Title

A Comparison of Perceived Satisfaction, Resilience, and Achievement Among Hispanic and Non-Hispanic White Childhood Cancer Survivors

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A Comparison of Perceived Satisfaction, Resilience, and Achievement Among Hispanic and Non-Hispanic White Childhood Cancer Survivors

DISSERTATION

Submitted in partial satisfaction of the requirements for the degree of

DOCTOR OF PHILOSOPHY

In Nursing Science

by

Paula Patricia Rosales

Dissertation Committee:
Professor Lorraine Evangelista, Chair
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2019

DEDICATION

To

Eric and Christian.

My loves.

My parents.

Thank you for your many sacrifices. This is for you.

My sister.

You showed me firsthand the unparalleled strengths of cancer survivors.

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ABSTRACT OF THE DISSERTATION

A Comparison of Perceived Satisfaction, Resilience, and Achievement Among
Hispanic and Non-Hispanic White Childhood Cancer Survivors

By

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Professor Lorraine Evangelista, Chair

Research on health-related quality of life (HRQOL) among childhood cancer survivors now includes exploration of positive outcomes. Post-traumatic growth, which includes finding meaning in a traumatic experience, is one such outcome and it can be measured through satisfaction, resilience, and achievement. The organismic theory explains that growth after a traumatic event can occur when proper resources are available to the individual. There are gaps in the literature that explore positive outcomes in childhood cancer survivors, as well as gaps in exploring the HRQOL of Hispanic survivors. The aims of this exploratory, descriptive study were to 1) compare the levels of satisfaction, resilience, and achievement among Hispanic vs. non-Hispanic White survivors; and 2) examine the relationships between sociodemographic characteristics (e.g., age, gender, ethnicity, years of schooling, income), clinical factors (e.g., prior mental health or behavioral problems, age at time of cancer diagnosis, type of cancer), and HRQOL (e.g., satisfaction, resilience, and achievement). Survivors (*N* = 116) were recruited from Children's Hospital of Orange County (CHOC). Inclusion criteria included: 1) ≥ 12 years of age; 2) diagnosed with cancer between the ages of 5 and 18 years old; 3) diagnosed between 1990-2010; 4) completed treatment at least two years ago or five years from time of diagnosis and off therapy; 5) identify as Hispanic or non-Hispanic White; and 6) ability to speak/write in English or Spanish. Participants completed the Child Health and Illness Profile- Adolescent Edition. Comparisons (i.e., sociodemographic, clinical factors, HRQOL) between Hispanic (n = 55) and non-Hispanic White (n = 61) participants were conducted. No difference was found between Hispanic and non-Hispanic White participants' HRQOL scores in the area of satisfaction ($p = 0.95$). Resilience ($p = 0.003$) and achievement ($p = 0.005$) scores were lower among Hispanic survivors. One explanation for these findings are differences in resources available to survivors before and after their cancer. More Hispanic families reported incomes below the poverty line ($p = 0.00$). Additional studies are needed to explore these findings, including links between socioeconomic status and resources. Implications for clinicians include ensuring that Hispanic childhood cancer survivors have resources that promote readjustment after cancer.

Chapter 1: Introduction and Specific Aims

For children diagnosed with cancer, the future is now more hopeful than it has ever been. Available treatments have improved over the past few decades and survival is possible for many types of childhood cancers (Ward, DeSantis, Robbins, Kohler, & Jemal, 2014). Acute lymphoblastic leukemia (ALL), the most common type of cancer in young children, has seen the greatest survival rate improvement with greater than 90% of patients surviving their illness (Leukemia & Lymphoma Society, 2018). In addition to continuing to improve oncology treatments and consequently survival rates, the challenge now is for clinicians and researchers to understand how children function post-cancer treatment. The *late effects* of cancer -- the physical and psychological medical problems caused by cancer treatments that may not be evident for years after completion of treatment -- threaten to leave survivors in a poor state of health (Galligan, 2017; Kanellopoulos, Hamre, Dahl, Fossa, & Ruud, 2013; Oeffinger et al., 2006; Zeltzer et al., 2008). It is the hope of those caring for children with cancer that they will not only survive but also that they will thrive. Health-related quality of life (HRQOL) --defined as how "an individual or group [perceives] physical and mental health over time" -- is one measure that has been used to explore how well children are doing post-treatment completion (Center for Disease Control and Prevention, 2018). Survivorship studies exploring HRQOL most often measure the negative health outcomes related to the late effects of childhood cancer treatment. This has been an appropriate approach considering that longitudinal studies of children treated for cancer demonstrate that this population faces many health problems including other cancers, heart problems, stroke, obesity, and increased chances for developing chronic illnesses when compared with healthy groups (Essig et al., 2014; Mody et al., 2008; Oeffinger et al., 2006).

Recently, identifying positive health outcomes in childhood cancer survivors and their impact on HRQOL have become part of the HRQOL research model (Arpawong, Oland, Milam, Ruccione, & Meeske, 2013; Shin, Bartlett, & De Gagne, 2019; Zebrack et al., 2012). Post-traumatic growth (PTG) is one construct that helps to capture positive HRQOL after surviving childhood cancer. When an individual has achieved PTG they report having a clearer sense of who they are (e.g. improved self-esteem); improved mental health and ability to understand the plight of others; improved relationships; and overall, a greater sense that they have a purpose for their life (Joseph & Linley, 2005). The ability to perceive a past experience with cancer as a positive occurrence and gain strength and meaning from it has been shown to protect childhood cancer survivors from lower HRQOL and this is one reason for the inclusion of positive outcomes in survivorship research (Parry & Chesler, 2005; Shin et al., 2019).

Post-traumatic growth is a broad concept and measuring it can pose many difficulties. Satisfaction (i.e. how one perceives his/her life) (Weinstein et al., 2018), resilience (i.e. lack of maladjustment to trauma and actions taken for positive outcomes) (Castellano-Tejedor, Blasco-Blasco, Pérez-Campdepadrós, & Capdevila-Ortís, 2014), and achievement (i.e. academic and/or work-related accomplishments) (Frederiksen et al., 2019) are three concepts that can be used to operationalize PTG in childhood cancer survivors. Furthermore, the organismic theory on growth post-trauma can be used to explain the mechanism by which positive outcomes (satisfaction, resilience, and achievement) can be achieved (Joseph & Linley, 2005). The organismic theory explains that in order to achieve positive outcomes after trauma one must be able to readjust pre-trauma goals and needs to fit the new normal and resources are needed to do so. Differences in these resources is one explanation for what allows some survivors to grow, others to remain the same, and some to have negative outcomes (Joseph & Linley, 2005).

Given the infancy of research on positive health outcomes following cancer, many gaps exist in the literature. Specifically, there is a need to address finding positive outcomes after cancer in the Hispanic community of childhood cancer survivors. Hispanic childhood cancer survivors represent a group that has been disproportionately affected by cancer (Giddings, Whitehead, Metayer, & Miller, 2016; Siegel et al., 2017; Ward et al., 2014). In the United States (U.S.), Hispanic children have the highest incidence of ALL, the most common childhood cancer, when compared with non-Hispanic White, non-Hispanic Black and Asian/Pacific Islander children (Barrington-Trimis et al., 2017; Giddings et al., 2016; Siegel et al., 2017; Ward et al., 2014). Evidence of lower survival rates also exists for this population as a result of lower levels of maternal education and lower enrollments in clinical trials among other things (Ward et al., 2014). As a result of low enrollment in survivorship studies, research on positive outcomes after cancer treatment fails to explore the experience of Hispanic childhood cancer survivors, specifically in the areas of satisfaction (Seitz et al., 2011), resilience (Howard Sharp et al., 2015), and achievement (Frederiksen et al., 2019). This lack of diversity in research perpetuates a legacy of ignoring a disadvantaged population.

Clearly, additional research examining positive health outcomes after surviving childhood cancer and their ability to shield survivors from lower HRQOL (Arpawong et al., 2013; Jörngården, Mattsson, & Von Essen, 2007; Weinstein et al., 2018; Zebrack et al., 2012) are warranted. Research that explores differences in satisfaction, resilience, and achievement among Hispanics vs. non-Hispanic Whites is needed to provide empirical evidence for the development of support programs for this understudied population.

The specific aims of this exploratory, descriptive study were to

1) compare the levels of satisfaction, resilience, and achievement among Hispanic vs. non-Hispanic White childhood cancer survivors;
2) examine the relationships between sociodemographic characteristics (e.g., age, gender, ethnicity, years of schooling, income), clinical factors (e.g., prior mental health or behavioral problems, age at the time of cancer diagnosis, type of cancer), and HRQOL (e.g., satisfaction, resilience, and achievement).

Chapter Summary

This chapter outlines a shift in research to focus on positive health outcomes in childhood cancer survivors (Arpawong et al., 2013; Ward et al., 2014). A lack of research for Hispanic childhood cancer survivors exists, specifically as it relates to their levels of satisfaction, resilience, and achievement post-treatment. Comparisons will be made for the scores of these three measures between Hispanic and non-Hispanic White survivors to identify where future research is needed and as a first step to developing appropriate interventions. In addition, relationships between participant characteristics will be explored.

Chapter 2: Background and Significance

Chapter Introduction

This chapter describes the growing population of childhood cancer survivors and their health-related quality of life (HRQOL) outcomes. Outlined here as part of HRQOL assessments are the positive outcomes that may result from having survived cancer, represented in this study as post-traumatic growth (PTG). Specifically, satisfaction, resilience, and achievement are explored as measurable constructs that can be used to assess PTG in survivors. The gaps in research for positive outcomes in childhood cancer survivors and the gaps in research of Hispanic childhood cancer survivors are highlighted.

Childhood Cancer and Survivorship

Rates of childhood cancer incidence and survival are collected by the National Cancer Institute (NCI), the Center for Disease Control and Prevention (CDC), and the North American Association of Central Cancer Registries (NAACCR), with the NAACCR alone covering 95% of the U.S. population (Ward et al., 2014). This data has been analyzed to allow for a better understanding of risk factors, trends, and opportunities for future oncology research. In the U.S., the average number of children diagnosed with cancer before turning 15 years old is one in 408, and one in 285 will be diagnosed before the age of 20 years old. The most common cancers among children 0-14 years old are acute lymphoblastic leukemia (ALL) (26%), brain and central nervous system (CNS) (21%), and neuroblastoma (7%). For adolescents ages 15-19 years old the most common cancers are Hodgkin lymphoma (15%), thyroid carcinoma (11%), and brain and CNS (10%). As a result of advances in cancer treatments, five-year survival rates that help predict positive future health outcomes, have improved for children (Ward et al., 2014). As of 2015, there were a total of 429,000 cancer survivors who were diagnosed before turning 20 years old (National Cancer Institute, 2018). Acute lymphoblastic leukemia, in particular, has seen the greatest increase in the survival rate, improving from a survival rate of 14% in the 1960s to over 93% by 2012 (Leukemia & Lymphoma Society, 2018).

The chances of developing childhood cancer and the likelihood of survival vary by race and ethnicity. Between 2006-2010 the highest incidence of childhood cancer was found in non-Hispanic White and Hispanic children and adolescents when compared with non-Hispanic Black and Asian children (Ward et al., 2014). A recent study describing prevalence trends in ALL in California found that from 1990-2012 the number of ALL cases were significantly higher for Hispanic children and adolescents (n = 4711) than for Non-Hispanic Whites (n = 2861), Asian/Pacific Islanders (n = 780) and Non-Hispanic Blacks (n = 324) (Giddings et al., 2016). In addition, despite standardized treatment protocols, survival statistics reveal lower survival rates among Hispanic children ages 0-14 years old (80.3%) and adolescents ages 15-19 years old (75.8%) compared with than non-Hispanic White children (84.2%) and adolescents (85.9%) (Ward et al., 2014).

The reasons for the racial and ethnic disparities of cancer incidence and survivorship in the U.S. are not completely understood and findings has been contradictory. Among hypothesized explanations for the higher incidence of cancer incidence among Hispanic children are genetic predispositions (Giddings et al., 2016) and parental exposures to pesticides given the types of jobs Hispanic parents have (Barrington-Trimis et al., 2017; Giddings et al., 2016). Interestingly, some studies have found associations between socioeconomic status and the chances for developing childhood cancer in children (Adam, Rebholz, Egger, Zwahlen, & Kuehni, 2008), while others have not (Ward et al., 2014). Parents' years of education, knowledge about the cancer diagnosis, health insurance status, and enrollment in clinical trials have been cited as possible explanations for lower survival rates (Ward et al., 2014).

For healthcare providers caring for childhood cancer survivors, the focus lies in monitoring the *late effects* of cancer treatments in order to improve physical well-being and HRQOL. *Late effects* refer to physical and psychological medical problems caused by cancer treatments that may not be evident until years after completion of care (Galligan, 2017; Kanellopoulos et al., 2013; Oeffinger et al., 2006; Zeltzer et al., 2008). Longitudinal studies of children treated for childhood cancers demonstrate that this population faces an increased risk of premature mortality, other cancers, congestive heart failure, stroke, obesity, and neurocognitive deficiencies (Essig et al., 2014; Mody et al., 2008). The Childhood Cancer Survivor Study (CCSS), the largest ongoing cancer survivorship study made up of 31 institutions in the U.S. and Canada, has been key in exploring health among survivors (Oeffinger et al., 2006). One study compared over 10,000 survivors treated between 1970 and 1986 with healthy siblings and found that 62.3% of survivors had at least one chronic illness, 37.6% had at least two chronic illnesses, and 23.8% had at least three chronic illnesses (Oeffinger et al., 2006). The healthy siblings in the study had no history of cancer and had much lower rates of chronic illnesses with 36.8% reporting one chronic illness, 13.1% reporting at least two chronic illnesses and 5.4% reporting three chronic illnesses or more (Oeffinger et al., 2006). These chronic illnesses included major joint replacement, congestive heart failure, second malignant neoplasms, cognitive dysfunction, cerebrovascular accident, renal failure or dialysis, hearing loss, blindness, and ovarian failure (Oeffinger et al., 2006).

More recent data collected from participants who had fewer toxic treatments under new protocols also showed similar findings. In a study comparing childhood ALL survivors to healthy siblings treated between 1970 to 1986, but only including participants who received care under current standards that limit exposure to radiation treatments, 70% of survivors had a chronic illness versus 61% of the healthy sibling group (Essig et al., 2014). In addition, 61% of survivors had more than one chronic health problem versus 47% of healthy siblings group (Essig et al., 2014). Of note, both of these large sibling studies from CCSS consisted of over 80% non-Hispanic White participants (Mody et al., 2008; Oeffinger et al., 2006) and only the study conducted among ALL survivors provided the percentage of Hispanic children in the sample (6.5%) (Mody et al., 2008). Research on late effects has consisted predominantly of non-Hispanic White survivors and had little Hispanic representation (Armstrong et al., 2016; Essig et al., 2014), leaving a gap in understanding health among Hispanic survivors.

Health-Related Quality of Life in Childhood Cancer Survivors

Quality of life (QoL) is defined “as an individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns” (World Health Organization, 2018). When discussing health, a more accurate measure would be one that focuses on HRQOL defined as “ an individual’s or group’s perceived physical and mental health over time” (Center for Disease Control and Prevention, 2018). In this section, QoL and HRQOL will be used interchangeably depending on how the individual study discussed uses it (McDougall & Tsonis, 2009). Research on the effect of childhood cancer treatment on HRQOL has resulted in inconsistent findings (Kanellopoulos et al., 2013; McDougall & Tsonis, 2009). Among the possible reasons for varying findings are differences in the characteristics of the participants, differences in cancer diagnosis, use of different measures, and unclear definitions for HRQOL and QoL which are often used interchangeably in the literature (Kanellopoulos et al., 2013; McDougall & Tsonis, 2009; Shin et al., 2019). Some studies did not find differences when comparing the HRQOL of childhood cancer survivors with the general population (Nayiager, Anderson, Cranston, Athale, & Barr, 2017) and some have found significantly lower HRQOL among survivors (Kanellopoulos et al., 2013).

In a study exploring HRQOL among childhood cancer survivors, mixed results were found when comparing HRQOL among survivors, siblings of survivors, and the general population. This was a large study that consisted of 7,147 survivors between the ages of 18 and 45 years old and with varying types of cancer (Zeltzer et al., 2008). Survivors and their siblings scored better on the mental health domains of HRQOL than the general population but survivors scored worse on physical domains except for pain (Zeltzer et al., 2008). Lower HRQOL scores were associated with the following variables: female gender; unemployment; <$20,000 annual income; and lack of health insurance. Worst HRQOL was also associated with older age and less education (Zeltzer et al., 2008). A sub-analysis based on race and ethnicity and identified disparities among survivors. Hispanic participants (3.7% of the sample) had a higher risk of having low scores in the areas of physical and social functioning when compared to the non-Hispanic Whites (Zeltzer et al., 2008). The small number of Hispanic participants limits how much one can generalize findings to the Hispanic community and demonstrates the difficulty in understanding the unique concerns of this population.

A systematic review of thirteen studies between 2001-2008 that discussed HRQOL in survivors of childhood cancers was published by McDougal and Tsonis (2009) and sheds light on the overall state of the science. Their review concluded that despite varying findings in the studies, survivors reported high levels of HRQOL except in the area of physical health (McDougall & Tsonis, 2009). However, this finding should be taken with caution because most studies relied on self-reports and that some survivors may have exaggerated the positive answers (McDougall & Tsonis, 2009). The findings also showed that when parent-proxy reports were used, the scores were much lower compared to the self-perceived HRQOL of the child (McDougall & Tsonis, 2009). It is possible that the survivors may have a positive outlook because of the obstacles they have already overcome (McDougall & Tsonis, 2009). Nevertheless, drawing generalizable conclusions is difficult since many of the studies looked at multiple cancers, ages, groups of survivors, and geographic location of where the studies were conducted (e.g., U.S., Canada, Austria, Belgium, and the Netherlands) (McDougall & Tsonis, 2009). In addition, a total of 20 different instruments were used to measure HRQOL (McDougall & Tsonis, 2009). Future studies should use of homogenous subgroups of the population, validated tools, multiple sources of data (parent-proxy and child), and inclusion of qualitative components in order to provide data to support the development of interventions (McDougall & Tsonis, 2009).

Adding to the work of McDougall & Tsonis (2009) is a recent integrative literature review that looked specifically at childhood cancer survivors who were diagnosed as adolescents and examined predictive factors for HRQOL in this population (Shin, Bartlett, and De Gagne, 2019). A total of 15 studies were included in this review and the majority demonstrated no difference between HRQOL in survivors and healthy controls. The exception was three studies with results showing survivors had higher psychological HRQOL scores. Further echoing what was found in the previous review, the identified risk factors for poor HRQOL were the type of cancer (CNS and bone cancers) and specific patient demographics (income <$20,000, no education past high school, female gender). Interestingly, in addition to demographic and clinical factors (e.g., older age, longer time since diagnoses), higher HRQOL was associated with subjective feelings such as happiness, strong self-esteem, and optimism. Physical symptoms were also shown to be reduced when survivors had high levels of optimism. Lastly, social support was associated with better HRQOL (Shin et al., 2019).

Positive Outcomes Related to the Cancer Experience

Highlighting the strengths of childhood cancer survivors as part of the assessment of HRQOL represents a recent shift in pediatric cancer survivorship research (Arpawong et al., 2013; Shin et al., 2019; Zebrack et al., 2012). Research demonstrates that a positive outlook on the experience of having had and survived cancer has the ability to shield survivors from negative psychological outcomes and lower HRQOL (Parry & Chesler, 2005; Shin et al., 2019). The PTG theory has emerged as one way to capture this part of the survivorship experience and consists of "a stronger sense of self and values, increased psychological maturity and empathy, improved interpersonal relationships, more engagement in activities, a greater sense of purpose, and greater planning for the future" (Arpawong et al., 2013, p. 2235). As the definition demonstrates, this umbrella term captures the concepts of satisfaction, resilience, and achievement that are the primary outcomes of this study.

In order to achieve PTG, cancer survivors must have a simultaneous realization of their weaknesses, an increased belief in their strengths, and find purpose in their lives and relationships with others (Arpawong et al., 2013; Tedeschi, Calhoun, & Gullickson, 1997). This list of tasks to achieve before gaining growth from illness is long and complex, yet numerous studies have demonstrated the ability of survivors to do so (Arpawong et al., 2013; Tedeschi et al., 1997). Bellizzi et al.'s (2012) seminal study on adolescent and young adult survivors of childhood cancer was the first multisite study to explore positive health outcomes in survivorship along with negative late effects. Survivors who were diagnosed in three different age ranges were included in the study in order to compare how their growth and development affected positive and negative outcomes. The age groups at diagnosis were 15-20 years old, 21-29 years old, and 30-39 years old. Among the positive health outcomes reported in all three age groups were positive outcomes related to the strength of their relationships, future plans/goals, and health competence or ability to take care of their own health. The relationships that saw improvements including those with mothers, fathers, siblings, friends, and spouses all dependent on their age group. When it came to making plans for the future, 46% saw a positive impact as a result of their cancer diagnosis (Bellizi et al., 2012).

Arpawong and colleagues (2013) also reported positive outcomes after the completion of cancer treatment. In their study, the majority of children reported PTG within six months of completing treatment. Of the 102 participants, 68-74% had PTG in the areas of changed sense of self and how they viewed their relationships, while only 4%-15% stated they had negative changes. When examining racial/ethnic differences, no differences in PTG were found between non-Hispanic White, Hispanic and other races/ethnicities, however, scores were lower for Hispanic survivors who spoke English at home when compared with those who did not (Arpawong et al., 2013). Survivors' positive attitudes have also been compared with healthy controls. In a study comparing perceived positive impact (PPI) -- defined as how much an individual makes the life changing event part of how they define themselves and view the world -- among 6,425 childhood cancer survivors with healthy siblings, scores were higher for survivors when compared to healthy siblings even after adjusting for age, gender and race (Zebrack et al., 2012). Survivors who identified as non-White were more likely to report PPI when compared to their counterparts.

Two literature reviews exist that summarize findings on positive outcomes after experiencing childhood cancer. The first examined studies published between 1990-2005 and explored the impact of a childhood cancer diagnoses and treatment on life values, relation to others, and relation to self (Mattsson, Lindgren, & Von Essen, 2008). Survivors described positive outcomes in all three categories including increased gratitude for life; a reduction in worrying; an increased want to help others; improved relationships with family and friends; increased confidence; and an overall feeling that they were somehow better individuals for having survived cancer. When survivors were compared to a control group, most studies reported little difference when it came to interactions with others and to oneself. However, some studies found that survivors struggled with friendships, marriage, and concerns about fertility as a result of their previous cancer. This consequently led to dissatisfaction with this aspect of their lives (Mattsson et al., 2008). This study was the first to outline information on positive outcomes of having survived cancer and as a result, a call was made for longitudinal studies that explore positive outcomes in more homogenous groups (same diagnosis, age at diagnosis, time since diagnosis) and with the same tools given the heterogeneity of identified studies and consequent inability to generalize findings (Mattsson et al., 2008).

The second review examined both the experiences of the survivor and family members with cancer (Duran, 2013). Although there was some overlap with the previous review (Mattsson et al., 2008), data continued to show that childhood cancer survivors had positive health outcomes after their cancer diagnosis and treatment. The following themes were identified: "making sense of the cancer experience; appreciation for life; greater self-knowledge; positive attitudes toward family and a desire to pay back to society" (Duran, 2013, p. 183). All of these studies have laid a foundation for future research to focus on more specific groups of survivors in order to create appropriate interventions.

Race and ethnicity play a role in survivors' perspective on health and life during survivorship (Arpawong et al., 2013; Casillas, Zebrack, & Zeltzer, 2006; F. Phillips & Jones, 2014). Existing information regarding the experience of Hispanic childhood cancer survivors is inadequate and makes it difficult to provide care that is culturally appropriate. A person's culture has been shown to influence how they view themselves and others, as well as how they direct their actions and decision-making processes (Munet-Vilaró, 2004). One of the first studies to address the meaning of survivorship in Hispanic childhood cancer survivors consisted of nine interviews with survivors between the ages of 14-21 years old (Jones et al., 2010). Hispanic adolescent survivors discussed how grateful they were for family and healthcare providers who provided support during their illness, as well as an appreciation for life. There was also a focus on humor, which one participant thought was unique to how Hispanics dealt with adversity and the need to have a positive attitude. Adolescents felt that cancer had happened to them for a reason, a fatalistic outlook often seen in Hispanic culture (Munet-Vilaró, 2004). Some cited that school was now important and they had stopped dangerous behaviors they were involved with before their cancer diagnosis. Lastly, faith in God and relationships with family members were strengthened as a result of their diagnosis. These positive outcomes emphasize Hispanic childhood cancer survivor's ability to reflect on their experience in a way that encouraged growth and personal and professional success in the future (Jones et al., 2010).

Phillips and Jones' (2014) qualitative work on Hispanic childhood cancer survivors also revealed how Hispanic survivors process their experience and draw meaning from it. After in-depth interviews with 14 Hispanic childhood survivors, the following four themes were identified: borrowed strength of family and hospital staff, sustained positive attitude, perceived vulnerability and being branded a cancer survivor. As might be expected given the cultural emphasis on family, Hispanic survivors saw their family, not just as support but also a source of continual strength both during treatments and survivorship. Family is such a focus in the Hispanic community that healthcare professionals who provided compassionate care were valued as family members, and those relationships endured into survivorship. Hispanic survivors believed that the positive attitudes that helped them through the painful treatments and uncertainty, continued in the survivorship period. This positive attitude emerged into having a unique perspective that they could endure any challenge successfully and consequently this contributed to increased self-confidence. Lastly, a positive perspective can also be seen in the theme of "branded as a survivor." While survivors did not want cancer to be the only way they were defined, they accepted cancer as a part of their past that helped to build the strong individual they now were. What is known about the positive outcomes of surviving childhood cancer in the Hispanic community is extremely limited (F. Phillips & Jones, 2014) and consists of mostly qualitative work. The information provided by these two qualitative studies are the first steps to designing more studies and developing culturally competent interventions, but additional studies are warranted.

Gaps in HRQOL Research: Satisfaction, Resilience, and Achievement

To fully understand a complex concept such as HRQOL in childhood cancer survivors it is necessary to break it down into smaller constructs that can be measured. Satisfaction, resilience, and achievement are three such areas that provide important information about how survivors view their well-being post-treatment completion and a way to measure PTG. Weinstein and colleagues (2018) measured satisfaction and PTG in over 2000 long-term childhood cancer survivors and explored their relationships with health outcomes later in life. Satisfaction was defined as the stable way that a person perceives his/her life; this should not be equated with how an individual is feeling about his/her life on a certain day (e.g. happy, angry) (Levin & Currie, 2014). This longitudinal study included data from childhood cancer survivors collected between the ages of 12-17 years old (adolescence), 19-24 years old (young adulthood), and 23-28 years old (adulthood) and was the first of its kind because it sought to explore causality and not just associations between variables (Weinstein et al., 2018). A total of 2,802 participants were included in this study. Findings showed positive satisfaction and good mental health in childhood cancer survivors. Higher levels of satisfaction during young adulthood was associated with better social skills during adolescence and better social skills led to stronger relationships with others which consequently helped survivors have a sense of purpose within society. At their last data collection point in adulthood, survivors exhibited positive outlooks related to their health, including pain, and less mental health issues. Satisfaction was not predictive of chronic illness; however, satisfaction with one’s life influenced how survivors perceived their health including pain. High satisfaction was also associated with better mental health. Lastly, PTG was found in those participants with worse health at baseline. This demonstrates that PTG exists when there is a realization of one’s vulnerability and growth occur from a realistic assessment of one’s health in the context of an illness. Like most research conducted in pediatric patients with cancer, the sample in this study was 81% non-Hispanic Whites and only 3% Hispanics. Previous work on satisfaction has shown different results with childhood cancer survivors having lower satisfaction than healthy comparison groups (Seitz et al., 2011) demonstrating that more work is needed in this field, particularly with exploring trends in racial/ethnic minorities.

The current study also focused on resilience as a factor associated with PTG. Resilience-- defined as consisting of both the lack of maladjustment to a traumatic event and the ability to seek positive actions to adjust to the situation-- creates a balance that does not allow the traumatic event to affect a person's daily life (Castellano-Tejedor et al., 2014). There has been reported difficulty in defining resilience (Aburn, Gott, & Hoare, 2016) and consequently resilience is often used interchangeably with HRQOL and PTG but it is important that it is explored as an independent concept. This is necessary to identifying what makes it possible to achieve resilience after a traumatic event. The factors that lead some people to be resilient and some to have other outcomes after a traumatic event are not clear, but in childhood cancer survivors, family and friends seem to provide patients the ability to adjust to difficult situations (Howard Sharp et al., 2015; Orbuch, Parry, Chesler, Fritz, & Repetto, 2005). This is consistent with research showing resilience has been linked to feeling connected with family and friends in this population (Howard Sharp et al., 2015; Orbuch et al., 2005). In a study by Howard Sharp et al. (2015), connectedness was defined as a relationship where the child with cancer felt they were also contributing to the relationship and not just taking from it. This study consisted of 71.2% White and 1.3 % Hispanic participants. Overall, there is a lot of confusion regarding the definition of resilience, and therefore, measuring the concept has also been a problem. However, social support appears to be a main pathway towards resilience. To the best of our knowledge, no studies exist that study resiliency in Hispanic childhood cancer survivors exclusively.

In a recent systematic literature review exploring the socioeconomic status of childhood cancer survivors, findings related to educational and employment achievements were outlined (Frederiksen et al., 2019). A total of 52 studies with comparison groups, written in English, Danish, Finnish, French, German, Norwegian, or Swedish and published between 2000-2017 were included in the review. Mixed findings were found when examining whether survivors were more likely to repeat a grade when compared to a healthy group or with siblings. However, most studies did find that survivors did not do as well in terms of grades when compared to the healthy groups and siblings, and they had lower overall school attainment. Findings were also mixed for being employed vs. unemployed and for the type of work a survivor is likely to have (managerial vs. professional). Lastly, most studies did show lower income in childhood cancer survivors when compared to healthy groups or siblings. Those childhood cancer survivors who had brain tumors, CNS cancers or leukemia that required cranial radiation therapy had worst outcomes in all of these areas when compared to the healthy groups or siblings. In another study looking at job turnover, 30% of participants reported intent to leave their job and cited discrimination due to their cancer diagnosis/treatment as the reason (Crom et al., 2018). A gap exists in the literature regarding achievement, both scholastically and professionally among Hispanic childhood cancer survivors. In Frederiksen et al.'s (2019) review, two of the U.S. studies reported participants were > 91% White (Crom et al., 2007; Pui et al., 2003), one reported they were 84.7% White (Ness et al., 2005), and one failed to provide participant demographics (Ottaviani, Robert, Huh, Palla, & Jaffe, 2013)

Chapter Summary

Childhood cancer survivors represent a growing population (Ward et al., 2014) that as a result of the late effects of their treatments may face negative health outcomes (Galligan, 2017). A recent shift in HRQOL research has been to explore the positive outcomes childhood cancer survivors may have after surviving cancer (Shin et al., 2019; Zebrack et al., 2012). These outcomes are often referred to as PTG and have been shown to protect survivors from negative psychological consequences (Arpawong et al., 2013). Satisfaction, resilience, and achievement have been used to measure positive outcomes in childhood cancer survivors but the research is limited (Frederiksen et al., 2019; Howard Sharp et al., 2015; Seitz et al., 2011). Overall, survivors report experiencing positive outcomes (e.g. better relationships, meaning in life) after cancer (Duran, 2013) and further exploration is warranted. Gaps exist in research exploring differences in positive outcomes for Hispanic childhood cancer survivors (Jones et al., 2010).

Chapter 3: Conceptual Framework

Chapter Introduction

This chapter describes the conceptual framework used to guide this study. Specifically, it depicts how in this study satisfaction, resilience, and achievement are used as measures for post-traumatic growth (PTG), which can contribute to positive health-related quality of life (HRQOL). The organismic theory of growth is used to explain the coping processes needed to get from a traumatic event to a positive outcome such as PTG.

Conceptual Framework

The purpose of this study is to compare satisfaction, resilience, and achievement scores between Hispanic and non-Hispanic-White childhood cancer survivors. In this study, these three outcomes are used to measure PTG and provide a different perspective on HRQOL-- defined as "an individual's or group's perceived physical and mental health over time" (Center for Disease Control and Prevention, 2018)-- than has been seen in the existing survivorship literature. The majority of existing HRQOL literature on childhood cancer survivors has concentrated on the physical and psychological problems faced by this population, however, research that accounts for survivors' strengths represents a new focus of attention (Arpawong et al., 2013; Shin et al., 2019; Zebrack et al., 2012). Post-traumatic growth is one way to capture that strength and it consists of having "a stronger sense of self and values, increased psychological maturity and empathy, improved interpersonal relationships, more engagement in activities, a greater sense of purpose, and greater planning for the future" (Arpawong et al., 2013, p. 2235). There is a positive association between PTG and lower levels of depression and improved well-being, (Helgeson, Reynolds, & Tomich, 2006), all of which can contribute to better HRQOL. This relationship between PTG and HRQOL creates a possible pathway to creating interventions that improve the lives of survivors.

Figure 1 illustrates that positive HRQOL in childhood cancer survivors can be influenced by PTG. In this study, PTG is measured through satisfaction, resilience, and achievement in the survivorship period. These outcomes are influenced by coping mechanisms that come after the traumatic event of having cancer as a child. As explained in the organismic theory, coping results from being able to readjust goals and needs to fit a new post-trauma reality (Joseph & Linley, 2005). The ability to readjust or cope is influenced by the experiences and opportunities one has prior to a cancer diagnosis (the traumatic event) and the experiences and opportunities one has after entering into the survivorship period (Joseph & Linley, 2005). For this study we refer to these experiences and opportunities as *pre- and post- cancer resources* because resources (i.e. financial resources, social resources, etc.) are what allows for experiences and opportunities. We have placed coping in the middle circle because it is the link between trauma and growth, and consequently positive HRQOL.

Our study suggests that satisfaction, resilience, and achievement are interrelated as positive outcomes that tell a story of strength in childhood cancer survivors. Satisfaction is defined as how a person perceives their life, looking for an overall stable perception and not a feeling that could change on a daily basis (Levin & Currie, 2014). The Child Health and Illness Profile-Adolescent Edition (CHIP-AE), measures satisfaction by asking questions about satisfaction with health (e.g. general health rating) and self-esteem (Starfield et al., 1995). The CHIP-AE measures resilience by examining behaviors that could influence health either negatively or positively (e.g. physical activities, social health, home safety and health, and family involvement) (Starfield et al., 1995). Resiliency is more difficult to define than the other outcomes since it is often used interchangeable with post-traumatic growth (Aburn et al., 2016; Castellano-Tejedor et al., 2014). It is for this reason that the questions in the CHIP-AE measure many aspects of an adolescent's life. An integrative review of how resilience is defined in health literature showed more than one definition and provided the following five themes associated with the word: "rising above to overcome adversity, adaptation, and adjustment, 'ordinary magic' [strength possessed by ordinary people], good mental health as a proxy for resilience and the ability to bounce back" (Aburn et al., 2016, p. 991). The most fitting definition for this study is a state consisting of both the lack of maladjustment to a traumatic event and the ability to seek positive actions to adjust to the situation, thus creating a balance that does not allow the traumatic event to affect a person's daily life (Castellano-Tejedor et al., 2014). Lastly, achievement has been defined in survivorship studies in relation to school performance (Bonneau et al., 2011; Lorenzi et al., 2009) and/or work performance (Crom et al., 2018). The CHIP-AE contains both school and work questions for this domain (Starfield et al., 1995).

The coping mechanisms that lead to PTG are best described using the organismic theory, a name that reflects human beings' desire to take an "active role in their growth" (Joseph & Linley, 2005, p. 269). This theory provides explanations for why childhood cancer survivors may differ in their reactions to the traumatic events surrounding cancer (e.g. experience growth, no change, or a negative psychological outcome). The organismic theory states that each person has a *valuing process* which is "an innate ability to know what is important to them, their own best directions in life that will lead them toward greater well-being and a more fulfilling existence" (Joseph & Linley, 2005, p. 271). By achieving those goals set by the valuing process one can reach psychological well-being, also known as becoming an *authentic* person. However, when an individual's ability to achieve those goals is no longer possible as a result of trauma, coping requires readjustment. Growth occurs when an individual is able to rearrange his/her valuing system based on his/her new condition after the traumatic event. An authentic person has a realistic understanding of how their needs, values, and goals may need to change to accommodate life after trauma. Unfortunately, one's ability to readjust is based on factors not always under ones' control. Among the factors affecting the ability to readjust, is having already had experiences and opportunities that led that individual to becoming an authentic person. Individuals who have had success in this are more likely to be resilient when given a challenging situation. Those who have never been able to reach this authenticity may struggle with coping after trauma. Lastly, having resources that promote autonomy, competence, and relatedness after a traumatic event will help the individual with coping post-trauma (Joseph & Linley, 2005).

Chapter Summary

This study uses a conceptual framework that identifies satisfaction, resilience, and achievement as helping to operationalize PTG. It is this growth that leads to higher levels of HRQOL. The organismic theory is used to explain the mechanism through which coping can occur. Factors that affect coping and consequently growth after the trauma of cancer include the individual's experiences and opportunities before and after cancer (pre- and post- cancer resources).

Figure 1 Conceptual Framework: Achieving Positive HRQOL After Surviving Childhood Cancer

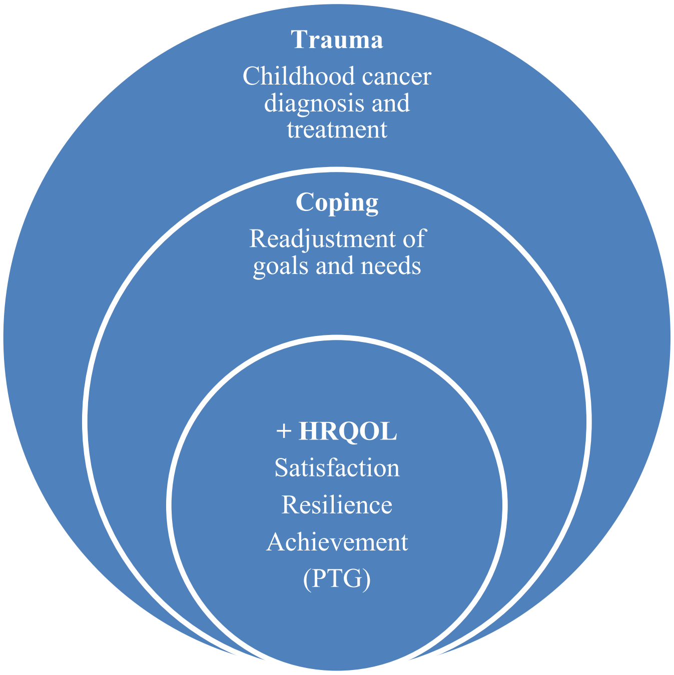

Figure1. This illustration demonstrates the influence of post-traumatic growth (PTG) on positive health-related quality of life (HRQOL) among childhood cancer survivors. PTG is operationalized in this study with satisfaction, resilience, and achievement. Following the organismic theory, coping and consequently PTG occur by successfully readjusting goals and needs to fit a post-cancer reality after a traumatic event such as being diagnosed with cancer (Joseph & Linley, 2005).

Chapter 4: Methodology

Chapter Introduction

This chapter describes the methodology for this study. Included are details about the study design, sample population, inclusion/ exclusion criteria, and recruitment process. We also include a description of data collection measures and procedures and data analyses.

Methods

Study Design:

This was a cross-sectional, exploratory study designed to compare satisfaction, resilience, and achievement between Hispanic and non-Hispanic White childhood cancer survivors. The current study was based on a secondary analysis of data for a larger study of health behaviors in adolescent Hispanic and non-Hispanic White survivors (Ruiz, Sender, Torno, & Fortier, 2016). Ruiz, Sender, Torno, and Fortier (2016) explored associations between age and ethnicity of adolescent and young adult childhood cancer survivors and cigarette smoking, marijuana use, and alcohol consumption. This current study explores adaptive outcomes.

Sample:

Study participants were recruited from CHOC Children's Hospital of Orange County, a 334-bed children's hospital affiliated with the University of California, Irvine (CHOC Children's Hospital of Orange County, 2018). CHOC is located in Orange County and serves a wide range of racial/ethnic groups; recent statistics show that 34.2 % of the children Orange County are Hispanic and 40.5% are non-Hispanic White (United States Census Bureau, n.d.). Participants were recruited from a cancer registry list; potential participants were contacted by mail and telephone or during in-person visits to the CHOC Children's Hospital after Cancer Treatment Survivorship Program.

Inclusion criteria included the following: 1) ≥ 12 years of age; 2) diagnosed with cancer between the ages of five and 18 years old; 3) diagnosed between the years of 1990 and 2010; 4) completed treatment at least two years ago or five years from time of diagnosis and off therapy; 5) identify as Hispanic or non-Hispanic White; and 6) ability to speak and write English or Spanish. Exclusion criteria included the inability to read or write, developmental delays, and the inability to complete the survey without assistance. A total of 555 patients on the CHOC Children's Hospital cancer registry list were eligible for the initial study but only 209 were successfully contacted. Of these 209, 32 did not complete the enrollment process, nine declined to enroll, and 12 had developmental delays that made them ineligible. In total, 156 enrolled in the study (75% recruitment rate) but only 116 completed the survey (73% retention rate).

Data collection

Procedures:

The first step of the study protocol was to mail a letter with the study information sheet that explained the purpose of the study as well as the informed consent form. Two weeks after receiving the information, participants received a telephone call from a research assistant to invite them to participate in the study. Participants were also approached about participating in the study while in the survivorship clinic. Of the 116 that enrolled and completed the survey, 50 were recruited in person while at their survivorship clinic appointments and 66 were recruited from the mailings and telephone calls. Those who agreed to participate completed the online survey in-person (43%) during a visit to the survivorship clinic using a tablet that was provided to them or at home (57%) using an online link provided to the participant via email. All participants completed the survey without assistance. Cancer diagnosis information was abstracted from the CHOC medical records. A $20 Target gift card was provided as a token of appreciation for participants' study completion. This study was approved by the Institutional Review Boards (IRB) of CHOC Children's Hospital and the University of California, Irvine. This study qualified for HIPAA and informed consent waivers due to minimal risks.

Measures:

The Child Health and Illness Profile: Adolescent Edition (CHIP-AE) is a health assessment for adolescents based on self-report; the instrument is written at a fifth-grade level and takes approximately 20-30 minutes to complete (Starfield et al., 1995). Questions in this measure are broad and intended to comprehensively measure health in diverse (ethnically, sociodemographic, etc.) groups of adolescents. In order to capture the physical, psychosocial and social definitions of health, questions were categorized into the following six domains: satisfaction, discomfort, resilience, risks, disorders, and achievement (Starfield et al., 1995). For the purpose of this study, only satisfaction, resilience, achievement domains will be analyzed, along with one mental health question from the disorders domain were analyzed.

The satisfaction domain consists of two subdomains; satisfaction with his/her health and self-esteem (Starfield et al., 1995). The resilience domain focuses on activities or situations that can negatively or positively affect future health and included questions within the following subdomains: physical activity, social problem-solving, home safety and health, and family involvement. Lastly, the achievement domain was broken down into school and work performance subdomains. Answers were scored on a scale from 1-5; higher domain scores represented higher HRQOL in that domain (Starfield et al., 1995). Reliability of this measure was strong when tested in different populations of adolescents. Cronbach's alpha for the majority of subdomains that were single-construct scales was at least 0.70 (criterion set at 0.70) in two or more of the four populations where it was tested. Content validity was assessed using focus groups of diverse groups of children, parents and healthcare professionals. This measure is intended for children and adolescents ages 11-17 years old (Starfield et al., 1995), however, it has previously been used in older adolescents and young adults survivor (Klosky et al., 2014).

Data Analysis:

Descriptive statistics were calculated for participants' age (years), age at diagnosis (years), time since diagnosis (years), gender, years of schooling, income, prior mental health or behavioral problems, type of cancer and leukemia diagnosis. Dummy variables were created for household income, presence of mental health problems and leukemia diagnosis. Participants with household incomes of $24,999 or less were classified as being below the poverty line based on the U.S. Department of Health & Human Services Poverty Guideline of $25,750 for a family of four (United States Department of Health & Human Services, 2019). The CHIP-AE Disorder domain was dummy coded into either never having had a problem or having had a problem at some point in their life. A diagnosis of leukemia was also dummy coded to having leukemia vs. having another type of cancer. This was done because leukemia is the most common type of cancer in children (Leukemia & Lymphoma Society, 2018) and represented the largest number of cases in this data set. The comparisons (i.e., sociodemographic, clinical factors, HRQOL domains) between Hispanic (n = 55) and non-Hispanic Whites (n = 61) were conducted using t-test or chi-square, depending on levels of measurement. Associations were examined using Pearson moment or Spearman rho correlations. All data were analyzed using SPSS software (25th edition) (IBM Corp, 2017).

Chapter Summary

This study used a cross-sectional, exploratory design to compare satisfaction, resilience, and achievement between Hispanic and non-Hispanic White childhood cancer survivors.

Participants were recruited from CHOC Children's Hospital of Orange County using mailings followed by telephone calls or in-person during survivorship clinic visits. A total of 116 survivors completed the survey. The CHIP-AE tool was used in this study and data was analyzed using SPSS software (25th edition).

Chapter 5: Results

Chapter Introduction

This chapter provides the study findings. Sociodemographic and clinical comparisons between Hispanic and non-Hispanic White survivors including age (years), age at diagnosis (years), time since diagnosis (years), gender, years of schooling, income, prior mental health or behavioral problems, and type of cancer diagnosis are presented. Mean comparisons between Hispanic and non-Hispanic White childhood cancer survivors are also provided for satisfaction, resilience, and achievement. Lastly, associations between sociodemographic, clinical characteristics and the domains of interest (satisfaction, resilience, and achievement) are discussed.

Data Analyses

Table 1 provides descriptive statistics for participant demographics. There was a total of 116 participants with 61 non-Hispanic White and 55 Hispanic survivors. The average age of participants was 19.0 ± 4.2 years and the average age at the time of cancer diagnosis was 10.0 ± 3.9 years. Non-Hispanic White survivors were more likely to be older than their Hispanic counterparts ($p = 0.18$). The average amount of time since diagnosed with cancer was 9.0 ± 3.7 years. There were 47 men and 69 women, with no difference noted in gender distribution between non-Hispanic White and Hispanic survivors. No difference was found between the two groups and years of schooling, with an average of 11.9 ± 3.1 years ($p = 0.91$). Hispanic childhood cancer survivors reported having a household income below the poverty line ($p = 0.00$). Non-Hispanic White survivors reported being told by a doctor that they had an emotional/mental problem or behavioral problem ($p = 0.5$). Lastly, Hispanic survivors were more likely to have leukemia ($p = 0.01$).

Comparisons between satisfaction, resilience, and achievement domains are summarized in Table 2. No significant difference was found for the satisfaction domain between non-Hispanic White and Hispanic survivors (*p* = 0.95). However, scores were significantly lower for Hispanic survivors than White survivors in the domains of resilience (*p* = 0.003) and achievement (*p* = 0.005).

Table 3 provides a correlation matrix of the key variables (e.g., sociodemographic, clinical characteristics and the domains of interest [satisfaction, resilience, and achievement]). Ethnicity was negatively associated with both resilience (*p* <0.01) and achievement (*p* <0.01). There were also associations between ethnicity and income below the poverty line and leukemia diagnosis. Achievement was also associated with years of schooling (*p* <0.01). Lastly, resilience was positively associated with both satisfaction (*p* <0.01) and achievement (*p*<0.01).

Chapter Summary

The data analyses demonstrate similar findings between Hispanic and non-Hispanic White participants for age (years), age at diagnosis (years), time since diagnosis (years), gender, years of schooling, and prior mental health or behavioral problems. Only income and type of cancer diagnosis were noted to be different. Mean satisfaction was noted to be similar between the two groups, however, resilience and achievement mean differed. Correlations were noted between Hispanic ethnicity and income, as well as leukemia diagnosis.

Table 1

Demographic Information

Characteristics	Combined *N= 116* (100%)	Non-Hispanic White *n= 61* (52.6%)	Hispanic *n= 55* (47.4%)	P value
Age, years				
Mean ± SD	19.0 ± 4.2	19.5 ± 4.6	18.5 ± 3.5	0.18
Age at diagnosis, years				
Mean ± SD	10.0 ± 3.9	10.1 ± 4.0	10.0 ± 3.8	0.8
Time since diagnosis, years				
Mean ± SD	9.0 ± 3.7	9.5 ± 3.9	8.4 ± 3.3	0.12
Gender				
Male	47(40.5%)	25(53.2%)	22(46.8%)	0.91
Years of schooling				
Mean ± SD	11.9 ± 3.1	12.2 ± 3.3	11.5 ± 3.0	0.29
Income				
Below poverty line	22(19.0%)	5(8.2%)	17(30.9%)	0.00
Above poverty line	63(54.3%)	42(68.9%)	21(38.2%)	
Missing	31(26.7%)	14(23.0%)	17(30.9%)	
Prior mental health or behavioral problems				
Positive	15(12.9%)	9(14.8%)	6(10.9%)	0.5
Negative	100(86.2%)	51(83.6%)	49(89.1%)	
Missing	1(0.9%)	1(1.6%)	0(0%)	
Type of cancer				0.04
Leukemia	41(35.3%)	15(24.6%)	26(47.3%)	
Lymphoma	24(20.7%)	16(26.2%)	8 (14.5%)	
*CNS tumor	18(15.5%)	13(21.3%)	5(9.1%)	
Bone Tumor	13(11.2%)	5(8.2%)	8(14.5%)	
Sarcoma	1(0.9%)	0(0%)	1(1.8%)	
Kidney tumor	2(1.7%)	2(3.3%)	0(0%)	
Neuroblastoma	2(1.7%)	2(3.3%)	0(0%)	
Other cancer	15(12.9%)	8(13.1%)	7(12.7%)	

Note: *CNS= central nervous system

Table 2

Health-related Quality of Life Domain Means

Domain	Combined *N=116* (100%)	Non-Hispanic White *n= 61* (52.6%)	Hispanic *n=55* (47.4%)	95% CI	P value	Effect Size (Cohen's d)
Satisfaction	3.22 ± .54	3.22 ± .60	3.23 ± .47	-0.19 to 0.21	0.95	0.02
Resilience	3.20 ± .42	3.32 ± .41	3.08 ± .41	-0.39 to -0.08	0.003	0.59
Achievement	2.15 ± .39	2.24 ± .38	2.04 ± .38	-0.34 to -0.06	0.005	0.53

Table 3

Key Variables Correlation Matrix (N=116)

Variable	1	2	3	4	5	6	7	8	9	10	11
1.Hispanic vs Non-Hispanic White											
2.Age, years	-0.08										
3.Age at diagnosis, years	-0.02	0.46**									
4.Time since diagnosis, years	-0.13	0.4**	-0.42**								
5.Gender	0.01	0.02	-0.01	0.02							
6.Years of Schooling	-0.12	0.83**	0.45**	0.22	0.04						
7.Income below the poverty line	0.39**	0.02	-0.05	0.04	0.04	-0.12					
8.Prior mental health or behavioral problems	-0.06	0.03	0.09	0.02	0.16	-0.03	-0.05				
9.Leukemia diagnosis	0.24*	-0.09	-0.3**	0.14	-0.09	-0.11	-0.12	-0.02			
10.Satisfaction	-0.04	-0.1	0.03	-0.02	-0.09	-0.11	-0.09	-0.13	0.09		
11.Resilience	-0.32**	0.09	-0.05	0.14	-0.00	0.18	-0.18	0.01	0.02	0.44**	
12.Achievement	- 0.29**	0.06	0.11	-0.03	0.15	0.3**	-0.22	-0.09	-0.15	-0.15	0.39**

*P <0.05, **P<0.01

Chapter 6: Discussion and Conclusion

Chapter Introduction

This chapter presents the findings of this study by outlining what they add to the literature on positive outcomes post cancer treatment and to our understanding of Hispanic survivors' experiences. Satisfaction, resilience, and achievement are used to measure post-traumatic growth (PTG), and consequently positive health-related quality of life (HRQOL). The organismic theory of growth after trauma is used to explain possible reasons for findings from this study. The clinical implications of the findings will also be addressed as well as the strengths and limitations of the study.

Discussion

Understanding the numerous ways that individuals can respond to traumatic events such as a cancer diagnosis in childhood and then surviving that cancer has not been an easy task. The increasing number of childhood cancer survivors that have resulted from breakthroughs in treatments (S. M. Phillips et al., 2015), however, have drawn attention to the need to do so. As a result of what may be researcher bias, survivorship literature examines mostly only the negative aspects of surviving cancer, such as the consequences of late effects (Aziz & Rowland, 2003). Another explanation for this negative perspective towards survivors is that researchers have followed a post-traumatic stress disorder (PTSD) model that views trauma only in the context of maladjustment (Joseph & Linley, 2005). It is just recently that the lens used to study childhood cancer survivors has broadened to try and identify outcomes that are marked by survivors' strengths (Arpawong et al., 2013; Shin et al., 2019; Zebrack et al., 2012). More specifically, there is a growing interest in a view that explores how traumatic events might be turned into PTG (Joseph & Linley, 2005). Findings from this study comparing satisfaction, resilience, and achievement between Hispanic and non-Hispanic White survivors contributes to the limited amount of research that aims to understand positive outcomes after a cancer diagnosis. It also adds to the limited research on Hispanic childhood cancer survivors. To our knowledge, no other studies were identified that explored the HRQOL concepts of satisfaction, resilience, and achievement as a combination of three positive outcomes that contribute to PTG. Likewise, there are no studies comparing these outcomes among Hispanics and non-Hispanic White childhood cancer survivors. For this reason, it is a significant contribution to the literature and a starting point for future exploration.

The data analyses showed no difference in the means for the satisfaction domain between Hispanic and non-Hispanic White survivors. Satisfaction was measured in the CHIP-AE by asking questions about satisfaction with personal health and self-esteem (Starfield et al., 1995). Finding no difference between the two groups supports previous work on PTG showing that belief in one's own strength and abilities (self-esteem) did not differ between Hispanic and non-Hispanic White survivors (Arpawong et al., 2013). Our findings support the idea that despite the inherent differences that culture may bring to the table (Munet-Vilaró, 2004), there may be a universal set of attitudes among survivors about what it means to be alive and the life perspective cancer provides. Previous survivorship studies demonstrate that childhood cancer survivors often compare current problems to having been diagnosed with cancer, thus making most problems seem less daunting (McDougall & Tsonis, 2009). Like findings from satisfaction studies with mostly non-Hispanic White survivors (Seitz et al., 2011; Weinstein et al., 2018), qualitative work in Hispanic childhood cancer survivors also demonstrates this special perspective and an appreciation for life (Casillas et al., 2006; Jones et al., 2010; F. Phillips & Jones, 2014). There are measurable advantages to having a positive attitude about life. Studies show a positive attitude among survivors to be protective against negative psychological outcomes (e.g. anxiety and depression) and lower HRQOL (Parry & Chesler, 2005; Shin et al., 2019). Pain perception is also influenced by whether survivors have a positive outlook on life (Weinstein et al., 2018). Perhaps it is a defense mechanism or even a learned behavior to choose to focus on positive aspects in one's life and not the negative. This has been echoed in studies of Hispanic childhood cancer survivors (Jones et al., 2010; F. Phillips & Jones, 2014). As one Hispanic survivor stated, "Keeping positive is one of the keys to staying… to surviving" (F. Phillips & Jones, 2014, p. 43).

Differences in resilience were found between Hispanic and non-Hispanic White survivors. Resilience has been difficult to define and for this reason, measuring it has posed a problem (Castellano-Tejedor et al., 2014). The CHIP-AE contains very specific questions within four domains (physical activity, social problem solving, home safety and health, and family involvement) that clearly shows how resilience is operationalized (Starfield et al., 1995), making this an ideal tool to assess this construct. Resilience has been linked to PTG by its ability to improve relationships, specifically the feeling of being connected to others (Howard Sharp et al., 2015; Orbuch et al., 2005). The use of the organismic theory of growth (Joseph & Linley, 2005) provides one possible explanation for why Hispanic childhood cancer survivors find themselves with significantly lower levels of resilience in this study, despite having shown no difference in how they are doing in terms of life satisfaction. This theory explains that the ability to grow (e.g. be resilient) after a traumatic event, as opposed to having no change or having a negative change, has to do with one's ability to readjust goals and needs to fit the new reality. Readjustment is influenced by pre-treatment experience with having achieved goals and met needs, as well as with available support post-treatment (Joseph & Linley, 2005), described in this study as pre and post- cancer resources. Hispanic childhood cancer survivors may come from disadvantaged backgrounds, and even before their cancer trauma they may have had greater challenges in achieving their goals and meeting their needs. This study found that more Hispanic survivors were living below the poverty line when compared to non-Hispanic White survivors. Evidence exists that Hispanic children often have poorer socioeconomic and health outcomes than non-Hispanic White survivors (Langellier, Chen, Vargas-Bustamante, Inkelas, & Ortega, 2016; Terriquez, 2014). These previous disadvantages can prevent them from knowing how to readjust goals after a traumatic event, consequently leading to lower resilience. Although Hispanic childhood cancer survivors have reported high levels of support during and after treatment from family, friends, and healthcare providers (F. Phillips & Jones, 2014), it does not seem enough to undo pre-treatment shortcomings and lack of post-treatment resources.

The achievement domain examined a survivor's performance at school and work (if applicable) and findings showed a significant difference between the two ethnic/racial groups. Hispanic survivors had lower achievement domain means when compared to non-Hispanic White survivors. This study illustrates that although previous qualitative work and findings from this study demonstrates Hispanic survivors found meaning in their cancer experience and satisfaction with life (Jones et al., 2010; F. Phillips & Jones, 2014), it may not translate to traditional definitions of achievement on the CHIP-AE. It is important to consider that the CHIP-AE may have failed in some ways to accurately measure achievement in this sub-group of the population. There may be ways to measure achievement other than with school and work domains, but more studies are needed to explore this idea. In addition, disparities in quality of schools exist (Zambrana & Carter-Pokras, 2010) and may add to the factors influencing achievement among Hispanic survivors.

Variable correlations found in Table 3 demonstrated that ethnicity was positively associated with income below the poverty line and with a leukemia diagnosis. We know from findings in this study that there were more Hispanic children living with family incomes below the poverty line. This association between ethnicity and income may reveal some differences in available resources between the two groups. Finances may be one key pathway that cancer survivors have access to resources that promote positive outcomes after cancer. The positive association between ethnicity and acute lymphoblastic leukemia is supported by the higher number of Hispanic children diagnosed with this type of cancer in this study. Ethnicity was negatively associated with the resilience and achievement domains and this association is confirmed with the lower means found within these domains for the Hispanic survivors. Lastly, resilience and satisfaction, and achievement and resilience were positively associated. These constructs are used together in the CHIP-AE to measure HRQOL and therefore the association reflects their similar characteristics.

Strengths and Limitations

This study is innovative in three distinct ways. First, it adds to the limited data on positive health outcomes after having survived cancer and it does so with three different constructs of PTG (satisfaction, resilience, and achievement), thus painting a clearer picture of where the growth is occurring or lacking. Secondly, it adds quantitative data to our understanding of how Hispanic childhood cancer survivors function post-cancer treatment, specifically in finding growth from their cancer experience. Lastly, to the best of our knowledge, this was the first time the CHIP-AE tool was used to explore positive childhood cancer outcomes, specifically satisfaction, resilience, and achievement. Shin et al. (2019) explained in her literature review that previous survivor study participants have shown a tendency to overestimate positive outcomes, our study was able to catch differences between Hispanic and non-Hispanic childhood cancer survivors. This shows a potential for the CHIP-AE to serve as a useful tool in survivorship studies.

Limitations of this study include its cross-sectional design that did not allow for comparisons over time or the exploration of causal relationships. Also, data was only collected from survivors and there is the risk of bias related to self-report. Studies that include parent-proxy help to verify findings. In addition, looking at quantitative data alone fails to provide an understanding of why participants answer survey answers in a certain way. Future studies should be mixed-methods to gain greater insight into the survivorship experience. Lastly, participants were only recruited from one site and the average age of our participants was 19 years old (average time since diagnosis was 9 years), thus these results reflect a very specific group of patients and again the results are not generalizable to all survivors.

Implications for Clinical Practice and Future Research

One of the clinical implications of this study is that Hispanic childhood cancer survivors need additional support in their survivorship period to improve resilience and achievement outcomes. Resources to help Hispanic survivors meet their physical and psychological readjustment needs (resilience), as well as school and employment needs (achievement), will help to decrease disparities in PTG between Hispanic and non-Hispanic White survivors. In addition, interventions that encourage Hispanic survivors to find meaning in their experience may help in their ability to have PTG and consequently improve health outcomes. This may require additional training of medical providers as well as ensuring survivors have access to mental health services.

Identifying the best tool for measuring HRQOL in Hispanic childhood cancer survivors should be a focus of future research. The CHIP-AE is a broad measure that is intended for diverse groups but more studies of Hispanic survivors using this tool are needed to assess its appropriateness. Future studies should include qualitative studies that allow responses to surveys to be explained, thus providing a more accurate portrayal of survivors' satisfaction, resilience, and achievement. Lastly, future research should explore the coping mechanisms discussed in the conceptual framework that were outside the scope of this study. Comparing resources and support pre and post- cancer between Hispanic and non-Hispanic White survivors might shed light into reasons for differences in resilience and achievement between the two groups, eventually leading to clinical interventions to improve outcomes.

Conclusion

Differences exist in positive outcomes after cancer, as measured by satisfaction, resilience, and achievement, between Hispanic and non-Hispanic White childhood cancer survivors. Although Hispanic childhood cancer survivors are just as satisfied with their lives as non-Hispanic White survivors, differences were noted between the two groups with resilience and achievement domains. The lower outcomes in Hispanic survivors may be explained by a lack of resources that help with coping. In addition, there is always a challenge with identifying the best tool to use when measuring outcomes. The CHIP-AE shows a lot of promise with childhood cancer survivors but may pose some unintended biases when assessing Hispanic children.

Chapter Summary

This study found that the mean scores for satisfaction between Hispanic and non-Hispanic survivors were similar, however, resilience and achievement scores were lower. The organismic theory of growth helps to explain the differences as most likely the result of the availability of pre- and post- cancer resources. However, this study is the first of its kind in terms of comparing those three HRQOL outcomes between Hispanic and non-Hispanic White survivors and more studies are needed to understand differences in scores. Future research is also needed to identify the best tool to assess HRQOL in Hispanic childhood cancer survivors, keeping in mind how access to resources and culture might affect answers on surveys. Mixed methods studies with qualitative portions would help to gain a more complete understanding of perspective and meaning finding post-cancer int the Hispanic population.

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