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Life balance in adult healthy siblings of individuals with childhood cancer.

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LIFE BALANCE IN ADULT HEALTHY SIBLINGS OF INDIVIDUALS WITH
CHILDHOOD CANCER

By

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B.A., Kentucky State University, 2008
M.B.A., Colorado Tech University, 2009
M.Ed., University of Louisville, 2012

A Dissertation
Submitted to the Faculty of the
College of Education and Human Development
In Partial Fulfillment of the Requirements
For the Degree of

Doctor of Philosophy in Counseling and Personnel Services

Department of Counseling and Human Development
University of Louisville
Louisville, Kentucky

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A Dissertation Approved on

July 19, 2016

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DEDICATION

This dissertation is dedicated to my amazing little people, Ariel and Willow, and my husband Duran. Thank you for being so patient and understanding throughout this long process. I love you more than the all the stars in the sky and the water in the oceans and everything in between. Thank you all for making my life better times infinity.

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ABSTRACT

LIFE BALANCE IN ADULT HEALTHY SIBLINGS OF INDIVIDUALS WITH CHILDHOOD CANCER

Yolanda A. Williams

July 19, 2016

Siblings of children who were diagnosed with cancer in childhood experience significant stress and psychological difficulties as a result of the cancer. Furthermore, the needs of siblings have often been overlooked in the cancer literature, prompting the need for more studies. The purpose of this dissertation is to examine the life balance and social support outcomes of adults who grew up in the household with a sibling that was diagnosed with cancer. The study sample consisted of 120 adult healthy siblings who grew up in a household with a sibling that was diagnosed with cancer prior to age 19. Participants completed the Juhnke-Balkin Life Balance Inventory (JBLI), Medical Outcomes Study: Social Support Survey (MOS-SSS), and Multidimensional Scale of Perceived Social (MSPSS). Demographic information was also collected. Findings indicated that there is a significant difference in life balance outcomes for adult healthy siblings and the normal population. Contrary to expectations, whether or not the sibling died as a result of cancer did not influence life balance outcomes. The ten life balance subscales were significant predictors of both social support and perceived social support. Implications for counselors were provided, including the need for counselors in the cancer treatment settings. Suggestions for future research include longitudinal research

on the outcomes of healthy adult healthy siblings; identifying subgroups of healthy siblings that are at risk for adverse outcomes, as well as protective factors that can improve healthy sibling outcomes; and an exploration of the relationship between life balance, social support, and perceived social support.

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CHAPTER I

INTRODUCTION

Cancer is the leading cause of disease-related death for youth in the United States, with an estimated 15,780 individuals age 19 and under diagnosed with cancer in 2014 (National Cancer Institute, 2014). Almost 2,000 of those diagnosed in 2014 are expected to die from cancer (National Cancer Institute, 2014). The most common types of cancer diagnosed in children and adolescents are leukemia, brain and central nervous system tumors, lymphoma, rhabdomyosarcoma, neuroblastoma, Wilms tumor, bone cancer, and gonadal (testicular and ovarian) germ cell tumors (American Cancer Society, 2015a; National Cancer Institute, 2014). Leukemia accounts for nearly one-third of all childhood cancers (American Cancer Society, 2015a). Although overall cancer survival rates have significantly increased over the past 50 years, patients with different types of cancers have better outcomes and survival rates than others. For example, the five-year survival rate for children and adolescents with non-Hodgkin lymphoma is around 85% (National Cancer Institute, 2014). In contrast, less than 10% of children diagnosed with a type of brain tumor known as diffuse intrinsic pontine glioma survive two years post-diagnosis (International DIPG Registry, 2014). The experience of having a child in the family with cancer has profound consequences for the family: even in instances where the child has been cured of cancer, there appears to be a lingering negative effect on the family (Adams & Deveau, 1987).

Cancer patients and family members who experience a high level of distress and/or difficulty coping are often referred for mental health counseling to help them work through their challenges (American Society of Clinical Oncology, 2015). The integration of mental health professionals, such as counselors, into the cancer treatment setting is becoming more prevalent. The counselor's role is multifaceted and includes tasks such as offering support and education to the cancer patient and family, assisting them in finding community resources that they may need, helping them work through psychosocial problems, serving as an advocate for the cancer patient and their family, helping the family work through practical and logistical issues (e.g., transportation), and assessing and evaluating mental functioning (American Cancer Society, 2015b; CancerCare, 2015). Amid these many challenges, counselors often overlook healthy siblings and their needs. Healthy siblings may not seek out counseling for themselves until later in life, when their mental health challenges are much more severe.

Almost 80% of children grow up with at least one sibling (U.S. Census Bureau, 2015), suggesting that many children with cancer are likely to have a sibling. Researchers examining the mental health needs of families in which one child has been diagnosed with cancer have found that the emotional needs of siblings were less likely to be adequately addressed over the needs of other family members (Martin, 2000; Murray, 1998; Spinetta, 1981), leaving many siblings feeling alone and distressed during a time that is already stressful for the family. Though there is an abundance of literature that examines how having a child with cancer in the family influences the family unit, siblings are often overlooked in literature on effects of childhood cancer (Bally et al., 2014; Chesler & Barbarin, 1987; Coulson & Greenwood, 2012; Da Silva, Jacob, &

Nascimento, 2010; Davies, 1983; Eapen, Mabrouk, & Bin-Othman, 2008; Long & Marsland, 2011; Ljungman et al., 2014; Murray, 2000; Ozono et al., 2010; Rollins, 1990; Schweitzer, Griffiths, & Yates, 2012; Wakefield, McLoone, Evans, Ellis, & Cohn, 2014; Warner, Kirchhoff, Nam, & Fluchel, 2014; Williams, McCarthy, Eyles, & Drew, 2013).

Statement of the Problem

The majority of the research that exists on siblings of individuals with cancer is dated and limited in its scope (Bluebond-Langner, 1978; Evans, 1968; Madan-Swain, Sexson, Brown, & Ragab, 1993; Share, 1972; Slavin, O'Malley, Koocher, & Foster, 1982). Researchers who investigated the outcomes of individuals who had siblings that were diagnosed with cancer in childhood have primarily focused on short-term psychological outcomes in children and adolescents (e.g. Chesler, Allswede, & Barbarin, 1991; Gogan, Koocher, Foster, & O'Malley, 1977; Gogan & Slavin, 1981; Nolbris, Enskär, & Hellström, 2007; Sargent et al., 1995; Woodgate, 2006). Very little attention was on the long-term effects of childhood cancer on siblings or adults whose siblings had cancer during childhood. There is also very little to no literature that examines life balance in this population.

The literature that does exist on siblings of individuals who had childhood cancer is plagued with methodological issues; one of the most prevalent issues is small sample size. For example, Nolbris et al.'s (2007) study had ten participants, Prchal and Landolt's (2011) study had seven participants, and Murray's (1998) study had only one participant. Some researchers included siblings who have psychiatric conditions (Cain, Fast, & Erickson, 1964) or emphasized reactions to death (e.g. Cain et al., 1964; Gordon, 1974; Lindsay & MacCarthy, 1974), therefore limiting the generalizability of the results.

Research data were collected from secondary sources, such as parent and teacher reports (Birenbaum et al., 1989; Davies, 1983; Gerhardt et al., 2012; Lähdenmäki, Huostila, Hinkka, & Salmi, 2002), instead of collecting data from the siblings themselves. In other studies, siblings were used as the control group and were not the primary focus of the study (Larcombe, Mott, & Hunt, 2002; Tao, Julianne, Guo, & Robert, 1998; Zebrack et al., 2002; Zebrack et al., 2004; Zebrack et al., 2007). Among the researchers who did focus on siblings, several did not use a control group (e.g. Alderfer, Labay, & Kazak, 2003; Chesler et al., 1991; Davies, 1983; Houtzager, Grootenhuis, & Last, 2001; Kaplan, Kaal, Bradley, & Alderfer, 2013). Many of the studies appear to be missing important demographic information, specifically information on race/ethnicity, socioeconomic status, or education attainment.

Purpose of the Study

Healthy siblings of individuals with cancer are often overlooked in the literature; yet their sibling's cancer has a profound psychological effect on healthy siblings. Furthermore, healthy siblings are at risk for psychological issues due to the stress and challenges associated with having a sibling with cancer (Chesler et al., 1991; Gogan & Slavin, 1981; Sargent et al., 1995). There is a need for new interventions for adult healthy siblings and for more in-depth information about the long-term effects of having a sibling with cancer. The purpose of this study is to examine life balance outcomes of adult healthy siblings of individuals with childhood cancer and the relationship between social support and life balance outcomes.

Significance of the Study

Although literature exists that examines the psychological effect of cancer on healthy siblings during adolescence and childhood, this information is severely lacking for adult healthy siblings. The present study benefits the field of counseling because it enhances knowledge about the psychological and social outcomes of healthy siblings of individuals who were diagnosed with cancer in childhood. This research can provide a starting point for mental health professionals to consider offering more intentional social and psychological support for healthy siblings.

The central role of professional counselors is to help individuals achieve and maintain a style of living that allows individuals to reach the highest level of health and well-being (Fetter & Koch, 2009; Mellin, Hunt, & Nichols, 2011). Life balance is one measure of an individual's style of living that has recently become an important concept in professional counseling (Davis, Balkin, & Juhnke, 2014). Very little, if any, literature exists that examines the life balance outcomes of adult healthy siblings of individuals with childhood cancer. Given the psychological effects of having a sibling with cancer (Alderfer & Hodges, 2010; Alderfer et al., 2003; Houtzager, Grootenhuis, Caron, & Last, 2004; Kramer, 1981; Van Dongen-Melman, De Groot, Hählen, & Verhulst, 1995), it is evident that more research in this area is needed.

The expanded insights into adult healthy sibling outcomes have the potential to result in the adoption of new intervention strategies to facilitate the healthy siblings' emotional and social adaptation to the sibling with cancer's experience. This research could potentially assist mental health professionals, including counselors and social workers, in identifying special issues when working with adult healthy siblings of

individuals with childhood cancer, lead to improved care for adult healthy siblings, and highlight an often forgotten population. This study establishes a foundation for future studies aimed at improving psychosocial adjustment of adult healthy siblings. This study may help provide knowledge of the importance of social support in long-term psychological outcomes of adult healthy siblings. Finally, this study serves as an important contribution to understanding the long-term effects of growing up with a sibling with childhood cancer and identifying the areas for providing counseling services for this population.

Research Questions

The major research questions for this study include the following: 1) What is the extent of the differences in life balance outcomes for adult healthy siblings and the norm group of the Juhnke-Balkin Life Balance Inventory (JBLI; Davis et al., 2014)? 2) After controlling for time since diagnosis and income, what is the extent of the differences in life balance outcomes for adults whose siblings survived childhood cancer versus those whose sibling died? 3) What is the relationship between life balance and social support? 4) What is the relationship between life balance and perceived social support?

Assumptions and Limitations

There are several assumptions pertaining to this study. The first assumption is that having a sibling with cancer can influence life balance outcomes. Furthermore, the assumption is made that sibling relationships can influence life balance outcomes. One of the major limitations of this study is that the data are collected using only one method, a web-based survey platform. The accuracy of the data depends on the willingness of the research participants to respond honestly to questions on the self-report questionnaires.

Data was collected several years after the diagnosis and/or sibling death, so the accuracy of the data might be affected by the retrospective nature of the questions.

Definition of Terms

Bereaved siblings are healthy individuals whose siblings died as a result of their cancer. *Non-bereaved siblings* refer to healthy individuals whose siblings did not die as a result of their cancer.

Healthy siblings refer to individuals who do not have any chronic physical health conditions (including cancer), psychotic disorders, neurological disorders, or developmental disorders, and have at least one sibling who was diagnosed with cancer before age 19.

Adult healthy siblings refer to individuals age 18 or older who do not have any chronic physical health conditions (including cancer), psychotic disorders, neurological disorders, or developmental disorders, and have at least one sibling who was diagnosed with cancer before age 19. For this study, the sample will only include adult healthy siblings since they are age 18 and older.

Life balance is defined according to the life balance model created by Matuska (2012a). In order to live a balanced life, what people actually do must be congruent with their desired activities and must meet their needs for physiological health, fulfilling relationships, positive identity, and challenge (Matuska, 2012b). Life balance refers to a pattern of behaviors that meet a person's unique individual needs and can lead to reduced stress, improved mental and physical health and well-being, and increased life satisfaction (Matuska & Christiansen, 2008). In this study, life balance is operationally defined by the JBLI (Davis et al., 2014).

Perceived social support refers to the quality of social support available from family, friends, and a significant other. Perceived social support has three dimensions: 1) family, 2) friends, and 3) significant other. Here, perceived social support is operationally defined by the Multidimensional Scale of Perceived Social Support (Zimet, Dahlem, Zimet, & Farley, 1988).

Sibling with cancer or child with cancer refers to an individual who was diagnosed with cancer before the age of 19 and has at least one sibling who is a healthy adult.

Social support is the extent to which a person's interpersonal relationships fulfill specific functions. Social support has four dimensions: 1) emotional/ informational support, 2) tangible support, 3) positive social interaction, and 4) affectionate support. Social support is operationally defined in this study by the Medical Outcomes Study: Social Support Survey (Sherbourne & Stewart, 1991).

Chapter Summary

Siblings of children who were diagnosed with cancer in childhood experience significant stress and psychological difficulties as a result of the cancer. Furthermore, the needs of siblings have often been overlooked in the cancer literature, prompting the need for more studies. The existing literature has several methodological issues; namely, the research is outdated, had small sample sizes, included siblings that have psychiatric conditions, did not primarily focus on siblings, lacked control groups, and did not report demographic data. This study seeks to provide more detailed information about the long-term effects of having a sibling with cancer and to result in improved treatment and outcomes for the adult sibling population.

In the second chapter, a review of the literature relevant to the research study is presented. The third chapter covers the methodology used to answer the research questions. The results of the data analyses are presented in the fourth chapter. In the fifth chapter, the implications of the study and suggestions for future research are provided.

CHAPTER II

LITERATURE REVIEW

In this chapter, literature relevant to life balance outcomes in healthy siblings of individuals with childhood cancer is discussed. Because there have been very few studies pertaining to topics relating to the outcomes of healthy siblings in the past two decades, the literature reviewed was expanded to include publications from the last 40 years. This chapter begins with a discussion of the negative experiences of individuals who have siblings with childhood cancer, followed by a discussion of the positive experiences. Next, an overview of the psychosocial outcomes of healthy siblings in childhood and adolescence is provided. Then an examination of the academic outcomes is presented. A summary of the adult outcomes of healthy siblings of individuals with childhood cancer is given, along with an examination of sociodemographic factors related to healthy sibling outcomes and social support for healthy siblings. Then, the literature focuses on the sibling bond and how cancer influences the sibling relationship. Finally, bereavement in siblings is discussed, the factors that influence sibling bereavement are examined, the relationship between life balance and cancer are explained, and a conceptual overview of life balance is offered.

Negative Experiences of Healthy Siblings

Several researchers examined the experiences of healthy siblings, mainly using qualitative methods. Gogan, Koocher, Foster, and O'Malley (1977) conducted one of the earliest studies on the experiences of healthy siblings. Unlike earlier studies on healthy

siblings that relied on parental reports to assess the impact of cancer on siblings, Gogan and associates conducted interviews with the healthy siblings themselves. The researchers interviewed 13 healthy siblings between the ages of 8 and 28 who were born before their sibling was diagnosed with cancer. Results of the study suggested that healthy siblings often feel jealous of the attention that the child with cancer receives (Gogan et al., 1977). These findings were later supported by Alderfer et al. (2010); Chesler, Allswede, and Barbarin (1991); Kaplan, Kaal, Bradley, and Alderfer (2013); Murray (1998, 2000); and Prchal and Landolt (2011).

In addition to the lack of attention, several other factors contribute to the jealousy of healthy siblings. When a sibling is diagnosed with cancer, it causes significant changes within the family structure (Chesler et al., 1991; Gogan et al., 1977). Parents become preoccupied with the welfare and treatment of the child with cancer, which in turn decreases parent's availability to their healthy children (Chesler et al., 1991). As the parents spend more time away with the child with cancer at the hospital and appointments, they have less time to spend with their healthy children (Chesler et al., 1991). With their parents' increased concern over the child with cancer, healthy siblings often do not get as much emotional support or attention as they need, which leads to feelings of jealousy (Chesler et al., 1991; Gogan & Slavin, 1981; Spinetta, 1981). Although healthy siblings acknowledged these feelings of jealousy, Woodgate (2006) found that siblings did not report any lasting resentment toward their parents or the child with cancer.

Woodgate (2006) interviewed 30 healthy siblings and found that their needs were not being met due to the child with cancer receiving more attention. Healthy siblings

reported that their parents did not treat them the same as they treated the child with cancer (Chesler et al., 1991; Havermans & Eiser, 1994; Martin, 2000). For example, Chesler et al. (1991) found that siblings reported that their parents would often punish them for breaking rules that the child with cancer broke quite often without repercussion. Such differential treatment can negatively impact the relationship between siblings (Kramer, 2014). Siblings reported a loss of family routines, including mealtime rituals, and changes in family events, including holidays (Chesler et al., 1991; Nolbris et al., 2007; Prchal & Landolt, 2011; Sargent et al., 1995; Woodgate, 2006). Family vacations had to be canceled to accommodate treatment schedules and financial restraints (Martinson & Campos, 1991). Time, parental attention, and parental energy were diverted from the healthy child and invested in taking care of the child with cancer (McKeon, 1987); for instance, parents were no longer available to help with homework. Siblings acknowledged that their everyday lives were different after their sibling had been diagnosed with cancer and would never be the same as it was before (Nolbris et al., 2007). Given these findings, one could see why healthy siblings lose the sense of security and normalcy they once had within their families after a sibling has been diagnosed with cancer (Sidhu, Passmore, & Baker, 2006; Woodgate, 2006).

Jealousy is not the only intense emotion that healthy siblings experience. Siblings reported feeling guilty about being jealous of their sibling (Packman et al., 1997). Some siblings even felt guilty for their sibling's cancer and blamed themselves for the illness (Gogan et al., 1977). They also felt guilty for not being as involved with the child with cancer's care as much as they feel they should be and not being with their sibling during treatment (Woodgate, 2006). Just hearing about the cancer upset some healthy siblings

and caused emotional distress (Kaplan et al., 2013; Murray, 1998); therefore, many siblings tried to avoid the topic of cancer by either not thinking about it or not letting themselves feel anything about the cancer (Chesler et al., 1991; Gogan et al., 1977; Kaplan et al., 2013). Having to spend time away from both their parents and the sibling with cancer contributed to feelings of isolation (Chesler et al., 1991; Gogan et al., 1977; Gogan & Slavin, 1981; Spinetta, 1981). Other intense emotions reported by healthy siblings include anger, hate, and hopelessness (Alderfer et al., 2010; Kaplan et al., 2013; Murray, 1998, 2000; Prchal & Landolt, 2011).

Recent literature indicated that healthy siblings feel intense sadness (Alderfer et al., 2010; Woodgate, 2006). In their review of literature on the psychological functioning of healthy siblings, Alderfer et al. (2010) found that sadness was evident in all 18 studies that provided data on the psychological functioning of healthy siblings. Woodgate (2006) found that sadness was the most prevalent emotional response of healthy siblings. The sadness lasted even in cases where the child's cancer treatment was successful. Woodgate (2006) attributed the sadness to the changes that occurred within the family as a result of the cancer, the physical and emotional suffering that the child with cancer endured as a result of their cancer symptoms and treatments, and the emotional toll the cancer took on the parents.

Having a sibling with cancer also influences school and social life. Nolbris et al. (2007) found that healthy siblings often reported being conflicted between being there for their sibling and their own interests. For example, healthy siblings acknowledged that they needed to be in school, but at the same time they wanted to spend more time with their sibling with cancer (Nolbris et al., 2007). Alderfer et al. (2010) had similar

findings: healthy siblings experienced trouble in school and reported that their preoccupation with their sibling's condition has caused their academic performance to decline (Chesler et al., 1991; Kaplan et al., 2013; Maguire, 1983; Prchal & Landolt, 2011; Tiller, Ekert, & Rickards, 1977). Prchal and Landolt (2011) noted that these effects may only be temporary. Healthy siblings also reported that they were frequently asked about their sibling's condition by their teachers and peers, which can make school uncomfortable. In the same way that parents changed their schedules to accommodate the child with cancer, so did healthy siblings; consequently, healthy siblings reported that they did not spend as much time participating in social activities as they did before the cancer diagnosis (Chesler et al., 1991; Kaplan et al., 2013; Prchal & Landolt, 2011). For example, Prchal and Landolt (2011) found that healthy siblings reported spending significant amounts of time at the hospital with the sibling with cancer and not wanting to participate in social activities when their sibling's condition was unstable. Healthy siblings also found peer relationships difficult to maintain.

Healthy siblings tend to lose sight of themselves and their needs, instead focusing on their sibling and their parents. Nolbris et al. (2007) found that healthy siblings were more likely to report they were doing well when the child with cancer was doing well (i.e., in remission) and reported themselves as more negative when the child with cancer was not doing well (e.g., when the child with cancer was in treatment). Woodgate (2006) found that healthy siblings hardly focused on their own experiences, but instead emphasized the experiences of their parents or the child with cancer. Healthy siblings reported that it is important for them to be actively involved in caring for their sibling with cancer and how good it made them feel to know they are contributing to their

sibling's care (Chesler et al., 1991; Gogan & Slavin, 1981; Kramer, 1981; Prchal & Landolt, 2011; Sourkes, 1980; Woodgate, 2006). At the same time, helping a sibling with an illness can lead to the healthy sibling moving into a parental role, which contributes to the loss of self (Chesler et al., 1991; Woodgate, 2006). Healthy siblings may find themselves either forced or voluntarily taking on additional responsibilities, such as cleaning the house, watching other siblings while parents are away, or preparing meals (Chesler et al., 1991; Nolbris et al., 2007; Prchal & Landolt, 2011). Out of concern for their parents, many healthy siblings attempted to provide both emotional and physical support. Healthy siblings also altered their behavior (e.g., trying to be the perfect child) in an attempt to prevent their parents from experiencing any additional stress (Alderfer et al., 2010; Chesler et al., 1991; Woodgate, 2006). Often times, this meant that the healthy siblings would not assert their own needs or worries (Woodgate, 2006).

Healthy siblings also experience constant worrying about their sibling with cancer. The worrying can be pervasive, even in situations where the healthy sibling would normally feel happy (Nolbris et al., 2007). Healthy siblings have to watch the child with cancer suffer through the cancer treatments and symptoms (e.g., hair loss, weight loss, and vomiting), which can, in turn, lead to negative emotions (Nolbris et al., 2007; Prchal & Landolt, 2011; Sargent et al., 1995). Healthy siblings worried about the implications of their siblings' diagnosis and how their siblings would respond to the cancer treatment (Alderfer, Labay, & Kazak, 2003; Chesler et al., 1991; Prchal & Landolt, 2011). There is great concern about the child with cancer's ability to cope with the illness and the emotional toll it will take (Woodgate, 2006). Healthy siblings also worry when the child with cancer has to go to an exam and what the exam might reveal

(Nolbris et al., 2007). Another common worry is that the child with cancer is going to die during treatment (Alderfer et al., 2003; Kaplan et al., 2013).

Another part of the sibling cancer experience is dealing with anxiety and stress (Chesler et al., 1991; Murray, 1998, 2000; Nolbris et al., 2007). The stress that the healthy sibling experiences is very similar to that of the child with cancer (Murray, 1998). Research conducted by Alderfer et al. (2003) showed that adolescent healthy siblings had higher levels of post-traumatic stress than adolescents whose families had no history of chronic mental or physical illnesses. These findings were supported by Kaplan et al. (2013) and Packman et al. (2004). Post-traumatic symptoms include difficulty concentrating, sleeping problems, and irritability (Kaplan et al., 2013).

Positive Experiences of Healthy Siblings

Though a majority of healthy sibling research has focused on the adverse aspects of the experience, not all of the experience is negative. One of the predominant positive outcomes of having a sibling with cancer is increased cohesion and closeness in the family unit (Alderfer et al., 2010; Chesler et al., 1991; Martin, 2000; Prchal & Landolt, 2011; Sargent et al., 1995; Woodgate, 2006). Chesler et al. (1991) found that 20 out of the 21 healthy siblings interviewed felt increased closeness between family members as a result of a sibling's cancer. This finding was similar to the results of Prchal and Landolt's (2011) study, in which 6 out of 7 healthy siblings reported increased family cohesion and closeness. These findings were supported by several other researchers (Alderfer et al., 2010; Martin, 2000; Sargent et al., 1995; Woodgate, 2006).

Kramer (1981) found that healthy siblings reported greater maturation as a result of the cancer experience. These findings were supported by Chesler et al. (1991), Murray

(1998, 2000), and Sargent et al. (1995). Healthy siblings developed increased empathy toward others, especially their siblings and their parents (Chesler et al., 1991; Martin, 2000; Murray, 1998; Sargent et al., 1995). Studies conducted by Heffernan and Zanelli (1997) and Murray (1998) revealed that healthy siblings of children with cancer had higher levels of empathy compared to those who have healthy siblings. Healthy siblings tended to value life more and many expressed the desire to help others with similar experiences (Havermans & Eiser, 1994; Kramer, 1981; Murray, 1998; Sargent et al., 1995). Healthy siblings also reported being more responsible.

Psychosocial Outcomes in Childhood and Adolescence

Research on the psychological outcomes of healthy siblings has been mixed. Van Dongen-Melman et al. (1995) examined the outcomes of healthy siblings between ages 4 and 16 after their sibling had been successfully treated for cancer. The researchers found that there was no difference in emotional or behavioral problems between healthy siblings and the control groups (Van Dongen-Melman et al., 1995). Similarly, Labay and Walco (2004) found that there was not a significant difference between the psychosocial adjustment of healthy siblings and that of a control group. The participants in Labay and Walco's study (2004) were 7-16 years old and the child with cancer was actively being treated and at least 3 months had passed since the initial diagnosis. Despite these findings, recent research has suggested that healthy siblings are, in fact, more likely to have adverse psychological outcomes.

Although some studies show that healthy siblings do not experience mental disorders at a higher rate, other studies indicate that there exists a subset of healthy siblings that experience negative emotional reactions (e.g. post-traumatic stress; Alderfer

& Hodges, 2010; Alderfer et al., 2003; Houtzager et al., 2004). Alderfer et al. (2003) conducted a self-report study using 78 siblings 4 months to 15 years after a sibling had been diagnosed with cancer. They found that healthy siblings reported higher amounts of post-traumatic stress when compared with reference group, but both groups had similar levels of anxiety. This finding was supported by Kaplan et al. (2013). Houtzager, Grootenhuis, Hoekstra-Weebers, Caron, and Last (2003) examined psychosocial problems in healthy siblings 1 to 6 months after the cancer diagnosis. The authors found that female healthy siblings between the ages of 12 and 18 had significantly higher measures of internalizing problems and anxiety when compared to the norm group (Houtzager et al., 2003). Healthy siblings between the ages of 7 and 11 had greater impairments in physical quality of life when compared to the norm group. Both age groups reported impaired emotional, social, and physical quality of life. By 6 months after diagnosis, the quality of life of 7-11 year olds had improved such that there was no significant difference with the normal population; however, the emotional, social, and overall quality of life of 12-18 year olds was still significantly lower than the normal population (Houtzager et al., 2003).

Houtzager et al. (2004) conducted a study using 46 healthy siblings from the previous study 2 years after the cancer diagnosis. Healthy siblings were required to complete four questionnaires that were used to assess healthy siblings' quality of life, emotional and behavior problems, and anxiety. Houtzager et al. found that among healthy siblings 7–11 year olds, 42% reported emotional impairments, 34% reported social impairments, 47% reported impairments in total quality of life, and 26% reported physical impairments (Houtzager et al., 2004). These percentages were significantly

higher than those of the 7-11 norm group. Among adolescents age 12-18, 29% reported emotional impairments, which was significantly higher than the norm group. Healthy siblings age 12-18 also reported more internalizing behaviors than the norm group. There was no difference found in quality of life between healthy siblings age 12-18 and the control group (Houtzager et al., 2004).

Research is unclear as to what the relationship is between the time of the diagnosis and psychological outcomes. Hamama, Ronen, and Feigin (2000) found that anxiety decreased the further away from diagnosis. Healthy siblings of a child with cancer who had been ill for a smaller period of time were more anxious than those whose siblings had cancer for a longer period. Labay and Walco (2004) found no relationship between time since diagnosis and behavioral problems. The studies above suggest that psychological difficulties are more likely to be found within the first 2 years after the initial cancer diagnosis, but more research is needed (Alderfer et al., 2003; Houtzager et al., 2003; Houtzager et al., 2004; Lähtenmäki, Sjöblom, Korhonen, & Salmi, 2004). One could gather from the research that the psychological outcomes for healthy siblings are generally within the normal range, with elevations occurring closer to the cancer diagnosis (Alderfer et al., 2010). In another study, Hamama, Ronen, and Rahav (2008) found that healthy siblings who had higher levels of self-control and self-efficacy reported less anxiety and psychosomatic symptoms.

Several researchers have found no differences in social functioning in healthy siblings when compared to control groups. For example, Houtzager, Grootenhuis, Hoekstra-Weebers, and Last (2005) found no difference in social functioning between healthy siblings age 7-18 and norms one month after the initial cancer diagnosis. Madan-

Swain et al. (1993) found no differences in siblings and norms between the ages of 5 and 16 within 2 years of the initial cancer diagnosis—findings similar to those of Lähteenmäki et al. (2002). Like psychological problems, social problems in healthy siblings were rarely reported in the research, but when differences did exist, they occurred closer to the time of diagnosis (Houtzager et al., 2003; Houtzager et al., 2004; Lähteenmäki et al., 2002).

Academic Outcomes in Children and Adolescence

Lähteenmäki et al. (2002) used school grades, healthy sibling questionnaires, and teacher questionnaires to assess the academic and social functioning of healthy siblings. They found no difference between healthy siblings and healthy controls in either domain. The authors in this study did not note how long ago the child with cancer had been diagnosed with cancer; however, Labay and Walco (2004) found that healthy siblings within 2.5 years of diagnosis were less involved in academic, social, and extracurricular activities compared to their peers. When they did participate, healthy siblings were less successful than their peers and had more difficulty. French et al. (2013) found that healthy siblings between 4 and 17 years from initial diagnosis missed significantly more days of school than their peers. Lähteenmäki et al. (2004) found that 3 months and 1 year after diagnosis, school-aged healthy siblings exhibited more learning problems than their peers.

Adult Healthy Sibling Outcomes

Research on adult healthy siblings has been limited. Data from the National Health Interview study showed no difference in smoking behaviors between adult healthy siblings and the normal population (Tao et al., 1998). Larcombe et al. (2002) found no

differences between adult healthy siblings (ages 18-30) or their peers in health behaviors, including alcohol consumption, drug use, tobacco use, and diet. Lown et al. (2013) found that adult healthy siblings (age 18-56) are more likely to engage in risky and heavy drinking than national controls. Lown's participants were taken from the Childhood Cancer Survivor Study cohort. Zebrack et al. (2002, 2004, 2007) conducted three studies using the Childhood Cancer Survivor Study, which is a "cohort study of childhood cancer survivors diagnosed between 1970 and 1986 who have survived five or more years after diagnosis" (Lown et al., 2013, p.1135) and their siblings. The conclusions on adult psychological functioning were the same in all three studies; namely, there was no significant difference in the psychological distress between adult healthy siblings and the normal population (Zebrack et al., 2002, 2004, 2007). Zeltzer et al. (2008) found that adult healthy siblings reported greater psychological functioning than population norms.

Sociodemographic Factors and Healthy Sibling Outcomes

Several researchers have examined the relationship between gender and healthy sibling outcomes. Barrera, Fleming, and Khan (2004) found that adolescent females (age 11-18) who were referred to a group intervention for behavior problems were more anxious than adolescent females who were not referred and all males in the sample. Three of the aforementioned studies found that female healthy siblings have higher levels of post-traumatic stress, anxiety, and social issues when compared to males (Alderfer et al., 2003; Houtzager et al., 2004, 2005). Among adult cancer survivors and healthy siblings, Zebrack et al. (2002, 2004, 2007) found that males had better adjustment than females. These findings were supported by Zeltzer et al. (2008). One study (Hamama et al., 2000) did not find differences between male and female healthy siblings in loneliness

or anxiety. The research suggests that in cases where there are gender differences in healthy sibling outcomes, it is the females who report higher levels of impairment (Alderfer et al., 2003; Alderfer & Hodges, 2010; Houtzager et al., 2004, 2005; Zebrack et al., 2002, 2004, 2007).

Another sociodemographic factor that is related to healthy sibling outcomes is socioeconomic status. Several authors have suggested that siblings in families from high socioeconomic status backgrounds have better adjustment (Barbarin et al., 1995; Buchbinder et al., 2011; Cohen, Friedrich, Jaworski, Copeland, & Pendergrass, 1994; Sahler et al., 1994; Van Dongen-Melman et al., 1995; Sloper & While, 1996; Zeltzer et al., 1996, 2008). Houtzager et al. (2003, 2004) found age-specific reactions to cancer, which suggests age of the sibling also influences healthy sibling outcomes. The time since diagnosis also influences healthy sibling outcomes (Alderfer et al., 2003; Hamama et al., 2000; Houtzager et al., 2003; Houtzager et al., 2004; Lähteenmäki et al., 2004). In addition to the healthy sibling's age and gender, Van Dongen-Melman et al. (1995) found that the sibling's age at diagnosis also influenced healthy sibling outcomes. More specifically, they found that healthy siblings who were older than 4 at the time of the initial diagnosis had lower scores on scholastic competence (Van Dongen-Melman et al., 1995).

Labay and Walco (2004) found a significant relationship between family size and birth order and healthy sibling outcomes. Healthy siblings that are older than the cancer child have a higher rate of behavioral, social, and academic problems than healthy siblings that are younger (Labay & Walco, 2004). This finding contradicts Buchbinder et al.' study (2011), which found that healthy siblings who are younger than the cancer child

have higher rates of psychological distress. Labay and Walco (2004) also found that siblings from larger families are more likely to have adjustment problems than siblings from smaller families, which contrasts research conducted by Madan-Swain et al. (1993), who found that having more siblings in the family is related to better adjustment.

McDonald, Patterson, White, Butow, and Bell (2014) found that age differences between the healthy sibling and the child with cancer, and whether the cancer child is on treatment or has relapsed, also influence healthy sibling outcomes. The bigger the age difference, the more unmet needs the healthy sibling experiences. Likewise, periods of treatment or relapse contribute to distress in the healthy sibling (McDonald et al., 2014). Other outcomes that have been shown to contribute to psychological distress include the death of the cancer child, low education, being unmarried, unemployment, having a household income under \$20,000, not having medical insurance, and having a chronic health condition (Buchbinder et al., 2011; Martinson & Campos, 1991; Zeltzer et al., 2008).

Social Support for Healthy Siblings

One method that has been consistently shown to improve psychosocial outcomes for healthy siblings is social support. Discussing the child with cancer's condition with peers can be a beneficial experience for healthy siblings because peers can serve as a source of comfort and hope for healthy siblings (Chesler et al., 1991; Prchal & Landolt, 2011). Peers can also provide a way for healthy siblings to temporarily escape cancer-related issues (Prchal & Landolt, 2011). Unfortunately, healthy siblings have a hard time maintaining peer relationships due to those same issues (Chesler et al., 1991; Kaplan et al., 2013; Prchal & Landolt, 2011). Barrera et al. (2004) found that healthy siblings who

report high levels of social support are less likely to have depression, anxiety, or behavioral issues than healthy siblings that report low levels of social support. Newman, Newman, Griffen, O'Connor, and Spas (2007) found that healthy siblings who have greater family support experience less psychological distress than those who do not. In addition to family support, Alderfer and Hodges (2010) found that healthy siblings who have support from school teachers, classmates, and peers are less likely to have emotional, behavioral, or academic problems than those who have low levels of social support. Support groups for healthy siblings ages 7-18 have been shown to increase coping ability and decrease anxiety (Houtzager et al., 2001). Participation in camps for healthy siblings is associated with increased self-concept (Murray, 2001), emotional well-being and self-esteem (Packman et al., 2008), health-related quality of life (Packman et al., 2005), and psychosocial functioning (Sidhu et al., 2006).

The Sibling Bond

The relationship between siblings is complex, multidimensional, and transforms over time (Kim, McHale, Crouter, & Osgood, 2007; Kramer, 2014). The sibling relationship involves a balancing act in which its participants swing back and forth between harmony and conflict (McKeon, 1987). For example, a healthy sibling may discuss experiencing high levels of jealousy when the sibling receives all the attention, but may later mention understanding that the sibling is sick and wishing to be there more for the sibling (Chesler et al., 1991). McKeon (1987) referred to this phenomenon as “dialectical tension” (p. 130). The sibling bond is heavily dependent upon access (Bank & Kahn, 1982; Cicirelli, 1982). Access can be characterized as either low or high and siblings who are close in age, are the same sex, are brought up in the same household by

the same parents, and have a shared personal history are what Bank and Kahn (1982) referred to as “high access siblings.” In contrast, “low access siblings” are those who have larger age gaps, possess little shared time or space, and have different personal experiences (Bank & Kahn, 1982). High access is an important component of sibling bonds. The earlier the access and the longer the sibling relationship lasts, the more influential the sibling relationship tends to be (Bank & Kahn, 1982; McKeon, 1987). Sibling relationships span the course of a lifetime, and for this reason, sibling relationships tend to be one of the most enduring relationships that people experience (Howe & Recchia, 2014). Sibling relationships influence many aspects of each other’s lives, including identity, social skills, emotional intelligence, psychological functioning, and peer relationships (Dunn & McGuire, 1992; Kim et al., 2007; Kramer, 2014; Labay & Walco, 2004). Siblings can give each other support and comfort (Harding, 1996). Siblings can serve as protectors, teachers, and friends (Davies, 1999). The sibling relationship heavily influences socialization and childhood development (Davies, 1991; Foster et al., 2011).

The interactions that siblings have in early childhood can provide the foundation for social development and understanding (Kim et al., 2007). Furthermore, scholars suggest that a link exists between the quality of sibling relationships and the quality of peer relationships (Dunn & McGuire, 1992). The affection between siblings can decrease the internalizing behaviors that children display when they encounter life events that are stressful (Kramer, 2014). In addition, increased age differences are linked with more warmth and less sibling rivalry (Labay & Walco, 2004).

There is very little literature on adult sibling relationships as they relate to cancer; however, the literature on childhood and adolescent siblings suggests that sibling closeness is rooted in childhood family relations (Cicirelli, 1982). When the nature of how siblings relate to one another changes in adolescence or adulthood, it is most likely due to a crucial incident (Cicirelli, 1982). Researchers suggest that most siblings who are close in childhood remain so in adulthood and old age, even growing closer as they reach their final years of life (Bank & Kahn, 1982; Cicirelli, 1982).

According to Kramer (2014) sibling relationships greatly influence emotional experiences. Sibling relationships provide the means to develop emotional language, as well as one's own emotional experiences; knowledge about mixed emotions and how to distinguish one emotion from another; the ability to distinguish one's own emotions from others and consider their viewpoint; and the ability regulate how emotions are expressed (Kramer, 2014). This development occurs through sibling conflict (e.g., having a difference of opinion with a sibling), positive sibling engagement (e.g., playing video games with a sibling), and navigating relationships with parents (e.g., responding to unequal treatment). For example, healthy siblings often report that their parents treat them differently than the cancer child (Chesler et al., 1991; Havermans & Eiser, 1994; Martin, 2000).

The experience of differential treatment provides the means for healthy siblings to learn about emotions (Kramer, 2014). The healthy sibling could respond by acknowledging feelings of jealousy and managing jealousy by appropriately expressing feelings to parents. The healthy sibling could also take the perspective of the sibling with cancer and try to rationalize the differential treatment as a special need for the sibling

with cancer (Kramer, 2014). Kim et al. (2007) found that positive adjustment is linked to sibling intimacy, while maladjustment is linked to sibling conflict. Researchers also suggest that the younger siblings are not more affected by the sibling experiences than older siblings (Kim et al., 2007).

Influence of Cancer on the Sibling Relationship

According to Rollins (1990), the sibling bond is often stronger after a cancer diagnosis, which is also supported by Pavlov (1992). Nolbris et al. (2007) found that, not only did the majority of the healthy siblings in their study report stronger and closer sibling relationships after the cancer diagnosis, the siblings also became more aware of their relationship and how special it was. Healthy siblings also reported deep admiration for their sibling with cancer (Pavlov, 1992). Nolbris et al. (2007) noted that healthy siblings reported that they were dependent upon the sibling with cancer and vice versa, and they also reported both giving and receiving support in multiple situations. Such support continues even when the siblings are separated (Pavlov, 1992). Pavlov (1992) found that both healthy siblings and children with cancer reported spending more time with each other and communicating more frequently after the cancer diagnosis.

At the same time, cancer can also hinder communication and positive engagement between siblings. When a sibling is receiving treatment for cancer, the healthy sibling has less time to play or interact with the sibling with cancer (McKeon, 1987), which limits opportunities for positive sibling engagement and the opportunities for the siblings to develop emotional and social skills (Kramer, 2014). Parental behavior and attitudes also heavily influences the sibling relationship (Pavlov, 1992). Having a child with an illness can make it impossible for parents to provide the support needed to foster the

sibling relationships, especially when compared to normal situations (McKeon, 1987). The parental focus shifts to the sick child and cancer, resulting in less time and energy available for other siblings and potentially leading to negative emotions in healthy children. Such tensions can also increase conflict in the sibling relationship, which could ultimately lead to poor adjustment for the healthy sibling. With the absence of parental support, this occurrence is likely even in situations where siblings had positive relationships before the cancer diagnosis (McKeon, 1987).

Researchers have concluded that positive sibling relationships (sibling relationships that are warm and close) can lead to increased levels of emotional understanding (Howe et al., 2001; Kramer, 2014); however, a sibling's cancer is likely to cause negative emotions within the family (e.g. fear, anger, and jealousy; Alderfer et al., 2010; Kaplan et al., 2013; McKeon, 1987; Murray, 1998, 2000; Prchal & Landolt, 2011). Healthy siblings often pick up on these changes and may keep their negative emotions to themselves in order to protect their family members, which further isolates the healthy sibling and decreases communication and support in the sibling relationship (Alderfer et al., 2010; Chesler et al., 1991; McKeon, 1987; Woodgate, 2006).

Bereavement in Siblings

Although the advancements in cancer treatment have increased the rate of cancer survivorship, many children die each year due to cancer or its treatments. No matter what its cause, a person's death can have a profound effect on siblings. Even in cases where the sibling with cancer has been sick for a while, the healthy sibling may not be prepared for their sibling to die (Nolbris & Hellström, 2005). Even if the healthy sibling had little to no psychological issues prior to the sibling's death, bereavement can lead to

anxiety, guilt, fear, depression, or psychosomatic symptoms such as headaches (Adams & Deveau, 1987). Healthy siblings often feel guilt after a sibling's death; for example, they may feel guilty for wishing their sibling would die or that they are alive instead of their sibling (Adams & Deveau, 1987). Many times parents are so overwhelmed in their own grief that they are unable to adequately help their remaining children (Adams & Deveau, 1987; Martinson & Campos, 1991). The remaining children may feel that they are not as important as their deceased sibling, and that they can only grieve in ways that are deemed appropriate by society and their parents (Adams & Deveau, 1987). In addition, parents may become overprotective and individuals outside the family may try to avoid talking about the death.

Combine all of the aforementioned factors with the unmet needs that the healthy sibling already has, and one can see how the death of a sibling can begin to take its toll (Adams & Deveau, 1987). In instances where bereaved siblings are able to communicate with their parents about how the loss of their sibling is affecting them and discuss painful feelings with their parents, it can make the parent-child bond even stronger and allow the siblings to draw emotional support (Martinson & Campos, 1991). While research related to sibling bereavement exists, it is mostly qualitative and full of methodological issues (e.g., no control group, no use of standardized measures, relies heavily on parent data). In the upcoming paragraphs, the short-term and long-term outcomes associated with bereavement are examined. Since the causes and circumstances of death heavily influence bereavement responses (Bowlby, 1980), the focus is on articles that looked at outcomes for healthy siblings who had lost a sibling to cancer.

Davies (1983) collected data from 34 families related to the responses of surviving children ages 6-16 to the death of a sibling to cancer. Data were collected within the first 3 years after the sibling's death. Davies (1983) concluded that bereaved siblings experience a higher rate of internalizing behaviors and lower social competence than the normal population. Internalizing behaviors were found to continue up to 9 years after the sibling's death and were thought to last into adulthood (Birenbaum et al., 1989; Davies, 1991; Nolbris & Hellström, 2005; Sveen, Eilegård, Steineck, & Kreichbergs, 2014). Over 50% of the bereaved siblings in Davies's (1983) study displayed argumentative behavior and internalizing behaviors. The internalizing behaviors that were demonstrated were self-isolation, nervous, unhappiness, sadness, or being depressed (Davies, 1983). Another study conducted by Davies (1991) included interviews with 12 bereaved adults ages 25–75 who lost their sibling to cancer in adolescence. Davies found that the feelings of sadness and loneliness persisted into adulthood.

In addition, anger, jealousy, and externalizing behaviors (e.g., acting-out and fighting) have also been present in bereaved siblings years after the sibling with cancer had died (Nolbris & Hellström, 2005; Sveen et al., 2014). When using a control group of non-bereaved siblings, Eilegård, Steineck, Nyberg, and Kreichbergs (2013) found that there was not an increased risk of anxiety or depression in bereaved siblings. Bereaved siblings had sleep problems such as insomnia, nightmares, sleepwalking, and sleep-talking (Davies, 1983; Eilegård et al., 2013), were not eating well (Davies, 1983), and possessed psychosomatic symptoms including stomach cramps and headaches (Davies, 1983).

Adult bereaved siblings also reported that the loss of a sibling with cancer in childhood and adolescence had a negative influence on their development (Davies, 1991). The loss of a sibling led to them maturing and becoming more serious at a younger age, which led them to avoid the normal childish behavior that was considered developmentally appropriate for their age group. As a result, they were isolated from their peers in both childhood and adulthood, and felt they had never really learned how to develop or maintain social relationship (Davies, 1991). These findings support the conclusion that bereaved children respond to sibling's death in a variety of ways, but primarily by exhibiting internalizing behaviors. It is important to note that Davies's (1983) study relied solely on the mother's report of the sibling behaviors: no data was collected from the children themselves. Likewise, Birenbaum et al. (1989) also did not collect data from the children, but instead collected data from parents and teachers.

Gerhardt et al. (2012) collected data from the teachers and classmates of 105 bereaved siblings to compare the peer relationships of bereaved siblings to those of their classmates. Classmates were matched to bereaved siblings on three variables: age, sex, and race. Teachers reported that the classmates were less social than the bereaved siblings, a finding not supported by prior research that suggests that bereaved children have lower social competency than the normal population (Birenbaum et al., 1989; Davies, 1983). Bereaved elementary school siblings were more likely to be perceived as less prosocial by their peers and less accepted by peer groups, while bereaved middle and high school siblings were perceived as being leaders and more popular by peers and teachers (Gerhardt et al., 2012). Bereaved boys were also more likely to be perceived as sensitive-isolated and victimized by their peers. These findings suggest that there may be

certain subgroups of bereaved siblings (i.e., males and elementary students) who are at a higher risk for social problems.

Other researchers have found that the death of a sibling with cancer can lead to both positive and negative outcomes for siblings (Davies, 1991; Foster et al., 2011, 2012; Nolbris & Hellström, 2005). Bereaved siblings reported that they were more mature (Davies, 1991; Nolbris & Hellström, 2005) and had increased personal strength (Nolbris & Hellström, 2005) after their sibling's death. Eilegård et al. (2013) found that, when compared to non-bereaved siblings, bereaved siblings have an increased risk of low self-esteem and maturity. Foster et al. (2012) conducted a study in which they assessed both bereaved parents' and bereaved siblings' views related to the sibling's response 6 to 19 months after a sibling's death. Sibling participants were between the ages of 8 and 17. Only 15% of the siblings reported that they have not changed as a result of their sibling's death and 44% of the siblings reported that their personality had changed in positive and negative ways (Foster et al., 2012). For example, 15% of the siblings felt they had become more mature, 23% reported being more compassionate, 8% were sad, and 5% were withdrawn (Foster et al., 2012). Furthermore, 26% of the siblings noticed a change in their academic functioning, including trouble concentrating, 21% of siblings reported that their priorities had changed since their sibling's death (i.e., they have a deeper appreciation for life and decided to pursue a career related to cancer), and 33% of the bereaved siblings reported that their friendship dynamics had changed significantly as a result of the sibling's death (some friendships were lost while others were gained, and some friendships became weaker while other friendships became stronger).

Additionally, 23% of siblings believed that their families had grown closer after the death while 8% believed that their families had grown apart (Foster et al., 2012). Chesler et al. (1991) also found that the bereaved sibling in their study reported that their families had grown apart. Other responses reported by siblings according to Foster et al. (2012) included a change in interests and activities, adjusting to new family roles (e.g., being the only child), and motivation (e.g., striving to be a hard working just like the deceased sibling).

Bereaved siblings also engage in purposeful bonds with their deceased sibling, though they are less likely to do so than their parents (Davies, 1991; Foster et al., 2011; Nolbris & Hellström, 2005). Using the same sample from their 2012 study, Foster et al. examined how parents and siblings engaged in purposeful bonds with the deceased sibling within 6 to 19 months after the death. The authors found that 92% of the bereaved siblings, compared to 100% of the mothers and fathers, reported engaging in purposeful activities to remind themselves of the deceased sibling. The bonds most frequently reported by siblings include keeping something that belonged to the sibling such as clothes (44%), visual reminders such as pictures and videos (28%), visiting places that the deceased sibling occupied such as their bedroom (18%), and participating in special events as a way to honor their sibling (Foster et al., 2011). Additionally, 8% of the bereaved siblings did not purposefully seek out reminders of the deceased sibling, but encountered them unexpectedly. These findings were similar to those of Nolbris and Hellström (2005), who found that between 1.5 and 6 years after the sibling's death, bereaved siblings valued private memories and special objects the most. In Foster et al.' study (2011), 28% of bereaved siblings reported comforting effects from the purposeful

bonding activities, while 3% reported that these experiences led to discomforting effects. The researchers concluded that when the reminders caused siblings to recall positive memories, the effects are more comforting, while distressing results occur when the reminders lead to feelings of hurt or sadness. Bereaved siblings also reported being especially distressed by the fear of developing cancer themselves or the possibility of their future children developing cancer (Davies, 1993). Researchers also concluded that these reminders could cause both comforting and distressing effects at the same time (Foster et al., 2011).

Bereaved siblings may also have issues working through their grief. For example, Martinson and Campos (1991) found that 16% of the bereaved sibling in their study had not worked through their grief even 7-9 years after their sibling had died. Similarly, Sveen et al. (2014) found that over half of the bereaved adult siblings in their study were still working through their grief or had not even begun working through it. Bereaved siblings were found to follow a unique grieving process, in which they had random periods of mourning that they could not control (Nolbris & Hellström, 2005).

Factors that Influence Sibling Bereavement

Sveen et al. (2014) examined several factors associated with bereavement outcomes and found that the healthy sibling's age, gender, education, employment status, and whether or not the healthy sibling had lost another loved one after the sibling's death were not associated with bereavement outcomes. There are two environmental factors that have been showing to play a significant role in bereavement outcomes: shared life space and family environment (Davies, 1993). Shared life space refers to how close the siblings are to each other, both emotionally and physically (e.g., if they live in the same

household). The closer the siblings are, the higher the chance of the surviving sibling experiencing internalizing behavior problems after bereavement (Davies, 1983, 1993). The family environment is important for several reasons; for instance, when a child dies, the event does not just affect the surviving siblings, but it also affects the entire family unit. The family's response to the child with cancer's death influences how the surviving siblings respond to the death. In addition, it is the family that creates the atmosphere in which the surviving siblings grieve (Davies, 1993). Davies found that bereaved siblings that came from families that had high levels of cohesiveness, were active, and had a high emphasis on religion experienced fewer behavioral problems after a sibling's death (Davies, 1983, 1988). Families that were supportive and had high commitment also had bereaved siblings who experienced fewer internalizing and acting out behaviors (Davies, 1983).

Life Balance and Cancer

Research studies have examined life balance in individuals with rheumatoid arthritis (Backman, Kennedy, Chalmers, & Singer, 2004; Stamm et al., 2009), women with stress-related disorders (Håkansson, Dahlin-Ivanoff, & Sonn, 2006; Håkansson & Matuska, 2010), women with multiple sclerosis (Matuska & Erickson, 2008), bereaved caregivers who lost their spouse to cancer (Holtslander, Bally, & Steeves, 2011), mothers of children with disabilities (McGuire, Crowe, Law, & VanLeit, 2008), first-time mothers (Horne, Corr, & Earle, 2005), middle school students (Kuhnle, Hofer, & Kilian, 2012), and healthy working adults (Wagman, Björklund, Håkansson, Jacobsson, & Falkmer, 2011). Very little, if any, empirical evidence exists that examines life balance in adult healthy siblings of individuals with cancer.

There is a positive association between life balance and psychological well-being and positive health outcomes (Matuska & Christiansen, 2008; Matuska, 2012a; Matuska, Bass, & Schmitt, 2013). There is a negative association between life balance and stress and negative health outcomes (Matuska, 2012a; Matuska et al., 2013). In other words, those who live more balanced lives are more likely to experience favorable physical and psychological health outcomes including reduced stress and less chronic illness (Matuska & Christiansen, 2008; Matuska, 2012a; Matuska et al., 2013; Pentland & Mccoll, 2008; Sheldon, Cummins, & Kamble, 2013). Life balance is heavily influenced by situational and environmental factors (e.g., socio-economic status, unemployment, culture, family life, physical safety) (Matuska et al., 2013; Wagman et al., 2011). Being a healthy sibling of an individual with cancer in childhood is an important contextual factor that has been linked to stress and psychological outcomes, which are two factors that are associated with life balance. In other words, being a healthy sibling of an individual with childhood cancer can potentially influence life balance.

Conceptual Overview: Life Balance

The concept of life balance has been defined in several ways throughout the years. Life balance is often defined in relation to time (Gropel & Kuhl, 2006, 2009; Sheldon et al., 2010), occupation (Håkansson & Matuska, 2010; Pentland & Mccoll, 2008; Wagman et al., 2011), and needs (Matuska, 2012a; Matuska et al., 2013; Matuska & Christiansen, 2008). Some theorist view life balance as a dualistic concept where a person is either balanced or imbalanced (Pentland & Mccoll, 2008) while others hold that life balance is a continuum with balance and imbalance on opposing ends (Wagman et al., 2011).

Gropel and Kuhl (2006) defined life balance as allocating appropriate amounts of time to major life domains so that it leads to satisfaction. Gropel and Kuhl (2009) later modified their definition to how successfully individuals can proportion time across major life domains including work, social relationships, and health. This definition is similar to Sheldon, Cummins, and Kamble's (2010) definition of life balance, which not only requires spreading out time among major life domains, but also spreading time in such a way that the individual feels that it is congruent with their ideal time use. According to this view, life balance "denotes more abstract ideals and prescriptions for optimal living, to be achieved by balancing competing choices and necessities across all of the many domains of life, not just work and family" (Sheldon et al., 2010, p. 1094).

Christiansen and Matuska (2006) defined life balance as "...sustained patterns of occupation that meet biological and psychological needs within the unique environments of individuals [that] can lead to reduced stress, improved health and well-being, and greater life satisfaction" (p. 16). There are five dimensions of life balance according to Christiansen and Matuska (2006): 1) the need for biological health, security, and physical safety, 2) the need for relationships that are rewarding and self-affirming, 3) the need for occasions to feel competent and engaged by participating in occupations that are appealing and challenging, 4) the need for a meaningful life and develop a positive personal identity, and 5) the need to organize time in such a way that one is able to meet one's goals and produce opportunities to renew energy.

Similarly, Wagman et al (2011) divided life balance into four theoretical pieces: 1) activity balance between work life, family life, and leisure/mandatory activities; 2) balance between oneself and the being a part of the social environment; 3) balancing time

so that you can meet your needs, obligations, and seek pleasure; and 4) balance between having a healthy mind and body.

Matuska (2012) created the life balance model, which holds that the best way to understand life balance is by examining how people go about their lives (Matuska, 2012a, 2012b; Matuska et al., 2013). Life balance can be assessed by looking at “actual configurations” of what people do (Matuska, 2012b, p. 230). These configurations are balanced when they meet people’s needs, and imbalanced when they do not (Matuska, 2012b). In order to be balanced, actual configurations must 1) be congruent with people’s desired activity configuration and 2) meet people’s needs for physiological health, fulfilling relationships, positive identity, and challenge (Matuska, 2012b; Matuska et al., 2013). Time management is an important part of achieving life balance.

According to Davis et al. (2014), life balance consists of ten domains: positive orientation, global health, quality of relationships, substance use, spiritual support, sleep disturbance, stress/anxiety, sex/intimacy, career, and friendship.

Theoretical Framework

The goal of the current study is to examine life balance outcomes and social support in adult healthy siblings of individuals with childhood cancer. Two theories are used to guide this study: transactional model of stress and coping and family systems theory.

Transactional Model of Stress and Coping

The application of the transactional model of stress and coping (Thompson & Gustafson, 1996) provides a framework from which to analyze the adult sibling’s response to the stress that comes from with growing up with a sibling who has childhood

cancer. It also provides a framework for looking at sibling outcomes by examining the variables that influence sibling outcomes. According to the transaction model of stress and coping, stressful experiences such as watching a sibling deal with cancer are thought of as transactions between a person and the environment (Lazarus & Folkman, 1984). Whenever these transactions cause one to perceive a discrepancy between what the situation demands and the resources available to help to cope with those demands, individuals may experience stress (Lazarus & Folkman, 1984; Hocking & Lochman, 2005). An example of a coping resource that can help individuals deal with situational demands is social support (Pearlin, Menaghan, Lieberman, & Mullan, 1981; Thoits, 1986). The coping mechanisms that a person uses in order to deal with stress leads to various outcomes (Garcia, 2010). For example, Lazarus (1993) found that people who used positive reappraisal and planful problem solving experienced positive changes in emotions and reported satisfactory outcomes. These findings suggest that having a sibling with childhood cancer can potentially be a major stressor, which can influence mental health outcomes such as life balance. Furthermore, this theory establishes a relationship between personal and environmental factors, including social support and income, and sibling outcomes (Gold, Treadwell, Weissman, & Vichinsky, 2008).

Family Systems Theory

According to the family systems theory, a family can be thought of as a single, complex unit that consists of family members who are not only dependent upon each other, but exert considerable influence on each other (Minuchin, 1988; Cox, 2010). Whenever a change occurs in one part of the family system, it effects the entire system (Bronbrenner, 1986; Williams, Williams, & Williams, 2014). In addition, several

researchers suggest that the relationship between siblings plays an important role in emotional and behavioral development even through adulthood (Davies, 1991; Cox, 2010; Foster et al., 2011; Kramer, 2014). It follows that having a sibling diagnosed with cancer not only has a profound influence on the family system as a whole, but each individual member of the family, including siblings. Furthermore, this influence lasts throughout the entire life span.

Conceptual Framework

Chapter Summary

Having a sibling with cancer can be both a positive and negative experience. For example, a sibling's cancer can cause feelings of guilt, jealousy, and sadness. In other instances, healthy siblings may experience increased closeness in the family and greater maturation. Research examining the psychosocial outcomes of healthy siblings has led to mixed results, with some researchers finding that healthy siblings are not at a higher risk for social and emotional problems, while others have concluded the exact opposite.

Healthy siblings are also plagued with academic problems; however, the literature suggests that these problems do not persist into adulthood. Sociodemographic factors that influence the outcomes of healthy siblings are gender, socioeconomic status, and age difference. In addition, social support also plays a role in outcomes. Literature supports the influence of the sibling bond on emotional development, the influence of cancer on the sibling relationship, and the effect of bereavement on social and emotional outcomes. Transactional model of stress and coping and family systems theory both support a connection between life balance, social support, and perceived social support. This is the first study to my knowledge that actually examines the relationship between life balance and having a sibling with childhood cancer, though the literature suggests a relationship may exist.

CHAPTER III

METHOD

The purposes of this study are to (a) compare life balance outcomes of adult healthy siblings with the normal population, (b) explore the relationship between life balance and bereavement in adult healthy siblings of an individual who has been diagnosed with cancer in childhood, and (c) examine the relationship between life balance and social support. This study is intended to contribute to a better understanding of life balance in adult healthy siblings and, therefore, contribute to the knowledge base of mental health providers around this issue.

The major research questions for this study are as follows:

1. What is the extent of the differences in life balance outcomes for the siblings of individuals who were diagnosed with childhood cancer and the norm group of the JBLI?
2. After controlling for time since diagnosis and income, what is the extent of the differences in life balance outcomes for bereaved and non-bereaved siblings?
3. What is the relationship between life balance and social support?
4. What is the relationship between life balance and perceived social support?

This chapter contains a description of the research design and setting, inclusion and exclusion criteria, instruments, recruitment strategies, ethical considerations and the data analysis.

Participants

Participants were included in this study if they (a) were between the ages of 18 and 45, (b) grew up in the same household with a sibling who was diagnosed with cancer before the sibling turned 19, (c) had no psychiatric hospitalizations within the past 6 months, and (d) could read and respond to English. Participants were excluded from the study if (a) they were diagnosed with a psychotic disorder, (b) their sibling died less than 6 months prior to the date of study, (c) they were diagnosed with a neurological, psychotic, or developmental disorder.

Procedure

Participants were recruited for this study through social media posts on Reddit, Facebook and postings in “UofL Today,” the University of Louisville’s campus e-newsletter (7.5%, $n=9$), and Amazon Mechanical Turk (MTurk) (92.5%, $n=111$). The study was approved by the Institutional Review Board (IRB) of the University of Louisville (See Appendix A).

Participants recruited through Reddit, Facebook, and UofL Today postings were provided information about the study, which included access to an online link to the survey on Qualtrics. Eligibility was clearly described in a letter that the participants read prior to completing the survey. Participants were required to complete a preamble consent form before they could access the survey. Research participants recruited using social media and UofL today were given the option to enter into a random drawing to win one of eight \$50 gift cards once they completed the survey. Because MTurk participants were already being compensated, it was decided that they would not be allowed to enter into the drawings for a \$50 gift cards. As a result, two separate preamble consent forms

were created, one for participants recruited via social media and UofL today (Appendix B) and one for participants recruited via MTurk (Appendix C).

MTurk is a crowdsourcing platform that lets researchers, or “Requesters,” post their research requests, which MTurk refers to as “Human Intelligence Tasks” (HITs). HITs usually involves tasks that can be completed with minimal or no training and tasks that only humans can complete. Each HIT contains the name of the Requester, the amount of compensation that will be received for completing the task, and a brief description of what the HIT entails. The humans who complete the HITs are referred to as “Workers”. Workers can browse from a list of available HITs on the MTurk website and select the specific ones they would like to complete. Once the Worker successfully completes the HIT, they are compensated through Amazon’s MTurk website.

Researchers examining MTurk reliability have found that research participants recruited via MTurk are more socio-economically, demographically, and ethnically diverse than other traditional research samples, i.e. college students, internet samples, or laboratory samples (Buhrmester, Kwang, & Gosling, 2011; Casler, Bickel, & Hackett, 2013; Paolacci & Chandler, 2014; Bui, Myerson, & Hale, 2015). MTurk allows participants to be recruited quickly and cost-effectively when compared to other methods (Buhrmester et al., 2011; Holden, Dennie, & Hicks, 2013; Bui et al., 2015).

Compensation rates are not related to data quality on subjective response tasks (Buhrmester et al., 2011; Paolacci & Chandler, 2014). Data provided by MTurk participants is just as or more reliable than data obtained through traditional research methods (Buhrmester et al., 2011; Johnson & Borden, 2012; Casler et al., 2013; Holden

et al., 2013; Bui et al., 2015). In addition, MTurk workers are more attentive to instructions than traditional research samples (Hauser & Schwarz, 2016).

Participants recruited via MTurk were compensated \$2.25 for completing the survey. A description and a link to the survey were posted on the MTurk site. Once participants clicked on the link, they were sent to Qualtrics where the survey was completed. No research data was collected through the MTurk website. The participants were required to use the mouse to explicitly state that they have read, understood, and agreed to the information on the preamble consent form before they could begin the survey. Qualtrics generated a random code for each MTurk participant. The code was presented to the MTurk participants once the participants completed the survey. The participants were then instructed to enter the code into MTurk to receive payment. The Qualtrics-assigned codes (recorded in the data) were compared to the list of Worker-entered codes on MTurk. For each verified matching code, payment was approved for that worker.

Measures and Covariates

Juhnke-Balkin Life Balance Inventory

The Juhnke-Balkin Life Balance Inventory (JBLI) is an 81-item self-report measure used to measure life balance (Davis et al., 2014). There are 9 demographic questions on the JBLI, including age and marital status. The remaining 72 all contain declarative statements that must be rated on a 5-point Likert-type scale from *Strongly Agree* to *Strongly Disagree*. The items on the JBLI were derived from theory and a review of the literature (Davis et al., 2014). Evidence of internal structure was demonstrated through exploratory factor analysis. Evidence of relationship to other

variables was demonstrated through regression analyses with the Outcome Questionnaire 45.2 (Davis et al., 2014). The JBLI has ten subscales (Davis et al., 2014): 1) Positive Orientation, (e.g., *My future looks exciting to me*); 2) Stress/Anxiety, (e.g., *I tend to overreact to stressful events*); 3) Substance Use/Abuse, (e.g., *Within the last 6 months I have not misused prescription drugs*); 4) Spiritual Support, (e.g., *I am comfortable with my spiritual–religious beliefs*); 5) Friendship, (e.g., *My friendships and interpersonal relationships with others are mostly rewarding*); 6) Sleep Disturbance, (e.g., *I often awaken at least once a night and have difficulty falling back to sleep*); 7) Career, (e.g., *I am good at what I do in the workplace*); 8) Sex/Intimacy, (e.g., *I generally find little sexual joy or satisfaction*); 9) Global Health, (e.g., *I have few if any major aches or pains*); and 10) Quality of Relationships, (e.g., *My marital partner or significant other and I have a good relationship*). The reliability of the scores for each of the ten subscales was estimated to be between 0.77 and 0.92 (Davis et al., 2014).

Medical Outcomes Study: Social Support Survey.

The Medical Outcomes Study: Social Support Survey (MOS-SSS) is a 19-item self-report measure used to measure different types of social support that a person is able to access (Sherbourne & Stewart, 1991). Each of the 19 items contains declarative statements that must be rated on a 5-point Likert-type scale from *All of the Time* to *None of the Time* and are summed to produce each subscale total. There are four subscales, (Sherbourne & Stewart, 1991): 1) Emotional/ Informational support, (e.g., *Someone to give you good advice about a crisis*); 2) Tangible support, (e.g., *Someone to prepare your meals if you were unable to do it yourself*); 3) Positive social interaction, (e.g., *Someone to have a good time with*); and 4) Affectionate support, (e.g., *Someone who shows you*

love and affection). Four subscales were identified using a multi-trait scaling analysis; results were replicated using a confirmatory factor analysis (Sherbourne & Stewart, 1991). The reliability for the overall score of the MOS-SSS has been estimated to be 0.97 (Sherbourne & Stewart, 1991). The reliability of the scores was estimated to be 0.96 for Emotional/Informational support, 0.92 for Tangible Support, 0.91 for Affectionate Support, and 0.94 for Positive Interaction (Sherbourne & Stewart, 1991).

Multidimensional Scale of Perceived Social Support

The Multidimensional Scale of Perceived Social (MSPSS) is a 12-item self-report measure used to measure one's perception of social support available from one's family, friends, and a significant other (Zimet et al., 1988). The MSPSS items contain a declarative statement that has to be rated on a 7-point Likert-type scale from *Very Strongly Disagree* to *Very Strongly Agree*. There are three subscales (Zimet et al., 1988): 1) Family, (e.g., *My family really tries to help me*); 2) Friends, (e.g., *I can talk about my problems with my friends*); and 3) Significant Other, (e.g., *There is a special person in my life who cares about my feelings*). Several researchers who have used the MSPSS in their studies have found the internal reliability estimates of the MSPSS total score and subscale scores to be greater than 0.85 across different samples including American and Spanish students (Calvete & Connor-Smith, 2006), college students (Clara, Cox, Enns, Murray, & Torgrudc, 2003), urban adolescents (Canty-Mitchell & Zimet, 2000), Mexican Americans enrolled in college (Miville & Constantine, 2006), and students enrolled in an urban college (Dahlem, Zimet, & Walker, 1991). The three-factor structure of the MSPSS has been confirmed through multiple factor analyses (Canty-Mitchell & Zimet, 2000; Dahlem et al., 1991).

Demographic Survey

The researcher created a self-report survey for the purposes of this study. Participants were asked to report basic demographic information using this survey. The demographic information includes sex, age, level of education, ethnicity, employment status, time since sibling's cancer diagnosis, time since sibling's death, sibling's cancer diagnosis, number of siblings living in household during cancer diagnosis, current marital status, and current household income. Sibling health-related factors included self-reported general health using a five-category response scale: poor, fair, good, very good, and excellent. Sibling cancer-related factors included healthy sibling's age at diagnosis of the sibling with cancer, age of cancer sibling at diagnosis, and relative ages of the survivor and the sibling age (i.e., survivor older/sibling older). Participants were asked to report any mental/physical conditions that they have been diagnosed with and any mental/physical conditions for which they are currently being treated.

Time Since Diagnosis

Time since diagnosis was measured using the demographic survey that the researcher created. Several researchers have found that the time since the cancer diagnosis influences healthy sibling outcomes (Alderfer et al., 2003; Hamama et al., 2000; Houtzager et al., 2003, 2004; Lähteenmäki et al., 2004). In particular, the more time that has passed since the sibling's diagnosis, the better the outcomes for the healthy sibling tend to be.

Income

Income was measured using the demographic survey that the researcher created. The item on the demographic survey that measures income asks, "What is your annual

household income?” Several studies suggest that siblings in families from high socioeconomic status backgrounds have better adjustment and outcomes (Barbarin et al., 1995; Buchbinder et al., 2011; Cohen et al., 1994; Sahler et al., 1994; Sloper & While, 1996; Van Dogen et al., 1995; Zeltzer et al., 1996, 2008). Income is commonly used to indicate socioeconomic status (Buchbinder et al., 2011; Cohen et al., 1994; Zeltzer et al., 1996, 2008).

Research Design and Setting

This research study employed a quantitative, cross-sectional survey design. Cross-sectional studies involve collecting data from participants at a single point in time (Creswell, 2013). A cross-sectional design was chosen because it allowed the researcher to compare multiple variables at the same time. Survey studies produce quantitative data of a specific population being studied, which is analyzed by the researcher and used to make conclusions about the population under investigation (Fowler, 2013). The survey method was chosen because it allowed large amounts of data to be collected quickly.

This survey was conducted via Qualtrics, a web-based platform. Web-based surveys do not require paper resources, nor do they require costs associated with distribution and printing (i.e., postage). Participants were able to complete web-based surveys at their own convenience, which increased the likelihood of disclosing sensitive information (Pealer, 1999). Another benefit to web-based survey is that it expands the potential study sample to include any adults in the United States with access to the Internet. For instance, 87% of Americans age 18 and older use the Internet (Pew Research Center, 2014), and over 74% have access to the internet in their home (File & Ryan, 2014). In addition, 77% of Whites, 61% of Blacks, 86% of Asians, and 66% of

Hispanics have access to the internet in their homes. Internet users also come from a variety of educational, geographic, and income levels (File & Ryan, 2014). For example, 77% of individuals with an annual household income of less than \$30,000, 85% with an annual household income between \$30,000 and 49,999, 93% of households with an annual household income between \$50,000 and \$74,000, and 99% of households with an annual household income over \$75,000 use the Internet (Pew Research Center, 2014).

In order to prevent people from sending in multiple surveys, survey responses were screened for multiple IP addresses. If duplicate IP addresses were found in the data, the participant's responses were excluded from the analysis. In order to increase the reliability of the data, a duplicate question was included and the responses were checked for accuracy. For example, one survey question required participants to select whether they were older, younger, or the same age as their sibling with cancer. Two other items on a separate page required participants to list both their age when their sibling was diagnosed with cancer, and their sibling's age. The responses on these items were compared. If there was a discrepancy in the responses, (e.g. if the participant indicated that they were older than their sibling, but reported that they were 6 and their sibling was 8 when the sibling was diagnosed, which would make the sibling with cancer older) the participant's responses were excluded from the analysis. Text responses were also examined to make sure participants were paying attention and completing the survey correctly.

Data Analysis

There are four hypotheses that were tested. The first hypothesis is that there is a significant difference in life balance outcomes for adult healthy siblings and the JBLI

norm group (Davis et al., 2014). The second hypothesis is that a significant difference in life balance outcomes for bereaved and non-bereaved siblings. The third hypothesis is that there is a significant, positive relationship between life balance and social support. Lastly, a significant, positive relationship exists between life balance and perceived social support.

The first hypothesis was evaluated using a multiple analysis of variance (MANOVA). MANOVA requires one or more categorical independent variables and two or more continuous dependent variables (Pituch & Stevens, 2015). In this study, the 10 life balance subscales were the dependent variables since the JBLI does not contain a total life balance scale (Davis et al., 2014). The independent variable was adult sibling status (either you are a part of the JBLI norm group, or you are an adult healthy sibling of an individual with childhood cancer).

The second hypothesis was evaluated using a multiple analysis of covariance (MANCOVA). MANCOVA requires one or more categorical independent variables, one or more covariates, and two or more continuous dependent variables (Pituch & Stevens, 2015). The 10 life balance subscales were the dependent variables for the second hypothesis (Davis et al., 2014). The independent variable was bereavement and the covariates were time since diagnosis and income.

The third and fourth hypotheses were answered using multiple regression. In the third hypothesis, the dependent variables were the ten JBLI subscales and the independent variable was the MOS-SSS total score. In the fourth hypothesis, the dependent variables were the ten JBLI subscales and the independent variable was the MSPSS total score.

In order to use MANCOVA, Pituch & Stevens (2015) reported that there should be a significant relationship between the covariates and the dependent variables. Correlation analyses were performed in order to test this assumption. MANCOVA and MANOVA require homogeneity of variance (Pituch & Stevens, 2015). Box's Test of Equality of Covariance Matrices was conducted to test the assumptions of homogeneity of variance and covariance matrix. Bartlett's Test of Sphericity was used to test the assumption of the variance of covariance. The assumption of homogeneity of regression coefficients was evaluated by examining the interaction effect of the independent variable and the covariates on the dependent variables.

MANCOVA, MANOVA, and multiple regression assume normality of data (Pituch & Stevens, 2015). Therefore, the distribution of data was examined for normality. In order for there to be multivariate normality, one of the conditions is that there is univariate normality (Pituch & Stevens, 2015); therefore, each variable was separately tested for normality. A Shapiro-Wilks analysis was run to determine normality as well as kurtosis and skewness.

In multiple regression, it is assumed that a linear relationship exists between the independent and dependent variables (Pituch & Stevens, 2015). This assumption was checked by looking at scatterplots of the data. The assumption of homoscedasticity was also examined by looking at scatterplots. Tolerance and VIF values were examined to make sure that multicollinearity was not an issue. Data was checked for outliers, since outliers can have a major influence on the size of the correlation coefficients (Pituch & Stevens, 2015). Data was also examined for auto-correlation.

Alpha level was set to $p < 0.05$. All data was entered into a computer software program and analyzed. Descriptive analyses (frequencies, means, standard deviations, ranges, correlations) were completed for demographic variables in order to describe the sample.

Ethical Considerations

Protection of Human Subjects

IRB approval was obtained from the University of Louisville. All participants signed an electronic informed consent form prior to participating in the study. Participation in this study was completely voluntary. Participants were notified that they had the right to leave the study at any time. To maintain confidentiality, consent forms with participant identifiers linked to the study number were maintained in a password-accessible file separate from any data. All electronic data was maintained in a password-accessible file available only to the study researchers. Participants were able to contact the researcher at any time with questions and/or clarification of the study.

Risks to Subjects

No major risks were anticipated to result from participation in this study. One possible risk was anxiety and sadness provoked by the discussion of sensitive issues related to their experiences as a sibling of an individual with cancer. In order to reduce this risk, participants were able to terminate the survey at any point.

Potential Benefits to Subjects

Subjects may have directly benefited from participating in this study by developing insight into the connections between their life outcomes and their experiences as a healthy sibling of an individual with cancer. Though it is not a direct benefit to

participants, they could be assured that the information that they are providing by participating in this study will be critical in helping healthy siblings of individuals with childhood cancer in the future.

Chapter Summary

The purpose of this study was to examine the life balance outcomes of adult healthy siblings of individuals who were diagnosed with childhood cancer. This research study employed a quantitative, cross-sectional survey design that allowed participants to complete the survey via web-based platform. Participants were recruited through social networking sites (Reddit and Facebook) and through Amazon's MTurk service. Life balance was measured by the Juhnke-Balkin Life Balance Inventory. Social support was measured by the Medical Outcomes Study: Social Support Survey and perceived social support was measured by the Multidimensional Scale of Perceived Social Support. A demographic survey was also used to collect basic demographic information such as age, ethnicity, and employment status. Data analysis methods included MANOVA, MANCOVA, and multiple regression. The alpha level for all statistical tests were set to 0.05. The results for the data analysis will be presented in the next chapter.

CHAPTER IV

RESULTS

In chapter four, the results of this research study are examined. The purpose of this study was to investigate the life balance outcomes of adult healthy siblings of individuals with childhood cancer, the role that social support plays life balance outcomes, and explore the relationship between life balance and bereavement in adult healthy siblings of individuals who have been diagnosed with cancer in childhood.

Demographic descriptions of the study sample are presented in chapter four. The results of correlations, multivariate analyses, and multiple regressions are also provided.

Participants

Adult Healthy Siblings

The subjects for this study were 120 adult healthy siblings who grew up in a household with a sibling that was diagnosed with cancer prior to age 19. At the time of completing this survey study, adult healthy siblings ranged in age from 19 years to 45 years, with an average age of 30 (S.D. 6.17). Fifty-nine percent ($n=71$) of the adult healthy siblings were male and 41% ($n=49$) were female. Yearly household income for the adult healthy siblings ranged from \$0 to \$210,000 with an average of \$59,068 (S.D. \$40,020). In terms of racial identity, 77% ($n=92$) of adult healthy siblings identified as White, 11% ($n=13$) identified as Black or African American, and 8% ($n=10$) identified as Asian, and 4% ($n=5$) identified as other racial categories. In terms of ethnic identity, 7% ($n=8$) of adult healthy siblings identified as Hispanic or Latino, while 93% ($n=112$) did

not. Thirty-five percent ($n=42$) were married, 5% ($n=6$) were divorced, 32% ($n=38$) were single or never married, 27% ($n=33$) were members of an unmarried couple, and close to 1% ($n=1$) were separated. Most of the adult healthy siblings (68%, $n=82$) have at least an Associate degree. Almost all of the adult healthy siblings (98%, $n=117$) described their health as Good (38%, $n=46$), Very Good (44%, $n=53$), or Excellent (15%, $n=18$). Seventy-two percent ($n=86$) of adult healthy siblings were employed full-time, 10% ($n=12$) were employed part-time, 7% ($n=8$) were self-employed, 8% ($n=9$) were full-time college students, 2% ($n=3$) were homemakers, and close to 2% ($n=2$) were military.

At the time of completing this study, the adult healthy siblings reported that their sibling was diagnosed with cancer between 1 and 34 years prior, with an average time since diagnosis of 17.7 years (S.D. 7.65 years). The age of the adults at the time that their sibling was diagnosed with cancer ranged from 2 years to 31 years, with an average of 12.88 years (S.D. 5.34 years). Most adult healthy siblings (50%, $n=60$) were between the ages of 10 and 16 when their sibling was diagnosed with cancer. A majority of the siblings (92.5%, $n=111$) were biologically related, 4% ($n=5$) were adopted siblings, and 2.5% ($n=3$), were siblings by marriage. Eleven percent ($n=13$) of adult healthy siblings reported that only they and the sibling with cancer was living in the household at the time of the cancer diagnosis, 45% ($n=54$) reported having two siblings living in the household, 33% ($n=40$) had three siblings, 9% ($n=11$) had four siblings, and 2% ($n=2$) had 5 siblings. Seventy-one percent ($n=85$) of the adult healthy siblings are older than the sibling with cancer, 26% ($n=32$) are younger than the sibling diagnosed with cancer, and 3% ($n=3$) are the same age as the sibling diagnosed with cancer. Almost all of the adult healthy

siblings (92%, $n=111$) described their relationship with their sibling with cancer as Good (28%, $n=33$), Very Good (35%, $n=42$), or Excellent (29%, $n=35$).

Sibling with Cancer

The age of the sibling at the time that he/she was diagnosed with cancer ranged from less than 1 year to 18 years, with an average of 10.4 years (S.D. 4.54 years). Most siblings (53%, $n=64$) were between the ages of 9 and 15 when they received their cancer diagnosis. The four most common cancer diagnoses were leukemia (48%, $n=58$), lymphoma (8%, $n=10$), melanoma (7%, $n=8$), and bone cancer (6%, $n=7$).

JBLI Norm Group

The JBLI norm group consisted of 178 males and 166 females, with ages ranged from 18 years to 67 years, with an average age of 30.28 (S.D. 10.64). One hundred eighty-eight participants were recruited from non-clinical settings, while 166 were recruited from clinical settings (Davis et al., 2014).

Research Questions

Research Question 1

Is there a significant difference in life balance outcomes for the siblings of individuals who were diagnosed with childhood cancer and the JBLI norm group? A one-way MANOVA was conducted to determine if there was a significant difference in life balance outcomes between the JBLI norm group and adults who had siblings that were diagnosed with childhood cancer (Davis et al., 2014). The JBLI norm group is separated into two groups: clinical and nonclinical. Descriptive statistics for the dependent variables across study groups are shown in Table 1.

Table 1

Basic Descriptive Statistics for the JBLI and Adult Sibling Groups

Variable	<i>JBLI Clinical</i>			<i>JBLI Non-clinical</i>			<i>Adult Healthy Siblings</i>		
	<i>M</i>	<i>SD</i>	<i>N</i>	<i>M</i>	<i>SD</i>	<i>N</i>	<i>M</i>	<i>SD</i>	<i>N</i>
Career	3.67	0.63	180	3.90	0.67	166	3.75	0.70	120
Friendship	3.80	0.68	180	4.17	0.59	166	3.83	0.65	120
Global Health	3.38	0.76	180	3.30	0.77	166	3.59	0.63	120
Positive Orientation	3.83	0.68	180	4.15	0.64	166	3.89	0.67	120
Quality Relationships	3.53	0.75	180	3.81	0.90	166	3.91	0.84	120
Stress/Anxiety	3.08	0.77	180	3.19	0.78	166	3.42	0.81	120
Sleep Disturbance	3.03	0.92	180	3.17	0.83	166	3.35	0.90	120
Sex/Intimacy	3.74	0.70	180	3.83	0.74	166	3.85	0.70	120
Spiritual Support	3.81	0.78	180	3.94	0.85	166	3.53	0.71	120
Substance Use	3.16	0.87	180	3.98	0.85	166	3.89	0.77	120

Normality was examined by looking at box plots of the data. Some of the normal q-q plots showed slight deviation from normality, but since MANOVA is robust to minor deviations from normality (Pituch & Stevens, 2015), the MANOVA was interpreted. Only two of the ten subscales had minor deviations from normality at the univariate level.

Preliminary assumption checking revealed that there were two univariate outliers in the non-clinical group on the Positive Orientation Scale, as assessed by inspection of a boxplot for values greater than 1.5 box-lengths from the edge of the box. There were four multivariate outliers, as assessed by a Mahalanobis distance of greater than 29.59, $p > .001$ (Pituch & Stevens, 2015). Both a MANOVA and discriminant analysis were ran with and without the outliers. Results of the analyses were essentially the same, so the outliers were maintained in the analyses.

Barlett's Test of Sphericity was used. Results revealed that the analysis was statistically significant, approximate chi square = 1742.525, $p < .05$. This indicated that the correlation between the dependent variables was sufficient to run a MANOVA. As shown

in Table 2, there was no multicollinearity, as assessed by Pearson correlation $r < .68$ for all combinations of dependent variables, $p < .05$ (Pituch & Stevens, 2015). The research design eliminated the issue of independent observation, as explained earlier.

Table 2

Pearson Correlation Matrix for JBLI Subscales

	CS	FS	GHS	POS	QRS	SAS	SDS	SIS	SSS
Friendship (FS)	.44**								
Global Health (GHS)	.32**	.46**							
Positive Orientation (POS)	.49**	.68**	.5**						
Quality Relationship (QRS)	.27**	.35**	.27**	.49**					
Stress Anxiety (SAS)	.37**	.47**	.49**	.62**	.33**				
Sleep Disturbance (SDS)	.24**	.35**	.45**	.53**	.33**	.55**			
Sex Intimacy (SIS)	.31**	.47**	.41**	.56**	.55**	.39**	.33**		
Spiritual Support (SSS)	.30**	.37**	.27**	.47**	.19**	.29**	.29**	.21**	
Substance Use (SUS)	.26**	.31**	.16**	.41**	.30**	.29**	.23**	.22**	.17**

** $p < 0.01$.

Box's Test was used to check the assumption of homogeneity of the covariance matrices. Analysis revealed that *Box's M* was significant (*Box's M* = 157.428, $F = 1.386$, $p < .05$), which indicates that the dependent variable covariance matrices are not equal across the levels of the independent variable (three groups). Given the large sample size among the three groups (see Table 1), it is not surprising that Box's Test was found to be significant. A significant Box's Test can signify that there is an increased probability of making a Type I error. In order to account for this, the alpha level for Research Question

1 was reduced to 0.01. Field (2009) recommended using Pillai's Trace to determine multivariate significance in instances where *Box's M* is significant.

Results. Pillai's Trace was significant, $\Lambda_{\text{Pillai}} = .414$, $F(20, 910) = 11.890$, $p < .01$. This indicates that there is a significant difference in life balance outcomes for the adult healthy siblings and the JBLI norm group. Effect size is the measure of the observed effect that is explained in the statistical analysis (Field, 2009). For this analysis, partial eta square was determined to be .207 for Pillai's Trace. This indicated that 20.7% of the total variance in life balance outcomes was accounted for by group membership. Practical significance was assessed using Cohen's *d*. A moderate effect size was noted between the adult sibling group and the JBLI clinical group on Stress/Anxiety ($d = .435$), adult sibling group and JBLI non-clinical group on Friendship ($d = -.547$), and adult sibling group and JBLI non-clinical group on spiritual support ($d = -.526$). Large effect sizes were noted between adult sibling group and JBLI clinical group on substance use ($d = .880$). Large effect sizes were indicative of very strong practical significance (Cohen, 1988; Pituch & Stevens, 2015).

A post hoc discriminant analysis was conducted to determine how the study group differences were manifested across the dependent variables. Table 3 provides the structure coefficients and the standardized discriminant function correlation coefficients. The first discriminant function was significant, Wilks' $\lambda = .628$, chi-squared (20) = 212.960, $p < .001$. Approximately 53% of the variance in the model was accounted for in the first discriminant function across study groups. Friendship ($r = .623$), Global Health ($r = -.706$), and Positive Orientation (.774) are strongly correlated with the first discriminant function. Friendship ($r = .473$), Positive Orientation ($r = .366$), Spiritual

Support ($r = .349$) and Substance use ($r = .349$) all loaded strongly on the first discriminant function. Based on this, the first discriminant function is called Positive Social Worth. Substance use ($r = .863$), is strongly correlated with the second discriminant function. The JBLI non-clinical group had the highest scores in Positive Social Worth, while the adult healthy siblings had the lowest scores. Centroid means for the discriminant functions indicated that the JBLI non-clinical group (.672) had the most effect in Function 1, compared to the adult sibling group (-.615) and JBLI clinical group (-.210) samples.

The second discriminant function was significant, Wilks' $\lambda = .802$, chi-squared (9) = 100.890 $p < .001$. Approximately 47% of the variance in the model was accounted for in the second discriminant function. Substance use ($r = .863$) is strongly correlated with the second discriminant function. Substance use ($r = .838$), Quality relationships ($r = .391$), and stress/anxiety ($r = .322$) all loaded strongly on the second discriminant function. Based on these results, the second discriminant function is called Emotional Fulfillment. The adult healthy sibling group had the highest scores in emotional fulfillment, while the JBLI clinical group had the lowest scores. Centroid means for the discriminant functions indicated that the adult sibling group (.608) had the most effect in Function 2, compared to the JBLI clinical group 1 (-.591) and JBLI non-clinical group (.202) samples.

Table 3

Correlation Coefficients and Standardized Function Coefficients of JBLI subscales

Variable	<i>Function 1</i>		<i>Function 2</i>	
	Correlation Coefficients with Discriminant Function	Standardized Function Coefficients	Correlation Coefficients with Discriminant Function	Standardized Function Coefficients
Career	.23	.05	.18	.05
Friendship	.47	.62	.20	.08
Global Health	-.26	-.71	.15	.06
Positive Orientation	.37	.77	.20	-.41
Quality Relationships	.03	-.19	.39	.34
Stress/Anxiety	-.125	-.54	.32	.24
Sleep Disturbance	-.08	-.14	.28	.20
Sex/Intimacy	.02	-.17	.14	-.13
Spiritual Support	.35	.24	-.18	-.41
Substance Use	.35	.21	.83	.86

Research Question 2

After controlling for time since diagnosis and income, what is the extent of the differences in life balance outcomes for adults whose siblings survived childhood cancer vs. those whose sibling died? Descriptive statistics for the dependent variables across bereavement groups are shown in Table 4.

Table 4

Basic Descriptive Statistics for Bereaved and Non-Bereaved Siblings

Variable	<i>Bereaved Siblings</i>			<i>Non-Bereaved Siblings</i>		
	<i>M</i>	<i>SD</i>	<i>N</i>	<i>M</i>	<i>SD</i>	<i>N</i>
Career	3.87	.55	19	3.72	.73	100
Friendship	4.06	.48	19	3.78	.68	100
Global Health	3.72	.55	19	3.57	.65	100
Positive Orientation	3.99	.63	19	3.87	.68	100
Quality Relationships	4.20	.59	19	3.85	.87	100
Stress/Anxiety	3.59	.85	19	3.38	.80	100
Sleep Disturbance	3.70	.80	19	3.28	.91	100
Sex/Intimacy	3.92	.62	19	3.83	.72	100
Spiritual Support	3.56	.73	19	3.52	.71	100
Substance Use	3.84	.62	19	3.90	.80	100

The issue of data normality was discussed in the previous assumption section. In order to use MANCOVA, Pituch & Stevens (2015) reports that there should be a significant relationship between the covariates and the dependent variables. As shown in Table 5, there is a significant relationship between the covariate time since diagnosis and the dependent variable Stress/Anxiety, $r=.206$, $n=20$, $p<.05$ and Substance Use, $r=.183$, $n=120$, $p<.05$. However, there is not a significant relationship between time since diagnosis and the other 8 subscales. Given that the literature suggests that time since diagnosis may have an influence on life balance outcomes and that 2 of the subscales are significantly correlated with time since diagnosis, the decision was made to proceed with time since diagnosis as a covariate. If you look at Table 5, you can see that there is a significant relationship between the covariate income and 9 of the 10 the dependent variables. Therefore, income was also kept as a covariate. Neither covariate was

significantly related to the Spiritual Support Subscale (Time since diagnosis, $r = .084$, $n=120$, $p > .05$; Income, $r = .113$, $n=119$, $p > .05$).

Table 5

Pearson Correlation Matrix for Covariates and Dependent Variables

	CS	FS	GHS	POS	QRS	SAS	SDS	SIS	SSS	SuS
Time Since Diagnosis	.14	.06	.02	.07	.03	.21**	.15	.05	.08	.18*
Income	.32**	.29**	.29**	.33**	.23*	.25**	.18*	.22*	.11*	.25**

** $p < 0.01$. * $p < 0.05$.

There was one univariate outlier in the data in the bereaved sibling group on the Friendship scale, as assessed by inspection of a boxplot for values greater than 1.5 box-lengths from the edge of the box. This outlier was kept since it was determined that this was an accurate reflection of the data and it had minimal influence on the analysis. There were three multivariate outliers, as assessed by a Mahalanobis distance of greater than 29.59, $p > .001$. MANCOVA analysis was performed both with and without the multivariate outliers. The MANCOVA results with and without the outliers were compared; they were essentially the same. Therefore, the decision was made to keep the multivariate outliers in the analyses.

There was a linear relationship between the covariates (time since diagnosis and income) and dependent variables for both the bereaved and non-bereaved group, as assessed by visual inspection of scatterplots. Normality was examined by looking at box plots of the data. Some of the normal q-q plots showed deviation from normality. Since $N < 50$ for the bereaved group, the Shapiro-Wilk's statistic was examined. The Shapiro-Wilk's statistic was not significant for all subscales except Friendship. Standardized residuals were not normally distributed for the non-bereaved group on the quality

Relationship Scale, Sex/Intimacy Scale, or Spiritual Support Scale, as assessed by Shapiro-Wilk's test ($p > .05$). This means that the within-group residuals for those scales violates the normality assumption. Given that MANCOVA is robust to deviations from normality (Pituch & Stevens, 2015), the test was ran anyway.

Prior to conducting the main analysis, the assumption of homogeneity of regression coefficients was evaluated by examining the interaction effect of the independent variables (bereaved and not bereaved) and the covariates of time since diagnosis and income on the dependent variables (10 JBLI subscales). If you look at the interaction term (Q17 * Time_DX), you will see that the interaction is not significant, $F(10, 104) = .259, p > .05$. The second interaction term (Q17 * Q19), is also not significant, $F(10, 104) = .204, p > .05$. This indicated that the slopes for each of the two levels of the independent variable were equal. There was homoscedasticity, as assessed by looking at the standardized residuals plotted against the predicted values. Examining scatterplots suggested that each covariate is positively and linearly related to each of the 10 outcome variables.

Box's Test of Equality of Covariance Matrices was conducted to test the assumptions of homogeneity of variance and covariance matrix. Box's Test was not significant (*Box's M* = 89.538, $F = 1.279, p > .05$), which indicates that the dependent variable covariance matrices are equal across the two independent variables (bereaved and not bereaved). Since Box's Test was not significant, Wilks' Lambda was used when examining multivariate effect. Bartlett's Test of Sphericity tests the assumption of the variance of covariance. Bartlett's Test of Sphericity was statistically significant

(approximate chi square = 458.268, $p < .05$), which indicates that the covariance matrix is an identity matrix. Therefore, the MANCOVA can be conducted.

Results. Wilks' Lambda for bereavement status was not significant, $\Lambda_{\text{Wilk}} = .932$, $F(10, 106) = .770$, $p < .05$. This indicates that there is not a significant difference in life balance outcomes for bereaved and non-bereaved siblings.

Research Question 3

What is the relationship between life balance and social support? Normality of the three social support variables was examined by looking at box plots of the data. All three of the social support variables (Significant Other, Friends, Family) were negatively skewed and contained several outliers. Therefore, the normality assumption was violated for the social support subscales. As Table 6 shows, there is a significant correlation between the ten JBLI subscales and the three MOS-SSS subscales. The MOS-SSS Friends Scale was highly correlated with the MOS-SSS Family Scale, $r = .804$, $n = 120$, $p < .01$.

Table 6

Pearson Correlation Matrix for Social Support and Life Balance Subscales

	CS	FS	GHS	POS	QRS	SAS	SDS	SIS	SSS	SUS	SOS	Fam S
Significant Other (SOS)	.32**	.50**	.32**	.53**	.66**	.30**	.37**	.60**	.28**	.28**		
Family (FamS)	.36**	.57**	.45**	.49**	.41**	.42**	.40**	.41**	.17	.18*	.66**	
Friends (FriS)	.37**	.66**	.52**	.61**	.40**	.43**	.47**	.52**	.15	.20*	.61**	.80**

** $p < 0.01$. * $p < 0.05$.

Given the presence of a total scale for social support as measured by the MOS-SSS, it was determined that a multiple regression would be the most appropriate measure

for answering research question 3. Descriptive statistics for the JBLI Subscales can be found in Table 1. The adult healthy siblings had an average total social support score of 3.92 (S.D. .87).

Linearity assumption was met for the independent variables and social support as assessed by looking at partial regression plots and scatterplots of the studentized residuals against the predicted values. The homoscedascity assumption for social support was met, as assessed by visual examination of a plot of studentized residuals against the unstandardized predicted values. There was no evidence of multicollinearity, as assessed by tolerance values greater than 0.1 and VIF values less than 10 (Pituch & Stevens, 2015). As Table 2 shows, none of the independent variables have high correlations ($>.80$). Although the distribution of the data on the P-P plots is not perfectly aligned along the diagonal line, it is close enough to conclude that the residuals are close enough to normal for both multiple regression analyses to proceed. As multiple regression analysis is fairly robust against deviations from normality (Pituch & Stevens, 2015), it was determined that data transformation was not necessary. There were two outliers present, as assessed by studentized deleted residuals values greater than ± 3 standard deviations. A multiple regression was ran both with and without the outliers. There was only a minimal difference in terms of data normality and the Durbin Watson statistic decreased from 1.891 to 0.4, which meant that deleting the outliers led to autocorrelation issues so that the residuals were no longer independent (Fahidy, 2006; Gupta, Kabe, & NiwitPong, 2010). Therefore, none of the outliers were excluded from the analysis. Although there were 7 risky leverage values ($>3p/n$, or >0.275), there were no cook

values higher than 1 (there were no highly influential data points), so none of the data was excluded from the analysis on this basis (Pituch & Stevens, 2015).

Results. Review of literature did not suggest a theoretical grounding for the multiple regression; therefore, we used simultaneous multiple regression to examine the extent of the relationship between social support and the life balance scales. The dependent variable is social support; the ten life balance scales are the independent variables. R^2 for the overall model was 67.1% with an adjusted R^2 of 64.1%, a large size effect according to Cohen (1988). The ten life balance subscales statistically significantly predicted social support, $F(10, 109) = 22.277, p < .05$. Only Friendship, Positive Orientation, Quality Relationships, and Sex/Intimacy contributed significantly to the prediction, $p < .05$. In other words, adult cancer siblings with higher scores on these scales were expected to have higher social support, after controlling for the other variables in the model. Regression coefficients and standard errors can be found in Table 7.

Career was a not statistically significant predictor of social support and uniquely accounted for approximately 0.13% of the variance. Friendship was a statistically significant predictor of social support and uniquely accounted for approximately 8% of the variance. Global Health was not a statistically significant predictor of social support and uniquely accounted for approximately .33% of the variance. Positive Orientation was a statistically significant predictor of social support and uniquely accounted for approximately 1.3% of the variance. Quality Relationships was a statistically significant predictor of social support and uniquely accounted for approximately 4.2% of the variance. Stress/Anxiety was not a statistically significant predictor of social support and uniquely accounted for approximately .8% of the variance. Sleep Disturbance was not a

statistically significant predictor of social support and uniquely accounted for approximately .002% of the variance. Sex/Intimacy was a statistically significant predictor of social support and uniquely accounted for approximately 3.06% of the variance. Spiritual Support was not a statistically significant predictor of social support and uniquely accounted for approximately .7% of the variance. Substance Use was not a statistically significant predictor of social support and uniquely accounted for approximately .01% of the variance. Power was sufficient for this study; given the sample size of $n = 120$, statistical significance would be detected for small effect sizes, $R^2 > .22$ (Faul, Erdfelder, Lang, & Buchner, 2007).

Table 7

Multiple Regression for Social Support

Predictor	<i>B</i>	<i>SE B</i>	<i>B</i>	<i>t</i>	<i>p</i>	<i>sr</i> ²	<i>rs</i>
Career	.06	.08	.05	.67	.505	.001	.213
Friendship	.58	.11	.44	5.17	.000	.081	.703
Global Health	-.11	.11	-.08	-1.05	.295	.003	.294
Positive Orientation	.28	.13	.22	2.09	.039	.013	.569
Quality Relationships	.29	.08	.28	3.75	.000	.042	.641
Stress/Anxiety	-.15	.09	-.14	-1.68	.097	.008	.196
Sleep Disturbance	-.01	.08	-.01	-.07	.947	.000	.271
Sex/Intimacy	.31	.10	.25	3.18	.002	.030	.626
Spiritual Support	-.12	.08	-.1	-1.50	.136	.007	.121
Substance Use	-.02	.08	-.01	-.21	.831	.000	.175

Research Question 4

What is the relationship between life balance and perceived social support?

Normality of the four perceived social support variables was examined by looking at box plots of the data. All four of the perceived social support variables (Emotional/Informational, Tangible, Affectionate, and Positive Social Interaction) were negatively skewed. However, only affectionate support contained multiple outliers.

Therefore, the normality assumption was violated for the four perceived social support subscales.

As Table 8 shows, there is a significant correlation between the four perceived social support subscales and the ten JBLI subscales. Tangible Support was highly correlated with both Affectionate Support, $r = .806$, $n = 116$, $p < .01$ and Positive Social Interaction, $r = .827$, $n = 116$, $p < .01$. Affectional Support was also highly correlated with Positive Social Interaction, $r = .859$, $n = 116$, $p < .05$. Given the presence of a total scale score for perceived social support as measured by the MSPSS, it was determined that a multiple regression would be the most appropriate measure for answering research question 4. Descriptive statistics are reported in Table 9.

Table 8

Pearson Correlation Matrix for JBLI Subscales and Perceived Social Support

	CS	FS	GH	PO	QR	SA	SDS	SIS	SS	SU	EIS	TS	AS
Friendship (FS)	.44**												
Global Health (GH)	.33**	.61**											
Positive Orientation (PO)	.53**	.67**	.55**										
Quality Relationship (QR)	.26**	.48**	.37**	.53**									
Stress Anxiety (SA)	.40**	.55**	.48**	.67**	.32**								
Sleep Disturbance (SDS)	.29**	.53**	.58**	.58**	.44**	.61**							
Sex Intimacy (SIS)	.27**	.52**	.51**	.57**	.61**	.41**	.45**						
Spiritual Support (SS)	.28**	.43**	.37**	.54**	.32**	.43**	.35**	.28**					
Substance Use (SU)	.24**	.36**	.31**	.51**	.36**	.45**	.27**	.38**	.32**				
Emotional/Informational Support (EIS)	.37**	.72**	.49**	.58**	.59**	.36**	.37**	.59**	.26**	.34**			
Tangible Support (TS)	.31**	.55**	.37**	.53**	.56**	.27**	.38**	.56**	.25**	.20*	.73**		
Affectionate Support (AS)	.34**	.55**	.31**	.53**	.66**	.29**	.42**	.60**	.22*	.33**	.77**	.80**	
Positive Social Interaction (PIS)	.32**	.58**	.36**	.60**	.62**	.39**	.42**	.62**	.30**	.37**	.77**	.82**	.85**

** $p < 0.01$. * $p < 0.05$.

Table 9

Basic Descriptive Statistics

Variable	<i>M</i>	<i>SD</i>	<i>N</i>
Perceived Social Support	5.52	1.18	116
Career	3.77	.71	116
Friendship	3.84	.66	116
Global Health	3.62	.62	116
Positive Orientation	3.92	.66	116
Quality Relationships	3.96	.82	116
Stress/Anxiety	3.44	.82	116
Sleep Disturbance	3.41	.87	116
Sex/Intimacy	3.88	.69	116
Spiritual Support	3.56	.71	116
Substance Use	3.88	.78	116

Linearity assumption was met for the independent variables and perceived social support, as assessed by looking at partial regression plots and scatterplots of the studentized residuals against the predicted values. The homoscedascity assumption for perceived social support was met, as assessed by visual examination of a plot of studentized residuals against the unstandardized predicted values. There was no evidence of multicollinearity in the multiple regression, as assessed by tolerance values greater than 0.1 and VIF values less than 10 (Pituch & Stevens, 2015). As Table 8 shows, none of the independent variables have high correlations (>.80).

Although the distribution of the data on the P-P plots is not perfectly aligned along the diagonal line, it is close enough for to conclude that the residuals are close enough to normal for both multiple regression analyses to proceed. As multiple regression analysis is fairly robust against deviations from normality (Pituch & Stevens, 2015), it was determined that data transformation was not necessary. There were four outliers present, as assessed by studentized deleted residuals values greater than ± 3 standard deviations and casewise diagnostics. A multiple regression was ran both with

and without the outliers. Data normality improved, the Durbin Watson stayed approximately the same, and the regression was still significant and accounted for slightly more of the variation. Therefore, the decision was made to exclude the four outliers from the analysis. Although there were 7 risky leverage values ($>3p/n$, or >0.275), there were no cook values higher than 1 (there were no highly influential data points), so none of the data was excluded from the analysis on this basis (Pituch & Stevens, 2015).

Results. Review of literature did not suggest a theoretical grounding for the multiple regression; therefore, we used simultaneous multiple regression to determine the extent of the relationship between perceived social support and life balance. The dependent variable is perceived social support; the ten life balance scales are the independent variables. R^2 for the overall model was 66.9% with an adjusted R^2 of 63.7%, a large size effect according to Cohen (1988). The ten life balance subscales statistically significantly predicted perceived social support, $F(10, 105) = 21.221, p < .005$. Only Friendship, Positive Orientation, Quality Relationships, and Spiritual Support added significantly to the prediction, $p < .05$. In other words, adult cancer siblings with higher scores on these scales were expected to have higher perceived social support, after controlling for the other variables in the model. Regression coefficients and standard errors can be found in Table 10.

Career was a not statistically significant predictor of perceived social support and uniquely accounted for approximately 0.09 % of the variance. Friendship was a statistically significant predictor of perceived social support and uniquely accounted for approximately 4.3% of the variance. Global Health was not a statistically significant

predictor of perceived social support and uniquely accounted for approximately .6% of the variance. Positive Orientation was a statistically significant predictor of perceived social support and uniquely accounted for approximately 6.6% of the variance. Quality Relationships was a statistically significant predictor of perceived social support and uniquely accounted for approximately 1.5% of the variance. Stress/Anxiety was not a statistically significant predictor of perceived social support and uniquely accounted for approximately .03 % of the variance. Sleep Disturbance was not a statistically significant predictor of perceived social support and uniquely accounted for approximately .9% of the variance. Sex/Intimacy was not a statistically significant predictor of perceived social support and uniquely accounted for approximately .81% of the variance. Spiritual Support was a statistically significant predictor of perceived social support and uniquely accounted for approximately 4.9% of the variance. Substance Use was not a statistically significant predictor of perceived social support and uniquely accounted for approximately .5% of the variance. Power was sufficient for this study; given the sample size of $n = 120$, statistical significance would be detected for small effect sizes, $R^2 > .22$ (Faul et al., 2007).

Table 10

Multiple Regression for Perceived Social Support

Predictor	<i>B</i>	<i>SE B</i>	<i>B</i>	<i>t</i>	<i>p</i>	<i>sr²</i>	<i>rs</i>
Career	.06	.11	.04	.54	.589	.001	.267
Friendship	.59	.16	.33	3.68	.000	.043	.703
Global Health	.21	.15	.11	1.34	.183	.006	.402
Positive Orientation	.87	.19	.49	4.58	.000	.066	.718
Quality Relationships	.24	.11	.16	2.16	.033	.015	.440
Stress/Anxiety	.04	.13	.03	.31	.755	.000	.331
Sleep Disturbance	-.19	.11	-.14	-1.69	.094	.009	.252
Sex/Intimacy	.22	.14	.13	1.61	.111	.008	.509
Spiritual Support	-.44	.11	-.27	-3.93	.000	.049	.064
Substance Use	-.13	.11	-.09	-1.24	.218	.005	.183

Chapter Summary

The results of the statistical analyses were presented in this chapter. There is a significant difference on the Life Balance subscales between the JBLI norm group and adult healthy siblings. Bereavement status did not influence Life Balance subscale scores. The ten life balance subscales statistically significantly predicted both social support and perceived social support. In the next chapter, the implications from the findings and conclusions that were drawn from the study are discussed.

CHAPTER V

IMPLICATIONS AND RECOMMENDATIONS

The purpose of this study was to explore life balance outcomes and the relationship between life balance and social support in adults who grew up in the same household with a sibling that was diagnosed with cancer during childhood. Life balance outcomes for the adult healthy siblings were significantly different than the life balance outcomes for the normal population. Specifically, adult healthy siblings receive less comfort and support from spirituality and have more trouble with friendships than the normal population who are not receiving mental health treatment. Compared to those who are receiving mental health treatment, adult healthy siblings are more satisfied with their interpersonal relationships and are less likely to use drugs. In addition, adult healthy siblings are more likely to experience emotional fulfillment compared to those in the normal population who are receiving treatment and those who are not receiving treatment. These findings are not surprising given that healthy siblings report greater maturation, increased empathy toward others, and a higher value of life as a result of the cancer experience (Kramer, 1981; Chesler et al., 1991; Havermans & Eiser, 1994; Sargent et al., 1995; Heffernan & Zanelli, 1997; Murray, 1998, 2000; Martin, 2000). Adult healthy siblings are least likely to experience positive social worth. Given that healthy siblings spend less time participating in social activities as they did before the cancer diagnosis and found it difficult to maintain peer relationships, (Chesler et al.,

1991; Kaplan et al., 2013; Prchal & Landolt, 2011) it is no surprise that their social worth suffers.

Contrary to expectations, adult healthy siblings are less stressed and/or anxious than both those who are receiving mental health treatment and those who are not. It is unclear why adult healthy siblings are less stressed. One hypothesis that may account for this finding is that adult healthy siblings have experienced significant stress early in life when their sibling was diagnosed with cancer (Chesler et al., 1991; Gogan & Slavin, 1981; Murray, 1998, 2000; Nolbris et al., 2007; Sargent et al., 1995), so the stress that they are encountering now may seem small in comparison.

Several researchers found that the time since the cancer diagnosis influences healthy sibling outcomes (Alderfer et al., 2003; Hamama et al., 2000; Houtzager et al., 2003, 2004; Lähteenmäki et al., 2004). In particular, the more time that has passed since the sibling's diagnosis, the better the outcomes for the healthy sibling tend to be. However, time since diagnoses was not associated with life balance outcomes in this study. These findings are similar to those of Labay and Walco (2004), who found that there was no link between time since diagnosis and psychological outcomes.

Previous literature has shown that losing a sibling to childhood cancer can result in several adverse psychological outcomes, including sleeping problems, externalizing behaviors, stress, anger, developmental difficulties, and social problems (Adams & Deveau, 1987; Birenbaum et al., 1989; Davies, 1983; Davies, 1991; Martinson & Campos, 1991; Nolbris & Hellström, 2005; Sveen et al., 2014), all of which can last through adulthood. As such, it was expected that adults whose siblings died as a result of their cancer would have lower life balance scores than those whose siblings did not die.

However, this was not the case. Bereavement did not influence life balance outcomes in this study. One reason for this finding may be that the majority of the previous literature collected data from bereaved siblings who were age 19 or younger (e.g. Adams & Deveau, 1987; Davies, 1983; Foster et al., 2011; Foster et al., 2012; Gerhardt et al., 2012; Martinson & Campos, 1991), while all of the current study's participants are 18 and older. It could be that bereavement plays a bigger role in life balance outcomes during childhood and adolescence, but less of a role in adulthood. Also, there was a huge discrepancy in the sample sizes for each group: there were only 19 participants who were bereaved compared to 100 participants whose sibling did not die.

According to the transactional model of stress and coping (Lazarus & Folkman, 1984; Thompson & Gustafson, 1996) a relationship exists between social support and life balance. The findings in this study support the transactional model of stress and coping. Life balance subscales were major predictors of both social support and perceived social support. Adult healthy siblings who reported their friendships were adequate, a positive outlook on life, satisfaction with their interpersonal relationships, and adequate sexual and intimate experiences had higher social support. Friendship accounted for most of the variation in social support. Adult healthy siblings who reported their friendships were adequate, a positive outlook on life, satisfaction with their interpersonal relationships, and spirituality reported higher perceived social support. Having a positive outlook on life accounted for most of the variation in perceived social support.

Implications for Counseling

The findings from this study contribute unique information about the life balance outcomes of adults who grew up with siblings that had childhood cancer, because the

counseling literature is lacking in evidence-based information about the needs of adult healthy siblings. This study has highlighted that adult healthy siblings do experience difficulties later in life; thus counselors who are working with this population may want to spend time paying attention to the outcomes. This study illuminates the need for counselors in the cancer treatment settings (i.e. hospitals and cancer treatment clinics). By working in these settings, counselors will have an opportunity to effect change in both research and clinical practice that is directed at meeting not only the needs of the individual with cancer and their parents, but also the needs of the sibling as well.

As counselors and other mental health professionals learn more about how childhood cancer influences the entire family unit, researchers, counselors, and other mental health professionals are becoming increasingly aware that a comprehensive approach to sibling intervention is needed, just as it is with children with cancer. This study illuminates that understanding the psychosocial needs of not only the ill sibling and the parents, but the adult healthy siblings as well, needs to be an integral part of family care. Counselors who are working with children whose sibling has cancer are in the unique position of being able to minimize and possibly prevent some of the social and psychological difficulties that are seen even into adulthood. Counseling programs should consider course topics that examine the issues that healthy siblings face when their siblings are diagnosed with cancer and other chronic illnesses.

Friendship is an important factor in both social support and perceived social support, however adult healthy siblings have significantly lower friendship scores than the normal population. In addition, healthy siblings reported difficult building and maintaining social relationships, trouble relating to their peers, and impairments in social

skills (Chesler et al., 1991; Davies, 1991; Kaplan et al., 2013; Prchal & Landolt, 2011). Given these findings, group counseling for healthy siblings might be warranted. Group counseling is particularly beneficial for this population because participating in group counseling can decrease feelings of isolation, provide a safe and supportive environment where healthy siblings can communicate their problems and get feedback from others who are in a similar situation, improve social skills, improve the ability to relate to others, and foster social development (Coholic & Eys, 2016; Jacobs, Masson, Harvill, & Schimmel, 2011; Yalom & Leszcz, 2005).

As previously reported, the needs of the healthy sibling are often overlooked by counselors and parents, healthy siblings don't get the emotional support or attention that they need, and healthy siblings tend to lose sight of themselves and their needs (Alderfer et al., 2010; Chesler et al., 1991; Gogan & Slavin, 1981; Nolbris et al., 2007; Spinetta, 1981; Woodgate, 2006). Therefore, individual counseling may be particularly useful when working with healthy siblings. Counselors can focus solely on the healthy sibling and addressing the healthy sibling's unmet needs in individual sessions. Individual counseling can provide a safe space for healthy siblings to talk about their experience without worrying about the focus being on anyone else. Individual counseling also allows for a more in-depth analysis of the healthy sibling's experience. It might also be necessary for a counselor to advocate for the healthy sibling.

Limitations

The ability to recruit participants was a limitation. The majority of the data were collected from one site (MTurk) while only a few surveys participants were recruited from all other methods combined. The number of people who met the criteria is limited

and hard to reach. Social media and word-of-mouth recruiting provided few participants. There were not enough people collected via other methods to do a comparison on the different sampling methods. Given that over 90% of the current study's participants were recruited from MTurk, selection bias may be an issue. Given that the current research study employs nonrandom sampling, the generalizability and replicability may be compromised.

Another limitation to this study is the uneven sample sizes in the groups. For example, there were only 19 adult healthy siblings in the bereavement group compared to 100 in the non-bereaved group. It is possible that the small sample size contributed to the finding that bereavement did not influence life balance outcomes. This limitation was due to the fact that the population was so specific and there was a limited amount of time to collect data. Perhaps future studies could address this issue.

This study solely relies on self-report data, which is not the most accurate way to collect data. Obtaining data from additional sources (i.e. parents, teachers, siblings, and significant others) would have provided a wider picture of the adult sibling's life balance and could be used to check the accuracy of the self-report data. Future researchers could keep this in mind when developing future studies.

The data is only collected at one point in time, which makes it impossible to gain important information about the change in life balance and social support over time. Assessing the healthy siblings at various points throughout their lives (i.e., right after the cancer diagnosis, during treatment, and every few years after that) could provide important information about how life balance and social support changes over the course of the healthy sibling's lifespan. Some of the variables in the study showed minor

deviations from normality. Since the assumption of normality was made in all of this study's analyses, this may compromise the validity of the test results.

Suggestions for Future Research

The findings of this study are helpful in that they support the idea that siblings of individuals with childhood cancer may need psychological support not only during childhood, but as adults as well. However, there is still much to be learned. More longitudinal research needs to be done to examine psychological outcomes of healthy adult healthy siblings over time. Longitudinal research may help counselors identify critical periods through the lifespan where extra supports are needed. This information could in turn be used to develop interventions that can be aimed at those critical periods. As previously mentioned, obtaining data from several sources could provide a wider picture of the outcomes of adult health siblings.

The literature suggests that there may be certain subgroups healthy siblings who are at a higher risk for psychosocial problems. For example, females, healthy siblings that are older than the child with cancer, healthy siblings that come from low SES backgrounds, and having a big age difference are all associated with an increased risk for negative outcomes in healthy siblings during adolescence and childhood (Alderfer et al., 2003; Alderfer & Hodges, 2010; Barbarin et al., 1995; Buchbinder et al., 2011; Cohen et al., 1994; Houtzager et al., 2004, 2005; Sahler et al., 1994; Van Dogen et al., 1995; Sloper & While, 1996; Zebrack et al., 2002, 2004, 2007; Zeltzer et al., 1996, 2008). Further studies can aim at exploring the risk factors and their influence on both social support variables and life balance outcomes. It could be similarly beneficial to identify protective factors that could improve life balance outcomes in healthy siblings.

The current study illuminated the relationship between life balance and social support, and life balance and perceived social support. However, further examination of the relationship between the previously mentioned variables is needed. Given that the transactional model of stress and coping suggests that social support can be a mediator to life balance outcomes, future studies should aim at examining the nature of the relationship between life balance, social support, and perceived social support, and how they interact with one another. Future research should also examine the role that social support and perceived social support play in coping with the experience of having a sibling with cancer over time, and how sociodemographic factors may influence this.

One of the unexpected findings of this research study was that adult healthy siblings are less stressed than the normal population. The nature of the relationship between stress, life balance, and social support needs to be explored in future studies. There is definitely a need for further research to be done to look at stress in healthy siblings, not only in adulthood but also at different periods throughout their lives.

Although the current study examined social support in adult healthy siblings, the current study did not use a control group. Likewise, the study also did not use a control group when examining perceived social support. Therefore, the relationship between social support and perceived social support, and having a sibling with cancer was not explored in this study. Future studies might aim to examine social support and perceived social support in both adult health siblings and the normal population to determine if having a sibling with childhood cancer influences either social support variable.

Literature has been mixed on whether academic and career outcomes suffer as a result of having a sibling diagnosed with cancer (Lähteenmäki et al., 2002; Labay &

Walco, 2004). Academic and career outcomes of healthy siblings warrant further study. Researchers might want to compare educational and career outcomes of adult healthy siblings to the normal population to see if there is a difference. These findings could be especially relevant to career and school counselors who work with healthy siblings.

The earlier the access and the longer the sibling relationship lasts, the more influential the sibling relationship tends to be (Bank & Kahn, 1982; McKeon, 1987). Sibling relationship variables, such as sibling access, should be further explored in relation to the healthy sibling experience. One important question to address in the future is how does sibling access influences life balance outcomes in adult health siblings. For example, future research can examine life balance outcomes in high access adult healthy siblings and compare it to life balance outcomes of low access siblings.

Both the MSPSS and the MOS-SSS contained subscales that deserve further examination. Due to the high correlations of the MOS-SSS subscales, it was not possible to look at the different types of social support (emotional/ informational, tangible, positive social interaction, and affectionate) and how they are related to life balance outcomes. Likewise, the different sources of social support (family, friends, and significant other) and how they influenced life balance outcomes was not examined. Further research studies should aim at examining the relationships between these variables. It might also be interesting to examine whether the effect of the perceived social support depends on the source of the social support in adult healthy siblings.

Life balance is heavily influenced by situational and environmental factors (e.g., socio-economic status, unemployment, culture, family life, physical safety) (Matuska et al., 2013; Wagman et al., 2011). Future research should examine how specific sibling,

family, and disease factors influence healthy sibling outcomes. More research needs to be done to identify possible mediating factors that influence life balance and other psychosocial outcomes, such as age, gender, illness severity, etc.

Research needs to be done to develop effective models to assess and work with healthy siblings, not only as children but also as adults. And finally, research investigating sibling life balance outcomes should be done with siblings with other chronic illnesses (i.e. Down Syndrome, Spina bifida, etc.) to determine the generalizability of the current study findings. All of the research questions that were asked and proposed in this study, including the suggestions for future research, can be asked about healthy siblings of individuals with other chronic illnesses.

Conclusions

The current study revealed that growing up in the same household with a sibling that has childhood cancer influences life balance outcomes in adulthood. Bereavement did not influence life balance outcomes of adult healthy siblings. When compared to adults receiving mental health treatment, adult healthy siblings report a higher level of satisfaction with their interpersonal relationships and lower substance use. When compared to adults who are not receiving mental health treatment, adult healthy siblings reported being less spiritual and greater trouble with friendships. Adult healthy siblings are more emotionally fulfilled than adults in the normal population, but adult healthy siblings have lower positive social worth. Life balance outcomes were significant predictors of both social support and perceived social support. These findings suggest that having a sibling with cancer can result in long-term psychological and social consequences. The information provided by this study reveals the important role that

counselors can potentially play in minimizing the some of the effects of having a sibling with cancer. This study illuminates the need for counselors in the cancer treatment settings, the need for a comprehensive approach to treating healthy siblings, the importance of making sure that the psychosocial needs of healthy siblings is an integral part of care when working with families of children with cancer, and the development of course topics that deal with the issues that healthy siblings of individuals with cancer and other chronic children face. Group counseling and individual counseling have the potential to be useful in addressing the needs of healthy siblings.

Several areas are in need of further research, namely 1) longitudinal research on the outcomes of healthy adult healthy siblings; 2) identifying subgroups of healthy siblings that are at risk for adverse outcomes, as well as protective factors that can improve healthy sibling outcomes; 3) an exploration of the relationship between life balance, social support, and perceived social support; 4) an exploration of the relationship between stress, life balance, and social support; 5) research that uses control groups to compare social support outcomes; 6) an examination of the academic and career outcomes of adult healthy siblings; 7) how sibling relationship variables influence the healthy sibling experience; and 8) how the type and source of social support influence adult healthy sibling outcomes; 9) the development of effective models of working with healthy siblings; and 10) investigate life balance outcomes of individuals whose siblings had another chronic illness in childhood.

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APPENDICES

APPENDIX A

IRB Approval Letter

Human Subjects Protection Program Office
MedCenter One – Suite 200
501 E. Broadway
Louisville, KY 40202-1798
Office: 502.852.5188 Fax: 502.852.2164

DATE: April 30, 2016
TO: Richard S Balkin
IRB NUMBER: 15.1045
STUDY TITLE: Copy of Life Balance in Adult Siblings of Individuals with Childhood Cancer
REFERENCE #: 537760
IRB STAFF CONTACT: Christy LaDuke
852-2541

The amendment request has been received by the Human Subjects Protection Program Office and approved by the Chair/Vice Chair of the Institutional Review Board (IRB) on 04/29/2016 through the expedited review procedure according to 45 CFR 46.110(B). The following documents have been reviewed and approved:

Title	Version Number	Version Date	Outcome
Non-Mturk Consent Form	Version 2.0	04/21/2016	Approved
Mturk consent form	Version 1.0	04/16/2016	Approved
MTurk survey description	Version 1.0	04/16/2016	Approved
Study Protocol 4-16-16	Version 3.0	04/16/2016	Approved

The modifications include:

- Using Amazon Mechanical Turk (MTurk) in order to recruit research participants.
- Compensating the MTurk workers \$2.25.
- Using a separate preamble consent form for the Mturk participants excluding the MTurk participants from the drawing for 1 of 8 \$50 giftcards.

Please begin using your newly stamped approved documents with any new subjects. The committee will be advised of this action at a regularly scheduled meeting.

If you have any questions, please contact the HSPPO at (502) 852-5188 or hsppofc@louisville.edu.

Thank you for your submission.

A handwritten signature in black ink, appearing to read "Peter M. Quesada".

Peter M. Quesada, Ph.D., Chair

Social/Behavioral/Educational Institutional Review Board

Appendix B

Informed Consent (Non-MTurk)

LIFE BALANCE OF ADULT SIBLINGS OF INDIVIDUALS WITH CHILDHOOD CANCER

You are being invited to participate in a research study by answering the attached survey about life balance and social support. There are no known risks for your participation in this research study. The information collected may not benefit you directly. The information learned in this study may be helpful to others. The information you provide will assist counselors in identifying special issues when working with adult cancer siblings and lead to improved care for adult cancer siblings. Your completed survey will be stored on secure servers. The survey will take approximately 20-40 minutes to complete.

Individuals from the Department of Education, the Institutional Review Board (IRB), the Human Subjects Protection Program Office (HSPPO), and other regulatory agencies may inspect these records. In all other respects, however, the data will be held in confidence to the extent permitted by law. Should the data be published, your identity will not be disclosed.

Taking part in this study is voluntary. By completing this survey, you agree to take part in this research study. You do not have to answer any questions that make you uncomfortable. You may choose not to take part at all. If you decide to be in this study you may stop taking part at any time. If you decide not to be in this study or if you stop taking part at any time, you will not lose any benefits for which you may qualify.

If you are selected in the random drawing to receive a \$50 gift card for participating in this study, the University of Louisville may collect your name, address, social security number, and keep records of how much you are paid. You may or may not be sent a Form 1099 by the University. This will only happen if you are paid \$600 or more in one year by the University. This will not include payments you may receive as reimbursement, for example mileage reimbursement. We are required by the Internal Revenue Service to collect this information and you may need to report the payment as income on your taxes. You can still be in the study even if you don't want to be paid.

If you have any questions, concerns, or complaints about the research study, please contact: Yolanda Williams at yaluca01@louisville.edu or 502-597-6723.

If you have any questions about your rights as a research subject, you may call the Human Subjects Protection Program Office at (502) 852-5188. You can discuss any questions about your rights as a research subject, in private, with a member of the

Institutional Review Board (IRB). You may also call this number if you have other questions about the research, and you cannot reach the research staff, or want to talk to someone else. The IRB is an independent committee made up of people from the University community, staff of the institutions, as well as people from the community not connected with these institutions. The IRB has reviewed this research study.

If you have concerns or complaints about the research or research staff and you do not wish to give your name, you may call 1-877-852-1167. This is a 24-hour hot line answered by people who do not work at the University of Louisville.

Sincerely,

Richard Balkin, PhD, LPC, NCC
Investigator

Yolanda Williams, MBA, MEd
Co-Investigator

Appendix C

MTurk Informed Consent

LIFE BALANCE OF ADULT SIBLINGS OF INDIVIDUALS WITH CHILDHOOD CANCER

You are being invited to participate in a research study by answering the attached survey about life balance and social support. There are no known risks for your participation in this research study. The information collected may not benefit you directly. The information learned in this study may be helpful to others. The information you provide will assist counselors in identifying special issues when working with adult cancer siblings and lead to improved care for adult cancer siblings. Your completed survey will be stored on secure servers. The survey will take approximately 20-40 minutes to complete.

Individuals from the Department of Education, the Institutional Review Board (IRB), the Human Subjects Protection Program Office (HSPPO), and other regulatory agencies may inspect these records. In all other respects, however, the data will be held in confidence to the extent permitted by law. Should the data be published, your identity will not be disclosed.

Taking part in this study is voluntary. By completing this survey you agree to take part in this research study. You do not have to answer any questions that make you uncomfortable. You may choose not to take part at all. If you decide to be in this study you may stop taking part at any time. If you decide not to be in this study or if you stop taking part at any time, you will not lose any benefits for which you may qualify. Those who complete the survey are eligible to receive a payment from Amazon for \$2.25. Once you complete the survey, you will be given a validation code. In order to receive payment from Amazon, you must enter the validation code into MTurk. If the validation code entered into MTurk matches the code you were given, payment will be sent to you within seven days. Researchers will have access to your MTurk worker ID which may be able to be linked to your personal information including your Amazon public profile page. Amazon will have access to your MTurk ID and personal information (social security number, IP address, bank account information, etc...). MTurk worker IDs will not be shared with anyone and will be used solely for the purposes of distributing compensation. Worker IDs will not be stored with the data set. All study results will be reported without worker ID so that no one viewing the results will ever be able to match you with your responses.

If you have any questions, concerns, or complaints about the research study, please contact: Yolanda Williams at yaluca01@louisville.edu or 502-597-6723.

If you have any questions about your rights as a research subject, you may call the Human Subjects Protection Program Office at (502) 852-5188. You can discuss any questions about your rights as a research subject, in private, with a member of the Institutional Review Board (IRB). You may also call this number if you have other questions about the research, and you cannot reach the research staff, or want to talk to someone else. The IRB is an independent committee made up of people from the University community, staff of the institutions, as well as people from the community not connected with these institutions. The IRB has reviewed this research study.

If you have concerns or complaints about the research or research staff and you do not wish to give your name, you may call 1-877-852-1167. This is a 24 hour hot line answered by people who do not work at the University of Louisville.

Sincerely,

Richard Balkin, PhD, LPC, NCC

Investigator

Yolanda Williams, MBA, MEd

Co-Investigator

CURRICULUM VITA

NAME: Yolanda A. Williams

ADDRESS: Carver Hall 129A
400 E Main Street
Kentucky State University
Frankfort, KY 40229
Y.a.williams@outlook.com

DOB: Benton Harbor, MI – October 17, 1986

EDUCATION
& TRAINING: B.A., Psychology
Kentucky State University
2004-2008

B.A., Liberal Studies
Kentucky State University
2004-2008

M.B.A., Human Resources
Colorado Tech University
2008-2009

M.Ed., Counseling Psychology
University of Louisville
2010-2012

Ph.D., Counselor Education and Supervision
University of Louisville
2012-2016

AWARDS: Commission on Diversity and Racial Equality Graduate Student Research
Grant
2015

American Association of Colleges for Teacher Education Holmes Scholar
2012-2015

Gates Millennium Scholar
2004-2008

Horatio Alger Scholar
2004

PROFESSIONAL SOCIETIES

American Association of Colleges for Teacher Education
American Counseling Association

PRESENTATIONS

Williams, Y. (March, 2008). The effects of fetal alcohol syndrome on the brain: implications for creating new state laws that protect fetuses. Presented at the Southern Regional Honors Conference in Birmingham, Alabama.

Cunningham, N., Tucker, S., Williams, J., & **Williams, Y.** (October, 2012). Using your power for good: Bullying in middle school. Presented at the Kentucky Counseling Association Conference in Louisville, Kentucky.

Williams, Y. (March, 2014). Mitigating Summer Reading Loss through Summer Boost Reading. Accepted at the American Association of Colleges for Teacher Education Conference in Indianapolis, Indiana.

Williams, Y. (February, 2015). Clinical Preparation Programs According to Teacher Candidates. Presented at the American Association of Colleges for Teacher Education Holmes Scholars Symposium in Atlanta, Georgia.

EMPLOYMENT

Research Experience

Graduate Research Assistant — University of Louisville, College of Education, Research Office (Nov 2013-Aug 2015)

Collected and analyzed data for a grant funded research project. Evaluated implementation and outcomes for teacher preparation program. Conducted field observations in a middle school. Wrote field notes. Developed interview schedule. Conducted face-to-face interviews with teachers, school administrators, and college students. Presented findings and made program recommendations based on research to key stakeholders. Analyzed qualitative and quantitative research data, including survey data. Used NVivo and SPSS to assist with data management and analysis. Presented research findings at national conferences.

Graduate Research Assistant — University of Louisville, College of Education, Nystrand Center (Sept 2011-Nov 201)

Collected and analyzed quantitative data for a grand funded research project. Evaluated implementation and outcomes for elementary reading program. Performed reading assessments in a local elementary school. Conducted literature review. Maintained the Louisville Writing Project database. Used ATLAS.ti and SPSS for data management and

analysis. Presented research findings at national conferences. Helped plan and facilitate meetings.

Teaching Experience

Visiting Instructor — Kentucky State University (Aug 2015-Present)

Courses Taught: Foundations of Western Culture, Honors University Orientation, Seminar I – Ethics/Early Civilizations, and Seminar IV – Self and Society in a Multi-Cultural World

Graduate Teaching Assistant — University of Louisville (Aug 2013-Dec 2014)

Courses Taught: Advanced Theories of Counseling and Psychotherapy, Learning Systems Theory and Practice, and Theories of Counseling and Psychotherapy

Related Experience

Disability Adjudicator II — Cabinet for Health and Family Services (Oct 2008-Sept 2011)

Used Social Security Administration's guidelines to determine who receives disability. Used AS/400 to manage electronic caseload. Maintained contact with doctors and disability claimants. Assessed severity of mental and physical conditions