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# Examining Demographic and Environmental Factors in Predicting the Perceived Impact of Cancer on Childhood and Adolescent Cancer Survivors

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Examining Demographic and Environmental Factors in Predicting the Perceived Impact  
of Cancer on Childhood and Adolescent Cancer Survivors

by

Nazan Cetin

A dissertation submitted in partial fulfillment of the  
requirements for the degree of

Doctor of Philosophy  
in  
Social Work and Social Research

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2022

## Abstract

Cancer survivors' perceptions on how cancer has impacted their lives has been identified as a "critical predictor" of psychosocial well-being and quality of life outcomes. Given the dramatic increase in survival rates and the long-term health and psychosocial challenges, as well as survivorship care barriers, this study focuses special attention on childhood and adolescent cancer survivors and is guided by Tedeschi and Calhoun's theory of posttraumatic growth and Hammond's theory of distinctiveness. This study aims to examine the influence of demographic (i.e., age at diagnosis, biological sex, race/ethnicity, type of cancer) and environmental factors (i.e., geographical location and insurance type), as well as the interaction effects (i.e., age at diagnosis  $\times$  biological sex, and geographical location  $\times$  insurance type), in predicting negative impacts of cancer (NIOC) and positive impacts of cancer (PIOC). Study findings provide insights to better understand the differential perceptions of female adolescent cancer survivors, as well as those residing in rural locations with public health insurance.

Study respondents were cancer survivors attending Oregon Health and Science University's Doernbecher Cancer Survivorship Clinic (DCSC) in Portland, Oregon, who were diagnosed with and treated for cancer between the ages of 0-19 years old and were in remission from cancer for a minimum of two years at the time of the study. During their first visit to DCSC, the Impact of Cancer for Childhood Cancer Survivors (IOC-CS) questionnaire was completed by participants 13 years and older (otherwise, after they turned 13 years old) to measure NIOC and PIOC scores. Demographic and environmental variables were derived from the Survivorship Repository and a retrospective chart review

through OHSU's electronic medical record (EPIC). Of the 470 respondents, years since diagnosis ranged from 6-50 years, including 79% who were childhood cancer survivors (i.e., diagnosed between the ages of 0-14 years old, *vs.* 21% were adolescent cancer survivors diagnosed between 15-19 years old); 51% identified as male (*vs.* 49% were female); and 73% identified as non-Hispanic White (*vs.* 21% were non-White). Participants' current age ranged between 14-55 years old, with 67% residing in urban geographical locations (*vs.* 33% in rural) and 65% with private insurance (*vs.* 35% with public). Type of cancer featured three main groups, hematological cancers (60%), CNS/Brain tumors (11%), and solid tumors/soft tissue tumors/other cancers (29%).

To examine how well a new set of study variables predicted the outcome variables over and above the previously entered set of variables, hierarchical ordinary least squares (OLS) regression was utilized. Controlling for years since diagnosis, three sets of data analysis, including only demographic variables were entered in the first model, environmental variables were then added to the second model, and the interaction effects added in the final model. Each model was developed and tested separately for each dependent variable (NIOC *vs.* PIOC). Prior to OLS regression analysis, factor analysis was conducted to examine the factor structure of NIOC and PIOC.

Interestingly, PIOC scores were consistently higher than NIOC scores for all groups. Preliminary data analysis using *t*-tests found that NIOC was higher among female, adolescents, and participants with public health insurance compared to their counterparts; PIOC was higher among females, and carriers of private insurance; but no significant differences were found between non-White *vs.* non-Hispanic White, rural *vs.*

urban, and types of cancer. All three OLS models were significant in predicting outcome variables. The final model including the interaction effects significantly increased model description above the second model for both NIOC (additional 1.6% of the variance,  $F(10, 433) = 3.88, p < 0.001$ ) and PIOC (additional 1.8% of the variance,  $F(10, 433) = 3.31, p < 0.001$ ). Being a female adolescent cancer survivor was identified as a risk factor for increased NIOC and decreased PIOC. Having public health insurance significantly increased NIOC, while the main effect disappeared after adding the interaction term (i.e., rural x public insurance). In addition, being a childhood and adolescent cancer survivor living in a rural location with public insurance was a significant risk factor for increased NIOC. Furthermore, having public insurance as a main effect was significant in decreasing PIOC.

Study respondents (i.e., childhood and adolescent cancer survivors) consistently endorsed higher PIOC than NIOC. This finding is not surprising and may be indicative of being in remission from cancer for a minimum of two years, and as years since diagnosis elapses, these individuals may experience an improvement in their physical health, personal growth, as well as greater health literacy. Furthermore, their social networks may have improved alongside family support. These individuals' stories may motivate survivors newly transitioning into post-treatment survivorship in navigating and overcoming the challenges involved in adjusting to life after cancer.

Consistent with previous studies, while it appeared that having public health insurance was a risk factor for increased NIOC, the contributing factors were complicated – study participants residing in *rural* areas with *public* health insurance had significantly

increased NIOC. The accessibility and quality of health care services may explain these differential experiences.

Study findings also highlight that the experience of being a female survivor diagnosed with cancer during adolescence may feature distinct experiences. These survivors reported not only reduced PIOC, but increased NIOC. Mixed-method study designs may help in deepening an understanding of their lived experiences to better inform the development and implementation of gender sensitive and developmentally specific cancer survivorship support programs.

Interestingly and contrary to prior research, being diagnosed with a CNS/brain tumor cancer type did not yield significant differences in NIOC as previously reported. Study findings provide insights on the need for survivorship cancer research to move towards frameworks of social determinants of health in further examining the accumulated effects of medical and non-medical indicators including socioeconomic factors and exposure to early childhood trauma that may influence NIOC and PIOC.

**Dedication**

To all the participants in this study

&

To my family

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## **Preface**

### **Positionality Statement**

Among the many lessons engaging in the research process has taught me is that any research I conduct cannot be understood unless I contextualize my positionality in it. As a woman, refugee, mother, sister of a cancer survivor, and social work scholar, who I am within the scope of this research study matters. In acknowledging my positionality, I have the responsibility to be in constant critical reflection of the biases and assumptions that I bring into the research process (Muhammad et al., 2015). As I analyze, interpret, and present the findings from this study, I also remain mindful of the privilege and power I bring into the research process in recognizing that the quantified experiences I describe in this study do not fully capture the ways in which young people who have experienced cancer understand themselves and their places in the world.

My interest in pursuing this project stems from both my professional experiences as a social work clinician and my personal experiences as a sibling of an adolescent cancer survivor. As a clinician working with children and adolescents experiencing a chronic physical condition, I found that assessments and intervention models utilized in community mental health settings often either generalized or inadvertently failed to capture the experiences of young people living with chronic physical conditions such as cancer and very often misrepresented or pathologized challenges facing young cancer survivors. These gaps in clinical approaches lacked a comprehensive understanding of issues relevant to the needs of young cancer survivors which often inhibited survivors from receiving the support services they needed. Additionally, as the sister of a young

cancer survivor, I know the emotional and psychological distress that cancer generates on both survivors and their families. Challenges posed by cancer are often further exacerbated for immigrant and refugee families who are in the process of learning how to navigate mainstream medical systems and for the young cancer survivor trying to establish their identity within school systems and peer groups.

In 2019, I had the privilege of observing a clinical session at Oregon Health and Science University (OHSU) Doernbecher Cancer Survivorship Program. It was during this observational session that I came to learn about the program and the different survivorship care support services provided. It was a joyous moment to see how much cancer survivorship support had evolved within the last 15 years since my sibling had been diagnosed but also a somber one in knowing that there are so many cancer survivors who do not have access to such quality services due to health system, socioeconomic, and racial/ethnic barriers and disparities. It is encouraging to see the potential of what is possible for cancer survivorship care, but at the same time a reminder of how much work still needs to be done.

While my family experiences may not reflect the myriad of experiences that exist amongst other families who have experienced a loved one's cancer diagnosis, my personal and professional experiences have served as a guide in illuminating gaps that exist within the literature. As such, this study reflects my commitment to expanding an understanding on the impact of cancer on young survivors.

## **Chapter 1: Introduction**

### **Purpose of Study**

Advancements in medicine over the last 30 years have dramatically increased survival rates for children and adolescents diagnosed with cancer (Aziz, 2007). There are an estimated 483,000 survivors of childhood and adolescent cancer (diagnosed between the ages of birth-19 years old) in the United States (U.S.) (National Cancer Institute, 2019). While improvements in medical treatment continue to extend life expectancy, research demonstrates that over 60% of adolescent and young adult survivors of childhood and adolescent cancer remain at risk for long-term health and psychosocial late effects of treatment (National Cancer Institute, 2019) and more than 95% will develop a chronic health, emotional, and/or psychological condition by the time they are 45 years old (Bhakta et al., 2017; Hudson et al., 2013).

In response to the multitude of health and psychosocial impacts of cancer, over the last decade initiatives and standards have been developed recommending a critical need to improve long-term survivorship care and enhance quality of life outcomes for childhood and adolescent cancer survivors (Children's Oncology Group, 2018; Commission on Cancer, 2010; Hewitt et al., 2006). These standards have illuminated the importance of viewing survivorship as part of a continuum of medical care that incorporates not only biomedical follow-up visits, but also assessments and interventions attuned to the psychosocial impacts of cancer (Children's Oncology Group, 2018; Commission on Cancer, 2010). However, despite greater attention on enhancing quality of life, research demonstrates that long-term childhood and adolescent survivors do not



receive “adequate or appropriate long-term follow-up care” (Ford et al., 2020; Klosky et al., 2008; Oeffinger et al., 2004; Tonorezos et al., 2018, 2022; Zebrack & Landier, 2011, p.1605), and report a significant number of unmet health information and psychosocial support needs (Klosky et al., 2008; Oeffinger et al., 2004a; Oeffinger & Hudson, 2004; Tonorezos et al., 2018; Zebrack & Landier, 2011).

The presence of late treatment effects coupled with survivorship care barriers have drawn attention to the importance of delivering comprehensive long-term survivorship care that is age-specific and unique to the experiences of childhood and adolescent cancer survivors (Jones et al., 2011; Tonorezos et al., 2022; Zebrack & Zeltzer, 2003). Researchers have recognized the importance of distinguishing between survivors who are diagnosed during childhood (0-14 years old) and those diagnosed during adolescence and young adulthood (15-39 years old) (Lang et al., 2018; Perez et al., 2020; Smith et al., 2013). Research suggests that age group distinctions highlight the different biomedical and psychosocial needs (Lang et al., 2018b; Overholser et al., 2017; Smith et al., 2013) and demonstrate the importance of understanding the impact of cancer in relation to developmental age at diagnosis (Bellizzi et al., 2012; Tonorezos et al., 2022).

Research demonstrates that cancer survivors’ perceptions on how cancer has impacted their lives is a “critical predictor” of psychosocial distress and quality of life outcomes (Zebrack et al., 2012 p. 1601; Taylor, 2000; Taylor et al., 1984). However, little is known about the extent to which perceptions of the impact of cancer interact with being diagnosed at a particular developmental stage. In addition, research suggests the

importance of understanding how experiences of the impact of cancer vary depending on demographic factors such as biological sex, race & ethnicity, and type of cancer (Bellizzi et al., 2012; Nilsson et al., 2014, Bava et al., 2017; Kirchhoff et al., 2014; Lang et al., 2018; Moore et al., 2020; Zebrack & Zeltzer, 2003) and environmental factors such as type of insurance and geographical location (Miedema et al., 2013; Roth et al., 2022). Given the dramatic increase in survival rates and the complexities that childhood and adolescent cancer survivors face, there is a need to better understand how demographic factors and environmental factors interact with how childhood and adolescent survivors perceive the impact of cancer on their lives.

This study seeks to expand the existing knowledge base to better understand how childhood and adolescent cancer survivors experience the impact of cancer. This purpose will be met through achieving the following specific aims: 1) To identify the extent to which demographic (i.e., biological sex, age at diagnosis, race/ethnicity, type of cancer) and environmental factors (i.e., geographical location and health insurance type) *separately* predict the negative impact of cancer (NIOC) and the positive impact of cancer (PIOC); and 2) To identify the extent to which the interaction effects (age at diagnosis  $\times$  biological sex, geographical location  $\times$  insurance type) predict NIOC and PIOC. This study uses secondary data collected from childhood and adolescent cancer survivors at the Oregon Health and Science University's Doernbecher Cancer Survivorship Clinic (DCSC) from the years 2009-2019.

Implications from this study will be useful in contributing to the knowledge base for childhood and adolescent cancer survivors. Findings from this study may also

contribute to strengthening, adapting, and/or developing support services. Furthermore, findings may provide guiding principles to healthcare professionals in childhood cancer survivorship clinics on what areas of supportive care needs, services, and resources may need further development.

### **Relevance to Social Work**

This study is relevant to social work in several ways. Social workers play a critical role within the field of pediatric oncology by supporting children, adolescents, and young adults as they manage the diagnosis, treatment, and survivorship of cancer (Jones et al., 2018; Zebrack et al., 2018). Working as members of multidisciplinary care teams, oncology social workers are *primary providers* of psychosocial support services (Zebrack et al., 2022) and administer comprehensive assessments, care-coordination, case and behavioral health management, and interventions throughout the continuum of cancer care (Hedlund, 2015; Zebrack et al., 2018). Additionally, research suggests that oncology social workers play a vital role within multidisciplinary teams in educating team members on the application of psychosocial screenings and evidence-based interventions (Hedlund, 2015; Jones et al., 2018; Zebrack et al., 2022). Findings from this study may be useful in enhancing knowledge on how to better support survivors as they not only transition from the cancer treatment to the post-treatment phase, but also in supporting survivors manage the potential long-term health and psychosocial late effects of treatment.

Additionally, findings from this study help to support healthy development for all young people, which is one of the 12 Grand Challenges for Social Work and is

considered a priority in improving the health and psychosocial wellbeing of all youth (Jenson, 2019). In 2018, the U.S. Congress passed the Childhood Cancer Survivorship: Treatment, Access, and Research (STAR) Act. The Act was developed in response to the need for advancements in childhood survivorship research to improve treatment, access, and enhance support services and resources for survivors and their families (STAR Act, 2018). Findings from this study may provide useful information on the impact of cancer on long-term survivorship and support needs of childhood and adolescent cancer survivors, so that policymakers can advocate for the development or enhancement of programs and resources for survivors and their families.

Lastly, findings from this study may contribute to the growing knowledge base established by both the Association of Pediatric Oncology Social Workers (APOSW) and the Association of Oncology Social Workers (AOSW). Both organizations are guided by social work values and a commitment to social justice and seek to advance psychosocial cancer research, policy, culturally competent cancer care, and identify health disparities in cancer care experienced by underserved communities (AOSW, 2015; Oktay & Zebrack, 2018)

## **Chapter 2: Literature Review**

This chapter presents the theoretical framework for this study, and a review of the literature that is relevant to the current study on the perceived impact of cancer on childhood and adolescent cancer survivors. First, several terms and concepts relevant to oncology research are presented. Second, an overview of the status of survivorship care in the U.S. are followed. Third, a discussion on the impact of cancer on survivors diagnosed during childhood (0-14 years old) is stated. Fourth, a discussion on the impact of cancer for survivors diagnosed during adolescence (15-19 years old) is presented. Lastly, a summary of the review and need for further research is discussed.

### **Theoretical Framework**

Responding to the complex medical and psychosocial impacts of cancer survivorship requires a unique theoretical paradigm to understand how the perceived impact of cancer “intersects” with the psychosocial development of childhood and adolescent cancer survivors (D’Agostino et al., 2011; Zebrack et al., 2010 p.217). This study draws from approaches of Hammond’s (2016) theory of a singular message of “Distinctness,” and Tedeschi and Calhoun’s (2004) posttraumatic growth theory.

### ***Theoretical Approaches on Normative Identity Development***

Researchers studying psychosocial development have long come to represent childhood and adolescence as critical periods in development. These critical periods are characterized by shifts in cognitive and emotional growth in which identity formation and explorations of self are key processes and important markers for healthy psychosocial development (Ferro & Boyle; Erikson, 1968). In his seminal work on the psychosocial

theory of human development through a life span, Erikson (1968) conceptualizes the formation of development as not only a period in which an adolescent's identity is socially influenced, but also a period in which the development of autonomy is considered central to developmental success. Erickson's theory is constructed on eight stages of psychosocial development and centers on answering the question, "how does a person compose a life centered in the self?" (Sorell & Montgomery, 2001, p.101).

Elements of Erickson's theory carry utility in understanding factors that shape and influence psychosocial development in children and adolescents. However, his reliance on a set of defined stages of psychosocial development are not useful in providing a framework for understanding the developmental trajectories of children and adolescents who have experienced cancer.

### ***Gaps in Erickson's Psychosocial Stages of Development***

Due to the biomedical aspects of their cancer diagnosis and treatment, many childhood and adolescent survivors of cancer experience a delay in growth, puberty, and/or have altered changes to their appearance (Bhakta et al., 2017). Given the biological, psychological, and social changes posed by the potential impacts of cancer, childhood and adolescent survivors do not fit into a defined trajectory of development in the way that is endorsed by Erickson's life span approach. Moreover, childhood and adolescent survivors often go through periods in which identity exploration can be disrupted due to the impacts of prolonged treatment, as well as periods in which they experience recurrent concern over their identity and mortality (Patterson et al., 2015).

While Erickson's emphasis on autonomy as one of the core elements of forming a strong and consistent sense of identity has provided theoretical grounding for many scholars in describing psychosocial development (Sorell & Montgomery, 2001), his reliance on the achievement of autonomy does not carry utility for many childhood and adolescent survivors. For example, many survivors often rely upon the impact of cancer as perceived by their family members and caregivers (Zebrack, 2000).

Furthermore, many young survivors depend on healthcare systems and healthcare professionals to provide support and education on the management of the late effects of cancer treatment (Zebrack, 2000). Due to the many complex biomedical and psychosocial challenges the experience of cancer presents, it is important that developmental frameworks further examine how psychosocial development shapes or influences a survivor's perceptions of the impact of cancer.

### **Against a Singular Message of "Distinctness"**

In against a singular message of "distinctness," Hammond (2016) suggests that dominant human developmental approaches portray the experiences of young cancer survivors as universal when, in fact, identifying and addressing the needs of survivors is dependent on multiple "intersecting sociodemographic factors" (p.45). Moreover, he argues that mainstream models of human development are often elicited in oncology research through the use of quantitative methods that center the impacts of cancer based on what is assumed to be normative developmental tasks such as autonomy, romantic intimacy, social integration, and career pursuits (Hammond, 2016). For example, research often characterizes childhood and adolescent survivors as one identical group of

survivors with the same support needs and experiences and ignores the increasingly growing population of survivors who are culturally and socioeconomically diverse (Odo & Potter, 2009). Moreover, the ways in which young cancer survivors are represented in research and within healthcare systems are limiting to understanding the developmental trajectories of young survivors within a diverse and multicultural world (Hammond, 2016). Hammond argues that these ‘singular’ portrayals disregard the “multiplicity of medical, social, and psychological” issues that young survivors experience (Hammond, 2016, p.47). Consequently, to explore psychosocial development in young cancer survivors, Hammond proposes four interrelated sociodemographic contexts (p. 45):

1. The precarious labor conditions affecting adolescent and young adult survivors’ financial and work lives.
2. Changing timetables and priorities for developmental tasks.
3. Sexual and gender plurality.
4. The expanding cultural diversity of adolescent and young adult survivors.

The first category in the theory of “distinctness” is an understanding of the financial and employment burdens that childhood and adolescent cancer survivors may face. While financial barriers to cancer care are acknowledged within research and healthcare, the challenges that young cancer survivors face in accessing employment, paid leave, and financial challenges due to unemployment are relatively ignored in research (Hammond, 2016; Stone et al., 2017). For example, many young survivors may experience disruptions to employment and education due to chronic health and



neurocognitive conditions (Parsons et al., 2012). Recognizing these factors within interventions are imperative considering that poverty, employment related stress, and financial instability are risk factors for lower health and psychological quality of life (Wilkinson et al., 1998).

Second, by recognizing the changing timelines and priorities of childhood and adolescent survivors, Hammond (2016) argues that viewing development under a task-oriented framework means that there are a set of milestones for when young people should graduate high school and college, establish a career, marry, and have children. However, deviations from these normative assumptions are often assessed as developmental delays within oncology research and healthcare settings and are not viewed as acceptable developmental trajectories (Odo & Potter, 2009; Pritchard et al., 2011; Tonorezos & Oeffinger, 2011).

Third, given sexual and gender plurality and the reality that cancer treatment may impact fertility (Gardino et al., 2011), child and adolescent survivors should receive age-appropriate and comprehensive information regarding fertility as they mature (Crawshaw & Sloper, 2010; Filippi et al., 2021; Hammond, 2016). For example, fertility preservation decisions are often made by caregivers and parents of childhood patients and as survivors become young adults healthcare providers need to revisit potential issues related to infertility and provide age-appropriate resources and support services (Quinn et al., 2011).

Fourth, with the expanding cultural diversity of the young cancer population, it is important to consider that experiencing intersecting marginalization including racism, sex

and gender discrimination, healthcare access and discrimination, and poverty can compound financial, health, and psychosocial difficulties (Aziz, 2002; Gotay et al., 2002; Reeves et al., 2021). Understanding the role that both demographic factors and environmental factors may play in how a young cancer survivor perceives their experience of cancer is important in further challenging the lack of heterogeneity in mainstream developmental frameworks. The theory of “distinctness” introduces an effective framework for providing necessary contextual nuance to childhood and adolescent development. This theory shifts away from discourse presenting young cancer survivors as one singular group and moves towards addressing the diverse challenges they may face within individual, social, and societal contexts. Moreover, this theory provides great utility in offering researchers and healthcare professionals a framework that enhances culturally, socioeconomically, and developmentally responsive cancer and survivorship care that is adaptable to young survivors and the developmental trajectories they experience (Hammond, 2016).

While Hammond’s theory of “distinctness” provides a developmental framework to better understand the *diverse* impact of cancer on psychosocial development, posttraumatic growth theory offers principles to explore how young cancer survivors may derive negative and positive perceptions of their experiences with cancer.

### **Posttraumatic Growth: A New Perspective on Psychotraumatology**

Theoretical approaches focused on describing the subjective experiences of a life threatening or chronic health condition have historically stemmed from the experiences of adults. Bury (1982) was one of the first scholars to theorize the experience of an illness

as causing a "biographical disruption" (p.1). Bury's characterization of the experience of illness as a disruption to identity contributed to the way that other scholars began to form conceptualizations about subjective experiences of illness.

In her extensive research with adults experiencing chronic illness and disability, Charmaz (1995), like Bury, suggests that the experience of an illness, "assaults the body and threatens the integrity of the self" (Charmaz, 1995, p.3). Furthermore, she states that illness "undermines the unity between body and self, and forces identity changes" (Charmaz, 1995, p.3). Many empirical studies have used Bury and Charmaz's arguments regarding illness as a *disruption* and *threat* to explain the experiences of childhood and adolescent cancer survivors. However, while research demonstrates that many childhood and adolescent survivors report symptoms of psychological distress related to depression, posttraumatic stress, and anxiety (Hobbie et al., 2000; Kwak et al., 2013; Meeske et al., 2001; Stuber et al., 2010), research also indicates that many adolescent and childhood survivors describe perceived benefits of their cancer experience and report resilience, personal growth, better-quality relationships, and greater health competency (Barakat et al., 2006; Bellizzi et al., 2012; Parry & Chesler, 2005; Phipps et al., 2007).

The capacity for individuals to perceive positive outcomes after experiencing a traumatic event is grounded in Tedeschi and Calhoun's (2004) conceptualizations of "post-traumatic growth." Post-traumatic growth is defined as "positive psychological change experienced as a result of the struggle with highly challenging life circumstances" (p.5). Based on post-traumatic growth theory, positive perceptions may arise from trauma associated with cancer experiences that are distressing enough to alter life values and

worldviews (Tedeschi & Calhoun, 2004). Individuals experiencing a trauma are more likely to engage in “existential questions” related to their own mortality and purpose in life (Tedeschi & Calhoun, 2004, p.2). Tedeschi and Calhoun suggest that reevaluating or reconstructing one’s concept of self, the world, and the future after a traumatic event supports posttraumatic growth (Tedeschi & Calhoun, 2004). In a study examining the relationship between post-traumatic stress and post-traumatic growth among adolescent and young adult cancer patients, Zebrack and colleagues (2015) endorse that posttraumatic growth is a cognitive process that is psychologically adaptive for cancer patients and helps them to facilitate coping. Post-traumatic growth provides a useful framework in understanding how cancer survivors may perceive positive aspects of having experienced cancer.

### **Summary of Theoretical Background**

This study builds on theories of human development and post-traumatic growth to better understand how childhood and adolescent cancer survivors experience the impact of cancer. As discussed in this review, both Hammond’s theory of “distinctness” and Tedeschi and Calhoun’s theory of posttraumatic growth not only provide utility in gaining an understanding on factors that shape and influence development in childhood and adolescent survivors but also offer a useful framework in understanding how cancer survivors may come to identify and understand positive aspects related to having experienced cancer. Furthermore, both theoretical frameworks provide researchers with a guide in widening the scope of data collection to capture data such as race/ethnicity, gender, cancer type, geographical location, insurance type. Expanding the scope of data

collection can be useful in further explicating demographic and environmental factor differences that may influence experiences of negative and positive impacts of cancer.

## **Terms and Concepts in Oncology Research**

### **Cancer Survivorship**

The term “cancer survivorship” symbolizes “the state or process of living following a diagnosis of cancer, regardless of how long a person lives” (Zebrack, 2003, p.198). Derived from his personal experiences of living with cancer, physician Fitzhugh Mullan compared cancer survivorship to “seasons of the year” (Mullan, 1985, p. 5). He identified three “seasons of survival”: “acute” (diagnosis), “extended” (completion of treatment), and “permanent” (cancer free). A recognition of survivorship as an “ever-changing process” is considered essential in understanding not only the physical impacts of cancer but also the psychosocial impacts (Aziz, 2007; Zebrack et al., 2013, p.198). The participants in this study are in Mullan’s third phase of survivorship “permanent” (cancer free).

### **Defining Long-Term Childhood Cancer Survivor**

According to the Children’s Oncology Group [COG], a long-term cancer survivor is defined as any child, adolescent, or young adult, who has completed cancer treatment and has been in remission from cancer for a minimum of 2 years (COG, 2018).

Childhood cancer refers to cancers diagnosed in children (Bhakta et al., 2017) and “childhood” comprehensively include children and adolescents diagnosed between the ages of 0-19 years old (Molinaro & Fletcher, 2018; Nolan et al., 2014). However, in consideration of different human developmental status, “childhood” also distinguishes

children between 0 to 14 years of age (Dockerty et al., 2003) and adolescents between the ages of 15 to 19 years old (American Society of Clinical Oncology, 2017).

It is important to note that in 2005, the National Cancer Institute (NCI) formed a progress review group recommending the need to distinguish research and cancer care focused on adolescents and young adults (AYAs) diagnosed with cancer between the ages of 15-39 years old (Smith et al., 2016). This distinction was made for two primary reasons. First, research demonstrates that AYAs are “medically distinct” than those diagnosed before the age of 15 years old and those diagnosed after the age of 39 years old (Bleyer, 2007). This distinction is due to differences in the types of cancers diagnosed within this age group (Bleyer, 2007). Additionally, AYAs have not seen survival rates as high as for those diagnosed between the ages of 0-14 years old and adults diagnosed after the age of 39 years old (Bleyer, 2007). Second, AYAs are considered “psychosocially distinct” due to a diagnosis of cancer during the critical developmental periods of adolescence and young adulthood (Bellizzi et al., 2012; Overholser et al., 2017).

Due to the term AYA encompassing several human developmental life stages within the 15-39 age range (Zebrack et al., 2013) the term childhood cancer survivors in this study refers to two distinct groups: children diagnosed with cancer between the ages 0-14 years old and adolescents diagnosed with cancer between the ages of 15-19 years old.

### **Support Services for Cancer Survivors in the United States: An Overview**

In the U.S. survivorship care is a term used to define approaches addressing the medical and psychosocial support needs of cancer survivors (Agostino et al., 2011). The

requirements for long-term survivorship care services for cancer survivors were first specified in 2005 by the Institute of Medicine (IOM, 2005). These specifications recommend that programs offer screenings, resources, and education to help prevent or minimize the risks of cancer treatment and enhance quality of life (Salz et al., 2012). Subsequently, in 2010, the first cancer survivor-centered accreditation standards were introduced by the Commission on Cancer (CoC). These standards require that all CoC accredited cancer centers provide cancer survivors a Survivorship Care Plan (SCP), psychosocial assessments, and patient navigators (Commission on Cancer, 2010). The SCP is defined as a comprehensive document that provides survivors with a detailed summary of their cancer treatment, a schedule for screening late-effects, and recommendations on nutrition and health behaviors (Salz et al., 2012).

The Children's Oncology Group [COG] recommends that childhood and adolescent cancer survivors attend follow-up care in facilities where multidisciplinary healthcare professionals provide follow-up care specific to developmental needs and health promotion strategies, and monitor and manage late effects (Lowe et al., 2016). The primary goal of survivorship care is to offer childhood and adolescent survivors access to age-appropriate support services that encompasses the full spectrum of care (diagnosis, treatment, long-term survivorship) (D'Agostino et al., 2011).

Despite the importance of monitoring for long-term health and psychosocial impacts, research demonstrates that childhood and adolescent survivors face "shortcomings and disparities" in receiving long-term follow-up care (Klosky et al., 2008; Oeffinger et al., 2004; Tonorezos et al., 2018; Zebrack et al., 2022, p.1087;

Zebrack & Landier, 2011) and report a significant number of unmet needs (Klosky et al., 2008; Oeffinger & Hudson, 2004; Tonorezos et al., 2022; Zebrack & Landier, 2011). Moreover, a study of over 20,000 adult survivors of childhood cancer representing over 27 cancer institutions in the U.S., found that as childhood cancer survivors age they are less likely to receive cancer-related follow-up care (Oeffinger et al., 2004a). To respond to the increasing need, in 2019, the CoC launched a project to "analyze, review and improve" the standards of cancer survivorship care (Association of Community Centers[ACCC], 2019, para.6). The CoC is mandating health systems to approach survivorship as part of the continuum of care with the primary goal of ensuring that standards of cancer care result in "improvement of patient care" (ACCC, 2019, para.6). This new mandate highlights the urgent need for research to examine a more comprehensive understanding of the impact of cancer.

### **Impact of Cancer**

Existing research examining quality of life in childhood and adolescent cancer survivors have historically focused on the "late effects" of cancer. According to the NCI, late-effects are defined as "health problems that occur months or years" after cancer treatment has ended (National Cancer Institute, 2019, para.1). While studies examining late effects reveal the multitude of chronic health and psychosocial challenges that cancer survivors face, these studies primarily define late effects of cancer solely as a negative experience. However, a growing but small body of research also suggests that understanding the impact of cancer through the perception of cancer survivors themselves is a vital component in enhancing quality of life (Zebrack & Landier, 2011). For



example, studies examining chronic or life-threatening health conditions from the perspectives of patients demonstrate that how patients perceive their health condition is a more reliable predictor of distress than examining objective factors such as the presence of late effects (Cordova & Andrykowski, 2003; Taïeb et al., 2004; Zebrack et al., 2012). Furthermore, evidence suggests that examining perceptions of the impact of cancer offers opportunities to not only focus on the negative impacts of cancer but also perceptions of the positive impacts of experiencing cancer including personal growth and resilience (Zebrack et al., 2012). In this study, “impact of cancer” is defined in terms of how cancer negatively and/or positively impacts survivors across physical and psychosocial quality of life domains (Zebrack & Landier, 2011) and specific to a survivor’s developmental age at diagnosis, biological sex, race/ethnicity, cancer type, geographical location, and insurance type.

### **Childhood Cancer Survivors**

Research examining the impact of cancer on childhood survivors demonstrates that children diagnosed at 0-14 years of age have different physiological and psychosocial factors than those diagnosed during adolescence (Pizzo & Poplack, 2016). For example, while cancer treatments differ according to type of cancer, research suggests that due to how rapidly the bodies of children develop, almost all the types of cancers diagnosed during this stage have treatment modalities that are “long, painful, and dangerous” (Patterson et al., 2004, p.390).

In examining psychosocial factors of the impact of cancer, research demonstrates that caregivers play an important role in providing social, emotional, and financial

support to children diagnosed during this stage (Gutiérrez-Colina et al., 2017). In addition, the interaction between children and their parents may influence how positively or negatively a child perceives cancer and treatment (Harper et al., 2019).

Research examining the long-term negative impacts of cancer for survivors diagnosed during childhood is limited to objective measures examining the negative impacts of cancer treatment. Depending on the type of cancer, treatment modality, and duration of treatment, survivors are at risk for developing chronic health conditions such as secondary cancers, cardiovascular disease, organ damage (e.g., Bhakta et al., 2017; Hobbie et al., 2000; Langeveld et al., 2002; Mertens & Marchak, 2015; Ostroff & Steinglass, 1996; Suh et al., 2020), diabetes and obesity (e.g., Bhatia & Meadows, 2006), physical impairments and disabilities (e.g., Evans & Radford, 1995; Oeffinger & Hudson, 2004), learning disabilities and neuropsychological effects (e.g., Challinor et al., 2000; Mitby et al., 2003; Raymond-Speden et al., 2000), and posttraumatic stress disorder and isolation (Stuber et al., 2010). Also, the impact of cancer on physical health contributes to low self-esteem and a negative outlook on life in survivors diagnosed during this stage (e.g., Zebrack & Chesler, 2001).

Given the young developmental stage at which survivors are diagnosed, family functioning is considered a critical element in contributing to positive impacts and potentially mitigating the negative psychosocial impacts of the illness and treatment (Alderfer et al., 2009; Cetin, 2022). A study on the positive impacts of cancer demonstrates that 60% of childhood survivors in the study report positive experiences related to having empathy for others, 54% report an ability to cope with tragedy, 52%

report a positive sense of identity and spiritual well-being (Zebrack et al., 2012). In addition, childhood survivors report positive experiences related to a strong sense of psychological and emotional maturity, personal growth and appreciation for life, and resilience in enduring challenging situations (Parry & Chesler, 2005).

### **Adolescent Cancer Survivors**

Cancer survivors diagnosed during adolescence between the ages 15-19 years old are distinct from childhood survivors because they are confronted with a cancer diagnosis at a time in which they are trying to navigate the critical developmental transitions such as developing their own concept of self, forming more intimate social relationships, learning to navigate health care systems, and pursuing educational goals (e.g., Bellizzi et al., 2012; Overholser et al., 2017; Pennant et al., 2019).

Similar to survivors diagnosed during childhood, research on the negative impacts of cancer is limited to examinations of objective factors. Depending on the cancer type, duration of treatment, and treatment modality, adolescent cancer survivors are at risk for secondary cancers, cardiovascular disease, organ damage, physical disabilities, learning disabilities, and neuropsychological effects (e.g., Albritton & Bleyer, 2003; Bhakta et al., 2017; Clinton-McHarg et al., 2010; Suh et al., 2020). In addition, evidence suggests that survivors diagnosed with cancer during adolescence also report significant psychosocial challenges related to emotional and psychological distress (e.g., Bellizzi et al., 2012; Overholser et al., 2017; Pendley et al., 1997).

Research on the positive impacts of cancer demonstrate that some survivors report positive impacts such as resilience and personal growth. For example, a study by Barakat

and colleagues (2006) found that 32% of the adolescent survivors in the study report positive impacts of cancer such as relationships with peers and family members, and future goals and planning. Similarly, a study examining psychosocial adjustment in adolescent survivors found that survivors were more likely than their siblings to report positive perceptions of the impact of cancer related to their marital status and educational attainment (Zebrack et al., 2012). Adolescent survivors also report the important role that parental support plays in lowering psychological distress (McDonnell et al., 2020; Wilford et al., 2017).

### **Biological Sex**

Research demonstrates that females diagnosed with cancer between the ages of 15-39 report significantly higher negative impacts of cancer related to uncertainty and worry about their social lives, and lower cognitive functioning compared to their counterparts (Benedict et al., 2020a; Husson & Zebrack, 2017). In addition, a study examining mood disorders in adult childhood cancer survivors found that female survivors diagnosed in early childhood report more negative impacts related to psychological and emotional distress than male survivors (Zeltzer et al., 1997). However, there are also conflicting research studies that found no differences in experiences related to positive and negative impacts of cancer based on biological sex (Cox et al., 2016; Bellizzi et al., 2012; Zebrack & Landier, 2011).

### **Race and Ethnicity**

Research examining the impact of cancer as experienced by race/ethnicity demonstrate that race may play a critical role in quality of life outcomes. Several studies

document that non-White adult cancer survivors report lower health and psychosocial quality of life outcomes compared to White survivors (Aziz, 2002; Marshall et al., 2011; Spencer et al., 1999). Furthermore, a study by Phillips & Jones (2014) found that Latinx adult survivors report greater psychological distress, financial challenges, and lower rates of life contentment than White survivors.

In examining the impact of cancer amongst childhood and adolescent survivors from diverse racial and ethnic backgrounds, Casillas and colleagues (2006) found that Latinx cancer survivors report lower health quality of life with significant challenges related to physical pain and infertility compared to White survivors. In addition, several studies have found that survivors from culturally diverse backgrounds report greater survivorship support needs (Jones et al., 2011) and higher rates of isolation after cancer treatment (Foster et al., 2011; Wakefield et al., 2013).

In contrast, research also demonstrates that having a strong racial identity may be a contributing factor in influencing positive perceptions of the impact of cancer (Phillips & Jones, 2014). Phipps and colleagues (2007) found that Black and African American survivors report greater positive impacts of cancer compared to White survivors which indicates more personal growth and lower levels of post-traumatic stress. In addition, greater family support amongst Latino adolescent survivors is linked to more positive attitudes regarding the impact of cancer (Phillips & Jones, 2014). Furthermore, Latinx adolescent survivors who speak their native language at home report significantly higher post-traumatic growth, which is linked to more positive psychosocial functioning and lower levels of post-traumatic stress (Arpawong et al., 2013). However, studies also

demonstrate that survivors from diverse racial/ethnic backgrounds also report greater negative experiences of cancer compared to White survivors (Husson & Zebrack, 2017).

### **Type of Cancer**

Research on the influence of cancer type on the impact of cancer demonstrate that physical and psychosocial challenges may be influenced by the type of cancer at diagnosis (Weatherer et al., 2021). For example, several studies have found that childhood brain tumor survivors have the poorest health related quality of life among childhood cancer survivors (Hocking et al., 2011; Oeffinger et al., 2006; Zeltzer et al., 2009). In addition, brain tumor survivors demonstrate lower rates of neurological functioning compared with survivors of other cancers (Hobbie et al., 2016), and endorse higher rates psychological distress compared to their siblings (Zebrack et al., 2004; Zeltzer et al., 2009). Brain tumor survivors are also less likely to live independently, be employed, or have a college degree compared with siblings (Zebrack et al., 2004), as well as survivors of other types of cancers (Ness et al., 2010).

While few differences have been observed between survivors diagnosed with other types of cancers, a study from the Childhood Cancer Survivor Study (Zeltzer et al., 2009) examining a cohort of 6192 survivors diagnosed between the ages of 11-21, found that survivors of leukemia experience increased rates of depression and anxiety compared to their siblings. However, studies have also found that childhood leukemia survivors are also significantly more likely to report positive impacts of cancer compared to survivors of other cancer types (Zebrack et al., 2012).

## **Type of Health Insurance**

Research examining factors related to health insurance and the impact of cancer indicate that the implementation of the Affordable Care Act (ACA) in 2010 has increased survival outcomes for adolescent and young adult cancer patients (Roth et al., 2022). Furthermore, the enactment of the ACA and the expansion of dependent coverage has also lowered rates of uninsured cancer survivors between the ages of 19-25 thus improving access to healthcare and early cancer detection screenings (Roth et al., 2022).

However, despite increases in access to health insurance, research suggests that disparities continue to exist between privately insured and publicly insured childhood and adolescent cancer patients (Penumarthy et al., 2020; Weatherer et al., 2021). For example, recent studies indicate that childhood and adolescent survivors with public insurance have poorer survival outcomes compared to patients with private insurance independent of cancer prognosis, biological sex, race/ethnicity, and age (Kline et al., 2018; Penumarthy et al., 2020). In addition, cancer survivors with public insurance often face challenges related to lack of transportation to attend medical appointments (Li et al., 2015), lower health literacy (Hydeman et al., 2019) and financial barriers related to covering deductibles and prescription costs (Weigel et al., 2020).

## **Geographical Location**

Research demonstrates that geographical location has considerable impact on access to health care and health outcomes (Miedema et al., 2013). In particular, rural cancer patients are considered a high-risk population who face poorer access to oncology

services and limited access to survivorship care programs compared to patients living in urban geographical locations (Levit et al., 2020; Miedema et al., 2013). Furthermore, studies indicate that compared with urban survivors, rural cancer survivors have poorer long-term health, increased psychological distress, and financial and insurance barriers (Miedema et al., 2013; Olson et al., 1993; Yabroff et al., 2020). However, despite disparities related to health care access and health outcomes, Warner and colleagues (2014) found that rural young adult cancer survivors report higher levels of satisfaction with their care compared to urban cancer survivors and are willing to travel several hours to receive specialty cancer care services.

### **Years Since Primary Diagnosis**

Research demonstrates that the probability of reporting a negative impact of cancer decreases as survivors move further in years from their initial cancer diagnosis (Husson & Zebrack, 2017; Phipps et al., 2007) because physical health conditions may improve (Langeveld et al., 2004), as well as the emotional and psychological distress associated with the cancer experience may decrease (Husson & Zebrack, 2017).

### **Summary of Literature Review**

In the U.S., many empirical studies have been conducted to improve survivorship care by identifying the long-term health and psychosocial impacts of childhood and adolescent cancer survivors over the past decade. As a result, approaching survivorship not only as a part of the continuum of care but also recognizing the importance of prioritizing a survivor's current age and their age at diagnosis in the delivery and/or



development of survivorship care programs are vital parts of improving survivorship care outcomes (Lang et al., 2018; Smith et al., 2013).

As the population of childhood and adolescent cancer survivors continues to grow, studies demonstrate the importance of investigating how survivors experience not only the negative impacts of cancer but also how they perceive the positive impacts that cancer may present for personal growth in their lives. However, many questions remain regarding the extent to which the experiences of the impact of cancer interacts with being diagnosed at a particular developmental stage, biological sex, race/ethnicity, type of cancer, geographical location, and type of insurance (Kirchhoff et al., 2014; Lang et al., 2018b; Levit et al., 2020; Penumarthy et al., 2020; Roth et al., 2022; Zebrack & Zeltzer, 2003).

As indicated in this literature review, understanding the long-term impacts of cancer that consider developmental stage at diagnosis, biological sex, race/ethnicity, cancer type, geographical location, and type of insurance, while controlling for the influences of years since primary diagnosis, is critical to develop age relevant and responsive care to cancer survivors' differential experiences. However, research exploring the impact of cancer continues to be sparse and features several limitations. For example, most of the studies in this review are limited to utilizing standardized measures and questionnaires focused on the ways in which the late effects of cancer negatively impact physical and psychosocial health (e.g., Challinor et al., 2000; Suh et al., 2020). Moreover, these measurements do not address the life domains that are of specific

concern to childhood and adolescent cancer survivors such as relationships with family, friends, life challenges, body and health, and health literacy.

In addition, only a few studies capture perceived positive aspects of cancer including personal growth based on the perspectives of long-term adolescent and childhood cancer survivors (e.g., Husson & Zebrack, 2017; Zebrack et al., 2012). Furthermore, few existing studies assess the extent to which long-term survivors perceive cancer as having an impact on specific and developmentally relevant life issues (Bellizzi et al., 2012; Husson & Zebrack, 2017). Also, studies investigating survivors diagnosed during adolescence (aged 15-19) are often grouped together with survivors diagnosed between the ages of 15-39 years old (e.g., Mertens & Marchak, 2015; Overholser et al., 2017). The variability of life stages is quite significant, and therefore difficult to assess how cancer impacts adolescent survivors aged 15-19 years old (Zebrack et al., 2013). Although research on the impact of cancer continues to be sparse, some existing studies suggest unique associations with positive and negative impacts of cancer in relation to demographic (i.e., age at diagnosis, biological sex, race and ethnicity, cancer type) and environmental factors (i.e., geographical location, insurance type) (e.g., Bellizzi et al., 2012; Cox et al., 2017; Phillips & Jones, 2014).

While the studies included in this review demonstrate the importance of examining the perceived negative and positive impacts of cancer, it remains unclear the extent to which demographic and environmental factors predict the impact of cancer. To the researcher's best knowledge, this is the first comprehensive study to examine

demographic and environmental factors, as well as the interaction effects in predicting the negative and positive impact of cancer.

### **Chapter 3: Methods**

This quantitative study is exploratory in nature to investigate the experiences of childhood and adolescent cancer survivors, and explanatory for the purpose of examining the influences of demographic and environmental factors in predicting outcome variables: negative impact of cancer and positive impact of cancer, separately. Hierarchical OLS was utilized to test how well a new set of study variables predicted the outcome variables over and above the previously entered set of variables. A sequential blockwise entry method was used with demographic factors (age at diagnosis, biological sex, race/ethnicity, cancer type), followed by environmental factors (geographical location, insurance type), and then interaction effects (age at diagnosis  $\times$  biological sex, and geographical location  $\times$  insurance type) were entered. Since previous studies reveal that the negative impact of cancer may diminish depending on years since diagnosis (e.g., Husson & Zebrack, 2017; Langeveld et al., 2004), years since diagnosis was included in this data analysis as a control variable. The positive and negative impact of cancer was measured by the Impact of Cancer – Childhood Survivors (IOC-CS; Zebrack & Landier, 2011) instrument, and used in this study as outcome variables (i.e., NIOC and PIOC respectively). The total mean score of NIOC and PIOC serve as the two outcomes variables tested separately.

#### **Research Questions and Hypothesis**

Research questions and hypothesis are organized by outcome variables: NIOC and PIOC, separately, and the order for OLS blockwise entry.

### *Predicting NIOC*

1. First block: To what extent do demographic factors (age at diagnosis, biological sex, race/ethnicity, cancer type) predict NIOC?

Research hypothesis: Diagnosed during adolescence (*vs.* childhood), being female (*vs.* male), diagnosed with CNS/brain tumors (*vs.* hematological and solid tumors/soft tumors/other cancers, separately) will express higher NIOC than their counterparts.

2. Second block: To what extent do environmental factors (insurance type and geographical location) predict NIOC? Does the addition of environmental factors account for significantly more variance than the first block (*i.e.*, demographic factors alone) in predicting NIOC?

Research hypothesis 2-1: Having public health insurance (*vs.* private), residing in rural geographical location (*vs.* urban location) will express higher NIOC.

Research hypothesis 2-2: Adding environmental factors increases the model description significantly in comparison to the capacity predicted by the first block.

3. Third block: To what extent do interaction effects (biological sex  $\times$  age group at diagnosis, geographical location  $\times$  insurance type) predict NIOC? Does the

addition of interaction effects account for significantly more variance than the second block in predicting NIOC?

Research hypothesis 3-1: Individuals who are biologically female and diagnosed during their adolescence will express higher NIOC than all other participants.

Research hypothesis 3-2: Adding environmental factors will increase the model description significantly in comparison to the capacity predicted by the second block.

### *Predicting PIOC*

1. First block: To what extent do demographic factors (age at diagnosis, biological sex, race/ethnicity, cancer type) predict PIOC?

Research hypothesis: Diagnosed during adolescence (*vs.* childhood), being female (*vs.* male), diagnosed with CNS/brain tumors (*vs.* hematological and solid tumors/soft tumors/other cancers, separately) will express higher PIOC than their counter parts.

2. Second block: To what extent do environmental factors (insurance type and geographical location) predict PIOC? Does the addition of environmental factors account for significantly more variance than the first block (*i.e.*, demographic factors alone) in predicting PIOC?

Research hypothesis 2-1: Having public health insurance (*vs.* private), residing in rural geographical location (*vs.* urban location) will express higher PIOC.

Research hypothesis 2-2: Adding environmental factors increases the model description significantly in comparison to the capacity predicted by the first block.

3. Third block: To what extent do interaction effects (biological sex  $\times$  age group at diagnosis, geographical location  $\times$  insurance type) predict PIOC? Does the addition of interaction effects account for significantly more variance than the second block in predicting PIOC?

Research hypothesis 3-1: Individuals who are biologically female and who were diagnosed during their adolescence will express higher PIOC than all other participants.

Research hypothesis 3-2: Adding environmental factors increases the model description significantly in comparison to the capacity predicted by the second block.

### **Study Setting**

Oregon Health and Science University's Doernbecher Cancer Survivorship Clinic (DCSC) in Portland, Oregon is the setting for this study. Since its inception in 2009, DCSC has provided comprehensive medical care and psychosocial support for cancer survivors of all ages diagnosed with cancer during childhood, adolescence, or young adulthood. The clinic serves an estimated 270 survivors every year from all 36 counties in Oregon, as well as survivors in Southwestern Washington State, Alaska, Montana, Idaho, and Northern California. To attend the DCSC, a cancer survivor must have completed cancer treatment (chemotherapy, surgery, and/or radiotherapy) and be in

remission from cancer for a minimum of two years. Survivors may be referred to the clinic through their oncologist or primary care physician, however referral is not required if the survivor is eligible to attend.

When eligible survivors contact DCSC, an initial assessment is conducted by the program coordinator to collect medical and psychosocial information. During their first visit at DCSC, the Medical History Questionnaire (MHQ) is used to collect not only medical history and health behaviors, but also demographic information. The Impact of Cancer for Childhood Cancer Survivors (IOC-CS) questionnaire is also completed by the survivor during their appointment. A team of multidisciplinary healthcare providers (pediatric oncologist, nurse practitioner, social worker, and clinical psychologist) offer survivors information to better understand treatment exposures and how they may impact future health. In addition, survivors are provided with support services including health literacy, social and emotional support, educational support regarding managing the late effects of cancer treatment, and support on how to navigate healthcare systems and transitions. DCSC also provides an Early Survivorship program for survivors who are transitioning from cancer treatment and have not yet been in remission from cancer for a minimum of two years. The Early Survivorship program includes an oncology social worker, a pediatric neuropsychologist, and a hospital schoolteacher who assist in providing support services for both survivors and their families. Services include support with adjusting to life after cancer treatment and psychosocial and financial concerns.



## **Study Data**

This study utilizes secondary data from the Oregon Health and Science University's Doernbecher Survivorship Repository and the patient electronic medical record (EPIC). The data repository features clinical information that has been collected since the clinic's inception in 2009 and continues to be collected and utilized by the multidisciplinary team at DCSC to inform patient care. While the DCSC Repository continues adding new participant data, this study includes data from only those who were first diagnosed during childhood and adolescence (i.e., 0 to 19 years old). The repository features data from the Impact of Cancer for Childhood Cancer Survivors (IOC-CS) questionnaire (a survivor must be 13 years old to complete the questionnaire), study identification numbers, date of birth, date of first diagnosis, date of first visit to the survivorship clinic, date the IOC-CS questionnaire was completed, years since diagnosis, and current age. While data is collected at the DCSC during several time points, this study only uses data from the first IOC-CS questionnaire the survivor completed, or the first time the questionnaire was completed after the survivor turned 13 years old. The researcher also reviewed the medical chart of eligible study participants to collect additional demographic data (cancer type, health insurance type, race/ethnicity, and geographical location). The two sources of data were merged into one Excel file spreadsheet for data analysis purposes in this study. Patient confidentiality was carefully assessed and maintained throughout this study. Study data were stored in the OHSU cloud storage OneDrive. The Institutional review board (IRB) of Oregon Health and

Science University and Portland State University reviewed and approved all procedures of this study.

### **Study Participants**

Since the clinic's inception in 2009 until the World Health Organization (WHO) declared the outbreak of the novel coronavirus (COVID-19) on January 30<sup>th</sup>, 2020, a total of 510 patients who were first-time diagnosed with cancer during childhood and adolescence (i.e., between the ages of 0-19 years old), attended survivorship care appointments at the DSCS. Patients who had their first clinic visit during the novel coronavirus (COVID-19) pandemic 2020-2022 were excluded from this study, since their experiences could be significantly different from those in the pre-pandemic period. Of 510 participants, 13 individuals were excluded because they did not meet the eligibility criteria, including: 1) 11 did not have a cancer diagnosis, and one cancer survivor was not in remission from cancer at the time of the study, and 2) one had a duplicate patient record. The final number of study participants were 470.

### **Study Variables**

Positive and negative impact of cancer are used as outcome variables and introduced below. Study predictors are organized by demographic and environmental factors. Years since primary diagnosis is a control variable in this study.

### **Outcome Variables**

Negative and positive impact of cancer were measured using the Impact of Cancer for Childhood Cancer Survivors (IOC-CS) questionnaire (Zebrack et al., 2006). Based on qualitative interviews with 64 childhood cancer survivors, Zebrack (2009) identified the

negative and positive impact of cancer survivorship, and highlighted issues that were unique to survivors. The IOC-CS consists of 45 items in which participants endorsed their experiences and perceptions of the impact of cancer on a 5-point Likert scale (1 = No impact at all, to 5 = Great impact). The *negative impact of cancer* (NIOC) includes 20 items organized by three subscales: life challenges, thinking and memory problems, and financial problems; the *positive impact of cancer* (PIOC) includes 25 items grouped with five subscales: health literacy, socializing, body and health, talking with parents, and personal growth. The IOC-CS was developed in the U.S. and is a reliable and validated scale. Psychometric properties of the eight subscales have been discussed in previous research studies and demonstrate robust internal consistency (Cronbach's alpha between .70 to .86) and internal and external validity (Zebrack et al., 2010; Zebrack & Landier, 2011). Additionally, reproducibility and cross-cultural reliability and validity have been observed in three languages (Italian, Dutch, and Norwegian) (Dahl et al., 2012; Muzzatti et al., 2013; Oerlemans et al., 2013). The mean of NIOC and PIOC scores were calculated separately for data analysis purpose. The range of the mean scores includes 1 to 5, and higher scores indicated a greater impact of cancer.

### **Study Predictors**

**Age at Primary Diagnosis.** To measure the impact of cancer based on developmental age at diagnosis, age at primary diagnosis was categorized and coded into two groups: 0 = childhood (0-14 years old), and 1 = adolescent (15-19 years old).

**Biological Sex.** The participant's biological sex was collected by the researcher through a retrospective patient chart review. Based on the information listed in patient

records under ‘legal sex,’ biological sex was coded as a binary variable, with 0 = male, and 1 = female.

**Race/Ethnicity.** There were five categories race/ethnicity identified in patient records for race/ethnicity: *Non-Hispanic White/Caucasian, Hispanic, Black/African American, Asian/Pacific Islander, and American Indian/Native American*. After careful review of the race/ethnicity variable and consulting with DCSC, there was no indication presented in patient records whether race/ethnicity categories were self-identified by the participant or entered through a third party. Due to the limited number of participants belonging to each specified race/ethnicity subgroup, for purposes of data analysis, race/ethnicity was limited to two categories and coded as a dichotomous variable: 0 = Non-Hispanic White, vs. 1 = Non-White.

**Cancer Type.** There were a considerable number of cancer types indicated in patient medical records. With consultation from DCSC’s led pediatric hematologist/oncologist, each cancer type was carefully reviewed and coded into three distinct cancer type categories: 0 = hematological (includes leukemias, lymphomas), 1 = CNS/brain tumors (includes all malignant tumors within the brain and spinal cord), and 2 = solid tumor/soft tissue tumors/others (includes rhabdomyosarcoma, germ cell tumors, Wilms tumor, osteosarcoma, other tumors not specified).

**Geographical Location.** This study utilized participant geographical location zip codes in accordance with the U.S. Census Bureau’s statistical measurement guidelines for rural and urban designations (Ratcliffe et al., 2016). The Rural Health Information Hub (RHIfhub) was utilized to enter zip code data to search and retrieve geographical location

designations. RHI is a federally funded program providing data and analysis on population health in rural communities (Vohra et al., 2022). Each zip code coincided with a county that was classified by population size and level of urbanization and rurality to generate two categories for geographical location: 0 = urban, 1 = rural.

**Insurance Type.** Insurance type information was gathered through patient records and coincided with the date/year participants completed the first IMPACT questionnaire. The primary types of health insurance included: 1) an employer purchased health plan, 2) a family purchased health plan, 3) a Medicare health plan, and 4) a Medicaid or other state program health plan. After consultation and being reviewed by the DCSC's Social Worker and the OHSU office of Financial and Medicaid Services, insurance type was categorized into two groups and coded as a dichotomous variable, with 0 = private, and 1 = public.

### **Control Variable**

Since previous research indicates that the likelihood of reporting negative impacts of cancer decreases as survivors move further away from the first time they were diagnosed with cancer (e.g., Husson & Zebrack, 2017; Langeveld et al., 2004), *years since primary diagnosis* (how many years have elapsed since the first initial cancer diagnosis) was included as a control variable for this study.

### **Data Analysis Plan**

All statistical analysis for this study were conducted using the IBM Statistical Package for Social Sciences version 28.0 (SPSS). The preliminary data analysis was conducted to assess missing data. Little's MCAR test was used to find the most

appropriate method to address missing data, and all variables were assessed to check if the missingness is systematic or “ignorable” (Kline, 2011, p.55). Descriptive statistics covering frequencies and central tendencies, and correlation analysis were used to summarize characteristics of the main variables and the associations between variables of interest. A series of *t*-test and one-way ANOVA was implemented to test mean differences between independent and dependent groups. Factor analysis with orthogonal rotation (i.e., Varimax rotation) was followed to assess the construct and factor structure of NIOC and PIOC, separately. Finally, a set of hierarchical ordinary least squares (OLS) regression using the blockwise method was applied to examine how well a new set of study variables predicted the outcome variable over and above the previously entered set of variables. Three models of OLS regression analysis were conducted for NIOC and PIOC, separately, as dependent variables. The first model examined demographic variables including: biological sex, age at diagnosis, cancer type, and race/ethnicity. The second model examined environmental variables including: geographical location, insurance type, and the final model included the interaction effects (i.e., biological sex × age at diagnosis; insurance type × geographical location).

## Chapter 4: Results

In this chapter, results are presented with preliminary findings including an assessment of missing data, factor analysis findings, and mean difference tests.

Hierarchical OLS analysis findings are followed.

### Preliminary Findings

#### Missing Data

Missingness in the dataset ranged from 0.0% (i.e., biological sex, insurance type, geographical location, age group at diagnosis, cancer type, years since diagnosed) to 5.5% (i.e., race/ethnicity), or 7.9% of incomplete (i.e., IOC-CS question items #56, #65). The missing data were examined to see if patterns were present. Most missing data were due to incomplete items which likely happened on later items of the IOC-CS questionnaire. During the first visit to the DCSC survivorship clinic, study participants were asked to respond to *many* questions, and the IOC-CS questionnaire was just one part of a lengthy survey process, which might have resulted in many items left incomplete towards end of the questionnaire. The mean of NIOC and PIOC scores were calculated separately in order to consider the incompletes. Due to such few incidents of missing data with race/ethnicity, and no patterns were determined, those individuals were dropped from analyses.

#### Factor Analysis

Factor analysis was conducted to: 1) understand the structure of the set of variables, 2) assess or construct a questionnaire to measure an underlying variable, and 3) reduce a data set to a more manageable size while retaining as much of the original

information as possible (Field, 2009). Factor loadings were carefully reviewed for consistency as suggested by previous research utilizing the IOC-CS questionnaire (Zebrack & Landier, 2011), as well as for potential modification, based on exploratory factor analysis and theoretical construct. Before the factor analysis, wordings of the 45 items were reviewed, and if necessary, the coding structure was reversed to be congruent with the subscale's negative or positive focus.

Principle axis factoring was utilized at each iteration to examine 20 items of NIOC, and 25 items of PIOC. Varimax was used as the rotation method to assess factor loading patterns based on its ability to “maximize the dispersion of loadings within factors” (Field, 2009, p. 644). The number of factors to retain for each NIOC and PIOC subscales was determined based on theoretical groundings from previous literature (Zebrack & Landier, 2011), the results of the scree plot, and an eigenvalue of above 1. Furthermore, in consideration of the study sample size, items that loaded at 0.3 or above were included (Stevens, 2002) to form subscales.

Factor analysis for the NIOC scale retained all 20 items and 3 factors (i.e., life challenges, thinking/memory problems, and financial problems) showing strong loadings consistent with the findings of Zebrack and Landier (2011). The first factor explained 24.5% of the variance, the second factor explained 7.1% of the variance and the third factor explained 5.9% of the variance. Together the three factors explained 37.5% of the common variance (see Table 1).



Table 1.

*Negative Impact of Cancer Rotated Factor Loadings*

	Factor		
	1	2	3
Worry about health	0.48		
Want to forget cancer	0.34		
I wonder why I got cancer	0.50		
I wonder why I survived and others do not	0.53		
I feel like something I did caused me to get cancer	0.42		
I am angry about having had cancer	0.58		
I feel like cancer controls my life	0.52		
I feel like time in my life is running out	0.66		
I am afraid to die	0.41		
I worry that I might die at a young age	0.71		
I feel like I missed out on important life experiences while I had cancer	0.41		
Having had cancer makes me feel unsure about my future	0.61		
It is easy for me to make decisions <sup>R</sup>		0.48	
It is easy for me to learn new things <sup>R</sup>		0.49	
I have a hard time thinking or concentrating		0.66	
I have a hard time remembering things from long ago		0.60	
I have trouble remembering things, even for just a few minutes		0.69	
I have financial problems related to having had cancer			0.79
My parents have financial problems related to my cancer and treatment			0.57
I have 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			0.69
Eigenvalue	5.49	1.94	1.77
% of Total Variance	24.5%	7.08%	5.87%

*Note:* Extraction Method: Principal Axis Factoring. Rotation Method: Varimax with Kaiser Normalization  
<sup>R</sup>: Scores were reversed to be consistent with the content.

Factor loadings for the PIOC retained 22 of the original 25 items (i.e., item numbers 15, 24, and 27 were excluded). Although the factor structure retained 5 subscales, as in the original instrument (Zebrack & Landier, 2011), this analysis produced different factor loadings. This psychometric analysis indicated that the initial version of the IOC-CS instrument measures (Zebrack & Landier, 2011) distinct and relevant

constructs for childhood and adolescent cancer survivors. All five factors together explained 51% of the common variance (see

Table 2).

Table 2.

*Positive Impact of Cancer Rotated Factor Loadings*

	Factor				
	1	2	3	4	5
I lead a healthy life			0.80		
I eat a healthy diet			0.69		
I exercise			0.50		
I am healthy as others who have never had cancer			0.46		
I believe I'm an attractive person	0.63				
I like the way my body looks	0.66				
I have confidence in myself	0.66				
I feel in control of my life	0.49				
I am comfortable discussing my cancer with my mother		0.63			
I am comfortable discussing my cancer with my father		0.87			
My mother is comfortable discussing my cancer with me		0.59			
My father is comfortable discussing my cancer with me		0.77			
I feel a special bond with people with cancer					0.51
Good things have come out of having had cancer					0.65
I have learned about myself because of having had cancer					0.86
When I have a health problem, I know who to see for medical care				0.41	
I am confident that any doctor I see knows about the long-term effects of childhood cancer treatment				0.42	
I have all the information I need about my cancer, its treatment, and possible long-term effects				0.74	
When I need information about cancer I know where to find it				0.70	
I make friends easily	0.53				
I avoid social activities <sup>R</sup>	0.54				
I feel left out from my friends' lives or activities <sup>R</sup>	0.58				
Eigenvalue	5.28	2.53	2.07	1.72	1.54
% of Total Variance	19.0%	8.30%	6.35%	4.79%	3.93%

*Note:* Extraction Method: Principal Axis Factoring. Rotation Method: Varimax with Kaiser Normalization. <sup>R</sup>: Scores were reversed to be consistent with the content.

Correlations between the three subscales of NIOC were significant with medium (e.g.,  $r = 0.28$ ) to large ( $r = 0.47$ ) effect (Cohen, 1988) (see Table 3.); the five subscales

of PIOC were also significant with small ( $r = 0.12$ ) to strong ( $r = 0.62$ ) effect (see Table 4). Psychometric properties of the eight subscales demonstrate robust internal consistency (Cronbach's alpha ranged between 0.70 to 0.83) and feature expected associations with standardized measures of health-related quality of life measurements (Zebrack et al., 2010; Zebrack & Landier, 2011).

Table 3.

*Correlation and Internal Consistency of NIOC subscales*

	Factor 2	Factor 3	Cronbach Alpha
Factor 1	$r = 0.30^{***}$	$r = 0.28^{***}$	0.83
Factor 2	-	$r = 0.47^{***}$	0.77
Factor 3	-	-	0.76

Note. \*\*\*:  $p < 0.001$

Table 4.

*Correlation and Internal Consistency of PIOC subscales*

	Factor 2	Factor 3	Factor 4	Factor 5	Cronbach Alpha
Factor 1	$r = 0.14^{**}$	$r = 0.62^{***}$	$r = 0.37^{***}$	$r = 0.13^{**}$	0.79
Factor 2	-	$r = 0.12^*$	$r = 0.15^{***}$	$r = 0.14^{**}$	0.82
Factor 3	-	-	$r = 0.37^{***}$	<i>ns</i>	0.73
Factor 4	-	-	-	<i>ns</i>	0.69
Factor 5	-	-	-	-	0.72

Note. \*:  $p < 0.05$ ; \*\*:  $p < 0.01$ ; \*\*\*:  $p < 0.001$

**Mean Difference Test**

Using a series of independent samples  $t$ -test, mean scores of NIOC and PIOC were tested, separately, with demographic (biological sex, race/ethnicity, type of cancer, and age group at diagnosis) and environmental variables (geographical location and insurance type). Findings revealed significantly higher NIOC mean score with female (*vs.* male,  $t(495) = 3.12$ ,  $p = 0.001$ ); diagnosed during adolescent (*vs.* childhood,  $t(495) =$

2.25,  $p = 0.001$ ); and public health insurance (vs. private insurance,  $t(495) = 3.09$ ,  $p = 0.001$ ). There were no statistically significant mean differences found in NIOC scores for geographical location and race/ethnicity. Using one-way ANOVA, the mean differences among the three types of cancer (hematological, CNS/brain tumor, solid tumor/soft tissue tumors/other) on NIOC and PIOC were tested, separately, and found no significant mean differences.

Using a series of paired samples  $t$ -test, mean differences between NIOC and PIOC in each group were tested. Results indicated that PIOC mean scores were consistently significantly higher than NIOC mean scores across all groups: males ( $\bar{x} = 4.15$ ,  $SD = 0.46$  vs.  $\bar{x} = 2.93$ ,  $SD = 0.59$ ), females ( $\bar{x} = 4.07$ ,  $SD = 0.47$  vs.  $\bar{x} = 3.11$ ,  $SD = 0.71$ ), survivors diagnosed during childhood ( $\bar{x} = 4.11$ ,  $SD = 0.46$  vs.  $\bar{x} = 2.99$ ,  $SD = 0.66$ ), diagnosed during adolescence ( $\bar{x} = 4.11$ ,  $SD = 0.49$  vs.  $\bar{x} = 3.15$ ,  $SD = 0.62$ ), White survivors ( $\bar{x} = 4.10$ ,  $SD = 0.48$  vs.  $\bar{x} = 3.02$ ,  $SD = 0.64$ ), non-White survivors ( $\bar{x} = 4.11$ ,  $SD = 0.39$  vs.  $\bar{x} = 3.08$ ,  $SD = 0.69$ ), amongst survivors diagnosed with hematological cancers ( $\bar{x} = 4.12$ ,  $SD = 0.48$  vs.  $\bar{x} = 3.02$ ,  $SD = 0.66$ ), CNS/Brain tumor cancers ( $\bar{x} = 4.02$ ,  $SD = 0.51$  vs.  $\bar{x} = 3.15$ ,  $SD = 0.64$ ), and solid tumor/soft tissue/other cancers ( $\bar{x} = 4.13$ ,  $SD = 0.42$  vs.  $\bar{x} = 2.99$ ,  $SD = 0.66$ ), survivors residing in urban geographical locations ( $\bar{x} = 4.12$ ,  $SD = 0.45$  vs.  $\bar{x} = 3.05$ ,  $SD = 0.64$ ), rural locations ( $\bar{x} = 4.09$ ,  $SD = 0.49$  vs.  $\bar{x} = 2.98$ ,  $SD = 0.68$ ), having private health insurance ( $\bar{x} = 4.15$ ,  $SD = 0.45$  vs.  $\bar{x} = 2.96$ ,  $SD = 0.61$ ), and public insurance ( $\bar{x} = 4.04$ ,  $SD = 0.48$  vs.  $\bar{x} = 3.15$ ,  $SD = 0.71$ ) (see Table 5).

Table 5.

*Statistical Mean Difference Test*

	Independent <i>t</i> -test/One-way ANOVA		Dependent <i>t</i> -test
	NIOC	PIOC	NIOC vs. PIOC
<i>Biological Sex</i>			
Male	$t(468) = -2.99^{**}$ $\bar{x}=2.94 (SD= 0.6)$ vs.	$t(468) = 1.84^{**}$ $\bar{x}=4.16 (SD= 0.46)$ vs.	$t(239) = -20.96^{***}$ $\bar{x}=2.93 (SD= 0.59)$ vs. $\bar{x}=4.15 (SD= 0.46)$
Female	$\bar{x}=3.12 (SD= 0.7)$	$\bar{x}=4.17 (SD= 0.47)$	$t(242) = -14.62^{***}$ $\bar{x}=3.11 (SD= 0.71)$ vs. $\bar{x}=4.07 (SD= 0.47)$
<i>Age Group at Diagnosis</i>			
Childhood	$t(458) = 2.13^*$ $\bar{x}=2.99 (SD= 0.66)$ vs.	$t(468) = 0.01, ns.$ $\bar{x}=4.11 (SD= 0.46)$ vs.	$t(369) = -23.0^{***}$ $\bar{x}=2.99 (SD= 0.66)$ vs. $\bar{x}=4.11 (SD= 0.46)$
Adolescence	$\bar{x}=3.15 (SD= 0.62)$	$\bar{x}=4.11 (SD= 0.49)$	$t(99) = -9.60^{***}$ $\bar{x}=3.15 (SD= 0.62)$ vs. $\bar{x}=4.11 (SD= 0.49)$
<i>Race/Ethnicity</i>			
White	$t(442) = -.76, ns.$ $\bar{x}=3.02 (SD= 0.64)$ vs.	$t(195.22) = -.22, ns.$ $\bar{x}=4.10 (SD= 0.49)$ vs.	$t(343) = -20.91^{***}$ $\bar{x}=3.02 (SD= 0.64)$ vs. $\bar{x}=4.10 (SD= 0.48)$
Non-White	$\bar{x}=3.08 (SD= 0.69)$	$\bar{x}=4.11 (SD= 0.39)$	$t(99) = -11.57^{***}$ $\bar{x}=3.08 (SD= 0.69)$ vs. $\bar{x}=4.11 (SD= 0.39)$
<i>Type of Cancer</i>			
Hematological	$F(2,467)=1.13, ns.$ $\bar{x}=3.02(SD= 0.66)$ vs.	$F(2,467)=1.30, ns.$ $\bar{x}=4.12(SD= 0.48)$ vs.	$t(282) = -19.05^{***}$ $\bar{x}=3.02 (SD 0.66)$ vs. $\bar{x}=4.12 (SD= 0.48)$
CNS/Brain Tumor	$\bar{x}=3.15(SD= 0.64)$ vs.	$\bar{x}=4.01(SD= 0.51)$ vs.	$t(51) = -6.50^{***}$ $\bar{x}=3.15 (SD= 0.64)$ vs. $\bar{x}=4.02 (SD= 0.51)$
Solid/Soft Tissue Tumor/Other	$\bar{x}=2.99(SD= 0.66)$	$\bar{x}=4.13(SD= 0.42)$	$t(134) = -14.84^{***}$ $\bar{x}=2.99 (SD= 0.66)$ vs. $\bar{x}=4.13 (SD= 0.42)$
<i>Geographical Location</i>			
Urban	$t(468) = 0.92, ns.$ $\bar{x}=3.05(SD= 0.64)$ vs.	$t(468) = 0.68, ns.$ $\bar{x}=4.12 (SD=0.45)$ vs.	$t(313) = -20.16^{***}$ $\bar{x}=3.05 (SD= 0.64)$ vs. $\bar{x}=4.12 (SD= 0.45)$
Rural	$\bar{x}=2.99 (SD= 0.68)$	$\bar{x}=4.09 (SD=0.49)$	$t(155) = -14.34^{***}$ $\bar{x}=2.98 (SD= 0.68)$ vs. $\bar{x}=4.09 (SD= 0.49)$
<i>Insurance Type</i>			
Private	$t(468) = -3.04^{***}$ $\bar{x}=2.96 (SD= 0.61)$ vs.	$t(468) = 2.38^{**}$ $\bar{x}=4.16 (SD=0.45)$ vs.	$t(319) = -23.4^{***}$ $\bar{x}=2.96 (SD= 0.61)$ vs. $\bar{x}=4.15 (SD= 0.45)$
Public	$\bar{x}=3.15 (SD= 0.71)$	$\bar{x}=4.04 (SD=0.49)$	$t(176) = -11.7^{***}$ $\bar{x}=3.15 (SD= 0.71)$ vs. $\bar{x}=4.04 (SD= 0.48)$

Note: \*:  $p < 0.05$ ; \*\*:  $p < 0.01$ ; \*\*\*:  $p < 0.001$

## Participant Characteristics

Of 470, the range of participant age was 14-55 with a mean age of 26.7 ( $SD = 7.3$ ); 79% ( $n = 370$ ) were childhood cancer survivors diagnosed between the ages of 0-14 years old, and 21% ( $n = 100$ ) were adolescent cancer survivors diagnosed between the ages of 15-19 years old. About half of participants (51%,  $n = 240$ ) were identified as male (vs. 49%,  $n = 230$  female). There were 344 (73%) non-Hispanic White/Caucasian cancer survivors (vs.  $n = 100$ , 21% non-white). Hematological cancers accounted for 60% ( $n=283$ ), CNS/brain tumors accounted for 11% ( $n=52$ ), and solid tumors, soft tissue tumors and other cancers accounted for 29% ( $n=135$ ). Years since diagnosis ranged from 6-50 years, with a median time of 17.0 years since diagnosis (see

Table 6).

Table 6.

### *Participant Characteristics' Description (n = 470, 100%)*

Demographic Variables		
<i>Biological Sex</i>		
Male	$n = 240$	(51%)
Female	$n = 230$	(49%)
<i>Age Group at Diagnosis</i>		
Childhood	$n = 370$	(79%)
Adolescence	$n = 100$	(21%)
<i>Race/Ethnicity</i>		
White	$n = 344$	(73%)
Non-White	$n = 100$	(21%)
<i>Type of Cancer</i>		
Hematological	$n = 283$	(60%)
CNS/Brain Tumor	$n = 52$	(11%)
Solid Tumor/Soft Tissue Tumor/Other	$n = 135$	(29%)
Environmental Variables		
<i>Geographical Location</i>		
Urban	$n = 314$	(67%)
Rural	$n = 156$	(33%)
<i>Insurance Type</i>		

Private	$n = 304$	(65%)
Public	$n = 166$	(35%)
Control Variable: <i>Years since diagnosis</i> ( $\bar{x} = 18.3$ , $SD = 7.6$ ; range = 6–50 years)		

### Hierarchical OLS Analysis Findings

Using blockwise methods, three models utilizing hierarchical ordinary least squares (OLS) regression were developed and analyzed separately for each outcome variable (negative impact of cancer vs. positive impact of cancer). Controlling for *years since diagnosis*, the first model consisted of demographic variables, the second model consisted of environmental variables, and third model consisted of interaction effects to investigate whether a new set of study variables predicts positive and negative impact of cancer over and above demographic and environmental predictors.

### Predicting NIOC

Results for Model NIOC-1 revealed that a set of demographic variables (biological sex, age group at diagnosis, race/ethnicity, type of cancer) statistically significantly describes NIOC,  $F(6, 437) = 2.95$ ,  $p < 0.01$ , explaining 2.6% of the variance. Being female ( $\beta = 0.13$ ,  $p < 0.01$ ) was a risk factor for increased NIOC. Additionally, being diagnosed during adolescence was a statistically significant predictor for decreased NIOC ( $\beta = -0.13$ ,  $p < 0.01$ ) (see Table 7).

In Model NIOC-2, by introducing environmental factor variables (geographical location and type of insurance), the model description significantly added 1.9% of the variation to the previous model:  $F(8, 435) = 3.61$ ,  $p < 0.001$ ). Having public health insurance was a statistically significant risk factor with increased NIOC ( $\beta = 0.15$ ,  $p <$

0.00). Being female ( $\beta = 0.13, p = 0.01$ ) and diagnosed during adolescence ( $\beta = -0.12, p = 0.02$ ) remained significant as in comparison to the previous model (see Table 7.).

In Model NIOC-3, interaction effects were introduced, adding 1.6% of the variance above the previous model:  $F(10, 433) = 3.88, p < 0.001$ ). Two predictors: being female and diagnosed during adolescence were no longer significant, but their interaction term: female cancer survivors who were first diagnosed during adolescence was a significant risk factor to increase NIOC ( $\beta = 0.15, p = 0.02$ ). Additionally, living in a rural geographical location and having public insurance was also found to be a risk factor with increased NIOC ( $\beta = 0.13, p = 0.05$ ) (see Table 7).

Table 7.

*Predicting NIOC using Hierarchical OLS*

	Model NIOC-1		Model NIOC-2		Model NIOC-3	
	<i>Beta</i>	<i>Sig</i>	<i>Beta</i>	<i>Sig</i>	<i>Beta</i>	<i>Sig</i>
(Constant)		0.00		0.00		0.00
Female ( <i>ref</i> : male)	0.13	0.01	0.13	0.01	0.07	0.16
Adolescent ( <i>ref</i> : childhood)	-0.13	0.01	-0.12	0.02	-0.03	0.68
Non-White ( <i>ref</i> : White)	0.05	0.26	0.02	0.64	0.04	0.47
CNS/Brain tumors ( <i>ref</i> : hematological)	0.09	0.07	0.07	0.13	0.07	0.14
Solid and soft tissue tumors/other ( <i>ref</i> : hematological)	-0.01	0.87	-0.01	0.79	0.00	0.98
Years since diagnosis	0.03	0.56	0.03	0.55	0.03	0.51
Public insurance ( <i>ref</i> : private)			0.15	0.00	0.08	0.17
Rural ( <i>ref</i> : urban)			-0.05	0.33	-0.11	0.05
Female x Adolescent					0.15	0.02
Rural x Public insurance					0.13	0.05
Model Summary	$F(6, 437) = 2.95^{**}$		$F(8, 435) = 3.61^{***}$		$F(10, 433) = 3.88^{***}$	
	$adjR^2 = 0.03$		$adjR^2 = 0.05$		$adjR^2 = 0.06$	
			$\Delta R^2 = 0.02^{**}$		$\Delta R^2 = 0.01^{**}$	

Note. \*:  $p < 0.05$ , \*\*:  $p < 0.01$ , \*\*\*:  $p < 0.001$



## Predicting PIOC

Results from Model PIOC-1 revealed that a set of demographic variables (biological sex, age group at diagnosis, race/ethnicity, type of cancer) are statistically significant predictors of PIOC,  $F(6, 437) = 2.48, p < 0.05$ ), explaining 2% of the variance. Years since diagnosis ( $\beta = -0.16, p = 0.00$ ), was the only statistically significant predictor (see Table 8.).

Results of Model PIOC-2 revealed that with the addition of environmental variables (geographical location and type of insurance), the model description significantly added 1.2% of the variation to the previous model:  $F(8, 435) = 2.82, p < 0.01$ ). Having public health insurance was a statistically significant risk factor in decreasing PIOC ( $\beta = -0.12, p < 0.01$ ). Years since diagnosis ( $\beta = -0.01, p < .000$ ) remained to be significant in comparison to the previous model (see Table 8).

In Model PIOC-3, by introducing the interaction effects, the model description significantly added 1.8% of the variance above the previous model:  $F(10, 433) = 3.31, p < 0.001$ ). Having public insurance was no longer significant, but years since diagnosis ( $\beta = -0.17, p < 0.001$ ) remained significant. Additionally, the interaction term: female cancer survivors who were first diagnosed during adolescence was a significant risk factor for decreased PIOC ( $\beta = -0.21, p < 0.00$ ) (see Table 8).

Table 8.

### *Predicting PIOC using Hierarchical OLS*

	Model PIOC-1		Model PIOC-2		Model PIOC-3	
	<i>Beta</i>	<i>Sig</i>	<i>Beta</i>	<i>Sig</i>	<i>Beta</i>	<i>Sig</i>
(Constant)		0.00		0.00		0.00
Female ( <i>ref</i> : male)	-0.06	0.22	-0.07	0.16	0.01	0.84

Adolescent ( <i>ref</i> : childhood)	0.05	0.32	0.05	0.29	-0.08	0.24
Non-White ( <i>ref</i> : White)	-0.01	0.79	0.01	0.88	0.00	1.00
CNS/Brain tumors ( <i>ref</i> : hematological)	-0.06	0.22	-0.05	0.31	-0.05	0.31
Solid and soft tissue tumors/other ( <i>ref</i> : hematological)	0.01	0.81	0.02	0.76	0.00	0.95
Years since diagnosis	-0.16	0.00	-0.16	0.00	-0.17	0.00
Public insurance ( <i>ref</i> : private)			-0.12	0.01	-0.10	0.10
Rural ( <i>ref</i> : urban)			-0.03	0.49	-0.01	0.85
Female x Adolescent					-0.21	0.00
Rural x Public insurance					-0.04	0.56
Model Summary	$F(6, 437) = 2.48^*$		$F(8, 435) = 2.82^{**}$		$F(10, 433) = 3.31^{***}$	
	$adjR^2 = 0.02$		$adjR^2 = 0.03$		$adjR^2 = 0.05$	
			$\Delta R^2 = 0.02^{**}$		$\Delta R^2 = 0.02^{**}$	

Note. \*:  $p < 0.05$ , \*\*:  $p < 0.01$ , \*\*\*:  $p < 0.001$

## Chapter 5: Discussion

The purpose of this study was to examine the influence of demographic and environmental factors *separately*, as well as the interaction effects in predicting NIOC and PIOC outcomes in childhood and adolescent cancer survivors. Notably, this study contributes insights to better understand the differential perceptions of female adolescent cancer survivors, as well as those residing in rural locations with public health insurance. This chapter presents a discussion of the four main study findings, study limitations and future research, and implications for social work practice and policy.

### Positive Impacts of Cancer

Study participants consistently endorsed higher PIOC compared to NIOC across all demographic and environmental categories including biological sex, age at diagnosis, cancer type, insurance type, and geographical location. Findings of higher PIOC in this study corroborate with Tedeschi and Calhoun's post-traumatic growth theory (2004) explaining that individuals may attach positive meanings to traumatic events. Recent studies have further expanded an understanding of post-traumatic growth in childhood and adolescent cancer survivors by indicating that survivors may face a *dual reality*, in which they are able identify both the challenges and the positive experiences involved with cancer (Dattilo et al., 2021; Kim, 2017). Individuals' stories matter and may motivate survivors newly transitioning into post-treatment survivorship in navigating and overcoming the challenges involved in adjusting to life after cancer.

Reporting higher PIOC is also consistent with previous studies demonstrating that despite the biomedical, psychosocial, and survivorship care complexities, a subset of

childhood and adolescent cancer survivors report positive experiences of cancer (Dattilo et al., 2021; Husson & Zebrack, 2017; Taylor, 2000; Zebrack et al., 2012; Zebrack & Landier, 2011). In particular, recent studies (Weatherer et al., 2021; Miller et al., 2017) suggest that childhood and adolescent survivors who participate in survivorship programs are more likely to experience higher PIOC due to increased self-confidence, personal growth, social support, and health literacy.

On the other hand, research also indicates that while cancer survivorship programs are considered to be “critical to the well-being” of cancer survivors, the majority of childhood and adolescent survivors do not participate in cancer survivorship programs (Weatherer et al., 2021; Miller et al., 2017, p2.; Tonorezos et al., 2022). Since data in this study were derived from participants’ initial visit to the Doernbecher Cancer Survivorship Clinic (DCSC), in which the program’s effects would influence study participants, endorsement of higher PIOC may not be indicative of the benefits of attending a survivorship program. Study participants were either referred by their oncologist or primary care physicians or self-referred to the program and their participation was totally voluntary. Selection bias may have occurred with study participants, which may have resulted in consistently higher PIOC than NIOC.

Participation in a survivorship program has been identified with individual attributes such as greater self-confidence in managing healthcare needs and a sense of empowerment for one’s own health (Casillas et al., 2011; Foster et al., 2015; Miller et al., 2017; Rosenberg-Yunger et al., 2013). Additionally, environmental factors such as a successful healthcare

transition, having health insurance, and accessibility to a survivorship program have also been discussed (Casillas et al., 2011; Yunger et al., 2013).

### **Living in Rural Locations with Public Health Insurance**

Not surprisingly, living in rural locations, and having public health insurance were identified as risk factors to increase NIOC. However, when their interaction term was entered, the main effect of living in rural locations was no longer significant, while having public health insurance remained significant. Previous studies suggest that a lack of accessibility to quality healthcare in rural areas is a critical contributor to poorer physical and psychosocial health outcomes, especially for cancer survivors (Levit et al., 2020; Miedema et al., 2013; Penumarthy et al., 2020).

Separately, financial barriers including high insurance copays among cancer survivors with public health insurance have been discussed intensively as one substantial contributor (e.g., Weatherer et al., 2021; Park et al., 2017; Penumarthy et al., 2020) to delayed access to cancer support services (Penumarthy et al., 2020). For example, studies show that there is a lack of public health insurance coverage for quality healthcare services including fertility treatments, sexual health services, and mental health services, as well as a lack of accessibility to survivorship programs that are often found in urban locations (Argenbright et al., 2016; Penumarthy et al., 2020). Research also demonstrates that cancer survivors with public health insurance often face barriers related to lack of transportation to medical appointments, lower health literacy, housing insecurity, and lack of social and financial support (Afulani et al., 2015; Penumarthy et al., 2020; Syed et al., 2013). Studies suggest that these barriers may be due to the effects of lower

socioeconomic status among survivors with public health insurance (Penumarthy et al., 2020; Wolfson, 2021).

As the interaction effect finding indicates, cancer survivors living with both risk factors together may further exacerbate the NIOC indicated by increased life challenges, thinking/memory problems, and financial problems. While previous studies have discussed public health insurance type as a proxy for socioeconomic status (Penumarthy et al., 2020; Wolfson, 2021), on the contrary, results from this study may be indicative of support services not being equitably available and accessible for survivors living in rural locations with public insurance (Weatherer et al., 2021; Levit et al., 2020; Weaver et al., 2013).

Recent studies suggest a critical need in expanding cancer support services to improve access to survivorship support services to cancer survivors living in rural geographical locations (Morris et al., 2022). One proposed strategy is to increase the use of telehealth services in rural geographical locations to connect cancer survivors to more medical providers, social workers, and support services (Devine et al., 2018; Doorenbos et al., 2010; Morris et al., 2022). Telehealth and other digital health services have been found to be an effective method in improving access to cancer support services such as peer support, patient navigation, and survivorship cancer care resources and information (Brown et al., 2018; Doorenbos et al., 2010; Viola et al., 2020).

### **Being Female and Diagnosed with Cancer During Adolescence**

While research on developmental age at diagnosis has primarily focused on the distinct biomedical and psychosocial differences between childhood and adolescent

survivors, studies on the influence of gender and developmental age at diagnosis are sparse. As hypothesized in this study, the interaction effect of being female and being diagnosed with cancer during adolescence is a risk factor with increased NIOC and lowered PIOC, compared to all other groups of survivors. This finding supports previous studies suggesting that higher NIOC is associated with greater physical and mental health distress in female cancer survivors (Husson & Zebrack, 2017; Zeltzer et al., 1997). Moreover, a recent study found that females diagnosed during adolescence experience greater worry and uncertainty related to 1) reproductive health, 2) future life goals, and 3) managing intimate and social relationships (Benedict et al., 2020b). These are consistent with findings from this study, especially for female (vs. male) survivors, and those who were diagnosed during adolescence (vs. childhood) reporting higher life challenges, which resulted in a significant interaction effect.

Contrary to overgeneralized perceptions on cancer survivorship, female survivors diagnosed with cancer during adolescence may have distinct experiences (Cathcart-Rake et al., 2021; Hammond, 2016) influenced by larger socioeconomic and cultural factors. A danger of overgeneralization of adolescent cancer survivors being described as *one* group due to their biomedical needs calls for greater attention (Bellizzi et al., 2012; Bleyer, 2007; Overholser et al., 2017). It is essential to distinguish gender and consider developmental life course in cancer survivor support programs.

### **CNS/Brain Tumor Survivors**

Research on NIOC and PIOC has long indicated that long-term physical, psychological, and social challenges may be influenced by the type of cancer at diagnosis

(e.g., Bellizzi et al., 2012; Zebrack et al., 2012). In particular, studies demonstrate that childhood and adolescent survivors diagnosed with brain cancer have poorer health and psychosocial wellbeing compared with survivors of other cancer types (Hocking et al., 2017; Oeffinger et al., 2004b; Zeltzer et al., 2009). However, in this study, being diagnosed with a CNS/brain tumor cancer type did not yield significant differences in NIOC and PIOC. Previous studies (Chao et al., 2020) have shown that the impact of cancer on patients vary because of cancer treatment drug side effects and duration of treatment. But these two factors were not considered in this study.

In addition, Deatruck and colleagues (2018) found that in comparison to other cancer types, brain tumor survivors reported experiencing greater family support and family-focused skills (i.e., ability to manage child's condition and special needs). Studies indicate that due to long-term cognitive, behavioral, and physically debilitating effects of treatment, childhood and adolescent brain tumor survivors are more likely to be dependent on caregivers longer than survivors of other cancer types even after treatment is complete (Beek et al., 2015; Hocking et al., 2017).

Furthermore, posttraumatic growth theory suggests that an individual's ability to apply positive meaning to traumatic life experiences may make physical pain and impairments less salient (Barakat et al., 2006; Tedeschi & Calhoun, 2004). Cancer survivors who experience greater intensity of treatment and severity of disease often endorse greater personal growth (Jansen et al., 2011; Lelorain et al., 2012).



### **Study Limitations and Future Research**

Previous studies have found that patients who attend survivorship programs are more likely to have higher levels of health literacy, health care self-efficacy, and be more adherent to following treatment recommendations compared to survivors who don't attend survivorship programs (Kazak et al., 2010; Miller et al., 2000). While all study participants were attending a survivorship program, study data were collected during their first visit before they received any benefits from support services. In this regard, study findings could be interpreted as cancer survivors' overall experiences in the community. It is important to also note that all study participants were either referred by their oncologist, primary care physician, or self-referred. Self-selection bias may occur due to the voluntary nature of the participation.

Furthermore, study participants may not be nationally and population representative of adolescent and childhood cancer survivors. Racial cancer disparities have been a growing concern in the U.S. While cancer affects all population groups, socioeconomic and environmental disadvantages have caused certain groups of the population to bear a disproportionate burden of cancer compared with other groups (NIH, 2016). In this study, White cancer survivors (73% vs. 21% of non-White) were overrepresented. Certain racial/ethnic groups may not be well representative due to other culturally responsive survivorship programs that exist in the region. For example, the Asian Cancer Resource & Support Services (ACRSS) at the Asian Health and Service Center in Portland, Oregon is one example of a survivorship program providing culturally responsive and linguistically specific support services for cancer patients and their

families in Asian communities, especially targeting Chinese, Vietnamese, and Korean communities. Additionally, with increases in cancer care disparities among immigrant and refugee communities in the U.S. (Kamaraju et al., 2022), it is important to learn more about the types of cancer support services that exist in the State of Oregon and nationally for refugee/immigrant survivors. It is also critical for future studies to deepen an understanding on the survivorship care support needs of refugee/immigrant cancer survivors. Furthermore, future studies should extend the study setting and the scope of data collection in order to be more inclusive of racial/ethnic minorities, as well as immigrant/refugee cancer survivors, both groups are often not only under-represented in cancer survivorship research but also cancer survivorship programs (Bhatia et al., 2016; Fang & Ragin, 2020).

While testing racial disparities in cancer was one of the interests of this study, surprisingly, no statistically significant race/ethnicity differences were observed. The race/ethnicity data in this study were derived from patient medical records. Upon conducting a retrospective chart review and seeking consultation from survivorship program staff, the researcher was not able to confirm whether race/ethnicity data in patient charts were self-reported by the patient, patient's family member, or by a third party not related to the patient. As race/ethnicity is considered an important determinant of health in the U.S and racial disparities in cancer have been identified and discussed with great concern (Bhatia, 2011; Bhatia et al., 2016), it is essential to move towards data collection that features the adequate collection of demographic and socioeconomic data (Ploeg & Perrin, 2004).

Previous research has revealed different experiences between male and female cancer survivors (Husson & Zebrack 2017; Zeltzer et al., 1997), therefore gender differences in the perceived impact of cancer was another study interest. However, patient medical records did not *adequately* collect gender information data of patients during the study timeframe period (i.e., from 2009 to 2019), thus biological sex was used as a proxy. In alignment with gender equity and social justice perspectives, OHSU hematology and oncology started collecting data on gender identity in 2019. It is important for future studies to draw attention to the cancer experiences of this population, especially considering that the lack of adequate gender identity data collection in electronic medical records, as well as the absence of gender-neutral language in medical questionnaires and surveys has led to a limited understanding of the specific needs and support services required for gender minorities (Pratt-Chapman et al., 2021; Wheldon et al., 2018).

While this study did not observe significant differences in NIOC among CNS/brain tumor cancer survivors as reported in previous research, it is important to mention that the CNS/brain tumor survivors participating in this study may not be nationally or population representative. Before CNS/brain tumor type participants attend DCSC, they participate in a pediatric neuro-oncology cancer support program at OHSU's Doernbecher Children's Hospital. This program is specialized in providing CNS/brain tumor survivors with biomedical and psychosocial support services tailored to their specific support needs. In this regard, receiving support services prior to study participants' first visit to DCSC may have served as a buffer for NIOC, thus influencing

study findings. It is important for future studies to examine how receiving early intervention cancer support survivors after treatment may impact NIOC and PIOC.

This study observed important findings regarding higher NIOC among participants residing in rural geographical locations with public health insurance. However, due to utilization of secondary data and a cross-sectional design, this study did not have the capacity to identify participants' previous health insurance coverage, as well as how long study participants have had public health insurance coverage. Prior research demonstrates that participants eligible for public health insurance may perceive healthcare discrimination and stigma related to their health insurance type (Alcalá et al., 2020; Allen et al., 2014). Future studies should utilize longitudinal methods in examining the effects of health insurance type across the cancer care continuum (diagnosis, treatment, and post-treatment).

The IOC-CS instrument was developed to capture the unique and multidimensional experiences of childhood and adolescent cancer survivors, and this instrument was used in this study. However, during exploratory factor analysis it was revealed that factor loadings for the five PIOC subscales (body and health, talking with parents, personal growth, health literacy, socializing) indicated two distinct factorial structures from the initial version of this instrument (Zebrack & Landier, 2011). Follow-up studies using confirmatory factor analysis are needed to confirm these findings, as well as provide further information on the validity and variability of the IOC-CS constructs.

In addition, previous studies demonstrate that the perceived impact of cancer is a critical factor to predict quality of health and life outcomes (e.g., Husson & Zebrack, 2017; Zebrack & Landier, 2011). However, this study did not connect NIOC and PIOC to such measures (e.g., health related quality of life, psychological distress). Further studies should carefully include outcome variables to build a causal relationship(s) predicted by the PIOC and NIOC.

Lastly, due to significant changes in the delivery of outpatient healthcare services because of the novel coronavirus (COVID-19) (Punia et al., 2020), this study did not include data from the years 2020-2022 because the pandemic has introduced new life circumstances that may be significantly varied from data collected at DCSC from 2009-2019. For example, the pandemic has caused delays, postponements, and disruptions to cancer survivorship programs appointments within DCSC and nationally (Prasad et al., 2022; van den Oever et al., 2022). In addition, many survivorship programs have reduced support services in order to provide more resources to patients on active treatments (Prasad et al., 2022). Future research is needed to address and examine the unique exposures and experiences associated with this pandemic.

### **Implications for Social Work Practice and Social Work Policy**

This study contributes important implications for social work practice in oncology healthcare settings and social work policy. Social workers play a critical role within the field of pediatric oncology and cancer survivorship programs by supporting children, adolescents, and young adults as they manage the diagnosis, treatment, and survivorship of cancer (e.g., Jones et al., 2018; Zebrack et al., 2018). Cancer survivorship programs

and social workers should consider the implications of this study for developing and/or strengthening survivorship support services and interventions for childhood and adolescent cancer survivors.

This study found that residing in rural areas with public health insurance is a significant risk factor for increased NIOC. Social workers and cancer survivorship programs should focus special attention on understanding the needs of survivors living in rural geographical locations with public health insurance. For example, providing more accessibility and quality of health care services may reduce the risk of NIOC among survivors in rural areas with public insurance (Weatherer et al., 2021; Penumarthy et al., 2020). One strategy would be to increase utilization of telehealth and peer support services in rural geographical locations (Doorenbos et al., 2010; Morris et al., 2022). Additionally, social workers can work towards cultivating partnerships with rural agencies and clinics to improve access to support services in rural locations.

Another significant study finding was that female survivors diagnosed with cancer during adolescence reported not only reduced PIOC, but increased NIOC. Social workers working with this population must be mindful of the experiences of female survivors. The experiences of these individuals may intersect with socioeconomic, cultural, family, and trauma related factors (Cathcart-Rake et al., 2021). Therefore, deepening an understanding of the lived experiences of this population is essential for the implementation of gender sensitive, gender-affirming, and developmentally specific cancer survivorship support programs.

In addition, study findings provide insights on the need for social workers and survivorship care programs to further assess the effects of medical indicators such as type of cancer along with non-medical indicators including socioeconomic factors and exposure to early childhood trauma that may influence NIOC and PIOC. One possibility may be to include questions about previous childhood trauma exposures to psychosocial questionnaires (Coughlin, 2021).

While it is essential for social workers to understand and address the psychosocial needs of childhood and adolescent cancer survivors, it is also important to target local and national policies that will improve funding, delivery, and access for more survivorship care programs, especially in rural geographical locations and for survivors with public health insurance (Miller et al., 2017; Penumarthy et al., 2020; Weatherer et al., 2021). Laws like the Childhood Cancer Survivorship, Treatment, Access and Research (STAR) Act (STAR Act, 2018) which was enacted in 2018 and is in the process of being refunded, are important next steps. This law funds an expansion in the collection of clinical and demographic information and supports increasing the delivery of quality cancer support services to both survivors and their families. These efforts may help to maximize the delivery of quality healthcare services to individuals living in rural geographical areas as well as support an expansion of public insurance to include coverage for more long-term cancer support services.

## **Conclusion**

This study sought to deepen an understanding on the extent to which demographic and environmental factors, as well as the interaction effects predict the positive and

negative impact of cancer in childhood and adolescent cancer survivors. Guided by Hammond's theory of "Distinctness," and Tedeschi and Calhoun's posttraumatic growth theory, study findings offer insights to better understand the differential perceptions of female adolescent cancer survivors, as well as those residing in rural locations with public health insurance. Findings are indicative of the complex ways in which developmental age at diagnosis, biological sex, geographical location, and health insurance type interact to predict NIOC and PIOC.

Implications from this study provide social workers working in oncology settings with insights on what areas of supportive care needs, services, and resources may need further strengthening, adapting, and/or developing in responding to the distinct needs of female survivors diagnosed during adolescence and survivors living in rural locations with public health insurance.

Findings from this study also highlight the need for the IOC-CS questionnaire to be accompanied by additional measures such as health-related quality of life and psychological distress to examine overall quality of life as outcome variables. Important next steps for future research studies should include such measures to build a causal relationship(s) using longitudinal study designs.

Additionally, it is important for policymakers to advocate for the development or enhancement of programs and resources that increase the delivery, accessibility, and quality of cancer support survivors, particularly for survivors residing in rural locations with public health insurance. Policy efforts should be targeted towards supporting an



expansion of public health insurance to provide coverage beyond inpatient services and into long-term cancer survivorship.

Lastly, this study also provides further evidence on the need for survivorship cancer research to move towards frameworks of social determinants of health by examining the accumulated effects of medical indicators and non-medical indicators including socioeconomic factors and exposure to early childhood trauma that may influence NIOC and PIOC. Providing adequate and comprehensive management and support for cancer survivors is complex and requires contribution from a range of medical specialists and healthcare professionals. Findings from this study provide insights into the interdisciplinary (i.e., medical profession and social work) and interinstitutional (i.e., OHSU and Portland State University School of Social Work) collaboration that was able to strengthen the research design and help to better understand impacts of cancer among childhood and adolescent cancer survivors. Based on study findings, it is hoped that negative impacts of cancer are reduced, and cancer survivorship experiences are improved.

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**Appendix: Impact of Cancer-IOC-CS, 45 items****Negative Impact of Cancer****Life challenges**

1. Worry about health
2. Want to forget cancer
3. Wonder why I got cancer
4. Wonder why I survived
5. Something I did caused cancer
6. Angry about cancer
7. Cancer controls my life
8. Time is running out
9. Afraid to die
10. Worry I will die at young age
11. Missed out on life
12. Unsure about future

**Thinking/memory problems**

13. Easy to make decisions<sup>a</sup>
14. Easy to learn<sup>a</sup>
15. Hard time thinking
16. Trouble w/long-term memory
17. Trouble w/short-term memory

**Financial problems**

- 18. Financial problems from cancer
- 19. Parents financial problems from cancer
- 20. Trouble getting assistance/services

**Positive Impact of Cancer****Body and health**

- 21. Lead healthy life
- 22. Eat healthy diet
- 23. Exercise
- 24. Healthy as those w/o cancer
- 25. Believe I'm attractive
- 26. Like my body
- 27. Self-confident
- 28. Feel in control

**Talking with parents**

- 29. Can talk with mom about cancer
- 30. Can talk with dad about cancer
- 31. Mom comfortable talking about cancer w/me
- 32. Dad comfortable talking about cancer w/me

**Personal growth**

- 33. Cancer part of self
- 34. More mature than those without cancer
- 35. Special bond with others with cancer
- 36. Good things came from cancer
- 37. Learned about self

**Health literacy**

- 38. Know who to see for medical problems
- 39. Feel doctor knows cancer effects
- 40. Easy to talk to doctor about cancer
- 41. Have all cancer info I need
- 42. Know where to find cancer info

**Socializing**

- 43. Make friends easily
- 44. Avoid social activities<sup>a</sup>
- 45. Left out of friends' lives<sup>a</sup>

<sup>a</sup> *Reverse scoring*