PERCEIVED SOCIAL SUPPORT, COPING, AND BENEFIT FINDING ABILITIES AMONG CAMPERS AT AN ONCOLOGY SUMMER CAMP PROGRAM

A thesis presented to the faculty of the Graduate School of
Western Carolina University in partial fulfillment of the
requirements for the degree of Specialist in School Psychology.

By

Bridget Colette Ryan

Chair: Dr. Ethan Schilling
Assistant Professor
Department of Psychology

Committee Members: Dr. Lori Unruh, Psychology
Dr. Bruce Henderson, Psychology

March 2017

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

ABSTRACT

PERCEIVED SOCIAL SUPPORT, COPING, AND BENEFIT FINDING ABILITIES AMONG CAMPERS AT AN ONCOLOGY SUMMER CAMP PROGRAM

Bridget Colette Ryan
Western Carolina University (March 2017)
Chair: Ethan Schilling, Ph.D.

Survival rates for pediatric cancer have increased over recent years due to improvement and changes in cancer treatment. However, even with increased survival rates, previous research has shown that children undergoing treatment and pediatric cancer survivors often experience deleterious effects as a result. Children with cancer and childhood cancer survivors experience negative physical, cognitive and academic, emotional, and social effects stemming from a cancer diagnosis and undergoing treatment. Therefore, it is important to examine the coping strategies and positive supports children with cancer utilize to deal with these stressors. One support available to children with cancer and their families is pediatric oncology camp programs. In recent years, there has been an increase in the research related to pediatric oncology camp programs and the services they provide for children with cancer and their families. The current study will expand on the current literature related to pediatric oncology camp programs and their effectiveness in supporting children with cancer by examining the self-reported levels of social support, coping, and benefit finding among children attending a children's oncology summer camp program.

INTRODUCTION

The National Cancer Institute (NCI; 2014) estimates approximately 15,700 children and adolescents between the ages of 0 to 19 in the United States received a new cancer diagnosis in 2014. According to the NCI (2014), the most commonly diagnosed childhood and adolescent cancers include leukemia, brain and central nervous system tumors, lymphoma, rhabdomyosarcoma, neuroblastoma, Wilms tumor, bone cancer, and gonadal germ cell tumors. Although childhood cancer is relatively rare, cancer is still among the leading causes of disease-related deaths in children and adolescents living in the United States (NCI, 2014). Whereas the mortality rate of childhood cancers has decreased over 50 percent as of 2010 (Smith, Altekruse, Adamson, Reaman, & Seibel, 2014), approximately 2,000 children die of cancer in the United States each year (NCI, 2014). As a whole, more than 80 percent of children and adolescents with a cancer diagnosis survive at least five years past their diagnosis; however, some childhood cancers have better survival rates than others (NCI, 2014). For example, the median survival rate for children with diffuse intrinsic pontine glioma, a specific type of brain tumor, is less than one year following diagnosis. In contrast, children diagnosed with Wilms tumor between the ages of 10 and 16 have a worse five-year survival rate than children diagnosed at a younger age; the five-year survival rate for children diagnosed with acute lymphoblastic leukemia is about 90 percent; and survival rates for children diagnosed with non-Hodgkin lymphoma are about 85 percent. In addition, the five-year survival rate for children and adolescents diagnosed with soft tissue sarcomas ranges from 64 percent (rhabdomyosarcoma) to 72 percent (Ewing sarcoma); and the 5-year survival rate for children diagnosed with central nervous system cancers ranges from 70 percent (medulloblastoma) to 85 percent (astrocyotoma; NCI, 2014).

Although overall survival rates of children diagnosed with cancer have increased, childhood cancer survivors often experience physical and emotional effects following treatment. Some of the negative effects of childhood cancer include damage to organ tissue and body function (i.e., nerve damage in the hands or feet, loss of bladder and/or bowel control, etc.); problems in growth and development (i.e., delays in normal development); changes to mood (i.e., symptoms of anxiety and depression); difficulties thinking and learning (i.e., problems paying attention, difficulty with solving problems, and a slower ability to learn and use new information); social and psychological adjustment problems (i.e., social withdrawal or difficulty maintaining friendships with peers); and a risk of second cancers (The National Cancer Institute, 2014; NCI). Furthermore, Ruland, Hamilton, and Schjødt-Osmo (2009) conducted a meta-analysis examining the complexity of symptoms as well as common difficulties experienced by childhood cancer survivors during treatment and rehabilitation. In the studies reviewed, 36% of symptoms and difficulties children reported were of a psychological or emotional nature, including but not limited to fear, anxiety, alienation, hopelessness, embarrassment, loss of independence, and post-traumatic stress disorder, among others. Thirty-one percent of symptoms and difficulties children reported were physiological, including but not limited to bleeding, pain, hair loss, infection, decreased strength, gastrointestinal symptoms, and respiratory distress. Twenty-two percent of symptoms and difficulties children reported were both physical and psychological, including but not limited to autonomy, body image, acute and chronic pain, cognition, and fatigue. Furthermore, 11% of symptoms and difficulties children reported were related to school or behavioral problems, including but not limited to decreases in academic performance, school-related anxiety, strained peer relationships, integration into school, absenteeism, and neurocognitive deficits. Given the range of negative consequences that may occur as a result of childhood cancer, it is important to provide support to children and adolescents currently undergoing cancer treatment or in recovery. Children's oncology camps represent one such method of support.

Although many children's oncology camps exist throughout the United States, there have been few previous studies examining the benefits of attending camp programs for children with cancer. Therefore, the purpose of the current study is to further examine the benefits of attending a children's oncology camp by focusing on the influence camp programs have on improving a child's level of perceived social support, use of effective coping strategies, and ability to find benefits from a cancer diagnosis. Given the identified benefits and positive supports oncology camps provide for pediatric cancer patients and their families, the goal of the current study is to further examine the relationship between oncology camp programs and social support, in addition to less-researched areas such as coping strategies and benefit-finding abilities in campers attending such camps. Campers attending Camp Happy Days summer camp, a children's oncology camp program, participated in the current study.

The summer camp program is one of Camp Happy Days' signature programs offered to children and families; however, they offer other programs in order to support children and their families facing pediatric cancer. Camp Happy Days' (2017) mission is to offer support and encouragement to children diagnosed with cancer and their families by providing cost free year-round programs, special events and access to crisis resources. Their goal is to improve the physical, emotional and psychological health of entire families facing pediatric cancer (Camp Happy Days, 2017). Other programs provided include age-specific on-going programs, family counseling and financial assistance, "dream dates," hospital visits, holiday giving, etc. For the purposes of the current study, I will be focusing on the summer camp program. Camp Happy

Days summer camp program is a weeklong residential camp program designed for children diagnosed with cancer and their sibling ages 4-16. This program provides children with the opportunity to build self-esteem, courage, confidence and trust in an incredibly active, high-energy environment. Activities offered to campers during Camp Happy Days' summer camp program include the following: Sewing, Arts N' Crafts, Ceramics, Painting, Wood Working, Derby Car Races, Glitz N' Glamour, Yoga, Cooking, Shutterbug Studios (Photography), High Ropes Course, Fishing, Tubing, Boating, Swimming, Dance Lessons, Themed Dances, Ice Skating, a Petting Zoo, Paint Ball, Team Building Activities, a Talent Show, etc.

CHAPTER ONE: REVIEW OF THE LITERATURE

Overview of Pediatric Cancers and their Treatments

The National Cancer Institute (NCI, 2014) reports the types of cancer most commonly occurring in children between the ages of 0 and 14 include acute lympthocytic leukemia (ALL), brain and central nervous system (CNS) tumors, and neuroblastoma, which are expected to account for more than half of new cases diagnosed in 2015. Other common childhood cancers include lymphoma, rhabdomyosarcoma, Wilms tumor, bone cancer, and gonadal germ cell tumors.

Effects of Childhood Cancer

Children undergoing cancer treatment including surgery, radiation therapy, chemotherapy, immunotherapy, targeted therapy, hormone therapy, or stem cell transplants may experience a number of negative effects as a result. These side effects can vary depending on factors including the amount and frequency of treatment, age at treatment, and the presences of other health difficulties compromising treatment (National Cancer Institute, 2015). Stein, Syrjala, and Andrykowski (2008) report that the number of long-term pediatric cancer survivors is increasing in the United States due to advances in screening, early detection, treatment strategies, and management of treatment toxicities. However, those same treatments that improve cancer survival rates can lead to physical and psychological long-term effects, which can last five years or longer post-treatment (Stein et al., 2008). Pediatric cancer treatment can also lead to late effects (i.e., difficulties not initially present during or initially following completion of cancer treatment, which present later, Stein et al., 2008).

Physical effects. NCI (2015) reports that common physical effects stemming from childhood cancer treatments include anemia, appetite loss, bleeding and bruising, constipation, diarrhea, edema, fatigue, hair loss, infection, and neutropenia. In addition, children undergoing cancer treatment can experience lymphedema, memory or concentration problems, mouth and throat problems, nausea or vomiting, nerve problems, sexual and fertility problems in males and females, skin and nail changes, sleep problems, and urinary and bladder problems. Results of another study examining interviews conducted with parents and their children with a cancer diagnosis also revealed that physical stressors related to pain associated with needle sticks/port access/spinal taps, and taking medicine are common (Hildenbrand, Clawson, Alderfer, & Marsac, 2011). NCI (2015) also reports that some common late effects of treatment for childhood cancers affecting the brain and spinal cord include: headaches, loss of coordination or balance, seizures, loss of the myelin sheath that covers nerve fibers, movement disorders, nerve damage in the hands or feet, stroke, hydrocephalus, loss of bladder and or bowel control, and cavernomas (cluster of abnormal blood vessels). It is not uncommon for these potential physical effects to cause distressing emotional reactions in children who have received cancer treatment (Hildebrand et al., 2011).

Cognitive and academic effects. Other effects more commonly experienced by childhood cancer survivors may present in the form of deficits in current cognitive and academic functioning. These individuals often experience general difficulties in their educational functioning, mainly as a result of learning and memory problems (NCI, 2015; Ruland, Hamilton, & Schjødt-Osmo, 2009; Daly, Kral, & Brown, 2008). When examining effects of childhood brain and CNS cancers, it is known that tumors can grow into or press into areas of the developing brain, preventing or halting parts of the brain from functioning normally (NCI, 2015).

For example, CNS primitive neuroectodermal tumors (PNETs) are tumors that typically form in brain cells in the cerebrum. When a child has a CNS PNET, he or she may experience problems with learning, problem solving, speech, reading, and writing. Four types of CNS PNETs include CNS neuroblastomas, CNS ganglioneuroblastomas, medulloepitheliomas, and ependymoblastomas.

The treatment of brain and spinal cord tumors, rather than the disease itself, has been shown to result in cognitive as well as academic deficits among survivors. For example, Mulhern, Merchant, Gajjar, Reddick, and Kun (2004) observed a decline in intelligence quotient (IQ) for children who received treatment for brain tumors. These authors explain that this decline in IQ is most likely attributable to the loss of cerebral white matter following treatment subsequently leading to less efficient cognitive processing. Other studies have examined the effects of treatment for childhood medulloblastomas, and similarly found that children demonstrated declines in intellectual functioning as time since treatment increased (Palmer et al., 2003). That is, when evaluated with an assessment of intelligence, older cancer survivors demonstrated a decline in intellectual abilities most apparent six years post-diagnosis (Palmer et al., 2003). Moreover, Palmer Reddick, and Gajjar (2007) explain that declines in IQ may be directly attributable to new presenting attention, memory, and processing speed deficits following treatment as a result of decreased cerebral white matter.

Additionally, research has found that treatment for childhood cancers with direct CNS involvement often results in neurocognitive late effects, which are effects that may develop months or years following the completion of treatment (Daly, Kral, & Brown, 2008). That is, research has shown children regularly experience difficulties related to nonverbal reasoning, mental arithmetic, visual-motor integration, and reduced processing speed following the completion of treatment involving cranial radiation therapy (Copeland et al., 1988 as cited in Daly et al., 2008). In contrast, children with childhood acute lympthocytic leukemia (ALL) treated without cranial radiation therapy (CRT) often demonstrate a different set of cognitive and academic difficulties including perceptual-motor deficits, declines in academic achievement, more modest declines in arithmetic, visual-motor integration problems, and verbal fluency deficits (Brown et al., 1998; Copeland et al., 1996 as cited in Daly et al., 2008). Moreover, some childhood brain tumor survivors continue to experience academic failure, deficits in memory and attention, sequencing, information processing speed, visual perceptual abilities and language throughout their schooling (Daly et al., 2008).

Finally, a more recent meta-analysis examining difficulties experienced by children with cancer indicated that 11% of those problems typically experienced by childhood cancer survivors are school-related (Ruland et al., 2009). School-related difficulties in the context of studies examined included neurocognitive deficits, decreases to overall academic performance, difficulties thinking, general learning problems, and study skills deficits. Other cognitive difficulties reported by parents of childhood cancer survivors include reduced functional communication, increased attention problems, and atypicality (Wolfe-Christensen, Mullins, Stinnett, Carpentier, & Fedele, 2009).

Emotional effects. In addition to potential cognitive and academic difficulties, children with cancer are also at an increased risk of developing emotional and behavioral difficulties in relation to healthy peers. Multiple studies have found that children with cancer experience a number of difficulties including, but not limited to, symptoms of depression and anxiety as well as PTSD, and low levels of self-esteem (Li, Chung, & Chiu, 2010; Li, Lopez, Chung, Ho, & Chiu, 2013; Ruland et al., 2009; Stein, Syrjala, & Andrykowski, 2008; Wolfe-Christensen, Mullins, Stinnett, Carpentier, & Fedele, 2009;). Furthermore, as high as 36 percent of problems identified by children with cancer represent concerns related to psychological or emotional functioning (Ruland et al., 2009). Some of the more common psychological and emotional difficulties children with cancer experience include fear, anxiety, behavior problems, feelings of hopelessness and self-doubt, mood dysregulation, depression, and symptoms of Posttraumatic Stress Disorder. (Compas et al., 2014; Ruland et al., 2009; Stein et al., 2008).

Results of another recent study indicated that more than half of children who experience cancer report depressive symptoms and lower self-esteem than healthy controls (Li, Lopez, Chung, Ho, & Chiu, 2013). Similar studies have shown that children diagnosed with cancer score high on measures of trait anxiety and also report a high number of depressive symptoms (Li, Chung, & Chiu, 2010). In another study, interviews with children who have had cancer revealed the presence of distressing emotional reactions such as feeling scared or nervous, uncertainty, fear related to the possible recurrence of cancer and second malignancies, increased thoughts about being sick, fear of death, and not wanting to discuss their cancer with others (Hildenbrand, Clawson, Alderfer, & Marsac, 2011; Li et al., 2013). In addition, children with cancer generally experience sadness, unhappiness, and worry to a greater degree than healthy peers (Li et al., 2010).

When examining parent ratings on the Behavioral Assessment System for Children, Second Edition (BASC-2), Wolfe-Christensen, Mullins, Stinnett, Carpentier, and Fedele (2009) found that most childhood cancer survivors were rated in the subclinical range in most areas of emotional functioning; however, significant differences were observed between ratings of childhood cancer survivors and healthy children in the control group. The most significant differences were observed in the areas of Somatization and Withdrawal. Moreover, parents of childhood cancer survivors reported increased somatic concerns, depressive symptomology, and withdrawal compared to parents of healthy children in the control group (Wolfe-Christiansen et al., 2009).

Social effects. In addition to those effects discussed previously, children with cancer also regularly experience negative effects to their general social functioning (Li, Lopez, Chung, Ho, & Chiu, 2013; Li, Chung, & Chiu, 2010; Ruland et al., 2009). Interviews conducted with childhood cancer survivors have revealed that survivors often report a reduction in physical strength and endurance after remission, leading to the inability to adequately participate in activities with peers (Li et al, 2013). Pediatric cancer survivors also often identify general concerns with confinement, feelings of estrangement, and disruption in daily routine (Hildenbrand, Clawson, Alderfer, & Marsac, 2011; Li et al., 2010). More specific concerns voiced by survivors of pediatric cancer include not being able to attend school, being restricted to the home, not being able to see friends or siblings regularly, and wanting to be normal (Hildenbrand et al., 2011; Li et al., 2010). Issues of bullying/teasing and difficulty maintaining healthy relationships with peers also often represent concerns of parents of children with cancer (Hildenbrand et al., 2011). Some additional social difficulties experienced by childhood cancer survivors include isolation (i.e., social and physical, loneliness, and confinement), strained peer relationships (i.e., rejection and lack of acceptance), impaired social functioning (i.e., dissatisfaction with relationships with family, recreation and leisure functioning, and level of social support), and difficulties with peer relationships at school (i.e., concerns with social reputation, social acceptance, social competence, social desirability, emotional well-being, and loneliness (Ruland et al., 2009). Given these recognized potential negative effects of childhood cancer, it is important to identify protective factors that might serve to promote healthy development in children dealing with a cancer diagnosis. Three such factors are adequate coping, social support, and benefit finding, which are discussed in what follows.

Coping with Childhood Cancer

Aldridge and Roesch (2007) state that a flood of emotions often accompanies a recent cancer diagnosis. It is therefore essential to understand the ways children cope and adjust to childhood cancer. The process of coping can be divided into two main categories: problem-focused coping and emotion-focused coping (Aldridge & Roesch, 2007). Emotion-focused coping is defined as working to manage one's emotions associated with a particular stressor and problem-focused coping refers to working to reduce conflict between an individual and his or her environment by means of dealing with the stressor head-on (Aldridge & Roesch, 2007). In addition, Aldridge and Roesch indicate the presence of further classifications of coping processes, namely approach and avoidance coping. Approach coping (analogous to problem-focused coping) is a coping strategy that is focused on dealing directly with a stressor, and avoidance coping (analogous to emotion-focused coping) is seen as a coping activity that involves efforts to avoid stressful thoughts or feelings associated with a threat (Aldridge & Roesch, 2007). Hildenbrand, Clawson, Alderfer, and Marsac (2011) examined coping in pediatric cancer patients and their parents. Analysis of interviews conducted as part of this study revealed that children reported using mostly approach coping strategies including cognitive restructuring, using relaxation, practical strategies, seeking social support, and expressing feelings openly. The only avoidance coping strategies reportedly utilized by children with cancer in this study was distraction.

Aldridge and Roesch (2007) have also found that those children who utilized emotion-focused (avoidance) coping strategies also show improvement in overall adjustment; however, the utilization of emotion-focused coping strategies was related to poor adjustment as the time since diagnosis increased. This may be due to the fact that a child’s life is completely altered after receiving a cancer diagnosis, and they are experiencing a flood of emotions (Aldridge & Roesch, 2007). Therefore, the utilization of emotion-focused coping strategies including social support and threat minimization are positive adaptive coping strategies that reduce the negative flood of emotions accompanying a diagnosis and allow the child to regain strength. Furthermore, as time since diagnosis increases, utilization of approach and problem-focused coping strategies tend to be more successful at improving psychological adjustment. In addition, the type of stressor experienced by the child as well as the amount of perceived control by the child often moderates the coping-adjustment relationship. That is, problem-focused coping is more successful at improving psychological outcomes when a situation is perceived as controllable, and emotion-focused coping is more successful when the situation is perceived as unchangeable (Aldridge & Roesch, 2007). Aldridge and Roesch (2007) explain that children who report coping with cancer in general by confronting their illness in a direct way, emotionally or instrumentally, usually experience more improvement in their psychological and physical health as a result. Given the role that effective coping strategies can play in greater adjustment to a cancer diagnosis and recovery, it is important to understand efforts that might be used to ensure the use of such strategies.

Social Support

Past research has examined the role of perceived social support in adolescents and young adults diagnosed with cancer (Corey, Haase, Azzouz, & Monahan, 2008). Results have revealed that adolescents’ and young adults’ level of perceived social support is significantly related to better general mental health. More specifically, more support from family and friends is related to lesser feelings of depressed mood and anxiety among this population of children (Corey et al., 2008). In addition, more perceived support from health care providers is often significantly related to less anxiety (Corey et al., 2008).

Wesley, Zelikovsky, and Schwartz (2015) also examined the role perceived social support from family and friends plays in relation to physical symptoms and psychological health of adolescents with cancer. Results indicated that physical symptoms were significantly associated with both positive and negative affect. Specifically, adolescents who reported fewer physical symptoms (e.g., pain, fatigue, or nausea) also reported higher positive affect and negative affect. In addition, perceived social support from friends was associated with positive affect and not negative affect. The authors propose that social support from friends may help create a sense of normalcy in adolescents with cancer.

A study conducted by Varni and Katz (1997) further examined perceived stress and perceived social support in relation to response to a new cancer diagnosis across three time intervals (Time 1: within one month after diagnosis; Time 2: 6 months post-diagnosis; Time 3: 9 months post-diagnosis). Results indicated that both perceived stress and perceived social support were independently predictive of negative affectivity. More specifically, higher perceived social support was related to lower negative affectivity at Time 1 as well as Time 3. In addition, higher perceived stress was related to higher negative affectivity at both Time 2 and Time 3. In conclusion, the construct of social support appears to be an important predictor of adjustment to childhood cancer. Moreover, “Perceived social support is one of the most critical and effective factors in helping adolescents and adults cope with and adjust to life changes” (Haluska et al., 2002, p. 1317). Therefore, efforts to increase social support in this population are certainly warranted.

Benefit Finding

Researchers have previously examined cancer patients' and survivors' ability to find benefits stemming from their illness. Benefit-finding is described as identifying positive changes in one's life or uncovering a "silver lining" as a result of an individual's illness (Currier, Hermes, & Phipps, 2009; Phipps, Long, & Ogden, 2007). One study examined the psychological predictors of benefit finding in individuals diagnosed with head and neck cancer (Llewellyn et al., 2013). More specifically, the authors looked at coping strategies and levels of optimism as predictive factors for benefit finding. Results showed that patients with head and neck cancer reported moderate to high levels of benefit finding, both pre-treatment and post-treatment. In addition, coping strategies and optimism were predictive of benefit finding. More specifically, active coping, the utilization of emotional support, positive reframing, and optimism were related to finding more positive consequences of a cancer diagnosis. Therefore, research indicates that interventions targeting increasing the use of more positive coping strategies (i.e., problem-focused or approach methods) may foster benefit finding in patients with cancer (Llewellyn et al., 2013).

Researchers have also examined the construct of benefit finding in a pediatric cancer population using the Benefit Finding Scale for Children (BFSC) and the Benefit/Burden Scale for Children (BBSC; Currier, Hermes, & Phipps, 2009; Phipps, Long, & Ogden, 2007). In the context of these studies, benefit finding was positively associated with optimism, positive affect, and self-esteem (Phipps, Long, & Ogden, 2007; Currier, Hermes, & Phipps, 2009). In contrast, benefit finding was negatively associated with pessimism, and was not related to measures of psychological distress. A significant positive correlation was found between benefit finding and the age at diagnosis (Phipps, Long, & Ogden, 2007). More specifically, children who received a cancer diagnosis at age five or younger reported the lowest benefits in relation to older children who reported a greater capacity for benefit finding. It is reasonable to believe that being able to find some benefit from a cancer diagnosis and subsequent recovery can be advantageous for children in their current and future adjustment to this difficult situation. It is therefore important to identify potential methods for increasing this important skill in children.

Oncology Camp Programs

Children who attend oncology camps typically include cancer survivors as well as children who are currently undergoing treatment ranging in age from 4 to 19 (Conrad & Altmaier, 2009; Gillard & Watts, 2013; Martiniuk et al., 2014; Woods, Mayes, Bartley, Fedele, & Ryan, 2013). Children's oncology camp programs can be day programs, weekend programs, or traditional weeklong residential programs (Martiniuk et al., 2014). These programs aim to provide support to children with cancer and their families (Children's Oncology Camping Association, International, 2014; COCA-I; Martiniuk et a., 2014). Some of the activities typically included in camp programs are archery, riflery, horseback riding, and arts and crafts, music and drama, photography or film, field games, swimming, team sports, ropes course, campfires, rock climbing, sailing, canoeing/kayaking, etc. (Conrad & Altmaier, 2009; Gillard & Watts, 2013; Martiniuk et al., 2014). Other specialized camp activities offered can include, but are not limited to, karaoke, movies, a dance, and an end-of-the-week campfire, carnivals, cooking, “glamour shots,” Spa Day, tubing on the lake, a trip to an amusement center, and Olympic Day (Conrad & Altmaier, 2009; Gillard & Watts, 2013). Researchers explain that camps designed for children with chronic illness provide children with these opportunities to participate in novel and challenging activities in order to promote a sense of mastery (Woods et al., 2013)..

Impact of oncology camp programs. Researchers have examined the impact of pediatric oncology summer camp programs for children with cancer in increasing social support, adjustment, developmental experiences, mood, learning, and friendships in children who have had cancer (Conrad & Altmaier, 2009; Gillard & Watts, 2013; Martiniuk et al., 2014; Wellisch, Crater, Wiley, Belin, & Weinstein, 2007; Woods, Mayes, Bartley, Fedele and Ryan, 2013). Conrad and Altmaier (2009) examined the impact of a specialized summer camp program for children with cancer on improving social support and adjustment in campers. Participants consisted of campers from The Heart Connection organization and their parents. The Heart Connection provides support to families dealing with pediatric cancer (Conrad & Altmaier, 2009). During the children's time at camp, there is no organized time for the children to discuss their cancer experiences; however, children often have those discussions with each other throughout the week. Results showed that female campers reported receiving more emotional/informational support (EIS) than males; however, this trend was not significant when examining emotional/esteem-enhancing support (EEES) and tangible support (TS). Authors explain that boys may have been focusing more on the camp activities, and girls may have focused more on socializing. In addition, boys and girls reported receiving more support for all three types social support (EIS, EEES, and TS) within the camp setting than other children reported in their lives in general. This result was not surprising to the authors due to one of the main goals of The Heart Connections summer camp: providing support to campers.

Researchers further examined how specific program features of camps for children with cancer might support children's developmental experiences. In order to examine specific program features, Gillard and Watts (2013) conducted a case study on a residential, one-week long camp for children with cancer and blood disorders. The goal of this particular camp was to "provide a safe, emotionally healing and fantastic adventure that gives every camper the opportunity to grow in independence and self-esteem and leave [camp] a stronger survivor." Interviews and focus groups conducted with campers revealed the following positive developmental experiences: increased positive attitudes (i.e., increased sociability, perseverance and confidence, and gratitude and appreciation) as well as feelings of respite, meaning experiencing freedom and finding a balance between "just being a kid" and managing difficult cancer issues. The program features identified as supporting those developmental experiences included the following: full accommodation, such as integrated and accessible facilities and activities, and opportunities to be physically active; and intentional programming, meaning "a habit of fun", proximity to similar others, engaging activities, caring relationship, and opportunities to maintain connection (Gillard & Watts, 2013).

In addition, studies have examined the constructs of health-related quality of life (HRQOL) and hope in children following participation in a summer camping program for children with chronic medical conditions (Woods, Mayes, Bartley, Fedele & Ryan, 2013). Health-related quality of life is defined as an individual's understanding of the effect of illness on one's social, physical, and emotional functioning (Epstein, Stinson, & Stevens, 2005); whereas hope is defined as "a positive motivational state that is based on an interactively derived sense of successful (a) agency (goal-directed energy), and (b) pathways (planning to meet goals)" (Snyder, Irving, & Anderson, 1991, p.287). Results showed that children attending this summer camp program reported higher levels of hope following participation in camp. In addition, post-camp levels of agency-related hope were meaningful predictors of post-camp HRQOL.

In order to understand affective changes in pediatric cancer patients and their siblings following participation in a weeklong summer camp for children with cancer and their siblings, (Wellisch, Crater, Wiley, Belin and Weinstein (2007) examined mood, social integrations, and relationships with children and adults Results indicated that significant differences were seen between baseline and post-camp depression ratings, signifying a decrease in the overall depression scores for campers. More specifically, campers showed borderline significant improvement in Negative Mood and Interpersonal subscales between baseline and follow-up 1, and showed statistically significant improvement on subscales of Negative Mood and Anhedonia between baseline and follow-up 2.

Finally, Martiniuk, et al. (2014) examined the role camps for children with cancer play on learning and friendship in a sample of camps across the United States and Canada. Younger campers (ages 6-9) reported learning about friendship skills and family citizenship from camp. In addition, younger campers reported experiencing an increase in developing competence, independence, greater exploration, an appreciation of teamwork, and responsibility. In contrast, older campers (ages 10 and above), reported a significant increase in their friendship skills during their time at camp as well as their enjoyment of the time spent with friends (Martiniuk et al., 2014). Moreover, camps for children with chronic illness foster positive social relationships between children with similar challenges caused by their medical conditions (Woods et al., 2013). It is clear that camp programs can be of great benefit in leading to improved adjustment of campers. It is the goal of the current study to examine whether programs are similarly beneficial in increasing the less well-understood constructs of coping, social support, and benefit finding in this population. This information will be important for improving overall recovery and wellbeing of children who have/had cancer, and it will provide more information on ways to most effectively help children who experience cancer.

CHAPTER TWO: STATEMENT OF THE PROBLEM

The current study aims to expand the research regarding the role of pediatric oncology camps on encouraging the adjustment of children diagnosed with and recovering from cancer. Children diagnosed with cancer experience a multitude of negative long-term and late-effects related to their cancer experience. The negative effects children experience may lead to cognitive dissonance when thinking about what they used to look and feel like, or what they might have been able to do physically, and thinking about those same things following their cancer experience. These children may not have high self-efficacy due to physical changes, limitations, or restraints during and/or following their experience with cancer. In addition, children experiencing cancer may need to rely on caregivers more often than before, leading to decreased independence and autonomy. Finally, children who have or had cancer may engage in social comparison due to the negative effects and changes from cancer and its treatment, ultimately leading to a negative self-image, feelings of isolation, distress, or depression. However, research has shown positive effects in the functioning of children diagnosed with cancer related to increased feelings of social support, positive coping strategies, and the ability to find benefits related to their diagnosis, despite experiencing negative effects.

Moreover, recent studies have examined the beneficial effects oncology camp programs can have on increasing the support for and emotional wellbeing of children diagnosed with cancer. Specifically, Wesley, Zelikovsky, and Schwartz (2015) proposed that social support received at these camp programs might lead to a sense of normalcy in children with cancer. Camp Happy Days, a pediatric cancer camp, aims to increase this ‘normalcy’ in children with cancer and provides them with an environment to just be a kid again. The Camp Happy Days organization explains, “At Camp Happy Days, kids discover the power within them – as they share life-changing experiences with kids just like themselves who are battling cancer. Kids can be kids again as they have fun and gain confidence. What cancer takes away, Camp Happy Days helps give back" (Camp Happy Days, 2017). Camp Happy Days incorporates a range of activities, similar to activities identified in previous research (Conrad & Altmaier, 2009; Gillard & Watts, 2013) and aims to provide children with the opportunity to build self-esteem, courage, confidence, and trust. By including these activities, with the goal of building and improving personal characteristics of campers, the specific design and activities offered at Camp Happy Days may influence the perception of social support, the use of coping strategies, as well as campers’ ability to find benefits related to having had cancer. The specific program features incorporated into Camp Happy Days summer camp program work towards the goal of improving physical, emotional, and psychological health of children and families affected by pediatric cancer. Due to the structure of the camp, which mirrors program features in Gillard and Watts’ (2013) research, and the identified goal, these factors may lead to increased levels of social support, the ability to find benefits related to having had cancer, and the use of more positive coping strategies.

The goal, structure, and content of children’s oncology camp programs work to provide children with the support to give back what cancer may take away. More specifically, camp programs provide children with the opportunity to build independence, relationships, autonomy, self-efficacy, positive self-image, have support from others who understand their experiences, engage in social comparison and feel a sense of normalcy, and participate in activities they used to be able to do or activities they could not imagine themselves doing. Because of these possible positive effects from oncology camp programs, and those researched, children’s oncology camp programs may influence children's perceived social support, coping skills utilized, and benefit finding. This study will add to the literature by examining social support, coping, and benefit finding abilities among campers attending Camp Happy Days. The following research questions will be addressed in the current study:

Research Question 1: Do children attending a pediatric oncology camp program display high levels of social support, coping and benefit finding abilities?

Research Question 2: Are campers' specific demographic characteristics (i.e., age, gender, ethnicity, months since diagnoses, years attended camp, etc.) related to reported levels of perceived social support, coping skills, and benefit finding abilities?

Research Question 3: Are the three constructs being measured related to each other?

Based on the general design of children's oncology camps and the support provided to children diagnosed with cancer and their families, it is first hypothesized that campers will report using more approach/problem-focused (positive) coping strategies than negative coping strategies. Second, it is hypothesized that campers will report a high degree of benefits. Third, it is hypothesized that campers will report the highest levels of perceived support from a close friend and other children at camp when compared to adults at camp. Fourth, it is hypothesized that campers' age, months since diagnosis, and number of years attended camp will influence levels of perceived social support, the number of coping strategies used, the number of positive/approach or negative/avoidance coping strategies used, and the ability to find benefits. More specifically, it is expected that children who are older, who have attended camp previously, or children who are more removed from their initial diagnosis, will have had more time to develop effective strategies in dealing with stressors related to their cancer, including greater social support, positive/approach coping strategies, and benefit finding abilities. Finally, it is hypothesized that campers’ levels of perceived social support will be related to their ability to find benefits and use of positive/approach coping skills (and vice versa).

CHAPTER THREE: METHODS

Participants

Participants in this study were recruited from Camp Happy Days, a weeklong camp for children diagnosed with cancer ages 4-16. The researcher, as well as other camp administrators, approached potential camper participants through caregivers who provided informed consent at camp registration/check-in. Eighty-two out of 261 campers' caregivers provided consent. The criteria for camper participation selection included campers being between the ages of 7 and 16 and currently or previously having had cancer. The low number of parental consent was due to some campers being too young and some children never having had cancer before (e.g., siblings of children with cancer). Camp Happy Days is a camp for siblings of children who have or had cancer as well. All campers approached during this study provided assent prior to completing the three measures.

In the current study 38 campers (14 female; 24 male) completed the surveys during the 2016 camp session. The graduate student conducting research met with the campers during meal times, so as to not take away from the campers' participation in camp activities. As a result, the researcher was not able to meet with all 82 children whose parents had filled out consent for their participation in the study. Participants' ages ranged from 7 to 16 ($M = 12.18, SD = 2.67$). Because the authors of the KidCOPE measure divided their questionnaire by age ranges, the researcher divided campers' ages into those same age ranges as well: 7-12 years ($n = 20$) and 13-16 years ($n = 18$). Ethnic backgrounds of the participants are as follows: Caucasian (65.8%), African American or Black (18.4%), Hispanic or Latino (7.9%), and Other (7.9%). Diagnoses received include Leukemia ($n = 16$); Lymphoma (n = 4), Brain Cancer (n = 12), and Other (n =

6). Months since diagnoses are also categorized by ranges: 0-25 months, 26-50 months, 51-75 months, 76-100 months, 101-125 months,126-150 months, and 150+ months. Out of the campers surveyed, 28 had attended camp prior to this year. The number of years campers' had attended camp previously ranged from 1 year to 8 years (*M = 3.68, SD = 2.11*).

Procedures

A Memorandum of Understanding (MOU) was signed between Camp Happy Days and Western Carolina University on October 7, 2015. The MOU is an agreement allowing the graduate student from Western Carolina University to collect data from children attending Camp Happy Days during the summer 2016 camp sessions. Institutional Review Board (IRB) approval was obtained from Western Carolina University. Consent was obtained from parents of children attending Camp Happy Days during the camp registration/check-in process for the 2016 summer camp session, and campers provided assent prior to participating in the current study. Campers completed three measures during their camp session. The measures the children completed included the Benefit Finding Scale for Children (BFSC; Phipps, Long, & Ogden, 2007), the KidCOPE measure (Spirito, Stark, & Williams, 1988), and a modified version of the Children's Assessment of Perceived Social Support (CAPSS; Wu, Geldhof, Roberts, Parikshak, & Amylon, 2013). Demographic information for participants was also collected. Completion time of the three measures ranged anywhere from 15 minutes to 25 minutes, depending on the camper.

Measures

Demographics

Demographic information for participants was obtained from camper applications, completed by parents. Information obtained from camper applications included age, gender, ethnicity, diagnosis received, time since diagnosis, and numbers of years attended camp prior to this year.

Benefit Finding

The Benefit Finding Scale for Children (BFSC; Phipps, Long, & Ogden, 2007) is composed of 10 items examining the ability to find potential benefits of illness (See Appendix A). Each item is answered on a 5-point Likert scale ranging from “not at all true for me” to very true for me”. The measure begins with the statement “Having had my illness”, and children answer items such as “has helped me become a stronger person”, “has helped me learn who my real friends are”, and “has helped me know how much I am loved”. The BFSC provides a Total benefit finding score. Authors completed psychometric analysis of the BFSC by using the Principal Component Analysis (Phipps, Long, & Ogden, 2007). The internal reliability of the BFSC has been estimated as .834.

Coping

The KidCOPE (Spirito, Stark & Williams, 1988) is a brief checklist designed to measure cognitive and behavioral coping in children and adolescents. There are two versions of KidCOPE: one for children ages 7 to 12 and one for adolescents ages 13 to 18 (See Appendix B). The version designed for adolescents consists of ten items, each representing a coping strategy: distraction, social withdrawal, cognitive restructuring, self-criticism, blaming others, problem solving, emotional regulation, wishful thinking, social support, and resignation. The version designed for children consists of 15 items, including two items for some of the coping strategies listed. Items on the KidCOPE can be divided into two categories: positive/approach coping methods and negative/avoidance coping methods. Children and adolescents completing this measure are provided with a specific stressor (e.g., hospital or illness specific), and they are told to keep the stressor in mind as they complete the items. For the current study, children were asked to keep in mind changes they've experienced as a result of having cancer. Each item on the KidCOPE has two scales: frequency (”Did you do this?”) and efficacy (“How much did it help?”). On the younger version of the frequency scale, children respond “yes” or “no”; while, on the older version, adolescents respond using a 4-point Likert scale (0= “not at all” to 3= “all the time”). Children and adolescents completing the KidCOPE answer the efficacy scale only after proving a response greater than zero to the frequency scale. On the younger version of the efficacy scale, children respond using a 3-point Likert scale (0= “not at all” to 2= “a lot”); while, on the older version, adolescents respond using a 4-point Likert scale (0= “not at all” to 3= “very much”). Authors indicate that psychometric assessment for the KidCOPE was completed using groups of “typical”, children who attended diabetes camp, and children from a pediatric psychiatric outpatient program (Spirito, Stark & Williams, 1988). The test-retest reliability estimates of the KidCOPE over a 3 to 7 day period ranges from .41 to .83. Moderate correlations were found between the KidCOPE and other measures of children's coping strategies, such as Coping Strategies Inventory, which provides evidence of concurrent validity for the KidCOPE measure.

Perceived Social Support

The Children's Assessment of Perceived Social Support (CAPSS; Wu, Geldhof, Roberts, Parikshak, & Amylon, 2013) is designed to measure children's perception of social support at home as well as within the context of a chronic illness summer camp programs for children. The areas measured at home include perceived support from parents, teachers, classmates, and a close friend at home. The areas measured within the context of summer camp programs include perceived social support from counselors, other children at camp, and a close friend at camp.

Items are rated on a 5-point Likert scale (1 = not at all true for me, 5 = very true for me). Furthermore, the CAPSS measure aims to examine the effectiveness of summer camps as intervention for improving the psychosocial functioning of children with chronic illness such as cancer. The CAPSS measure was developed from another reliable and valid social support measure, the Social Support Scale for Children, which demonstrates item alphas ranging from .72-.88. The CAPSS instrument contains 42 items; however, for the purposes of measuring perceived social support in the current study, the measure will be modified to only include those items measuring perceived social support gained from adults, kids, and a close friend at camp. The items pertaining to social support from parents, classmates, teachers, and close friends were left off due to the goal of the current study. The modified version designed for the current study contained 18 items (See Appendix C).

Data Analysis

In order to test the proposed hypotheses, a series of psychometric tests were conducted. Campers' overall reported levels of social support, coping abilities, and benefit finding were examined and interpreted in light of the scoring criteria for these respective measures. Descriptive statistics were examined in order to gain information about the number of coping strategies used, the efficacy of the coping strategies reportedly used, reported levels of social support, and campers' reported benefits related to having experienced cancer. Independent-samples *t-tests* were conducted in order to determine the difference in campers' ratings of perceived social support, benefit finding, and coping strategies utilized based on campers' gender and if they had previously attended camp or not. A series of *analysis of variance* (*ANOVA*) tests were also run in order to determine group differences in perceived social support, benefit finding, and coping strategies based on age, ethnicity, the number of years campers have attended camp, time since diagnosis, and specific diagnosis received. In order to understand the relationship between the different constructs measured, a series of correlations were examined. Finally, qualitative analyses related to observations and interviews conducted with current and former campers were also utilized for the purposes of corroborating the reported effectiveness of this camp program via reports from the very population it serves (campers).

CHAPTER FOUR: RESULTS

Coping

See Table 1 for a summary of campers' self-ratings on the effectiveness of coping strategies utilized when dealing with a stressor related to their experience with cancer. The stressors reported by campers were related to physical stressors (i.e., pain, changes in appearance, limitations, etc.), social stressors (i.e., not being able to see friends/family, not fitting in, having to stay at home, not going to school, etc.), emotional stressors (i.e., depression, worry, others worrying, etc.), and medical stressors (i.e., medication, needles, doctor visits, hospital stays, etc.). When comparing the average number of positive/approach coping strategies used by participants, results indicate that, campers reported using more positive/approach coping strategies ($M = 3.19, SD = 1.023$) than negative/avoidance coping strategies ($M = 2.46, SD = 1.325$). Further analysis indicated that the difference between the average number of positive coping strategies reportedly used and the average number of negative coping strategies reportedly used is significant [t (36) = 3.069, p = .004].

See Figure 1 for a summary of the coping strategies participants reportedly utilized when dealing with stressors related to their cancer experience. When examining the specific coping strategies reportedly used by campers, the two positive coping strategies used the most also had the highest efficacy ratings: Cognitive Restructuring and Social Support. This demonstrates that on average, campers who utilized these coping strategies indicated that it helped them a little or a lot in dealing with stressors related to their cancer diagnosis. The two negative/avoidance coping strategies reportedly used the least often by campers also had the lowest efficacy ratings: Self-Criticism and Blaming Others. This shows that on average, campers who utilized these coping strategies indicated that using these strategies did not help them at all or only a little in dealing with presenting stressors. When examining the efficacy of positive/approach coping strategies compared to negative/avoidance coping strategies, campers' average ratings of positive/approach coping strategies ($M = 2.18$) used was higher than average ratings of negative/avoidance coping strategies ($M = 0.96$) used. This reveals that positive coping strategies were generally perceived by campers to be more helpful in dealing with stressors related to cancer than negative coping strategies.

A significant difference was found when examining the number of years campers have attended camp and the following: the number of coping strategies used [F (8,29) = 6.099, p = .000] and the number of positive/approach coping strategies used [F (8,29) = 4.446, p = .001]. A significant difference was also found when examining months since diagnosis and the following: the number of coping strategies used [F (6,31) = 3.170, p = .015], the number of positive/approach coping strategies used [F (6,31) = 4.461, p = .002], and the number of negative/avoidance coping strategies used [F (6,31) = 3.073, p = .018].

Figure 1. *Participants' Reported Use of Coping Strategies*

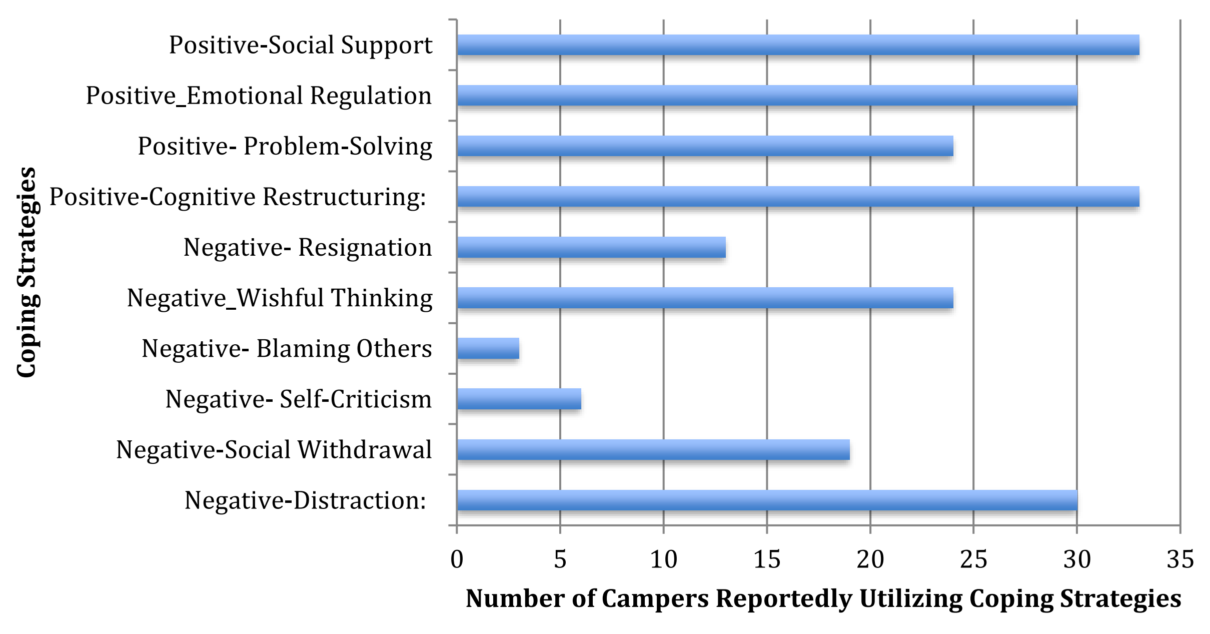

Table 1.

Summary of Participants' Reported Effectiveness of Coping Strategies

KidCOPE		
	Negative/Avoidance Coping	
Strategy	Mean	Standard Deviation
Distraction	2.00	1.139
Social Withdrawal	0.97	1.078
Self-Criticism	0.32	0.775
Blaming Others	0.16	0.594
Wishful Thinking	1.53	1.289
Resignation	0.78	1.158
	Positive/Approach Coping	
Strategy	Mean	Standard Deviation
Cognitive Restructuring	2.45	1.032
Problem-Solving	1.66	1.361
Emotional Regulation	2.13	1.189
Social Support	2.49	1.044

Note. This is divided into positive and negative coping strategies and provides information regarding mean efficacy ratings for each strategy.

Perceived Social Support

In general, results indicated that campers perceived similar levels of support from a Close Friend, Adults, and Other Kids at camp. See Table 2 for campers' average ratings of perceived social support from each source as well as the average total score on the perceived social support measure. Table 2 also provides information regarding the standard deviation for perceived support form the three sources examined as well as the total score. Although campers' perceived slightly more support from adults and other kids than from close friends, the difference was not significant. In addition, standard deviations for sources of perceived social support as well as the total score for social support are fairly high, indicating that some campers reported low levels of perceived support at camp. Camper's reported levels of perceived social support from the three sources did not differ as a function of age, gender, ethnicity, the type of diagnosis received, or months since diagnosis. A significant difference was found when examining campers' reported levels of perceived social support from a Close Friend at camp and the following: if campers have attended camp previously [$t(36) = 2.171$, $p = .037$] and how many times campers have attended camp [$F(8,29) = 2.553$, $p = 0.31$]. Camper's overall Social Support Total Score did not differ significantly as a function of age, gender, ethnicity, the type of diagnosis received, months since diagnosis, if campers previously attended camp, or the number of years campers had attended camp in the past. In addition, a significant positive relationship was found between campers' Total Score for Perceived Social Support and campers' Total Score on the Benefit Finding Scale for Children ($r = .575$). This indicates that as their ability to find benefits related to their illness increases, their perceived level of social support also increases…or vice versa.

Table 2.

Summary of Participants Reported Levels of Perceived Social Support at Camp

Perceived Social Support		
Source	Mean	Standard Deviation
Close Friend	23.42	6.446
Adult	24.82	5.342
Other Kids	24.32	4.114
Total	72.55	13.671

Benefit Finding

See Table 3 for a summary of campers' self-ratings regarding the benefits they have identified despite having experienced cancer. The table indicates campers' average ratings for each item as well as the average total score on the Benefit Finding Scale for Children. Relative to samples in prior research, results indicated that most kids at camp identified a high degree of benefits related to their illness ($M = 43.53, SD = 7.01$). Average results for campers' Total Score and average ratings on individual items are higher than what was found in research for the development of the Benefit Finding Scale for Children, which indicated a skew somewhat toward higher reports of benefit findings (Phipps, Long, & Ogden, 2007). When looking at individual items, all items except for one, had an average rating of 4 or higher, indicating that most campers reported that having cancer has done the following Quite a Bit or Very Much for them: has helped me become a stronger person, to learn who my real friends are, to know how much I am loved, to make some new best friends, and to learn to deal better with my problems; has taught me to be more loving to others, what is really important in life, and to be happy and enjoy the good things when they happen; and has brought my family closer together. The following item had an average rating below 4, indicating that most campers reported that this was only Somewhat True for them: Having had my illness has taught me to be more patient.

Camper's Benefit Finding Total Score did not differ significantly as a function of age, gender, ethnicity, the type of diagnosis received, months since diagnosis, or if campers had previously attended camp. A significant difference was found when examining Campers' Benefit Finding Total Score and the number of years campers attended camp [*F (8,29) = 3.383, p = .007*].

Table 3.

Summary of Participants' Identified Benefits

Benefit Finding Scale for Children		
Item	Mean	Standard Deviation
Having had my illness…		
Has helped me become a stronger person.	4.37	1.261
Has helped me learn who my real friends are.	4.11	1.203
Has helped me know how much I am loved.	4.66	0.745
Has helped me make some new best friends.	4.50	0.923
Has helped me learn to deal better. with my problems.	4.24	0.971
Has taught me to be more patient.	3.79	1.318
Has taught me to be more loving to others.	4.45	1.032
Has brought my family closer together.	4.21	1.234
Has taught me what is really important in life.	4.61	1.028
Has taught me to be happy and enjoy the good things when they happen.	4.61	1.001
Total	43.53	7.009

Qualitative Analyses

Informal interviews with current and former campers as well as observations of camp activities reflected the relationships and friendships that are fostered at camp. Former campers expressed how much Camp Happy Days has impacted their life. They specifically talked about how people at camp encourage, empower, and inspire them. A counselor-in-training, who was formerly a camper himself, stated that Camp Happy Days has given him a new appreciation for life, and that he has better learned the struggles of others. He further explained that camp has taught him that you don’t always know what someone else has struggled through, and you shouldn’t take that for granted.

When the graduate student asked campers about their favorite thing about Camp Happy Days, their answers revolved around fun activities, making close friends, and developing positive relationships with counselors. Both former and current campers generally discussed being able to relate to one another and having an understanding of each other’s experiences related to cancer. For example, after the graduate student asked what a camper liked most about camp, one camper stated, “You have fun, there are people who understand about you having cancer, and you get to make close friends.” A counselor, who was formerly a camper, stated that she is able to say to campers, “I know where you are, and I know where you’ve been.” She further explained that she is able to be there for campers and tell them, “Your cancer or your disability does not define who you are.” Similarly, the counselor-in-training explained that he is excited to be a junior counselor next year, and he cannot give back enough to Camp Happy Days. He also said that there is a sense of family at Camp Happy Days, and everyone is open-minded.

The graduate student noticed various trends while observing diffident activities such as woodworking, arts and crafts, glitz & glamour, the ropes course, and the climbing wall. Campers often worked together, supported each other, and cheered each other on as they tried new and difficult activities. Counselors continuously worked to help, cheer on, and keep their campers included and involved. A former camper explained that she had a lot of “firsts” at camp—canoeing, parasailing, swimming, etc. This former camper also said there are always people at camp cheering others on during these activities. Every experience observed involved making friends, bonding with one another, or building relationships. This experience was not about who had cancer or who didn’t have cancer; it was just about being a kid and having fun at camp.

CHAPTER FIVE: DISCUSSION

Although there were not many differences found based on demographic information, there were many positive trends identified. Campers reported using more positive/approach coping skills when dealing with a stressor related to cancer. This is in support of previous research documenting children with cancer reportedly using more approach-oriented coping strategies (Hildenbrand, Clawson, Alderfer, & Marsac, 2011). It is important to note that items on the KidCOPE measure included more items that were labeled as negative/avoidance coping strategies. Consistent with previous findings, the positive/approach coping strategies campers reportedly used were generally noted as more effective than any negative/approach coping strategies used (Spirito, Stark, & Williams, 1988). Campers also reported similar physical, social, and emotional stressors related to their cancer experience as stated in previous research (Hildenbrand et al., 2011; Li, Chung, & Chiu, 2010; NCI, 2015; Ruland et al., 2009). In addition, campers reported similar levels of perceived social support from close friends, adults, and other children at camp. This is similar to previous research where campers did not differentiate between various sources of support at camp. This suggests that children expand the types as well as sources of perceived support via oncology camp experiences; consequently increasing overall perceived social support (Williams et al., 2003 as cited in Wu, Geldhof, Roberts, Parikshak, & Amylon, 2013). Furthermore, results from the Benefit Finding Scales for Children demonstrated that most campers found benefits related to becoming a stronger person; learning who their real friends are; knowing how much they are loved; making new best friends; dealing better with their problems; learning to be more loving to others; learning what is really important in life; and learning to be happy and enjoy the good things when they happen. This is consistent with previous findings that reveal patients and survivors reporting positive outcomes related to their illness such as observed changes in one's focus, more appreciation for life as well as relationships, increased empathy and emotional strength, closer connections to others, and reorganizing one's life priorities (Affleck & Tennen, 1996; Antoni et al., 2001; Carver & Antoni, 2004; Cordova, Cunningham, Carlson, & Andrykowski, 2001; Tomich & Hegelson, 2004 as cited in Phipps, Long, & Ogden, 2007; Eiser, Hill, & Vance, 2000; Zebrack & Chesler, 2002 as cited in Patenaude & Kupst, 2005).

In the current study, the number of years campers have attended camp was related to their ability to find benefits, the number of total coping strategies used to cope with having cancer, and the number of positive/approach coping strategies reportedly used. In addition, the number of months since receiving a diagnosis was related to the number of coping strategies used, number of positive/approach coping strategies used, and the number of negative/avoidance coping strategies used. Inconsistent with the current study, past research has only shown differences in children's benefit finding abilities when looking at time since diagnosis (Phipps, Long, & Ogden, 2007). The lack of differences observed in benefit finding, coping, and social support may be due to the shared environment of the campers and the overall goal of the camp for all campers.

Most of the demographic and background information examined did not impact reported levels of social support reported, the number of coping strategies used, the number of positive/negative coping strategies reportedly used, and the ability to find benefits related to having cancer. This is consistent with previous research that showed that benefit finding did not differ when looking at diagnostic categories, age, gender, or SES groups (Phipps, Long, & Ogden, 2007). However, past studies have also shown significant differences in benefit finding abilities by race/ethnicity as well as time since diagnosis, which is inconsistent with findings from this study (Phipps, Long, & Ogden, 2007). To date, there has not been a research focus on the relationship between perceived social support using the Children's Assessment of Perceived Social Support (CAPSS; Wu, Geldhof, Roberts, Parikshak, & Amylon, 2013) measure and demographic characteristics or other measures (Wu, et al., 2013).

Qualitative observations and analyses reveled similar trends consistent with previous research (Gillard & Watts, 2013; Martiniuk et al., 2014; Wesley, Zelikovsky, & Schwartz, 2015; Woods et al., 2013). Interviews with current and former campers revealed the following positive experiences at camp: having a sense of normalcy and closeness to others (i.e., relating to others who have had cancer and others understanding what experiencing cancer is like); positive social relationships with campers and counselors; a sense of family; gratitude and appreciation; developing competence; and an appreciation for teamwork. These positive experiences reported in the current study as well as in past studies support the notion that camp provides children with the place to relieve any cognitive dissonance, reduce negative social comparison, improve one's self-image, and build self-efficacy, competence, and autonomy.

Limitations

The original aim of the current study was to compare reported levels of social support, coping, and benefit finding abilities among campers to those of children with cancer who have not attended a children's oncology summer camp program like Camp Happy Days. As such, it would've been easier to make a firm conclusion that it was the camp program itself that was most instrumental in leading to benefits in these domains. It is possible that children who have not attended camp can have lower levels of perceived social support, use different coping strategies, as well as find less benefits. However, it is also possible that children may use similar coping strategies and find, regardless of having the camp experience or not, due to the nature of experiencing cancer. The graduate student conducting research for the current study experienced great difficulty with getting feedback from families outside of the camp program. More specifically, the graduate student attempted to contact families who are affiliated with Camp Happy Days but have never attended the summer camp program; no families responded to this request. It is difficult to understand the relationship between camp and the three constructs examined without the inclusion of a control group as a result. If possible, future research may benefit from including a control group when examining these constructs in relation to the role of children's oncology camp programs. With the addition of a control group, it will be clearer to determine if the campers' ability to find benefits, utilize positive/approach coping strategies, and perceive social support is related to the specific nature and design of children's oncology summer camp programs. Another limitation in the current study is the lack of campers' surveyed. With the help of others surveying children during meal times, there would be more opportunities for campers to participate.

Implications

It is important for school psychologists to be advocates for students in their school who have been affected by cancer. According to the National Association of School Psychologists (NASP), a principle reflected in the 10 domains of school psychology practice includes the following: "School psychologists use effective strategies and skills in the domains to help students succeed academically, socially, behaviorally, and emotionally." Research has identified many negative effects from having and being treated for cancer. Results from the current study and previous studies identify the positive support and benefits that Children's Oncology Camps provide for this population. By utilizing information from this current and past studies, and by ethically following this principle during practice, school psychologists can be a resource for positive supports available for families with children with cancer.

In addition, school psychologists should take note of the positive aspects of camp programs in promoting effective adjustment in children when faced with a difficult diagnosis such as cancer. By understanding and paying attention to these benefits, schools can try to incorporate similar efforts into the school climate for children who have or had cancer. For example, schools should attempt to promote a greater sense of normalcy for these children (i.e., focus on making the child feel like a student rather than a child with cancer). Additionally, schools should be mindful of the fact that children may be experiencing cognitive dissonance, negative self-image, low self-efficacy, decreased independence and autonomy, etc. By doing so, schools can focus on providing supports and activities targeting these negative psychological experiences. Schools can have student's complete a survey during the school's re-entry process for students with chronic illness in order to identify in which area(s) they need more support.

REFERENCES

Aldridge, A. A., & Roesch, S. C. (2007). Coping and adjustment in children with cancer: A meta-analytic study. *Journal of Behavioral Medicine, 30*(2), 115-129. doi:10.1007/s10865-006-9087-y

Camp Happy Days (2017). Retrieved from http://www.camphappydays.org/

Children's Oncology Camping Association, International (2014). Retrieved from http://www.cocai.org/

Compas, B. E., Desjardins, L., Vannatta, K., Young-Saleme, T., Rodriguez, E. M., Dunn, M., & ... Gerhardt, C. A. (2014). Children and adolescents coping with cancer: Self- and parent reports of coping and anxiety/depression. *Health Psychology, 33*(8), 853-861. doi:10.1037/hea0000083

Conrad, A., & Altmaier E. Specialized summer camp for children with cancer: Social support and adjustment. *Journal of Pediatric Oncology Nursing* [serial online]. May 2009;26(3):150-157. Available from: PsycINFO, Ipswich, MA. Accessed November 9, 2015.

Corey, A. L., Haase, J. E., Azzouz, F., & Monahan, P. O. (2008). Social support and symptom distress in adolescents/young adults with cancer. *Journal of Pediatric Oncology Nursing, 25*(5), 275-284. doi:10.1177/1043454208321117

Currier, J. M., Hermes, S., & Phipps, S. (2009). Children's response to serious illness: Perceptions of benefit and burden in a pediatric cancer population. *Journal of Pediatric Psychology, 34*(10), 1129-1134.

Daly, B. P., Kral, M. C., & Brown, R. T. (2008). Cognitive and academic problems associated with childhood cancers and sickle cell disease. *School Psychology Quarterly, 23*(2), 230-242. doi:10.1037/1045-3830.23.2.230

Epstein, I., Stinson, J., & Stevens, B. (2005). The effects of camp on health-related quality of life in children with chronic illnesses: A review of the literature. *Journal of Pediatric Oncology Nursing, 22*, 89–103.

Gillard, A., & Watts, C. E. (2013). Program features and developmental experiences at a camp for youth with cancer. *Children and Youth Services Review, 35*(5), 890-898. doi:10.1016/j.childyouth.2013.02.017

Haluska, H. B., Jessee, P. O., & Nagy, M. C. (2002). Sources of social support: Adolescents with cancer. *Oncology Nursing Forum, 29*, 1317-1324.

Hildenbrand, A. K., Clawson, K. J., Alderfer, M. A., & Marsac, M. L. (2011). Coping with pediatric cancer: Strategies employed by children and their parents to manage cancer-related stressors during treatment. *Journal of Pediatric Oncology Nursing, 28*(6), 344-354. doi:10.1177/1043454211430823

Li, H. C. W., Chung, O. K. J., & Chiu, S. Y. (2010). The impact of cancer on children's physical, emotional, and psychosocial well-being. *Cancer Nursing, 33*(1), 47-54.

Li, H., Lopez, V., Joyce Chung, O. K., Ho, K., & Chiu, S. Y. (2013). The impact of cancer on the physical, psychological and social well-being of childhood cancer survivors. *European Journal of Oncology Nursing, 17*(2), 214-219. doi:10.1016/j.ejon.2012.07.010

Llewellyn, C. D., Horney, D. J., McGurk, M., Weinman, J., Herold, J., Altman, K., & Smith, H. E. (2013). Assessing the psychological predictors of benefit finding in patients with head and neck cancer. *Psycho-Oncology, 22*(1), 97-105. doi:10.1002/pon.2065

Martiniuk, A. C., Amylon, M. D., Briery, B. G., Shea-Perry, M., Kelsey, K. P., Lam, G. W., & Körver, S. (2014). Camper learning and friendship at pediatric oncology camps in North America. *Journal of Psychosocial Oncology, 32*(2), 234-244. doi:10.1080/07347332.2013.874001

Mulhern, R. K., Merchant, T.E., Gajjar, A., Reddick, W.E., & Kun, L.E. (2004). Late neurocognitive sequelae in survivors of brain tumors in childhood. *Lancet Oncology, 5,* 399–408.

National Association of School Psychologists (2010). Model for comprehensive and integrated school psychological services. Retrieved from https://www.nasponline.org/standards-and-certification/nasp-practice-model/about-the-nasp-practice-model

National Cancer Institute at the National Institutes of Health (2014). Retrieved from http://www.cancer.gov/

National Cancer Institute at the National Institutes of Health (2015). Treatment: Side effects. Retrieved from http://www.cancer.gov/

Palmer, S. L., Gajjar, A., Reddick, W. E., Glass, J. O., Kun, L. E., Wu, S., et al. (2003). Predicting intellectual outcome among children treated with 35–40 Gy craniospinal irradiation for medulloblastoma. *Neuropsychology, 17,* 548–555.

Palmer, S. L., Reddick, W. E., & Gajjar, A. (2007). Understanding the cognitive impact on children who are treated for medullobastoma. *Journal of Pediatric Psychology, 32,* 1040–1049.

Patenaude, A. F., & Kupst, M. J. (2005). Psychosocial functioning in pediatric cancer. *Journal of Pediatric Psychology, 30*(1), 9-27

Phipps, S., Long, A. M., & Ogden, J. (2007). Benefit finding scale for children: Preliminary findings from a childhood cancer population. *Journal of Pediatric Psychology, 32(*10), 1264-1271.

Ruland, C. M., Hamilton, G. A., & Schjødt-Osmo, B. (2009). The complexity of symptoms and problems experienced in children with cancer: A review of the literature. *Journal of Pain and Symptom Management, 37*(3), 403-418.

Smith, M. A., Altekruse, S. F., Adamson, P. C., Reaman, G. H., & Seibel, N. L. (2014), Declining childhood and adolescent cancer mortality. *Cancer*, *120*, 497–2506. doi:10.1002/cncr.28748

Snyder, C. R., Irving, L. M., & Anderson, J. R. (1991). Hope and health. In C. R. Snyder & D. R. Forsyth (Eds.), *Handbook of social and clinical psychology: The health perspective* (pp. 285–305). Elmsford, NY: Pergamon.

Spirito, A., Stark, L. J., & Williams, C. (1988). Development of a brief coping checklist for use with pediatric populations. *Journal of Pediatric Psychology*, *13*(4), 555-574.

Stein, K. D., Syrjala, K. L., & Andrykowski, M. A. (2008). Physical and psychological longterm and late effects of cancer. *Cancer, 112*(S11), 2577-2592. doi:10.1002/cncr.23448

Varni, J. W., & Katz, E. R. (1997). Stress, social support and negative affectivity in children with newly diagnosed cancer: A prospective transactional analysis. *Psycho-Oncology, 6*(4), 267-278. doi:10.1002/(SICI)1099-1611(199712)6:4<267::AID-PON277>3.0.CO;2-O

Wellisch, D. K., Crater, B., Wiley, F. M., Belin, T. R., & Weinstein, K. (2007). Psychosocial impacts of a camping experience for children with cancer and their siblings. *Psycho-Oncology*, *15*(1), 56-65. doi:10.1002/pon.922

Wesley, K. M., Zelikovsky, N., & Schwartz, L. A. (2013). Physical symptoms, perceived social support, and affect in adolescents with cancer. *Journal of Psychosocial Oncology, 31*(4), 451-467. doi:10.1080/07347332.2013.798761

Wolfe-Christensen, C., Mullins, L. L., Stinnett, T. A., Carpentier, M. Y., & Fedele, D. A. (2009). Use of the Behavioral Assessment System for Children 2nd edition: Parent report scale in pediatric cancer populations. *Journal of Clinical Psychology in Medical Settings*, *16*(4), 322-330. doi:10.1007/s10880-009-9174-7

Woods, K., Mayes, S., Bartley, E., Fedele, D., & Ryan, J. (2013). An evaluation of psychosocial outcomes for children and adolescents attending a summer camp for youth with chronic illness. *Children's Health Care, 42*(1), 85-98. doi:10.1080/02739615.2013.753822

Wu, Y. P., Geldhof, G. J., Roberts, M. C., Parikshak, S., & Amylon, M. D. (2013). Initial examination of a new questionnaire assessing perceived social support in summer camp and home environments for children with cancer and their siblings. *Children's Health Care*, *42*(1), 67-84. doi:10.1080/02739615.2013.753817

APPENDIX A

Benefit Finding Scale for Children

We know that having a serious illness can be very hard on children or teens, but some kids also find good things about being sick. Below are listed some things, good and bad, that might happen to children or change in their life because of being sick. Please read each statement carefully, and circle a number from 1 to 5 to show how much these things have happened to you since you became ill.

		Not at all	A little bit	Somewhat	Quite a bit	Very Much
	Having had my illness					
1.	Has helped me become a stronger person.	1	2	3	4	5
2.	Has helped me learn who my real friends are.	1	2	3	4	5
3.	Has helped me know how much I am loved.	1	2	3	4	5
4.	Has helped me make some new best friends.	1	2	3	4	5
5.	Has helped me learn to deal better with my problems.	1	2	3	4	5
6.	Has taught me to be more patient.	1	2	3	4	5
7.	Has taught me to be more loving to others.	1	2	3	4	5
8.	Has brought my family closer together.	1	2	3	4	5
9.	Has taught me what is really important in life.	1	2	3	4	5
10.	Has taught me to be happy and enjoy the good things when they happen.	1	2	3	4	5

APPENDIX B

KidCOPE

KidCOPE: Younger Version

We are trying to find out how children deal with problems related to their cancer. Think about something that has to do with your cancer experience that has bothered you. Please describe the situation below:

INSTRUCTIONS: Please read each item and circle whether you have used any of the following methods to deal with this problem (if any). Then answer both questions to the right of each item, circling the best answer.	Did you do this?		How much did it help?		
1. I just tried to forget it	Yes	No	Not At All	A Little	A Lot
2. I did something like watch TV or played a game to forget it.	Yes	No	Not At All	A Little	A Lot
3. I stayed by myself.	Yes	No	Not At All	A Little	A Lot
4. I kept quiet about the problem.	Yes	No	Not At All	A Little	A Lot
5. I tried to see the good side of things.	Yes	No	Not At All	A Little	A Lot
6. I blamed myself for causing the problem.	Yes	No	Not At All	A Little	A Lot
7. I blamed someone else for causing the problem.	Yes	No	Not At All	A Little	A Lot

8. I tried to fix the problem by thinking of answers.	Yes	No	Not At All	A Little	A Lot
9. I tried to fix the problem by doing something or talking to someone.	Yes	No	Not At All	A Little	A Lot
10. I yelled, screamed, or got mad.	Yes	No	Not At All	A Little	A Lot
11. I tried to calm myself down.	Yes	No	Not At All	A Little	A Lot
12. I wished the problem had never happened.	Yes	No	Not At All	A Little	A Lot
13. I wished I could make things different.	Yes	No	Not At All	A Little	A Lot
14. I tried to feel better by spending time with others like family, grownups, or friends.	Yes	No	Not At All	A Little	A Lot
15. I didn't do anything because the problem couldn't be fixed.	Yes	No	Not At All	A Little	A Lot

KidCOPE: Older Version

We are trying to find out how people deal with problems and stresses related to their cancer. Think about something related to your cancer experience that has been difficult for you. Please describe the situation below:

INSTRUCTIONS: Please read each item and circle whether you have used any of the following methods to deal with this problem (if any). Then answer both questions to the right of each item, circling the best answer.	Did you do this?	How much did it help?
1. I thought about something else; tried to forget it; and/or went and did something like watch TV or play a game to get it off my mind.	Yes No	Not At A A All Little Lot
2. I stayed away from people; kept my feelings to myself; and just handled the situation on my own.	Yes No	Not At A A All Little Lot
3. I tried to see the good side of things and/or concentrated on something good that could come out of the situation.	Yes No	Not At A A All Little Lot
4. I realized I brought the problem on myself and blamed myself for causing it.	Yes No	Not At A A All Little Lot
5. I realized that someone else caused the problem and blamed them for making me go through this	Yes No	Not At A A All Little Lot

6. I thought of ways to solve the problem; talked to others to get more facts and information about the problem and/or tried to actually solve the problem.	Yes	No	Not At A A All Little Lot
7a. I talked about how I was feeling; yelled, screamed, or hit something.	Yes	No	Not At A A All Little Lot
7b. Tried to calm myself by talking to myself, praying, taking a walk, or just trying to relax.	Yes	No	Not At A A All Little Lot
8. I kept thinking and wishing this had never happened; and/or that I could change what had happened.	Yes	No	Not At A A All Little Lot
9. Turned to my family, friends, or other adults to help me feel better.	Yes	No	Not At A A All Little Lot
10. I just accepted the problem because I knew I couldn't do anything about it.	Yes	No	Not At A A All Little Lot

APPENDIX C

Perceived Social Support

These are sentences about people in your life.

Please circle how true each of these sentences is for you.

1. **I have a close friend who understands what I think about having cancer.**

Not at all true for me	A little true for me	Somewhat true for me	True for me	Very true for me

2. **An adult helps me if I am upset or have a problem.**

Not at all true for me	A little true for me	Somewhat true for me	True for me	Very true for me

3. **Kids sometimes make fun of me**

Not at all true for me	A little true for me	Somewhat true for me	True for me	Very true for me

4. **Kids pay attention to what I say about having cancer.**

Not at all true for me	A little true for me	Somewhat true for me	True for me	Very true for me

5. **An adult cares if I feel bad about having cancer.**

Not at all true for me	A little true for me	Somewhat true for me	True for me	Very true for me

6. **I have a close friend who understands me.**

Not at all true for me	A little true for me	Somewhat true for me	True for me	Very true for me

7. **I have a close friend who cares about my feelings about having cancer.**

Not at all true for me	A little true for me	Somewhat true for me	True for me	Very true for me

8. An adult cares if I feel bad.

Not at all true for me	A little true for me	Somewhat true for me	True for me	Very true for me

9. Kids understand what I think about having cancer.

Not at all true for me	A little true for me	Somewhat true for me	True for me	Very true for me

10. Kids pay attention to what I say.

Not at all true for me	A little true for me	Somewhat true for me	True for me	Very true for me

11. An adult understands what I think about having cancer.

Not at all true for me	A little true for me	Somewhat true for me	True for me	Very true for me

12. I have a close friend who listens to what I say.

Not at all true for me	A little true for me	Somewhat true for me	True for me	Very true for me

13. I have a close friend who listens to what I say about having cancer.

Not at all true for me	A little true for me	Somewhat true for me	True for me	Very true for me

14. An adult understands me.

Not at all true for me	A little true for me	Somewhat true for me	True for me	Very true for me

15. Kids understand me.

Not at all true for me	A little true for me	Somewhat true for me	True for me	Very true for me

16. Kids sometimes make fun of me for having cancer.

Not at all true for me	A little true for me	Somewhat true for me	True for me	Very true for me

17. An adult helps me if I am upset or have a problem because of cancer.

Not at all true for me	A little true for me	Somewhat true for me	True for me	Very true for me

18. I have a close friend who cares about my feelings.

Not at all true for me	A little true for me	Somewhat true for me	True for me	Very true for me