular involvement in college were definitely because of his health history.

Participant 7 also grew to embrace her cancer identity. Up until joining Colleges Against Cancer her freshman year at college, she never felt connected to her survivorship status, partially because her journey was so different than what people normally expect when they hear "cancer." Only her close friends knew that she had cancer.

> *It was weird to me at the time [right after treatment], and I definitely didn't try to bring it up in conversation. People kind of found out because it slipped out, or because it kind of had to, but even still if someone would about it and I would be like "Oh yea, I had cancer," I would be very like… kind of embarrassed about it.*

It was not until she was 19 years old, ten years after her cancer, that she "was able to confidently say 'yes, [she] had cancer.'" At that point in her life, she was ready to reflect, take the time to learn how it affected her and helped her embrace things, reanalyze things. Today, her cancer is something that's "a part of [her], will always be, and [she's] not ashamed of it." She embraces her journey, and even has a tattoo on the place where she had a biopsy to symbolize her connection and provide a conversation starting point.

Participants 14 and 18 likewise grew into their cancer identities. They both talked about trying to be “normal kids” throughout high school, and “staying away from cancer in a lot of ways.” After attending and working at the summer camp for children with cancer, Participant 14 described that he began to view his cancer experience differently. Now, he holds being a survivor as his master status because it gave his life direction. “It’s because of what I went through the way I think now. Everything I have now is because of what I went through before, everything happens for a reason.”

Similarly, Participant 18 began to view his cancer experience differently once he began college. During his undergraduate years, late-effects and health concerns came up more often. He was in a way forced to confront his cancer identity. Participant 18 also joined cancer awareness groups in college, and described his current love for Relay For Life. This group helped him accept his survivor status, and is a way for him to give back to a community that helped him heal. He wants to continue serving the cancer community, and said he hopes to work at Dana Farber or American Cancer Society in the future.

Participant 1 sees survivorship status as a large part of her identity because of the hole she felt when she did not tell others about her cancer. She said that she felt as though she was “hiding a large part of who she was” when she moved away from home and did not tell anyone new she met about her cancer for several months.

> *I eventually told my boss, because she liked to play music and talk at the same time, and it was really hard for my hearing. And so I was finally like “okay I need to tell you” and I didn’t have to go into details for why, but I did, I felt comfortable. And after I did, she was like “that makes so much sense why you're so calm all the time,” and so I do think it is, that I do identify largely with it.*

She embraces her identity, and sees her survivorship status as having helped her find her passions career-wise. She has held several jobs in the medical field, and currently works for an organization that develops programs for children and families affected by cancer. “As far as completely shifting gears career-wise, it is totally because of my background and because of what I know that can be so beneficial, being part of this organization.” Participant 1’s job working with young survivors is an avenue for her to spread awareness and support for the next generation.

Participant 2 said that her cancer has impacted almost every area of her life, and by default is a large part of her identity. She sees her current role as one of advocacy,

> *[Cancer] has been a big motivator for my life... I’m here to help [patients], for those who can't [advocate for themselves], and for those who don't know [about cancer]. So I'm trying to take all my experiences and others and kind of form that into something positive.*

Her experience helped direct her career path towards child life therapy. Child life specialists provided so much support to her through her journey, such as helping her understand her prognosis and come to terms with procedures, and she is excited to pay it forward and be that person for future patients.

> *I know that some people try to avoid [cancer], but for me it's just like… not because I survived I have to, but because I don't want anyone else to have to deal with this. I’m grateful for the experiences and opportunities I’ve had through it, but it is hard, it is difficult. And if somebody doesn’t have to go through that, and they can still live a happy, healthy, life, then I’d want that for them. So there’s a lot going on and stuff, and part of why I’m studying child life is to be able to set up programs for pediatric patients… just learning how I can help other people and places for pediatric cancer survivors to be in them, to clarify any misconceptions people have… like you know, just because something is true for someone doesn’t’ mean it’s true for others. There are oncology patients I’ve heard of who have few to no side effects, and I’m happy for them, but there are people who [have a lot] and it’s not okay to just ignore that fact. So yeah,*

> *I think pediatric cancer survivors, one of my main concerns about being one and knowing a lot is just trying to make sure that we're still receiving care related to our diagnosis.*

When cancer remains a large part of an individual's life, whether through a career, volunteer position, or other regular occurrences, being a survivor also stays at the forefront of a person's identity.

Identifying as a Survivor Subsides with Time

Six participants (38%) in the IOC-CS scale responded that cancer is somewhat a large part of who they are today, and three participants (16%) said the same in interviews. Participants 9, 10, and 11 see their cancer identity as having faded with time, and coming to the forefront at specific moments. Participant 9 said that her survivorship is a quieter part of her identity that "gets loud" at times, especially when late effects are really impactful. This happened most recently when she was having trouble starting a family with her husband. "Sometimes surviving cancer is almost harder than having gone through it," she explained. It is complex to navigate life after cancer alongside many other people, all of whom have their own health histories and life stories.

Participant 10 explained that while her cancer survivor status is a very important part of who she is, during the past few years it began to subside. On one hand, she said that when people do not know her cancer story, they do not know her true self. "That's one thing where I'm like, 'you need to know this aspect about me.'" It shaped her life and impacted many of the things she has done, but on the other hand, she feels that she is transitioning into a new stage of life where the cancer identity is not as strong. Participant 10 said that her diagnosis at age 12 marked a turning-point in her life, because for most kids it marks the entrance into teenage years, but for her, that transition was coupled with her cancer diagnosis.

> *"[I see cancer as] the start of a different part of my life. I really see it as two segments, like a before-and-after… The timing of it had a huge effect. You know, 12 years old that's like really the start of a different chapter [of life], and it started with that…"*

She now thinks that she is entering a third phase, and leaving her cancer chapter behind. "It's weird because I feel like I'm getting into a different part now. I feel like I've left [the cancer] chapter, too."

Like Participant 10, Participant 11 felt her survivor identity subside in time, due to cancer not being an every-day, all-consuming event. Her cancer journey inspires her to be more active volunteer-wise, but she sees her career path as separate and not shaped by her health history.

> *It was my identity during [treatment], then after it was kind of figuring out how to get back to where I was before my life became the hospital. Now it is still part of me in a big way, but it's not as prominent in the sense of like the first thing that will come into conversation. People will make a joke like "oh, that will give you cancer" and I'll go "yup, I already had it once, so I think I'm good" and they're like "whaaat?" So I think in that sense if it comes up I have no problem talking about it, but it's not really like consuming my mind everyday, if that makes sense.*

Survivors who felt their survivor identity fading in time also experienced life shifts. Cancer was no longer a center focus in their life, and as such the survivor identity subsided to let new identities take precedent.

Cancer is Not a Large Part of a Survivor's Identity

One respondent in the IOC-CS survey (6%) said that cancer is not at all a part of who they are today, whereas seven participants (37%) said that being a cancer survivor was not a main part of their identity in interviews (Participant 3, 5, 12, 13, 15, 17, 19). Rather, these individuals felt that cancer was something that happened to them, not something that defined who they are. Participant 19 currently sees identities rooted in personal connections and relationships rather than life experiences as prominent; a friend, sibling, son, student, and aspiring doctor. This contributed to his decision to not participate in survivorship groups, because he wanted to return to normal life as quickly as possible, and not participating in those groups was an avenue for normalcy.

> *It's kind of like it happened, it's over, and so leave it in the rearview mirror unless it's useful, I guess. I don't bring it up because for a long time I viewed it as if you lead with that, people will think of you as "oh, you're just the kid who had cancer, or the kid with cancer." And so just trying to, I guess kind of intentionally creating distance from that chapter of my life. And now, only calling on it when it's necessary I suppose, it makes a hell of a medical school personal statement [laughs]... I'll say it sometimes when it comes up, like I'll say "I'm a survivor," and I would probably check a box on a questionnaire that says I'm a survivor… So I would do it passively, but I would never actively be like the type of person to just go out there and portray that as my image, my personality, my identity.*

Interviewer: Do you think that's because of when you were diagnosed, like you were almost an adult already? You were so much older than if you were younger?

> *Participant 19: Um... no… I think that I would do at any point in my life because I just kind of see it as "you had it, you did it, you're done with it," and so, not that you ever stop being a survivor, but like it just kind of become old hat at some point… I like to keep it more current, rather than just like "oh, I'm a cancer survivor,'' Which is kind one-dimensional, but it's how I think about it I guess.*

Likewise, Participant 3 only sees her survivor status as a large part of her identity in the sense that she's always lived with it. She does not see it as having shaped her life path, or career choices, because she consciously made choices throughout her life that brought her to where she is today.

> *I mean as far as it being the defining factor to why I'm like this or why I do that… I don't really think that it's because of cancer, I think it's because of my choices, or make this out of it, or do that, more so than the actual fact that I had it.*

There are many choices that people can make after going through a certain experience, and she chose particular activities, such as studying and investing in her academics, that brought her to where she is today. Because of this, she would rather people see her for things beyond being a cancer survivor. Despite cancer being a part of her life for as long as she can remember, Participant 3 said that she is the way she is because of choices she has made, not because of the cancer itself.

Participant 17 also wants to be seen as a whole person instead of just a cancer survivor. He was very open about his cancer during high school, and was chairperson of his high school's Relay For Life because of his experience. As a result, he was viewed as the "kid with cancer." "College was an opportunity to break away from that… I want to be seen as everything else I am rather than just the cancer survivor aspect, which definitely followed me through high school." He does not necessarily hide his cancer identity, and is proud of it and willing to share it with others, but wants to be seen as more than just that.

Participant 12 likewise wants to be seen as all that she is because her cancer is in her past, and usually refrains from sharing her survivorship with people because of it. "It's kind of something that's a lot for people to take in, and I want them to get to know me for other things." She sees her cancer as having directed some aspects of her life, such as shifting her attention to architecture, but she does not see it as the forefront of her identity.

Participant 15 explained that in the military, the socialization expectation to have a collective identity pushes his cancer survivor identity to the side. While he also enjoys spending time on nature excursions with the survivorship group he found through his experience, he said that he leads two lives, "and those two lives are pretty separate."

> *[Being a survivor] is definitely a separate identity. It's not part of what I do every day, it's not something that comes up at work just because the military identity in itself is one that is like a "rough and tough, we are invincible, blah blah blah," and as an officer you are expected to [uphold certain standards], and whether that's right or wrong is a completely other discussion [laughs]... I don't really think I am a different person [in the military], but I think there's just a different side of me away from the army.*

Not all young adult survivors of childhood cancer hold their survivor status as a master status. Those who hold being a survivor as their master status center much of their current lives around cancer, whether it be in their profession or volunteer work. On the other hand, those who do not hold being a survivor as a master status center a majority of their lives around non-cancer subjects and activities. Survivors explained that they ultimately desire independence, do not want to burden others, and want life achievements to be under their control. Whether or not they hold cancer as a main aspect of their identity depends on the extent to which cancer relates to those three tenants.

How Survivors View the World

It is common for survivors of trauma to experience a shifted perception of the world (Perry et al., 1995; Zebrack et al., 2011). Some survivors maintain this altered perception of the world and how they draw meaning from life experiences for years. For others, the perspective fades as time further separates the present from their cancer journey. Eleven (69%) IOC-CS respondents replied that they often believe good things have come out of having had cancer, and five (31%) sometimes believe that good things have come out of their cancer.

Cancer Gives Survivors a Positive Outlook on Life

Thirteen participants (68%) said that cancer has changed their perspective on life for the better. They choose to see the silver linings during difficult situations, because having struggles and bad days is better than not having survived their cancer. While twelve IOC-CS scale respondents (75%) marked that they occasionally think about having had cancer, and six (38%) often wonder why they got cancer, nine (56%) marked in a follow-up question that they would not like to forget about having had cancer. Many survivors believe that things happen for a reason, and have found deep meaning through their cancer experience.

Participant 16 spent a lot of time reflecting on why he is so positive about his experience. He believes that he made a choice day in and day out to see the positive side of things, and it became a habit over time. Other people have that option, too, he says, to make positivity a habit or not after any life tragedy.

> *I think there's a lot of factors to it… because this is something that I always wondered too, like I wake up and I'm like "Why the hell am I so positive about this? There's every circumstance possible that gives me a reason why I shouldn't be [happy] and I think it's just because it becomes a choice and a habit, really to the core. And I think you have a feeling inside of you, and when you're doing things and see the positive… you can feel yourself… You just ultimately feel like a completely different person. And I think the more that you get that, it fills your bucket, and you feel completely fulfilled, just seeing the good in things. I think it becomes a habit. Faith was just a vehicle [for me to see the positive]. I think there's a lot of vehicles to see the good in things and be positive, but being positive is because I made that choice to do that. I felt inside of me a better person, I felt more fulfilled. But I feel like there are multiple vehicles in order to make that happen, whether that is the influence and external influences of other people. My nurses, my doctors, my camp staff, the other kids I was around, the experience – I mean just the positive experience, I think that's another huge thing; we talk about why we do what we do with Dance Marathon at CMN hospitals, and we try to bring life back into the hospitals, and creating spaces for these kids to heal. But I also think there's all these experiences in the children's hospitals that play a factor. And I think it's the choice of that kid to embrace it. Do they stay in their room and not have a positive influence in their life? Whether that is humans or experiences? Or do they embrace those opportunities in the hospitals that are trying to help them heal.*

Participant 7 remarked how much her perspective on life changed after coming to terms with her cancer. She now does not take things for granted, and is very aware of how lucky she is. From little details such as having a family to take her to appointments and not have to worry about medical bills, to larger details such as beating her cancer and living without major complications, she makes an effort to be self-aware of her blessed situation.

> *I think the perspective just changes because you lived, honestly. It could have been worse, you could have died, and you didn't. So knowing that, and knowing that I was in a situation that was so scary medical wise and was able to come through it, I know now that I don't want to take things for granted, that life is short, life's not guaranteed, I'm lucky to be healthy, but that could all change tomorrow. And so trying to be thankful that I'm able to go to yoga everyday, that I'm able to go to work, little things like that.*

Through her involvement with Relay for Life and Colleges Against Cancer in college, she found positives in her experience. From educating people on how to check moles, to helping break the cancer stigma of how a cancer patient 'is supposed' to look, she uses her experience as an opportunity to educate and help others.

> *Everything I went through was worth it if it means that someone else didn't have to go through it, or if someone else was saved because of it. So that's how I try to see things now, giving back and taking the time that I've been given to be grateful.*

Participant 3 tries to be optimistic and see the world with the glass half full, but recognizes that it is difficult to do all of the time. "It's not one of my best attributes at all [chuckles] but I do try my best… sometimes you just get caught in this spiral… but it's not every day, and everyone has bad days." She said she reminds herself that at the end of the day, she's grateful to be alive and have the opportunity to have bad days. Participant 3 does not question why she was diagnosed, "because if you're asking 'why,' you're not actually appreciating everything." In fact, she expressed gratitude for the people and organizations her experience has brought into her life.

Participants 9 and 12 likewise commented that they are lucky to have struggles, because at the end of the day some people do not have those opportunities. Participant 12 remarked how lucky she is to be here. She said that "days where my leg hurts, it's just a reminder of where I've come from and kind of makes me more thankful, puts things into perspective." Participant 9 similarly said her experience makes everyday problems trivial to her, especially the few months immediately following treatment.

> *Everyone has their own complaints, so I try to take that into account, but some of the things people get frustrated about… I remember immediately after treatment I was like, "Are you serious right now?" like that's so small in this giant world of people who have serious problems. So I remember that used to really frustrate me. I try to give people the benefit of the doubt now, because you know I'm still maturing, but it did frustrate me.*

Participant 6 also has a heightened appreciation for life. She has learned to look for the positives in life, and trusts that there is a purpose for things. For instance, when she first heard of her possible infertility, she was shocked, but feels that "it's leading her to a purpose." She's always wanted to adopt since she was young, she wonders if she is meant to adopt or foster. And when she was in the hospital, she witnessed a boy in the room next to her be abandoned by his mother. He was left alone for treatments, then was put up for adoption. "So ever since then it's always been in the back of my mind, like that's something I've always wanted to do. And maybe this is just meant to be, that I'm meant for adoption or to be a foster parent" She ultimately thinks that things happen as they are supposed to.

Participant 11 also said that she has grown to see her cancer as having happened for a reason. She explained that her cancer has made her a more positive person.

> *I think right after I was [frustrated], because I was just like "what the heck," kind of in shock… I think too teenage angst played into that thing as well, like "why me, this sucks." But I think now I've come to terms with it, I've been lucky enough to move forward and not have any real medical problems after. So I shouldn't be damning it for*

> *having happened, instead looking, trying to find the positive in something like that… I think [things happen for a reason]. I think it's helped me grow my confidence in myself, and not being the shy, quiet kid… I mean it would have been cool if it happened in a less "I'm sick 24/7" sort of way… I think for some people maybe it's like a little bit more debilitating, which is fine, everyone has their different way of dealing with it. But I think it's helped me become stronger, and have a better outlook on life. And I like being someone who can help other people in that sort of situation… I think I've always been a good listener, but I think it allows me to be a good listener, also give better advice. So I think it happened for a good reason, I don't know why that particular path, but I think so [chuckles].*

She now seeks opportunities to educate people and bring awareness to childhood cancer, so that others are not frightened of it or unsure how to address it. Participant 11 wants to be active in the cancer community as someone who can show other patients that there is life after cancer. "I want to be there as someone who has gone through it, like 'hey, here's where you can be, don't worry too much.'" Participant 2 likewise believes that there is a reason for things:

> *I think things do happen for a reason, I just don't think we understand those reasons… I love my job, but I wouldn't have tried out if I hadn't [a special experience with them from my cancer], I wouldn't have become a child life specialist if I hadn't [had cancer], I wouldn't have met my best friend, I wouldn't have met most of my friends, I wouldn't have chosen my degree program. I don't think I would have been so proactive, I don't think I would have such a strong work ethic.*

Both Participants 13 and 14 do not resent their cancer or dwell on missed opportunities, because they see their cancer as having directed their life path. Eleven (69%) IOC-CS scale respondents also agreed that they do not feel that they missed out on important life experiences because of cancer. Participant 13 commented that as strange and crazy as it may sound, he is grateful that he had cancer because of the people, organizations, and doctors that he met along the way. "It introduced me to parts of myself that I didn't know were within me, and I think in a lot of ways it completely changed my life for the positive."

Participant 14 likewise said that going through cancer and working at the summer camp for children with cancer helped him appreciate his life more. During treatment, he did not appreciate being restricted from sports, and he felt sorry for himself. But seeing people who have gone through cancer, and especially those who have lost someone, helped him appreciate his blessings. He said that cancer has not only changed how he evaluates problems, but it even "made him a nicer person."

> *Participant 14: I have the mentality now where it's like "I deal with this, this, and that…" Most people think a certain problem is huge, when it's really about the smallest thing in the world. Like if it's not a life and death situation, or like, life-changing, and people think it's like the worst of situations… So basically the biggest thing I got out of cancer, if it's not putting me in pain… I have, not a care-free mentality, but an open-understanding on why things aren't as bad as they seem to be.*

Interviewer: Do things happen for a reason?

> *Participant 14: Oh definitely, that's the biggest thing I think to myself now. I think about like "okay I could have been cancer-free my whole life, went to high school, did everything I wanted to do," and then just faded out to doing whatever. I feel that getting older and working at camp gave me time to slow down, because I wasn't rushing… and gave me time to appreciate [what I have]… I feel I'm in a good spot with my life right now… because of everything that I went through. I feel like if I wouldn't have gone through it, I wouldn't be here now, doing the things I do.*

In fact, thirteen IOC-CS survey respondents (81%) marked that they learned something about themselves because of having had cancer.

Participant 8 also wants to believe that everything happens for a reason, and works to find the positives that came from her cancer experience. However, she said it is challenging for her to find reasons behind friends passing away, or why others get sick.

> *I get so upset thinking about other people who have cancer. When I see little kids with it, I'm like "okay, I'll say everything happens for a reason," like in my case, but then there's no reason a three-year-old should have cancer.*

Participant 8 also used resent being sick, and was upset how it impacted her dance career and high school experience. But after missing a popular dance recital, she began to think of her experience differently. "I tried to stop thinking 'what if I hadn't gotten sick,' because it's just so sad [tears up] thinking 'oh, I would have been normal, I would have been killing this dance, I would have been applying to college,' [cries]." She listed all of the people she would never have met, experiences she never would have had, and noted how her cousin would have also been going through her cancer journey alone. "Now I look at it like, not thank God I got sick, but ever since I stopped being like 'what if I never got sick' I'm so happy, a lot more happy about it."

Participant 18 believed that his positive outlook on life has made him a happier person in general. He did not wonder why he was diagnosed, and said that "everything that happens, happens." Whether or not there was a particular reason, he said there is no use getting stuck in the past and that it is important to keep moving forward.

> *Even with my first round I gained so much perspective, I really thought it changed my life and made me a better person. I think I got the message the first time, though [chuckles] It's changed my life in a lot of ways for much better. I think generally I'm happier.*

Participant 18 also felt that he gained a lot of empathy throughout his experience. He notices that other friends do not have the same degree of empathy, and he responds to sadness and tragedy differently than others. However, Participant 18 said that the difference in perception is natural because everyone has had different experiences. He likened it to a maturity difference, but not in a bad way; "It's hard to gain that [empathy] without going through a struggle. Not necessarily cancer, or a life-threatening experience, but a struggle of some sort."

Participant 10 was also convinced that there was an order to the universe after her treatment. She chose to meet the Dalai Lama for her Make A Wish, an organization that grants a wish to a child going through a life-threatening illness. She traveled to California for a special event, and her experience was so incredible that she returned two years later. While there for the second time, Participant 10 met a young man from Belgium. The boy was on his own Make A Wish, and they began dating. The series of events convinced her that there was a reason for things, but when they broke up a few months later, it became “very hard to stick to that.”

> *When I broke up with my boyfriend who I had met through the whole Dalai Lama thing, that was a huge blow for me, because it really felt like I had a path before that. And then afterwards I feel very lost, like I wasn't sure where I was going, or what effect it had… it was very easy to feel like that was important to the path that I was on. Then when it ended I was very much like “what path am I on and how much of it is affected by what I've been through.” Because for a while it felt like… maybe that cancer was a road for me to meet him in some ways, I felt like that for a while. And then I was like “but it doesn't end here,” and it goes in a totally different direction. So I don't know, I feel like that's something that I've been wondering about for several years now, it's been about probably 4 years since then. And I have also been out of involvement with [the survivorship group] for a while, so I am at a very weird place right now. I'm not sure what the long-term effect is going to be. I used to think I knew, and now I'm not sure.*

Beating cancer changed many participants’ outlooks on life for the better. Many reported having a newfound appreciation for things, and a desire to always see the silver lining in seemingly negative situations. Furthermore, all participants who made connections with other young adults of childhood cancer viewed their cancer experience as an event that has brought positive meaning to their life.

After Time, the Increased Appreciation Fades

Participants 1, 8, 17, and 19 (21%), said that the intense appreciation for life that comes after cancer treatment is strong. However, they remind themselves that it is important to recognize challenges of daily life, because the ‘glass half full’ mentality naturally fades in time. Participant 1 noted that while she does have a more positive outlook on life, it is important to validate daily struggles and pains. It is easy to have a mindset of 'at least you are still here' but it is not fair to compare every life struggle to cancer. "I know my pain is real, and I can't just say 'no you have to deal with it because you survived.' No, my pain is actually a real thing."

Participant 8 similarly explained that she has a hard time letting herself be under the weather because sickness does not compare to her chemotherapy experience. She also attributed her desire to be healthy and never turn down invitations to the fact that she was incredibly dependent on others for so long.

> *I used to work with pneumonia because I had that mentality… when I'm sick, I don't ever feel as sick as I used to, so I tell myself "I don't feel that sick, I obviously can still do everything I want to do." But I also need to sit and rest, and I have a really hard time sitting and resting.*

She said she has a difficult time giving her body time to rest and recover because she does "not want to let anyone think I rely on them;" she craves independence. Participant 17 felt the same way:

> *Participant 17: Recently I've shifted into thinking like, I don't want to downplay everything that happens in my life just because… I definitely want to like, value things as anybody else would.*

Interviewer: What do you mean 'downplay?'

> *Participant 17: If something was happening in my life that was causing stress, just like take a step back and think "alright, if it doesn't work out, it's just a small thing…" but I also don't want to mistake that for not being careful about how I go about dealing with problems, because it will matter for that short time. So it's that weird interplay, figuring out…*

Participant 19 shared a similar sentiment. The cancer experience was formative and taught him many lessons that he said he will take with him into the future and his profession, but the intense appreciation for everything that hits after treatment faded with time.

> *I think it would be impossible not to [have a changed perspective]. I think to go through something as life-changing as that, and then say that you don't see anything differently, is*

> *either incredibly unaware, or you're really trying to not see it intentionally, or you have something to that effect. I definitely saw things differently, and see things differently. For a while, right off the bat, I had a bigger appreciation for life. But, as with anything like that, it subsides, where you're not as cognizant of it, it's not at the forefront of your mind all the time. but definitely for part of the time, and for the first couple years, you just have this hyper awareness and appreciation for everything, and you try to hold on to that, but eventually, the event that inspired that thought is far enough removed that it is no longer at the forefront. And good, bad, or indifferent, I think that's just kind of the way things go most of the time.*

As time created space between participants and their cancer journey, they found the intense feelings of optimism and gratitude fade. They described how it is important to acknowledge daily struggles, pains, and frustrations, because it is not fair to themselves to compare everything in their life to their cancer experience.

Cancer Reminds Survivors to Live in the Moment

In addition to leading some participants to see life in a more positive light, cancer also influenced some participants to live more ‘in the moment.’ Nine participants (47%) said that they approach each day like it is their last, because cancer taught them that nothing is ever for certain.

Participant 10 explained how she lives for the present instead of fearing the future. For instance, she chose Art History for a major in college because she enjoyed the classes, despite people telling her that it was not a good career path idea. She loved it, and is now heavily involved in theater.

> *Because one of the things I got out of [cancer] was “you don't know how much time you have to do the things you want to do…” And the other thing is maybe I'll relapse in two years and I won't be able to do anything anyway, so I'm going to do it now and enjoy it. It definitely affected things that way, I'm way more willing to go for something, and not plan it. I’m very much a planner, and I used to be way more of a planner, and losing like, the control, over your life is very scary. But once you're used to it, it's easier to do it*

> *again. So I tend to not plan as rigorously as I used to. Like if I hadn't been sick, I'm sure right now I would have an exact career plan, 5 years out, like this is where I'll be, and this is what I'm doing. I'm sure that would have been me, but no, not anymore. It's very easy to just be like "eell, I don't know what I'll be doing so I'm just going to do what I want to."*

She elaborated further:

> *You've got to just do what you can in the moment each day because you really can't plan anything, you can't control everything. And I think it's been a huge lesson in coming to peace with not being able to control everything. That's something that, you know, I've struggled with a lot since then… And I think it gives me a lot of courage to do things I wouldn't do otherwise. Because there is that idea that there is more of a time limit of like "well, who knows if that's going to be able to happen later, so I'm just gonna do it." So I think in that way it encourages me to go for things the first time, not wait.*

Participant 19 likewise commented that he does not the fear of relapse or secondary cancers dominate his day-to-day thoughts.

> *Just because one of two things are going to happen, it either is or it isn't [going to return], and I can either live my whole life in fear, and eat green kale salad, and pray to God that it doesn't come back, and have a pretty bland existence... or I can live a normal life, and if I get it, I get it, but I'm living the way I want to live.*

His mindset comes from his perspective during treatment itself, where he did not want to let cancer control his life; "I try to not let it change the way I would do things, just a bit of an independence thing, like it does not get to control me." Participant 4 also said that cancer helped her adopt a 'seize the moment' mentality:

> *In general, I want to go out and do stuff, and have fun. It's like oh, something fun comes up, and I'm like 'yeah like let me try and go do that.' In April I went to New York and I auditioned for the Rockettes, and that was a huge eye-opener for me. It was like "look what I can do, like I can go out, I can do anything I want…" Just little things, like day to day, I'm always so willing to try things. And I think I just have a very good outlook on life… I'm just chugging along and seeing where life takes me.*

Participants 11 and 7 also viewed their experiences as leading them to live by the motto ‘live in the moment.’ Participant 11 remarked:

> *I’m more aware of life and how it can take any turn, and you just have to be able to adapt and grow from it. I think a lot of times we get caught in the negative aspect of it. Sometimes I’d be like “this is stupid what the heck,” but it's made me try and focus on the positive.*

Participant 11 commented that even if a situation appears terrible in the moment, she tries to reflect and grow from it afterwards. She works to not focus on the negatives, on things that she cannot control.

Participant 7 said that cancer taught her to always give her best effort because nothing is ever guaranteed. “I just can't stop because I don’t know how to stop, I only know how to give like 1000% in a way, which is weird. It’s the mentality of, ‘I’ve had it worse, I can get through this.’”

Participant 12 likewise believes that it is important to focus on the present, instead of brooding over the things in the past that cannot be changed and the things in the future that cannot be controlled. She explained that she sometimes thinks of where she would be if she did not have cancer, especially because her physical limitations affect her day-to-day life. “I definitely think things happen for a reason, and sometimes that makes me bitter, but for the most part I’m glad for where I am. I think it’s made me appreciate and learn how to change as things come up,”

Participant 13 described that he was given a second chance at life, and like other participants, he treats every day as if it is his last:

> *I wanted to treat, and I still treat, every opportunity, every day that I wake up, you have to give it your all because obviously things can change in a heartbeat. And I saw people change in a heartbeat, kids I was in clinic with that were fine that had a full head of hair,*

> *and all of a sudden they lost 30 pounds because they had a complication… I think it gave me a completely different outlook on life.*

Having been faced with mortality and the harsh reality that nothing is guaranteed, young adult survivors of childhood cancer work to seize life's every opportunity.

Survivor's Guilt

Survivor's guilt is a concept that describes the feeling that occurs when a person 'survives' harm while others do not (Hutson et al., 2015). In healthcare, many chronic patients experience survivor's guilt when comparing themselves to other patients with a similar diagnosis but worse prognosis (Hutson et al., 2015). Many participants in this study explained the various ways that they experience survivor's guilt.

"Why Them and Not Me?"

Ten respondents in the IOC-CS scale (63%) marked that they often wonder why they survived cancer and others did not. Eight (42%) interviewees also said they question why they survived when others did not, and often feel guilty for doing so. Several participants voiced that survivor's guilt made it difficult to stay involved with the support groups. Recently, one of Participant 9's close friends from her survivorship group passed away. As much as it was great to be connected to other survivors, the losses took a toll on her.

> *Having known the group, and been part of it and volunteered with it now for the past 10 years, I just met so many amazing people. Then you find out their cancer is back, and you're like "why them and why not me?"... Those are the times that definitely, you realize that being a survivor is really hard, it's on the forefront of your mind, just because you're constantly thinking "why not me…" It has been a really challenging guilt piece of survivorship [people] don't tell you about.*
>
> (Participant 9)

Participant 10 also found that losing close friends made it too emotionally taxing to stay involved with the survivorship group:

> *Once I knew someone's diagnosis, that's where I'd be like "shit." Because I knew from the moment I met [a friend], he told me he had rhabdomyosarcoma, and that's what [my first friend who died] had… So the whole time I knew him, I was really, really, hoping it wasn't going to get him.*

She felt helpless while watching him slowly lose his fight, and an overwhelming sense of dread. That helplessness is one of the reasons that she has discontinued involvement with the survivorship group. "Knowing it's going to happen again, it's going to keep happening, I don't think I can do that" Participant 10 said.

Participant 1 feels survivor's guilt because she feels that a more 'valuable' life was taken than hers. "I think it goes back to me being so young, when you have a 12 year old who passes away who has friends, already has a personality..." she struggles to come to terms with the end of a socially situated and developed person's life, when her life as a baby was saved. She gets this feeling especially when she thinks about parents who have lost their kids.

Participant 6 feels a similar sense of guilt. The son of one of her close friends was diagnosed with cancer, and soon after the woman herself developed a soft tissue carcinoma. The woman lost her battle just eight months later, and Participant 6 wishes she could have fought the fight for her friend.

> *I felt so horrible for her little boy. And her character, how awesome she was, how innocent she was, and I don't know, I just, I wish I could have fought that fight for her, rather than her having to fight her fight and then also having to fight for her son. And now her son doesn't have a mom anymore. I was just torn up about that.*

Participant 12 feels overwhelmed when thinking about those she knew who have passed away, especially when seeing parents who have lost a child to cancer. She said "It could have been me, I can't imagine what their family is going through. And you know they were supposed to get better." Participant 8 shares a similar sentiment:

> *A mom is always so overly warm and loving and welcoming, and then after their kid died, they obviously like… it had been a while, and time does not heal anything at all I think… I could tell that they were uncomfortable, and I was uncomfortable because... they've also known how sick I was, a lot of them have seen me super sick. And I feel so bad, I feel like these kids were nicer and more kind and better than me. So it's just… I just feel bad [cries] Like I know I can't feel bad, but sometimes it's hard not to. And then it's missing them, too.*

"Am I Doing Enough?"

Several participants wonder if they are 'doing enough' with their lives, having beaten their cancers. "I've been given a second chance, so am I doing it right?" Participant 4 asks herself. It comes up at random times, and she has found that staying involved with camp alleviates that burden. She feels an obligation to camp in particular, and while she hasn't been able to volunteer at the summer programs, she's involved with the organization in other ways. "I want to, and I feel like I *need* to, give back to them, because they helped me find friends, find connections, find people that were just like me." Thinking of those who have lost their fights inspires her to succeed in life and make the most of it.

Participant 7 also feels that she is not giving back to the community to her fullest capacity. She feels guilty for not pursuing a career in the medical field, but she does not like needles. Furthermore, the scent of the hospital makes her nauseous, so she decided that she was not best-suited for a career in medicine. She therefore feels a need to do something extraordinary because someone else could have potentially made a "bigger difference."

> *It's a weird sense of survivor's guilt because there were times when I was like…I've had a lot of job changes lately and identity crises in terms of my career, and I very much measure myself by my career. There were points where I felt that because I didn't go to school to be in the medical field, that I was doing something wrong. That I wasn't giving*

> *back in a way that I should have been. Because a lot of people who do have cancer and live through it go into that field because they're like "these doctors saved my life, so I want to save other people's lives," there's that pay it forward sense… [sometimes I think] "why did I live and someone else didn't," "why did I live and someone who could have been an amazing doctor, someone who could have been like, the next, I don't know, Nobel Peace Prize winner, they died and I lived?" and I felt a sense of like having to do something really important with my life and almost as a way to justify living.*

Being involved with Relay for Life and Colleges Against Cancer helped alleviate her sense of guilt: "I really felt like I was giving back and was able to do something bigger than myself with the time that I was given."

"Survivor's Guilt Motivates Me"

Participants 2, 11, 13, 15, 16, 19 (32%) talked about how their survivor's guilt motivated them to pick up new interests or participate in certain activities later in life.

Participant 16 voiced that he experienced a lot of survivor's guilt up until his freshman year of college:

> *Throughout treatment I would be extremely depressed. I remember after a couple of friends passed away I would be home and just crying in bed. And then I'd pray for my life to be taken away instead of theirs. I was really frustrated and not understanding, thinking why did they not make it and I did? I questioned a lot of the why behind things.*

Once he went to college, the men in his fraternity connected him to the Dance Marathon movement, and his guilt shifted. He no longer found himself feeling guilty for living, but rather, called to make a commitment to honoring the lives of friends he lost. He saw a new purpose to celebrate how they would live their life, a vocation to always love others, work and serve.

> *There's an inherent part of me, a mentality of "I love to give, I love to serve." It was my choice, I knew that I had to commit to this because I never wanted to see another kid go through what I went through.*

Like Participant 7, Participant 16 is motivated to do his part to make sure no future child has to have a similar cancer experience. Participant 2 echoed that statement, and said that losing friends motivates her to make a difference for future patients and be an advocate for childhood cancer:

> *The greatest motivator, and it sounds really f***ing sad, I'm not going to lie, was going to camp and seeing friends that weren't there anymore, and that sucks [tears up, cries], and I don't want people to have to experience that. I relate to people who are dying… and that's a simple fact… and it's hard to lose them… And it's good to see people accepting the reality that they were given, but I don't want anyone else to have to… like "hey, Emily is great, she knows her circumstances, she's making the best of it," but I don't want her little brother or anybody else to have to deal with… Hearing ten year olds talk like that is not normal [sniffles]. And hearing six year olds who want to protect their parents or their family… it's great, but it's hard, it's hard. So you know, just waiting and hoping that the friends that you fell out of touch with would just show up again... And just hearing down the line that somebody didn't make it due to their diagnosis or their treatment is hard. And I feel like we always assume that grieving needs to be done in private, and you can't talk about them once they're dead or something, but um… I don't know… it feels like… those people, many of them wanted to do so much more, and they can't, so somebody has to. So... yeah, I guess that's why. Like, I don't feel guilty for surviving, but I do wish a lot more people did. And that's probably the main reason [cries]. Yeah, I guess that's it. It's hard to talk about, but it's something that I wish more people did.*

Participant 15 says that he feels guilty for how lucky he has been through his process. From not missing school because he was diagnosed during the summer, to life returning to 'normal' fast because his program required him to be in physical shape quickly, and having almost no late effects, he commented that he was very fortunate in some regards. Now, he "definitely looks at life as something that has a responsibility… [he tries] to do whatever [he] can for other people who have cancer now." Participant 15 takes time to volunteer for the survivorship program that he belongs to, and looks for other ways to give back to the cancer community.

Participant 13 was seventeen when he finished treatment, and also struggled with survivor's guilt for several years:

> *I mean it used to keep me up at night, because I never really dealt with mental illness, I was always very happy even when I was sick and everything… So I think more so than anything it was extra debilitating and crippling because I really have no history of mental illness in my family, so I really had no real way of identifying with it, anybody that I felt like I could turn to. Probably for a while I didn't even recognize that I had it, it was just something I look back on and realize how bad it was.*

He began volunteering for a camp for children who had cancer after treatment, and found it very therapeutic. Being involved and giving back helped relieve some survivor's guilt he felt, because he felt that he was able to be a positive factor, actively making a difference. He said that he feels a sense of duty and obligation towards camp to pay it forward:

> *As soon as I started doing camp I think it opened up my eyes, instead of feeling guilty for being alive and the friends that I've lost, to try to help the next generation fight their battle, and spread the light I can in the world… I really do think camp was the one thing that I can look back on to that kind of healed me of those wounds.*

Participant 13 also sees it as his duty to give a 'pep talk' to those that are fighting their own health battles. He shares his story, or stories about camp, as a way of inspiring people that there is a "light at the end of the tunnel, there is happiness to be found."

Similarly, Participant 18 said that since so many people did good for him, he wants to give back. He said that a "healthy amount of survivor's guilt" motivates him to serve. He is deeply involved with cancer-awareness fundraising and events such as Relay for Life. "It's great, I love it, it makes me feel good, thinking I'm helping, thinking I'm doing something."

Participant 19 feels obligated to his future patients to be a good doctor and serve them well. He explained that his experience as a cancer patient will enable him to be a better provider, thus he owes it to future patients to be there for them. He said that before cancer, medicine was interesting to him, and appeared to be a healthy challenge, but:

> *After being sick I think I got a much better sense for what it means to be a patient, to care for somebody, all that. And I had a lot of good doctors, but it's the bad doctors that*

> *drove me more toward medicine, because I would never want somebody to have to receive that kind of care, and I know I can do a better job, so I feel like I owe it to myself, to whoever patients are in the future, to not let them have a crappy doctor like that. I don't know what that says about not having trust in people...*

Downward Comparison

Participants 1, 3, 4, 5, and 7 (26%) downplayed aspects of their journey and survivorship during their interview. The themes "but it could have always been worse," and "I do not deserve the survivorship status because my experience was not as bad as others'" were ever present. Participant 1 explained that she struggles with identifying as a cancer survivor because she does not remember her experience, and therefore she does not feel like she's 'earned' the title of survivor:

> *I would almost rather have at least some of the memories, some of the knowledge, that I had… I've always felt like, because I don't remember it… There was another cancer survivor that said "oh you didn't really have cancer because you don't remember it" and I was like, "well, I did." And it was actually someone from camp, too [makes a cringe face]. So to me, I feel like I didn't earn that title because I don't have those memories. And sometimes I feel like when someone's like "oh you're so strong, you're such a warrior," I'm like "ahh I wasn't, I don't remember." So I struggle with that a lot, as far as identifying as a survivor.*

Because of this, Participant 1 finds it difficult to share her cancer story with potential significant others. She struggles to identify the right time to share her health history with that person, informing them of potential fertility issues, and not knowing how much the other person understands about chemotherapy's full extent of effects. And on top of that, she does not want them to change their opinion and image of her.

> *I struggle with that "you're a hero" complex, it's like suddenly to that person [you're different]. And the person I dated in college focused so much on that part of my life, and I was like "it is so much a part of me, but I don't need to be reminded every day." So*

> *that's where I struggle a little, so I think that's even more why I hesitate [with sharing my history].*

She then talked about how many people downplay their survivor status in some way, attributing it to something that's not themselves.

> *Participant 1: Do you think it's because growing up, we hear all the time, like as soon as someone finds out, they're like "oh you're so strong, you're such a hero," and you feel like you have to live up to that? So if you downplay it, you don't have to live up to that status anymore? I've always wondered that, because I've talked to other people too about it.*

Interviewer: Do you feel like you have to live up those comments?

> *Participant 1: I think so sometimes. So to me, it depends on the audience around me. Like when I'm around a parent that has a kid that's going through treatment, I feel like I have to be the best person I can possibly be, because I feel like they are looking to me for, I don't know, security, hope, whatever you want to say. And then when I'm around my family, I feel like they went through so much, as far as watching me go through treatment and having to do that. I feel like they did that for me, and now I have to be amazing for them. So yeah, I feel like sometimes I do have to live up to the status I've been given.*

Likewise, Participant 7 did not feel deserving of the label 'cancer survivor' for many years. It felt strange to her because her treatment was so short-lived, that she did not fight the same type of sickness that other survivors did. This made her feel like she was in a strange limbo; "You don't belong with the healthy kids because you still have issues that you need to take care of, but you don't always belong with the sick kids because you're not as sick as them."

Since Participant 7's cancer treatment did not involve radiation and chemo, she did not embody hallmark indicators of cancer treatment; becoming bald, losing weight, and becoming gauntly pale. When she was younger, she thought that she did not deserve to be called "strong," because she did not "fight" through treatment, she just had her cancer surgically removed. Participant 7 did not think of herself as a true cancer survivor:

> *I was like "I don't look like that, my situation is not as bad as them, I can't complain." And to an extent my mom did tell that to me, she was like "you know this could be*

> *worse…" I was seeing all those other kids that looked a lot worse than I did, so there was a big sense of me not wanting to discuss that whole part of my life, because I didn't feel like I was worthy of anyone's sympathy… not worthy of being a survivor, or of having cancer, because I didn't look like what everyone looked like, I had it relatively easy compared to other people.*

It was not until Participant 7 got to college and joined a club called Colleges Against Cancer where she reconnected with that part of her life. Through that club, meeting and connecting with other people, she was able to look inside herself and "reanalyze with a different perspective everything that had happened." She explained that she's definitely in a better headspace now than she was at the beginning of college in accepting her identity. Even though she does not fit the typical cancer patient archetype, she still had cancer, it just means that "not everyone fits into a mold."

> *You don't fit what everyone says that you should look like, or you should be, and so you just kind of believe that. So if I don't look like the kid on the poster for cancer, then I don't feel like I had cancer, and I don't feel like I should take that title from somebody who is "more deserving."… I didn't feel that I could claim that title, or speak for that, because I was always like "someone else has it worse than me," "someone went through more than what I went through," so therefore I'll just avoid the whole situation, and just not talk about it, and just like ignore it, push it under the rug… and yeah that's how I went on for years and years.*
>
> *(Participant 7)*

Participants 3, 4, and 5, also feel that their experiences were 'easier' than other cancer journeys because they were so young when they were diagnosed. Because they were babies during treatment, they do not describe themselves as having to actively fight their cancer and deal with short-term side effects.

> *Luckily I had a decent experience and I don't remember a lot of it, so I think I'm lucky in that sense… Probably some other kids were more affected by losing their hair, having scars, and stuff that's more visible, I think it would probably be a lot harder if I were to go through it at an older age.*

(Participant 4)

Participant 3 also thought that her lack of memory serves as a form of protection. “I can't even imagine what some people remember, and losing all your friends and all that.” Participant 5 explained that watching adult family members face health complications brought into perspective the gravity of her own diagnosis. It was so horrific for her to watch an adult go through a serious health diagnosis, so she “can’t imagine how a baby or a kid could go through it, in those formative years.”

Maturing Faster

Nine IOC-CS scale respondents (56%) said that they often feel more mature than peers their own age. Interview Participants 1, 3, 4, 6, 7, 10, 13, and 17 (42%), agree that there is a level of maturity that follows cancer.

Despite Participant 1, 3, 4, and 6 fighting their cancers as young children, they have always noticed a difference between themselves and their peers. They all commented that they did not find typical childhood and teenage drama interesting. Participant 1 sees the difference now even more than when she was a child; during work projects or other events, when others stress about bumps in the road or small challenges, she remains calm. “I never get very hyped up about things if they are going wrong… they’re just so small in comparison to so many other things” she said. Participant 6 echoes her sentiment, saying that after cancer, “You realize life is too short to deal with all that crap.” Other participants express similar feelings:

> *I think it definitely sped up the whole “growing up” process just having that kind of traumatic experience. It's something that I don't think a lot of my peers have run into, and obviously everyone has their own troubles, I just think that kind of thing is rare, it's definitely given me a certain sense of wisdom, just looking at life in general.*
>
> (Participant 17)

> *I think I had a much more secure sense of identity than a lot of people that are my age. Like I feel like I've got a whole extra layer of experience, like a whole extra 10 years of life experience in some ways. It's interesting, there's a whole lot that's been condensed into just that time period of my life.*
>
> (Participant 7)

> *Right when I finished treatment it was really apparent, like how different I was, my outlook was, from people my age. I resonated more with, I related more to people older than me. I think just cuz I had to grow up quickly, and I wasn't as worried about going to dances, or playing sports, or things like that cuz you know I couldn't be at that time.*
>
> (Participant 12)

Participant 12 also wrote about a maturity difference in the IOC-CS scale. She explained how cancer impacts many areas of life, including job-hunting and comparing health-insurance benefits:

> *Having had cancer at a young age takes away the invincible attitude that my friends have. The ignorance about the worst case scenarios has been taken away, forcing me to consider health insurance and how that can add a whole new level of challenges.*

Faith in God or a Higher Power

Eight IOC-CS scale respondents (50%) reported that having cancer makes them think about or question their religious faith or faigh in a higher power. Seven respondents (44%) said that they occasionally question their faith. In interviews, four participants (21%) talked about the impact cancer had on their faith.

Throughout Participant 16's unstable childhood and cancer journey, he had random positive influences. "I don't believe that they were accidental, but truly divine at the times that they were most needed, whether that was my mom making the decision to take us to church." Religion was his 'rock' that he was able to lean on when he felt that he had nothing else - he called it "the vehicle" he used to see the positive in situations. Since his experience, his said faith has become more of a spiritual experience that directs him to do the greatest good.

> *Knowing that there's something so much bigger in life that we can't even sometimes comprehend, or even understand [is comforting]. And ultimately, regardless of what afterlife is, [what matters is that] we do good right now when we can. And we just love people unconditionally no matter who we are, and we leave the world a better place, leaving a positive impact on those that we encounter.*

Participant 17 also found faith to be his rock in the most difficult times. During treatment, he had a prayer card taped to the bathroom, and he began to find comfort in saying the words.

> *That really, really, helped a lot, I think. I just started to really believe in myself and believe that God would help me through this. And I think that really gave me the strength to power through that time. Because before that, like I said, I was withdrawn and forgot about everything else in my life. But, it was a little bit like a beacon of hope, that little prayer card, I really liked that a lot.*

His faith helped him fight through and find meaning in his cancer experience. Participant 17 said that while he had moments where he wondered why cancer happened to him, believing that "God gives his greatest battles to the toughest warriors," helped him be more positive about the experience and its long-term effects.

Participant 10 explained that she sees her cancer journey as a very spiritual process. She wanted to explore her faith further after treatment, which played a role in her decision to meet the Dhali Lama for her Make-A-Wish.

While Participant 5 herself said she did not see religion as a large part of her journey, she explained how her mother relied on faith during her disease. Participant 5 commented that she believes the solace her mother found in religion was very interesting:

> *Participant 5: It was Good Friday when I went to the emergency room and I almost died, and my mom always talks about how she prayed to God every day for my life. And then on Easter Sunday, the emergency stopped, and it's kind of funny how that worked, because she was like "Jesus gave me another life," basically.*

Interviewer: Do you ever think of it that way? Whether religious or not, like that things are meant to pan out this way?

> *Participant 5: I don't know because my mom raised me as a strict Catholic, but she didn't want that for me, so she didn't raise me that way. But it's interesting to think about… I definitely think that my mom probably believes that… she definitely thinks that her faith made a difference.*

Concerns about Fertility and Family Planning

All IOC-CS survey respondents marked that they were concerned they may not be able to have children, 10 of which (63%) indicated they had this concern often. Participants 1, 3, 4, 5, 6, 8, 9, 10, 11, 16, 17, 18 (63%) expressed concerns about building future families after treatment in their interviews, as fertility complications are common side effects of chemotherapy and radiation (ACS 2020b; ACS 2020e).

> *So when I was dating my long-term boyfriend…I'd gone to my last pediatric oncologist appointment. And I asked her [about starting a family], and she actually brought up the fact that there are studies that show childhood survivors are more likely to become infertile because of all their treatments. So that's when it really hit me, and I just kind of lost it, because I was like "Wait I can't have kids?" And it just kind of all crashed. As I get older it's more like always in the back of your mind that it's something I'll probably never be able to do. I don't know how to describe it.*
>
> (Participant 6)

Many participants have since decided that there are many ways to build a family beyond having biological children.

> *I probably might not be able to have kids, my mom always told me that, and like, I know like for some people, having kids is like…that everyone wants to have their own kids. But I always knew that in the back of my mind that it doesn't have to be my kid….I know that there's definitely some test you can do [to find out if you can have kids], but I don't know if I really want to know right now. Because I'm not in a position where I want to have kids right now, so I feel like if I know or don't know then it's going to make me think about the things I'm not entirely ready for at the moment.*
>
> (Participant 5)

> *Maybe part of the reason for that is because I understand that like, it may not happen for me, so like why get in a mindset where I have to have kids when it may not even be a possibility? Like I don't want to put myself in that situation.*

(Participant 3)

Participant 3 is also anxious about having conversations with potential life partners about the implications their cancer can have down the road. She explained that "a lot of people have their mind set out on what they want, what they picture their life looking like… and of course it's going to depend on the [other] person," but it's daunting to tell someone that she does not know if she will be able to have kids. In fact, of the IOC-CS respondents that are not in long-term, committed relationships, six (60%) responded that they are very concerned about how to tell a potential life partner that they may not be able to have children.

Similar to Participant 5, Participant 3 said that fertility testing is a process that she is not ready to do at this point in life. "I'm so young right now, I won't even want to have kids for so long, it's like not even on my radar."

All IOC-CS scale respondents also voiced concern for their children being healthy or having cancer, 11 of which (69%) have the concern often. In interviews, several participants also voiced fear about watching their own child go through cancer and feeling at fault for it:

> *As far as fertility, I think as a teenager I long ago decided that I'm not really interested in having kids of my own. And there's like parts of it I think are definitely like me not actually wanting kids, but I think a large part of it too is what has played into that decision. Like I'm worried about side effects for me and I don't want to have a kid in the world alone. Or I wouldn't want to have… I know I would live in fear for that child every day, just because of what I've been exposed to.*
>
> (Participant 1)

> *I feel like it's going to be kind of my fault. Even though we know there's no way I can prevent it, I'm worried that they're going to have to go through it. So even though I didn't go through it when I was a kid, I'm going to have to like to see my kids go through it. So I'm going to experience it differently.*
>
> (Participant 4)

> *I'm still pretty nervous about it, I'm still mad they didn't listen to me when I said I wanted to freeze my eggs. Because I'm also nervous, what if they're damaged? And I*

> *have… like I wouldn't care if something is wrong with my kids obviously, but like I wouldn't want them to go through like the struggles or anything that I've been through.*
> (Participant 8)

> *For a while especially it was concerning, is [cancer] going to be part of my future, and if it is, am I going to pass it on to somebody? And especially when I was dating the guy from Belgium because he's also a cancer survivor, and chances go way up from there. So that's one thing we thought about because we were really expecting a long-term relationship, and one of the things I thought was "if we have kids, what's going to happen?"*
> (Participant 10)

> *I don't worry too much about telling a partner [my cancer history]… I think the partner doesn't realize it as much, because it's not a reality in their world… So I don't worry about telling them too much, just because I don't think they have the same feeling of reality fear… like they may have fear for it, but it's not like something they went through. Where I would feel so bad if I had a kid and then they got cancer. Not necessarily because it'd be because of me or something, but I think I would know the pain that they're going though, so I worry about it a little bit, but it's not something at this point in my life where it's like "I won't have kids because of it." Like I worry about it, but I don't want it to impede me living a 'normal life.'*
> (Participant 11)

Participant 9 was married five years ago, and had difficulties building a family with her husband due to chemotherapy late-effects:

> *[Family planning] wasn't really something that we faced head-on because things happened so quickly… it didn't become really on the forefront of my mind again until I met my now-husband, just because it was something that, as our relationship got more serious, I wanted him to be aware of that it was going to be a problem for us, as far as if we were going to get married and begin a family, it would be a really big challenge. … before I actually even considered saying yes to dating him, I said that we had to have a very serious conversation. I mean it wasn't like oh my gosh like about babies, it was more like "listen I've been through some stuff…"*

A year ago, Participant 9 and her husband adopted their first daughter, then six months later, they adopted again; so she has two small babies, 15 month old and 9 month old. "so between school and work and the children, it's absolute chaos, that's pretty much the sum of my life [chuckles]."

Concerns about Personal Health

All participants (100%) expressed an awareness that future health is not guaranteed, so they are sure to stay current on follow-ups. Nine IOC-CS scale respondents (56%) voiced that going to the doctor occasionally makes them nervous, and four (25%) said that they are often anxious when going to the doctor.

Some participants are nervous about recurrence or secondary cancers because they do not remember their cancer experience, or they are afraid of how their better understanding of cancer would impact the journey. Participant 1 spoke about how she seems to be "waiting for the shoe to drop." She said that since she does not have memories of cancer treatment, she feels that going through cancer again is somewhat inevitable. Participant 11 similarly is afraid to develop a second cancer:

> *I would hate to freaking do chemo again. I don't think it's the fear so much of if it happened again… I worry about being more conscious about what's going to happen if I did get cancer again. Because I feel like at 15 I knew you got chemo, but I didn't actually know what chemo was. And then I was like "oh, I just sit here all day and you just give me poison bags of IV, great." So I think I worry about it happening later and then being way too like "Oh my God everything's happening, what's this, what's that."*
> (Participant 11)

Some participants are so far removed from their cancer treatment that recurrence is no longer a daily fear, rather one that flares up from time to time. In her interview, Participant 9 described how she becomes "on-edge" when she attends annual well-women exams. "I mean I think everyone around those times could get a little bit antsy, but I think as a cancer survivor you're probably even a little bit more... "

Because she had cancer twice, Participant 12 becomes very anxious when something out of the ordinary happens. She found a lump a few years ago, and her mind immediately jumped to cancer. “It took me a while to approach my doctors about it because I was like I can't go down this whole road again, I’ve already done it twice. Luckily it wasn’t, but it’s just things like that. Small things become more monumental.” Other participants also expressed their feelings concerning future health.

> *Because every time there is a new pain, I’d be like oh my god is this happening again sort of thing. Like before, the bone infection thing even happened, like I was really, really, tired. So for the beginning of college, every time I was exhausted, it definitely was on my mind. But then I learned to attribute it to the exhaustion that college is, and just being so busy and stuff like that. So I don’t fear relapsing all that much anymore, especially having met this five year mark, which is a huge mark. But before, at least the first four years after treatment I was thinking about it a lot.*
>
> (Participant 17)

> *I’ve had quite literally dreams about friends getting sick and stuff, and it enters your head. I mean, relapse is in your head, too. A couple years ago I had a pulled abdomen in the same spot as the spleen, basically, the same area of the body. I was bugging a little bit [chuckles] I don't know*
>
> (Participant 18)

Attitudes Towards the Medical Field and Health Care

After undergoing a serious health care experience, many individuals have vivid memories of their experience and particular feelings towards the health care system. From varying degrees of trust in the medical field, to strange reactions to subsequent experiences, interviewees also voiced their attitudes towards the medical field.

Thirteen IOC-CS scale respondents (81%) marked that they sometimes or quite often feel confident that any doctors they currently see know about long-term effects of childhood cancer treatment. Also, fourteen participants (88%) feel more often than not that they have all the information they need about their cancer, its treatment, and possible long-term effects. Conversely, Participant 2 expressed her concerns with long-term survivorship care in her interview, and described the difficulties she faces with her long-term effects. The hardships she has faced with securing long-term care and adjusting to life after cancer led her to pursue becoming a Child Life therapist:

> *I know that some people try to avoid [cancer], but for me it's just like… not because survived I have to [pursue Child Life], but because I don't want anyone else to have to deal with this. I'm grateful for the experiences and opportunities I've had through it, but it is hard, it is difficult. And if somebody doesn't have to go through that, and they can still live a happy, healthy life, then I'd want that for them. Part of why I'm studying Child Life is to be able to set up programs for pediatric patients. After cancer and everything it can be really hard to know who's experienced things like you are, and after being on treatment you have this giant support system of the hospital, then leaving, and getting used to it when you're in the world and you're working…there aren't a lot of professions that are ready for that, they don't fully understand it, so just learning how I can help other people, to clarify any misconceptions people have… like you know, just because something is true for someone doesn't mean it's true for others. There are oncology patients I've heard of who have few to no side effects, and I'm happy for them, but there are people who [have a lot] and it's not okay to just ignore that fact. So yeah, I think pediatric cancer survivors, one of my main concerns about being one and knowing a lot is just trying to make sure that we're still receiving care related to our diagnosis. There's so many elements of care that pediatric survivors have to worry about even when they aren't in active treatment, like managing long-term effects and screening for new cancers.*

Several participants described visceral reactions they still have towards healthcare, even years after their treatment. When asked how she felt about not really having memories of her treatment, Participant 1 remarked that she wished she had some memory. She said that she occasionally has déjà vu moments, where some of those deep emotional memories jump out. Certain smells make her uneasy, and though she knows the uneasiness comes from the hospital setting, she cannot remember why. Once during an in-service at work, someone came towards her with a bag-valve mask, and she "freaked out and slapped it away."

Participant 10 also experienced similar deep-seeded reactions. She said that "being [in the hospital] really just does something to me." She described how she was there recently, and the beeping of all the IV machines "sent me right back in a very strange way… Even just seeing certain medical equipment, I'm just like 'Nope, nope' just got too much in there [points to her head]."

Some participants explained why they are now cautious and reserved with healthcare professionals. Participant 11 said that she is apprehensive of new providers because of how the dermatologist wrote off her symptoms for several few months. The providers told her that she was "doing this to [herself]," and that her symptoms were not real. "So I'm kind of wary when I have a new doctor, because I'm just like 'are they going to believe me and look into everything that I'm saying? … So that makes me a little bit nervous." However, she said she is very trusting of the doctors she currently has, because they know her health history and trust her judgement. Participant 17 similarly remarked that he plans to be very involved in his future children's care, especially because his own cancer was discounted for a bone infection.

Participant 8 spoke about similar frustrations she had with some providers not believing her symptoms and not speaking to her as an active member of her own care team. Since she was older when she was diagnosed, she wanted to be very involved in her treatment. But, some providers did not talk directly to her, and would instead talk to her mom as if she was not in the room herself. Participant 8 explained that she would become testy with providers and medical students who treated her like this:

Participant 8: I put him in his place, I did that to a lot of med students because they would piss me off.

Interviewer: What did they do?

Participant 8: I would be like "call my doctor, I'm in pain, I need meds, I need something, I'm crying, I can't sleep, this has been going on for 3 days, like do something," and they're like "um well… we can give you some bullshit," [laughs]… This one, I hated her so much, and she was like talkin me one day, and first of all, the audacity, and it was when I was super super super sick. It was the summer that I shouldn't have made it, it was really bad. And she was not listening to anything I would say, and would talk over me, and then talk to my mom, then my mom would get an attitude with her and be like "you need to listen to her, she knows her body, she knows what's going on with her… " while I was in the room. And I was like I was in so much pain, no one would do anything. So we would go off, like one time I had to go off on her, and nurses had to get involved and be like 'you're not listening to her, this is what's going on, she knows, stop doing this," and then my mom had to have a talk with her, and then she wanted to apologize…"

Summary

After a cancer diagnosis, participants passed three landmarks on their journey to recovery; the age they were diagnosed, the degree of friend network support in the transition to life after cancer, and generating meaningful connections with other young adult survivors of childhood cancer. The combination of these three checkpoints alter the feelings and attitudes survivors have about the themes addressed in the Impact of Cancer - Childhood Survivor scale. Overall, participants with more social support, whether through friend networks or knowing other young adult survivors, had positive adjustments to life after cancer and found meaning through their cancer.

CHAPTER 6. **DISCUSSION, RECOMMENDATIONS, IMPLICATIONS**

Introduction

Previous chapters introduced the topic of this project, research methodology and analytic strategy, and results of this study. This chapter will discuss the results and future implications for various groups. Limitations and areas of further research for long-term survivorship care conclude the chapter.

Discussion of Results

Measuring perceived quality of life is a common tool used by providers to assess the livelihood of individuals, especially those who have experienced adverse life events (Vance & Eiser, 2002; Zeltzer et al., 2008; Zebrack & Landier, 2011). Chapter 2 discussed the inadequacies of conventional cancer survivor quality of life measures in accurately capturing the attitudes and feelings of young adult survivors of childhood cancer (Zebrack et al., 2010; Quinn et al., 2013; Stuber et al., 2010; Wengenroth et al., 2015). Most scales fail to account for subjects of particular concern to young adult survivors, such as personal health and fertility concerns, socializing with others, and sense of self (Quinn et al., 2013; Zebrack et al., 2010). Zebrack et al. (2010) therefore created the Impact of Cancer for Childhood Cancer Survivors scale (IOC-CS), asking questions about twelve domains of life; ‘Your Body and Your Health,’ ‘Cancer Treatment and HealthCare,’ ‘Having Children,’ ‘Who are You,’ ‘Talking and Thinking About Cancer,’ ‘Meaning of Cancer,’ ‘Memory and Thinking,’ ‘Finances and Money,’ ‘Family ,’ ‘Relationships ,’ ‘Socializing and Being with Friends’ and ‘Life Goals.’ They administered it to a group of 30 individuals to test the efficacy of the scale. They found that their scale highlighted areas of relevance identified by Quinn et al. (2013), suggesting that it is more reliable and valid than other available resources (Zebrack et al., 2010).

The researcher of this study administered a hybrid survey to nineteen young adult survivors of childhood cancer, comprising questions from three quality of life scales that Quinn et al. (2013) found incomprehensive (Appendix C). The survey primed the subjects on topics that the researcher later addressed during a semi-structured interview.

The researcher then held 45-minute interviews with the 19 participants, asking open-ended questions grouped in six key areas (Appendix D). After the interview, participants filled out the IOC-CS scale (Appendix E). At the conclusion of the survey, they explained whether or not they felt the IOC-CS survey was more comprehensive than the initial hybrid survey. All participants who filled out the IOC-CS survey felt it addressed topics of greater importance and relevance compared to the initial survey, specifically in the areas of relationships and social development. Results from interviews also revealed that these topics were meaningful to survivors. Respondents spoke in-depth about each category, explaining how their cancer affected their social networks, outlook on life, identity, and more.

Furthermore, it was apparent that three key checkpoints occurred in participants' lives *before* the formation of attitudes towards each domain of survivorship. These landmarks therefore create a "Trail of Survivorship," which shapes how survivors draw meaning from their experiences. The outcomes of each checkpoint along the trail of survivorship therein influence the perceived quality of life of a young adult survivor.

Checkpoint 1: Age at Diagnosis

Elder et al. (2003) explained that the outcome of an event over the lifecourse depends on the age at which it occurred. Rutter (1985) and Haase & Phillips (2004) further explained how the timing of an adverse event and eventual outcome depends on the child's ability to comprehend the event. By this rationale, if the child does not understand the true magnitude of the situation, such as in the case of a baby, the child will likely not have a negative understanding of the event. However, Perry et al. (1995) suggested that infants and young children, since their brains are still growing and establishing neuronal connections, are *more* prone to developing maladaptive responses to traumatic stressors.

Participants 1-6 were diagnosed with cancer as infants or young children, and were unable to remember their cancer diagnosis or treatment. However, these participants did not develop neuropsychiatric symptoms later on in life. Instead, conceptualization of their cancers relied on subsequent cancer-related events and how they attached meaning to those events. For example, Participant 4 spoke about how her earliest memories of the hospital were enjoyable, because her mom and family made special occasions out of them; lunch dates, little gifts, and quality time. As participants grew older, the efforts their families made to create positive experiences out of cancer-related events favorably influenced the participant's cognitive perceptions of their cancer. These findings demonstrated Rutter (1985), Haase & Phillips (2004), and Juth et al. (2015)'s theory that an individual's response to objective adversity is modified by the person's subjective understanding of the event.

On the other hand, Participants 7-19 were diagnosed with cancer at an older age, and had concrete memories of their diagnosis and treatment. Each of these participants voiced how cancer was an unexpected turning point that interrupted important parts of their lives (Elder et al., 2003). From athletics, to enrolling at new schools, to graduation, cancer was a disruption, a negative life event. In addition to interrupting important life events, these participants also experienced disruptions in developing their sense of self. Like Decker (2007), Quinn et al. (2013), and Zebrack (2011) explained, cancer disrupts important stages of personal development: developing a positive body image, increasing involvement with peers and dating, decisions about careers and higher education, independence from parents, and formation of identity.

Participants diagnosed with cancer as an older child or teenager commented about disruptions in each of these areas: Participant 4 talked about difficulties accepting her scars, and Participant 7 mentioned how it was difficult for her to develop a positive body image while also practicing skin protection measures. Participant 8 said that she feels sorry for her high-school self, that she spent so much time and energy lamenting the fact that she never was able to take part in the high school dating scene. Participants 10 and 12 both explained how cancer affected the degrees they pursued in college, and Participants 8, 15, and 19, described that having felt like burdens to others during treatment, they now make special efforts to not be dependent on others. Nearly all participants spoke about how cancer impacted their identities, some seeing being a survivor as a large part of their identity, while others want to be seen as more than someone who had cancer, so they keep their survivor status private.

Since Participants 7-19 reported that cancer affected their personal development more so than Participants 1-6, they initially had more negative ideations of their cancer than their younger counterparts. In order for an individual to have an overall positive outcome after adversity, the sum of his or her positive experiences must outweigh the sum of the adverse stressors (Rutter, 1985). Therefore, these participants required more positive factors such as social networks and resilience to ameliorate the initial negative impacts of cancer and generate an overall positive perception of their cancer (Coyne & Downey, 1991; Decker, 2007).

Checkpoint 2: Re-Integration

Many childhood cancer survivors face difficulties transitioning to life after cancer, especially relating to self-image and socialization (Decker, 2007; Quinn et al., 2013; Zebrack & Landier, 2011). Most participants who were diagnosed during their school-age years also had significant periods of absence due to treatment (ACS, 2020f). Vance and Eiser (2002) suggest that difficulties in transitions and social adjustment may be due to people's inability to understand and relate to the cancer patient. Participants 8, 9, 11, 12, 14, and 16 experienced a similar effect; they spoke about hardships they faced trying to connect with their friends, because they felt unequipped to explain their cancer to others, or they felt that their peers were unable to understand what the participant was going through. And while Participant 2, 3, and 6, were finished with treatment long before attending school, the inability for their peers to understand and accept their physical late effects led to challenges in school. Furthermore, the quality of the social ties mattered; Participants 9, 12, and 16, commented that their friend group shrunk after treatment, and that they lost 'peripheral' friends due to cancer (Rutter, 1985).

Seven participants (37%) also described feeling the need to hide aspects of their cancer or treatment from peers due to this lack of understanding, and a fear of being ostracized (Goffman, 1959, 1963). Participants described their range of late effects: portacath scars on chests, surgery scars on legs and abdomens, bald spots, limps, prosthetics, mobility limitations, chronic pain and fatigue, epilepsy, hearing and gastrointestinal issues, short term memory loss, and more. Like many other cancer survivors, these late effects quickly identify participants as different from their peers, and contributed to feelings of shame, embarrassment, and body image issues (ACCO, 2020c; ACS, 2020f). Goffman (1963) explains the impacts that stigmatized attributes have on individuals. Cancer patients may not perfectly fit into socially normalized categories; they may display physical differences, and the very existence of their health history separates them from 'healthy' peers (Campbell, 2009). As such, it was common for participants to report that their desire to not be treated differently motivated many decisions in terms of sharing their health history with others.

Five participants experienced role strain, specifically between performing gender and being a healing cancer patient, when transitioning to life after cancer. It was challenging for Participant 7 to meet societal standards of beauty, as her late effects necessitated that she protect her skin from the sun. Studies show that physical late effects from cancer may lead to feelings of shame and embarrassment, especially for women (Bellizzi et al., 2012; ACS, 2020f). Likewise, Participants 13, 14, and 17, faced difficulties in performing masculinity. Their physical limitations prevented them from continuing participation in athletics. These participants used negative language such as "devastating" and "heartbreaking" to describe how not being able to partake in typically masculine activities impacted their sense of self (Connell & Messerschmidt, 2005). Goffman (1959) explains that actors attempt to perform idealized roles, such as the ideal masculine athlete. However, events that impact one's ability to perform the idealized role may lead to distress and embarrassment (Goffman, 1963). Furthermore, Participant 16 faced difficulty performing masculinity because he was also navigating his sexuality. The mobility limitations he faced due to treatment led him to prolong coming out longer than he likely would had he not had cancer. The shame and embarrassment felt from stigmatized attributes lead survivors to practice impression management, attempting to appear ‘normal’ to others and hide their cancer attributes (Goffman, 1959, 1963).

It is known, however, that the presence and quality of social ties are protective against maladaptive results of trauma (Rutter, 1985; Coyne & Downey, 1991; Decker, 2007). Therefore, social networks may offset the negative attitudes formed towards cancer despite the experience of adverse short-term effects. Participants 10, 13, 18, and 19, specifically spoke about support their friend networks provided during their treatment. They mentioned that friend networks both helped them maintain healthy mindsets while undergoing treatment and eased the transition back to school. While some participants generated negative feelings and attitudes towards cancer due to the impact it had on their friend groups and transition back to school, other participants had easy, positive, transitions back to school due to the quality of their friend networks. Decker (2007) likewise found that involvement with peers led to lower levels of depression, higher optimism, better adjustment to cancer, and was necessary to help survivors develop a sense of identity and autonomy, factors which were threatened by cancer.

Checkpoint 3: Network Support of Other Survivors

Fifteen interview participants (79%) explained the direct positive impacts that knowing other childhood cancer survivors had on their transition to life after cancer. These networks had a similar positive effect that peer networks did in transitioning back to school; they helped participants make positive memories associated with their cancer experience (Rutter, 1985).

Moreover, these networks also provided comfort and solidarity to participants, many of whom felt alone as a cancer survivor. Participants 3, 4, 7, 8, and 17, voiced that they felt somewhat isolated during treatment. No one except other pediatric cancer survivors truly understood what they experienced, and issues they still face today. But knowing other survivors alleviated feelings of loneliness; they connected with those who understood the little annoyances during treatment, such as the taste of contrast, and laughed together showing each other their scars. These connections and similarities helped survivors, such as Participants 14, embrace their cancer identity (Haase & Phillips, 2004; Decker, 2007). Similarly, Goffman (1963) writes that being around others who share a stigma can provide the individual with support, and help them feel accepted as a "normal" person.

These networks not only assisted survivors during and shortly after their treatment, but aided participants years after their therapy ended. Participant 7's survivorship group helped her come to terms with her diagnosis ten years after she was diagnosed. Until then, she had a highly negative perception of her cancer and its effects on her life. But individuals in the Colleges Against Cancer group helped her accept her survivorship status and re-conceptualize her cancer as something that brought meaning to her life. Reconceptualizing adversities into events for potential growth is important in preventing a survivor from developing unfavorable attitudes towards cancer (Zebrack & Landier, 2011).

Furthermore, seeing what other survivors have done in life augmented the transition to life after cancer. It even inspired several participants to pursue their own goals. Participants 11 and 16 spoke about how essential these aspects were to the survivorship groups in which they were involved. Representation matters; just as it is vital for survivors of sexual assault to see other survivors speaking out, just as it is essential for LGBTQ children to see other children and adults in the community being open and proud, so it is too, that childhood cancer survivors need to see other childhood cancer survivors. Representation shows survivors that they are not alone, shows them how to cope, what they have the capacity to do, and inspires them to achieve their dreams (Goffman, 1963).

The four participants who chose not to participate in survivorship programs or did not find meaning through a group said that their friend groups provided support during their transition to life after cancer. They did not need, per se, the social support of survivorship networks to cope with the stresses of cancer and prevent future distress. However, they lacked the ability to connect with others about facets of survivorship (Goffman, 1963). Participant 17 wrote in the IOC-CS that he wishes he could talk to other survivors about their survivorship. Therefore, it is likely those who do not have survivorship networks will feel the lack of connection as they face late effects more so than those who do have strong survivorship networks.

Positive memories made with other survivors through activities at camps and survivorship programs contributed to positive ideations of participants' cancer experiences (Rutter, 1985). But not only did these programs create happy memories for the participants, they led survivors to accept and appreciate their cancer journey, provided support networks and mentors, and helped participants navigate the unknown; life after cancer.

Quality of Life Key Domains

It is only after these three checkpoints that IOC-CS scale factors come to fruition in the lives of participants. Therefore, attitudes towards survivorship domains are the *result* of experiences that occurred during and directly after treatment. Tracing the trail of survivorship shows that those who lacked strong peer networks after checkpoint two, or who lacked a survivor network after checkpoint three, had different attitudes and drew different meaning from life experiences than those who had such networks.

The researcher found the IOC-CS to be a reliable measure of the quality of life of young adult survivors of childhood cancer. Unlike many studies, it did not focus on the presence of particular late effects of cancer (ACS, 2020f; Schulte et al., 2018; Stuber et al., 2010; Haase & Phillips, 2004). Rather, it identified specific aspects of survivorship unique to young adult survivors, and elucidated *how* and *why* participants feel cancer affected and continues to affect their lives in specific and meaningful ways (Zebrack et al., 2010). Topics Quinn et al. (2013) found missing in other quality of life surveys, such as survivors guilt, obligation to be valuable, maturing faster, fear of burdening others, anxiety about fertility issues, and fear of children getting cancer, were covered both in the IOC-CS scale and interviews. All participants agreed that the scale accurately addressed pertinent issues of young adult survivorship (Table 4). Several commented that it was so encompassing that they had not quite connected some topics in the scale to their cancer before. Furthermore, the domains were rich topics of conversation during the interviews, reinforcing that the IOC-CS scale was accurate and that its domains were meaningful to the participants.

Identity

Participants who currently view being a survivor as a large part of their identity were also heavily involved in survivorship groups. These groups increased the occurrence of positive cancer-related activities, thereby increasing the frequency that survivors created positive memories of the experience. The persistence of favorable events strengthened the extent to which survivors attached positive meaning to their cancer experience (Lazarus & Folkman, 1984; Rutter 1985; Zeltzer et al., 2008; Goffman, 1963). In contrast, each of the four participants who chose not to join survivorship groups do not currently see being a cancer survivor as a large part of their identity.

But several participants, both those who see being a cancer survivor as a main identity and those who do not, explained that their identity was rooted in places where they felt in control and independent. Since cancer taught participants that nothing is guaranteed, the survivors desired to take charge of other aspects of their lives. For instance, Participants 8 and 14 specifically said that they make the most of every moment because they do not want people to take pity on them, or for people to think they depend on them. They consciously chose which activities, academic tracts, professions, and volunteer opportunities, they devoted their time to (Elder et al., 2003). Thus, participants who devoted more time to survivorship groups created stronger positive associations to their cancer, and ultimately saw cancer as a larger part of their identity (Rutter, 1985; Zebrack & Landier, 2011; Juth et al., 2015). Likewise, participants who were not heavily involved in survivorship groups did not reinforce the survivorship connection, and see other identities as more central. Goffman (1963) similarly explained that individuals with stigmas, such as illnesses, experience oscillations in their identification with and participation among that community.

Positive Affect & Resilience

However, seeing survivorship as a large part of one’s identity was not associated with positive attitudes towards cancer more so than those who did not report survivorship being a large part of their identity. In fact, all participants in the IOC-CS scale reported that good things have come out of having had cancer, they learned something about themselves through cancer, and positive subjective qualities of life (Table 4). Like Participant 16 said, the participants in this study “had every reason in the world not to be happy,” yet still displayed positive attitudes and reported that good things have come out of having had cancer.

Why do all participants hold positive views of their cancer? The participants in this study all demonstrate resilience (Campbell-Sills et al., 2006). They not only coped with their cancer and beat it, but displayed positive adaptation by reporting meaningful and personal growth through cancer (Luthar et al., 2000; Zeltzer et al., 2008). Despite the objective characteristics of their treatment and late effects, participants held both positive recollections of cancer and positive perspectives on their quality of life (Zebrack & Landier, 2011). They describe their cancer in favorable terms, supporting Lazarus and Folkman (1984) and Zebrack et al. (2010)’s theories that reporting beneficial impacts attenuates the influence of perceived negative effects of cancer on one’s subjective well-being. Participants in this study also reported more positive and less negative outcomes of their cancer, reflecting a phenomenon in which some survivors grow to experience an enhanced quality of life as a result of having cancer (Zeltzer et al., 2008; Zebrack et al., 2010). Moreover, many participants explained that they developed an overall positive affect *after* their cancer diagnosis and treatment. These optimistic mindsets were not innate character traits, rather, they developed as a result of personal growth through adversity (Campbell-Sills et al., 2006).

Participants also demonstrated growth beyond young adults who did not experience a similar trauma (Campbell-Sills et al., 2006; Zeltzer et al., 2008). They reported feeling more mature than their peers, as daily stressors do not impact them as much as stressors impact their peers. They exhibit healthier and more effective coping strategies than peers, such as learning to live in the present each day and not fear things that they do not have control over. Participants 10, 17, and 18, said that they do not expect others who have not had this experience to understand or have the same degree of empathy or positive outlook on life. Participant 19 even said that it would be "impossible" not to have a changed perspective on life after having cancer.

Summary

A survivor's perception of how cancer affected them is a critical predictor of future distress and quality of life (Zebrack et al., 2008; Zeltzer & Landier, 2011). By objective clinical measures, participants in this study experienced significant trauma from cancer and its treatment. Yet, participants reported positive meaning and growth through cancer, positive qualities of life, and little to no symptoms of current distress. This growth and positive affect exhibits high measures of resilience (Luthar et al., 2000; Campbell-Sills et al., 2006). Social support networks also aided participants, both by buffering the adjustment to life after cancer, and helping patients create positive cognitive ideations of their experience (Rutter, 1985; Decker, 2007; Zebrack & Landier, 2011). As such, it is not practical to measure the quality of life of young adult survivors with the IOC-CS scale in hopes of improving the subjective well-being of survivors. Zebrack (2011) showed that survivors draw subjective meanings and construct ideations of the cancer experience soon after the event, making the time directly surrounding cancer treatment the period of greatest growth, or greatest detriment. Therefore, interventions must occur immediately during and after treatment. Patients, parents, healthcare workers, and the community, must work to increase the persistence of favorable cancer-related experiences and memories for childhood cancer patients. These experiences have the potential to mitigate the formation of maladaptive traits later in life and affect the attitudes towards key domains of young adult cancer survivorship.

Implications

The findings of this study suggest that there are important implications for various groups.

Implications for Patients and Parents

Zebrack (2011) found that patients are less likely to report strong positive or negative impacts of cancer as distance from treatment increased. It is therefore necessary to create positive memories and perceptions about cancer as quickly as possible, so that survivors do not develop distress towards cancer later in life. Studies also report that objective measures of cancer are not related to subjective perceptions of the experience (Juth et al., 2015; Haase & Phillips, 2004; Lazarus & Folkman, 1984). Furthermore, Juth et al.'s (2015) findings indicate that subjective perceptions of cancer are the strongest predictor of distress symptoms later in life. This further demonstrates the importance of the adage "mind over matter:" it is essential to create favorable cognitive perceptions of the cancer experience both during and immediately after treatment in order to prevent the development of negative attitudes towards cancer later in life.

Therefore, both patients and parents of childhood cancer patients should encourage their child to partake in opportunities that reinforce positive cancer experiences. From staying connected to friends and being honest with the support the child needs, to joining survivorship groups to feel connected to those with similar experiences, the importance of social networks in coping with trauma is well demonstrated (Rutter, 1985; Haase & Phillips, 2004; Decker, 2007). Survivors should also be honest if they need accomodations. Like Participants 2 and 3 explained, hiding late effects in school or work causes higher levels of distress. Moreover, parents should monitor how their child is coping, and suggest counseling if cancer causes the child high levels of distress. Participant 7, like many survivors, said that she felt that she did not have the mental support she needed to manage her diagnosis and late effects (ACS, 2020f). She wishes she sought help earlier in her journey, because it took her ten years to come to terms with and fully understand what she experienced.

Several participants also talked about how their family "pushed cancer under the rug," or did not know how to best cope with the participant's illness. It is therefore important for parents to create a safe environment for the patient to talk about their experiences. It is also essential for parents to treat their child like their 'normal' selves so that the child is not surrounded by extra anxiety. Participant 19 remembered how frustrating it was for adults to ask the same questions all the time, and that all he wanted to do was feel normal again. Ultimately, patients and parents should understand the effect that positive mental states and attitudes have on future perceived quality of life. Thus, patients and parents alike should be sure to create as many positive experiences and memories as possible during and after treatment, in order to prevent the formation of maladaptive mindsets later in life.

Implications for the Community

There are over 110 organizations in North America that host summer camp programs for children ages 4-18 currently battling cancer and cancer survivors (Ped-Onc Resource Center (PORC), 2018a; Children's Oncology Camping Association - International (COCA-I), 2016c).

The mission of many of these camps are the same; to empower kids affected by cancer, and help them feel like kids again. Camp Quality Kansas (2019) writes on its homepage:

> *Camp breaks down those barriers for children and families and restores the childhood experience. Surrounded by new friends that can relate, loving volunteers who care, and loads of fun experiences, Camp Quality campers find joy, courage and renewed hope for the future. They are free to be themselves . . . free to be kids again.*

There are 110 registered members of the Children's Oncology Camping Association, Int., and 86 are Gold Ribbon-accredited Camps (COCA-I, 2016c; COCA-I, 2016b). Gold Ribbon Camps are awarded the designation based on meeting criteria that demonstrate they provide a medically and emotionally safe pediatric oncology camp experience (COCA-I, 2016a). Over 100 organizations are located within the continental United States, and others take place in Canada (PORC, 2018a; COCA-I, 2016c).

Over 100 organizations are able to provide camp services free of charge to families, recognizing the financial toll that cancer takes on a family (PORC, 2018a; COCA-I, 2016c). Generous donors and community support enable organizations to operate at no cost to the families served there. Organizations unable to close the gap between operations expenses and donor dollars do provide scholarships and reduced registration fees (COCA-I, 2016c; PORC, 2018a). In addition to summer camp programs, these organizations also host year-round activities, such as outings to professional sport games and holiday parties (COCA-I, 2016c).

There are also over thirty groups and organizations that provide special services to families during their child's cancer journey, such as financial assistance, emotional and social support, meal services, and family programming (PORC, 2018b; ACCO 2020b). At least 10 of these programs (PORC, 2018b; ACCO, 2020b; 13Thirty Cancer Connect, 2020; Prisma Health, 2020) offer teen and young adult-specific support groups and programming. One program in upstate New York hosts member brunches, game nights, workout classes, and an annual gala that showcases an artistic performance by group members (13Thirty Cancer Connect, 2020).

Each respondent in this study who attended a camp or participated in a support group gushed about how beneficial the programs were in terms of helping them adjust to life after cancer. Whether the participants were younger and found support through other children experiencing the same thing, such as Participant 1, or the survivors were older and connected with adults, such as Participant 12, they expressed that the network made a positive difference in how they perceived their cancer, and how they felt about themselves. While not interviewed in this study, siblings are also affected when someone in the house gets cancer. The 'sick child' often is the recipient of much parental (and community) attention, which can have adverse effects on the 'healthy' child's sense of self/development (Zeltzer et al., 2008). Of the organizations that provide summer camp experiences to children with cancer, more than 100 also provide specialized sibling programming (COCA-I, 2016c; PORC, 2018a).

Therefore, it is of utmost importance that communities continue to support these programs, through volunteering, donating through galas, auctions, raffles, and in any other way possible. A rich body of literature shows the buffering effect that social networks have in managing stressors (Goffman, 1963; Rutter, 1985; Coyne & Downey, 1991; Decker, 2007). Studies also demonstrate the importance of creating positive attitudes surrounding adverse experiences in order to prevent distress later in life (Campbell-Sills et al., 2006; Juth et al., 2015; Zebrack, 2011; Zebrack & Landier, 2011). Survivorship groups that create joyful camp memories and strong support networks are essential to helping create positive attitudes towards the cancer experience. Ultimately, communities must work with the organizations to bridge the financial gap so that no family has to decide between paying bills and sending their child to summer camp.

Communities must also create more young adult survivorship groups. Compared to over 110 summer camps that cater to children and teenagers, the researcher located less than 10 young adult-specific survivorship groups (COCA-I, 2016c; 13Thirty Cancer Connect, 2020; Prisma Health, 2020). Even though a survivor finishes cancer treatment, cancer does not leave their lives (ACS, 2020f). As seen through this study, late effects from cancer and its treatment stay with survivors for years (ACS, 2020f; Wengenroth et al., 2015; Zebrack, 2011). It is therefore just as important for survivors to connect with each other through shared experiences as they age as it is for them to connect with other survivors when they are actively undergoing treatment.

The community must also recognize the stigma surrounding disability and accessibility issues, and should work to end it (Goffman, 1963; Campbell, 2009). Participants 3 explained that she is nervous to ask for accomodations for her job, as she fears that her workplace will not be willing to work with her. Likewise, Participant 15 voiced that he chooses to hide his cancer survivor identity from his workplace, because he worries that future bosses will not honor his healthcare accommodations. Participant 2 voiced that her need for auditory and GI accommodations played a large role in her decision to pursue homeschooling throughout most of her educational career. Taboo and stigma surrounding accessibility concerns and accommodations hinder survivors' abilities to feel comfortable in their daily environments (Goffman, 1963; Campbell, 2009). No one should feel uncomfortable asking for accomodations that allow them to perform at their highest level in their school or place of work. In the same vein, communities should be cognizant of accessibility issues, and plan accessible and inclusive programming without needing a person to ask for accomodations first. Field trips, physical education classes, lunch rooms, and other public spaces, should be accessible to individuals of all abilities so that someone who needs accommodations will not be further ostracized by asking for them.

Implications for Healthcare Workers

Just as it is important for the community to support survivorship programs, it is essential that healthcare workers encourage patients to become involved with survivorship organizations. For many patients, their only exposure to these groups are when a social worker approaches them during treatment to talk about community resources, or when they see a flier on a hospital billboard. If after the first impression, the patient does not want to learn more, that is usually the end of conversation about the topic. However, this should not be the case. During active treatment, attending summer camp or joining a survivorship is likely near the bottom of the patient and family's priority list. But, Zebrack (2011) showed that the time during and immediately following treatment is both the period of greatest risk for developing distress towards cancer, and also the period for greatest potential. It is thus the responsibility of healthcare workers to remain engaged with the patient throughout his or her cancer journey, and remind the patient of the community resources during follow-up appointments. Treatment and follow-up regimens with providers should be integrated with social workers and other healthcare professionals that work with the survivorship organizations, so that the whole care team encourages the patient to join programs for survivors.

Also, it is critical for child life specialists, social workers, and healthcare providers, to continuously explain what is happening to both the patient and their parents. Participants 14 and

11 explained that they did not feel equipped to explain their sickness to friends, contributing to feelings of isolation. Parents and patients should be confident in sharing, explaining, and educating, their close friends and other family members on what is happening to prevent the child from being further isolated. Vance and Eiser (2002) analyzed existing school-reintegration intervention programs and found that a social skills training program to provide children with skills to deal with questions from others (i.e. ‘what happened to your hair’) was successful. For a young child, the ‘toolkit’ of explanations that the healthcare professional gives them might include “*When I get chemotherapy, the medicines do not know what is cancer and what is not, so I get very weak and tired. Some days I have to wear a mask to protect myself from germs, but I cannot give my sickness to you if I sneeze*.” Programs like this should be instituted for all cancer patients returning to school to equip them with the skills to talk about their experience.

Along the same lines, a healthcare professional, for instance a child life specialist, should share a presentation or host an assembly at the school the patient attends. For many children, the only exposure they have to cancer is losing an elderly loved one. Anxiety and thoughts about their friend’s mortality likely flood the child, so it is important to educate the patient’s peers. child life specialists can help address concerns about what others might think of the patient, misconceptions about a cancer diagnosis, or lack of knowledge of side effects of the medication, by providing educational seminars to schools (Palau, 2012). These presentations should cover topics such as what the child might experience upon return for school staff members, and educational and interactive programs for the child’s peers to increase their understanding of the medical condition (Palau, 2012). For programs created for younger children, the presentation should include language such as “*Your friend might look different when they come back, they* *might have no hair because of their medicine, but do not be afraid, they are still your friend!*" and for older children, the presentation should include conversation etiquette and verbiage the teenagers can use to ask questions in a respectful way.

Vance and Eiser (2002) saw that intervention programs aimed towards teachers increased teacher confidence in helping the cancer patient adjust to academic rigor of school. They also found that intervention sessions geared towards fellow students that explained issues such as how cancer is caused, how it is treated, that it is not contagious, were successful; classmates more willing to interact with the patient, and children with cancer had reduced depression, and increased self-esteem (Vance & Eiser, 2002)

Finally, there should be an increased focus on long-term survivorship training for providers. Like Participant 2 explained, childhood cancer survivors often have difficulties with long-term care (ACS, 2020f). Should adult oncologists be trained to oversee pediatric survivors once they turn 18? Or should pediatric oncologists oversee their patients as adults? Or should an adult oncologist be added to the care team to generate familiarity and create a patient-provider relationship? Since the rate of developing a second cancer for survivors is higher than the general population, and pediatric patients would be treated by an adult oncologist if they developed a second cancer as an adult, the patient and provider would benefit from establishing a relationship before a second diagnosis occurs (ACS, 2020f). Familiarity and trust between the adult oncologist and patient may diminish the fear and uncertainty a survivor feels if they develop a second cancer.

Furthermore, providers should be very clear with the continuum of care for the patient. They should explain the rationale behind the follow-up schedule, which tests they are ordering and why, and specific things that the patient should look out for. Ultimately, because a cancer diagnosis affects the patient for life, providers and the healthcare field should treat cancer as a chronic disease (ACS, 2020f). Not only asking about topics relating to the original cancer diagnosis, but also asking questions about their late effects and future health concerns, are essential to helping a survivor navigate life after cancer.

The implications for patients and their families, the community, and healthcare workers, rest on the findings that positive experiences shape the subjective interpretations of objective stressors. These groups of people must constantly work towards finding ways to create favorable mindsets and attitudes towards cancer, as these perceptions significantly influence young adult survivors of childhood cancer's quality of life.

Limitations

There were several limitations in study design, data collection methodology, and analysis strategy, for this project.

Study Design

The nature of this study was a limitation in itself. As an advanced independent study project, the researcher was the sole contributor to the project; designing the study, recruiting participants, collecting and analyzing data, and all written documents, were completed by the researcher. More contributors on the project would have broadened the size and scope of the study in the same timeframe (one academic calendar year). Interview method also limited results. Due to resource availability, convenience, and time constraints, most interviews were held over video chat. This limited the socioeconomic diversity of participants because participants needed to have access to a method of video chat.

Recruitment

There is bias inherent in qualitative research recruitment. Recruitment for qualitative studies leads to selection bias because participants voluntarily elect to participate. Therefore, those who choose to participate in studies must identify somewhat with the objectives of the study to feel that it is worth their time. A person who was severely distressed by their cancer experience and finds it difficult to recount their experiences would likely not have volunteered to be part of the study. Thus, the study is limited in terms of recruiting participants who do not have positive attitudes towards their cancer experience.

Also, due to resource availability, the researcher had limited recruitment potential. The largest network she had access to was her social media; she was not permitted to advertise the study in hospitals or survivorship groups. Recruitment method therefore limited the sample to those in her extended Facebook friend network, which comprised mainly individuals from the northeast. As a result, the respondents she gathered through this method mostly attended the same summer camp and young adult survivor group. This limits transferability of the impact of survivor social networks, because the positive impact survivorship groups had on participants could have been due to those specific programs, instead of due to survivorship programs in general.

Recruiting via Facebook further limited potential participants to those who had access to devices that allowed them to use social media. This contributes to socioeconomic homogeneity, as low SES individuals are less likely to have access to internet-enabled devices and video-chat methods. Moreover, the researcher posted the study announcement in Facebook survivor groups, limiting participants to those who already chose to be connected to other survivors. This increased the proportion of respondents who reported positive experiences with survivorship groups, as well as increased the proportion of respondents who hold being a survivor as a large part of their identity. The respondent did not have a method for increasing recruitment of survivors who do not already belong in survivorship groups, skewing the representation of those who are involved in survivorship groups versus those who are not.

The sample for this study is primarily female (63%). This limits the transferability of research findings because childhood cancer (age 0-14) affects males 10% more than females, rendering males underrepresented in this study (Siegel et al., 2020). This adds confounding factors to the study. For instance, the proportion of males who chose to not participate in survivorship programs is larger than the proportion of females who elected not to participate in survivorship programs (43% and 8%, respectively). If there were more males in the sample, would the proportion decrease, or do truly 40% of all male childhood cancer patients choose not to participate in survivorship programs? If 40% of all male childhood cancer patients choose not to participate in survivorship programs, then implications would shift to focus on male survivors; if females organically join survivorship support programs, then healthcare workers should focus on encouraging males to join survivorship groups.

Data

Social desirability bias likely affected results as well. Social desirability bias refers to the innate desire of people to provide socially desirable responses in research (Fisher & Katz, 2000).

Therefore, they may not want to appear distressed when recounting personal experiences, or provide overly negative answers, in an effort to appear most desirable (Fisher & Katz, 2000).

Furthermore, the researcher personally knew ten (53%) participants before they elected to participate in the study. The pre-existing friendship between the interviewer and respondents may have exacerbated social desirability bias. Did the researcher's presence influence respondents to answer questions in a certain way, given that they were already familiar with her attitudes towards survivorship programs and other topics? Would increasing the sample size to be composed of all strangers reduce social desirability bias? Or, were participants more comfortable sharing their honest, sometimes negative, feelings about topics during the interview because they were familiar with the researcher?

Recommendations for Future Research

Future studies would benefit from having a larger and more diverse sample in terms of gender, socioeconomic status, geographic area, and relation to the cancer community. As described in the limitations, this study was composed of mostly middle-class, northeastern females, many of whom chose to be in Facebook survivorship groups. Future studies should recruit participants from hospitals across the country, in order to generate more heterogeneity in the sample. A larger and more diverse sample would also decrease the likelihood that the researcher knows the participants. The researcher personally knew ten (53%) participants, which as explained likely led to social desirability bias on account of the participants. Having a more anonymous interviewer will ensure respondents greater confidentiality, leading them to answer questions more honestly and openly.

Designing a longitudinal study would also contribute to the findings of this study (Elder et al., 2003). Following a cohort of patients from their diagnosis until age 30 with bi-annual follow-ups, or another schedule regimen, would allow the researcher to monitor the attitudes and feelings of each patient as they passed through the three checkpoints of survivorship. This would add depth to the current study's findings because longitudinal data would illuminate whether there is a causal relationship between the role of social support networks and attitudes towards young adult survivor quality of life domains. It would also demonstrate Zebrack (2011)'s theory that positive experiences soon after an adverse event, such as cancer, can prevent the development of negative attitudes about the event.

Conclusion

Being diagnosed with cancer as a child has significant impacts on the life course (Elder et al., 2003; ACS, 2020f). However, existing quality of life surveys do not fully address areas of importance for young adult survivors of childhood cancer (Zebrack et al., 2010). Existing surveys tend to ask about the patient's attitudes during treatment, or ask adults about their cancer experience (Quinn et al., 2013). The researcher only identified a handful of surveys that claimed to specifically address young adult survivorship, and of these, only one claimed to address all aspects of survivorship (Zebrack et al., 2010). The developers of this survey argue there are twelve key domains specific to young adult survivors of childhood cancer, and developed their own quality of life scale that addresses each key topic (Zebrack et al., 2010).

The researcher of this current study administered a hybrid survey of three existing quality of life surveys to 19 young adult survivors of childhood cancer (Appendix C). This recorded initial quality of life measures, and primed subjects on topics that the interview would address.

The researcher conducted a semi-structured interview with each participant, addressing topics that are commonly missing in existing quality of life surveys (Quinn et al., 2013).

After the interview, study participants filled out the IOC-CS survey and explained whether or not they agreed that the IOC-CS scale was more comprehensive than the hybrid (Appendix E).

Upon analyzing results, data showed that key domains identified by the IOC-CS scale were of importance to nearly every participant, and that subjects preferred the second survey to measure aspects of their survivorship (Table 4). This substantiates Zebrack et al. (2010)'s claim that the IOC-CS survey is an accurate measure of young adult survivorship.

Moreover, it was apparent that three key 'checkpoints' occurred in the lives of young adult survivors of childhood cancer. These checkpoints create a "Trail of Survivorship," which shapes how survivors draw meaning from their experiences (Elder et al., 2003). Cancer and subsequent experiences cannot be interpreted as isolated life events, rather, the outcomes of each checkpoint along the lifecourse of survivorship influence the eventual perceived quality of life of a young adult survivor (Elder et al., 2003). As such, the IOC-CS scale measures factors that are the *result* of experiences that occurred during and directly after treatment.

Therefore, it is not enough to measure the quality of life of young adult survivors with the IOC-CS scale years after their cancer experience in efforts to improve the lives of those who report low scores. Rather, there must be more intervention and monitoring during and immediately after cancer treatment (Zebrack, 2011). The results of this study demonstrated resilience and positive affect as a result of favorable cancer-related experiences throughout the lifecourse of survivorship (Lazarus & Folkman, 1984; Rutter, 1985; Elder et al., 2003; Zebrack et al., 2008). Positive cancer-related experiences such as strong social networks that assist with the transition to life after cancer, support from survivorship groups, and more, lead survivors to develop positive subjective perceptions of their cancer (Haase & Phillips, 2004; Coyne & Downey, 1991; Decker, 2007). Positive ideations of adverse experiences mitigate adverse outcomes later in life, and affect the feelings and attitudes survivors have regarding the key domains of young adult cancer survivorship (Bellizzi et al., 2012; Juth et al., 2015; Barnett et al., 2016). Therefore, it is of utmost importance to create as many positive cancer-related experiences for young adult survivors of childhood cancer as possible.

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APPENDICES

APPENDIX A: **RECRUITMENT FLIER**

Are you a childhood cancer survivor and between 21-30 years old?

I'm looking for survivors to participate in an online survey and in-person / video chat interview for my senior thesis at Boston College.

Please contact Bridgette Merriman at merrimab@bc.edu or (585) 507-5926 if you are interested

Boston College IRB
Approved
August 19, 2019

APPENDIX B: **DOCUMENT OF CONSENT**

Boston College Consent Form
Boston College Sociology Department
Informed Consent to be in study *Impact of Childhood Cancer on Young Adult Survivors*
Researcher: *Bridgette Merriman*
Adult Consent Form

Invitation to be Part of a Research Study

You are invited to participate in a research study. You were selected to be in the study because you are an individual between the ages of 21-30, diagnosed with cancer prior to age 18, and have been off active treatment/therapy for at least two years. Taking part in this research project is completely voluntary, and you may stop at any time.

Important Information about the Research Study

- The purpose of the study is to investigate the impact that childhood cancer has had on young adult survivors. If you choose to participate, you will be asked to fill out an online Quality of Life survey, participate in an in-person or video-chat interview, and fill out a post-interview online survey. The surveys will take about 5-10 minutes, and the interview will take about 30 minutes.
- Risks or discomforts from this research include potential stress from talking about your cancer experience and feelings that followed.
- The study will have no direct benefits. However, indirect benefits include knowing that you have helped contribute to a growing body of research that aims to improve the well-being of young adult survivors of childhood cancer.
- Taking part in this research project is voluntary. You don't have to participate and you can stop at any time.

Please take time to read this entire form and ask questions before deciding whether to take part in this research project.

What is the study about and why are we doing it?

The purpose of the study is to investigate the effects that a childhood cancer diagnosis has on young adult survivors. There is a lack of research on young adult survivors, and current scales to measure the quality of life of young adult cancer survivors do not accurately measure all aspects of survivorship. Researching the effects of cancer and the experiences of young adult survivors can lead to better support tools and more effective ways to measure the quality of life of these individuals. The total number of people in this study is expected to be 30.

What will happen if you take part in this study?

If you agree to take part in this study, you will be asked to fill out an online, abbreviated version of the Quality of Life in Adult Cancer Survivors survey, which will take approximately 5-10 minutes. It can be completed wherever you have access to the internet at a time that is convenient for you. Then, you will participate in an in-person or video-chat interview, which will take approximately 30 minutes. I will ask questions about your cancer experience and experiences following your cancer journey, such as "How open are you with others about your survivor status? Tell me about a time where you have felt it necessary to either tell someone that you are a cancer survivor, or have felt the need to keep that status private, and what made you decide to take that course of action." These questions may bring up sensitive topics, and I remind you that answering questions is completely voluntary; you are not required to answer all questions. I will use an audio-recording, non-internet accessible, device to record the interview in order to transcribe it at a later time. Directly following the interview, you will take an online abbreviated version of the Impact of Cancer for Childhood Cancer Survivors Scale, which will take approximately 5-10 minutes.

How could you benefit from this study?

Although you will not directly benefit from being in this study, others might benefit because your experiences will contribute to a growing body of research that aims to improve the well-being of young adult survivors of childhood cancer.

What risks might result from being in this study?

There are some risks you might experience from being in this study. There is an informational risk, for example a breach of confidentiality. We describe below how we minimize informational risk (see 'How will we protect your information?'). There is a psychological risk of recounting experiences that may be sensitive. There may be unknown risks. If during the course of the study you wish to contact support services, below is contact information for counseling resources:

Rochester:
Mental Health Association: **(585) 454-3530** http://mharochester.org/
Self-help drop-in hours are available 7 days a week 5pm-9pm at 539 South Ave, Rochester NY 14620.

13Thirty Cancer Connect: **(585) 563-6221** http://13thirty.org/
Young adult cancer survivor support group.

Monroe County Office of Mental Health: **(585) 275-5151**
Crisis line open 24/7 for all emergency and non-emergency mental health and human service issues.

Boston:
Boston Cancer Support: http://bostoncancersupport.org/
Cancer support resources and community outreach programs.

Samaritans: **(877) 870-4673** http://samaritanshope.org/
24/7 call and text Helpline.

Boston College:
University Counseling Services: **(617) 552-3310** http://bc.edu/counseling
Appointments can be made by calling UCS or by visiting the office in Gasson 001 during regular office hours of Monday through Friday 8:45 AM to 4:45 PM. 25-minutes same-day consultations are available, as well as 15-minute phone call clinician triage appointments.

Lean on Me: **(617) 553-6655** https://lean0n.me/bc/
Peer-to-peer texting support service.

How will we protect your information?

The records of this study will be kept private. In any sort of report I may publish, I will not include any information that will make it possible to identify you. Research records will be kept in a locked file to which I am the only one who has the password.

All electronic information will be coded and secured on the Boston College Sociology departmental server. I will assign to each participant a unique, coded identifier that will be used in place of actual identifiers. I will separately keep a record that links each participant's coded identifier to his or her actual name. This separate record will not include research data.

I will keep audio recordings of interviews in order to transcribe them. I am the only individual who will have access to recordings and I will transfer them from a non-internet enabled recorder to the secure departmental server. I will erase the recordings once transcriptions are complete.

Mainly just the researchers will have access to information; however, please note that a few other key people may also have access. These might include government agencies. Also, the Institutional Review Board at Boston College and internal Boston College auditors may review the research records. Otherwise, I will not release any information that identifies you unless you give permission, or unless I am legally required to do so.

What will happen to the information I collect about you after the study is over?

I will keep your research data to use for potential future research. Your name and other information that can directly identify you will be kept secure and stored separately from the research data collected as part of the project.

How will we compensate you for being part of the study?

There will be no compensation for your participation in this study.

What are the costs to you to be part of the study?

There is no cost to you to be in this research study.

Your Participation in this Study is Voluntary

It is totally up to you to decide to be in this research study. Participating in this study is voluntary. Even if you decide to be part of the study now, you may change your mind and stop at any time. You do not have to answer any questions you do not want to answer. If you decide to withdraw before this study is completed, please email me, and I will erase any data linked to you.

If you choose not to be in this study or discontinue your participation, it will not affect your current or future relations with Boston College.

Getting Dismissed from the Study

I may dismiss you from the study at any time if it is in your best interests (e.g. distress has resulted)

Contact Information for the Study Team and Questions about the Research

If you have questions about this research, you may contact Bridgette Merriman at merrimab@bc.edu (585) 507-5926, or faculty advisor Wen Fan at wen.fan@bc.edu (617) 552-6864

Contact Information for Questions about Your Rights as a Research Participant

If you have questions about your rights as a research participant, or wish to obtain information, ask questions, or discuss any concerns about this study with someone other than the researcher, please contact the following:

Boston College
Office for Research Protections
Phone: (617) 552-4778
Email: irb@bc.edu

Your Consent

By signing this document, you are agreeing to be in this study. Make sure you understand what the study is about before you sign. I will give you a copy of this document for your records and will keep a copy with the study records. If you have any questions about the study after you sign this document, you can contact the study team using the information provided above.

I understand what the study is about and my questions so far have been answered. I agree to take part in this study.

____
Printed Subject Name

____
Signature Date

Consent to Use Data for Future Research
I agree that my information may be shared with other researchers for future research studies that may be similar to this study. The information shared with other researchers will not include any information that can directly identify me. Researchers will not contact me for additional permission to use this information.

YES_________ ***NO_________***

____
Signature Date

Consent to be Contacted for Participation in Future Research
I give the researchers permission to keep my contact information and to contact me for future research projects.

YES_________ ***NO_________***

____
Signature Date

APPENDIX C: **QUALITY OF LIFE IN ADULT CANCER SURVIVORS SURVEY - HYBRID**

INSTRUCTIONS: I'd like to ask you about some demographic information. [Choose one answer for each question]

What is your age?
What is your gender identity?
What is the highest level of education you have completed?
1 = Some high school 2 = high school 3 = some college 4 = college 5 = some graduate school 6 = graduate school
Self-reported current health status: 1 = very unhealthy 2 = unhealthy 3 = more or less unhealthy 4 = neither unhealthy nor healthy 5 = more or less healthy 6 = healthy 7 = very healthy

Now I'd like to ask you about some things that can affect the quality of people's lives. Some of these questions may sound similar, but please be sure to answer each one. Below is a scale ranging from "never" to "always". Please indicate how often each of these statements has been true for you in the past four weeks. [Choose one answer for each question]
1 = never 2 = seldom 3 = sometimes 4 = about as often as not 5 = frequently 6 = very often 7 = always

In the past 4 weeks ...
1. You had the energy to do the things you wanted to do.
2. You had difficulty doing activities that require concentrating.
3. You had trouble remembering things.
4. You felt fatigued.
5. You felt happy.
6. You felt blue or depressed.
7. You enjoyed life.
8. You worried about little things.
9. You didn't have energy to do the things you wanted to do.
10. You were bothered by pain that kept you from doing the things you wanted to do.
11. You felt tired a lot.
12. You were reluctant to start new relationships.
13. Your mood was disrupted by pain or its treatment.
14. You avoided social gatherings.

15. You avoided your friends.
16. You had aches or pains.
17. You had a positive outlook on life.
18. You felt anxious.
19. You were reluctant to meet new people.
20. Pain or its treatment interfered with your social activities.
21. You were content with your life.

The next set of questions asks specifically about the effects of your cancer or its treatment. Again, for each statement, indicate how often each of these statements has been true for you in the past four weeks, and choose one answer for each question.

22. You appreciated life more because of having had cancer.
23. You had financial problems because of the cost of cancer surgery or treatment.
24. You worried that your family members were at risk of getting cancer.
25. You realized that having had cancer helps you cope better with problems now.
26. You were self-conscious about the way you look because of your cancer or its treatment.
27. You worried about whether your family members might have cancer-causing genes.
28. You felt unattractive because of your cancer or its treatment.
29. You worried about dying from cancer.
30. You had problems with insurance because of cancer.
31. You were bothered by hair loss from cancer treatment.
32. You worried about cancer coming back.
33. You felt that cancer helped you to recognize what is important in life.
34. You felt better able to deal with stress because of having had cancer.
35. You worried about whether your family members should have genetic tests for cancer.
36. You felt people treated you differently because of changes to your appearance due to your cancer or its treatment.
37. You had financial problems due to a loss of income as a result of cancer.
38. Whenever you felt a pain, you worried that it might be cancer again.
39. You were preoccupied with concerns about cancer.
40. Do you feel that these questions accurately address all relevant aspects of survivorship?

1 = Not at all 2 = A little bit 3 = Somewhat 4 = Quite a bit 5 = Very much

Please explain:

41. May I contact you to set up a 30 minute interview?

Yes No

If so, please email Bridgette at merrimab@bc.edu once you are finished with this survey.

42. [QUALTRICS- function to generate random 7-digit ID number]

Take a picture of this ID number and show it to Bridgette during the interview

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APPENDIX D: **INTERVIEW GUIDE**

Interview Guide: 30 minute interview, semi-structured guide that gives the participant space to elaborate on close-ended questions asked in the questionnaire.

The outline below lists the areas missing in all survey instruments as found by Quinn et al. (2013). They are separated into Rowland's five categories. Start with the life history of the participant and, with the participant's survey responses guiding you, ask some of the questions below. For example - if the participant does not feel that they matured faster because of their experience, you can ask why, but don't spend long on it. But, if the person said that they do feel that they matured faster, talk to them and ask them why they think that and for stories that show it. If a topic (i.e. feeling like a burden to others) does not pertain to them, skip it. If one topic is rich in information, stay on that topic for a while. Explore the 5 Paradigmatic Principles of Life Course Theory - the principles of life-span development, agency, time and place, timing, and linked lives - to create a framework of development.

Life History:

Life Before Cancer

- Tell me about your family - your parents and siblings, relationships with them and your extended family
- Tell me about your friends, hobbies/interests, jobs/activities and school experience before cancer
- Before cancer, what did you want to do when you were older, what were your dreams/goals/wishes?
- Where did you envision yourself living, and with what type of job/family (kids, single, travelling the world, etc)?

Cancer

- Tell me your cancer story (how you found out you had cancer and a little bit about your journey to remission)

Immediate Aftermath

- What was life like after you ended treatment? Did things go back to 'normal' - what was the new normal? What felt different - returning to school, job, and why?

Identity/Achievement of Life Goals:

Identity Formation

- Tell me about the identities that are most important to you (son/daughter, student, sister/brother, athlete, musician, etc.)
- Do you see your survivor status as a large part of your identity? Why?

Maturation Rate

- Do you feel that you matured faster because of your cancer experience? How? Describe a time where you felt that you matured faster than your peers because of it / felt that you could not relate to them

Changed Outlook on Death

- What are your views on death? Are you afraid of dying? Has your cancer experience shaped your views?

Missed opportunities/unfinished or unresolved issues

- Did having cancer interrupt something important in your life? Now, what are your dreams/goals/wishes. Describe to me how having cancer shifted your life-course, if at all.
- Do you feel that you have unresolved issues or missed opportunities as a result of cancer?

Existential Concerns:

Survivor Guilt

- Do you have survivor guilt? How? When do you feel this way?

Obligation to Take Care of Body

Obligation to Be Valuable

- Tell me about your health habits prior to having cancer - eating, fitness, sun safety, other measures to take care of yourself.
- Do you feel that you owe it to others (your family, friends, etc.) to take care of your body and be on top of your health? Do you do anything differently now than before cancer, or as time has passed do you notice yourself practicing different health habits?
- Do you feel that you owe it to others to be valuable?

Fear of Burdening Others

- Do you fear that you are a burden to others if you share your story/feelings/worries with them? Does feeling as though you are a burden shape how you interact with others and what you share with them?

Dependence/Independence:

Desire for Autonomy

Overprotective Parents

- How involved with your health life / life in general were your parents before you had cancer? Has this changed at all since having cancer? Do you feel that they are overbearing / do you feel that you have to hide information from them to keep them from being over protective? If so, please describe how.

Concerned Family will Resent Poor Health/Limited Functioning

Need for Transitional/Disability Resources

Concerns about Body & Self-Image:

Making Efforts to Hide Cancer/be 'Normal'

- How open are you with others about your survivor status? Tell me about a time where you have felt it necessary to either tell someone that you are a cancer survivor, or have felt the need to keep that status private, and what made you decide to take that course of action."

Treated as if Still Have Cancer

- Are people overly cautious around you, or do they treat you as if you are still sick? If so, please describe a time when this occurred.

Specific Concerns Related to Scars

- Do you have visible markers of your survivor status? How do you feel about others seeing them? Are you more comfortable in some environments than others / with some people than others about showing them? How so? Tell me about a time when you were concerned with your scars or not concerned and what about the situation made you feel that way.

Worried About Health Status / Fearing that Quality of Life will Worsen

- Do you think about the future often?
- Are you concerned about recurrence or relapse? Why/why not?
- Are you worried about your future health status and quality of life? Does this fear/lack thereof impact your present actions?

Interpersonal Relationships:

Difficult to Disclose/Trust Others' Willingness to Keep Friendship

- Do you find it harder to create trusting friendships now than it was before you had cancer? Do you find it difficult to disclose your survivor status or other private information to friends? Why or why not?

Worry About/Have Difficulties Forming Romantic Relationships

- What about for romantic relationships?

Worried Children will Get Cancer

- Do you worry that you will have difficulties having children or that your children will get cancer? Does this fear make you reluctant to have children?

APPENDIX E: **IMPACT OF CANCER - CHILDHOOD SURVIVOR SCALE**

(Adapted from Zebrack, 2009)
Please provide your ID number:

INSTRUCTIONS: I'd like to ask you about some things that can affect the quality of people's lives, specifically about the effects of your cancer or its treatment. Some of these questions may sound similar, but please be sure to answer each one.

YOUR BODY AND YOUR HEALTH

I am interested to know how having had cancer affects your body and your health **NOW**, if at all.

Please select one answer for each statement that best describes you.

1 = Not at all 2 = A little bit 3 = Somewhat 4 = Quite a bit 5 = Very much

1. I lead a healthy life.
2. I eat a healthy diet.
3. I exercise.
4. I am as healthy as others who have never had cancer.
5. I worry about my health.
6. Having had cancer limits my ability to work (including school work).
7. It is difficult to know whether to push myself physically or to be careful and rest.
8. I like the way my body looks.
9. I wear clothing to cover up parts of my body I don't want others to see.
10. Visible signs of my cancer (scars, braces, prosthesis) make me feel embarrassed or insecure.

CANCER TREATMENT AND HEALTH CARE

Please select one answer for each statement that best describes you.

1 = Not at all 2 = A little bit 3 = Somewhat 4 = Quite a bit 5 = Very much

11. When I have a health problem I know who to see for medical care.
12. Going to the doctor makes me nervous or anxious.
13. I am confident that any doctors I see know about the long-term effects of childhood cancer treatment.
14. It is easy for me to talk to doctors about my cancer history.
15. I have all the information I need about my cancer, its treatment, and possible long-term effects.
16. When I need information about cancer I know where to find it.
17. My health insurance plan makes it difficult for me to see the doctors I want or need to see.
18. My health insurance plan pays for any cancer-related expenses (such as medical treatment for long-term effects of treatment, check-ups with an oncologist, medical equipment, prostheses, etc.)

HAVING CHILDREN

Please select one answer for each statement that best describes you.
1 = Not at all 2 = A little bit 3 = Somewhat 4 = Quite a bit 5 = Very much.

19. I am concerned that I may not be able to have children (get pregnant, get someone pregnant).
20. I am concerned about my children getting cancer.
21. I am concerned about whether my children will be healthy.

WHO ARE YOU?

Please select one answer for each statement that best describes you.
1 = Not at all 2 = A little bit 3 = Somewhat 4 = Quite a bit 5 = Very much

22. I have confidence in myself.
23. I am a cautious or careful person.
24. Cancer is part of who I am, the person I am today.
25. I feel I am different than other people my age who have not had cancer.
26. I feel I am more mature than people my own age.
27. I am a risk-taker.
28. I feel in control of my life.

TALKING AND THINKING ABOUT CANCER

Please select one answer for each statement that best describes you.
1 = Not at all 2 = A little bit 3 = Somewhat 4 = Quite a bit 5 = Very much

29. I think about having had cancer.
30. I would like to forget about having had cancer.
31. I need to talk about cancer and what I went through.
32. I feel comfortable talking about cancer.
33. I wonder why I got cancer.
34. I wonder why I survived and others do not.
35. I feel like something I did caused me to get cancer.
36. I am angry about having had cancer.
37. People treat me differently after they find out I have had cancer.
38. I feel like cancer controls my life.
39. I feel a special bond with people with cancer.
40. I feel like time in my life is running out.
41. I am afraid to die.
42. I worry that I might die at a young age.

MEANING OF CANCER

Please select one answer for each statement that best describes you.
1 = Not at all 2 = A little bit 3 = Somewhat 4 = Quite a bit 5 = Very much

43. Good things have come out of having had cancer.
44. I learned something about myself because of having had cancer.
45. Cancer has been the most difficult experience of my life.
46. Having had cancer makes me think about or question my religious faith, faith in God or a higher power.

FINANCES AND MONEY

Please select one answer for each statement that best describes you.

1 = Not at all 2 = A little bit 3 = Somewhat 4 = Quite a bit 5 = Very much

47. Concerns about losing health insurance keep me in school or in the job I have now.
48. My decision to take a job has been, or will be, based on whether or not health insurance benefits are included.
49. I/my parents have financial problems related to my cancer and treatment
50. I have had trouble getting assistance or services that I need, such as insurance, disability or social security benefits, time off from work for doctors' visits, extra time to finish work or exams, specialized medical equipment, etc.

If you would like, please describe your answer to #50 here:

FAMILY

Please select one answer for each statement that best describes you.

1 = Not at all 2 = A little bit 3 = Somewhat 4 = Quite a bit 5 = Very much

51. Having cancer brought my family closer together.
52. I feel guilty for what my family members had to go through when I had cancer.
53. My mother worries about me.
54. My father worries about me.
55. I am comfortable discussing my cancer with my mother.
56. I am comfortable discussing my cancer with my father.
57. My mother is comfortable discussing my cancer with me.
58. My father is comfortable discussing my cancer with me.

Do you have brothers or sisters?

0 No **skip to QUESTION 61 below**
1 Yes **continue with QUESTION 59 below**

59. I worry about how my cancer has affected some or all of my brothers and/or sisters.
60. I have a brother or sister with problems that might be related to my having had cancer (for example, drug or alcohol problems, learning or school problems, behavior problems, or trouble with the law).

61. Are you currently married, living together as married, or in a significant committed relationship?

1 Yes **skip to QUESTION 65 below**
0 No **continue with QUESTION 62 below**

62. I worry about not having a spouse, partner, boyfriend or girlfriend.
63. I worry about telling a potential spouse, partner, boyfriend or girlfriend that I have had cancer.
64. I am concerned about how to tell a potential spouse, partner, boyfriend or girlfriend that I may not be able to have children.
65. If I have a health problem, I feel comfortable talking to my spouse/partner about it.

66. I worry about my spouse/partner leaving me if I were to get cancer again.

SOCIALIZING AND BEING WITH FRIENDS

Please select one answer for each statement that best describes you.

1 = Not at all 2 = A little bit 3 = Somewhat 4 = Quite a bit 5 = Very much

67. I make friends easily.
68. I avoid social activities.
69. I feel left out from my friends' lives or activities.
70. I feel love and support from my friends.
71. I feel like I missed out on important life experiences while I had cancer.

LIFE GOALS

Please select one answer for each statement that best describes you.

1 = Not at all 2 = A little bit 3 = Somewhat 4 = Quite a bit 5 = Very much

72. I feel like I have goals in life.
73. I feel like I know what I have to do to reach my goals.
74. Having had cancer makes me feel unsure about my future.

75. Do you feel that the questions asked in this survey address all relevant aspects of survivorship?

1 = Not at all 2 = A little bit 3 = Somewhat 4 = Quite a bit 5 = Very much

Please explain: