

A closer look at the social and emotional outcomes for childhood cancer survivors

by

Katie L Riley

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Program of Study Committee:
Christine Lippard, Major Professor
Carolyn Cutrona
Megan Gilligan
Brenda Lohman
Daniel Russell

The student author, whose presentation of the scholarship herein was approved by the program of study committee, is solely responsible for the content of this dissertation. The Graduate College will ensure this dissertation is globally accessible and will not permit alterations after a degree is conferred.

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ABSTRACT

The outlook for children with cancer has improved greatly, leading to an ever-increasing population of survivors of childhood cancer. A childhood cancer diagnosis can impact concurrent and future development. In order to provide a deeper understanding for the increasing childhood cancer survivor population, this dissertation focused on the social support experiences of adolescent cancer survivors (ACS) and how these social support experiences are associated with psychosocial wellbeing outcomes, both concurrently and in emerging adulthood. For chapter 2, an interpretative phenomenological approach was utilized to explore the social experiences of 16 ACS at an oncology camp. To further explore ACS social support experiences and its relationship to an important aspect of adolescent development, the third chapter examined the association between sources of support and specific self-esteem domains (i.e., performance, social, and appearance). Lastly, to explore the possible long-term impact of social support for ACS, the fourth chapter analyzed the association between adolescent social support and depression and self-esteem in emerging adulthood. Furthermore, this paper explored the influence of age of a cancer diagnosis on the relationship between adolescent social support and depression and self-esteem in emerging adulthood, and if one source of support was more influential on depression or self-esteem in emerging adulthood

The key findings from chapter 2 indicated that ACS who attended oncology camp strongly identify as a cancer survivor regardless of the age at which they were diagnosed and received treatment, and creating and maintaining relationships with other ACS peers is an important and unique support that they value. The results from chapter 3 indicated

that parents and peers are both influential on ACS self-esteem, but peers may be more impactful on appearance self-esteem than parents. Lastly, the population-based sample within the Add Health dataset in chapter 4 did not yield an association between adolescent social support and wellbeing outcomes in emerging adulthood. However, we did find that mother support in adolescence was more influential on depression in emerging adulthood.

Overall, these chapters shed light on the importance of social support for ACS, as their perceptions of support are related to key developmental tasks in adolescence (i.e., identity and self-esteem). For some ACS, creating friendships with other ACS is desired, and a way for them to feel better supported as a survivor. These relationships with other ACS and healthy peers help to increase the ACS self-esteem.

CHAPTER 1. INTRODUCTION

Childhood Cancer Diagnosis and Survivorship

In 2017, an estimated 15,300 children and adolescents, ages 0-19, in the United States were diagnosed with cancer (Siegel, Miller, & Jemal, 2017). More than 80% of children diagnosed with cancer before the age of 20 years survive at least five years (SEER Cancer Statistics Review, 2011). As of January 1, 2014 approximately 419,000 survivors of childhood and adolescent cancer were alive in the United States (SEER Cancer Statistics Review, 2017). Given the number of adolescents who are survivors of childhood cancer, research has begun to focus on positive mechanisms that may buffer the harmful social and emotional effects cancer can have on the developmental trajectory of children.

The beneficial effects of social support on the physical and psychological wellbeing of an individual have been recognized within literature on healthy adolescents for many years (Helsen, Vollebergh, & Meeus; 2000; Levitt, Guacci, Franco, & Levitt, 1993; Raja, McGee & Stanton, 1992; Sasikala & Cecil, 2016). Healthy adolescents who perceive higher levels of support report lower levels of depression (Stice, Ragan, & Randall, 2004), fewer health complaints (Gecková, van Dijk, Stewart, Groothoff, & Post, 2003), higher self-esteem (Dumont & Provost, 1999), and better wellbeing (Chu, Saucier, & Hafner, 2010). Given that perceptions of social support have been related to optimal developmental outcomes, research has expanded to focus on social support for adolescents diagnosed with a chronic illness.

Psychosocial changes for children following a cancer diagnosis inevitably impact their social development trajectory, making adolescent cancer survivors (ACS) a vulnerable population for experiencing medical and psychosocial consequences from their treatment (Cantrell & Lupinacci, 2008). The majority of pediatric cancer survivorship literature focuses

on social support outcomes, combining the developmental stages of adolescence and emerging adulthood. Few studies distinguished between these time periods, and therefore findings are typically generalized. Although adolescence and emerging adulthood are similar, it is important to recognize the differences when thinking about how an early life cancer diagnosis may impact the social developmental trajectory from childhood to adolescence and emerging adulthood. As these stages encompass different developmental tasks, it is important to examine how developmental outcomes in each stage may be impacted by a childhood cancer experience. Further understanding of how social support may be associated with the outcomes of cancer survivors in each developmental stage can be used to develop interventions that best fit the needs for that developmental period.

Theoretical Framework

The current studies draw from two theoretical frameworks: (1) symbolic interactionist perspective; and (2) life course theory. According to the symbolic interactionist perspective, the meaning that individuals create for objects and interactions manifests from social interaction with others (Blumer, 1986). This meaning can then be modified through an interpretive process and, in turn, factors into a person's behavior (Blumer, 1986). Thus, ACS derive meaning from interactions with their parents and friends, and this in turn, influences their behavior. Within chapter 2, I am particularly interested in the meaning making that is derived from social experiences that occur within the oncology camp context. Furthermore, within chapter 2, I am interested in the meaning making that arises in ACS social interactions (e.g., mothers, fathers, & peers) and how this influences their perception of self (i.e., performance, social, appearance esteem).

Life course theory is utilized in chapter 4 to better understand how a childhood cancer diagnosis may alter an individual's social and emotional developmental outcomes (Elder,

1998). The life course framework posits that life events can shape individuals' social outcomes, and in turn, influence behavior (Elder, 1998). Additionally, the principle of time is important, and is viewed as being influential in how the individual responds to that event and how it shapes their future development (Elder, 1998). For chapter 4, life course theory informs analyses to determine if the age of childhood cancer diagnosis moderates how social support is related to depression and self-esteem in emerging adulthood.

Literature Review

Although each of the three chapters presented here focuses on ACS social and emotional developmental experiences, the majority of ACS participants experienced their cancer diagnosis and treatment in childhood. Thus, the following literature review highlights typical social and emotional development in childhood and adolescence, and then discusses the impact of childhood cancer on children and adolescents. Lastly, literature on therapeutic camps as a psychosocial intervention for ACS is presented. Given that emerging adult development is specific to the study in chapter 4, typical emerging adult development is addressed there.

Childhood Social and Emotional Development

Early positive social and emotional development provides a foundation for lifelong development. Social and emotional development refers to the skills necessary to foster secure attachment with others, maintain healthy relationships, regulate one's behavior and emotions, and develop a healthy concept of self-identity (Steinberg, Bornstein, Vandell, & Rook, 2011). From infancy through adolescence, social and emotional developmental experiences influence children and adolescents' social relationships, behavior, and overall wellbeing.

During early childhood (ages 0-6), children's social experiences play a significant role in shaping emotional development skills (Saarni, 2000). The development of social and

emotional competence in early childhood is imperative, as these experiences act as a foundation for social and emotional development (Ladd & Pettit, 2002). In infancy, children use emotion to elicit attention and nurturance from the adults around them (Steinberg et al., 2011). These emotional behavioral cues parallel the formation of attachments with parents and other caregivers. The formation of secure relationships is advantageous, as children are more likely to form positive playgroups and manage their emotions and actions (Steinberg et al., 2011).

In middle childhood (ages 6-10), children continue to develop more advanced social and emotional skills. In addition to parent relationships, children begin placing more importance on friendships and their standing in peer groups (Steinberg et al., 2011). The increasing importance of peer relationships and peer group acceptance influences children's sense of self (Eisenberg & Morris, 2004), as children develop gender schemas (Halim et al., 2006), self-esteem (Harris, 1995), and moral identity (Turiel, 2002). In addition, the social context becomes broader as children participate in organized activities, become more fluent with digital media, and spend time without adult supervision (Steinberg et al., 2011).

The social and emotional skills developed throughout childhood act as a foundation for future peer relationships and self-identity formation. During this developmental period children's social experience begins to shift as family becomes less influential and friendships deepen with peers. These social changes are important, as children are beginning to think about themselves in relation others.

Adolescent Development

Adolescence (ages 11-18) is a period of developmental transition between childhood and emerging adulthood, involving multiple physical, intellectual, social, and emotional developmental changes (Steinberg, 2001). These developmental changes influence identity

development of adolescence, and have been associated with emotional wellbeing in young adulthood.

The physical changes adolescents experience impact their social experience. Adolescents experience many changes as they begin physical maturity. For females, physical changes during puberty include breast development, changes in body shape and height, growth of body hair, and the start of menarche (Steinberg & Morris, 2001). For males, physical maturity also includes changes in body shape and height, and growth of body hair. The timeline for these changes varies, with females typically exhibiting physical changes before males (Steinberg & Morris, 2001). As this is a developmental stage when social comparison behaviors with peers and siblings are more prevalent, these drastic changes may be difficult for adolescents to manage. Some research has shown that social comparison behaviors in adolescence may result in less positive perception of one's physical appearance, which may lead to difficulty establishing a positive sense of self (Thornton & Moore, 1993; Martin & Kennedy, 1993).

Changes in cognition also impact social and emotional development in adolescence. In this developmental stage, adolescents are able to understand abstract ideas and concepts. This increase in their cognitive ability enables them to begin developing their own morals, values, philosophies, and ultimately, an identity separate from their parents. Thus, the process of adolescent identity formation typically parallels their desire for autonomy from parents. While parents still play an important role in an adolescent's identity formation, peers become more influential on behaviors, attitudes, and decisions than parents (Steinberg, 2014). As a result, peer experiences are a critical aspect of an adolescents' identity and self-concept development (Hergovich, Sirsch, & Felinger, 2002).

The social changes adolescents experience are also a critical aspect of this developmental stage. The peer group changes throughout adolescence, with early adolescents (ages 10-13) spending time in peer groups that consist of same gender, non-romantic friendships. The individuals in these peer groups typically dress alike, share rituals, and participate in the same activities (Steinburg, 2014). In mid-adolescence (ages 14-16), the peer group may change, as males and female begin participating in activities together. For example, social gatherings where both genders are present may be more desirable and occur more often than in early adolescence. At this time, romantic friendships may form from the peer group. Lastly, late-adolescence (ages 16-18) typically marks a time when peer groups consist of both genders, and many adolescents are involved in romantic friendships.

As peer relations and peer groups become a priority, adolescents have a heightened need to fit in and an increased interest in friendship and romantic relationships (Brown & Larson, 2009). As the peer group becomes less important in mid- to late adolescence, peers in late adolescence typically report belonging to one peer group, rather than identifying with more than one peer group. This shift in adolescents' perceptions of a peer group parallels their self-identity. As late adolescents become more confident in themselves, in turn, they place less emphasis on the need to belong in a peer group.

Childhood Cancer Experience

Childhood cancer survivors experienced many social and emotional developmental milestones while receiving their cancer diagnosis and treatment. On average, children with cancer between the ages of 0-4 will experience the highest rate of hospital stays per year (35.4 stays), while children with cancer between the ages of 5-14 typically experience between 23 and 25 hospital stays per year (Price, Stranges, & Elixhauser, 2012). On average, the length of a typical hospital stay for children with cancer (ages 0-17) is 12 days per year

(Price et al., 2012). Following treatment, children may have survived cancer, but three out of five will suffer problems related to their cancer treatment in survivorship (Childhood Cancer Statistics, 2016). Some examples of late effects include chronic pain, school-absence issues, emotional health, early puberty, reproductive issues, and sensory problems (Childhood Cancer Statistics, 2016). Depending on the severity of these late effects, children may be at a greater risk for having these late effects influence other aspects of their social and emotional development. For example, some children may be less likely to engage in social activities with their peers, such as leisure sports, due to the chronic pain they are experiencing. Furthermore, during a time when children are beginning to engage in more self-comparison behaviors, they may be frustrated with their physical maturation when compared to their peers. These examples have the potential to inhibit the child's social experiences, and in turn, inhibit their ability to develop a positive sense of self.

While children with cancer were experiencing multiple hospital visits and lengthy stays, they were isolated from peers, and sometimes even had limited contact with family members. Thus, children with cancer have different social experiences than healthy children, as they may have missed opportunities to develop and maintain social interactions. These social and emotional developmental differences in social interactions and potential late-effects may in turn impact children with cancer's social and emotional developmental trajectory.

Adolescent Survivorship Experience

Studies suggest that the majority of ACS report both positive and negative psychosocial consequences as a result of their cancer experience (Castellano-Tejedor et al., 2015; Mattsson, Ringner, Ljungman, & Von Essen, 2007; Servitzoglou, Papadatou, Tsiantis, & Vasilatou-Kosmidis, 2009). Some ACS report feeling satisfied with the support they

receive from friends and parents, and felt they had an increased awareness for the value of personal relationships (Castellano-Tejedor et al., 2015; Sundberg, Lampic, Björk, Arvidson, & Wetterren, 2009). On the other hand, some ACS indicated withdrawing from peer interactions as they sensed peer discomfort when explaining their childhood cancer diagnosis (Palmer et al., 2000). In addition, peers have reported not knowing how to react when an ACS discloses their cancer journey, and have indicated that upon learning this history, they displayed fear, excessive touch, and uncertainty (Palmer et al., 2000). These negative consequences differ from social support literature on healthy adolescents, as healthy adolescents indicate peers as being the most important source of support (Steinberg & Morris, 2001).

As studies have shown that ACS may experience different social development experiences when compared to healthy adolescents (Decker, 2007), research has also investigated how these social differences are related to other developmental outcomes. ACS who reported positive psychosocial consequences as a result of a childhood cancer diagnosis also reported better physical wellbeing, autonomy, and emotional regulation (Castellano-Tejedor et al., 2015; Klassen et al., 2011). Other studies have found that although ACS report positive psychosocial consequences, such as feeling more confident and mature, they also report feeling less healthy and more susceptible to illness than healthy adolescents, and fear relapse (Servitzoglou et al., 2009). This body of literature is important, as these physical, social, and emotional developmental factors play a role in identity development, and health outcomes in emerging adulthood (Kroger, 2007).

In 1994, a cancer diagnosis was added to the Diagnostic and Statistical Manual of Mental Disorders, 4th Edition (DSM-IV) as a traumatic childhood event (Pai, Suris, & North,

2017). Since then, numerous studies have demonstrated a connection between ACS levels of perceived social support and depressive symptoms, where a lack of support is a risk factor for developing depressive symptoms in young adulthood (Corey, 2008; Hann, et al., 2002; Schroevers, Ranchor, & Sanderman, 2003). Furthermore, psychosocial problems in survivorship have also been related to lower physical and appearance self-esteem (Postma et al., 1992; Von Essen et al., 2000). Although the research base is limited, it is evident that ACS social experiences play a role in their concurrent identity development and young adulthood wellbeing.

Oncology Camp

Due to the heightened short and long-term risks for developing physical, social, and emotional problems, oncology camps have continued to grow in popularity as a psychosocial opportunity for childhood cancer patients and survivors. The camps are represented by the Children's Oncology Camping Association International, which started in 1982 and now consists of over 80 member camps globally (COCA-I Brochure, 2014). The camp programs are designed to be a supportive and fun setting for children to be treated like typical campers, where they can participate in activities such as swimming, boating, archery, and rock wall climbing (COCA-I Brochure, 2014). These programs may include day, weekend, or more traditional, weeklong overnight stays in a normal camp setting. This setting acts as an escape from stressors at home, the hospital, and school. In this setting, children have opportunities for positive peer interactions with a unique population of peers who have similar experiences; they have all experienced a life-threatening diagnosis and share commonalities from coping with the disease during treatment and in survivorship (Meltzer & Rourke, 2005).

Parallel to the increase in camp popularity for ACS, researchers have explored this unique psychosocial opportunity and the potential benefits of attending a camp. A review

published in 2003 summarized the research on childhood oncology camps covering the years from 1960 to 2001. This literature review found nine studies published during this time (Martiniuk, 2003). Most of the publications examined in this review were focused on describing the camp environment or camp program with little focus on the potential developmental benefits for the camper. A more recent review by Martiniuk, Silva, Amylon, and Barr (2014) focusing on articles from 2001 to 2013 found that the literature base provides strong evidence for the multiple developmental benefits of attending camp, such as social functioning, emotion regulation, and self-esteem (Barr, et al., 2010; Martiniuk, et al., 2014; Wellisch, Crater, Wiley, Belin, & Weinstein, 2006; Wu, Prout, Roberts, Parikshak, & Amylon, 2011). Further understanding ACS lived experience and how an oncology camp context may influence social support can help to shed light on the therapeutic benefits of attending an oncology camp.

Dissertation Organization

The following chapters will report on three studies addressing the social experiences of ACS and how these social experiences may influence short and long-term wellbeing outcomes. In chapter 2, an interpretive phenomenological approach was utilized to explore ACS lived social experiences at a weeklong oncology camp.

In chapter 3, the association between ACS social support and self-esteem were explored. Specific associations were evaluated between source of support and specific self-esteem domains (i.e., performance, social, and appearance). Furthermore, these associations were tested to determine if any one source of support was more influential on specific self-esteem domains.

In chapter 4, the long-term impact of social support for ACS was explored with a population-based sample from the National Longitudinal Study of Adolescent Health (Add

Health) dataset. The influence of adolescent social support was analyzed to determine the extent to which it predicted depressive symptoms and self-esteem in emerging adulthood. Furthermore, we explored the influence of age of a cancer diagnosis on the relationship between adolescent social support and depression and self-esteem in emerging adulthood.

IRB approval was obtained from the Iowa State Institutional Review board in order to conduct the studies within chapter 2 and 3 and can be found in the appendix. In addition, in order to use the Add Health dataset, IRB approval was obtained through a contract between Dr. Lohman and Carolina Population Center who is responsible for The National Longitudinal Study of Adolescent and Adult Health data.

CHAPTER 2. ADOLESCENT CANCER SURVIVORS ONCOLOGY CAMP EXPERIENCE

A paper to be submitted to *Qualitative Health Research*

Katie L Riley

Human Development and Family Studies, Iowa State University, Ames

Address correspondence to Katie L Riley, Human Development, and Family Studies; Iowa State University; 0060 LeBaron Hall; Ames, Iowa 50011. E-mail: klriley@iastate.edu

Abstract

To date, literature has generally documented psychosocial benefits for adolescent cancer survivors (ACS) who chose to attend oncology camps, but with few detailed looks into the uniqueness of the social phenomena that occur within the camp context. Therefore, this study utilized an interpretive phenomenological approach to explore the meaning of the lived social experiences of 16 ACS (ages 11-19) within the context of an oncology camp. Key findings shed light on the importance of peer relationships with other ACS, as ACS felt a deeper connection with others who have experienced cancer rather than others who had not. Furthermore, these interactions facilitated a positive sense of self as a cancer survivor.

Key words: adolescent cancer survivor, oncology camp, peers, identity

Introduction

As of 2016, an estimated 10,380 new cases of childhood cancer (ages 0-14) are diagnosed annually among children in the United States. As treatments continue to become more effective, the survival rates for children diagnosed with cancer have reached 80% (Cancer in Children and Adolescents, 2016), and in turn, the population of adolescent cancer survivors (ACS) has increased. As the number of ACS has increased over the last four

decades, more research has emerged that focuses on psychosocial outcomes and experiences for ACS. The term *adolescent cancer survivor* includes those individuals who received a cancer diagnosis at some point between birth and 19 years of age and are no longer receiving cancer treatment (Reis et al., 1999). Thus, ACS are children or adolescents who have successfully completed treatment during childhood and have transitioned into survivorship, and will be referred to as ACS throughout this document.

Psychosocial research in adolescent cancer literature has emphasized the importance of social support for ACS as they transition to life post-treatment. These findings have led researchers to explore their psychosocial experiences, where a growing body of literature has documented the positive outcomes associated with attending oncology camps (Martiniuk, Silva, Amylon, & Barr, 2014; Wu, Prout, Roberts, Parishak, & Amylon, 2001). Although the adolescent cancer literature has explored types and sources of social support and camp as a psychosocial opportunity for ACS, no one has investigated their lived social experiences for in the oncology camp context. In order to address this gap in the literature, the present study will utilize an interpretive phenomenological approach to explore the meaning of the lived social experience for ACS in the context of a weeklong summer oncology camp.

Theoretical Framework: Symbolic Interaction Theory

In accordance with the symbolic interactionist perspective, an individual's reality is created by their social interactions, ideas, and thoughts (Stryker, 1968). The current study is informed by three concepts from symbolic interaction theory—*meaning making* from interactions with others, *roles*, and *role salience*. The concept of meaning making from interactions suggests that how adolescents perceive their interactions with others, operationalized in the current study as perceived social support, influences their behaviors. Additionally, the meaning that individuals form from communicating with others can modify

their behavior (Ingoldsby, Smith, & Miller, 2004). ACS in the oncology camp context may view camp as a time to interact with peers who have also been diagnosed with cancer and these interactions may make them feel supported (Blueblond-Langner, Perkel, & Goertzel, 1991). These interactions might help them make meaning of their own cancer experiences in a different way than interactions with their healthy peers, and meaning made from interactions with ACS may be more supportive and valued. Thus, in the current study, when participants are asked about specific supports in their life while attending an oncology camp, they may be more likely to identify fellow campers because of the support they have received during their social interactions within this context. Additionally, as these ACS are attending an oncology camp, the meaning they derive from their interactions with their peers may be unique and a valuable source of support that affects their behavior within the camp context and when they return home.

Another relevant concept from symbolic interaction theory is self-defined *role* (Ingoldsby et al., 2004). According to Ingoldsby et al. (2004), an individual's *role* is defined as a set of social norms for a specific situation, and individuals can have more than one. Roles look different for each person, and the expectations for a role can vary across people (Ingoldsby et al., 2004). For ACS attending camp, their role as a fellow camper at an oncology camp influences their behavior in that they may behave in a way that is supportive to others in the camp. In other words, the lived social experience at camp may influence the ACS role, such that they will participate in social experiences in a caring and supportive manner. In turn, the camp environment may influence ACS role as a cancer survivor. While in the camp context, the support they receive from peers may encourage ACS to be more confident in their role as a cancer survivor. Thus, these social experiences within the camp

environment may provide the ACS with a unique psychosocial opportunity to serve a supportive role for others, and receive support as they continue to develop their role as a cancer survivor.

The last theoretical concept utilized to inform this study is *role salience*. *Role salience* is described as the role individuals view as important, which typically is the role they spend the most time in (Ingoldsby et al., 2004). Thus, symbolic interaction perspective suggests that individuals choose to participate in particular environments or interactions that support the role they choose to invest in. For ACS, attending an oncology camp in the camper role may be an important psychosocial opportunity that adolescents do not want to miss, as the camp experience may be an opportunity to feel similar to their peers. In addition, the behaviors associated with the cancer survivor role may become more positive while attending camp because this environment enables them to participate in supportive activities, successfully complete activities, and maintain or create new friendships with other campers. Guided by these symbolic interaction concepts, the current study will explore ACS lived oncology camp experience and seek to better understand the unique social experiences that occur within the context of an oncology camp.

Adolescent Identity Development

The formation of one's identity is a basic developmental challenge in adolescence (Steinberg, 2014). Adolescents' cognitive capacity enables them to understand abstract ideas and think more deeply about the way they see, evaluate, and think about themselves than they were able to in middle childhood (Steinberg, Bornstein, Vandell, & Rook, 2011). This broadening of their intellectual capabilities provides a new way of thinking about their own moral philosophies, values, and opinions separate from their parents. In turn, these increasing cognitive abilities influence an adolescent's identity development, as they are more aware of

the many possible identities they can adopt and how this identity may impact them long-term (Steinberg et al., 2011). This identity formation process has the potential to manifest some social and emotional difficulties, as research has found that young adolescents sometimes feel confused about their identity because their self-descriptions can be contradictory (Harter & Monsour, 1992). For example, a ninth grade female reported wanting to be more care free and playful when she was with her friends, but then had the desire to be more serious at school because that would contribute to helping her become smarter (Harter & Monsour, 1992). Although distress may be the result of recognizing these identity inconsistencies, this self-awareness and practicing different identities enables an adolescent to continue to develop a stronger sense of their actual self.

An adolescents' identity formation typically parallels the adolescents' quest for independence from parents and closeness to peers. Although parents still play an important role in an adolescent's life, peers emerge as primary sources of influence and support (Steinberg et al., 2011). In early adolescence (ages 10-13), the peer group typically includes same gender, nonromantic friendships where children share rituals, participate in the same leisure activities, and consist of a small group of friends (Steinberg, 2014). As adolescents transition to mid-adolescence (ages 14-16) the peer group may change. At this time, the peer group normally consists of same gender peers, but they are more likely to participate in mixed gender activities. As adolescents move into late adolescence (ages 16-18) the peer group begins to disintegrate as pairs of adolescents who view themselves as couples typically split off from activities with the larger group (Kuttler & La Greca, 2004). Groups of couples may spend time together, but the peer group atmosphere has shifted. These peer experiences throughout adolescence are a critical aspect of identity development as this is an opportunity

to engage with peers who encompass different identities and provide a context where adolescents can experiment with their own identities (Brown, 2004).

Adolescent Cancer Survivor Identity Development

Adolescent cancer survivors experienced many social developmental milestones when their illness was diagnosed and treated that influenced their identity development. Depending on the severity of the diagnosis and treatment, children may have spent long periods of time in the hospital or at home where they were isolated from peers within their typical environment. These limited childhood social opportunities place ACS at a higher risk for experiencing psychosocial consequences from their treatment (Cantrell & Lupinacci, 2008). As children are transitioning to survivorship from active treatment, research has found that it can be challenging to return to normal life and recover their old identity (Cantrell & Conte, 2009). Jones, Parker-Raley, and Barczyk (2011) interviewed twelve ACS and found that identity was a challenge, as the participants reported feeling caught in between their identities as cancer patients and their identities as survivors. The researchers believed that an identity challenge was reported because when healthy individuals change their social identity, they are able to remove themselves psychologically and physically from their previous relationships (Jones et al., 2011). For ACS transitioning into survivorship, difficulty in shifting their identity may manifest, as they feel tied to their cancer social identity (Jones et al., 2011). In addition, as ACS are transitioning into survivorship, they may experience late treatment effects that act as constant reminders of their cancer experience. The results from this study suggest that ACS may have greater difficulty discovering their identity, as they may be experiencing a social paradox where they are not sure which social group they fit into (Jones et al., 2011).

Perceived social support. Social support represents the information leading an individual to believe that they are cared for, loved, esteemed, and a member of a network of mutual obligations (Cobb, 1976). To date, perceived social support is most often used in the literature as an indication of the quality of support (Wills & Shinar, 2000). Thus, the adolescent's perception of support is more meaningful than the actual receipt of support. As the field of social support literature has grown over the past several decades, research has focused on the perceived sources and types of social support for ACS.

Although adolescence is a time when most adolescents report receiving more support from peers (i.e., same-age friends within the school setting or participating in the same activities) than parents (Steinberg, 2014), the ACS literature is mixed. Some studies have found that ACS report parental support as being more important than peer support (Haluska, Jessee, Nagy, 2002; Ritchie, 2001). Parental support was reported as important because parents provided comfort and consistent support (Jones et al., 2011). On the other hand, some ACS have reported peers who have not been diagnosed with cancer as equally important as parents during the initial phases of treatment because they felt more comfortable sharing information about their cancer experience with them rather than their parents (Enskär et al., 2002; Kazak & Meadows, 1989; Kyngas et al., 2001; Manne & Miller, 1998). Alternatively, some research has found that ACS report an overall lack of support as a cancer survivor. Jones et al. (2011) found that ACS felt support was abundant during the cancer experience, but in survivorship, support from peers and medical staff declined. The inconsistency in ACS literature focusing on sources of support has been most widely attributed to study limitations such as sample sizes, vague inclusion criteria in regards to age, diagnosis, and definition of survivorship, and limitations of inconsistent conceptualization, and measurement of social

support (Decker, 2007). However, the literature exploring sources of support for ACS highlight the importance of understanding ACS perceptions of social support sources, as this may be a key component to the successful psychosocial transition into survivorship.

In addition to identifying sources of support for ACS, some literature has focused on the type of support different sources provide. The majority of studies have found that parents and peers both provide emotional support (Brown, Madan-Swain, & Lambert, 2003; Deverensky, Tsanos, & Handman, 1998; Dunsmore & Quine, 1997; Ritchie, 2001), with mothers identified as the main source of emotional support (Ritchie, 2001). Adolescent cancer survivors have also reported parents as providing informational support about cancer-related content (Dunsmore & Quine, 1997). Although not as often, nurses and medical staff are also reported as providing informational support (Dunsmore & Quine, 1997; Nichols, 1995; Rechner, 1990). To date little is known about how ACS perceive the type of support they are receiving from sources in their life, however, these findings may suggest that parents are providing multiple types of support, whereas peers or medical staff predominantly provide one type of support. Research allowing ACS to discuss support in their own words might provide further insight into whom the support sources are in their life, the type of supports these sources provide, and how they are providing those types of support to ACS.

Oncology Camp

An increasingly popular context for youth who have been diagnosed with cancer is summer oncology camp programs. These camps provide an opportunity for youth with cancer to be treated like typical campers, where they can participate in activities such as swimming, boating, archery, and rock wall climbing. At these camps, youth also experience support for developmental processes, including emotional regulation, peer relationship building, exploring emerging identities and interests, and building character, skills, and

relationships (Bialeschki, Henderson, & James 2007). Spending time at camp can also provide a community of peers with an important similarity, as they have all experienced a life-threatening diagnosis and share commonalities from coping with the disease during treatment and in survivorship.

In general, oncology camps seek to provide a supportive environment with an overall goal to positively impact physical, psychological, and social functioning (COCA-I Brochure, 2014). Oncology camp programs for children with cancer may include day, weekend, and more traditional weeklong programs where children usually sleep away from home in a tent or cabin with others. The camps are represented by the Children's Oncology Camping Association International, which started in 1982 and now consists of over 80 member camps globally (COCA-I Brochure, 2014). A review published in 2003 summarized the research literature about childhood cancer camps covering the years from 1960 to 2001. This literature review found that nine studies were published during this time (Martiniuk, 2003). At that time, most of the publications regarding childhood cancer camps were descriptions of the program with little focus on the process how attending camp may increase children's mental and social wellbeing (Martiniuk, 2003). The studies that did measure the process or outcomes variables included small samples, very few standardized measures, and the children were from one camp (Martiniuk, 2003).

A more recent review of the literature examined the findings of childhood cancer camp research published from 2001- 2013 (Martiniuk et al., 2014). Martiniuk et al. (2014) found 20 articles on childhood cancer camps. Though the camps had varying goals, they shared an overarching theme of providing a typical camp experience while improving psychosocial functioning. The newer literature found that camps help children discover and

explore new interests, and increase their physical and emotional skills (Martiniuk et al., 2014; Wu et al., 2016). The camp experience is meant to help children cope more effectively with their illness by increasing their self-confidence and self-esteem, making new friends, and having fun (COCA, 2013). Martiniuk et al.'s (2014) review uncovered some studies that discussed a lack of change for campers, such as camp not impacting the campers' self-concept (Brown, 2008). But, it was noted that the timing of data collection could have played a role in this, as the majority of the other studies in this review found positive effects (Conrad & Altmaier, 2009; Torok et al., 2006). The implications from the two cancer camp literature reviews, along with other cancer camp studies that have been published since 2013, offer limited understanding of ACS lived camp experience and how the camp context influences their social support. Although quantitative studies have demonstrated campers reporting higher levels of emotional, physical, social, and self-esteem functioning following attending camp (Wu et al., 2016), little is known about the underlying processes and actual relational experiences of ACS within the camp context.

Camp social interactions. As adolescence is a time when youth rely heavily on social interactions with peers to provide feedback about physical and emotional functioning (Steinberg et al., 2011), the oncology camp atmosphere is an ideal environment for ACS to interact with peers who may be currently experiencing cancer or are survivors. A mixed methods study by Gillard and Watts (2013) provided rich detail for ACS social interactions at camp, where they found that 25% of campers reported they had lost friends or became more distant from their healthy peers because of the cancer experience. Therefore, ACS chose to attend camp in order to connect and engage in caring relationships with other ACS (Gillard & Watts, 2013). The ACS also indicated camp as an environment that increased their

sociability and promoted feelings of being valued, cared for, and peer closeness (Gillard & Watts 2013). These social interaction opportunities led to building more friendships that were unique from the friendships created outside of camp. More specifically, a camper reported that a bond between two cancer patients is special because both individuals truly understand what each person endured during their cancer journey (Gillard & Watts, 2013). For ACS, a healthy peer may not be the most helpful person to provide support and illness-related feedback, as they may not fully understand how cancer affected their friends' life. Thus, the social experience for ACS at an oncology camp is a unique opportunity to interact with peers who also experienced cancer.

The camp environment also provides ACS with opportunities to interact with younger children, camp staff, and medical professionals. The multiple social interaction sources may be beneficial for ACS, as they can receive support from and provide support to a variety of individuals at camp. The relationships they form may then have a different meaning for ACS than with other individuals in their lives outside of the camp context. Gillard and Watts (2013) found that camp contained features, such as camp staff interactions and mentoring that enhanced the ACS social support and ultimately contributed to an increase in psychological wellbeing.

Given the literature to date, it is important to better understand the oncology camp setting because the social interactions may be different than everyday interactions. Past research has established the intervention potential of an oncology camp (Bialeschki et al., 2007; Martiniuk et al., 2014; Meltzer & Rourke, 2005; Wu et al., 2016), but it is important to understand the particular aspects of camp that seem to be the most meaningful for ACS. Therefore, this study will explore ACS social experiences within the camp context.

Method

Design

In order to understand the lived experience of the participants, an interpretative phenomenological approach was utilized. By using this approach, the researcher uncovers commonalities and differences of lived experiences or events (Starks & Trinidad, 2007). The phenomenological approach has been popular in qualitative health research, as it is designed and written for clinicians and practitioners who need to understand the lived experience of the phenomenon of interest (Starks & Trinidad, 2007). This approach was particularly appropriate for this topic as it was important to understand the lived experience of ACS in the context of an oncology camp. By furthering our understanding of experiences at camp and how ACS are feeling supported, health professionals can tailor their interventions to best meet the psychosocial needs of adolescents in survivorship. In the current study, the lived support experience of an ACS at an oncology camp and how they report social support in the context of an oncology camp will be explored.

Utilizing a phenomenological approach, the first goal of this study was to explore ACS experiences at a weeklong oncology camp. Exploring the camp experience will contribute to the oncology camp literature, as very little research is available regarding *why* and *how* the camp phenomena is meaningful to ACS. As peers are typically an important source of support for healthy adolescents, the impact of the camp context and the social interaction opportunities in camp may, in turn, influence the ACS perceptions of support. The research questions are as follows: (1) What is the lived support experience of adolescent cancer survivors attending a one-week oncology camp? and (2) What is the meaning of social support to adolescents cancer survivors in the context of an oncology camp?

Study Participants

Sixteen ACS (ages 11-19) who attended a weeklong oncology camp in the Midwest agreed to participate. Fourteen of the adolescents were purposefully selected to participate in the interview in order to maximize the variety of individual experiences and age range, such that one to two adolescents were chosen from each cabin. The other two adolescents were interviewed because they approached the principal investigator (PI) and asked to be interviewed. A total of 8 were female and 8 were male. The mean age was 14.63 years. Within this sub-sample, 15 were non-Hispanic White and 1 was African American. On average, the ACS had been attending camp for 7 years. All campers were not new attendees with the shortest amount of time attending camp being five years. See Table 1 for further demographics of each participant.

Data Collection

Setting. This study was conducted at an oncology camp at a YMCA camp facility in the Midwest that served youth (ages 4-19) with cancer or who have had cancer. This oncology camp was free for the campers. The one-week overnight camp served approximately 183 school-age children and 87 adolescents. Adolescent participants (ages 11-19) resided in 11 cabins organized by age and gender. The camp consisted of a schedule structured to provide opportunities for campers to participate in multiple recreational activities, in addition to therapeutic activities that addressed hardships related to cancer. The activities were organized to encourage campers to mingle and thus were grouped by cabin or age. Participants who attended camp may have been newly diagnosed with cancer, currently receiving treatment, or were survivors. To be defined as an *adolescent cancer survivor* in this study, the participant had to not be taking any medication or undergoing any treatment to remove cancer from their body, and all 16 participants in the current study were survivors.

Medical staff members (i.e., doctors, nurses, a psychiatrist, and a child life specialist) who were associated with local pediatric cancer units were on-site at all times during the week to provide full medical services. Campers learned about camp through local youth cancer-serving organizations and medical hospital staff, and it is available to campers at no fee. This camp differed from typical summer camps as it only served children diagnosed with cancer and it offered advanced medical services and support. The camp staff consisted of camp counselors (with most being childhood cancer survivors and past camp attendees), medical staff, and camp volunteers.

As stated on the organization's website, the camp provided children with cancer a week of typical camp activities where they can spend time with others who were going through the same emotions and worry less about not fitting in due to their physical and emotional scars. Additionally, returning campers who are off treatment can provide hope to other campers. During camp, some of the structured daily activities included horseback rides, swimming, archery, a climbing wall, zip lining, and crafts. In addition, special events were incorporated such that children could participate in Camp Olympics, s'more night, a talent show, and dances. For this camp, each day had a theme and all campers, counselors, medical staff, and volunteers were encouraged to dress related to that theme. The themes for this camp included: MVP Monday, Team Tuesday, Around the World Wednesday, Party in the USA Thursday, and Flashback Friday. Therapeutic activities were also incorporated within the week. For example, campers and counselors could choose to donate their hair to organizations that made wigs for cancer patients and everyone participated in a ceremony to acknowledge campers who had lost their battle to cancer called Wish Night. The camp administrators sought to provide a normalizing environment where all children could

participate in all activities. Though some oncology camps include educational opportunities related to cancer or scheduled discussions about the children's cancer journey, this camp did not, but rather, focused on providing a fun, typical camp experience.

In comparison to other oncology camps across the United States, this oncology camp focused on providing a fun environment for children with cancer or survivors to feel like a "normal" kid. Although most camps typically have a fee, this camp was provided for free due to a donation from local donations each year. Additionally, this oncology camp was also similar in regards to the age range of children attending, with most camps choosing to allow children and adolescents to attend and participate in the same week. Therefore, the results from this study are generalizable to other ACS oncology camp experiences in the United States.

Procedure. For the current study, interviews and observational data were collected. The interview questions pertained to the sources of support participants receive in their everyday lives and at camp, and different aspects of the camp environment. For the social support questions, the participants listed specific sources that matched the type of support they receive. For the camp questions, participants were asked open-ended questions about their camp experience. Participant interviews were conducted during unstructured activities at the end of the camp week. In accordance with a phenomenological research perspective, purposeful sampling was utilized (Starks & Trinidad, 2007). To maximize variety of experiences and age ranges, one to two participants from each adolescent cabin were interviewed. The camp counselors were utilized to coordinate the times that the participant could be removed from the unstructured activity, and made suggestions as to which participant from their cabin might be the most engaged during interviews. Interviews lasted

10-15 minutes and were digitally recorded and transcribed verbatim. When appropriate, follow-up questions were used to probe deeper responses or to clarify information. Before the interview, participants were reminded that they could end the interview at any time and resources (i.e., psychiatrist and child life specialist) were available for the participants if they needed emotional support.

Informal observations were conducted in the activity areas during unstructured and structured camp activities and camp events. The PI was a participant observer each day of camp and served as an extra volunteer when needed. In the mornings, the PI spent time in the unstructured activity areas, and then followed assigned cabin groups during structured activities in the afternoon. In addition, the PI attended all scheduled camp events. During the mid-afternoon rest time, the PI recorded field notes and expanded upon these after camp. These informal camp observations were then used in data analysis to provide a deeper understanding of the ACS social interactions and experiences within the weeklong camp context.

Reflexive Statement. As a researcher, I utilized my practitioner certification as a certified child life specialist to develop this study. I have experience interacting with children and families who have been diagnosed with cancer, and have worked with children to develop interventions that best meet the children's needs following a cancer diagnosis in the hospital setting. My practitioner training enabled me to develop rapport quickly with the children at this camp, and some of the children remembered me from their time in the hospital. Therefore, while interacting with children in this study, I was able to utilize my training to probe further on responses during interviews and as I analyzed the interview data.

Data Sources

Demographics. The participants filled out demographic information on a survey that was also administered during the camp. Participants reported information on age, race, age diagnosed with cancer, and type of cancer diagnosis.

Social support. During the first part of the interview, the PI asked six questions from the Social Provisions Scale (Cutrona & Russell, 1987) to learn about the participants' personal or social relationships with others. They were asked about different kinds or types of support which may be important to them and who in their life provided that type of support. The six items asked about social integration, nurturance, guidance, reassurance of worth, reliable alliance, and attachment.

Five additional questions/prompts were asked during the interview to better understand the participants' perceptions of social support behaviors from peers, health practitioners, and social media. For example, participants were prompted with the statement, "Tell me how your friends with cancer make you feel like they care for you," and "Tell me how people at the hospital make you feel like they care for you." The participants talked about what made them feel supported. See Appendix B.

Camp social experiences. Participants were then asked seven questions about the support they receive while at the oncology camp. Examples of participant interview questions included: "What activities at camp make you feel like people care about you?" and "Do you come to camp because it helps you feel more supported? If so, what kind of support are you wanting when you come here?"

Observed support. Field notes were collected during the weeklong camp and focused on the camp setting, unstructured and structured activities, camp events, and participants interactions with peers and camp staff at various times throughout the day.

Data Analysis

Each interview was audiotaped and transcribed verbatim. The data were then coded and analyzed utilizing an interpretive phenomenological framework (Pietkiewicz & Smith, 2014). Both participants' and researchers' interpretation of the phenomena was taken into account in the process of analysis to investigate how individuals made sense and meaning of their experiences (Smith & Osborn, 2007).

First, utilizing the eidetic method, in Phase 1 the PI read through the transcript several times to become familiar with the responses. Then, in Phase 2, a column next to the original transcript was developed to document the PI's own interpretation of the ACS responses, with some words being pulled from the transcript in addition to new words being incorporated. These notes were typically comprised of 8-10 words. In Phase 3, the PI went through the transcript and underlined common words or phrases that encompassed the ACS response for each question. Once these words or phrases were underlined for each participant, a third column was developed in Phase 4 to specifically identify meaning units (Wertz, 2005). These meaning units were essential components of the camp experience that were unique and distinguishable from other daily life phenomena for the ACS (Pietkiewicz & Smith, 2014). These meaning units were comprised of two to five words, and were developed to best represent the ACS response, in addition to the PI's interpretation of the ACS response. Next, in Phase 5, the PI organized the meaning units and notes on the transcriptions into emerging themes by organizing the themes according to conceptual similarities framework

(Pietkiewicz & Smith, 2014). Then, when necessary, subthemes were added. Once the themes and subthemes were established, the PI looked for connections between the emerging themes, and grouped them into clusters according to conceptual similarities. Once each cluster was determined, a descriptive label was developed (Pietkiewicz & Smith, 2014). These descriptive labels allowed for the PI to interpret the common phenomena adolescents chose to share during the interviews about their camp experience. In Phase 5, a co-author reviewed the themes to provide external audit of the emerging themes based on a reading of the transcript and notes. The PI and co-author were xxx agreement.

In addition, the PI reviewed the observation notes collected during camp and in the interview for each ACS and these were incorporated into all phases of the data analysis process.. This comprehensive analysis helped to encompass how the participants' perceive and talk about objects and events related to their social support network and the camp experience.

Findings

Although each ACS experienced a personal and unique cancer journey, many of the interview responses reflected commonalities. These commonalities surfaced when they shared why attending oncology camp was important to them and the reasons they looked forward to continuing to participate in it each summer. Not only did their responses provide support for the many fulfilling social and emotional experiences that occur in the oncology camp context, but the observations throughout the week enabled deeper insight into the importance of these social interactions and how these interactions help ACS development in many ways. The seven themes that emerged through the data analysis process bring to light the uniqueness of the camp phenomena: (1) cancer survivor identity, (2), camp is a safe space, (3) friendships with other adolescent cancer survivors, (4) having fun, (5) the skeptical

camper, (6) confidence development, (7) home versus camp. The following themes are described in detail below.

Cancer Survivor Identity

Although the majority of ACS in this sample were diagnosed with cancer and treated in childhood, it was clear that they view themselves as a cancer survivor. This identity as a cancer survivor was important to a majority of the participants and a reason that they chose to attend the oncology summer camp every year. This formation of a cancer survivor identity can be developed and maintained when attending this camp because of the opportunities to interact with other ACS peers, younger campers, and counselors. Morgan (names have been changed to maintain anonymity) stated,

“Like I know there’s people around me that have like the same conditions and stuff like that. Like they have the same background or they’ve been through the same stuff...like I don’t tell my friends and stuff because I don’t want everybody to be like all over me about it. Because that is kind of like how people back at home are.”

At camp, Morgan, and many others in this sample, felt comfortable speaking about their difficult experiences as a cancer survivor with peers who understood what they went through. In addition, the camp atmosphere is a context to validate the importance of their cancer survivor identity, as this may not be an aspect of their identity that they are as comfortable expressing during their lives at home. Jason shared, “I felt like sometimes [at home], I’m like, well back to being the one person that I hate being, not myself.” This was the strongest word choice used in relation to the ACS identity as a survivor and the difficulty Jason faced with his identity when he was not in the camp context. Furthermore, since peers at camp have a better understanding of the experience, they are less likely to react in a way that the ACS does not want them to. During the interviews, two other campers also expressed

their hesitancy in sharing their cancer history with healthy friends' because of their reactions; it appeared that they chose to not share their cancer experience with friends at home because they did not want the relationship to become uncomfortable or different.

Camp is a Safe Space

At camp, ACS feel fully comfortable with their identities as cancer survivors. Rather than choosing to dissociate themselves from their cancer experience, ACS who attend camp feel this space is a time to be expressive about their cancer survivorship identity, and they are comfortable sharing their joys and hardships with other campers. At camp, they know they will not be judged for anything they say or do. One younger participant, Jason, shared his struggle with bullying at school, as he stated, "I get bullied at school cuz they call me germ freak...they say that stuff to me, and like there's a gang of boys who will say, like you are really stupid, and sometimes they'll mimic me." Throughout Jason's interview, he expressed his struggles with peers at school and their desire to pick on him because of his differences. Thus, this young boy found camp to be a place where he was comfortable in his own skin and surrounded by supportive peers who were okay with his differences, which was not something he experienced much in his daily life.

In addition, that 3 out of the 16 campers had not chosen to share their cancer journey history with peers at home, suggested that they felt camp was a safe space to identify as a cancer survivor. At camp, what they are experiencing as potential struggles in their daily life is understandable and common; most likely another person at camp has also had the same experience. These interactions with peers at camp provided ACS with opportunities to be comfortable in their identity, rather than shying away from the topic or a conversation because they were not sure what the response would be from their peers. Altogether, the

majority of ACS in this study perceived camp as a safe space for social interactions, emotional expression, and engaging in the cancer survivor role.

Friendships with other Adolescent Cancer Survivors

Although ACS only had an opportunity to interact with their ACS peers once a year at camp, it was evident that the interactions were extremely meaningful. Almost all ACS (15/16) reported that the relationships they created with peer survivors was a main reason they kept attending after they transitioned into survivorship. An older adolescent, Jake, shared,

“I’ve got friends here...you can always feel like you can say whatever you want. They don’t, they understand everything cuz we’ve all been through it, they all know what it was like. Some people at home, they don’t understand the hard part of it. They just think, “Oh you got treatment and now you’re better.” They don’t understand the stuff that goes on afterwards.”

Jake vocalized the uniqueness of his relationship with his friends that he had made at camp, and how important these friends at camp are to him because they are different than his friends at home. Many other campers looked forward to spending time with the ACS they had become friends with in previous years, and a few expressed enjoyment in making new friends each year that they attended camp. Thus, the camp context served as an environment where ACS could catch up on their lives since the last time they were with them at camp, and spend a week together having fun. These relationships among campers appeared to be easy-going, encouraging, and playful. Furthermore, these camper relationships seemed to form without any effort on either side, with both people choosing to become instant friends because they were both attending the camp. When asked about these camper relationships, all

of the campers attributed this instant friendship to the idea that both had experienced cancer. For instance, when asked a question about the camp environment, Kevin responded,

“Like the first time that I came I was kind of nervous about coming and didn’t know what to expect and after you come here and see that everybody is here for each other you go home feeling more confident and not really worrying about it...it’s great, there’s so many friends.”

These quickly formed relationships also appeared to be immediately viewed as a source of support because the new friend automatically understood the camper on a deeper level than other peers outside of camp. Furthermore, for Kevin, he specifically stated that it made him worry less about his current life struggles, and in turn, he felt more confident in himself.

Supplemental to the interviews, during my observations I found that these camper formed relationships may be more unlikely to form outside of camp, but because they are spending time interacting at camp the friendship is formed. Furthermore, the connection of a cancer experience also may contribute to all campers making an effort to initiate conversations with one another and getting to know other peers they may not typically seek out to form a relationship with.

Survivorship mentoring. Although the ACS appeared to refer to peer survivors as they spoke about their camp experience, my observations throughout the week brought to light the interactions and relationships formed between ACS and younger campers. During the first day of camp, ACS campers were engaging with younger campers while participating in various activities. ACS assisted younger campers in activities that they had learned at camp in previous years, such as creating a bracelet or helped younger campers to learn how

to play games that were popular at this camp. Both male and female ACS appeared to enjoy sharing their knowledge and making sure the younger camper learned new skills. When looking around the camp during free-time, many of the campers were observed mingling across ages and genders. Even if campers had physical or medical limitations that made the activity more difficult, other campers incorporated them in their activity and helped in any way that they could. Throughout the week, these campers were never left alone and always had another peer or other aged camper interacting with them or simply sitting next to them. Immediate bonds were not only created amongst peers, but also across ages. Throughout the entire week, ACS continued to interact and spend time with some of the younger campers that they had developed a bond with. It was evident that the younger children viewed the older campers as mentors, and they clearly enjoyed engaging with older campers. Kerry shared, “I know I can always make a difference when I come here”. This comment was unique compared to all the other campers, as she expressed this feeling that she liked coming to camp because she could make a difference for others. Although this comment was not further explored at the time, from the observations and remainder of the interview, it was evident that this ACS assumed a mentor role during his week at camp.

Additionally, two ACS in this sample were excited to potentially attend camp the following year as a camp counselor. Both campers were 18 years old, which is the oldest age a camper can be before they are unable to continue attending. During the interview, these campers were very interested in continuing their involvement with camp, but in the role of a counselor or mentor to the younger campers who attend

Having Fun

Out of all camps to attend, ACS chose to be at one that was focused on “having fun” while surrounded by other children who have experienced cancer. Rather than attending a

camp that enables ACS to be surrounded by peers with all backgrounds, it is evident they cherish the time that they have with other cancer survivors.

Although the main focus at this camp is “having fun”, there were several events that incorporated supportive techniques specific for children experiencing cancer and survivorship. For example, a hair-cutting event took place where all children had an opportunity to donate their hair to wigs made for children who had lost theirs due to cancer treatment. During this event, I noticed that many individuals who wanted to participate were ACS, and some had chosen to grow their hair out knowing they would be able to participate in this event at camp. As the entire camp watched the children receive their haircut, there was loud cheering and some tears shed. Following the ceremony, many children would approach the ACS and compliment them on their new hairdo. Another supportive event that would only be included at a camp specific for children who experienced cancer was “Wish Night”. This event is held on the last night of camp each year, and many campers spoke about the importance of this evening to them. At this event, campers have an opportunity to share their journey with cancer. It is a time for campers to be vulnerable about their experience, and to be vulnerable about their sorrow for the friends they have lost to cancer. As I experienced this event, I felt that this was a safe space for campers to openly grieve and process their hardship, whether they were thinking about themselves or the friends they had lost.

The Skeptical Camper

One older camper, Blake, reported a very different experience than the rest of the ACS campers. As he reflected on why he chose to continue attending camp, he provided information as to why he first began attending 8 years prior. He at first continued to attend because he felt that this camp was a space to be away from home, and a better alternative than being in the hospital, which is where he spent a lot of his time at that point in his life as

he was actively receiving treatment. He did not feel that the interactions with peers he had at camp were different than the interactions peers he had at home, and actually believed he did not have friends at camp. In Blake's interview when asked how his friends with cancer or camp counselors made him feel supported, he responded,

"I wouldn't necessarily say that they do. I don't think that I have had a single friend who has had cancer and that makes me feel that way... I receive more support here at camp, but also because it is their job, and for some reason it makes me feel worse. Cuz when people start doing things like that to me I know it's their job and it also makes me feel like a nuisance I guess, so."

However, these comments did not match the observations of this camper throughout the week. When I spent time with Blake's cabin, he was actively engaged in the activities with his peers, and appeared to be enjoying himself. Nonetheless, when this ACS reflected on his time at camp, he appeared to be very skeptical of the genuineness of the interactions with peers and camp counselors.

Confidence Development

During my observations at camp, it was evident that all ACS campers were encouraged to participate in all activities and to successfully complete them. Throughout the week, camp staff and campers constantly provided encouragement to other campers in all different types of activities or just in conversation. The more challenging activities or nerve-racking activities, such as zip-lining or rock wall climbing, typically evoked more encouraging words and gestures. Furthermore, the more difficult activities appeared to be a symbolic experience for some ACS. One camper provided an analogy of this experience in relation to completing cancer and being successful. Drew shared,

“Sometimes when you’re in treatment there’s like a, at first you have a tough time getting up to speed and being ready and then when you are busy climbing up that’s like the point of like you’re making progress and then when you get stuck on that part that’s like...what’s happening part, but then you finally find that opportunity, when you find that advance that one way to climb up that then you make your way up. In making progress in treatment and then you finally make it...you get more and more stronger and braver as you get through it...once you hit the top you’re done with, you have succeeded your journey.”

Following completion of these activities, I observed a sense of accomplishment and pride by the ACS who were initially scared or nervous. Three other campers spoke about their increased self-confidence following their time at camp. Two of these campers were younger ACS who specifically used the word ‘confidence’ in explaining their reason for continuing to attend this camp. An older camper spoke about her belief that other campers should attend because it will help them to feel like they fit in, which in turn may impact their self-confidence, Stephanie stated,

“It’s a great place for kids that feel like maybe people don’t care about them and if they come here I can about guarantee they are going to figure out that there are people that care and there’s people like you, you’ll fit right in.”

The inclusiveness of the camp environment facilitated the feeling of “fitting in”, and this in turn influenced ACS confidence. From the observations, confidence development for this unique population is incredibly important and one of the reasons they choose to attend. During camp they could increase their confidence in several important developmental tasks, such as creating and maintaining friendships, positive identity, self-efficacy in activities, social skills, independence from parents, and providing mentorship to younger campers.

Home Versus Camp

Although most of the interview revolved around the camp experience, more than half of the ACS brought up different aspects of their home life. The ACS expressed feelings about their home life experiences and why this was related to reasons they chose to attend camp each year. As campers thought about the friendships they created at camp, most would share the difference between the friendships at home, with two campers sharing that they felt they had more friends at camp than at home.

Sibling jealousy. One camper addressed issues with sibling jealousy during her cancer treatment and in survivorship. She expressed difficulty in her relationships with siblings because they felt that she received special treatment because of her cancer experience. As she shared this information, it was evident that this topic was bothersome to her. Megan shared,

“Like my brother makes a big deal because he thinks I’m spoiled. And I don’t know why, but like my dad was with me most of the time but he tries to make it sound like my mom and dad weren’t there at all, and weren’t there for my brothers or sisters, and that’s how he likes to make me feel...I get a little bit more respect [at camp] than I would at home.”

This ACS felt that her brothers’ jealousy had stemmed from when she was actively receiving treatment. Thus, camp was a space for Megan to not feel guilty about her past, and simply enjoy the relationships that she had at camp.

Difficulty in peer interactions outside of camp. Some ACS spoke about experiences that reflected their difficulty with peer relationships outside of camp. Two male ACS reported being bullied at school or treated poorly. With one ACS this appeared to be directly related to their childhood cancer diagnosis and the physical changes that occurred during treatment, Max stated, “When I was going through my chemo they [campers] never

made fun of me or were mean to me, they were supportive. Some of them even cut their hair to be bald like me. So I knew they cared.” These ACS appreciated being at camp so that they would not be made fun of by others, and rather experience supportive interactions by peers who they felt were friends. Thus, the support and acceptance received within peer interactions in the camp environment was highly valued by these ACS.

Discussion

The findings from this study provide further insight and understanding into ACS social experiences at a weeklong oncology camp. In accordance with the symbolic interaction theoretical framework, it is evident that ACS attended camp because of the meaningful interactions that occurred within this context. During interviews, ACS also provided responses that reflected their role as a camper, with some discussing the importance of being there for peers at camp in addition to the younger campers. Some ACS also mentioned interest in becoming a camp counselor the following year in order to continue being able to participate. Lastly, it was evident that the ACS in this study continued to attend camp because being a cancer survivor was a role, or identity, that they felt they could fully participate in when they were within the camp community. Thus, the camp environment encompassed meaningful and desired psychosocial opportunities for ACS to fully be themselves, and this was one of the main reasons they continued to attend camp each year in survivorship. This was an unexpected finding, with all ACS in this sample being at least 5 years into survivorship, and many experiencing cancer in childhood. But, the age at which they experienced cancer did not appear to matter in relation to their cancer identity and the desire to engage with other peers who experienced cancer.

In adolescence, identity formation is a critical developmental task (Steinberg et al., 2011). For the ACS in this study, as evidenced in the cancer survivor identity theme, it was

clear that they embraced the identity as a cancer survivor. This is consistent with other literature exploring childhood cancer survivors (Cantrell & Conte, 2009). Cantrell & Conte (2009) identified an identity paradox for ACS as they may be striving for normalcy, but still establish and accept the identity of a cancer survivor. This identity paradox was observed within this sample, with many ACS reporting that camp was an environment where they could feel like normal kids, but were still choosing to attend a cancer camp. In other words, camp did not pit being a typical kid and being a survivor against one another, but rather being a survivor was typical, and camp offered a unique setting to work through the identity paradox. These aspects of camp were a reason they first began to attend camp, and reasons they continued to attend camp in survivorship. Apart from camp ACS appeared to shift towards the identity of a typical adolescent, with some ACS choosing to not share past cancer experiences with friends, as they felt that sharing this information may negatively impact those home friendships.

The findings from this study bring to light the many benefits of attending an oncology camp, and the diverse reasons as to why ACS continue to attend this type of camp each summer. Furthermore, the motivation to continue to attend appeared to change as they transitioned from treatment into survivorship. When the ACS were in treatment they could go to camp because they were still under medical attention and could receive the treatment that they needed. Furthermore, this was an opportunity to be away from the hospital and home. Thus, camp was an alternative to the hospital setting and a possible motivator that is different in survivorship. As ACS transitioned into survivorship, the camp context became a space where they could interact with other ACS, share their possible survivorship struggles (i.e., friendships with peers who did not experience cancer & sibling jealousy), be a mentor for

younger campers, feel comfortable in their identity as a survivor, and ultimately continue to participate in activities and social interactions that facilitate positive developmental outcomes.

Limitations

Limitations from this study point to opportunities for future research. For example, after reviewing the transcripts from the ACS interviews, the interviewer was able to see missed opportunities to expand upon some responses that may have yielded a deeper understanding of their camp experiences. By probing further about different topics that appeared to be important to the ACS, the results could have had greater depth and the potential for other ideas may have surfaced. Future work can address this limitation by developing follow-up questions that are worded slightly differently in the case that some ACS may be more likely to expand on questions that are worded in a way that they connect better with. Additionally, as this was the first time for many ACS in being asked to share information to a researcher, the ability to develop rapport within a weeklong camp was difficult. Although the PI spent a lot of time building a relationship with the ACS during the first few days of camp, it may be advantageous to have more time to establish a relationship before the interview process. Alternatively, making use of follow up interviews after camp could enable the ACS to reflect on the initial questions in the interview and be able to potentially expand in greater depth on questions when asked a second time. Additionally, they may feel more comfortable during a follow-up interview, as they have a better idea of the interview process and the questions they are being asked. This study contributes to the limited research on oncology camp experiences by exploring the social experiences and perceptions of ACS who choose to attend camp.

Table 2.1 Participant Demographics & Key Quotes

Camper Name	Current Age	Cancer Diagnosis Age	Camp Attendance (Years)	Key Quotes
Kelsey	11	4.5	6	“Yeah, like I don’t tell my friends and stuff because I don’t want everybody to be like all over me about it. Because that is kind of like now people back at home are.”
Megan	14	2.5	9	“And it is just like a home away from home here... all my friends are here... like my brother makes a big deal because he thinks I’m spoiled. And I don’t know why, but like my dad was with me most of the time but he tries to make it sound like he was like my mom and dad weren’t there at all, and weren’t there for my brothers or sisters, and that’s how he like tries to make me feel. So I’m like okay, you know, whatever... I get maybe a little bit more respect than I would at home.”
Morgan	12	6	6	“I like that we all had cancer so like like, because we all, like when I talk about it with my friends at school they don’t really understand because they haven’t experienced but like how we all tell our own stories we’re like yeah yeah we all just know and stuff like that.”
Ben	14	5	8	“Everyone here has one thing, and it’s one thing you have in common, it’s that. And every single camper here has had that. And some of the counselors too. So it’s just kind of that sense of like family almost. And everyone’s got each other’s backs.”
Rachel	16	10	6	“Because it is fun, you meet new people. You meet old friends at its...it makes you feel like you’re important too and everything and I really like that.”

Table 2.1 (continued)

Camper Name	Current Age	Cancer Diagnosis Age	Camp Attendance (Years)	Key Quotes
Kyle	11	2	8	“I just really like love everybody here, like you can do whatever you want. And like, you be free basically.”
Jason	15	3	7	“I get bullied at school cuz they call me germ freak or they call me, they say that stuff to me, and like there’s a gang of boys who will say, like you are really stupid, and sometimes they’ll mimic me. And that stuff.”
Stephanie	19	17	3	“I’ll always remember the friendships I made here and how they helped.”
Drew	17	2	4	“Sometimes when you’re in treatment there’s like a, at first you have a tough time getting being up to speed and being ready and then when you are busy climbing up that’s like the point of like you’re making progress and then when you get stuck on one part that’s like the... that’s um like what’s happening part but then when you finally find that opportunity, when you find that advance that one way to climb up that then you make your way up In making progress in treatment and then when you finally make it as you’re making your way up you get more and more stronger and braver as you get through it. And as you, and once you hit the top you’re done with, you have succeeded your journey.”
Jake	17	11	6	“Some people at home, they don’t understand the hard part of it. They just think “Oh, you got treatment and now you’re better”. They don’t understand the stuff that goes on afterwards.”
Kevin	15	8	11	“Like the first time that I came I was kind of nervous about coming and didn’t know what to expect and after you come here and see that everybody is here for each other you go home feeling more confident and not really worrying about it.”

Table 2.1 (continued)

Camper Name	Current Age	Cancer Diagnosis Age	Camp Attendance (Years)	Key Quotes
Blake	17	8	7	“I would say I receive more support here at camp, but it is also because it is their job, and for some reason it makes me feel worse. Cuz when people start doing things like that to me I know it’s their job and it also makes me feel like a nuisance I guess, so.”
Max	13	4	6	“I know there’s friends that I know that come here almost every year and I know they’ll be here.”
Brittany	12	5	5	“I just come because it is fun.”
Kerry	18	3	10	“It makes me feel better about myself and that I’m not the only one like who has issues and stuff.”
Lindsay	17	9	4	“I think that since they understand what you’re going through you take it a little more to heart and so just helps you just kind of remember that it, it will get better eventually. It may not be right now but it does.”

Note. Pseudonyms are provided in order to obtain participant anonymity.

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CHAPTER 3. THE RELATIONSHIP BETWEEN SOCIAL SUPPORT AND SELF-ESTEEM IN ADOLESCENT CANCER SURVIVORS

A paper to be submitted to *Journal of Youth and Adolescence*

Katie L Riley

Human Development and Family Studies, Iowa State University, Ames

Address correspondence to Katie L Riley, Human Development, and Family Studies; Iowa State University; 0060 LeBaron Hall; Ames, Iowa 50011. E-mail: klriley@iastate.edu

Abstract

To better understand the psychosocial experiences of adolescent cancer survivors (ACS), the present study explored the associations among perceived sources of social support and domain-specific aspects of self-esteem (SE) (i.e., performance, social, and appearance). Data was collected from 78 ACS (ages 11-19) who completed perceived social support and SE measures at an oncology camp. Results revealed that ACS who reported higher perceived social support reported higher SE. In addition, perceived social support from parents was related to social and appearance SE, while perceived social support from peers and school were related to all domain-specific SE. Our findings support previous ACS literature on perceived social support, however, our study suggests that ACS may also find peer support to be more influential than parent support in adolescence, as our findings indicated peers were influential on all aspects of SE.

Key words: adolescent cancer survivor, social support, self-esteem

Introduction

Due to an increase in survivorship for young children with cancer, there is a heightened need to understand how childhood cancer impacts adolescent development. Currently, the 5-year survival rate for childhood cancer is 83%, up from 58% in the mid-1970s (Cancer.Net, 2016). The majority of adolescent cancer research has been conducted with adolescent cancer *patients* (ACP); only a few studies have focused on adolescent cancer survivors (ACS). Though there are important differences between adolescent cancer patients and adolescent cancer survivors, literature on adolescent cancer patients is reviewed within this paper, as needed, to lend some insight into the differences between healthy adolescents and those who are or who have received treatment for cancer. The term *adolescent cancer patients* includes those adolescents who are currently receiving cancer treatment, and the term *adolescent cancer survivor* includes those adolescents who received a cancer diagnosis at some point between birth and 19 years of age and are no longer receiving cancer treatment while in remission (Reis et al., 1999). As adolescence is a developmental period full of social, physical, and emotional changes and challenges, ACS may enter this period of time with physical and emotional difficulties related to their cancer treatment. ACS likely have unique psychosocial experiences in adolescence as a result of lasting effects associated with their childhood cancer. In order to better understand the psychosocial experiences of ACS, the current study explored the associations among sources and types of social support and both global self-esteem and domain-specific self-esteem (i.e., performance, appearance, and social) in a sample of ACS.

Theoretical Framework: Symbolic Interaction Theory

According to the symbolic interactionist perspective, an individual's reality is created by their social interactions, ideas, and thoughts (Stryker, 1968). The current study is

informed by three concepts from symbolic interaction theory—symbolism, meaning making from interactions with others, and identity (Stryker, 1968). The concept of symbolism defines the current population of interest, in that ACS share common perceptions as they progress in development following their cancer journey. In other words both the ACS and those they interact with have preconceived ideas about cancer survivorship. In society, the term ‘adolescent cancer survivor’ likely evokes different meanings and associations for people with different experiences of cancer, in turn, impacting the interactions for ACS. Thus, from a symbolic interaction perspective, this study examines associations between social support and self-esteem in ACS because their cancer diagnoses may influence this relationship differently from those of healthy adolescents.

Making meaning from interactions with others is a key concept of symbolic interaction theory that suggests that *how* adolescents perceive their interactions with others influences their identity development. In this study social support is operationalized as the meaning individuals form from interactions with others in their environment. Thus, adolescents’ knowledge is influenced by the interpretations of their interactions with others and is based on various perceptions that may change over time (Askan, Kisac, Aydin, & Demirbuken, 2009). For ACS, this may vary from healthy adolescents in that they may be seeking increased autonomy from their parents whereas ACS may still depend on parents for support. ACS may differ from ACP and healthy adolescents because of their cancer survivorship status, with ACS still feeling more connected and supported by their parents rather than their peers at school with whom they may have spent less time interacting during their cancer treatment. Thus, the current study will focus on the ACS population and examine the meaning making of their relationships with their mothers, fathers, and friends. Due to the

context in which the study is being conducted, the friends will encompass friends at camp and friends at home. This meaning making will be reflected in their reports of perceived social support.

An individual's' identity in symbolic interaction theory, particularly their sense of self-esteem, is developed by their mental processes and behaviors (Ingoldsby, Smith, & Miller, 2004). These behaviors that an adolescent engages in is a result of the socialization within their environment and interactions with others (White & Klein, 2008). Thus, symbolic interaction perspective suggests that individuals learn about themselves through interactions with various other people. When these interactions are positive, they can promote development of self-esteem for the individual (Fass & Tubman, 2002); whereas individuals who do not have positive interactions with peers and others may have less confidence in their own abilities and lower self-esteem (Harter, 1993). Given that adolescence is a time when individuals are shifting from closer relationships with parents to peers, parents and peers typically influence different aspects of adolescents' self-esteem (Paterson, Pryor, & Field, 1994). In the current study, I hypothesize that meaning making from social interactions influences ACS perceptions of themselves and their development of self-esteem. Thus, I examined associations among sources and types of social support and ACS self-esteem.

Adolescent Development

Adolescence is a time of increasing autonomy during which adolescents' cognitive capacity enables them to understand abstract ideas and think more deeply about their own moral philosophies, values, and opinions separately from their parents. As adolescents seek an independent identity, which is a crucial part of this developmental period, peers become more important sources of support (Steinberg, 2014). This typically parallels the adolescents' desire for more independence from parents (Steinberg, 2014). Although parents still play an

important role in the adolescents' life, peers emerge as a primary source of social support and become more influential than parents. These peer experiences are important for an adolescents' identity and self-concept development (Felson 1985; Harter, Stocker, & Robinson; 1996; Hergovich, Sirsch, & Felinger, 2002).

Experiencing puberty and physical maturation also impact adolescents' sense of self. Adolescent females undergo physical body changes, such as growth of hips and breasts and an increase in weight and height. Physical changes for adolescent males typically include increases in weight and height and body hair growth. The changes in their appearance may be drastic and occur at a time when adolescents are participating in more social comparison with their peers. These social comparison behaviors may then lead to lower self-perceptions of ones' attractiveness (Martin & Kennedy, 1993; Thornton & Moore, 1993). For ACS, these drastic physical changes may be more difficult and happen differently as bodies may still be impacted by the cancer treatments (Casellano-Tejedor et al., 2015). In addition, the developmental changes of adolescence may come at a time when ACS are still vulnerable from the physical changes they experienced during their treatments, which may lead to difficulty establishing a positive sense of self.

Parallel to cognitive and physical changes during adolescence, social changes are also occurring. As adolescents begin to form peer groups, this becomes a space for them to test new ideas and continue forming their own identities separate from their parents. In early adolescence (ages 10-13), the peer group typically consists of non-romantic friendships where children often try to dress alike, share rituals, and participate in the same activities (Steinberg, 2014). Additionally, the groups and activities normally consist of same gender individuals. As early adolescents move into mid-adolescence (ages 14-16) the peer group

may change. In mid-adolescence, the peer group normally consists of same gender individuals, but they are more likely at this time to participate in activities that include both males and females (Steinberg, Bornstein, Vandell, & Rook, 2011). For example, social gatherings with both genders are more desirable and occur more often than in early adolescence. Some adolescents may also participate in romantic friendships. The transition into late-adolescence (ages 16-18) typically marks a time when peer groups can be comprised of mixed genders, and many adolescents become involved in romantic friendships (Steinberg et al., 2011). In addition, from mid to late adolescence, it is also common to identify with many peer groups, rather than identifying with one group of friends (Steinberg et al., 2011). This signifies the adolescents' growth in identity development as they become comfortable with themselves as an individual and place less emphasis on the need to belong in a peer group.

Adolescent Cancer Survivor Experience

Adolescent cancer survivors experienced many social and emotional developmental milestones when their illness was diagnosed and treated. Depending on the severity of their cancer diagnosis, ACS likely spent long periods of time in the hospital as children, where they were often isolated from peers and sometimes even had limited contact with family members. Furthermore, the nature of the treatment plan for the ACS may have impacted the ACS ability to continue participating in everyday activities, as they may experience treatment side-effects (i.e., fatigue, moodiness, weaker immunity). The ACS experience is different than the typical adolescent experience, as they may have missed out on opportunities to develop and maintain social interactions when they were children. This places ACS at a higher risk for experiencing psychosocial consequences from their treatment (Cantrell & Lupinacci, 2008). These differences in social interactions and potential psychosocial

consequences related to treatment may impact ACS social and emotional developmental trajectory.

Positive and negative experiences. Studies suggest that the majority of ACS report both positive and negative consequences as a result of their childhood cancer experience (Castellano-Tejedor et al., 2015; Mattsson, Ringner, Ljungman, & Von Essen, 2007). A major focus has been on positive consequences and children's resiliency. More specifically, ACS have reported enhancement of psychosocial functioning, a deepened appreciation for life, increased maturity and self-confidence, a greater awareness of life purpose, and higher value for personal relationships (Castellano-Tejedor et al., 2015; Servitzoglou et al., 2009; Sundberg et al., 2009). Castellano-Tejedor et al. (2015) utilized a mixed methods approach to further explore the positive and negative consequences for ACS, with 88% of the sample (n = 41) identifying positive consequences and 63% identifying negative consequences in survivorship. More specifically, ACS indicated feeling more satisfied with the emotional support they received from social interactions with peers and this helped them to cope with their cancer and survivorship experiences (Castellano-Tejedor et al., 2015). For ACS, these positive consequences were associated with greater physical wellbeing, autonomy, emotion regulation, and social support (Castellano-Tejedor et al., 2015; Klassen et al., 2011).

On the other hand, some research indicates negative consequences of a childhood cancer diagnosis related to social support and self-esteem (Castellano-Tejedor et al., 2015). Even when ACS reported positive outcomes such as feeling more confident and mature, they also reported that they see themselves as more susceptible to health problems when compared to peers who were not diagnosed with cancer (Servitzoglou et al., 2009). Some adolescents indicated withdrawing from interactions as they sensed peer discomfort when

explaining their childhood cancer diagnosis (Palmer et al., 2000). In addition, peers of ACS have reported not knowing how to react when a friend discussed their cancer journey. They have also reported that upon hearing about the ACS cancer diagnosis they were fearful of the sickness, uncertain about the ACS health, and excessively touched the ACS by giving them hugs because they were unsure on how to interact (Palmer et al., 2000). Given that ACS have reported seeing themselves as more vulnerable to health problems and having discomfort in interacting with peers, there are reasons to expect that ACS may struggle with self-esteem.

Perceived social support: sources and types. Perceived social support is often used in research as an indicator of the quality of social support an individual is experiencing (Wills & Shinar, 2000). Social support in this study will be defined as the information leading an individual to believe that they are cared for, loved, esteemed, and a member of a network of mutual obligations (Cobb, 1976). As the social support literature has grown over the past several decades, research focused on ACP has examined the types and sources of social support.

During healthy adolescent development, the adolescent-parent relationship transforms such that less time is spent with parents and more time is spent with peers (Larson, Richards, Moneta, Holmbeck, & Duckett, 1996). Although there is a shift in the relationship, parents are still an important source of support for topics such as dating, sexual attitudes, morals and values issues, social issues, and future plans (Smetana, Campione-Barr, & Metzger, 2006). On the other hand, peers are a source of support and influential in other areas of adolescent development, such as style, appearance, and social identity (Harris, 1998).

Although adolescence is typically a developmental period when adolescents report more support from peers (Steinberg, 2014), ACP report family members as being the major

source of support (Enskär et al., 1997; Haluska, Jessee, & Nage, 2002; Nichols, 1995; Rechner, 1990), with mother support typically being reported as the most important (Decker, 2007; Ritchie, 2001). In a study where ACP were asked to rate their most important to least important source of support, research has found that parents are rated first, followed by friends and classmates (Trask et al., 2003). Although peers were rated second to parents as a source of social support for ACP, peers were still important in helping to provide normalcy. Several studies have found that peers help ACP to feel like normal adolescents, which was viewed as important and helped ACP to cope better with their diagnosis and treatment (Enskär et al., 1997; Kyngas et al., 2001; Rechner, 1990; Wesley, 2013). Thus, ACP differ from healthy adolescents in the extent to which they value parent and peer support. Given that a cancer diagnosis can change the importance of one source of support over another, adolescents' may also experience a change as they transition into survivorship. Such that, ACS may be more interested in re-engaging with peers, activities, and school. However, because of the cancer experience, ACS may continue to value and place importance on the support they receive from their parents. Thus, ACS may report equal perceptions of support from peers and parents in survivorship.

In addition to sources of support, the types of support adolescents experience have also been discussed in adolescent research. Types of support have been categorized in numerous ways, including Cutrona and Russell's (1990) five basic support dimensions that were derived from the most popular theoretical models (Cobb, 1979; Cohen, Mermelstein, Karmack, & Hoberman, 1985; Kahn, 1979; Schaefer, Coyne, & Lazarus, 1981; Weiss, 1974). The five basic support dimensions include emotional support, network support, esteem support, informational support, and tangible aid. Healthy adolescents report parents as

providing informational support, emotional support, and tangible aid (Steinberg & Silk, 2002). They are more likely to talk with their parents about impersonal topics related to schoolwork, finances, future plans, and social issues with peers (Larson, Richards, Moneta, Holmbeck, & Duckett, 1996; Noller & Callan, 1990). Alternatively, peers tend to provide more emotional, network, and esteem support during adolescence (Hazan & Zeifman, 1999). The difference between types of support for parents and peers appears to be related to the adolescents' social development, as they are more focused on peer social belonging and developing an identity separate from their parents.

Among ACS, the variability in and usefulness of different types of support has not been studied. However, Woodgate's (2006) longitudinal qualitative interpretive study of 15 ACP has provided rich information about types of support during treatment. After analyzing individual interviews, focus groups, and participant observation data, she uncovered the types of behaviors that ACP viewed as supportive during their cancer experience. For example, ACP indicated feeling like the supportive person was there for them, helped them to maintain a sense of purpose in the world, and made them feel connected, loved and cared about (Woodgate, 2006). For parents, the support that mattered most was that they would always be there for them (Woodgate, 2006). When reflecting on peer support, the ACP reported that their friend supported them by remaining their friend during the cancer diagnosis. Therefore, ACS may rely on different sources of support as they transition into survivorship because of the type of support they are interested in receiving. By understanding the most relevant sources of support and the types of support these sources are providing, health professionals working with ACS can help to facilitate supportive relationships that would be meaningful for the ACS.

Self-Esteem

Over the last 40 years, self-esteem research has included work on varied topics including self-concept, self-evaluation, self-respect, and self-confidence (Rosenberg et al., 1995). Along with the numerous names for the construct, many measures have been established assessing a wide range of diverse aspects of self-esteem (i.e., Coopersmith Self-Esteem Inventory, 1967; Piers-Harris Self-Concept Scale, 1969). Although earlier research (Wylie, 1979) concluded there were no systematic age differences in self-esteem, more recent literature has found changes in individuals' self-esteem depending on their developmental stage (Robins et al., 2002). To date, the general consensus for the global self-esteem trajectory is a relatively high self-esteem in childhood, lower self-esteem in adolescence, and a gradual increase into adulthood (Robins et al., 2002).

As prominent researchers have recognized the multi-dimensionality of identity (Harter, 1993; Marsh, 1990; Rosenberg, 1995), the field of self-esteem research has shifted back to focusing on domain-specific self-esteem. To date, the most widely used measure of global self-esteem is the Rosenberg Self-Esteem Scale (1989), and in more recent years it has been adapted to investigate several domain-specific aspects of self-esteem. This scale has yielded reliable and valid results with diverse populations, from children to adults, both healthy and chronically ill individuals (Seigel et al., 1990; Whiteside-Mansell & Corwyn, 2003).

Rapid physical and social changes during adolescence make this developmental stage a crucial time for development of self-identity, particularly self-esteem (Hill & Lynch, 1983; Rosenberg, 1986; Simmons et al., 1983). Earlier work studying adolescent global self-esteem has found that young adolescents typically have lower and less stable self-esteem paired with increased self-consciousness (Simmons, Rosenberg, & Rosenberg, 1973). This decrease in

self-esteem has been attributed to the changes occurring in school and peer relationships. For ACP, lower self-esteem has also been reported following the cancer diagnosis (Enskär, 1997; Wu, Chin, Haase, & Chen, 2009). The ACP attributed their decrease in self-esteem to the many challenges of having cancer and their inability to control their situation. In survivorship, research has shown that ACS self-esteem has also been impacted. Late effects due to treatment, such as appearance change (Abrams, Hazen, Penson, 2007; Bleyer, 2007) and physical mobility problems (Gurney et al., 2009), have been reported as common issues for ACS. In contrast, some investigators have found that global self-esteem among ACS were comparable to healthy adolescents (Gray et al., 1992; Olson, Boyle, Evans, & Zug, 1993). But in a more recent study of ACS with childhood leukemia, global self-worth was significantly lower for survivors (Seitzman et al., 2004). Although limited, these results indicate discrepancies in the literature, thus the current study will seek to provide greater insight into ACS global self-esteem and how this may be associated with the support they are receiving in survivorship.

In terms of domain-specific self-esteem, appearance self-esteem is particularly relevant for ACS. *Appearance self-esteem* refers to the extent to which an individual is satisfied with their physical appearance (Heatherton & Polivy, 1991). Von Essen and colleagues (2000) found that ACS reported lower physical self-esteem along with higher depression and anxiety levels after the cancer treatment period ended when compared to healthy children. This finding has been supported in more recent literature comparing ACS to the general population (Cantrell & Lupinacci, 2008; Geue et al., 2014). Adolescent cancer survivors' lower physical self-esteem may be attributed to disfigurements from cancer treatment; Postma et al. (1992) found that ACS who had experienced an amputation reported

lower levels of self-esteem and more isolation in their social life. Although amputation is an extreme form of cancer treatment, further investigation exploring all health domains (e.g., general health, mental health, functional status, activity limitations, cancer-related pain, and cancer related anxiety/fear) has shown that most ACS experience at least one negative health outcome as a result of their cancer treatment (Hudson et al., 2003). These findings bring to light the substantial risk for low appearance self-esteem following the termination of treatment. Given that ACS are experiencing health problems post-treatment, they may exhibit lower appearance self-esteem due to the physical changes caused by their cancer treatment.

The experience of childhood cancer also has the potential to impact adolescents' performance and social self-esteem. *Performance self-esteem* refers to the extent an individual feels their performance is worthy, and *social self-esteem* refers to confidence in their abilities and social interactions (Heatherton & Polivy, 1991). During adolescence, self-awareness and social comparison becomes more prevalent (Steinberg, 2014). Studies have found that this heightened focus on the self and extent to which others are watching and evaluating them is increasingly prevalent during early and mid-adolescence (Valkenburg, Peter, Schouten, 2006). Due to social comparison occurring at a greater rate in adolescence than in other developmental stages, ACS may be particularly vulnerable, as they may compare their performance abilities and social relationships to healthy peers who have a different developmental trajectory. In addition, social self-esteem is extremely relevant during adolescent development as this is a time when peer relationships become increasingly important and influential. Studies with ACP have indicated that ACP spend less time with peers than healthy adolescents and parents become a more important source of support (Haluska et al., 2002; Woodgate, 2006). This research suggests that ACS may then face

unique challenges with social esteem, as their cancer experience may inhibit their social interaction opportunities and impact their peer relationship.

Social Support and Self-Esteem

One of the major functions of social support is to increase or maintain feelings of self-esteem (Curbow & Somerfield, 1991). Domain-specific self-esteem research has also found that social support may bolster a sense of social identity and social integration (Wills, 1981). The impact of social support on self-esteem is particularly important during adolescence. As adolescents are developing their identity, they are experiencing social relationship changes from early to late adolescence. For healthy adolescents, research suggests that higher perceptions of social support are related to higher self-esteem (Harter, 1987; Ikiz & Cakar, 2010). Having higher perceptions of social support and self-esteem are beneficial for the adolescent, as both are related to positive emotional and behavioral outcomes (DuBois et al., 2002). More specifically, support from parent and peer relationships has both been identified as important for adolescent's self-development and global esteem (Black & McCartney, 1997; Hoffman, Levy-Shiff, & Ushpiz, 1993).

The role that social support plays in one's self-esteem may be differently associated with self-esteem for ACS as they are facing late treatment effects in addition to the developmental tasks associated with this period. Currently, adolescent survivorship literature has identified challenges, such as returning to school, forming relationships, poor academic performance, and permanent disfigurement (Evans & Radford, 1995). These challenges pose potential threats to social experiences, which can influence ACS self-esteem. Studies have shown that ACS report needing more support following treatment rather than before or during treatment, and that maintaining friendships helps them return back to everyday life (Kyngas et al., 2001). Provided that ACS report unique support needs during survivorship, in

addition to the possibility of late treatment effects, it is imperative that the pediatric survivorship literature has a clearer understanding of the relationship between social support and self-esteem. By understanding the influence that sources of support have on ACS self-esteem, health professionals working with ACS can tailor psychosocial interventions to meet the unique needs of adolescent's in survivorship.

Given the importance of social support for adolescent self-esteem and the indications that associations between social support and domain-specific self-esteem may vary for ACS, the current study examines these associations in a sample of ACS who attended a summer oncology camp in a Midwestern state. As indicated by reviews published about childhood cancer camps (Martiniuk, 2003; Martiniuk, Silva, Amylon, & Barr, 2014), collecting data at these camps has become increasingly common. Collecting data at childhood cancer camps enables researchers to collect an abundance of data on a specific developmental age, with majority of the participants within adolescence.

Hypotheses

The present study contributes to the pediatric survivorship literature by focusing the associations between social support and the development of self-esteem for ACS. The literature for healthy adolescents and ACP suggests that parents and peers are important sources of support. Some studies have also suggested that the type of supports these sources provide may influence social and emotional development. Although studies of quality of life have broadly included self-esteem as a construct of interest, to date, very few studies have focused on the specific associations between sources of social support and self-esteem among ACS. Based on symbolic interaction theory, the current study addresses three research questions. First, *do adolescent cancer survivors who perceive more social support have higher self-esteem than peers with lower perceived social support?* Given the known

associations between social support and self-esteem for healthy adolescents, we hypothesize that ACS will also have higher self-esteem when they perceive more social support. Second, *are different sources of support uniquely related to domain-specific aspects of self-esteem?* Previous findings suggest that different sources of support are related to different domain-specific aspects of self-esteem (Harter, 1999; Paterson et al., 1994), thus we expect that parental social support will be significantly related to performance self-esteem and peer social support will be significantly related to appearance and social self-esteem. Finally, to follow up on research question two, we examine *are certain sources of support more strongly related to specific domains of self-esteem?* Given findings that types of support can also be differentially related to domain-specific aspects of self-esteem (Allen & Land, 1999; Steinberg, 2011), this exploratory question examines the strength of the relationship between specific sources of support and aspects of self-esteem.

Methods

Procedures and Data Collection

Data for the current study were collected from participants at an oncology summer camp by having adolescent's complete surveys one time during the week-long camp. Parents and adolescents were first contacted about participation in the study through email from the primary investigator (PI) and camp director a week prior to camp. This email provided a broad description of the study. During camp registration, parents and adolescents were invited to participate in the study by the PI. Parents and adolescents were informed that participation was voluntary and that they had the right to discontinue participation at any time. If the parent and adolescent were interested in participating in the study, the parent completed the consent form and the adolescent completed the assent form before going to the next registration station.

On the second day of camp, the camp counselors who had eligible participants in their cabin were given packets that included a demographic questionnaire, social support measures, and a self-esteem measure. During afternoon rest time the camp counselors had the participants complete the questionnaires to the best of their ability. At this time a few participants sought their camp counselors for help, such as asking for assistance with word definitions, spelling, and handwriting. After rest time the camp counselors returned the packets to the PI. All procedures for this study were approved by the Iowa State University's Institutional Review Board and camp director.

Sample

Seventy-seven of the 84 ACS (ages 11-19; 92% participation) who attended a weeklong oncology camp in the Midwest agreed to participate. The participants all previously or currently had cancer. A total of 46 participants were female and 31 were male. The mean age was 14.32 years. A total of 70 were non-Hispanic White, 4 were Hispanic, 2 were African American, and 1 adolescent chose not to respond (see Table 1).

Measures

Perceived social support. The independent variable, perceived social support, was assessed using two measures. The first measure used 12 items adopted from the Add Health dataset (Cornwell, 2003; Musliner & Singer, 2014; Rawana, Jennine, 2013; Serido et al., 2014). Four items (i.e., “how close do you feel towards your mom”) measured support from a mother figure ($\alpha = .89$), four items measured support from a father figure ($\alpha = .94$; mother and parent support combined, $\alpha = 0.92$), one item measured peer support, and three measured school support ($\alpha = .91$). Responses ranged from 1 (*strongly disagree/not at all*) to 5 (*strongly agree/very much*). The published studies using the Add Health dataset have utilized

different variations of the 12-items depending on the research questions of interest, with one study using the full 12-item scale (Cornwell, 2003).

The second measure was an adapted version of the multidimensional Source-Specific Social Provisions Scale (Cutrona, 1989; Cutrona & Russell, 1987). The adapted version included 24 items rated on a 3-point scale that ranged from 1 (*no*), 2 (*sometimes*) and 3 (*yes*). The 24 items, assessing support in terms of reliable alliance, guidance, nurturance, social integration, attachment, and reassurance of worth were combined to a single scale, which had good reliability in the current sample ($\alpha = 0.85$). These items targeted the extent to which each of the six provisions of social support were currently available from their parents ($\alpha = .78$) and friends ($\alpha = .71$). This measure has not previously been used to assess adolescent cancer survivor's perceptions of support, but has been used and found reliable for adolescent mothers (Cutrona, 1989).

The two social support measures were highly correlated. Thus, the social support items from each scale were combined to total a 36-item social support measure (20 parent support items, 13 friend support items, & 3 school support items; $\alpha = .91$). Then, due to the high collinearity between the friend support items and school support items, the friend support scale and school support scale were combined to total a 16-item friend support measure ($\alpha = .87$).

Self-esteem. The dependent variable, self-esteem was measured using the 20-item Rosenberg Self-Esteem Scale (Heartherton & Polivy, 1989). This scale was administered on day 2 of the camp. The 20 items are subdivided into 3 components of self-esteem which had good reliability in the current sample: performance self-esteem ($\alpha = .77$), social self-esteem ($\alpha = .87$), and appearance self-esteem ($\alpha = .88$), with an overall reliability of $\alpha = .93$. All

items are answered using a 5-point scale that ranged from 1 (not at all) to 5 (extremely) to indicate the extent to which each item was true of the participant. Items included, “I feel confident about my abilities”, “I feel frustrated or rattled about my performance”, and “I am dissatisfied with my weight.

Demographic questionnaire. This questionnaire was created for the current study and was completed by participants. The questionnaire consisted of 6 questions assessing age, gender, ethnicity, type of cancer diagnosis, age when diagnosed with cancer, whether they were currently receiving medical treatment, and prior camp attendance (see Table 1). Both gender and age were entered as covariates in the analyses since both are expected to be related to the outcome variable, self-esteem. Literature suggests that males and younger adolescents may be more likely to report higher self-esteem than their female peers and older adolescents (Robins & Trzesniewski, 2005).

Statistical Analyses

The data was analyzed using SPSS for Windows and a *p* value of .05 was used as the criterion to indicate statistically significant associations. First, psychometrics were examined, then descriptives for all scales were developed. Composite scores were then created for each source of support and correlations were examined between the independent (i.e., social support) and dependent variable (i.e., self-esteem) to determine if there were associations with self-esteem. After this, separate linear regressions were conducted to examine associations among sources of social support and the different aspects self-esteem. For these linear regressions, age and gender were controlled, and the findings were interpreted by examining the overall R-square and coefficients. Furthermore, to determine whether a source of support was more related to a self-esteem domain, correlations were examined to determine the relationship between each the source of support and each self-esteem domain.

Lastly, a Wald's Test was run in STATA to establish which sources of support were more strongly related to different self-esteem domains (i.e., performance, social, and appearance).

Results

Descriptive Analyses

First, preliminary statistics, including means, standard deviations, ranges, and Cronbach's alphas were computed for each scale and subscale and are presented in Table 3.2. According to the social support scale mean, ACS reported feeling well-supported by their mother, father, and peers. Bivariate correlations are summarized in Table 3.3. Adolescent cancer survivors' perceived social support was positively associated with self-esteem and each subscale (i.e., social, appearance, performance). In addition, each source of support (i.e., parent, friend, and school) was positively associated with total self-esteem and each self-esteem subscale (i.e., social, appearance, performance). All study variables were significantly correlated in expected directions.

Perceived Social Support and Self-Esteem

To determine if ACS who reported higher perceived support would report higher self-esteem than ACS peer with low perceived support, a linear regression was performed. Results revealed that ACS who reported higher perceived social support reported higher self-esteem ($\beta = .68, p < .001$), while controlling for age and gender.

To address research question 2, associations between sources of support and domain-specific self-esteem were tested in three separate linear regressions, while controlling for age and gender. As indicated in Table 3.4, parent support is positively associated with social esteem ($\beta = .37, p < .001$), appearance esteem ($\beta = .25, p < .05$), and performance esteem ($\beta = .24, p < .05$). Other ACS support (friend and school) is also significantly associated with all

domain-specific aspects of self-esteem: social ($\beta = .33, p < .01$), appearance ($\beta = .45, p < .001$), and performance ($\beta = .41, p < .001$).

To test whether specific self-esteem domains (i.e., performance, appearance, and social) were more strongly related to peer or parent social support a Wald test was computed in STATA (Williams, 2015). To determine whether any one source of support was more strongly related to any specific self-esteem domain three Wald tests, using the *test* command in STATA, were computed. The Wald test determines whether any one independent variable is more strongly related to the dependent variable of interest than the other independent variables (Williams, 2015). None of the models were significant, indicating that all sources of support were equally related to the self-esteem domains.

Discussion

Overall, this study provided insight into the relationship between social support and self-esteem for ACS. Given that past research has established the relationship between social support and self-esteem (Pendley, Dahlquist, & Dreyer, 1997; Decker, 2007), this study highlights the relationship between specific sources of support and specific self-esteem domains. Altogether, we found both parents and peers to be important sources of support, with peers being particularly important for appearance and performance self-esteem. This is especially crucial for the ACS population, as approximately 2 out of every 3 survivors will experience at least one late treatment effect, such as cognitive impairments, organ dysfunctions, and delayed physical maturation as a result of their cancer treatment (Cancer Treatment & Survivorship Facts & Figures 2016-2017, 2016). These late effects, in turn, may make the ACS population more vulnerable to adverse psychological outcomes, such as low self-esteem.

Our findings support the symbolic interaction theoretical proposition that how ACS perceived their social interactions with others, in turn, influences their self-esteem. Thus, parent and peer support are important for an ACS self-esteem development, which is a critical issue for optimal adolescent development. The importance of social support and its relationship to well-being outcomes for ACS has not been a focus in the literature, thus, this study sought to better understand the potential benefits of social support for ACS. In alignment with our hypothesis, we found that social support is important for ACS, as this facilitates a more positive sense of self. This is especially important for ACS, as research has shown that ACS indicated that social support from parents and friends was extremely important in survivorship (Decker, 2007). This support typically included informational and emotional support, such as gaining knowledge about possible late effects or new treatment protocols, and empathy, care, and trust (Eriksson, Arve, & Lauri, 2006).

In addition to addressing the relationship between social support and self-esteem, this study also focused on the specific sources of support and specific aspects of self-esteem that are important during adolescence. Our results shed light on the importance of peer support, as peers were related to all aspects of self-esteem (i.e., performance, appearance, and social). This finding was not expected, as previous literature has shown that ACS may have different social experiences when compared to healthy adolescents. For example, in previous studies focused on social support for ACS, research has found that ACS indicated feeling more supported by parents rather than friends (Enskär et al., 1997; Kazak & Meadows, 1989). Thus, our finding aligns with the studies that show ACS report parents and peers as both being supportive (Decker, 2007). Furthermore, these findings reflect the importance of peer support because the participants were mostly ACS who self-selected to attend a camp with

ACS peers, and data for this study were collected in a context in which ACS peers were currently playing an important support role (Riley, under review).

These findings have positive implications for professionals working with survivors, as they can encourage ACS to find support from a wide variety of sources. Furthermore, as hypothesized, the impact of peer support for ACS may be more even than parents, as opposed to ACP who rely more on parents than adolescents. This finding reveals a potential issue for ACS, as some survivors struggle to establish typical peer relationships. Thus, if ACS lack supportive relationships with their peers, professionals working with ACS may want to aid ACS in connecting with one another and the larger survivorship community, to work on peer relationship-building skills, and to encourage ACS to continue drawing on parental support.

Furthermore, parent support was examined to determine its unique relationship to specific self-esteem domains. We found that parent support was related to performance, appearance, and social self-esteem. Thus, parent support matters equally to peer support. This finding was unexpected, as the majority of studies observing ACS social support have found parental support to be more important than peer support (Decker, Phillips, & Haase, 2004; Decker, 2007), leading to the hypothesis that parent support would be more influential on the specific self-esteem domain of performance. This finding in our study may be attributed to previous literature only investigating global self-esteem, rather than specific self-esteem domains. Additionally, in the context of an oncology camp, the ACS may be reflecting on their performance at camp, in which ACS peers may be more impactful on their performance abilities within the camp context. However, this information is useful, as health professionals

can better assist ACS who may express trouble with self-esteem by discussing ACS peer relations and how well they are feeling supported in these relationships.

Lastly, we did not find a difference between the magnitude of parent and peer support as associated with self-esteem. Given that no one source of support was significantly more influential, ACS self-esteem can be positively impacted by a variety of sources in their lives. This is advantageous, as some ACS may feel that a close friend is the most supportive individual in their life, rather than their mother or father. As indicated by the results in our study, support from friends was also positively associated with self-esteem.

Contrary to our hypotheses, this study found that ACS reported peers and parents as being meaningful sources of support, with only peers being significantly associated with ACS performance and appearance self-esteem. A possible explanation for the association between peer support and performance and appearance esteem is the ACS context. Peer support may be influential, and parents not, in relation to the ACS performance and appearance esteem because ACS are thinking about the peer interactions that occur at camp and school. This explanation is consistent with developmental literature and theory that discusses the importance of peers and peer groups on an adolescent's self-esteem and overall identity development within the school environment and in everyday activities (Steinberg, 2014).

Implications for Practitioners

The results from this study indicate the importance of encouraging positive and supportive relationships with parents and peers for ACS. As adolescence is a developmental phase that involves many changes in relationships and perceptions of support, it may be helpful to provide an intervention that facilitates ACS reflecting on their relationships and how these relationships are meaningful to them. These conversations with ACS about their

sources of support can also facilitate an increased awareness of the social support they did not realize people in their lives were providing to them. In addition, interventions could focus on skills for building relationships with peers as individuals make the transition from treatment to survivorship. For example, ACS can learn strategies to comfortably disclose their childhood cancer experience to new friends, as some literature has found that some ACS experience difficulty doing this with peers. This may be advantageous, as ACS will most likely be returning to school where they will be surrounded by peers.

Currently, ACS receive follow-up care that is focused on medical assessments. Current practice for health professionals working with the ACS population should consider also assessing psychosocial wellbeing, including access to social support from parents and peers. In survivorship, it may be beneficial for health practitioners to be aware and encourage ACS relationships with parents and peers. These specific populations may have greater difficulty creating and maintaining relationships with peers (Parry & Chesler, 2005), which may result in lower self-esteem, as indicated from the results from this study. This inability to develop a strong sense of self-esteem can be detrimental in adolescence, as this is a time of self-identity creation that will impact them throughout adulthood. By assessing psychosocial outcomes, including developing ones identity, school performance, or body image, in this at-risk population, health professionals can support ACS in increasing a better sense of self.

Limitations

Although, the ACS population in this study appear to be receiving support from their parents and peers, they may have been more aware of this need as they self-selected to attend a camp that encompassed multiple opportunities for supportive interactions. Thus, they may be more aware of the importance of supportive relationships in their life, and more active in seeking out interactions with peers. In addition, the camp context may have influenced their

feelings of support and how they feel about themselves at that current moment, as camp is a fun environment where ACS are surrounded by peers that also experienced cancer. This may contribute to higher feelings of self-esteem in relation to their appearance, performance in tasks, and ability to develop relationships.

Future research could address ACS social support through different data collection methods in order to minimize the possible influence of a camp environment. For instance, instead of administering the measures within camp, data collection could be done via the internet. Furthermore, the sample could be expanded to include ACS who do not choose to attend a summer oncology camp, as this may provide a more accurate representation of the ACS population as a whole.

Conclusion

This study shows that for some ACS peer social support may be more meaningful than previous literature had concluded. However, the results may reflect that ACS who attend an oncology camp were more aware and interested in the relationships they have with peers than previously studied ACS, as they have chosen to attend a camp that is focused on engaging in social interactions with other children who were diagnosed with cancer. Hence, researchers may benefit from further understanding the ACS population that may be more vulnerable to social and emotional distress in survivorship. For instance, the ACS who chose to attend an oncology camp may be less vulnerable, as they may be more interested in social interactions that are emotionally fulfilling at camp and in their daily lives, or more effective at seeking out and finding peer social support.

By knowing the vulnerable populations that need more psychosocial support, health practitioners can implement interventions that can best meet the needs of ACS. Additionally practitioners can better inform parents as to the unique needs of their children. The results

taken from this study can help health care professionals to design interventions to improve ACS self-esteem, and highlight the benefits of understanding ACS social support during treatment and throughout follow-up care.

Table 3.1 Participant Demographics

Participants N=77	<i>M</i> age = 14.32	<i>n</i>
Gender	Female	46
	Male	31
Age Range	11-19	
Race	White (non-Hispanic)	70
	Latina/Hispanic	4
	African American/Black	2
	Chose Not to Respond	1
Age when diagnosed with cancer	< 1 year old	5
	1-5	46
	6-10	17
	11-15	8
	16 years old <	2
Currently undergoing treatment	No	72
	Yes	5

Table 3.2 Descriptives

	<i>M</i>	<i>SD</i>	Range	Alpha
Add Health Social Support	4.16	.76	1.75-5.00	.93
Mother	4.48	.71	1.50-5.00	.89
Father	4.20	.99	1.00-5.00	.93
Parent	4.35	.77	1.63-5.00	.92
School	3.80	1.01	1.00-5.00	.91
Peer	4.00	.96	1.00-5.00	
Friend	3.86	.97	1.25-5.00	.89
Source Specific Provisions Scale	2.53	.33	1.63-3.00	.86
Parent	2.55	.36	1.58-3.00	.80
Friend	2.53	.33	1.33-3.00	.71
Total Social Support	2.59	.32	1.58-3.00	.91
Total Parent Support	2.65	.32	1.50-3.00	.86
Total Peer Support	2.52	.42	1.31-3.00	.83
Total Self- Esteem	3.84	.75	1.85-4.95	.93
Appearance	3.71	.92	1.00-5.00	.89
Performance	4.03	.70	1.86-5.00	.77
Social	3.77	.92	1.14-5.00	.87

Table 3.3 Summary of Correlations

	1.	2.	3.	4.	5.	6.	7.
1.Total Support	---						
2.Parent Support	.87***	---					
3.Peer Support	.88**	.53**	---				
4.Total SE	.68**	.57**	.62**	---			
5.Appearance Self-Esteem	.62**	.50**	.58**	.88**	---		
6.PerformanceSelf-Esteem	.56**	.453**	.53**	.88**	.70**	---	
7.Social Self-Esteem	.61**	.55**	.53**	.89**	.64**	.68**	---
8. Age	-.07	-.10	-.02	-.13	-.20	-.02	-.12
9. Gender	-.06	-.06	-.04	-.01	.04	.09	-.12

Note. * $p < .05$. ** $p < .01$. Gender: 1 = Female 0 = Male.

Table 3.4 Summary of Linear Regressions

	Total Self-Esteem			Appearance Esteem			Performance Esteem			Social Esteem		
	β	<i>SE</i>	B	β	<i>SE</i>	B	β	<i>SE</i>	B	β	<i>SE</i>	B
Research Question 1												
Social Support	.68***	.20	1.55									
Age	-.09	.03	-.03									
Gender	.04	.13	.06									
Research Question 2												
Parent Support	.33**	.23	.75	.25*	.30	.71	.24*	.25	.51	.37***	.30	1.02
Friend Support	.44***	.18	.77	.45***	.23	.97	.41***	.19	.68	.33**	.23	.70
Age	-.09	.03	-.03	-.17	.04	-.07	.00	.03	.00	-.07	.04	-.03
Gender	.04	.13	.06	.09	.17	.16	.12	.14	.17	-.09	.17	-.14

Note. * $p < .05$. ** $p < .01$. *** $p < .001$. Gender: 1 = Female 0 = Male

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CHAPTER 4. THE ASSOCIATION BETWEEN ADOLESCENT SOCIAL SUPPORT AND WELLBEING OUTCOMES IN EMERGING ADULTHOOD FOR ADULT CANCER SURVIVORS IN THE ADD HEALTH DATASET

A paper to be submitted to *Journal of Adolescent and Young Adult Oncology*

Katie L Riley

Human Development and Family Studies, Iowa State University

Address correspondence to Katie L Riley: Human Development and Family Studies, Iowa State University; 0060 LeBaron Hall; Ames, Iowa 50011. E-mail: klriley@iastate.edu

Abstract

Purpose: This secondary data analysis examined the association between adolescent social support and wellbeing outcomes (i.e., depression and self-esteem) in emerging adulthood among 78 emerging adult cancer survivors (EACS) from a population-based sample.

Methods: The sample was drawn from the National Longitudinal Study of Adolescent Health, and consisted of EACS who were diagnosed with cancer prior to the age of 20. Regression analyses were conducted to determine the potential association between adolescent social support and wellbeing outcomes in emerging adulthood, in addition to determining if the age of a cancer diagnosis moderated the associations between adolescent social support and wellbeing outcomes in emerging adulthood.

Results: The regression analyses did not yield significant associations between adolescent social support and wellbeing outcomes in emerging adulthood.

Conclusions: These findings were unexpected, but bring to light the potential uniqueness of this population-based sample of emerging adult cancer survivors who were not selected to be in the Add Health study due to their cancer history. Further studies may benefit from

analyzing EACS from population-based datasets to determine the potential difference in wellbeing outcomes for those who may not be seeking clinical treatment in survivorship, or interested in participating in clinical research.

Keywords: cancer survivorship, social support, wellbeing, emerging adulthood

Introduction

Each year in the United States, more than 12,000 children and adolescents ages 20 and under are diagnosed with cancer (Ries et al., 2005). With progress in the treatment of most types of childhood cancer, nearly 80% of the children and adolescents diagnosed with cancer survive 5 or more years (Gurney & Bondy, 2006). Thus, the majority of individuals diagnosed with cancer before age 18 will become long-term survivors.

During cancer treatment, children and adolescent's everyday experiences are disrupted by medical visits, hospitalizations, and procedures. This, in turn, can make reaching critical developmental milestones more challenging. Given that many developmental processes happen in adolescence that may lead to wellbeing in emerging adulthood, an increased awareness of cancer-related disruptions has led to a greater focus on the long-term mental health outcomes related to a childhood cancer diagnosis (ages 0-18) and survivorship in emerging adulthood (ages 18-26) (Gurney et al., 2009; Zebrack & Isaacson, 2012; Zeltzer et al., 2008). Although childhood cancer literature has begun exploring the long-term impact of a cancer diagnosis, little is known about the influence of social support on later mental health outcomes. Furthermore, little is known about how age of diagnosis impacts the relationship between social support and later mental health outcomes. Thus, the present study contributes to the pediatric cancer literature by examining the influence of sources of social support in adolescence on depression and self-esteem for emerging adult cancer survivors (EACS), and examining the moderating effect of the age of a cancer

diagnosis on associations between social support and depression and social support and self-esteem during emerging adulthood for EACS.

According to the symbolic interactionist perspective, an individual's reality is created by their social interactions, ideas, and thoughts (Stryker, 1968). The current study was informed by two concepts from symbolic interaction theory—*meaning making* from interactions with others and *identity*. The concept of meaning making from interactions suggests that *how* children and adolescents perceive their interactions with others, operationalized as social support in the current study, influences their development. Thus, children and adolescents develop a sense of self from the positive or negative symbols that they receive during social interactions with others (Ingoldsby, Smith, & Miller, 2004). For example, an adolescent may receive a hug after they reveal to a friend that they were diagnosed with cancer. In this interaction a positive symbol, the hug, may make the adolescent feel cared for and supported by this friend. For children and adolescents who have experienced cancer, the meaning they make from their social interactions with others may look different than healthy youth. Children and adolescents who have experienced cancer may interpret supportive meaning from interactions with others, and the cancer experience may have influenced the type of individual's with whom they surround themselves. This may differ from healthy adolescents, as children and adolescents who experienced cancer are more interested in supportive relationships that engage in meaningful interactions (Ishibashi, 2001; Woodgate, 2006), which may not be something healthy youth are aware of or seeking. Thus, in the current study, meaning making of relationships for children and adolescents who have experienced cancer was assessed via their reports of perceived social support from mothers, fathers, and school (including friends).

Another key concept of symbolic interaction theory, *identity*, can influence an individuals' behavior. An individuals' *identity* is developed by their mental processes and the behaviors they exhibit (Ingoldsby et al., 2004). These mental processes and behaviors are established during social interactions, as children and adolescents are developing their own perceptions of interactions and, in turn, providing behavioral responses. For children and adolescents who have experienced cancer, their identity development may have been influenced by cancer-related disruptions, such as hospitalizations, change in social interactions, or adverse medical effects. Thus, positive identity development may be more challenging for youth battling cancer and transitioning into survivorship because of the hardships they endured during their cancer journey. Given that social interactions during adolescence substantially contribute to identity and future adulthood behaviors, the social support experienced in interactions with parents and peers may influence aspects of wellbeing in young adulthood. Thus, in the current study, meaning making from social interactions will be operationalized as perceived social support. Furthermore, we hypothesize that the meaning making from social interactions would influence youths' perceptions of themselves and their development of self-identity. Therefore, regression analyses were used to examine whether sources of support during adolescence affect self-esteem and depressive symptoms in emerging adulthood for EACS.

The life course perspective offers a framework for understanding and explaining how changing social forces influence development throughout life (Newman & Newman, 2007). The current study was informed by two key concepts from the life course theory—*trajectory* and *transition*. The concept of trajectory can be used to describe a child or adolescent's cancer journey and includes a cancer diagnosis, active treatment, and survivorship. The

concept of transition is marked as a child or adolescent's cancer diagnosis, as a transition in the child's life occurs once they are diagnosed with cancer. For example, following a cancer diagnosis, the child may then be expected to begin chemotherapy treatment or be scheduled for surgery. Thus, the cancer diagnosis is a time when transition occurs for the child and family.

Life course theory suggests that social changes should be analyzed in an individual's life, as these changes may impact on future outcomes. When a child is given a cancer diagnosis, this marks a transition of social change that influences their life trajectory. Given that the age at which a child is diagnosed will impact the type of social transition for children and adolescents diagnosed with cancer, and life course theory posits that social changes typically occur following a transition, this study examined if the age of a childhood cancer diagnosis impacted the relationship between social support and depression and self-esteem in emerging adulthood.

Emerging adult cancer survivors who were diagnosed with cancer during childhood experienced critical social and emotional developmental milestones throughout their childhood cancer journey. Social development involves learning the values, knowledge, and skills that enable children to relate to others effectively and to contribute in positive ways to family, school, and the community (Steinberg, Bornstein, Vandell, & Rook, 2011). Children develop their social ability by learning from their caregivers and the social relationships in which they participate. Through these relationships with others, children grow awareness of social values and expectations, in addition to building a sense of who they are as an individual (Steinberg et al., 2011). Due to a cancer diagnosis and treatment, children may experience fewer opportunities to interact with family, peers, and individuals at school. This

decrease in social interactions limits a child's ability to practice skills and build relationships with individuals outside of their family. Thus, a child may experience more difficulty developing social skills and friendships that are important for overall child development (Steinberg et al., 2011). Furthermore, EACS also experienced emotional developmental milestones during their cancer journey. From birth through adolescence, children develop emotional skills as they learn what feelings and emotions are, recognize their own and those of others, and develop effective self-regulatory behaviors. As children are exposed to different situations, including social interactions, they have the opportunity to identify and express emotions, which in turn impacts their sense of self. Thus, a cancer diagnosis during childhood may make it difficult for children to manage their emotions due to repeated hospitalization, medical treatments, and adverse cancer outcomes. These experiences may be overwhelming and produce a wide range of feelings that the child may have a difficult time dealing with. Therefore, this experience may potentially inhibit the child's ability to deal with their own feelings or regulate them appropriately.

Childhood social and emotional development revolves around parents. During this developmental period, children with cancer and healthy children report parents as providing the most support (Bokhorst, Sumter, & Westenberg, 2009; Hockenberry-Eaton, & Minick, 1994). Parents provide support during a time when children experience a dramatic lifestyle change, such as a cancer diagnosis. For example, studies have shown that following a cancer diagnosis children typically spend more time at home or in the hospital rather than school, there is a decrease in opportunities to develop and maintain peer relationships, and depending on the treatment, children have limited activity options (Thompson, 2009). These experiences, in turn, impact the sources of support that the children are surrounded by and

with whom children spend the most time, with parents being the main source of support. When children are able to return to school after a period in the hospital, research has reported that they may not be as engaged and confident as healthy children, and that they report feeling fatigued, concerned about their appearance, and worried about falling behind in school coursework (Charlton et al., 1991). Given that a child experiences a dramatic lifestyle change that has the potential to impact all aspects of their normal routine when they are diagnosed with cancer, they may be faced with challenges in continuing to reach typical developmental milestones.

On the other hand, EACS who received their diagnosis and underwent treatment in adolescence had these cancer-related experiences during a developmental period in which social and emotional development revolved around peers instead of parents. For most adolescents, the majority of their time is spent with peers rather than parents (Steinberg, 2014). Typically, in early adolescence, adolescents spend time with same gender, nonromantic peers. This peer group then transitions, as adolescents are more likely to participate in mixed gender activities (Steinberg, 2014). At the end of the adolescent developmental stage, the peer group begins to separate as pairs of adolescents typically split off from the larger group (Kuttler & La Greca, 2004). As a result, adolescents' thinking and behavior become more influenced by peers (Steinberg, 2014). This in turn, impacts emotional development, as adolescents become more self-conscious about physical appearance and sensitive to peers reactions and emotions (Steinberg, 2014). However, for adolescent's undergoing cancer treatment, opportunities for social interactions with peers is much more limited as they typically spend more time at the hospital or home rather than school. Adolescent cancer patients (ACP) have reported peer support as not meeting their

expectations (Decker, 2007) and they experienced feeling left out or isolated from peers (Palmer et al., 2000; Stegenga & Ward-Smith, 2009). As a result, ACP report having a smaller number of close friends and feeling less satisfied with the state of their friendships as compared to before they were diagnosed with cancer (Mattsson, Ringnér, Ljungman, & Von Essen, 2007). This change in the quantity and quality of social interactions for ACP is reflected in social support literature, as ACP indicate parents as providing more support than friends (Haluska, Jessee, Nagy, 2002; Woodgate 2006;). Thus, the disruption of a cancer diagnosis impacts an ACP typical peer developmental trajectory.

Furthermore, ACP may experience difficulty in emotional development. Hedstrom, Haglund, Skolin, and Von Essen (2003) interviewed children 3-19 years of age, and found that adolescents within this sample reported feeling distressed about the change in their physical appearance due to cancer treatment. The physical changes ACP experienced, in turn, impacted peer relationships, consequently ACP avoided peer groups and peer interactions (Novakovic et al., 1996). Given the potential for cancer experiences to impact social and emotional development, I anticipate that EACS who were diagnosed with cancer during adolescence will report a stronger relationship between adolescent social support and wellbeing outcomes in emerging adulthood.

Emerging adulthood is defined as a time from the end of adolescence to young adulthood (Arnett, 2015). During this time period, typical emerging adults continue to develop their self-identity as they explore who they are and what they want for their life, in relation to work, school, and love. These individuals experience much more freedom from parental control and society-directed routine. Additionally, they change residences frequently, and have full freedom in determining their activities and overall schedule (Arnett,

2015). Some individuals do not feel they are provided with enough direction as they are still figuring out their own identity and role in society (Arnett, 2015). These developmental tasks, along with normal day-to-day stressors, may be challenging, and at times overwhelming, for emerging adults.

The stressors related to typical emerging adulthood, in addition to coping with cancer in survivorship has the potential to hinder EACS health outcomes (Weekes & Kagan, 1994). Studies have shown that a childhood cancer diagnosis is related to long-term social and emotional dysfunctions such as peer relationship difficulties, worries about fertility, poor quality of life, sexual dysfunction, fear about recurrence, and activity limitations (Brown, Madan-Swain, & Lambert, 2003; Zebrack et al., 2002). Mackie, Hill, Kondryn, and McNally (2000) found that EACS of acute lymphoma leukemia reported poorer functioning in romantic, non-romantic, and non-specific social contacts when compared to healthy emerging adults. This decrease in quantity of social relationships may be attributed to EACS having difficulty in knowing how to talk with others without disclosing one's cancer or how to talk about one's cancer experience (Zebrack, 2000). Some EACS indicate that cancer has become a part of their identity, so it is important to share that with people early on in new relationships. Others report that disclosing one's cancer past creates problems as peers may have a different understanding of cancer and react negatively to this part of the EACS identity (Zebrack, 2011). This social and emotional turmoil for EACS has been reported to lead to isolation, and in turn, difficulty in identity development (Zebrack, 2011). Given that emerging adulthood is a dynamic stage encompassing psychosocial and developmental changes, this makes the EACS population increasingly vulnerable to psychosocial stressors and difficulties adjusting following a cancer experience (Seitz, et al., 2010).

In addition, EACS may experience physical limitations. Numerous studies have found that children and adolescent cancer survivors are at an increased risk for several medical conditions that have the potential to continue into emerging adulthood. The most prevalent medical conditions include second cancers, the manifestation of diseases, improper organ growth, and cognitive, visual, and auditory impairment (Oeffinger et al., 2006). These medical conditions may, in turn, result in limitations to education attainment (Mitby et al., 2003), emotional wellbeing (Hobbie et al., 2000), and physical performance (Oeffinger et al., 2006). For example, a childhood cancer survivor may have lost a limb due to his or her cancer treatment. This individual will then have limited mobility and performance for the rest of their life. These mobility limitations due to cancer treatment may then impact choices in emerging adulthood, such as employment, activity participation, and appropriate residence. Additionally, research has found that these activity limitations have then been related to reports of poorer health (Tai et al., 2012). Furthermore, young adults who had childhood cancer experience a variety of late effects due to the treatment they received, such as cognitive impairment, infertility, and changes in development and growth of organs in survivorship (Bottomley, & Kassner, 2003). The physical limitations, in addition to psychosocial consequences, may work together to disrupt EACS development.

It is important to note that some studies have indicated positive short- and long-term outcomes after a childhood cancer diagnosis. Some researchers found that having cancer in adolescence may result in more maturity, self-confidence, and awareness of competence (Jörngården, Mattsson, & Von Essen, 2007; Servitzoglou et al., 2009). However the studies suggesting positive outcomes are currently outnumbered by studies pointing out the negative

consequences of a cancer diagnosis. This study will seek to better understand the social mechanisms associated with positive and negative outcomes in EACS.

Perceived social support is defined as the information leading individuals to believe that they are cared for, loved, esteemed, and a member of a network of mutual obligations (Cobb, 1976). Perceived social support is typically used in research as an indicator of the quality of an individual's support (Wills & Shinar, 2000). Thus, perceived social support reflects the individual feels that they are supported in the interactions they have with others, rather than the number of people they have as family, friends, or acquaintances in their life. To date, research has shown similar social support experiences for healthy children and children with cancer, but differences surface when comparing social support experiences for healthy adolescents and adolescent who experienced cancer.

From infancy through the school-age developmental stages, child-parent relationships are relatively stable for both healthy children and those who experienced cancer (Steinberg et al., 2014; Ell, 1996). Both groups depend on parents for nurturance and guidance (Steinberg et al., 2014; Ell, 1996). Although there is a shift towards more independence in the child-parent relationship as children get older, the parents are still the most important source of support throughout childhood for most children (Steinberg et al., 2014; Ell, 1996). However, as children enter adolescence and continue to develop social and emotional skills, peer relationships typically become increasingly prevalent and influential.

During typical adolescence the parent-child relationship transforms. Adolescents spend more time with peers and less with parents (Larson et al., 1996). This shift in the relationship is reflected in adolescents' perceptions of support; adolescents often report more support from peers than in childhood (Steinberg, 2014). Although parents are still an

important source of support for topics related to dating, sexual attitudes, morals and value issues, and future plans (Smetana, Campione-Barr, & Metzger, 2006), peers are an important source of support and influential in other areas, such as appearance and social identity (Harris, 1998).

Research on healthy adolescents and adolescents who experienced cancer has revealed a difference in reports of social support. Literature on source of support for ACP has reported that family members are the primary source of support (Enskär et al., 1997; Haluska, Jessee, & Nage, 2002; Nichols, 1995; Rechner, 1990), rather than peers for healthy adolescents. These findings were also supported in a literature review on adolescent cancer survivors (ACS), in which they found that support from parents was extremely important and ACS were most satisfied with family support (Decker, 2007). In regards to friend support, ACS reported feeling less satisfied (Decker, 2007). Thus, regardless of whether the adolescent is a patient or a survivor, research has found differences when compared to typical adolescent social development.

The difference in reports of primary source of support for ACP and ACS, as compared to their healthy peers, highlights the significance of this developmental stage in regards to social support. Although healthy children and children diagnosed with cancer both report parents as a primary source of support, when comparing healthy adolescents to ACS or ACP, there is a difference. Healthy adolescents typically report peers as a primary source of support, while ACS and ACP report parents as the primary source of support. As parent and peer relationships are extremely influential during adolescent development, it is likely that adolescents' perceptions of support will be related to health outcomes in emerging adulthood.

Further, social development throughout childhood may vary depending on the age at which a child was diagnosed with cancer.

In 1994, the DSM-IV identified a cancer diagnosis as one of the major trauma risk factors for posttraumatic stress symptoms (Cordova, Riba, Spiegel, 2017), and depression is one of the most common psychiatric disorders seen in adolescents undergoing cancer treatment (Valente, Saunders, and Cohen, 1994). Shortly after a cancer diagnosis, adolescents who indicated having more social support also reported less depression, anxiety, self-esteem, and hopelessness symptoms (Haluska et al., 2002; Woodgate, 2006). Thus, if ACP do not have higher levels of support, they are more likely to experience negative health outcomes, such as negative self-image, anxiety, or somatization (Çavuşoğlu & Sağlam, 2014; Corey, Haase, Azzouz, & Monahan, 2008; Goodall et al., 2012; Wesley, Zelikovsky, & Schwartz, 2013). Hedström, Haglund, Skolin, and Von Essen (2003) found that ACP undergoing cancer treatments, such as chemotherapy or surgery, indicated feeling isolated, less hopeful, more dependent on family, and separated from peers due to treatment side effects. Adolescent cancer patients have also reported emotional reactions, such as sadness, anger, and anxiety in response to treatment side effects (Corey et al., 2008). In a large-scale study on ACP, Hann and colleagues (2002) administered self-report measures to 342 ACP and found that greater perceived support and more satisfaction with family functioning were associated with less severe depression. Von Essen, Enskär, Kreuger, Larsson, and Sjöden (2000) compared ACP and ACS and found both groups have exhibited depressive symptoms. These depressive symptoms decreased when ACP reported feeling supported (Von Essen et al., 2000). When compared to ACP and healthy adolescents, ACS reported higher depression levels (Von Essen et al., 2000). These findings suggest the need to further investigate mental health

following a cancer diagnosis, and also at time points later during treatment and into survivorship.

Currently, there is little research that has followed children and adolescents who have experienced cancer into emerging adulthood to identify potential outcomes related to adolescent social support. One study investigated the presence of anxiety and depression in ACS within five years of the diagnosis; they found survivors had lower levels of depression and anxiety 18 months after diagnosis when compared to the general population (Jörngården et al., 2007). However, other studies have found that posttraumatic stress disorder (PTSD) symptoms tend to increase over time, such that EACS are at a greater risk than child or adolescent survivor groups (Hobbie, et al., 2000; Seitz, et al., 2010). Hobbie et al., (2000) conducted psychiatric interviews with 68 EACS and found that of this patient sample, 20.5% met the American Psychiatric Association Diagnostic and Statistical Manual criteria for PTSD. Additionally, EACS reported clinically significant levels of intrusive and avoidant behaviors, elevated anxiety, and psychological distress (Hobbie et al., 2000). Furthermore, when compared to healthy emerging adults, Schwartz and Drotar (2006) found that EACS were more likely to have PTSD and experience more depressed and negative affect. Sietz et al. (2010) found similar results with a larger sample of 820 ACS, where 22.4% reported clinically relevant symptoms of posttraumatic stress, anxiety, and depression. These findings are striking, as only 5% of the general emerging adult population in 2014 reported experiencing two or more symptoms of depression (Young Adult Depression, 2015). With current literature mixed on mental health challenges in emerging adulthood, the effect of age of a cancer diagnosis on EACS remains unclear.

To date, EACS self-esteem has been investigated in only a few articles. This is a key gap to address in the literature, as research has established that positive self-concept is a significant factor influencing overall mental health and psychological wellbeing (Coopersmith, 1981; Langeveld, Grootenhuis, Voute, De Haan, & Van den Bos, 2004). But, the mechanisms that increase positive self-concept in emerging adulthood remain unknown. Some psychosocial problems have been identified in EACS, including finishing school, gaining employment, difficulties in relationships, and appearance esteem, which are all related to and influenced by self-esteem (Evans & Radford, 1995). Most literature including self-esteem has viewed this construct as an aspect of quality of life (QoL) in emerging adulthood. This literature base illustrates differing reports about the impact of cancer. A literature review on quality of life for EACS found that most survivors report functioning well psychologically, but reports by subgroups of EACS yielded differences. It appeared that EACS psychological functioning varied depending on the type of cancer diagnosis, where some cancer types resulted in a greater risk for adverse psychological outcomes than others (Langeveld et al., 2004). More recent QoL literature has re-worded the construct as health-related quality of life (HRQOL) and includes self-esteem in the emotional construct in HRQOL. Research utilizing HRQOL is also mixed, as some studies have found a difference in emotion for EACS when compared to healthy emerging adults (Quinn et al., 2013), and others report no difference in emotion (Zeltzer et al., 2008). Thus, this study will address a gap in the literature by focusing narrowly on emerging adult self-esteem and its relationship to adolescents' social support.

Current Study

Given the importance of social support on later mental health outcomes and the potential social and emotional impact of a child or adolescent cancer experience, the current

study drew from a nationally representative sample to examine the influence of social support in adolescence on depression and self-esteem in emerging adulthood among individuals who had cancer prior to age 20. To date, very few studies have focused on cancer survivorship outcomes in emerging adulthood, especially in a nationally representative sample. Due to an increase in survival rates for child and adolescent cancer (Cancer in Children and Adolescents, 2016) and the unique developmental tasks associated with emerging adulthood (Arnett, 2014), the current study addresses existing research gaps by focusing on long-term outcomes in this population.

The present study contributes to the field by focusing on EACS unique social support experiences in adolescence and its relationship with mental health outcomes in emerging adulthood. The first research question is *For EACS, how is adolescent social support related to depression and self-esteem in emerging adulthood?* We hypothesize that more perceived social support from all sources in adolescence will be associated with fewer depressive symptoms and higher self-esteem in emerging adulthood. Previous findings suggest that the age of diagnosis may play a role in the impact of cancer on social and emotional development (Gurney et al., 2009), thus research question two asks, *For EACS, does age of cancer diagnosis moderate the association between adolescent social support and depression or self-esteem in emerging adulthood?* We expect that age of cancer diagnosis will moderate the associations between social support and depression and self-esteem in emerging adulthood, such that the associations are stronger for EACS who were diagnosed during adolescence. We hypothesize this because adolescence is marked as a time when social interactions are increasingly important and influential on an adolescents' behavior and identity formation. Thus, undergoing treatment at this time may be increasingly difficult for

adolescents, as they may not have as many opportunities for social interactions with their friends and peers at school. Finally, given that previous research has found that specific sources of support may be related to better health outcomes, we explore the third research question, *Is one source of support more influential on depressive symptoms and self-esteem than other sources of support in emerging adulthood?*

Method

Sampling Design

To examine these hypotheses, data from Waves 1, 3, and 4 in the nationally representative National Longitudinal Study of Adolescent Health (Add Health) were utilized. Add Health is a panel study of adolescents in 132 schools nationwide between grades 7 and 12. The in-school portion of the first Wave of survey data (1994-1995) included approximately 90,000 adolescents (ages 13-18), and researchers followed up with 20,745 adolescents in an in-home questionnaire and interview. Data collection for Wave 3 (ages 18-26) began in July 2001 and concluded in April 2002, and Wave 4 (ages 24-32) was conducted in 2008 following the same in-home interview data collection format (Harris, 2012). Thus, there are approximately 1-2 years between Waves 1 and 2, almost 6 years between Wave 1 and Wave 3, and 14-15 years between Wave 1 and Wave 4.

The analysis for the current study was limited to those participants who indicated being diagnosed with cancer between the ages 0 and 20 (collected in Wave 4 and completed Waves 1 and 3). This design allowed for the examination of social support during adolescence and its influence on depressive symptoms and self-esteem in emerging adulthood in a population of emerging adults who had survived cancer. The final sample size consisted of 78 participants (0.6% of the population). The gender distribution was 56 females and 22 males. A total of 52 participants were white, and remaining 26 were African

American, Hispanic, American Indian, or Asian. Refer to Table 1 for participant demographics.

Measures

Perceived social support. The independent variable, perceived social support, was gathered in Wave 1 from 12 items in the Add Health dataset (Cornwell, 2003; Musliner & Singer, 2014; Rawana, Jennine, 2013). Four items (e.g., “how close do you feel towards your mom?") measured support from a residential mother figure ($\alpha = .90$), four items measured support from a residential father figure ($\alpha = .93$), one item measured peer relationships, and three measured school support ($\alpha = .83$). Due to high collinearity, the peer relationship item and school support subscales were combined ($\alpha = .78$). Responses ranged from 1 (strongly disagree/not at all) to 5 (strongly agree/very much), with higher scores reflecting more perceived support from parents, friends, and school. Previously published studies using the Add Health dataset have utilized different variations of the 12-items depending on their research interest, with one study using the full 12-item scale to indicate overall support ($\alpha = .94$; Miller, Eposito-Smythers, & Leichtweis, 2014). Additionally, other studies have broken down the 12-item scale by source of support (Harker, 2001; Cornwell 2003; Musliner & Singer, 2014). In these studies they defined the measure as assessing relationship quality, social connectedness, social belonging, expressive support, and perceived social support. The social support scale was found to be highly reliable in this sample (12 items; $\alpha = .90$).

Depressive symptoms. Depression was gathered in Wave 3 with 9 items from a commonly used, modified version of The Center for Epidemiological Studies Depression Scale (CES-D; Radloff 1977). For example, “How often was each of the following things true during the past week? You felt depressed.” The responses ranged from “never or rarely” (0) to “most of the time or all of the time “ (3). Higher scores on the CES-D indicated more

depressive symptoms. Two items on this scale were reverse coded. The depression scale was found to be moderately reliable in the current sample (9 items; $\alpha = .68$).

Self-Esteem. Self-esteem was measured during Wave 3 by using four items that parallel Rosenberg's global self-esteem scale (Exner-Cortens, Eckenrode, & Rothman, 2012; Morrison et al., 2016; Rosenberg, 1965). Responses ranged from 0 (strongly disagree) to 4 (strongly agree). Higher scores on the scale indicate higher self-esteem ($\alpha = .78$; Exner-Cortens, Eckenrode, & Rothman, 2012). The self-esteem scale was found to be reliable (4 items; $\alpha = .76$).

Age of cancer diagnosis. The dichotomous variable, age of cancer diagnosis, was also created from responses in Wave 4. This variable indicated whether the child was diagnosed with cancer in childhood ($n = 47$; ages 0-10) or in adolescence ($n = 31$; ages 11-20). Thus, if ACS were diagnosed with cancer before they completed Wave 1 they were assigned to the childhood group, and if ACS were diagnosed following Wave 1 they were assigned to the adolescent group.

Covariates. The control variables sex, minority status, and parent education, were included in this study, as they have all been shown to be associated with depression in previous studies and have the potential to impact participants' perceptions of social support (Dohrenwend, Levav, ShROUT, & Shwartz, 1992; Riolo, Nguyen, Greden, & King, 2005; Weissman, Leaf, Holzer, Myers, & Tischler, 1984).

Missing Data

Due to using longitudinal data from a nationally representative sample, some strategies needed to be taken to account for missing data. To address all missing data, the models in this study were run using *Mplus* Version 7 software (Muthen & Muthen, 2012).

Full Information Maximum Likelihood (FIML) estimation was utilized to handle missing data and establish the best model fit for the data (Allison, 2003).

Lastly, each model was also run with just the participants who had complete data for both dependent variables in Wave 3 ($n = 67$) to determine the potential ways missing data might impact the results. No differences were found between these models and the full sample models run with FIML, thus the full sample models are reported here forward.

Analytic Plan

Basic descriptive analyses and correlations among the study variables were computed using SPSS. Next, linear regressions were performed using *Mplus* Version 7 software (Muthen & Muthen, 2012), and FIML was utilized to handle missing data within the Add Health dataset. Full information maximum likelihood was used, as it is a method for model estimation that produces the most accurate fit results and limits bias by using estimations based on all available variables within the dataset (Newsom, 2015). The Add Health dataset is weighted for the entire population, however for this model we did not utilize sampling weights as we were interested in the uniqueness of this add health subpopulation.

For research question 1, two separate linear regression analyses were performed in *Mplus* to determine if adolescent social support reported in Wave 1 was a predictor of EACS reported depressive symptoms and self-esteem in Wave 3. The covariates in these models included gender (male = 1), minority status (minority = 1), and parent education (1 = high school education or less). The social support variable was developed by calculating an overall scale mean of the 12 social support items.

For research question 2, first the age of diagnosis variable was created to represent participants diagnosed with cancer before Wave 1 and participants diagnosed with cancer after Wave 1. The childhood group consisted of participants who experienced cancer before

Wave 1 (n = 47), and the adolescent group consisted of participants who experienced cancer after Wave 1 (n = 31). Although the majority of the participants in Wave 1 were younger than participants in Wave 3, 8 participants overlapped in age. This was a result of participants being between ages 11-18 in Wave 1. Thus, a participant could be diagnosed with cancer at age 15 and complete Wave 1 at 17, but still be considered in the childhood sample because they were diagnosed with cancer before Wave 1. On the other hand, another participant could complete Wave 1 at age 11 and be diagnosed with cancer at age 12 and be in the adolescent group because they were diagnosed with cancer after the Wave 1 data was collected. Thus, the dichotomous variable, age of cancer diagnosis, was developed with 0 indicating children diagnosed with cancer and 1 indicating adolescents diagnosed with cancer.

Hierarchical regression analyses were performed to test whether the interaction of social support and age of diagnosis accounted for a significant amount of variance above their main effects (Cohen & Cohen, 1983). To test for a main effect, two steps were run. At step one, adolescent social support and depressive symptoms in emerging adulthood were entered into the model. At step two, depression and age of diagnosis were added. At step three, the interaction of social support X age of diagnosis was added. The same hierarchical regression analyses were employed to address the model that included self-esteem as a predictor variable.

To address research question 3, two separate correlation analyses were conducted to determine which source of support (i.e., father, mother, or peer) had a greater association with depression and self-esteem in emerging adulthood.

Results

Table 4.2 shows the preliminary statistics, including means, standard deviations, ranges, and Cronbach's alpha for each scale and subscale. Table 4.4 shows the correlations among study variables. Depressive symptoms were significantly correlated with self-esteem ($r = -0.36, p < 0.01$) and gender ($r = 0.37, p < 0.01$). Lastly, age of diagnosis was significantly related with race ($r = 0.28, p < 0.05$) and gender ($r = 0.41, p < 0.001$). Inconsistent with expectations, depressive symptoms and self-esteem in emerging adulthood were not correlated with the control variables race, gender, parent education, or age of diagnosis.

Contrary to our hypothesis, perceived social support in adolescence was not significantly associated with depressive symptoms ($\beta = 0.02, SE = 0.12$) or self-esteem ($\beta = -0.02, SE = 0.12$) for emerging adults who had experienced childhood cancer (See Table 4.5). In the depression model, the control variable, gender, was positively associated with depressive symptoms reported in emerging adulthood ($\beta = 0.30, SE = 0.14, p < 0.05$). This indicated that female EACS were more likely than male EACS to report depressive symptoms in emerging adulthood.

Hierarchical regression analyses were conducted to test if age of diagnosis moderated the association between adolescent social support and depressive symptoms in emerging adulthood. We did not find the interaction term (i.e., social support X age of diagnosis) to be significant, indicating that age of diagnosis did not moderate the relationship between adolescent social support and depressive symptoms in emerging adulthood (See Table 4.5).

Hierarchical regression analyses were also conducted to test if age of diagnosis moderated the association between adolescent social support and self-esteem in emerging adulthood, while controlling for gender, race, and parent education. We did not find the

interaction term (i.e., social support X age of diagnosis) to be significant, indicating that age of diagnosis did not moderate the relationship between adolescent social support and self-esteem in emerging adulthood (See Table 4.5).

Although the findings did not yield significant interactions between social support and age of a cancer diagnosis, hierarchical regression analyses were conducted to determine if age of diagnosis significantly interacted with the predictor variables race, gender, and parent education. These models were not supported.

Lastly, to test if one source of support was more influential than the others on depressive symptoms and self-esteem in emerging adulthood, two correlation analyses were ran while controlling for gender, race, parent education, and age of diagnosis. We found that depressive symptoms were significantly associated with father support ($r = .18, p < 0.05$). Furthermore, we found that peer support was moderately correlated with emerging adulthood self-esteem ($r = .12, p = .06$).

Discussion

Contrary to hypotheses, no associations between adolescent social support and self-esteem or depression in emerging adulthood were found. Furthermore, we did not find that the age at which a child was diagnosed with cancer influenced the associations between adolescent social support and depression or self-esteem in emerging adulthood. However, we did find that mother support in adolescence was more strongly correlated with depression in emerging adulthood than other sources of support. Additionally, although marginally significant, we found peer support in adolescence to be more strongly associated to self-esteem in emerging adulthood than mother or father support. While our hypotheses were not supported in this study, we did find that female EACS were more likely to report depressive symptoms in emerging adulthood than males. This finding is consistent with the literature on

healthy female emerging adults and within the cancer population (Hankin, Abramson, Moffitt, Silva, & McGee, 1998; Pettit, Roberts, Lewinsohn, Seelye, & Yaroslavsky, 2011).

That adolescent social support and depression and self-esteem in emerging adulthood were unrelated for EACS was unexpected. Previous research has demonstrated associations between social support and mental health outcomes for childhood cancer survivors; with higher perceptions of social support in adolescence linked to fewer reported symptoms of depression (Pettit et al., 2011; Stice, Ragan, Randall, 2004) and higher perceptions of self-esteem (Evan, Koffman, & Cook, 2006) in emerging adulthood. However, the findings from this population of EACS did not match this literature base. A possible explanation for the lack of associations amongst the variables in this sample may be attributed to the characteristics of our sample. As the Add Health questionnaires were not developed for childhood cancer survivors, the questions used to measure social support and self-esteem may not have been appropriate in assessing these concepts within this unique population. Several studies that utilized measures that were specifically designed for children with cancer or chronic illness have documented an association between social support and depression (Kazak, 1998; Kazak, Barakat, Meeske, Christakis, & Meadows, 1997) and social support and self-esteem (Cantrell & Lupinacci, 2007). Additionally, the number of questions that queried each construct was not ideal, with each construct being assessed with 12 questions or less. Thus, our ability to assess each construct in-depth was not an option within this dataset, which may have contributed to not finding an association between the variables of interest.

In addition, our findings did not support the second hypothesis that there would be a stronger relationship between social support and depressive symptoms for EACS who were diagnosed as adolescents (ages 11-20), rather than in childhood (ages 0-11). As we did not

find associations between adolescent social support and depression in emerging adulthood, nor moderation by age of diagnosis, we could not gain an understanding of how the age of diagnosis may impactful later developmental wellbeing in emerging adulthood.

Our study also addressed sources of support, in which we found that father support in adolescence was more influential on depressive symptoms in emerging adulthood. This is an interesting finding, as most literature discusses the importance of mother support in adolescence with ACS typically report feeling most satisfied with support from their mothers (Decker, 2007). However in this study, it appears father support is related higher depressive symptoms, indicating that father support may not be as beneficial for ACS.

The literature focused on EACS psychosocial outcomes is mixed, and at times inconsistent. Some studies have found that EACS are at a risk for decreased wellbeing (Fidler et al. 2015; Thompson, Marsland, Marshal, & Tersak, 2009; Zeltzer, et al., 2008), while others have not (Thompson et al., 2009; Zeltzer, et al., 2008). After further investigation within this literature base, the mixed findings may be attributed to the unique characteristics of the sample. For instance, when looking at specific developmental outcomes for each type of cancer diagnosis within the sample, Zeltzer et al. (2008) found unique risks and potential issues specific to these populations, while not finding these risks when studying the population as a whole. Thus, it would be advantageous to continue assess the characteristics of the populations that may be more vulnerable to adverse psychosocial outcomes. The Childhood Cancer Survivor Study literature has shed light on more vulnerable populations within their dataset, with leukemia, brain tumor, bone tumor, and lymphoma survivors experiencing more psychological distress in young adulthood (Zeltzer et al., 2008). As research continues to identify these vulnerable populations and the mechanisms behind

why these populations are vulnerable, interventions can be developed to target the specific needs of these survivors.

Additionally, the developmental stage of the child when they are diagnosed with cancer may result in different developmental outcomes. For example, a child who was diagnosed with cancer in early childhood may not be able to participate in activities that helped to develop autonomy. If this is a specific issue for early childhood cancer patients then it may be advantageous to focus on autonomy-building opportunities throughout treatment and in survivorship interventions. However, if diagnosis comes later in elementary school, the child may struggle with developing and maintaining peer relationships and thus psychosocial interventions might be more appropriate to address how to remain in contact with friends at school or ways to make new friends outside of the school setting. Further exploration on the impact a cancer diagnosis has on developmental milestones within each stage may uncover how the child is immediately impacted, and if these developmental difficulties continue to manifest throughout the remainder of their childhood and into adulthood.

Limitations and Conclusions

Although we did not find significant associations between adolescent social support and self-esteem and depression in emerging adulthood, this could be attributed to study limitations. The sample size was small, and missing data in Wave 3 ($n = 11$) on the outcome variables may have impacted the findings. To address the small sample size, it may be beneficial to utilize the bootstrapping method within this population sample. Other studies utilizing data from the Add Health study have also incorporated this method to increase the sample size of childhood cancer survivors (Cantrell & Posner, 2014; Cantrell & Posner, 2016).

Additionally, the sub-population of childhood cancer survivors within the Add Health dataset completed measurements that were not specifically tailored to this population.

Typically, research studies with this population utilize measures that have been found to be reliable and valid in gathering information related to social support, depression, and self-esteem to this population (Corey, Haase, Azzouz, & Monahan, 2008; Haluska et al., 2002; Nichols, 1995; Smith et al., 2013). Still, the measures used in this study demonstrated adequate reliability in the current sample. For a more comprehensive examination of these constructs, it would have been advantageous to analyze scales that consisted of more than four items and were better tailored to this population.

Despite these limitations, this is one of the few studies to draw from a population sample of childhood cancer survivors. This study is unique from other research in adolescent and emerging adult oncology field, as it was not gathered from a clinical sample of childhood cancer survivors who were recruited from hospitals, outpatient clinics, or a medical database, but rather a population sample. This may contribute to the uniqueness of this population, as EACS who were in the Add Health study were not necessarily seeking services or felt that their childhood cancer diagnosis was relevant to their current lifestyle in the way samples drawn from medical databases or hospitals (Brown, Madan-Swain, & Lambert, 2003; Deverensky, Tsanos, & Handman, 1998; Kazak & Meadows, 1989; Kyngäs et al., 2001; Rechner, 1990, Trask et al., 2003). Clinical samples often have the disadvantage of oversampling participants who are seeking treatment and services (Bonevski et al., 2014), as this is typically the way they recruit their participants. Thus, the Add Health sample was advantageous to analyze, as they may be more representative of the EACS population at large. Studies with greater statistical power may illuminate these differences in outcomes

among survivors drawn from a population study, when compared to clinical samples, suggesting that researchers and practitioners should anticipate differing needs from those seeking clinical services and those not.

Tables

Table 4.1. Participant Demographics

Sample Description	Full Cancer Sample <i>n</i> = 78	Childhood Group <i>N</i> = 23	Adolescent Group <i>N</i> = 55
Gender			
Female	56	10	46
Male	22	13	9
Race			
White	52	11	14
Minority	26	12	41
Parent Education			
No Formal Education	32		
GED	17		
Associate/Bachelor's	14		
Professor Degree	9		
Missing	6		

Table 4.2 Descriptives

	<i>M</i>	<i>SD</i>	Range	Alpha
Wave 1 Perceived	3.94	.68	1.88-5.00	.90
Social Support				
Mother	4.10	.81	1.75-5.00	.90
Father	4.00	1.01	1.00-5.00	.93
Peer	3.80	.81	3.25-5.00	.78
Wave 3 Depressive	.94	.43	.33-2.33	.68
Symptoms				
Wave 3 Self-Esteem	3.60	.60	1.25-4.50	.76

Table 4.3. Ages at Waves

	Full Cancer Sample	Childhood Group	Adolescent Group
Age at Wave 1	16.15 (1.7)	15.68 (1.2)	15.1 (1.7)
Age at Wave 3	21.67 (1.8)	22.70 (1.3)	21.23 (1.8)
Age of Cancer Diagnosis	13.60	6.81	18.0
<i>SD</i>	6.4	4.90	1.67
<i>Range</i>	0-20	0-16	14-20

Note. The age range for the full cancer sample was 0-20 years. The age range for the childhood group was 0-16 years, and the age range for the adolescent group was 14-20 years. Thus, there was some overlap in age depending on when the ACS completed Wave 1.

Table 4.4 Correlation Matrix

	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.
1. Wave 1 Total Social Support	---									
2. Wave 1 Mother Support	.88***	---								
3. Wave 1 Father Support	.88***	.81***	---							
4. Wave 1 Peer Support	.64***	.30*	.29*	---						
5. Wave 3 Total Self- Esteem	-.01	-.12	-.08	.18	---					
6. Wave 3 Total Depression	-.01	-.07	.05	-.01	.36**	---				
7. Race	.21	.08	.21	.21	-.01	-.03	---			
8. Gender	-.12	-.21	-.14	.08	-.07	.37**	-.01	---		
9. Parent Education	-.10	-.14	-.19	.01	.04	-.20	.01	-.34	---	
10. Age of Dx	.14	-.01	.17	.18	.02	.14	.28*	.41***	.05	---

Note. * $p < .05$. ** $p < .01$. *** $p < .001$. Gender: 1 = Female 0 = Male; Race: 1 = White 0 = Non-White, Parent Education: 0 = High School or Under, 1 = College and Above; Childhood = 0, Adolescence = 1.

Table 4.5. Summary of Regressions

	<u>Depression</u> <u>Model 1</u>			<u>Self-Esteem</u> <u>Model 2</u>			<u>Depression</u> <u>Model 3</u>			<u>Self-Esteem</u> <u>Model 4</u>		
	b	SE	β	b	SE	β	b	SE	β	b	SE	β
Social Support	.01	.12	.02	-.02	.12	-.02	.02	.02	.04	-.00	.03	-.00
White	-.04	.13	-.04	-.11	.13	-.08	.02	.02	.02	.00	.03	.00
Female	.29	.14	.30*	-.15	.16	-.11	.02	.02	.02	.00	.03	.00
Parent Education	-.06	.12	-.14	.03	.16	.06	.02	.02	.02	.00	.03	.00
Age of Diagnosis	.06	.15	.07	.12	.15	.09	.02	.02	.02	-.00	.02	-.00
Social Support X Age of Diagnosis	--	--	--	--	--	--	.02	.07	.01	.00	.08	.01
R ²	.11			.12			.14			.13		
N	78			78			78			78		

Note. * $p < .05$. ** $p < .01$. *** $p < .001$. Gender: 1 = Female, 0 = Male; Race: 1 = White, 0 = Non-White; Parent Education: 0 = High School or Under, 1 = College and Above; Childhood = 0, Adolescence = 1.

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CHAPTER 5. GENERAL CONCLUSIONS

The overarching goal of this dissertation was to explore adolescent and emerging adult cancer survivors' social experiences and the potential influence these experiences have on short and long-term well-being outcomes. More specifically, in chapter 2, we utilized an interpretive phenomenological approach to gain a deeper understanding of the oncology camp phenomena and the adolescent cancer survivors (ACS) social support experiences within this environment. In chapter 3, we explored the association between social support and self-esteem for ACS, in addition to associations between sources of support (i.e., mother, father, peer) and self-esteem domains (i.e., performance, social, and appearance). Lastly, in chapter 4, we utilized a population-based sample of emerging adult cancer survivors (EACS) from the Add Health dataset to explore how social support during adolescence was associated with depression and self-esteem in emerging adulthood. We also explored whether age of diagnosis (i.e., childhood or adolescence) would influence the relationship between adolescent social support and depression and self-esteem in emerging adulthood. Within this population-based sample, we assessed if a specific source of support (i.e., mother, father, peer) was more influential on depression or self-esteem in emerging adulthood. This chapter summarizes the key findings from each study, provides general conclusions across all studies, and implications for future research.

Summary of Results

In chapter 2, the phenomena of ACS social experiences at an oncology camp were explored. Findings from the interviews and camp observations highlighted that ACS viewed the camp environment as a safe space to engage in an identity that they strongly connected to—cancer survivor. This camp context included valuable social experiences for these ACS,

such as building and maintaining relationships. These relationships were particularly meaningful because they were with other individuals' who had survived cancer, and ACS seemed to perceive an automatic deeper understanding with one another. Furthermore, some ACS responses were unexpected during the interview, as they reflected on difficult social experiences that occurred at home with family and friends, and one male ACS not believing camp was a supportive environment for him.

Within chapter 3, the findings revealed that ACS who reported more social support also reported higher overall and domain-specific self-esteem (i.e., performance, social, and appearance). Contrary to previous literature, we found that social support from peers appeared to be associated to all aspects of self-esteem, while social support from parents was associated with performance and social self-esteem.

The fourth chapter utilized the Add Health dataset to analyze the association between adolescent social support and depression and self-esteem in emerging adulthood among a population-based sample of EACS. Contrary to our hypotheses and previous literature, we did not find support for the associations. However, these findings suggest that there may be differences between participants recruited through cancer related activities and population-based samples, and future research should explore this.

General Conclusions and Implications

As indicated by the qualitative and quantitative data collected for the studies presented in chapter 2 and 3, social experiences at home and at camp are important for ACS as they influence self-esteem, and overall identity as a cancer survivor. In chapter 3, ACS reported feeling well supported by mothers, fathers, and peers. This finding was expected, as many studies have found that ACS typically reported high satisfaction with the support they receive from parents and friends in survivorship (Decker, 2007). What stood out from our

studies, in comparison to other studies of ACS, was the role peers played in self-esteem and in identity development. Although parents were important sources of support and influential on performance self-esteem for ACS, our sample indicated peer support as being more highly associated with appearance and social self-esteem. The particular difference we identified was appearance esteem, with peer support being associated with this aspect of self-esteem while parents were not. This finding is similar for healthy adolescents, with peer support being influential on appearance and overall body image satisfaction (Ata, Ludden, & Lally, 2007; Shroff & Thompson, 2006).

Thus, medical professionals should develop and implement interventions that target appearance self-esteem and help ACS. Furthermore, these interventions may be particularly important for ACS who experience late treatment effects, as they may be increasingly vulnerable to appearance esteem issues when compared to ACS who do not experience late treatment effects. Therefore, by helping the ACS feel more supported in all areas of their life, whether that be at home, school, within the hospital setting, medical professionals can use sources of support as a strategy to address potential self-esteem pitfalls. As indicated in chapter 2, some ACS reported issues related to lack of support from siblings or friends because of jealousy or a lack of truly understanding about what the ACS went through when they experienced cancer. By understanding the unique support issues that ACS are experiencing during treatment and in survivorship, interventions can be tailored to help the ACS. For example, if ACS are experiencing difficulty in their relationship with siblings because of jealousy that manifested from the parent spending more time with the ACS, families may benefit from family counseling. Or if the ACS has difficulty creating new friendships in school because they are nervous about sharing their cancer history, perhaps

they would benefit from interventions that provide them with communication tools and techniques to explain their history and how this may have impacted their identity in adolescence. These experiences will ultimately empower the ACS to not only be confident in themselves, but also help to increase the amount of positive support they are experiencing in their lives.

Some studies have explored survivorship services for childhood cancer survivors, and if these interventions are meeting the needs for this population. Zebrack (2009) questioned young adult cancer survivors (ages 18-39), and found that approximately 60% of respondents expressed a desire or need for age-appropriate cancer information, complementary or alternative services, infertility information, mental health counseling, and camp or retreat programs for young adults. Furthermore, more than 50% of the young adult cancer survivors indicated that their needs for information and services had not been met, with unmet needs being more likely reported by respondents who were younger at the age of their cancer diagnosis (Zebrack, 2009). This finding was also supported in a population-based sample, with more than half of adolescent and young adult cancer survivors ($n = 523$) reporting unmet service needs in relation to physical and emotional health problems (Keegan et al., 2012). Thus, survivorship care for ACS is still a work in progress, with several studies indicating a deficiency in the availability and effectiveness of psychosocial support (Keegan et al., 2012; Zebrack et al., 2012). Therefore, it may be advantageous to implement interventions that bolster social support and opportunities for support in many areas of an ACS life during treatment and during post-treatment follow up appointments, in order to help ease the transition into survivorship.

Within our study, we found that attending an oncology camp is an example of a psychosocial service that may help to address the support needs for ACS. As indicated by chapter 3, the majority of ACS expressed the unique support a friend who also experienced cancer can provide for them. When the ACS first attended camp, many reported the desire to feel normal and feel like a typical child. As they transitioned into survivorship, one of the reasons ACS continued to attend camp because of the relationships they had created with other ACS. These relationships were viewed as deeper, and more meaningful than friendships at home because other ACS understood that cancer experience. Those interactions were treasured, and ultimately helped the ACS to feel more confident in themselves. This increased confidence was also reflected in their identity as a cancer survivor, with some ACS feeling that they could not be themselves at home because their friends who did not have cancer either did not know about their cancer history or did not understand. Thus, for children who are experiencing cancer, the oncology camp experience is a psychosocial service that can help to bolster their sources of support and self-esteem. Furthermore, this service should still be suggested to children and adolescents in survivorship, as this camp can help to meet the newer psychosocial needs that surface in survivorship. Furthermore, some ACS indicated their disappointment in turning 18, as this would be their last year to attend camp. These responses shed light on their continued desire to engage in psychosocial opportunities with other survivors, and perhaps they are unaware of services that they can utilize to continue feeling supported by this sub-group. These comments, in addition to past literature identifying the unmet needs of adolescent and young adult cancer survivors, indicate the value and desire for services that provide an opportunity for survivors to experience a supportive community of survivors.

Limitations and Future Directions

As stated throughout our papers, these analyses contain limitations. Limitations to the current study could be addressed in future research in ways that clarify current findings and suggest further strategies for meeting the survivorship needs of ACS. For example, these studies drew on two types of populations—a sample that self-selected into attendance at a cancer camp and cancer survivors who happened to be part of a population-representative sample of adolescents—and resulted in different findings. Each of these samples offers unique insight, and the naturally occurring subpopulation in the nationally representative sample holds the best possibility for generalizing findings to all ACS and EACS, beyond just those who seek out opportunities like camp. However, this sample size was limited to 78 survivors within the Add Health dataset, as thus statistical power for the analyses was very limited for a longitudinal study.

Future research could address these limitations in a few ways. First, data collection could be done at several oncology camp locations during a specific time period, or the participants could complete the survey prior to attending camp. One strategy may be to incorporate the survey into the application process. This type of data collection can help to decrease camp-bias, as campers are not yet in the camp environment, which may influence their feelings of support. However, this strategy would not elevate selection bias that choosing to attend camp may be related to particular social support needs or desires. Second, data collection should also incorporate children who do not choose to attend oncology camps, as there may be a difference between these individuals and survivors who self-selected into survivor-specific opportunities. For example, ACS who attended camp may place greater value on their identity as a cancer survivor and sharing this identity with other ACS, while ACS who did not attend camp may not want to identify as a survivor but rather being

“normal” is important to them. Combining these populations is most advantageous together in order to provide the most robust picture of how to promote wellbeing for ACS.

Furthermore, a larger sample size would be advantageous to observe the influence of other variables on our model, such as the incorporation of potential moderators or mediators. The population-based sample from the Add Health dataset in chapter 4 was small, and thus limited statistical power may explain the lack of associations within our models. This sub-sample within the Add Health dataset could be further explored in the future, as recent studies have utilized statistical methods, such as bootstrapping (Cantrell & Posner, 2016), to create a larger sample of ACS in order to increase the sample size and power of the model.

Lastly, in future research the life course theoretical framework may be the best suited theory for studying ACS, as the timing of diagnosis, duration of treatment, and developmental stage in which the transition to survivorship occurs may all have unique meaning for the survivor’s developmental trajectory. However, we had difficulties incorporating this theoretical framework in chapter 4 because of the difficulty with the variability amongst the age at which the participant completed the surveys, the age at which they were diagnosed with cancer, and differences in data collection within waves.

Additionally, as there is an age range, it is difficult to identify specific developmental stages, and how a cancer diagnosis may manifest unique outcomes. For instance, it would be best to understand the impact of a childhood cancer diagnosis by collecting data immediately following the diagnosis, throughout treatment, and into survivorship. By having a better understanding of the timeline of these events for children, research could provide a clearer picture of the short and long-term impact a cancer diagnosis has on a child’s later wellbeing outcomes. To address this limitation, one possible method of data collection may be to

incorporate health professionals, such as child life specialists, at the time of diagnosis and throughout the child's treatment in the hospital. As child life typically is involved at the time of diagnosis and during each treatment, this data collection method could be included each time child life specialists interact with ACP in the hospital setting. Furthermore, the point at which a child enters survivorship may be another important life event that reshapes the child's developmental trajectory, as they are most likely transitioning to attending school on a regular basis, more opportunity for peer interactions, and less time spent with parents and the health practitioners they developed relationships with. Thus, utilizing this theoretical framework is advantageous for gaining a deeper understanding of the impact of a cancer diagnosis.

Overall, the results from this dissertation contribute to the field by adding to our understanding of adolescent survivorship of childhood cancers. From these studies, ACS interviewed at an oncology camp appeared to be doing well in survivorship, with most of those surveyed feeling supported by parents and peers in their lives. These feelings of adequate support were important, as it contributed to their self-esteem. Furthermore, the oncology camp experience was valued for ACS, as this was a space for ACS to be surrounded by others who battled cancer and ultimately fostered a positive sense of self as a survivor.

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APPENDIX A. INSTITUTIONAL REVIEW BOARD APPROVAL

IOWA STATE UNIVERSITY
OF SCIENCE AND TECHNOLOGY

Institutional Review Board
Office for Responsible Research
Vice President for Research
1138 Pearson Hall
Ames, Iowa 50011-2207
515 294-4566
FAX 515 294-4267

Date: 5/27/2016

To: Katie Riley
205 NE 44th St Apt 304
Ankeny, IA 50023

CC: Dr. Christine Maynard
4380 Palmer, Suite 1354
Dr. Brenda Lohman
2330 Palmer, Suite 6230

From: Office for Responsible Research

Title: Exploring Adolescent's Oncology Camp Experiences

IRB ID: 16-242

Approval Date: 5/27/2016 **Date for Continuing Review:** 5/26/2018

Submission Type: New **Review Type:** Expedited

The project referenced above has received approval from the Institutional Review Board (IRB) at Iowa State University according to the dates shown above. Please refer to the IRB ID number shown above in all correspondence regarding this study.

To ensure compliance with federal regulations (45 CFR 46 & 21 CFR 56), please be sure to:

- **Use only the approved study materials** in your research, including the recruitment materials and informed consent documents that have the IRB approval stamp.
- **Retain signed informed consent documents for 3 years after the close of the study**, when documented consent is required.
- **Obtain IRB approval prior to implementing any changes** to the study by submitting a Modification Form for Non-Exempt Research or Amendment for Personnel Changes form, as necessary.
- **Immediately inform the IRB of (1) all serious and/or unexpected adverse experiences** involving risks to subjects or others; and (2) **any other unanticipated problems involving risks** to subjects or others.
- **Stop all research activity if IRB approval lapses**, unless continuation is necessary to prevent harm to research participants. Research activity can resume once IRB approval is reestablished.
- **Complete a new continuing review form** at least three to four weeks prior to the **date for continuing review** as noted above to provide sufficient time for the IRB to review and approve continuation of the study. We will send a courtesy reminder as this date approaches.

Please be aware that IRB approval means that you have met the requirements of federal regulations and ISU policies governing human subjects research. **Approval from other entities may also be needed.** For example, access to data from private records (e.g. student, medical, or employment records, etc.) that are protected by FERPA, HIPAA, or other confidentiality policies requires permission from the holders of those records. Similarly, for research conducted in institutions other than ISU (e.g., schools, other colleges or universities, medical facilities, companies, etc.), investigators must obtain permission from the institution(s) as required by their policies. **IRB approval in no way implies or guarantees that permission from these other entities will be granted.**

Upon completion of the project, please submit a Project Closure Form to the Office for Responsible Research, 1138 Pearson Hall, to officially close the project.

Please don't hesitate to contact us if you have questions or concerns at 515-294-4566 or IRB@iastate.edu.

APPENDIX B. INTERVIEW SCRIPT

The PI will select 15 adolescents to participate in a 20-30 minute audio-recorded interview. This interview will take place in a quiet space to minimize distractions. If the adolescent ever appears uncomfortable the interview will be stopped and will not continue unless the adolescent agrees to continue. If the adolescent appears upset after the interview the PI refer the adolescent to appropriate camp staff. (The italicized letters will not be communicated to the adolescent)

1. Principal investigator (PI): Thanks for agreeing to talk with me today! I will first ask you some questions about social support that are similar to the survey you completed. Then I will ask you some questions about your camp experience. Also, our talk today will be audio recorded. You have the right to not answer any questions you do not feel comfortable asking. Also, you can stop this interview at any time. Do you have any questions for me before we begin? (Proceed to 1a or 1b)

1a. If the adolescent says “No”: Okay, let’s get started then! I am going to turn on the audio recorder now. (Proceed to 2)

1b. If the adolescent says “Yes” the PI will answer all questions then proceed to the interview if it is okay with the adolescent (Proceed to 2). If not, the PI will say “It is totally fine that you do not want to participate in this interview. Let’s go see what area of camp you’re supposed to return to!” (End of conversation)

2. PI: Who are the people who provide you with a sense of friendship? These are people with whom you share common interests, concerns, and activities.

3. PI: Who are the people you turn to for advice and guidance?

4. PI: Who are the people that make you feel smart and worthwhile; that recognize your skills, talents and abilities?
5. PI: Who are the people you can count on for help, no matter what?
6. PI: Who provides you with a feeling of closeness and emotional security?
7. PI: Tell me how your friends without cancer make you feel like they care for you.
8. PI: Tell me how your friends with cancer make you feel like they care for you.
9. PI: Tell me how people at the hospital make you feel like they care for you.
10. PI: Do you ever receive unwanted support from people? If so, from who and what type of support is it?
11. Do you use social media, like a blog or online chat, to feel supported? If so, what type of support are you looking or asking for on social media?
12. PI: Thanks for answering the questions about social support. Now we are going to talk about your camp experience. Are you okay with continuing?
 - 12a. If adolescent says “Yes”: Great. (Proceed to 13)
 - 12b. If the adolescent says “No”: That is totally fine that you do not want to continue answering questions. Let’s go see what area of camp you’re supposed to return to! (End of conversation)
13. PI: How many times have you came to this camp?
14. PI: Why do you choose to participate in this camp?
15. PI: Do you come to camp because it helps you feel more supported? If so, what kind of support are you wanting when you are here?
16. PI: Is the support you receive from the camp different than your normal day-to-day support? If so, tell me some ways that it is different for you.

17. PI: Do you think the support you receive at camp impacts you after you leave camp?

(Proceed to 18 a or 18b)

17a. If adolescent says “Yes”: How so? (Proceed to 18)

17b. If adolescent says “No”: Why not? (Proceed to 18)

18. PI: What activities at camp make you feel like people care about you?

19. PI: What activities at camp help you to learn more about your cancer diagnosis?

20. PI: Thanks so much for taking the time to participate in this interview. Is there anything would like to share that I did not ask about? (Proceed to 20a or 20b)

20a. If the adolescent shares more information: Thank you for sharing. (Proceed to 21)

20b. If the adolescent says “No”: Okay! (Proceed to 20)

20. PI: Once again, thank you for your willingness to participate. . Let’s go see what area of camp you’re supposed to return to! (End of conversation)

APPENDIX C. SOCIAL SUPPORT AND SELF-ESTEEM SURVEY

Thanks for your participation in this study! Please circle the answer that you feel describes your relationship the best. Remember: you can skip any question that you do not want to answer.

1. How close do you feel to your **mom**? (Please circle one answer)
 - a. Strongly Agree
 - b. Agree
 - c. Neither agree nor disagree
 - d. Disagree
 - e. Strongly Disagree

2. Most of the time, your **mother** is warm and loving toward you.
 - a. Strongly Agree
 - b. Agree
 - c. Neither agree nor disagree
 - d. Disagree
 - e. Strongly Disagree

3. You are satisfied with the way your **mother** and you communicate with each other.
 - a. Strongly Agree
 - b. Agree
 - c. Neither agree nor disagree
 - d. Disagree
 - e. Strongly Disagree

4. Overall, you are satisfied with your relationship with your **mother**.
 - a. Not at all
 - b. Very little
 - c. Somewhat
 - d. Quite a bit
 - e. Very much

5. How close do you feel to your **father**?
 - a. Strongly Agree
 - b. Agree
 - c. Neither agree nor disagree
 - d. Disagree
 - e. Strongly Disagree

6. Most of the time, your **father** is warm and loving toward you.
 - a. Strongly Agree
 - b. Agree
 - c. Neither agree nor disagree

- d. Disagree
 - e. Strongly Disagree
7. You are satisfied with the way your **father** and you communicate with each other.
- a. Strongly Agree
 - b. Agree
 - c. Neither agree nor disagree
 - d. Disagree
 - e. Strongly Disagree
8. Overall, you are satisfied with your relationship with your **father**.
- a. Not at all
 - b. Very little
 - c. Somewhat
 - d. Quite a bit
 - e. Very much
9. How much do you feel that your **friends** care about you:
- a. Not at all
 - b. Very little
 - c. Somewhat
 - d. Quite a bit
 - e. Very much
10. You feel close to people at your **school**. Last year, you felt close to people at your **school**.
- a. Strongly Agree
 - b. Agree
 - c. Neither agree nor disagree
 - d. Disagree
 - e. Strongly Disagree
11. You feel you are a part of your **school**. Last year, you felt like you were a part of your **school**.
- a. Strongly Agree
 - b. Agree
 - c. Neither agree nor disagree
 - d. Disagree
 - e. Strongly Disagree
12. You are happy to be at your **school**. Last year, you were happy to be at your **school**.
- a. Strongly Agree
 - b. Agree
 - c. Neither agree nor disagree
 - d. Disagree
 - e. Strongly Disagree

These questions are designed to measure what you are thinking at this moment. There is of course, no right answer for any statement. The best answer is what you feel is true of yourself at the moment. Please circle **one** answer.

1. I feel confident about my abilities.
 - a. Not At All
 - b. A Little Bit
 - c. Somewhat
 - d. Very Much
 - e. Extremely

2. I am worried about whether I am regarded as a success or failure.
 - a. Not At All
 - b. A Little Bit
 - c. Somewhat
 - d. Very Much
 - e. Extremely

3. I feel satisfied with the way my body looks right now.
 - a. Not At All
 - b. A Little Bit
 - c. Somewhat
 - d. Very Much
 - e. Extremely

4. I feel frustrated or rattled about my performance.
 - a. Not At All
 - b. A Little Bit
 - c. Somewhat
 - d. Very Much
 - e. Extremely

5. I feel that I am having trouble understanding things that I read.
 - a. Not At All
 - b. A Little Bit
 - c. Somewhat
 - d. Very Much
 - e. Extremely

6. I feel that others respect and admire me.
 - a. Not At All
 - b. A Little Bit
 - c. Somewhat
 - d. Very Much
 - e. Extremely

7. I am dissatisfied with my weight.
 - a. Not At All
 - b. A Little Bit
 - c. Somewhat
 - d. Very Much
 - e. Extremely

8. I feel self-conscious.
 - a. Not At All
 - b. A Little Bit
 - c. Somewhat
 - d. Very Much
 - e. Extremely

9. I feel as smart as others.
 - a. Not At All
 - b. A Little Bit
 - c. Somewhat
 - d. Very Much
 - e. Extremely

10. I feel displeased with myself.
 - a. Not At All
 - b. A Little Bit
 - c. Somewhat
 - d. Very Much
 - e. Extremely

11. I feel good about myself.
 - a. Not At All
 - b. A Little Bit
 - c. Somewhat
 - d. Very Much
 - e. Extremely

12. I am pleased with my appearance right now.
 - a. Not At All
 - b. A Little Bit
 - c. Somewhat
 - d. Very Much
 - e. Extremely

13. I am worried about what other people think of me.
 - a. Not At All
 - b. A Little Bit
 - c. Somewhat

- d. Very Much
 - e. Extremely
14. I feel confident that I understand things.
- a. Not At All
 - b. A Little Bit
 - c. Somewhat
 - d. Very Much
 - e. Extremely
15. I feel inferior to others at this moment.
- a. Not At All
 - b. A Little Bit
 - c. Somewhat
 - d. Very Much
 - e. Extremely
16. I feel unattractive.
- a. Not At All
 - b. A Little Bit
 - c. Somewhat
 - d. Very Much
 - e. Extremely
17. I feel concerned about the impression I am making.
- a. Not At All
 - b. A Little Bit
 - c. Somewhat
 - d. Very Much
 - e. Extremely
18. I feel that I a less educated right now than others.
- a. Not At All
 - b. A Little Bit
 - c. Somewhat
 - d. Very Much
 - e. Extremely
19. I feel like I'm not doing well.
- a. Not At All
 - b. A Little Bit
 - c. Somewhat
 - d. Very Much
 - e. Extremely
20. I am worried about looking foolish

- a. Not At All
- b. A Little Bit
- c. Somewhat
- d. Very Much
- e. Extremely

In answering the next set of questions, please think about your current relationships with your **friends**. If you feel a question accurately describes your relationships with your friends you would say “yes”. If the question does not describe your relationships, you would say “no”. If you cannot decide whether the question describes your relationships with your friends you may say “not sure”.

- 1) NO
- 2) SOMETIMES
- 3) YES

1. Are there friends you can depend on to help you if you really need it? _____
2. Do you feel you could not turn to your friends for guidance in times of stress? _____
3. Are there friends who enjoy the same social activities that you do?

4. Do you feel personally responsible for the well-being of your friends? _____
5. Do you feel your friends do not respect your skills and abilities? _____
6. If something went wrong, do you feel that none of your friends would come to your assistance? _____
7. Do your relationships with your friends provide you with a sense of emotional security and well-being? _____
8. Do you feel your competence and skill are recognized by your friends? _____
9. Do you feel none of your friends share your interests and concerns? _____
10. Do you feel none of your friends really rely on you for their well-being? _____
11. Is there a trustworthy friend you could turn to for advice if you were

having problems? _____

12. Do you feel you lack emotional closeness with your friends?

In answering the next set of questions, please think about your current relationships with your **parents**.

- 1) NO
- 2) SOMETIMES
- 3) YES

1. Can you depend on your parents to help you if you really need it?

2. Do you feel you could not turn to your parents for guidance in times of stress? _____
3. Do your parents enjoy the same social activities that you do?

4. Do you feel personally responsible for the well-being of your parents?

5. Do you feel your parents do not respect your skills and abilities?

6. If something went wrong, do you feel that your parents would not come to your assistance?

7. Does your relationship with your parents provide you with a sense of emotional security and well-being? _____
8. Do you feel your competence and skill are recognized by your parents?

9. Do you feel your parents do not share your interests and concerns?

10. Do you feel your parents do not really rely on you for their well-being? _____

11. Could you turn to your parents for advice if you were having problems? _____
12. Do you feel you lack emotional closeness with your parents?

Thanks for taking the time to fill out this survey 😊

APPENDIX D. STUDY 3, REGRESSION ANALYSES WITH LENGTH VARIABLE

	<u>Model 1</u>			<u>Model 2</u>			<u>Model 3</u>			<u>Model 4</u>		
	<u>Depression</u>			<u>Self-Esteem</u>			<u>Depression</u>			<u>Self-Esteem</u>		
	b	SE	β	b	SE	β	b	SE	β	b	SE	β
Social Support	.01	.14	0.32	-.02	.13	-.03	.01	.02	.04	.00	.02	.00
White	-.05	.13	-.06	-.10	.13	-.08	.01	.01	.01	.00	.02	.00
Female	.31	.14	.32*	-.17	.16	-.13	.01	.01	.01	.00	.01	.00
Parent Education	-.09	.13	-.01	.03	.17	.02	.01	.01	.01	.00	.02	.00
Age of Diagnosis	.05	.15	.06	.14	.15	.11	.01	.01	.01	.00	.01	.00
Length Between Waves	.01	.16	.06	.00	.12	.01	.01	.08	.08	.00	.12	.01
Social Support X Age of Diagnosis	--	--	--	--	--	--	.01	.04	.04	.00	.06	.00
R ²	.10			.10			.14			.12		
N	78			78			78			78		

Note. * $p < .05$. ** $p < .01$. *** $p < .001$. Gender: 1 = Female, 0 = Male; Race: 1 = White, 0 = Non-White; Parent Education: 0 = High School or Under, 1 = College and Above; Childhood = 0, Adolescence = 1.