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Transition Experiences of Adolescent Survivors of Childhood Cancer: A Qualitative Investigation

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Transition Experiences of Adolescent Survivors of Childhood Cancer: A
Qualitative Investigation

by

Alana D. Lopez

A dissertation submitted in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy
Department of Psychological and Social Foundations
College of Education
University of South Florida

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DEDICATION

The support and encouragement of many people were instrumental in the successful completion of this project. First, I would like to sincerely thank each adolescent who volunteered to be a part of this study. I appreciate your willingness to share your experiences and perspectives. You each provided a unique richness to this study and your contributions are invaluable to not only this study but to others. Your perspectives have truly inspired me to continue to ask critical questions and listen to the voices of those who have survived. I also would like to dedicate this project to my mother, father, and brother. Mom and Dad, you have truly been my greatest supporters throughout this entire process. I am forever grateful for your love, guidance, encouragement, and profound dedication to lifelong learning. You have inspired me to become a better person each day through hard work, perseverance, stamina, and a deeply rooted appreciation for life. You both lead by example in your personal and professional lives, which has taught me the importance and meaning of making a difference in this world no matter how big or small. Tony, I am very proud to be your sister and grateful to have you in my life. I truly appreciated your phone calls and words of encouragement and valued your unconditional support throughout this process. Last but certainly not least, I would like to express my deepest gratitude to my significant other, Andy. Andy, I am forever grateful for your love, unwavering support, and patience throughout my educational journey. You truly are a selfless individual who always has encouraged and

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ABSTRACT

Adolescent survivors of childhood cancer are a growing population with unique needs as they face a combination of challenges associated with normal development and returning to life after treatment completion (Wakefield et al., 2010). One specific need identified in the research literature includes the effective delivery of transitional care and planning (Hewitt, Greenfield, & Stovall, 2005). It has been suggested that the provision of transition care and planning can help facilitate the shift from one phase of care to another and promote positive transition experiences (National Cancer Institute, 2008). The shift from off-treatment to post-treatment and school reintegration have been identified in the literature as significant transitions for adolescent survivors of childhood cancer (Cabat & Shafer, 2002; MacLean, Foley, Ruccione, & Sklar, 1996). However, limited research has been conducted to explore these transitions from the perspectives of adolescent survivors of childhood cancer.

An exploratory, qualitative study was conducted with eight adolescent survivors of childhood cancer between the ages of 14 and 17. A multiple case study research design was used to explore adolescent cancer survivors' perceptions of these transition processes, challenges associated with these transitions, and their beliefs about what supports/services were or would be beneficial during these transitions. Data collected for analysis included questionnaires, transcribed interviews and follow-up meetings, direct observation, documents, and parent feedback. These data were analyzed using a

combination of a template organizing style, immersion/crystallization (I/C) approach, and multiple case study strategies (Borkan, 1999; Crabtree & Miller, 1999, Stake, 2005; Yin, 2008).

Results indicated that adolescents perceived that change was occurring on some level during the shift from off-treatment to post-treatment and school reintegration but did not necessarily define this time as a “transition.” They defined these times in personalized terms that reflected more subtle changes in their lives. The focus was placed on returning to a sense of “normalcy” and capitalizing on opportunities to regain some control over one’s life. The improvement and/or absence of treatment residuals along with re-engagement in activities and roles served as signs, or indicators, that life was returning back to “normal” and provided feedback to the adolescent on their transition progress. Conversely, the presence of these signs continued to impact their lives as they restricted participation in desired activities and served as reminders that the effects of cancer and treatment extended beyond treatment completion. In addition to the presence of treatment residuals, fear of relapse also was a concern associated with the transition from off to post-treatment. However, adolescents tended not to let this be the focus of their lives. School reintegration challenges included disruption of school life and routines as well as academic and social concerns. Academic challenges included falling behind/catching up with work, maintaining motivation to do work, and readjusting to school demands and routines. Social challenges included answering peer questions, adjusting to peer awkwardness/discomfort, and managing peer reactions to their physical side effects. These challenges were not perceived by adolescents as sources of significant

distress and, often times, they adapted and employed coping strategies to address these concerns in the school setting.

Adolescents also varied in their perceived need for transitional care and support during these transitions. Support received during the shift from off-treatment to post-treatment included advice from health care team members as well as relationships with peer cancer survivors across school, community, hospital, and camp settings. They received a variety of academic and social support during school reintegration. Teachers, family members, and peers provided academic support across home, hospital, and school settings. Teachers were a particularly important source of academic assistance. Accommodations and modifications also were provided to these adolescents at school. Peers, teachers, and other school staff provided social support. Based on the findings of the study, suggestions for future research and practical implications are offered.

CHAPTER 1: INTRODUCTION

Statement of the Problem

The overall five-year survival rate of childhood cancer has reached approximately 80% among children diagnosed between birth and 19 years of age (American Cancer Society, 2006; Reis et al., 2006). There are a growing number of childhood cancer survivors living in the United States due to advances in early detection and the use of improved cancer treatments (Hewitt, Weiner, & Simone, 2003). A report by the Centers for Disease Control and Prevention (CDC) (2004) indicated that approximately 79% of childhood cancer survivors will be living five years after diagnosis and 75% 10 years after diagnosis. National recognition and awareness of this increasing population has grown considerably over the past 15 years as well as the necessity to provide coordinated care to meet their specific needs and increase cancer survivorship research efforts (Reuben, 2004; Shapiro et al., 2009).

The term “childhood cancer survivor” includes those individuals who received a diagnosis of cancer at some point between birth and 19 years of age and survived the disease (Reis et al., 1999). A survivor may be a child, adolescent, young adult, or adult who successfully completed treatment during childhood. This study focused on adolescent survivors of childhood cancer. They are referred to as “adolescent cancer survivors” throughout this document. As the population of childhood cancer survivors continues to grow, it is likely there will be a number of survivors reaching adolescence

(Bauld, Anderson, & Arnold, 1998). Adolescent cancer survivors are a unique group of survivors because they face a combination of challenges associated with normal developmental changes and life after the completion of treatment (Bauld et al., 1998; Thomas, Seymour, O'Brien, Sawyer, & Ashley, 2006; Wakefield et al., 2010; Whyte & Smith, 1997).

There is national recognition that adolescent cancer survivors are an understudied population and that more research is warranted to identify their specific needs and concerns (Adolescent and Young Adult Oncology Review Group, 2006; Haase & Phillips, 2004; Hare, Hinds, & Stewart, 2004; Hewitt et al. 2003; Nelson, Haase, Kupst, Clarke-Steffen, & Brace-O'Neill, 2004; Reuben, 2004; Soliman & Agresta, 2008). A particular need identified in the literature is the delivery of effective transitional care for these individuals (Hewitt et al., 2005; MacLean et al., 1996; Reuben, 2004; Thomas et al., 2006). Transitional care bridges the gap between different phases of care (e.g., active treatment to off-treatment, off-treatment to post-treatment) (National Cancer Institute, 2008). Transitional care planning is important for adolescent cancer survivors because it can facilitate a successful shift from one phase of care to another, help reduce feelings of uncertainty and anxiety associated with making transitions, and promote positive long-term outcomes (Hewitt et al., 2005; Labay, Mayans, & Harris, 2004; MacLean et al., 1996; National Cancer Institute, 2008; Wilkins & Woodgate, 2006). To date, transitional care planning and few interventions are offered to adolescent cancer survivors (Labay et al., 2004). Furthermore, cancer survivorship clinics typically do not enroll individuals until many years after treatment has been completed (e.g., five years and beyond), which

can leave a gap in care during the first few years after treatment has been completed (Oeffinger, Nathan, & Kremer, 2010; Wakefield et al., 2010).

Two significant transitions identified in the literature include: (a) the shift from off-treatment to post-treatment; and (b) reintegration into the school setting (Cabat & Shafer, 2002; Katz, Rubenstein, Hubert, & Blew, 1988; Katz, Varni, Rubenstein, Blew, & Hubert, 1992; MacLean et al., 1996; Thomas et al., 2006). Preliminary research has shown that adolescent cancer survivors experience a wide range of emotions (e.g., fear, uncertainty, and excitement) and have concerns and unmet needs associated with these transition periods (Duffey-Lind et al., 2006; Haase & Rostad, 1994; Weekes & Kagan, 1994; Woodgate & Degner, 2004). Despite these findings, much of the research has focused on children and adolescents who are on treatment or long-term survivors while less attention has been given to those who have recently completed treatment and face the transition from being a cancer patient to cancer survivor (Wakefield et al., 2010). Therefore, more research is needed to gain an in-depth understanding of these transitions from the perspective of adolescent cancer survivors.

Transition from Off-Treatment to Post-Treatment

Research has shown that adolescent cancer survivors believe the transition from off-treatment to post-treatment is important and have expressed a need for information and supportive care during this time (Duffey-Lind et al., 2006). A milestone that initiates this transition is the successful completion of cancer treatment. The literature has revealed that cancer survivors perceive unique challenges associated with completing treatment. Challenges include worrying about symptoms that present after treatment, feeling uncertain about the future, fearing the possibility of relapse, being uncomfortable

with the removal of a predictable treatment schedule and interaction with health care providers, and redefining or reestablishing family roles and/or daily functioning (Arnold, 1999; Duffey-Lind et al., 2006; MacLean et al., 1996; Haase & Rostad, 1994; Woodgate & Degner, 2004). More specifically, adolescent cancer survivors are challenged to redefine what “being normal” means, regain a sense of normalcy, re-establish family and peer relationships, and cope with fears associated with follow-up procedures and relapse (Haase & Rostad, 1994; Weekes & Kagan, 1994). Some survivors may experience mixed feelings related to the completion of treatment (e.g., happy treatment is over but sad about decreased communication with health care providers) (Weekes & Kagan, 1994). Other survivors have expressed a sense of hope for the future, actively pursued setting personal goals, and committed themselves to re-engage in daily living activities (Haase & Rostad, 1994).

Although research has revealed that adolescent cancer survivors have needs and concerns associated with this transition, few interventions are offered during this time (Labay et al., 2004). A limited number of interventions have been proposed in the literature that may facilitate a smoother transition from off-treatment to post-treatment. Two interventions include a formal transition conference held after the completion of treatment and the development of a survivorship care plan (Beil et al., 2007; Earle, 2007; Hewitt et al., 2005; MacLean et al., 1996). Very little research has been conducted on these two interventions, and more information is needed to determine their feasibility, acceptability, and effectiveness (Earle, 2007). In summary, adolescent cancer survivors experience a wide range of emotions and perceive a need for support during the transition

from off-treatment to post-treatment. However, few interventions exist to help facilitate this transition process for adolescents.

School Reintegration

Another critical transition for adolescent cancer patients and survivors is reintegration into the school setting (Labay et al., 2004). This is considered an important transition period because attending school can play a large role in regaining a sense of normalcy for children, adolescents, and their families (Bessell, 2001; Haase & Rostad, 1994). Furthermore, it is recommended that children and adolescents return to school as soon as possible because it provides an opportunity to engage in age-appropriate activities (e.g., completing academic work, engaging in social interaction) (DuHamel, Redd, & Johnson-Vickberg, 1999; Katz et al., 1988; Lansky, Cairnes, & Zwartjes, 1983; Spinetta, 1982). School reintegration can be particularly important for adolescents because the school setting is a place where they can work toward achieving developmental tasks such as gaining autonomy and establishing peer relationships (Cabat & Shafer, 2002).

It is recommended that health care professionals, school personnel, and family members anticipate difficulties that may arise and plan early for a successful school reintegration (Deasy-Spinetta, 1993; Hewitt et al., 2003). A preventative approach can better prepare all parties to adapt and cope with the difficulties associated with cancer and treatment. This is important because research has shown that cancer and treatment can affect various areas related to school functioning including school attendance, academic instruction, neurocognitive functioning, academic performance, behavioral and socio-emotional functioning, and peer relationships (Bessell, 2001; Butler & Haser, 2006;

Glasson, 1995; McCaffrey, 2006; Searle, Askins, & Bleyer, 2003; Upton & Eiser, 2006; Vance & Eiser, 2002). Furthermore, research has revealed that childhood cancer survivors are at-risk for unfavorable educational outcomes including special education placement, retention, and lower educational attainment (Bessell, 2001; Brown et al., 1998; Mulhern, Wasserman, Friedman, & Fairclough, 1989; Peckham, Meadows, Bartel, & Marrerro, 1988).

Research also has shown that children, adolescents, mothers, and teachers each have unique concerns related to the school reintegration process. Children and adolescents were found to have concerns about changes in their physical appearance, falling behind in academic work, and managing peer relationships (Glasson, 1995; McCarthy, Williams, & Plumer, 1998). Mothers were primarily concerned with the physical well-being of their child/adolescent at school and teasing by peers, whereas teachers expressed concerns with school adjustment, peer acceptance, and their lack of knowledge about cancer and its impact in the school setting (McCarthy et al., 1998).

To address the potential impact of cancer in the school setting and concerns of children, adolescents, caregivers, and teachers, comprehensive school reintegration programs (Katz et al., 1988; Katz et al., 1992) workshops for classmates (Benner & Marlow, 1991), workshops for teachers (Baskin, Saylor, Furey, Finch & Carek, 1983), and social skills training interventions (Barakat et al., 2003; Varni, Katz, Colegrove, & Dolgin, 1993) have been developed and empirically evaluated. Research has shown that these interventions produced positive outcomes for children, adolescents, peers, and teachers (Katz et al., 1988; Prevatt, Heffer, & Lowe, 2000). Despite preliminary evidence of positive outcomes, this body of research is limited due to reliance on

anecdotal data to document outcomes and lack of a theoretical framework to guide the development and implementation of these interventions (Suzuki & Kato, 2003).

Furthermore, follow-up data are lacking to determine if increases in teacher and peer knowledge of cancer are sustained over time and if this knowledge is translated into actual behavior change in the school setting (Prevatt et al., 2000; Suzuki & Kato, 2003).

More recent interventions also have been developed by national organizations such as internet-based school reintegration curricula (Ishola, 2009).

In summary, reintegrating back into the school setting can provide adolescents with a sense of normalcy and an opportunity to master developmental tasks. Due to the potentially widespread impact of cancer in areas related to school performance, school reintegration planning should occur in advance to anticipate potential problems and address the concerns of adolescents, caregivers, and school personnel. Preliminary research has been conducted on school reintegration programs and interventions with promising outcomes. However, more rigorous research is needed in this area.

Summary of the Literature

There are a growing number of childhood cancer survivors living in the United States. Those childhood cancer survivors who are now adolescents (i.e., adolescent survivors of childhood cancer) have received increasing attention by national organizations and within the research literature. An emphasis has been placed on addressing their needs and concerns during transition periods. Two critical transition periods identified in the research literature include the shift from off-treatment to post-treatment and school reintegration. The provision of care during these times can facilitate a smoother transition process, reduce feelings of uncertainty and anxiety, and potentially

promote positive long-term outcomes. Unfortunately, transitional care planning and interventions are infrequently offered to adolescent cancer survivors and there are gaps in providing care across the cancer continuum. Furthermore, there is limited research exploring the transition experiences of these individuals. Although preliminary research has shown that adolescent cancer survivors have concerns associated with the transition from off-treatment to post-treatment and school reintegration, there is a need for an in-depth examination of these transitions from the perspectives of adolescent cancer survivors and the ways in which they can be supported during these times.

Conceptual Framework

Schumacher and Meleis (1994) presented a framework for conceptualizing transitions based on multiple reviews of the nursing literature. Wilkins and Woodgate (2006) adapted and extended this framework to pediatric oncology and, more specifically, to transition issues faced by siblings of children with cancer. This adapted framework was used to develop research questions, formulate case specific questions in the interview guide, and guide the data analysis process in order to obtain a greater understanding of the transition experiences of adolescent survivors of childhood cancer (Yin, 2008). The framework includes the following four components: (a) antecedents to transitions; (b) key attributes or characteristics of a transition; (c) consequences related to a healthy transition process; and (d) consequences related to an unhealthy transition process. Figure 1 provides an illustration of this conceptual framework.

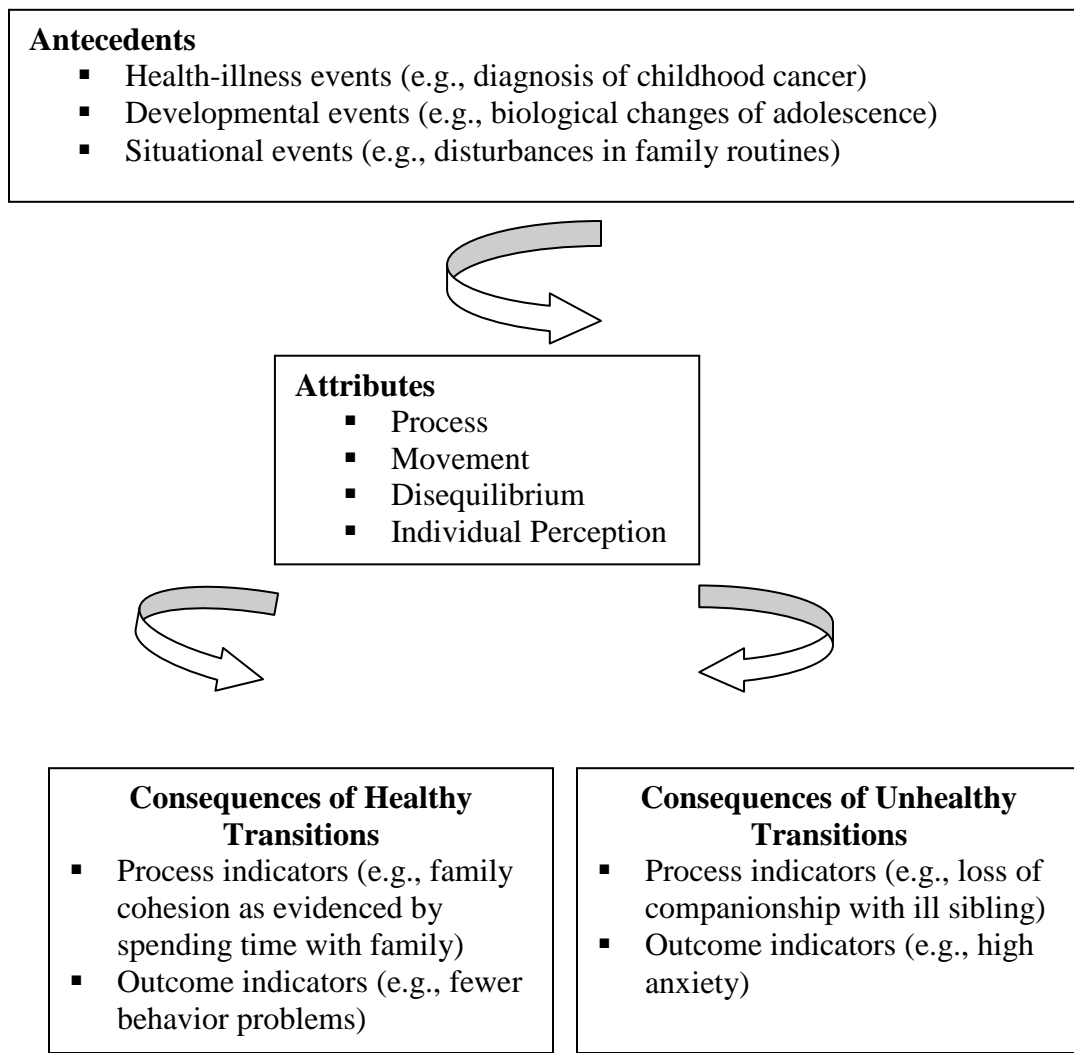


Figure 1. Illustration of Conceptual Framework. From “Transition: A Conceptual Analysis in the Context of Siblings of Children with Cancer,” by K. L. Wilkins and R. L. Woodgate, 2006, *Journal of Pediatric Nursing*, 21, p. 256- 265. Copyright 2006 by Elsevier Inc. Reprinted with permission.

Antecedents are conceptualized as events that initiate a transition process. Events can be categorized into health-illness, developmental, or situational domains (Chick & Meleis, 1986; Schumacher & Meleis, 1994). Developmental antecedent events include those brought on by biological processes and maturation such as experiencing body changes during puberty. Antecedent events related to health-illness can include initial

diagnosis, completion of treatment, or school reintegration for a child with chronic illness. Situational antecedent events such as changes in family routines or structure and separation from family members (e.g., physical or emotional separation) also can initiate a transition period. It is possible that multiple antecedent events can occur simultaneously and initiate one or more transitions. For example, an adolescent cancer survivor may undergo transitions initiated by both developmental and health-illness related events.

This framework also includes key attributes that define a transition. The defining attributes of a transition include: (a) process; (b) movement; (c) disequilibrium; (e) change; and (f) individual perception. A transition is considered a *process* as opposed to a one time static event that includes an entry into the transition period, passage through the transition, and an exit point. An individual navigate, or *move*, through this process and may experience *disequilibrium*. This state of disequilibrium can be characterized by feelings of uncertainty, confusion, or anxiety and make an individual feel unbalanced or outside of their “comfort zone.” When an individual experiences disequilibrium, s/he is challenged to actively respond, adapt, and experience change in order to restore a sense of balance in their lives. Finally, an *individual perceives* the transition experience in his/her own way, recognizes that some type of change is occurring, and assigns meaning to the transition experience (Schumacher & Meleis, 1994).

Lastly, this framework includes consequences associated with a healthy and unhealthy transition process. Certain types of indicators can be used to assess whether transitions are healthy or unhealthy in nature. Indicators can be observed both during (i.e., process indicators) and at the completion (i.e., outcome indicators) of the transition

process. Examples of process indicators associated with a healthy transition (i.e., signs that suggest an individual *is* successfully navigating the transition process) include an individual developing and utilizing coping skills to navigate the transition process or improvements in family communication. Outcome indicators related to a healthy transition (i.e., signs that suggest an individual *has* successfully navigated the transition process) can include adopting a new outlook on life or greater family cohesion. Process indicators related to an unhealthy transition (i.e., signs that suggest an individual *is not* successfully navigating the transition process) may include strained relationships with family members and/or friends or unfavorable changes in family routines. Examples of outcome indicators associated with an unhealthy transition (i.e., signs that suggest an individual *has not* successfully navigated the transition process) are decreased quality of life or a decline in school performance. Wilkins and Woodgate (2006) suggested that health care providers actively address the transitional needs and concerns of healthy siblings (and arguably adolescent cancer survivors) to promote healthy transitions.

Purpose of the Study

There is limited research examining the transition experiences of adolescent cancer survivors. Although preliminary research has been conducted in this area, more comprehensive and detailed information is needed to better understand the shift from off-treatment to post-treatment and school reintegration directly from the perspective of the adolescent cancer survivor. A qualitative research approach is deemed appropriate when there is little published research on a topic and exploratory research is needed to gain more insight into the topic (Creswell, 1998, 2003). Therefore, the purpose of this study was to conduct a qualitative investigation to examine adolescent cancer survivors'

experiences during the transition from off-treatment to post-treatment and school reintegration. Specifically, the study explored adolescent cancer survivors' perceptions of these transition processes, challenges associated with these transitions, and their beliefs about what supports/services were or would be beneficial during these transitions.

Research Questions

The conceptual framework by Wilkins and Woodgate (2006) was used to guide the development of the study and research questions. Two *health-illness antecedent events* of interest to this study were the completion of treatment and re-entering the school setting. These two events were conceptualized as initiating the following transition processes: (a) the shift from off-treatment to post-treatment; and (b) school reintegration. Due to the unique developmental changes associated with adolescence, it also is possible that adolescent cancer survivors would simultaneously undergo transitions triggered by *developmental antecedent events*. Regarding defining attributes of a transition, an emphasis was placed on gaining and in-depth understanding of adolescent cancer survivors' *individual perceptions* as well as the meanings they attached to the shift from off-treatment to post-treatment and school reintegration (Schumacher & Meleis, 1994). There also was an interest in learning more about the state of *disequilibrium* and *changes* made or experienced by an individual in response to the state of disequilibrium. Lastly, another interest included obtaining information on what supports and/or services did or may help adolescent cancer survivors experience a *healthy transition process*.

Research questions one through three focused on the transition from off-treatment to post-treatment. The interest in examining individual perceptions is reflected in

research question one. Research question two was created to learn about the disequilibrium and change experienced by adolescent cancer survivors. Finally, supports and/or services received or needed to facilitate a healthy transition process are highlighted in research question four. Research questions five through seven reflected the exact same interests as they pertain to school reintegration. The following research questions were used to generate information on these areas of interest:

1. How do adolescent survivors of childhood cancer perceive their transition from off-treatment to post-treatment?
2. What are the challenges faced by adolescent survivors of childhood cancer during the transition from off-treatment to post-treatment?
3. What are the beliefs of adolescent survivors of childhood cancer about the supports and/or services that were or would be beneficial during the transition from off-treatment to post-treatment?
4. How do adolescent survivors of childhood cancer perceive their school reintegration experience?
5. What are the challenges faced by adolescent survivors of childhood cancer during school reintegration?
6. What are the beliefs of adolescent survivors of childhood cancer about the supports and/or services that were or would be beneficial during school reintegration?

Definition of Terms

Childhood cancer survivor. A childhood cancer survivor is defined as an individual who received a cancer diagnosis at some point between birth and 19 years of age and survived the disease (Oeffinger et al., 2004; Reis et al., 1999).

Adolescent survivor of childhood cancer. An adolescent survivor of childhood cancer is defined as an individual between the ages of 12 and 17 who: (a) received a diagnosis of cancer during childhood; (b) completed treatment; (c) is in remission (i.e., absence of disease); and (d) has no history of relapse (i.e., the original disease has not returned and there is no new primary cancer) (Kazak et al., 2004).

Transition. According to Wilkins and Woodgate (2006), a transition is defined as, “a process that involves movement from a state of equilibrium to a state of disequilibrium and to a new state [of] equilibrium that results from siblings’ [or adolescent cancer survivors’] perception of change in themselves or in the environment” (p. 263).

Transition from off-treatment to post-treatment. The transition from off-treatment to post-treatment is defined as the time “from the completion of therapy to the first few years off of therapy” (Duffey-Lind et al., p. 336).

Transitional care. According to the National Cancer Institute (2008), the purpose of transitional care is to bridge the gap between phases of cancer care (e.g., off-treatment to post-treatment). The goal is to provide services to cancer patients and survivors with minimal disruption in care. Transitional care is typically provided when a patient's or survivor's treatment goals and/or location of care changes. Transitional care planning addresses current and/or anticipated problems, management of those problems, and strategies to reduce stress and improve quality of life outcomes.

School reintegration. School reintegration is a process during which school-aged cancer patients and survivors reestablish roles and relationships they had prior to initial diagnosis in an effort to continue to meet demands in the school setting (Labay et al.,

2004). An emphasis is placed on promoting positive academic, behavioral, and social outcomes for through targeted prevention and intervention efforts (Katz et al., 1988; Prevatt et al., 2000). For the purposes of this study, school reintegration applied to the following circumstances: (a) adolescent did not attend school during treatment and reintegrated on a full or half time basis after treatment was completed with clearance from medical team; or (b) adolescent was cleared by medical team to attend school during treatment, attended on an irregular basis, and returned to school for a full or half day after treatment was completed.

Organization of Remaining Chapters

The organization of the remaining chapters includes a review of literature, description of the methodology used in the study, results of the study, and a discussion of the findings. Specifically, Chapter Two includes a review of existing research relevant to the current study. Chapter Three includes a description of the research paradigm, research design, participants, instrumentation, data collection procedures, and data analysis. Ethical considerations, inclusion and exclusion criteria, and validity measures also are presented. Chapter Four includes demographic information, cancer histories or each participant, and the results of the cross-case analysis. Finally, a discussion of the results, limitations of the study, and future directions for research are presented in Chapter Five.

CHAPTER TWO: REVIEW OF THE LITERATURE

This chapter will review the literature on cancer survivorship and the transitions experienced by adolescent survivors of childhood cancer. Two transitions that are the main focus of this literature review are the transition from off-treatment to post-treatment and school reintegration. Research will be reviewed in the following areas: (a) childhood cancer survivorship; (b) adolescent survivors of childhood cancer; (c) transitional care and planning; (d) transition from off-treatment to post-treatment; and (e) school reintegration. Notably, the authors cited throughout this chapter operationalize “childhood cancer survivor” in different ways. In some studies, childhood cancer survivors are defined as those individuals who are currently undergoing treatment. Other studies defined these survivors as those who completed treatment and had no history of relapse. The former definition reflects existing definitions that define cancer survival as beginning at the time of initial diagnosis (Reuben, 2004). In order to minimize confusion, this author distinguished between those individuals undergoing active treatment as “cancer patients” and those who have completed treatment as “cancer survivors” throughout this chapter.

Childhood Cancer Survivorship

Advances in early detection and the use of improved treatments have increased the overall five-year survival rate of childhood cancer to approximately 80% among children from birth to 19 years of age (American Cancer Society, 2006; Reis et al., 2006).

One of the primary reasons for this improved overall survival rate is the successful treatment of childhood leukemia which accounts for approximately one-third of pediatric cancer cases (Reis et al., 1999). Consequently, there is a growing population of childhood cancer survivors. There are an estimated 270,000 survivors of childhood cancer living in the United States, and the number of cancer survivors is expected to continue to grow in the future (Hewitt et al., 2003).

Adolescent survivors of childhood cancer are the focus of the current study. Bauld et al. (1998) described these adolescent survivors of childhood cancer as those individuals who are “entering [or entered] adolescence either cured or in remission” (p. 120). Research will be reviewed to provide information on the unique experiences of this population that distinguishes them from the general population of childhood cancer survivors.

Adolescent Cancer Survivors

For the purposes of this study, the term “adolescent cancer survivors” will be used to refer to those adolescents who are survivors of childhood cancer. Adolescent cancer survivors have been identified as a unique subgroup of survivors who are a “new generation of cancer survivors” (Bauld et al., 1998, p. 120). They have to master specific development tasks associated with adolescence and simultaneously cope with the effects of cancer (Bauld et al., 1998; Thomas et al., 2006; Whyte & Smith, 1997). Erikson (1980) theorized that there are certain developmental tasks to be mastered throughout the lifespan. He proposed that one of the greatest tasks to be mastered during the adolescent period is to develop an identity and discover one’s place in the world. During this time, adolescents are challenged to figure out who they are and how they will represent

themselves in the world. Havighurst (1972) also identified specific developmental tasks of adolescence that include developing relationships with peers and individuals of the opposite sex, preparing for adulthood (i.e., marriage, career), achieving emotional independence from adults, developing social roles based on gender, accepting one's physical appearance, and developing a set of values and morals to guide one's own behavior. Adolescents are required to master such developmental tasks so that they can successfully function and adapt to their environment as well as prepare themselves to meet the expectations of adulthood (Bleyer, 2005). Mastery of these tasks is a challenge in of itself, and the presence of a stressor, such as a medical illness, may produce additional stress because the adolescent must meet a complex set of demands (e.g., adherence to treatment, dealing with the loss of some peer relationships while on treatment) (Bauld et al., 1998; Evan & Zeltzer, 2006; Palmer, Mitchell, Thompson, & Sexton, 2007). It is possible that mastering these developmental tasks and successfully adapting to various environments (e.g., home, school, and community) may be compromised by stresses and strains associated with cancer (Decker, 2007).

To illustrate this point, adolescents may have to compensate, or "catch up," as events associated with being on treatment may impede their developmental trajectory (Evan & Zeltzer, 2006; Jones, 2008). Events such as prolonged hospitalizations, receiving educational instruction outside of the school setting, and constant monitoring by caregivers and hospital staff can disrupt the course of normal development (Jones, 2008; Thomas et al., 2006). For example, prolonged hospitalizations can limit the opportunities an adolescent has to interact with age-appropriate peers. Late effects associated with cancer (e.g., social isolation, changes in physical appearance, lack of

confidence) also can delay the mastery of developmental tasks (Bauld et al., 1998). An adolescent who has experienced extreme changes in his/her physical appearance may be hesitant to approach or interact with peers and may not benefit from opportunities to practice relationship building skills. These examples illustrate the potential interaction between developmental level and cancer.

In summary, there are specific developmental tasks that adolescents are expected to master. Adolescent cancer survivors are unique because they are not only challenged to master these tasks but also cope with the effects of cancer. The next section will highlight the nationally recognized need for transitional care and planning for all cancer survivors including adolescent cancer survivors. Additionally, barriers associated with transitional care and planning are presented.

Recognized Need for Transitional Care and Planning

A number of national organizations including the President's Cancer Panel, Lance Armstrong Foundation, American Society of Clinical Oncology, Institute of Medicine, American Cancer Society, and National Cancer Institute have advocated for the needs of all cancer survivors. Transitional care and planning is one need that has recently been identified on a national level. For example, the Institute of Medicine released the report titled *From Cancer Patient to Cancer Survivor: Lost in Transition* in 2005. This report highlighted the need for transitional care and planning to promote positive outcomes for patients and survivors as they shift from one phase of care to another (Hewitt et al, 2005). The National Cancer Institute (2008) specifically identified transition periods as bridging the gap between different phases of cancer care. During these transitions periods, cancer survivors are challenged to utilize both internal and external resources to meet the

demands of the current phase of care (e.g., active treatment), deal with the approaching phase (e.g., being off-treatment), and navigate entrance into a new phase with its own unique set of challenges (MacLean et al., 1996). Due to the complexity of the transition process, it has been recognized that transitional care is important to facilitate a successful shift from one phase to another (National Cancer Institute, 2008). Despite this recognized need, the report concluded that there is a lack of coordinated transitional care and planning received by cancer survivors. The report devoted special attention to the transition from off-treatment to post-treatment and the lack of coordinated guidance and care delivered during this critical transition. Although the focus of this report was on adult cancer populations, these findings can provide insight into the state of transitional care for adolescent cancer survivors.

Barriers associated with transitional care and planning. Potential barriers have been identified that may offer insight into the lack of transitional care and planning received by cancer survivors (MacLean et al., 1996). One possible barrier includes lack of understanding by health care providers that transition times are a critical time in the lives of cancer patients and survivors that need to formally be addressed. There may be a misconception by health care professionals and the general public that patients will commence with their previous lives and return to normal once treatment has ended (Labay et al., 2004). Other barriers include lack of reimbursement for transitional services and lack of education and awareness of community health care providers about what is needed during this time to reintegrate patients into community-based settings (e.g., schools) (Duffey-Lind et al., 2006; Eiser et al., 2007). An additional barrier may be associated with the type of treatment setting. Those adolescent cancer survivors who

received treatment at established institutions with comprehensive cancer programs may obtain more effective transition care as compared to those attending smaller institutions with fewer resources (MacLean et al., 1996).

Several recommendations have been offered to improve transitional care and address these potential barriers (Hewitt et al., 2005). One recommendation is to provide cancer survivors with a survivorship care plan to help them navigate the transition process. Other suggestions include developing measures to monitor the type and quality of care received, providing health care professionals with training at the pre-service and in-service level, and advocating at federal and state levels for cancer survivors to have access to adequate health insurance that covers transitional care and other types of survivorship care. These recommendations have the potential to facilitate a successful shift from one phase of care to another for cancer patients and survivors.

The next section will discuss the shift from off-treatment to post-treatment and school reintegration (Katz et al., 1988; Hewitt et al., 2003; MacLean et al., 1996). Prior to the discussion of these transitions, it is important to note that this researcher makes a distinction between *events* that initiate, or mark the beginning, of a transition and the actual *process* of going through a transition. As described in the conceptual framework section in Chapter One, the two health-illness antecedent *events* of interest to this study are the *completion of treatment* and *re-entering the school setting*. These two events are conceptualized as initiating the actual *transition process* from off-treatment to post-treatment and reintegrating back into the school setting. For example, the completion of treatment is a particularly important milestone because it initiates the transition from off-treatment to post-treatment (MacLean et al., 1996; National Cancer Institute, 2008).

Although a distinction is made between an event and process for the purpose of the current study, the research presented on these transitions does not clearly distinguish between the two. The majority of the studies presented in the next section emphasize treatment completion while only one study clearly specified that the purpose was to investigate the transition from the completion of treatment to the first few years off treatment (Duffey-Lind et al., 2006).

Transition from Off-Treatment to Post-Treatment

The completion of cancer treatment has been characterized by feelings of uncertainty about the future, fear of reoccurrence, lack of structure due to the removal of a predictable treatment schedule and interaction with health care providers, redefining or reestablishing family roles, and resuming daily life activities (Decker, 2007; Haase & Rostad, 1994; Hewitt et al., 2005; MacLean et al., 1996). Cancer survivors may feel lost during this time when treatment is completed and may fear what the future will bring (Karahalios et al., 2007; Sloper, 2000). Additionally, they are often times challenged to return to their previous routines and roles in the family and reintegrate into community settings (Labay et al., 2004). One issue that is particularly salient to adolescents recently completing treatment is determining the type and amount of responsibility they will have over their lives as survivors. This may require parents and adolescent survivors to negotiate how much responsibility will be taken by the adolescent. Labay et al. (2004) also identified the removal of support from healthcare professionals (e.g., pediatric oncologist, nurses, psychosocial support staff) as an important issue to consider because it may evoke anxiety. Cancer survivors and their families may be accustomed to relying on healthcare professionals during treatment. The once constant flow of information

between patient and their medical team is likely to decrease when treatment ends. It is possible that cancer survivors and their families may experience feelings of abandonment as attention is withdrawn and given to families in need of immediate care. Furthermore, caregivers may be anxious about handling their child's health in the future and feel ill prepared to successfully navigate this transition. As a result of these multiple challenges, continued research efforts are warranted to examine this transition period, and intervention efforts are needed to facilitate a smooth transition and reintegration process for cancer survivors and their families. To date, only preliminary research has been conducted on the completion of treatment and the process of transitioning from off-treatment to post-treatment.

The following studies examined the completion of cancer treatment from the perspective of cancer survivors. Arnold (1999) conducted a descriptive and exploratory study on the experiences of seven Caucasian female cancer survivors aged 46 to 62 years who recently completed treatment. The mean time since completion of treatment for these participants was two to 19 months. These survivors were recruited from the Southeast region of the United States. Participants completed a questionnaire and were asked the following question: "Some women have said that they experience distress when their treatment is over. They have said that they feel frightened to be left without the 'safety net' of treatment. Since you completed treatment, have you ever felt this way?" A content analysis of the responses revealed that fear of relapse was one of the most frequently reported concerns. The removal of formal treatment and constant supportive care was perceived as a frightening aspect of completing treatment. Participants also indicated that they became very sensitive to minor aches and pains and

became worried that these might be signs of reoccurrence. Furthermore, the anticipation of follow-up visits evoked anxiety for many of these women. Overall, many respondents perceived that the “safety net” disappeared as the supportive, treatment-focused environment was no longer a constant in their lives. The author suggested that services (e.g., support groups, psychoeducation, and access to community services) should be available and utilized during this transition period.

This study found that the completion of treatment is a time characterized by unique challenges and concerns. Participants experienced a wide range of feelings and uncertainty for the future. Arnold (1999) indicated that “rather than turning patients loose into what one might believe is a world of newfound freedom from the limitations of cancer treatment, one must consider that the cessation of treatment is also a period that breeds fear and uncertainty” (p. 34). Therefore, it was suggested that cancer survivors would benefit from targeted support as they finish treatment and embark on the transition from off-treatment to post-treatment. Although this study focused on adult cancer survivors, these findings have potential to inform research and practice related to adolescent cancer survivors.

Haase and Rostad (1994) conducted a descriptive, phenomenological study to examine the experiences of seven children and adolescents ages five to 18 years who completed cancer treatment within the past year. The mean age of the participants was nine years old. Two participants were Hispanic and five were Caucasian. All children were recruited from a pediatric oncology program located in the Southwestern United States. Participants were interviewed to gain greater understanding of their experience completing cancer treatment. One of the interview questions included: “Please tell me

what it was like for you when you finished all of your treatments for cancer and you no longer needed to come to the clinic for treatments. Tell me everything you can remember happening and everything you thought and felt about it” (p. 1484). Interview data yielded the following five themes: (a) “gradual realization of completion;” (b) “hierarchical and cyclical recurrence [of] fears;” (c) “completion embedded within the cancer experience;” (d) “seeking a new normal;” (e) “modifying relationships;” and (f) “resolution and moving on” (p. 1486).

The “gradual realization of completion” theme revealed that these children and adolescents felt disbelief, happiness, and excitement when they found out treatment was ending. Participants wanted to know exactly what ending treatment meant and wanted to gain a better understanding of why they had checkups after treatment (e.g., blood work). They recognized signs, or cues, that strengthened their belief that treatment was over. Some signs included no more medications or hospitalizations, checkup appointments that did not involve treatment, and increased energy level. Negative aspects of completing treatment also were identified. These included less attention from parents and parental expectations to become more independent.

The second theme, “hierarchical and cyclical recurrence fears,” illustrated that participants had a constant, underlying fear that cancer might return and could not imagine going through treatments all over again. One participant shared, “I worry about having cancer, having to go through all that stuff one more time, which I don’t think I can handle, so, I’m not even going to try” (p. 1487). Participants’ worry diminished over time, but certain events triggered anxiety (e.g., follow-up appointments). In some instances, participants indicated that they preferred not to think or talk about the

possibility of reoccurrence whereas others felt comfortable but limited how much they thought about it.

The “completion embedded within the cancer experience” theme revealed that participants described not only completion of treatment but their entire cancer experience. They detailed salient aspects of their experience including receiving treatments, missing school, struggling to cope with cancer, and dealing with long-term effects of treatment. Participants indicated that certain reminders (e.g., scars, follow-up procedures) triggered unpleasant feelings associated with cancer and treatment. The fourth theme, “seeking a new normal,” revealed that participants desired to return to “normal,” everyday functioning both at home and school. They looked for signs of normalcy and were challenged to re-evaluate their current health status and redefine what it meant to be “normal.” Friends, family members, and the community were all sources of support that helped some of these individuals regain that sense of normalcy.

Another theme, “modifying relationships,” revealed that life after treatment required participants to modify and reassess relationships with health care professionals, family members, and friends. They wanted to continue relationships with their healthcare providers because they were a source of comfort, stability, and support. One participant indicated, “It kinda makes me feel better when I go [to clinic], because I know that if anything happens ever again that they’re still here to kinda support it” (p. 1489). Participants also reflected on the sacrifices their family had made and were appreciative of all their help and support. They attempted to normalize their relationships with their parents and siblings as many family dynamics had changed during treatment. For example, differential attention was given to the ill child and healthy sibling, and parents

modified rules to accommodate the child with cancer. Lastly, the theme “resolution and moving on” revealed that these individuals adopted a positive outlook on life after the completion of treatment and looked forward to planning for the future. Older participants embraced the completion of treatment as a time to improve themselves and work toward their personal goals.

In summary, participants perceived many challenges associated with completing treatment such as regaining a sense of normalcy, re-establishing relationships with family and friends, and coping with fears. They also expressed a sense of hope for the future as they set personal goals and made an active effort to return to everyday living. Haase and Rostad (1994) concluded that “the experience of completing cancer treatment has two faces—one of celebration and hope, and one of uncertainty and fear” (p. 1490). It was recommended that health care professionals recognize both positive and negative feelings associated with completing treatment and offer interventions to those child and adolescent cancer survivors who may be distressed.

Weekes and Kagan (1994) conducted a descriptive and exploratory longitudinal study investigating the experiences of 13 children and adolescents at three to six months before completion of treatment, at completion of treatment, three months post-treatment, and six months post-treatment. Participants were between the ages of eight and 18 years. The mean age of the participants was 12 years. No information was reported on the ethnic background of the participants. Participants were recruited from pediatric oncology clinics located in San Francisco and British Columbia. Data were collected using semi-structured interviews at all four phases of data collection. Many themes emerged from the interview data. However, results specific to the following time periods

will be reviewed: (a) at completion of therapy; (b) three months post-treatment; and (c) six months post-treatment. Findings indicated that adolescents perceived both negative and positive aspects of completing treatment. Difficulties associated with the completion of treatment included returning to a normal daily schedule (e.g., attending school), receiving less attention from healthcare professionals, and adjusting to increased parental monitoring of peer activities. Positive aspects included greater family cohesion, reduced risk-taking behavior, ability to participate in activities with friends and family, and less time at the hospital undergoing invasive procedures. Additionally, some adolescents reported having mixed feelings about certain aspects of completing treatment. For example, although there was minimal contact and communication with familiar health care professionals this also meant fewer hospital visits and procedures.

A prominent finding was that adolescents wanted to get back to a normal life and participate in activities that were restricted during treatment. They indicated that their parents also wanted them to return to a normal life (e.g., expecting them to do the chores). Lastly, these adolescents utilized coping strategies after the completion of treatment. Strategies included negotiation, seeking support from others, and positive thinking. For example, they negotiated with their parents about engaging in certain activities (e.g., what chores to do around the house, when they could go out with their friends). These adolescents also relived their cancer experience through volunteering and talking with others coping with cancer and tended to focus on the positive aspects of their own cancer experience.

These findings provide additional support for the idea that there are both positive and negative aspects associated with the completion of treatment. A unique finding

included that these adolescents experienced mixed feelings about certain aspects of finishing treatment and moving on with their lives. Furthermore, returning to normalcy was a prominent theme found in this study. This finding also is consistent with previous research (Haase & Rostad, 1994). Lastly, coping strategies were utilized after treatment to cope with parental expectations as well as their own personal issues related to their cancer experience.

Palmer et al. (2007) examined the physical and psychosocial needs among adolescent and young adult cancer patients and survivors in Australia. Participants included six individuals (one receiving cancer treatment, five completed treatment) with a mean age of 20 years who were diagnosed between the ages of 14 and 21 years and were an average of three years post diagnosis. A two hour focus group was conducted with the participants and data were analyzed within the grounded theory framework. Analysis yielded three overarching categories including information provision, treatment processes, and survivorship. For the purpose of the current study, the survivorship category will be reviewed. The themes of “finishing treatment”, “ongoing health concerns”, and “future directions” emerged from the survivorship category (p. 129). The theme “finishing treatment” revealed that participants had psychological difficulties after completing treatment yet few resources to access for help. They expressed that there was an abrupt loss of support and care after treatment was completed. For example, one participant said, “Everything is related to getting better but not past that point...There is no one there to look after you after that.” (p. 131). Another participant indicated, “They’ve cured you of having cancer so everything else is now irrelevant.” (p. 131). Participants also reported having fears of reoccurrence, especially prior to clinic follow-

up appointments and associated procedures. The second theme, “ongoing health concerns”, indicated that participants believed they were not as healthy as they were prior to being diagnosed with cancer (e.g., increased fatigue, greater propensity to become sick). They were unsure of who and where to discuss these concerns or where to obtain answers to their questions. The last theme of “future directions” revealed that participants felt that the intensity of their cancer treatment had an adverse impact on their ability to finish school, obtain/maintain employment, and become/remain independent, which in turn created uncertainty about their future. For example, one participant shared, “I was sort of young when I got sick and it’s made it harder for me to get a job now...like to go and have no experience.” (p. 132). In summary, these adolescent and young adult survivors expressed a variety of concerns associated with life after treatment. Concerns such as abrupt removal of support after treatment was completed despite psychological concerns, informational needs directly related to their physical health as a survivor, the ability to gain/maintain independence, and the desire to reintegrate into environments that foster a sense of independence (e.g., school, work) were identified by these participants. Although this study was conducted outside of the United States, the findings can provide insight into concerns and needs associated with the completion of treatment and transition from off-treatment to post-treatment.

The following study describes the impact of cancer symptoms on the family after the completion of treatment. Although this study focuses on the family, it can provide additional insight into the transition from off-treatment to post-treatment. Woodgate and Degner (2004) conducted a longitudinal investigation to explore the impact of cancer symptoms from pre-diagnosis to post-treatment on the lives of 39 children and

adolescents with cancer as well as their parents and siblings. A combination of grounded theory and narrative qualitative approaches were used to investigate the experiences of these families. Participants ranged in age from four to 18 years with a mean age of 10 years. Most participants were diagnosed with leukemia or lymphoma. The majority of families were Caucasian and resided in both urban and rural areas in Canada. Data collection methods included in-depth interviewing with individual family members and the entire family, observations, and narrative writing. Data were collected between July 1998 and December 2000.

Results indicated that changes in cancer symptoms represented transition periods and were considered “major rough spots” in the lives of these families (p. 360). The “cancer symptoms transition periods” closely corresponded to different phases of cancer including pre-diagnosis, initial diagnosis, active treatment, and post-treatment (p. 358). Symptom transition periods were labeled as the following: (a) “it is just the flu...;” (b) “it is more than the flu;” (c) “it hits home;” (d) “it is nasty;” (e) “it is not so bad;” (f) “it is dragsville” (p. 362-363). Findings related to the symptom transitions experienced after the completion of treatment will be presented.

The “it is just the flu...” transition period was experienced during post-treatment. At post-treatment, families believed that symptoms were associated with cancer but perceived them as normal and to be expected (e.g., “feeling sick”). However, these symptoms served as a constant reminder of the cancer. Families began to regain a sense of normalcy but did not take symptoms for granted as they did prior to initial diagnosis. The “it is more than the flu” transition period included families realizing that the symptoms were not a normal part of growing up and that they were associated with

something far more serious. When there was a chance of a relapse during active and post-treatment, families perceived cancer symptoms as serious and indicative of a “warning sign” or “comeback symptoms” of cancer (p. 362). At this time, families were fearful of a relapse and the possibility that the ill child might not recover. The transition period “it is dragsville” also was associated with post-treatment when the child was in remission. During this time, dealing and coping with symptoms became tiresome and difficult. Symptoms remained after the completion of treatment and served as reminders that life was limited by having to constantly deal with the aftermath of cancer and its treatment. Families described being “prisoners of the symptoms” and believed that they received limited social support from friends and felt isolated during this time (p. 365).

In summary, this study revealed that changes in symptoms experienced by the child with cancer represented transition periods for the entire family. These symptom transition periods also corresponded with different phases of cancer (e.g., pre-diagnosis, active treatment, post-treatment). Findings were specifically presented on three cancer symptom transition periods associated with post-treatment. At post-treatment, symptoms were perceived in a variety of ways including relatively normal and expected (“it is just the flu”), serious because they may be associated with relapse (“it is more than the flu”), and tiresome as they lingered beyond treatment (i.e., “it’s dragsville”). Symptoms served as constant reminder of cancer, and families no longer took them for granted. Fear of relapse was a significant concern as families were worried that symptoms may be indicative of a relapse. Symptoms that lingered after treatment were perceived as difficult to cope with and reminded families that life was not yet back to “normal.” Although findings were presented for post-treatment, these symptom transition periods were

experienced at other cancer phases (e.g. pre-diagnosis, in between treatments). This suggests that changes in cancer symptoms can play an important role in defining transition periods as well as facilitating or impeding the transition process. Therefore, it is important to examine both cancer symptoms and phase of care to determine the overall impact of cancer on the cancer patient/survivor, individual family members, and the entire family.

The following study specifically examined the transition from off-treatment to post-treatment. Duffey-Lind et al. (2006) conducted a qualitative pilot study to investigate the experiences of adolescent cancer survivors (n= 4), young adult survivors (n= 14), parents (n= 7), and community-based primary care physicians (n= 3) during the transition from off-treatment to post-treatment. The authors defined this transition as “a new phase of care or coming off treatment” and “from the completion of therapy to the first few years off of therapy” (p. 336). Adolescent cancer survivors were between the ages of 14 and 18 years. They were off treatment between one to five years with a median of two years. The median age of young adult cancer survivors was 24.5 years, and they were off treatment for at least one year. The median years off treatment for the young adult participants were 11. The majority of adolescent and young adult cancer survivors were female and Caucasian. Data collection methods included focus groups with adolescent and young adult cancer survivors and their families as well as individual semi-structured interviews with primary care physicians. Analysis of the data revealed six themes: (a) “current health status;” (b) “knowledge and anticipating late effects;” (c) “impression of primary care physicians’ knowledge;” (d) “post-treatment emotions and experiences;” (e) “difficulties after completing therapy;” and (f) “strategies for easing the

transition” (p. 338-340). Findings related to adolescent and young adult cancer survivors and their families will be highlighted.

The “current health status” theme revealed that adolescent cancer survivors did not readily discuss issues related to the possibility of reoccurrence and late effects. However, parents outwardly expressed concern for the possibility of relapse. Adolescents also reported less participation in risky behaviors (e.g., drinking and driving) after treatment was completed. The “knowledge and anticipating late effects” theme suggested that many adolescent and young adult cancer survivors had limited knowledge of late effects. Notably, some of the participants did express an understanding of late effects. Young adult survivors believed that they were not equipped with the appropriate information about late effects. Parents also reported limited knowledge of the purpose of diagnostic testing as well as post-treatment issues such as late effects. Young adults and parents indicated that medical professionals, educational materials (via internet or paper form), and verbal communication about late effects were all helpful ways to gain knowledge. Regarding perceptions of primary care physicians’ knowledge, all parties perceived that physicians had limited knowledge of late effects. This was especially true for young adult cancer survivors who believed they were more knowledgeable about late effects and the type of care they needed than their primary care physicians. Adolescent cancer survivors indicated that they felt comfortable addressing follow-up concerns with their oncologists because they were perceived to be more knowledgeable than other types of health care providers (e.g., primary care physicians, nurses).

The “post-treatment emotions and experiences” theme revealed that adolescent cancer survivors felt in limbo as they attempted to regain a sense of normalcy and

reintegrate into the school setting. Others reported feeling relieved because they no longer had to undergo treatment and had shorter hospital visits. Young adult cancer survivors believed it was difficult to make this transition and that structured care was no longer available (e.g., regular appointments, regimented treatment schedule). This lack of structure evoked feelings of fear and uncertainty. One young adult survivor expressed, “And it was kind of scary in a sense of like, ok, here I’ve had to be watched so carefully, and then all of a sudden, you’re free, you can do whatever sort of thing, and that was really kind of scary” (p. 339). Parents expressed that they were worried about the possibility of relapse and experienced stress during follow-up appointments.

The “difficulties after completing therapy” theme revealed that participants felt unsupported and isolated during this time. Both adolescent and young adult cancer survivors reported that there was a lack of information provided which made the transition from off-treatment to post-treatment difficult. Another challenging transition specifically noted was school re-entry for survivors, and in particular, reintegrating with peers. Lastly, the “strategies for easing the transition” theme revealed that adolescent and young adult cancer survivors believed that certain supports would have made the transition process easier. Supports identified included written and electronic information about treatment and medications, psychosocial support, and help facilitating the school re-entry process. Interpersonal supports included meeting/talking with other survivors in group and one-on-one settings, engaging in dialogue with medical personnel, and having access to support groups.

Overall, the findings of this study suggest that the transition from off-treatment to post-treatment is a critical time period for adolescent and young adult cancer survivors.

There are unique challenges associated with this transition that include regaining a sense of normalcy, reintegrating into the school setting, and navigating the new territory of survivorship. Survivors expressed that they would have liked more information about late effects and more options to access psychosocial support during this time. Survivors identified specific types of transitional care support that would have been beneficial during the transition from off-treatment to post-treatment.

In conclusion, research has been conducted on the experience of completing treatment and the transition from off-treatment to post-treatment from the perspectives of children, adolescents, young adults, and caregivers. Research has found that this is a unique transition period characterized by feelings of uncertainty, worry about future health status, fear of relapse, removal of predictable routines and support, a desire to regain a sense of normalcy, and concern with gaining or maintaining independence. It also was shown that the family unit can be significantly impacted at the completion of treatment and beyond. Another significant finding was that children and adolescents experienced positive, negative, and mixed feelings associated with the completion of treatment. Furthermore, adolescent and young adult cancer survivors expressed interest in having more information and access to support during the transition from off-treatment to post-treatment. Specific types of transitional support also were identified.

Proposed Interventions to Facilitate the Transition from Off-Treatment to Post-Treatment

Despite research indicating that adolescent cancer survivors have needs and concerns associated with the transition from off-treatment to post-treatment, limited transitional care planning and few interventions are offered during this time (Labay et al.,

2004). However, some interventions have been proposed in the literature to address this particular transition. One intervention identified in the literature is a formal transition conference held after the completion of treatment. This transition conference is beneficial because it can serve as a cue, or reminder, to health care professionals and cancer survivors that a formal transition is taking place that deserves an organized response. Specifically, the purpose of this conference is to provide closure and a sense of direction for cancer survivors and their families (MacLean et al., 1996). The conference has many goals which include: (a) acknowledging any worries, fears, or concerns the family may have about ending treatment; (b) providing a summary of active treatment; (c) offering the opportunity for families to ask questions and/or discuss issues pertinent to treatment or post-treatment; (d) introducing (or reintroducing) the ideas of late effects and the possibility of reoccurrence; (e) discussing the importance of quality of life and assess current functioning; and (f) preparing families for any changes in communication and care (e.g., transition from oncologist to primary care physician). It is recommended that physicians, nurses, social workers, psychologists, or any other individuals who play an important role in the cancer patient's current or future care attend this conference. Patients should be given a written summary of their cancer and treatment history (e.g., data of diagnosis, place of treatment, type of treatment received, major treatment complications) as well as a follow-up plan to provide them with a sense of direction for the future. Lastly, it may be beneficial to offer patients the names and contact information of organizations that could provide additional support (e.g., psychological services, community programs) (MacLean et al., 1996).

Another proposed intervention to facilitate the transition from off-treatment to post-treatment includes providing cancer survivors with a survivorship care plan (Beil et al., 2007; Earle, 2007). The Institute of Medicine's (IOM) report *From Cancer Patient to Cancer Survivor: Lost in Transition* specifically recommends that these plans be created for survivors to facilitate this particular transition and guide subsequent follow-up care (Hewitt et al., 2005). According to the report, essential elements of a survivorship care plan should include information on cancer type and treatment, possible late effects, type and frequency of recommended surveillance and follow-up, prevention practices/recommendations (e.g., smoking cessation, nutrition, and exercise), legal protections related to employment and health insurance, and psychosocial services in the greater community. It is recommended that this survivorship care plan be reviewed in detail with the patient and family during a formal meeting (e.g., such as in a transition meeting described above) and periodically updated. Beil et al. (2007) suggested that patients specifically ask for a survivorship care plan and use it to navigate their way through survivorship. For example, patients could give their survivorship care plan to their primary care physician so he or she will be informed of their cancer history and treat accordingly. The survivorship care plan also is seen as a tool that can empower patients and families to guide their own treatment and be as informed as possible.

It has been nationally recognized that survivorship care plans have the potential to benefit cancer survivors (Hewitt et al., 2003; Hewitt et al., 2005). However, there is limited empirical data to support their creation and/or implementation (Earle, 2007). Earle (2007) raised important issues related to the development and standardization of survivorship care plans. Currently, there is no standard form to guide their development,

and no consensus has been reached pertaining to content, format, and detail.

Furthermore, the development of these plans would be time consuming and physicians would need to be reimbursed for the time it would take to gather pertinent information and develop the plan (Hede, 2006). More research is needed to determine essential elements of survivorship care plans, whether targeted plans are needed for specific cancer populations, and which professionals would be optimal to share such information with patients/survivors (Earle, 2007).

Research on survivorship care plans has just recently emerged. For example, Hewitt, Bamundo, Day and Harvey (2007) investigated the acceptability and feasibility of survivorship care plans among cancer survivors, nurses, primary care physicians, and oncologists. Focus group and interview data indicated that all parties felt survivorship care plans would be beneficial for survivors. Primary care physicians felt that the plans would help inform their survivorship care practices, and nurses reported that they could play an important role in the development and implementation of the plans. Oncologists believed survivorship care plans would be helpful but reported they would be time consuming to develop considering other paperwork they have to complete. Despite the perceived benefits associated with survivorship care plans, preliminary research has shown that few childhood cancer survivors received a written summary of their diagnosis and treatment (Kadan-Lottick et al., 2002). Overall, more research is needed to provide a more solid empirical justification to adopt the development and dissemination of survivorship care plans (Hede, 2006; Hewitt & Ganz, 2007).

Transition from Off-Treatment to Post-Treatment: Limitations of the Research

There are a number of limitations to the existing research related to the transition from off-treatment to post-treatment. First, little research was found that examined the experiences of adolescent cancer survivors during the completion of treatment and the transition from off-treatment to post-treatment. Furthermore, many of the existing studies did not focus solely on the experiences of adolescents. These studies investigated multiple populations within the same investigation (i.e., children, adolescents, young adults, and family members) as opposed to targeting only the perspectives of adolescents. Second, a majority of these studies did not make a clear distinction between completion of treatment and the transition process of shifting from off-treatment to post-treatment. Furthermore, these studies did not explore the potential connections or relationships between treatment completion and the subsequent transition experience. Therefore, it is difficult to acquire a greater understanding of the transition process itself and distinguish key features of this particular transition.

Third, there is a lack of information regarding the positive and negative indicators and outcomes associated with the transition from off-treatment to post-treatment. Arguably, these are important concepts to explore as they can provide information that can be used to advocate for the need of transitional care as well as guide transitional care planning. Fourth, limited attention has been given to exploring the transitional care needs and perceived supports that would make this particular transition a smoother process. Only one study (Duffey-Lind et al., 2006) was found that explored the transitional care needs of adolescent cancer survivors as well as their beliefs about what supports would be beneficial during this particular transition. This was a pilot study, and data on

adolescent cancer survivors were collected via focus groups. Individual interviews may have yielded richer information on the experiences, perspectives, and beliefs of adolescent cancer survivors about their transition from off-treatment to post-treatment. Overall, relatively little is known about this transition period as compared to other cancer phases (e.g., initial diagnosis, long-term survival) (Labay et al., 2004). More research is needed to gain an in-depth understanding of this transition process from the perspectives of adolescent cancer survivors.

School Reintegration

Another significant transition faced by adolescent cancer patients and survivors is reintegration into the school setting. This is considered an important transition because school reintegration can play a large role in regaining a sense of normalcy for these individuals (Bessell, 2001; Haase & Rostad, 1994). It is recommended that children and adolescents return to school as soon as possible in order to provide them the opportunity to re-engage in social relationships, obtain support from others, continue with academic work, and achieve a sense of accomplishment (DuHamel et al., 1999; Katz et al., 1988; Lansky et al., 1983; Spinetta, 1982). School reintegration is especially important for adolescents because of their need for autonomy and desire to establish peer relationships (Cabat & Shafer, 2002). The school setting can provide opportunities for adolescents to achieve these critical developmental milestones. The following quotes illustrate the importance of school reintegration. Katz et al. (1992) stated, “the child who is denied continued school participation is, in effect, being denied a major opportunity to engage in age-appropriate, goal-directed behavior” (p. 69). Cabat and Shafer (2002) summarized the benefits of returning to school in the following statement: “School is the work of

children and a cornerstone of a child's quality of life. It provides opportunities for intellectual and social mastery. Going back to school after a cancer diagnosis symbolizes a return to normal, familiar, and often reassuring environment..." (p. 105).

Overall, there are numerous benefits of returning to school for these children and adolescents. As a result, the need for school reintegration services has been recognized by national organizations as well as in the research literature (American Cancer Society, 2006; Prevatt et al., 2000; Suzuki & Kato, 2003). The Institute of Medicine's report, *Childhood Cancer Survivorship: Improving Care and Quality of Life*, specifically recommended that systems and/or programs be in place to facilitate school reintegration to promote positive outcomes for children and adolescents (Hewitt et al., 2003). It is ideal that planning for school reintegration begin early to increase the chances of a successful transition and prevent future problems at school (Deasy-Spinetta, 1993; Hewitt et al., 2003). This is particularly important as research has shown that cancer and treatment can affect multiple areas related to school functioning and performance. The next section will provide information on those areas that have received attention in the literature.

Educational Impact of Cancer

The transition back to school can be difficult as research has shown that cancer and treatment can have an adverse impact on school adjustment and functioning (Labay et al., 2004). To illustrate the potentially widespread impact of cancer in the school setting, research will be reviewed in the following areas: (a) physical effects of treatment; (b) absenteeism and academic instruction; (c) impact on neurocognitive and academic functioning; (d) behavioral and socio-emotional functioning; (e) peer

relationships; and (f) educational outcomes. Due to the limited research base examining the school experiences of adolescent cancer patients and survivors, studies will be presented related to both children and adolescents. Although there are developmental differences between these two groups, research investigating children may provide insight into the school experiences of adolescents.

Physical effects of treatment. Physical effects associated with cancer and treatment can have an impact in the school setting for children and adolescents. Effects may include altered appearance (e.g., hair and limb loss, weight gain or loss, short stature), fatigue, physical limitations, decreased mobility, and muscle pain (Larcombe et al., 1990). As a result of such effects of treatment, children and adolescents have reported a wide range of difficulties. One difficulty commonly reported among adolescent cancer survivors is coping with body image and hair loss especially during school re-entry (McCaffrey, 2006; Pendley, Dahlquist, & Dreyer, 1997; Wallace, Harcourt, Rumsey, & Foot, 2007). Other difficulties related to physical effects include having to wear a hat at school to disguise hair loss, fielding intrusive questions from peers related to their appearance, drawing unwanted attention from peers, and being unable to participate in extracurricular activities (McCaffrey, 2006).

Absenteeism and academic instruction. Many children and adolescents may miss a significant amount of school due to treatment, prolonged hospitalizations, fatigue, and/or risk of infection (Larcombe et al., 1990; Prevatt et al., 2000; Upton & Eiser, 2006). Children and adolescents with cancer were found to miss more days than healthy controls or those with other chronic conditions (Charlton et al., 1991; Vance & Eiser, 2002). Absences are one of the biggest problems during the year after diagnosis but

generally decrease with time after diagnosis (Rynard, Chambers, Klinck, & Gray, 1998). However, absenteeism can still be a significant concern years after initial diagnosis (Lansky et al., 1983). Consequently, children and adolescents may have limited access to quality instruction and fail to keep up with in-class and homework assignments (Prevatt et al., 2000).

Children and adolescents undergoing cancer treatment may enroll in homebound and/or hospital-based school programs in an effort to continue their education during treatment (Glasson, 1995; McCaffrey, 2006; Searle et al., 2003). Searle et al. (2003) found that adolescent cancer patients aged 13 to 18 years and their caregivers perceived homebound instruction as less effective and meaningful than instruction provided in hospital and community settings. Adolescents and their caregivers reported that homebound services were unfavorable due to lack of quality instruction, little time allocated to instruction (i.e., four hours of instruction per week), inadequate educational materials, and limited training of homebound teachers. Bessell (2001) found that child and adolescent cancer survivors aged eight to 17 years who were enrolled in homebound schooling had poorer psychosocial adjustment compared to those who received instruction at local schools in the community. Furthermore, logistical difficulties such as obtaining information about services, lack of communication between homebound and school-based teachers, insufficient educational materials, and lack of quality instruction were factors that contributed to participants' negative outlook on homebound instruction. Many survivors in this study believed that homebound instruction did not prepare them to re-enter the school setting. Overall, there is a lack of empirical research on the

effectiveness of hospital and homebound services and subsequent placement when the child returns to school (Bessell, 2001).

Impact on neurocognitive and academic functioning. Many studies examining the effects of cancer and treatment on neurocognitive functioning have included survivors of acute lymphoblastic leukemia (ALL). Treatment for this type of cancer is intensive and can include central nervous system (CNS) chemotherapy and/or cranial radiation (Butler & Haser, 2006). Research has found that the combination of these treatments is associated with deficits in neurocognitive functioning and academic difficulties among child and adolescent cancer survivors (Raymond-Speden, Tripp, Lawrence, & Holdaway, 2000; Upton & Eiser, 2006). Neurocognitive deficits have been found in the areas of short-term memory, visual memory, auditory memory, attention, concentration, sequencing tasks, and non-verbal skills (Brown et al., 1998; Butler & Haser, 2006; Langer et al., 2002; Peckham et al., 1988). Butler and Haser (2006) provided a summary of the effects of cancer treatment on the neurocognitive functioning of childhood cancer survivors of ALL and brain tumors. Treatments associated with these types of cancers have been found to injure brain tissues (e.g., cerebral white matter). This damage is hypothesized to play a role in the neurocognitive problems seen in childhood cancer survivors. Intensive treatments were found to be associated with a more aversive impact on neurocognitive functioning (e.g., cranial radiation therapy). Additionally, more severe deficits have been associated with younger age at treatment. Academic difficulties also have been found in reading and math for children and adolescents (Kaemingk, Carey, Moore, Herzer, & Hutter, 2004; Peckham et al., 1988; Upton & Eiser, 2006). Delays in academic functioning may not be seen until years later (Bessell, 2001; Peckham et al.,

1988). A decline in grades also has been found among children and adolescents who were diagnosed with a brain tumor before 16 years of age when compared to matched controls (Lähteenmäki et al., 2007). Additionally, it has been found that academic performance significantly predicted social skill functioning and psychological adjustment among school-aged cancer survivors with poor academic functioning being associated with greater risk of social and adjustment problems (Newby, Brown, Pawletko, Gold, & Whitt, 2000). Findings such as these underscore the potentially significant role that academic achievement plays in the psychosocial adjustment of child and adolescent cancer survivors.

Behavioral and socio-emotional functioning. Vance and Eiser (2002) reviewed 19 studies related to the impact of cancer on the classroom behavior of children and adolescents aged eight to 15 years. Results indicated that there is mixed evidence about whether children and adolescents have significant behavioral problems in school compared to control groups. Different measures have been used across studies which may contribute to these mixed findings. However, research has found that teachers and caregivers have rated the behavior of children and adolescents with cancer in the normative range (Gartstein, Short, Vannatta, & Noll, 1999; Noll et al., 1999). Regarding socio-emotional functioning, research also has shown mixed results. However, many studies have found that cancer patients and survivors generally have few significant problems with social functioning and continue to adjust into long-term survivorship (Newby et al., 2000; Kupst et al., 1995).

Noll and colleagues (1990, 1991, 1993, 1997, 1999) conducted a series of studies to investigate the perceptions of teachers, peers, and caregivers about the socio-emotional

functioning of child and adolescent cancer patients and survivors. One of the initial studies found that teachers perceived children and adolescents with cancer aged eight to 18 years to be less sociable, more socially withdrawn, and having limitations in social skills when compared to other healthy students in the classroom (Noll, Bukowski, Rogosch, LeRoy, & Kulkarni, 1990). Another study indicated that peers rated cancer patients aged eight to 18 years as more socially isolated as compared to a control group; however there were no significant differences in regards to overall popularity, number of mutual friends, social competencies, loneliness, or self-concept (Noll, LeRoy, Bukowski, Rogosch, & Kulkarni, 1991). Noll, Bukowski, Davies, Koontz, & Kulkarni (1993) investigated self-report, teacher, and peer ratings on indices of social and psychological functioning among adolescent cancer survivors and matched controls across a two year period. Findings indicated that adolescent cancer survivors continued to be perceived as socially isolated but no significant differences were found among other social and psychology functioning domains (e.g., popularity, friendship, self-reported feelings of loneliness and depression).

Another study examined the behavioral adjustment and social functioning of school-aged survivors of acute lymphoblastic leukemia (ALL) 48 months after treatment completion based on parent and teacher ratings (Noll et al., 1997). Findings indicated that parents reported greater somatic complaints as compared to measure norms on the Child Behavior Checklist but no significant differences in areas such as academic problems, behavioral concerns, or a relationship between treatment intensity and behavioral problems. Lastly, Noll et al. (1999) found that teachers perceived children and adolescents with cancer aged eight to 15 years to be more sociable, and both peers

and teachers perceived them as less aggressive or disruptive. Furthermore, this study revealed that children and adolescents did not score significantly different on measures of depression, anxiety, loneliness, and self-concept as compared to healthy classroom peers. However, they reported lower satisfaction with their athletic competence. Other research suggests that type of cancer and treatment may play a role in socio-emotional outcomes. For example, children and adolescents aged four to 16 years with CNS tumors and bone marrow transplants were found to be at a high risk for social competence and emotional problems (Carpentieri, Mulhern, Douglas, Hanna, & Fairclough, 1993; Vannatta, Zeller, Noll, & Koontz, 1998).

Regarding the impact of cancer treatment on social functioning of cancer survivors, Reiter-Purtill, Vannatta, Gerhardt, Correll, and Noll (2003) investigated whether child and adolescent cancer survivors would have more social problems as compared to those who did not have a chronic illness and whether greater treatment intensity predicted more social difficulties over time. Participants included cancer survivors with non-central nervous system malignancies between the ages of nine to 17 years who were 17 months post-treatment on average and in remission. The findings indicated that cancer survivors did not have significantly more social problems as compared to the control group. It also was found that cancer survivors perceived themselves as more prosocial than the control group reported about themselves. Cancer survivors' prosocial views of themselves were significantly more stable over time (on and off treatment) as compared to the control group's self-ratings. Additionally, teachers and peers rated the cancer survivors as significantly less aggressive compared to the control group. Regarding treatment intensity, results indicated that those survivors who had

more intense treatment regimes were perceived by their peers as more prosocial and less aggressive yet as having fewer best friends. Overall, the authors concluded that cancer and associated treatments may not have a significant adverse impact on cancer survivors social functioning in the school setting. Of note, the participants included in this study received coordinated psychosocial care during their treatment which may have either prevented or minimized difficulties in social functioning post-treatment. Other studies also have found that school-aged cancer survivors generally demonstrate adequate social skills and have few internalizing or externalizing behavioral problems when compared to a control group (Madan-Swain et al. 1994; Newby et al., 2000; Spirito et al., 1990).

Peer relationships. A significant source of daily stress for many of these children and adolescents includes interacting with peers at school (Benner & Marlow, 1991). As a result of cancer and associated treatments, they may experience prolonged absences from school and are challenged to re-establish peer relationships upon their return. One study found that peers perceived school-aged cancer survivors as significantly more sick, fatigued, and absent from school when compared to other children who did not have a chronic illness; however, peer perceptions of being ill and school absences appeared to improve as time off treatment increased whereas perceptions of the cancer survivors as fatigued did not (Reiter-Purtill et al., 2003).

Other peer related difficulties may include difficulty identifying or relating with peers as school-aged cancer patients and survivors have faced tremendous hardship and have established a renewed sense of self and/or outlook on life (Labay et al., 2004). Teasing and harassment from peers may occur at school as well (McCaffrey, 2006). Children and adolescents also can experience feelings of isolation and loneliness because

peers may not understand cancer and reject them at school (Prevatt et al., 2000). These are important implications to address as research has found that social support from peers is associated with positive psychological adjustment more so than support from parents or teachers for children and adolescents (Varni, Katz, Colegrove, & Dolgin, 1994). Furthermore, peer acceptance has been found to play an important role in facilitating school re-entry (Haase & Rostad, 1994).

Educational outcomes. Brown et al. (1998) examined cognitive and academic late effects of treatment for 47 child and adolescent survivors of ALL aged five to 22 years. These survivors were off treatment from two to seven years. Demographic data indicated that approximately 36% received part-time special education services, 7% were in self-contained special education classrooms, and 24% had repeated a grade. Kazak, Crhistakis, Alderfer, and Coiro (1994) found that adolescent cancer survivors aged 10 to 15 years who received special education services were at greater risk for adjustment problems. Other studies have shown that child and adolescent cancer survivors were at risk for retention (Bessell, 2001; Mulhern et al., 1989; Peckham et al., 1988).

Mitby et al. (2003) investigated utilization of special education services and level of educational attainment among 12,340 survivors of childhood cancer and 3,410 sibling controls. Data were obtained through a self-report questionnaire. Survivors ranged in age from six to 47 years with a median of 23 years at the time they completed the questionnaire. Caregivers completed the questionnaire for participants under the age of 18 years. Results indicated that 23% of survivors reported they utilized special education services sometime during grades kindergarten through 12, whereas 8% of siblings indicated receiving such services. Younger age, female gender, and receiving intrathecal

methotrexate (i.e., chemotherapy) and/or cranial radiation treatment were factors associated with a greater likelihood of utilizing special education services. Participants also were asked to provide reasons for their placement in special education. Survivors diagnosed between birth and 15 years identified missed school days and low test scores as reasons for their placement. Those survivors diagnosed with cancer at a younger age remained in special education programs for a longer period of time. When treatment type was examined, data indicated that survivors who received high doses of cranial radiation remained in special education the longest. Regarding educational attainment, survivors of leukemia, CNS tumors, non-Hodgkin's lymphoma, and neuroblastoma were found to be less likely to complete high school when compared with siblings. All survivors (no matter what type of treatment received) were significantly less likely to finish high school as compared to control siblings. Survivors of CNS tumors as well as those who received both cranial radiation and special education services were less likely to complete college than siblings.

In summary, the effects of cancer and treatment can impact school performance and potentially result in negative educational outcomes. Children and adolescents must cope with both physical and psychosocial effects of treatment while navigating the school experience. Consequences of cancer and its treatment include increased absenteeism, lack of access to quality academic instruction, compromised cognitive functioning, poor academic performance, and negative educational outcomes. These potential consequences illustrate the need for proactive transitional care planning, collaboration among health-care and school professionals, and educating key stakeholders about the impact of cancer in the school setting (e.g., parents, teachers, and peers).

School Reintegration Concerns of Children, Adolescents, Caregivers, and Teachers

In addition to recognizing the potential widespread impact of cancer in the school setting, it also is important to examine the concerns of those who are involved in school reintegration process. Knowledge and identification of these concerns can prepare health care professionals and school personnel to better meet the needs of children, adolescents, and families as well as improve the school reintegration planning process. McCarthy et al. (1998) conducted a qualitative study investigating school reintegration concerns of 10 children and adolescents diagnosed with cancer, 10 mothers, and nine teachers. Children and adolescents were between the ages of five and 13 years with a mean age of eight years. They were Caucasian and resided in rural settings. All participants were recruited from an outpatient cancer treatment center located in the Midwest region of the United States. Data collection methods included individual semi-structured interviews with children, adolescents, mothers, and teachers.

Results indicated that mothers were concerned about their child/adolescent's physical well-being and the possibility that they would get an infection or have an accident at school. They also expressed fears that other students would tease them. Mothers reported being knowledgeable about cancer but did not feel comfortable sharing this information with school personnel. Teachers were primarily concerned about the child/adolescent's adjustment to his/her peers and how they would react and treat the student. They shared that they lacked of knowledge about cancer and its implications in the classroom, and some believed that medical issues were designated for the school nurse. Both teachers and parents were less concerned with academics upon returning to school.

Conversely, children and adolescents were primarily concerned with their academic performance and keeping up with academic demands and activities. One participant said, “I was worried with getting caught up with all my work again” (p. 148). Another participant shared, “I was worried that I don’t want to miss out of the fun things they do...like projects and different math things that are neat” (p. 148). Those individuals over the age of eight worried about their physical appearance and body image, peers’ reactions to such changes, and whether they would still be accepted. Lastly, findings revealed that communication might be limited among parents and school personnel. Some mothers and teachers reported difficulty sharing and relaying information about the child/adolescent’s health status and needs. However, other mothers indicated that communication was adequate and met their expectations.

Glasson (1995) conducted a descriptive and exploratory pilot study to examine the school reintegration experiences of five adolescents who received outpatient cancer treatment in the United Kingdom. Participants were between the ages of 12 and 16 years, received at least three weeks of instruction in the hospital, and subsequently returned to the community school setting. Data collection methods included semi-structured interviews conducted in the outpatient clinic setting. Interview data yielded the following three themes: (a) “disruption”, (b) “adaptation”, and (c) “normality” (p. 755).

The “disruption” theme revealed that these adolescents experienced both personal and interpersonal changes in their daily lives at school. They reported feeling isolated (e.g., “all alone”), confused (e.g., “didn’t know where to begin”), and self-conscious (e.g., “just didn’t feel right”) during school re-entry (p. 756). All of the adolescents indicated hair loss was a concern that impacted their self-image. They also described

how peers and teachers reacted to their return to school. One participant shared, “teachers couldn’t relate to me and my illness” (p. 756). Although teachers may have been unable to relate, adolescents perceived relationships with teachers as important and beneficial to their adjustment to school. Peers also teased some of the participants. However, those adolescents whose peers had seen them throughout treatment perceived fewer peer-related problems at school. Additionally, participants indicated that they were behind in their schoolwork and being absent from school exacerbated this concern. Younger adolescents believed that they could catch up with schoolwork whereas older adolescents did not express this belief. The second theme, “adaptation,” revealed that these adolescents made active strides to adapt and cope in the school environment. Strategies included changing their perception of certain situations (e.g., “Learnt who my real friends were”) and refusing to give up or give in (e.g., “Just decided to do it”) (p. 756). The “normality” theme highlighted the need for these adolescents to return to their everyday lives and engage in familiar activities related to school (e.g., “Once back I went as much as I could”) (p. 756).

Searle et al. (2003) investigated the experiences of 10 adolescent cancer patients who received academic instruction in homebound, hospital-based, and/or community-based settings using a case study approach. Adolescents were between the ages of 13 and 18 years and were in grades ranging from seventh to twelfth. Participants were recruited from a cancer center located in the South West region of the United States. The majority of adolescents received academic instruction in more than one setting. Individual interviews were conducted with adolescents, caregivers, and teachers.

Data revealed that some adolescents elected to receive homebound instruction due to their physical appearance and/or limitations. They did not want to attend community-based school until their hair grew back or when they regained physical strength. However, the majority of adolescents who received homebound instruction felt sad that they could not participate in regular school activities such as interacting with peers and teachers and attending social events at school. Those participants who received instruction in the hospital setting were concerned if they would be academically prepared to go back to their community-based school. Despite these concerns, the majority of students found that it was relatively easy to reintegrate back into the community setting. Those students who re-entered their community-based schools after receiving hospital and/or homebound instruction reported that their teachers made academic and environmental accommodations in the classroom. The nature of these accommodations was not reported. These adolescents also were concerned about being accepted by their friends at school and how people would react to their physical appearance. However, none of them reported having problems associated with these concerns. In fact, they indicated that they received more support from friends and teachers than they did prior to their diagnosis.

Additional concerns also were found in the literature. One study found that adolescent and young adult cancer survivors had difficulty reintegrating with peers at school and would have liked more information about school reintegration to guide them through the process (Duffey-Lind et al., 2006). Another concern is that teachers have reported feeling unprepared to meet the needs of children with cancer (Baskin et al., 1983; Chekryn, Deegan, & Reid, 1987; Greene, 1975). Greene (1975) highlighted some

of the potential concerns faced by teachers such as having limited knowledge of cancer, being unsure of the child's capabilities, and dealing with their own feelings toward the child with cancer.

In conclusion, children, adolescents, mothers, and teachers each have their own unique set of concerns that should be addressed during the school reintegration process. Many of these concerns were related to physical health, self-image, academic performance, peer and teacher relationships, communication between parents and school personnel, and informational needs. Major concerns reported by adolescents included coping with changes in physical appearance, falling behind in academic work, and navigating peer relationships. Another notable finding was that teachers reported a lack of knowledge about cancer. Additionally, children, adolescents, and mothers identified supports that could facilitate the school reintegration process. Supports included availability of information on school reintegration, supportive relationships with teachers and peers, and increased communication between home, school, and hospital. Each of these supports could potentially improve the school reintegration process. The next section describes steps that have been taken to facilitate the transition back into the school setting.

Interventions to Facilitate School Reintegration

School reintegration programs and interventions have been developed and evaluated in the literature. The literature includes studies on comprehensive programs (Katz et al., 1988; Katz et al., 1992), workshops for classmates (Benner & Marlow, 1991), workshops for teachers (Baskin et al., 1983), and social skills training (Barakat et al., 2003; Varni et al., 1993). Katz et al. (1988) developed one of the first comprehensive

school reintegration programs to help children and adolescents with cancer aged five to 17 years successfully reintegrate into the school setting. The focus of the project was to promote collaboration among health care professionals, school personnel, parents, and patients to facilitate the transition from the hospital to school setting. A school intervention package was developed that included the following main components: (a) preliminary activities to prepare for school reintegration; (b) conferences with school personnel; (c) classroom presentations on cancer; and (d) follow-up services to address concerns.

Preliminary activities were conducted to better prepare all parties for the school reintegration process. Activities included discussions with parents about reintegration, counseling services for parents, patients, and school personnel, help arranging educational services (e.g., homebound instruction) until the child or adolescent was ready for reintegration, and an assessment of school personnel knowledge of cancer. Conferences were held with school personnel to provide information about cancer, treatment, and side effects as well as to address anticipated absences and special education needs. Classroom presentations were given to classmates to educate them about cancer and dispel any myths. Follow-up services also were provided to patients, parents, and school personnel to assess their progress and problem-solve issues. Katz et al. (1988) evaluated this program by comparing those children and adolescents who participated in the intervention to a control group. Results indicated that students in the intervention group had significantly fewer behavior problems, increases in social competence and self-esteem, and were less likely to display symptoms of anxiety or depression. Teachers also rated children and adolescents in the intervention group as

better adjusted. Furthermore, patients, parents, and teachers rated this program as highly acceptable and found the program to be beneficial in increasing awareness and knowledge of cancer and its impact in the school setting (Katz et al., 1992).

Prevatt et al. (2000) conducted a review of school reintegration workshops and programs. Programs included school personnel workshops (n= 4 studies), peer education programs (n= 4), and comprehensive school reintegration programs (n= 6). The author concluded that the research on school personnel workshops has shown increases in knowledge of cancer and its impact in the educational setting. Peer education programs have targeted students in grades kindergarten through high school. Positive results of these programs included increased knowledge of cancer and interest in interacting with the child with cancer. Research on comprehensive school reintegration programs targeted students aged five to 17 years. These programs yielded positive results including improved attendance and attitude toward school for the student with cancer. Other positive outcomes for students were improved social and behavioral functioning and greater adjustment at school. Increases in teacher knowledge and acceptability of the program by patients, parents, and teachers also were promising outcomes.

Although some positive results have emerged, Prevatt et al. (2000) identified a number of limitations to this body of research. There is no clear theoretical model to guide the development or implementation of these workshops and programs. Regarding school personnel workshops, follow-up data is lacking to determine if increases in school personnel knowledge of cancer are sustained over time. Additional research is necessary to demonstrate if students benefit from these increases in knowledge. Data on the long-term effectiveness of peer education programs also is limited. Outcome data is lacking

on peer retention of knowledge and if increases in knowledge are associated with greater peer acceptance. Finally, research on comprehensive school programs is limited by reliance on anecdotal data to document outcomes. Suzuki and Kato (2003) also reviewed the literature on school reintegration programs and determined that more rigorous research with larger samples sizes is needed to evaluate the effectiveness of these programs. Again, it was concluded that much of the existing body of research relies on anecdotal evidence to assess program effectiveness. More research also is needed to determine which program components are most effective and practical.

Additionally, national cancer organizations have developed cancer school curricula and school re-entry programs to facilitate this transition and provide school staff and peers with user-friendly information about cancer, treatment, and survivorship. For example, The Lance Armstrong Foundation in collaboration with Scholastic created “Livestrong at School!” in the spring of 2008 (Ishola, 2009). Livestrong at School is a cancer curriculum available to elementary, middle, and high school teachers on the internet (<http://www.livestrong.org/What-We-Do/Our-Actions/Professional-Tools-Training/For-Educators/LIVESTRONG-at-School-Curriculum>). The curriculum meets national academic standards and can be used across multiple content areas such as language arts, math, and history. The website provides various learning materials including an overview of the lesson, student learning objectives, academic standards that each lesson meets, required resources to conduct each lesson, links to worksheets and informational videos, check for understanding assessments, and extension activities for additional learning. Livestrong at School curriculum has been adapted for use by schools across the United States and the world.

The Leukemia and Lymphoma Society and Lance Armstrong Foundation also have collaborated to develop the “Welcome Back: Facilitating the Return to School for Children with Cancer” program. This program was designed to help school personnel and families assist childhood cancer survivors with the transition back to the school setting. The objectives of this program are to increase school personnel’s knowledge of cancer, long-term and late effects, specific challenges of school reintegration and beyond, laws that protect childhood cancer survivors’ rights, strategies to help survivors succeed in the school setting, and helpful resources that can be utilized during the reintegration process (e.g., pamphlets, resource guides). As a part of the program, a national curriculum was developed and distributed to all chapters across the country.

Lastly, hospital-based programs have been developed to help meet the school reintegration needs of childhood cancer patients and survivors. For example, the Dana-Farber Cancer Institute and Children’s Hospital of Boston created the “Back to School Program” to assist with school reintegration for patients/survivors, families, and a variety of school personnel (<http://www.dana-farber.org/pat/support/back-to-school/default.html>). This program includes services such as individual and family counseling to prepare for the return back to school, developmentally appropriate classroom presentations, workshops for school personnel, and ongoing communication with the school. The Dana-Farber Cancer Institute also provides specialized school services through the School Liaison Program (<http://www.dana-farber.org/pat/support/school-liaison-program/default.html>). Children and adolescents with a diagnosis of leukemia or brain cancer who are enrolled in the first grade or higher and have demonstrated learning difficulties as a result of their cancer or treatment are

eligible to received services through this program. Services include educating school personnel about neurocognitive late effects, facilitating neuropsychological evaluations in collaboration with the Children's Hospital of Boston, providing on-going consultation to school personnel and families, and disseminating information to the community about the long-term effects of childhood cancer treatments.

In summary, school reintegration is seen as an important process that can help children and adolescent cancer patients and survivors achieve a sense of normalcy. The need for school reintegration planning has been recognized by professional organizations and in the research literature. It has been recommended that this planning begin early to promote positive outcomes for children and adolescents. Proactive planning is important because research has shown that cancer and treatment can affect multiple areas related to school functioning and performance. Additionally, research has shown that children, adolescents, mothers, and teachers have unique concerns related to school reintegration that require attention during the school reintegration planning process. Supports also were identified that could better facilitate the school reintegration process. To date, interventions have been designed to promote successful school reintegration for these children and adolescents. Interventions include comprehensive school reintegration programs, school personnel workshops, peer education programs, and social skills training. Preliminary evidence on these interventions yielded some positive outcomes for students, parents, and teachers. However, more rigorous research is needed to examine their effectiveness and sustainability over time. More recent interventions developed by national organizations include childhood cancer survivorship/school reintegration curricula and hospital-based school programs.

School Reintegration: Limitations of the Research

Despite the growing body of research showing that the effects of cancer and treatment can impact school performance and lead to negative educational outcomes, relatively little research has investigated the school reintegration experiences of children and adolescents. Some of the existing research has been conducted outside of the United States which is helpful in understanding aspects of school reintegration but limits the generalizability of the findings. Additionally, the existing research has primarily focused on the identification of school reintegration needs and concerns rather than exploring the actual school reintegration process, how a child/adolescent navigates this process, or indicators and outcomes of successful reintegration. Many school reintegration programs also have been evaluated but with little attention to how variables of these programs specifically meet the identified needs and concerns of adolescents to promote successful outcomes at school and whether or not the programs demonstrate meaningful, long-term positive outcomes that improve quality of life. Lastly, very little research was found on the school reintegration services/supports actually received by children and adolescents, satisfaction with their school reintegration experience, and their beliefs about what specific supports and/or services would have made the transition back to school a smoother process. Exploration of these topics as well as more in-depth information on adolescent cancer survivors' school reintegration experiences can strengthen the existing literature base.

Conclusions

Adolescent cancer survivors are a unique group of survivors because they face the challenge of coping with the impact of cancer in addition to attaining typical

developmental milestones associated with adolescence. They are considered an understudied population who warrant attention in both research and practice. One issue that has been identified in the literature and by national organizations is the need for transitional care and planning for these adolescents. The provision of transitional care and planning can help bridge the gap between phases of cancer care and promote positive outcomes for adolescent cancer survivors. Transitional care is needed as research has shown that transition periods are characterized by feelings of uncertainty, confusion, and anxiety. Two transitions that have received minimal attention in the literature include the transition from off-treatment to post-treatment and reintegration into the school setting. Research was reviewed on each of these transitions and limitations were discussed. Overall, very few studies have examined these transition experiences from the perspectives of adolescent cancer survivors. Furthermore, little research has investigated aspects of the transition process including perceived challenges associated with these transitions and supports and/or services that were or would be helpful during the transition process. More research is needed to provide an in-depth understanding of these transition experiences from the perspectives of adolescent cancer survivors. This study sought to address the limitations of the research and contribute to the existing literature base.

CHAPTER THREE:

METHODS

This study examined the transition from off-treatment to post-treatment and school reintegration from the perspectives of adolescent cancer survivors. This chapter describes the methodology that was used to conduct this investigation. A detailed description of the research paradigm, research design, participants, instrumentation, procedures, ethical considerations, data analysis, limitations, and validity measures that were used to address the limitations are presented.

Research Paradigm

Guba and Lincoln (1994) defined a research paradigm as “the basic belief system or worldview that guides the investigator, not only in choice of method but in ontologically and epistemologically fundamental ways” (p. 105). A researcher’s basic belief system is based on certain ontological (“what is knowledge”) and epistemological (“how we know it”) views (Creswell, 2003, p. 6). This belief system guides how researchers will approach their work and the research process (Guba & Lincoln, 1994). The constructivist paradigm was used to guide this principle investigator (PI) throughout the qualitative research process. This paradigm is espoused by those researchers who want to gain a greater understanding of a phenomena or topic from the perspectives of people themselves (Patton, 2002). Within this research paradigm, there is a belief that individuals attempt to make meaning and sense of the world in which they live (Creswell, 2003). Individuals actively construct and assign subjective meanings to their

experiences. According to Schwandt (1994) “constructions are attempts to make sense of or to interpret experience” (p. 129). These constructions are products of an individual’s mind and are largely created through interactions with others and the community. They are subject to change over time as individuals refine or modify their constructions (Patton, 2002). These constructions may be similar among people (e.g., collective vision or an idea held by many), and knowledge is defined as those constructions for which there is consensus (Guba & Lincoln, 1994). Furthermore, these meanings are constructed within social, historical, and cultural contexts. According to Creswell (2003), “humans engage with their world and make sense of it based on their historical and social perspective—we are all born into a world of meaning bestowed upon us by our culture” (p. 9). Thus, it is important to examine not only the meanings that individuals create, but also the contexts in which they function.

A central tenant of the constructivist paradigm is that there are multiple constructions of reality, and each individual’s perception of reality is considered valid, valuable, and worthy of attention (Crotty, 1998; Patton, 2002). There is no pursuit to find one, accurate reality that exists. Therefore, the researcher is primarily interested in understanding and learning about the multiple meanings participants assign to their experiences, their unique perspectives related to the phenomenon under study, and the contexts in which people function and live and how they influence and shape those constructed meanings. Regarding epistemology, knowledge is thought to be created through the interaction between the researcher and research participant. Knowledge is co-constructed as the researcher and participant talk with one another. Guba and Lincoln (1994) stated, “the investigator and the object of investigation are assumed to be

interactively linked so that the ‘findings’ are *literally created* as the investigation proceeds” (p. 111). A research strategy that is often used to learn about the meanings participants assign to their experience and the contexts in which they live includes asking open-ended questions. Open-ended questions provide the researcher and participant with an opportunity to develop and co-construct meanings of a situation or experience (Creswell, 2003; Guba & Lincoln, 1994). The researcher then attempts to describe and interpret those constructions to arrive at a greater understanding of the phenomenon (Guba & Lincoln, 1994). Notably, this co-creation of knowledge is a dynamic process, and it is recognized that biases and values will inevitably be introduced into the research process (e.g., interpretation of data is influenced by researcher’s experiences, biases, and beliefs). Therefore, validity, or trustworthiness, measures (e.g., credibility) were utilized to address this issue as well as enhance the quality of this study (Lincoln & Guba, 1985). These measures are described in detail at the end of this chapter.

Research Design

According to Stake (1995), a “case” can be an individual, several individuals, a program, or an event. The defining feature of a case is that it is a complex system bounded by time and location (Creswell & Maietta, 2002). Stake (1994, 1995) indicated that a case study is used to obtain an in-depth description and understanding of a case and the setting, or context, in which that case functions through data collection from multiple sources over time. Stake (1994) identified intrinsic and instrumental types of case studies. Intrinsic case studies are those that are primarily concerned with describing and understanding the case itself. An instrumental case is focused on selecting a case that will provide insight on a particular problem or phenomenon. The case itself is of

secondary importance and strategic selection of the case will facilitate a better understanding of the phenomenon.

A specific type of case study that is instrumental in nature is a multiple case study (Stake, 2005). Stake (2005) defined a multiple case study as a “small collection of people, activities, policies, strengths, problems, or relationships [that] is studied in detail” (p. vi). Individual cases that share common characteristics are selected and investigated to gain a greater understanding of a phenomenon or “quintain” (p. 6). Research questions also are identified across cases to learn more about the quintain. Overall, the main goal of a multiple case study is to examine cases, identify patterns within each case, and analyze cross-case findings in order to gain a greater understanding of the quintain.

A multiple case study research design was used to guide this study. More specifically, the experiences of several adolescent cancer survivors were examined (i.e., multiple cases). Each adolescent cancer survivor (i.e., case) was *instrumental* in gaining more in-depth information on transition processes, challenges faced, and supports/services needed (i.e., research questions), which directly related to the larger phenomenon or quintain (i.e., adolescent cancer survivorship and specific transitions). Careful attention was given to selecting cases that yielded the best information and promoted the greatest understanding of the quintain.

Participants

Cases that were most likely to provide rich information and an in-depth understanding of the adolescent cancer survivorship and significant transitions were selected using a purposeful sampling method (Miles & Huberman, 1994; Patton, 2002; Stake, 2005). According to Patton (2002), “the purpose of purposeful sampling is to

select information-rich cases whose study will illuminate the questions under study” (p. 46). The specific type of purposeful sampling that was used to recruit participants was criterion sampling. Criterion sampling involves the identification of specific pre-determined criteria that must be met to participate in the study (Patton, 2002). Each participant met the following inclusion criteria: (a) chronological age between 12 and 17 years (note: initial recruitment was limited to those adolescents who did not turn 18 years of age before the study was completed); (b) diagnosis of cancer other than brain tumor received during childhood; (c) diagnosis received at age five years or older; (d) off treatment for a minimum of six months and a maximum of five years; (e) cancer is currently in remission (i.e., absence of disease); (f) no history of a relapse; (g) currently attending school in the community (e.g., public, private, charter school); (h) willing and able to provide assent; and (i) caregivers willing to provide consent for participation.

Exclusion criteria included lack of fluency in English, mental retardation, adolescents in foster care, diagnosis of a brain tumor, below the age of five years at initial diagnosis, off treatment for less than six months or more than five years, and attending school solely at home (i.e., home schooled) or on the internet (i.e., virtual classes) during the study. Those individuals diagnosed with a brain tumor were excluded because of the likelihood of cognitive impairment often associated with this type of cancer. Adolescents who were diagnosed prior to five years of age were excluded due to the developmental concerns that these individuals would not be able to accurately process and reflect on their experiences related to cancer (Alderfer, Labay, & Kazak, 2003; Barakat, Alderfer, & Kazak, 2006). Individuals who completed treatment less than six months ago may not have enough time to fully reflect on their experience transitioning from off-treatment to

post-treatment. Alternatively, those adolescents who completed treatment over five years ago may not recall their experiences as accurately as others who recently completed treatment. Other research has used a similar criterion when examining the post-treatment experiences of adolescent cancer survivors (Duffey-Lind et al., 2006). Finally, those individuals who were home schooled or taking virtual classes at the time of the study were excluded because there was an interest in learning more about reintegration into the regular school setting. Therefore, recruitment was limited to those adolescent cancer survivors between the ages of 12 and 17 years who were in remission, had no history of a relapse, and were currently attending school in the community.

Regarding generalizability of the findings, it was not a goal of this study to generate findings that could be generalizable to the greater adolescent survivor population. Rather, a primary goal was to show trends and convey the experiences of those adolescents specifically selected for the study. This goal is consistent with case study research as there is more emphasis on careful selection of cases that yield similar results or patterns than generalizing results to other populations (e.g., generalizability). Therefore, the results of this study may provide insight into future research questions/agendas that could potentially be applied to a larger adolescent survivor population.

Instrumentation

Questionnaires. Participants answered a screener questionnaire during the initial phone contact from the PI (see Appendix A). This questionnaire was used to assess the pre-established inclusion and exclusion criteria and determine eligibility for participation in the study. The questionnaire took approximately five minutes to administer and

complete. Participants also completed a demographic questionnaire upon completion of the interview session. The demographic questionnaire elicited information such as sex, ethnicity, educational level, diagnosis, and type of treatment received (see Appendix B). The demographic variables included on the questionnaire are commonly reported in the pediatric oncology literature and considered important information to obtain from research participants. The demographic questionnaire took approximately one to two minutes for participants to complete. Notably, a few caregivers assisted their child in completing these questionnaires. For those adolescents who completed the questionnaire independently, the PI reviewed the responses with at least one parent to confirm the accuracy of the information.

Interview guide. A semi-structured, open-ended interview guide was utilized in this study (see Appendix C). This type of interview guide allowed the PI to systematically address topics of interest to the study yet have the flexibility to pursue other lines of questioning that led to more rich information (Patton, 2002). This semi-structured interview guide was developed based on recommendations by Carspecken (1996), Krueger (1998), and Patton (2002). The following components were included in the interview guide: (a) topic domains; (b) lead-off questions; and (c) probes. Four topic domains (i.e., experiences and challenges associated with school reintegration, supports/services to improve school reintegration, experiences and challenges associated with the transition from off-treatment to post-treatment, and supports/services to improve the transition from off-treatment to post-treatment) and corresponding lead-off interview questions were developed based on the conceptual framework, research questions, and overall purpose of the study. Lead-off questions were designed to open up, or introduce,

a topic domain. The lead-off questions developed for this study focused on asking participants to respond to concrete questions that required them to describe events, situations, or other instances that they have personally experienced. Lastly, probes were created to obtain more information on the topic of interest and expand on participant responses. The overall purpose of the semi-structured interview guide was to provide a loose structure to the interview session while allowing flexibility to pursue additional topics of interest to the study.

Documents and audiovisual material. Documents are prepared for personal reasons and may be either public (e.g., newspapers) or private (e.g., personal diaries) in nature (Hodder, 1994). Audiovisual material can include artwork, photographs, or films. For the purposes of this study, participants were asked to share any private documents (e.g., journals, letters, autobiographical writing) and audiovisual material (e.g., artwork) that they believed expressed their views or feelings related to their experiences during the transition from off-treatment to post-treatment and school reintegration.

Procedures

Preliminary activities. The screener and demographic questionnaires as well as the interview guide underwent expert review to assess the appropriateness of content, quality, and time commitment. Three experts from separate academic and/or medical institutions reviewed the study materials. These experts were knowledgeable in pediatric oncology, qualitative methodology, and cancer survivorship issues. Changes were made based on the feedback given from the expert reviewers. A pilot test was conducted with three adolescent cancer survivors between the ages of 15 and 17 years over the course of one week in December of 2009. The purpose of the pilot test was to assess the utility of

the semi-structured interview guide, appropriateness of the vignettes, and the overall interview process. On the day of the pilot test, approved assent and consent forms created for the pilot test were verbally reviewed in detail with each participant and their caregiver(s). Time was allotted for the participants and caregiver(s) to review the forms and ask questions prior to providing their signature. The following three scenarios were used in the pilot study: (a) interview with no vignettes and presentation of vignettes after interview to obtain the participant's thoughts and opinions (e.g., "what if I told you this story before I asked you the question?"); (b) interview with vignettes and brief discussion of vignettes after interview; and (c) interview with no vignettes and no discussion after. All participants also were asked a series of questions about the interview to obtain additional information about their experience (see Appendix D).

Results of the pilot study were consistent across all three participants. Based on the results, it was determined that the interview questions and probes were age-appropriate and made sense to the respondents and the time allotted for the interview was appropriate. Participants recommended reordering the sequence of questions and beginning the interview with school reintegration questions because they were most familiar with school life as opposed to the transition from off-treatment to post-treatment. They also suggested adding another question at the beginning of the interview to provide more structure to the interview (i.e., give me a timeline of your cancer experience). They also suggested adding a question regarding "what they learned" or "got out" of their cancer experience as well as how they coped with these transitions. Regarding the vignettes, participants indicated that they did not find the vignettes about specific adolescents beneficial for various reasons including they could not relate to the stories, it

was difficult to relate to as each person's experience is unique, and the vignettes inadvertently influenced and/or limited their responses (e.g., "kids may stick to what you say", "take out personality", "put ideas in someone's head"). However, participants reported that they found the support/services vignette to be helpful because it provided examples of specific services and helped to clarify the question. Lastly, all participants reported that they believed the study was useful and could make an important contribution to other adolescent cancer survivors. The original interview guide is presented in Appendix E and may be compared to the modified/final guide in Appendix C. Due to the changes made to the interview guide, a modification request was submitted to the appropriate Institutional Review Boards (IRB). The results of the pilot test were not used for data analysis.

Additionally, the PI engaged in the following activities to prepare to enter the field: (a) joined a qualitative research study team and analyzed interview data regarding oncologists' perspectives on fertility issues; and (b) participated in an interview to raise awareness of personal biases and expectations related to the study (Carspecken, 1996). This interview was conducted and audiotaped by a graduate student in the field of psychology who is familiar with the qualitative research process. The PI continually referenced the tape throughout the research process and reflected on how her biases and expectations influenced aspects of the study. Lastly, a personal journal was started prior to data collection and maintained throughout the study. The PI used this journal to reflect on her role in the research study as well as any biases that may have influenced data collection, analysis, or interpretation. Both the interview and personal journal are

summarized in this document to provide readers with an open and honest appraisal of the PI's role in the qualitative research process.

Participant recruitment. Participants were recruited from Johns Hopkins Hospital in Maryland and The Gathering Place in Ohio. A description of each site and recruitment procedures used at each are described below.

Johns Hopkins Hospital. Participants were recruited from the Pediatric Oncology Outpatient Clinic (POOC) and Long-Term Childhood Cancer Survivors Program (LCCSP) at Johns Hopkins Hospital. The POOC and LCCSP are run through the Pediatric Oncology Division of the Sidney Kimmel Comprehensive Cancer Center (SKCCC) (National Comprehensive Cancer Network, <http://www.nccn.org/members/Profiles/hopkins.asp>). The SKCCC is designated as a National Cancer Institute Comprehensive Cancer Center. The POOC serves children and adolescents up to age 21. Each child/adolescent is assigned a primary pediatric oncology physician, nurse, social work, and physician's assistant that follow him/her from diagnosis to long-term follow-up care (<http://www.nccn.org/members/profiles/hopkinsPediatric.asp>). Children and adolescents may attend scheduled visits to the POOC for either continued outpatient treatment or monitoring and surveillance once treatment has been completed. Children and adolescents who are in remission for three to five years are able to transfer to the LCCSP. The LCCSP is a multidisciplinary regional resource that was created in 1993 and follows the Children's Oncology Group (COG) long-term follow-up care guidelines for survivors of childhood, adolescent, and young adult cancer (see <http://www.survivorshipguidelines.org/>

for more information on these guidelines). There is no defined upper age limit to attend the clinic but it is recommended that treatment was received before the age of 23. The overarching goals of the LCCSP are to promote and maintain the physical and psychosocial health of childhood cancer survivors and improve quality of life (http://www.hopkinsmedicine.org/kimmel_cancer_center/centers/pediatric_oncology/programs/longterm_survivors.html). Specific activities within the clinic include monitoring and treating long-term complications and promoting healthy lifestyle behaviors to reduce risks associated with cancer and treatment. Before a child/adolescent has his/her first visit to the LCCSP, treatment records are reviewed and a treatment history is generated to develop an individualized survivorship care plan. During the first visit, the treatment history is reviewed and discussed with the child/adolescent and family and a plan for necessary medical tests and follow-up appointments is outlined.

The PI contacted the coordinator of the LCCSP by phone and verbally provided information on the general purpose of the study as well as the inclusion and exclusion criteria for participants. The director and coordinator requested that a written description of the proposed study be sent via email to assess the quality, appropriateness, and feasibility of the proposed study (see Appendix F). A face-to-face meeting also was conducted with the coordinator to further discuss the study and answer questions. After reviewing all materials, the director and coordinator approved the proposed study and wrote a letter of support on October 8, 2008 (see Appendix G).

Recruitment began after approval was obtained from the Johns Hopkins Medicine and University of South Florida Institutional Review Boards (IRB). Recruitment methods included flyers placed at the check-in desk and nurses' station in the POOC (see Appendix H) as well as phone and/or clinic contact with potential participants. The phone contact and clinic-based recruitment method will be described below. After approval was obtained, the LCCSP coordinator developed a list of 36 potential participants who met the specified study criteria. The LCCSP coordinator, a research coordinator in pediatric oncology, and a nurse who worked in both the LCCSP and POOC contacted potential participants via phone or email to introduce the study and inquire if they would like to be contacted by the PI for further information. After these recruitment efforts, a total of 11 potential participants expressed interest in the study and provided verbal consent/assent for the PI to contact them in accordance with the Health Insurance Portability and Accountability Act (HIPAA). Regarding the other 25 potential participants, 21 were contacted via phone or email on multiple occasions but did not call or email back, one individual was incarcerated, one potential participant's caregiver indicated that although the family was interested in the study, her child's transition experiences were "too traumatic" to discuss at the present time, and two potential participants were deemed ineligible because they would have turned 18 years-old during the course of the study.

Demographic characteristics for these 25 adolescents are presented including age, diagnosis, treatment type, and years since treatment completion. This information was obtained from the Johns Hopkins online patient records

system and provided to the PI by the LCCSP research coordinator. Adolescents ranged from 12-17 years of age with a mean of 14.4 years. Regarding diagnosis, adolescents were diagnosed with the following types of cancer: leukemia (n=10), lymphoma (n=6), carcinoma (n=3), sarcoma (n=3), dysplastic lesion of mid-back (n=1), melanoma (n=1), and spindle cell neoplasm (n=1). Adolescents received a variety of treatments including chemotherapy only (n=7), surgery only (n=5), chemotherapy and radiation (n=3), chemotherapy and bone marrow transplant (BMT) (n=3), chemotherapy, radiation, and surgery (n=2), radiation and BMT (n=1), chemotherapy and surgery (n=1), and chemotherapy, radiation, and BMT (n=1). Of note, two treatment histories were not provided. Regarding years since treatment completion, adolescents were in one of five categories including six months to one year (n=3), one to two years (n=5), two to three years (n=5), three to four years (n=7), and four to five years (n=5) post treatment completion.

The PI then made contact with the 11 potential participants who met study criteria and agreed to provide their contact information by phone or an in-person meeting at the POOC/LCCSP. The PI contacted one potential participant's caregiver and provided information on the study. The caregiver indicated that she would ask her child if he was interested in participation as well. The PI made multiple attempts to follow-up with this family; however, the adolescent or caregiver did not return the PI's phone calls. For the remaining 10 potential participants, the PI obtained oral consent/assent prior to administering the screener questionnaire (see Appendix I). The PI informed each adolescent and their caregiver(s) that their participation in the phone call or clinic meeting was

completely voluntary, steps were going to be taken to protect their health information in accordance with HIPAA, and their care at Johns Hopkins Hospital would not be affected if they chose not to participate. Those adolescents and their caregivers who verbally granted the PI permission to ask questions were administered the screener questionnaire. Caregivers assisted the adolescent in answering the questions. Once all of the questions were asked, the PI reviewed each answer to verify that the responses were accurate. Two adolescents did not meet criteria to participate in the study. One potential participant was home schooled during and after treatment completion, the other adolescent was five years post-treatment completion. The PI explained to these adolescents and their caregiver(s) why they were ineligible to participate in the study and thanked them for their time. The PI informed those adolescents and their caregivers who were ineligible that all information collected would be destroyed. The PI subsequently destroyed all the information associated with that particular individual.

Those eight adolescents and their caregivers who met criteria and expressed continued interest in participating in the study were informed that the information collected from the screener questionnaire would be stored in a password protected database. All participants provided the PI consent/assent to be included in the database. They were told that they could request that their name and information be removed from the database at any time. Adolescents and their caregivers were then asked if they would like: (a) to schedule a day, time, and location for the interview; (b) additional time to make a decision and have the co-investigator contact them within a week via phone; or (c) to decline participation.

Each potential participant and their caregiver(s) was given ample time to ask questions, voice concerns, and think about whether they would like to participate in the study. Six adolescents either scheduled a day/time for the interview during the initial phone call or requested additional time to think about whether they wanted to participate in the study. For those who requested additional time, the PI made a follow-up phone call on the date and time requested by each participant and their caregiver(s). The remaining potential participants agreed to enroll in the study during the follow-up phone call. All interviews were scheduled based on participant and caregiver(s) day, time, and location preferences. Of note, the two other potential participants agreed to be a part of the study but experienced a relapse prior to scheduling an interview. Therefore, a total of six adolescents were recruited from Johns Hopkins.

The six participants were then mailed or emailed an informational packet that included: (a) an introductory letter that briefly described the purpose of the study and listed all documents in the informational packet (see Appendix J); (b) consent and assent forms approved by the Johns Hopkins Medicine and University of South Florida IRB for participant review (see Appendix K and L); and (c) a quick guide for the interview and follow-up meeting (see Appendix M). If requested, the PI called or emailed participants and their caregiver(s) one week before their scheduled interview to answer any questions about the informational packet and provide a reminder about the day, time, and location of the interview. They also were informed that they needed to review and sign assent and consent forms before the interview began and complete a demographic questionnaire

immediately after the interview. Additionally, adolescents were asked to bring any documents (e.g., journals, letters) and/or audiovisual material (e.g., drawings, other artwork) to the interview session. The PI informed them that they could bring documents and/or audiovisual material they already have or create something if they chose. They also were notified that their documents and/or audiovisual materials would be collected at the end of the interview session so the PI could copy/scan them. Adolescents were told that their original items would be returned to them at the follow-up meeting. In the event that an adolescent was uncomfortable with leaving original documents and/or audiovisual material in the possession of the co-investigator, they were given the option to copy/scan these items themselves and bring them to the interview.

The Gathering Place. The Gathering Place is a non-profit cancer organization and support center located in Ohio. The Gathering Place was established in January of 2000 with the goal of providing free support, education, and programming for individuals and families impacted by cancer in the community. In October of 2008, The Gathering Place opened a second location to reach a greater number of people. A variety of services are offered by clinical staff to address social, emotional, physical, and spiritual needs of cancer survivors and their families. Examples of services include an on-site medical library, public lectures by local cancer experts, adult, teen, and child supports groups, cancer specific groups (e.g., leukemia, myeloma, prostate), exercise classes, and nutrition/health cooking classes. According their website, The Gathering Place to

date has served approximately 17,500 individuals within the community (<http://www.touchedbycancer.org/>).

The Gathering Place was contacted because recruitment efforts at Johns Hopkins Hospital were exhausted and more participants were needed to reach saturation. The PI contacted the volunteer coordinator at The Gathering Place by phone and verbally provided information on the general purpose of the study as well as the inclusion and exclusion criteria for participants. The volunteer coordinator spoke with the director of the volunteer/program staff regarding the study. The director then requested that a written description of the proposed study be sent via email to assess the quality, appropriateness, and feasibility of the proposed study (see Appendix N). A face-to-face meeting was scheduled with the director of volunteer/program staff as well as the director of programming to discuss details of the study and recruitment opportunities. The directors granted approval for the study and referred the PI to speak directly with the teen program facilitator. The PI spoke with the teen program facilitator via phone to further discuss the study. The teen program facilitator agreed to assist with participant recruitment and wrote a letter of support on March 9, 2010 (see Appendix O).

Recruitment began after approval was obtained from the University of South Florida Institutional Review Board (IRB). After approval was obtained, the teen program facilitator presented the study to the teen group. Following the meeting, the facilitator provided the PI with a name of a potential participant who met eligibility criteria and expressed interest in participating in the study. This adolescent then referred the PI to another adolescent in his teen group. The PI

informed the teen program facilitator of this recommendation, and she contacted that particular adolescent and caregiver(s). For each potential participant, the facilitator obtained verbal consent and assent prior to disclosing contact information to the PI. An initial phone call was made directly from the PI to the two potential participants who met study criteria and agreed to provide their contact information. All interviews were scheduled based on participant and caregiver(s) day, time, and location preferences. The remaining recruitment procedures were the same as those used at Johns Hopkins (see Appendix P, Q, R, S, and T).

Interview sessions. The PI conducted all interviews. Seven interviews occurred at the home residence of the adolescent, and one was completed at Johns Hopkins Hospital in the LCSSP coordinator's private office. Interviews ranged between 38 minutes to an hour and 36 minutes and were audiotaped. On the day of the interview, the IRB approved informed assent and consent forms were verbally reviewed in detail with each adolescent and their caregiver(s). Time was allotted for the participants and caregiver(s) to review the forms and ask questions prior to providing their signature. Participants were reminded that there were two phases of the study (i.e., interview and follow-up session). Based on recommendations from Carspecken (1996), each individual was then briefed about the purpose and structure of the interview. Participants were informed that the interview would be audiotaped so that the PI could analyze the data at a later point and that handwritten notes would be taken during the interview. The PI answered any questions related to this information prior to starting the interview. All participants elected to use only their real first name for the purposes of preserving their

confidentiality during the taped interview. Caregivers were not present in the room for seven of the interviews. The remaining interview was conducted with a caregiver in close proximity to the interview room. This particular adolescent verbally indicated that he was comfortable with the presence of his caregiver and did not perceive the need to change the interview location. The interview protocol was used to guide each interview session. Participants also were permitted to present and describe any documents and/or audiovisual material during the interview. One participant presented a document during their interview. The other adolescents in the study indicated that they did not have any documents or audiovisual material that they felt were relevant to the study or would help to better describe their experiences. At the end of the interview session, the PI clarified and summarized information shared by the participant and, if necessary, asked follow-up questions to clarify and/or elaborate on responses.

After the interview was completed, each participant completed the demographic questionnaire. Some caregivers assisted their adolescent in completing the questionnaire. The questionnaire was collected and immediately assigned a number to maintain the confidentiality of the participants. This number was used to link the questionnaire to the interview data. After the demographic questionnaire was collected, the PI provided an opportunity to debrief about the session (Carspecken, 1996). Each participant and their caregiver(s) were given the opportunity to ask questions about their interview experience. For those participants and caregivers who requested, the PI provided more detailed information about the study and reviewed confidentiality. Of note, none of the participants requested to stop the interview due to distress or discomfort. Therefore, there was not a need to provide any participant with psychological services referral

information. Hand-written notes also were taken during and after each interview to document salient quotes and/or key phrases from participants, non-verbal activity, and thoughts/impressions on interviews, documents, and/or audiovisual material (Patton, 2002). Hand-written notes were formatted and typed into a Microsoft Word document.

Follow-up meetings. Participants who completed the interview received a phone call from the PI to schedule a follow-up meeting approximately one month from the date of the initial interview. All eight participants completed a follow-up meeting. The day, time, and location of the follow-up meeting were based on the adolescent's preference and schedule. Three follow-up meetings were conducted in person at the participant's home residence. The remaining follow-up meetings were completed via phone.

Participants were mailed or emailed a summary of their interview so that they could review this information prior to the scheduled follow-up meeting. Caregivers were allowed to assist with the review of this information if necessary. The PI developed an individualized list of follow-up questions to guide the follow-up meeting. Of note, two of the eight participants received both the transcript and interview summary prior to the follow-up meeting. All remaining participants received the transcript after the follow-up meeting was completed due to delays in receiving transcribed documents from the transcriptionist.

During the follow-up meeting, findings were presented to the participants. Participants were given the opportunity to verify the accuracy of the interview summary as well as share their thoughts and comments. The PI also asked any follow-up questions after the interview summary was discussed. The duration of the follow-up meetings ranged from 10 to 38 minutes. The PI took hand-written notes during and after the

meeting. These notes were formatted and typed into a Microsoft Word document. Of note, one participant offered to share a document with the PI during the follow-up meeting. The participant mailed a copy of the document to the PI's home residence. Once the document was received, the PI contacted this participant to schedule a phone call to discuss the document. The meeting was scheduled within a few weeks after the follow-up meeting with permission from both the adolescent and caregiver. Overall, there were three formal contacts with seven of the participants that included the screener phone call, interview session, and follow-up meeting. For the remaining participant, there were four contacts because an additional meeting was scheduled to discuss a document.

Caregiver participation. Although caregiver perspectives were not the focus of the study, some caregivers informally shared information about their child's cancer experience and/or provided their perspectives on the topics under investigation. The PI documented the caregivers' thoughts and comments in a Word document. These data were informative to the study and also provided a rich opportunity for triangulation (i.e., obtaining multiple perspectives to facilitate a deeper understanding of the transition from off-treatment to post-treatment and school reintegration).

Compensation for participation. Participants were given a \$10 gift card for their participation in the interview and another \$10 gift card for participation in the follow-up meeting. Therefore, participants received up to \$20 for their participation. Payment was disbursed at the end of each session. Pilot test participants were given a \$10 gift card for their participation.

Ethical Considerations

Several steps were taken to protect the privacy of participants throughout the entire qualitative research process (Kvale, 1996). First, the PI obtained approval to conduct the study from the University of South Florida and Johns Hopkins Medicine IRB. No data were collected until IRB approval was obtained. Second, participants and their caregiver(s) were required to review and sign assent/consent forms prior to the interview. These forms were given to participants and their caregiver(s) in advance so they had the opportunity to review them. The consent and assent forms included information on the overall purpose of study, research design, possible risks and benefits of participation, procedures employed to maintain confidentiality, and the rights of participants to withdrawal from the study at any time. These forms also included the PI's contact information so participants and caregivers could ask any questions and/or voice concerns at any time.

Steps to ensure confidentiality were taken. Participants were assigned a code number as soon as they signed assent and consent forms. This number was used throughout data collection, analysis, and reporting. Screener and demographic questionnaires, notes, audiotapes, transcripts, and documents were labeled using this code number to protect the confidentiality of each participant. All information used in the peer review process included the code number as well. Randomly selected pseudonyms were used when writing up the results of the study. The PI maintained a list of the participants' names, corresponding code number, and assigned pseudonyms in a locked file cabinet at her residence. All the information that was collected prior to the interviews (i.e., contact information provided by directors, screener questionnaire) and during the

data collection process (i.e., signed consent/assent forms, notes, audiotapes, transcribed interviews, and documents) was kept in the locked file cabinet as well. Screener and demographic questionnaire items stored in Excel files as well as notes, personal journal entries, and transcribed interviews in Word files were stored in password protected files on the PI's computer. These documents were saved on a CD as a backup. This CD was stored in the locked file cabinet as well. Only the PI had access to the locked file cabinet and computer. Lastly, only participants' first names were used in email correspondence during the study. Data collected from six of the participants under the Johns Hopkins IRB will be retained until the participants reach the age of 23. After they turn 23 years of age, all data associated with these participants will be destroyed. Data collected from the remaining two participants under the University of South Florida IRB will be kept for five years and then destroyed.

Data Analysis

The use of multiple data sources to arrive at a greater understanding of the cases, research questions, and quintain is a central feature of case studies (Stake, 1995, 2005; Yin, 2008). Therefore, data were generated through five sources: (a) questionnaires; (b) typed notes taken during and after the interviews and follow-up meetings; (c) transcribed interviews and follow-up meetings; (d) documents; and (e) parent feedback. These data were collected from February to September of 2010. To guide the analysis of these data, a combination of a template organizing style, immersion/crystallization (I/C) approach, and a multiple case study approach were used (Borkan, 1999; Crabtree & Miller, 1999, Stake, 2005; Yin, 2008).

The template organizing style is used to develop codes and a codebook to organize the data as well as apply the codes to segments of data and sort those coded segments into similar categories (Crabtree & Miller, 1999; Miles & Huberman, 1994). The primary purpose of this approach is to reduce the amount of raw data (i.e., data reduction) and prepare the data to be analyzed (Miles & Huberman, 1994). Once the data are organized, the I/C approach can be used to analyze the coded segments of data. According to Borkan (1999), the I/C approach requires the PI to *immerse* herself in the data by conducting multiple, in-depth examinations of the data over a prolonged period of time. *Crystallization* occurs when the PI disconnects from being immersed in the data to reflect on her analysis experience and attempt to identify themes. These two processes (i.e., immersion and crystallization) occur throughout data collection and analysis until all the data are analyzed and meaningful patterns emerge. Key features of this approach include prolonged engagement with the data and the use intuition and/or the research literature to develop insights on the phenomenon under study. This particular approach is deemed appropriate when the goal of the research is to understand the experiences of others and little research exists on the topic because it allows the researcher to remain open and intimately involved with the data yielded from participants' stories (Miller & Crabtree, 1994). The I/C approach occurs throughout the entire research process. Additionally, a multiple case study approach is used to examine individual cases as well as commonalities and differences among cases (i.e., cross-case analysis) in order to arrive at a greater understanding of a phenomenon (i.e., quintain) (Yin, 2008). A focus is placed on cross case analysis to formulate assertions about the phenomenon. Assertions are findings about the quintain, which must be based on evidence from individual cases.

This method of data analysis is considered appropriate if the goal is to learn more about a general phenomenon while still attending to the uniqueness and importance of individual case contributions. Figure 1 illustrates this analytic process (Yin, 2008). Of note, the red solid line in the figure illustrates the “feedback loop” (p. 56), which represents when a pertinent discovery arises during data collection and requires the investigator to reconsider or redefine the conceptual framework used to guide the study.

The next section includes details on the use of the template organizing style, I/C approach, and cross-case analysis used in this study. Prior to this discussion, it is important to note that data analysis was conducted throughout the data collection process (Huberman & Miles, 1994; Patton, 2002). Data analysis is considered a cyclical process during which data are continually collected, reflected upon, and analyzed to assess how the research process is progressing and whether new topics surface that require exploration (Creswell, 1998).

First, the data were prepared for analysis (Miles & Huberman, 1994). Interviews and follow-up meetings were audiotaped and transcribed verbatim by a transcriptionist. Steps to maintain and preserve participant confidentiality were taken during transcription. The PI stated the participant’s unique code number at the beginning of the interview and follow-up meeting. Additionally, only the participant’s first name was used in the recordings. Therefore, the transcriptionist had no knowledge of any facet of the participant except their code number and first name. The transcriptionist’s sole responsibility was to transcribe the interviews and follow-up meetings verbatim and return the documents directly to the PI. Each transcribed interview and follow-up meeting was then reviewed multiple times by the PI to ensure accuracy.

Transcribed interviews and follow-up meetings as well as notes were typed into Word documents. The one participant who shared a document elected to make a copy and send the copy to the PI. Of note, receipt of transcribed interviews and follow-up meetings from the transcriptionist was at times delayed over the course of the study due to logistical and time management concerns. As a result, it was not always feasible to analyze transcribed data immediately after collection. It was essential that the data collection and analysis process continue. Therefore, the PI listened to audiotapes and examined notes, documents, and questionnaires when transcripts were not available. This allowed the PI to stay actively engaged in the data collection and analysis cycle. The PI was able to make modifications and/or changes to the interview guide, formulate additional questions to ask during follow-up meetings, and assess how well the data were answering the research question

To begin data analysis, interview and follow-up meeting transcripts, notes, documents, questionnaires, and parent feedback for each individual case were reviewed multiple times throughout the study to obtain a general sense of the data and become familiar with the overall content. Notes were written to record general impressions, ideas, and themes (i.e., reading and memoing) (Creswell, 1998). Once a general sense of the data were obtained and documented, the template organizing style strategy (i.e., development of codes and a codebook to organize data) was utilized to describe and classify data (Crabtree & Miller, 1999; Miles & Huberman, 1994). Stake (1994) indicated that if research questions derived from the literature are known in advance, then the researcher might take advantage of a deductive coding approach (i.e., applying pre-established codes to data). A deductive coding approach was used in this study because

the research questions were already identified based on the literature. Furthermore, the semi-structured interview protocol included topic domains and corresponding questions that were developed to address each research question. The interview protocol and, more specifically, the topic domains, were used to develop broad, “start-up” codes. This approach “forces the analyst to tie research questions or conceptual interests directly to the data” (Miles & Huberman, 1994, p. 65). An inductive coding approach also was used as new information was yielded from the data that required new codes to adequately capture the experiences of the participants.

A codebook was developed by the PI and a graduate student who was familiar with qualitative data analysis to organize participant responses into codes and categories that corresponded with the interview protocol and research questions. Based on recommendations from Miles and Huberman (1994), the PI and peer randomly selected two interview transcripts to begin developing the codebook using the interview protocol as a guide. The PI and peer independently read the two transcripts, assigned codes that best captured the meaning of text segments, and developed a preliminary code list. The PI used a hand coding method, and the peer utilized computer-based coding method (i.e., track changes in Word) to select segments of text and assign codes to the text segments.

The PI and peer then had an in-person meeting to share and discuss their respective code lists as well as cross-check and validate the codes. These codes were merged to develop the working codebook. The PI and peer coded another randomly selected transcript together to make sure they had a mutual understanding of the codes. Once a mutual understanding of the working codebook was achieved, the PI and peer named codes and developed operational definitions for each code. The PI and peer

independently coded the remaining transcripts and continued to refine the codebook. When there was a disagreement, the PI and peer re-assessed the segment of text and discussed it in-depth until consensus was reached on the code that best reflected the segment of text. Inter-rater reliability was calculated for the remaining interview transcripts (n=5) (Miles & Huberman, 1994). The PI randomly selected four pages of text and tallied each line as either an agreement or disagreement. Agreements were divided by the total number of lines on all four pages and then multiplied by 100. Inter-rater reliability ranged from 80% to 90%. Ultimately, each transcript was discussed at length during the meetings and 100% agreement was reached on all transcripts.

The PI applied the codebook to the follow-up transcripts, typed notes, questionnaires, documents, and parent feedback. As data were coded, the PI manually cut and pasted text segments and placed them under their designated category in a Word document. This strategy allowed the PI to review all coded text segments in an efficient and organized fashion, which facilitated more in-depth data analysis. Next, the PI completed a case report worksheet for each case to summarize information yielded from each case (e.g., observations, unique context of the case) (Stake, 2005; see Appendix U). Special attention was given to examining whether data converged or triangulation occurred within each case.

The PI then utilized the I/C process to review the individual case study reports, identify and “crystallize” themes, and establish relationships among themes that were relevant to the research questions. Of note, the peer coder also was involved in this process as the PI often shared insights and discussed her thought process to gain another perspective on the data. First, the PI immersed herself and engaged in an intensive and

prolonged examination of data using a regimented process (Borkan, 1999). During those weeks when data were available, the PI examined data yielded from one participant for two consecutive hours. Next, the PI distanced herself from the data for two hours in order to allow “crystallization” of emerging insights, ideas, and new and/or refinement of themes to occur. Journal notes were then taken by the PI during these distancing periods to document insights and other salient thoughts. This process was repeated later that day. The same process was conducted the next day, however, individual case data was compared with data collected from other participants to obtain a greater sense of how the individual case data related to the overall multiple case study analysis. Over the course of the study, the process of categorical aggregation occurred during these prolonged periods of immersion as meaningful instances found in the data accumulated and led to the development of a theme (Stake, 1995). The development of themes was based on the PI’s own views, peer coder’s perspective and feedback, and research literature (Stake, 1994). The I/C process continued until thematic saturation was reached (Lincoln & Guba, 1985).

The PI strived to achieve “analytic generalization” which is defined as when “a previously developed theory is used as a template with which to compare the empirical results of the case study [or studies]” (Yin, 2008, p. 38). Therefore, data were interpreted relative to the conceptual framework and research literature to develop assertions or overarching findings. These assertions and their relationship with the themes were then presented in a graphic illustration that built upon the existing conceptual framework used for the study. An effort was made to provide the reader with the most accurate and cogent explanation of the findings (Johnson & Christensen, 2004).

Throughout the data collection and analysis process, member-checking was conducted with participants during follow-up meetings. The PI shared interview summaries with the participants to determine if they believed it accurately represented their experiences. Participants were asked additional questions and/or to offer clarification on interview responses and were also encouraged to share any other comments or perspectives. Participants identified some discrepancies in the interview summaries. The PI and participant discussed these discrepancies and resolved them during the follow-up meeting. In many instances, clarification was gained and additional questions yielded additional information that was useful in answering the research questions.

Findings also were discussed with one professional in the psychology field and one doctoral committee member who were familiar with the qualitative research process but not directly involved in the study. Conference calls were held with each individual to gain their perspectives and insights on the findings. The primary task of these two reviewers was to challenge the PI and require her to discuss and justify her decision-making process as well as analysis and interpretation of the data (Johnson & Christensen, 2004). As a result, the PI re-evaluated some of her findings based on reviewer feedback and reviewed the data again. The conferences with the reviewers promoted a greater understanding of the data and facilitated the “crystallization” process.

Validity Measures

The following strategies were used to enhance the validity of the study (Carspecken, 1996; Johnson & Christensen, 2004; Merrick, 1999; Patton, 2002): (a)

reflexivity; (b) data recording; (c) methods triangulation; (d) member checking; (e) peer review; (f) negative-case sampling; (g) audit trail; and (h) low-inference descriptors.

Reflexivity. The PI engaged in critical self-reflection to assess her own biases, expectations, and past experiences that may have influenced the qualitative research process. First, a peer familiar with the qualitative research process conducted an interview with the PI to raise awareness of biases and expectations related to the study. Second, the PI reflected and documented observations about herself, her role in the research, and insights on the research process in a personal journal. Information gleaned from these two reflective exercises was meant to provide readers with an honest and open description of the PI's role throughout the entire research process (Patton, 2002).

Data recording. Steps were taken to accurately describe what happened and what was said during participant interviews and follow-up meetings. The PI audiotaped all interviews and follow-up meetings as well as took notes during and immediately after each session. Additionally, a qualified transcriptionist transcribed the interviews and follow-up meetings verbatim. The PI thoroughly reviewed all transcribed documents to assess accuracy.

Detailed description of the methodology. Based on the recommendations of Johnson and Christensen (2004), the PI provided a detailed description of the methods used in the study. This information will provide readers with a step-by-step description of the methodology for those who may want to replicate the study.

Methods triangulation. The study incorporated the use of multiple data collection methods to improve the credibility of the findings. Data collection methods included in-depth individual interviews and follow-up meetings, notes taken during and after the

interviews and follow-up meetings, documents, parent feedback, and questionnaire. The PI compared these data and determined that the information yielded by these multiple data sources was consistent (Patton, 2002).

Member checking. Follow-up meetings were used to conduct member checks with each participant. Participants were mailed or emailed a summary of their interview so they could review the information prior to the scheduled meeting. Adolescents reviewed the summary, and they had an opportunity to provide feedback and determine whether they believed their perspectives were accurately and fairly represented in the summary. The main purposes of the member check included confirmation of demographic information, data error reduction, and verification of accuracy of the interview data.

Peer review. Peer review sessions were conducted with two professionals who were familiar with the qualitative research process but not directly involved in the research study. Conference calls were held with each reviewer to gain their perspectives, insights, and feedback on the findings. Each session was used to discuss and challenge the PI's findings as well as resolve any disagreements between the PI and reviewer. The purpose of these sessions was to recognize and address any researcher bias as well as obtain another perspective on the interpretation of the data (Onwuegbuzie, 2002; Teddlie & Tashakkori, 2003).

Negative case sampling. Patton (2002) indicated that there are no established rules for searching for deviant cases but recommended that researchers identify these cases and discuss possible reasons for these discrepant data in the final document. Therefore, the PI actively searched for cases that disconfirmed her expectations or did not

fit the observed patterns in the data. The PI examined these deviant cases in close detail and provided descriptions of the case(s) in the results section.

Audit trail. An audit trail was left for one of the peer reviewers to review and determine if the reported findings could be traced back to their original data sources. The PI left an audit trail consisting of various types of data (e.g., notes, coded interviews, documents, personal journal entries) and an explanation of data analysis procedures (Lincoln & Guba, 1985, Stake, 2005). These data were made available to the peer reviewer (while maintaining the confidentiality of each participant) so he/she could determine how the PI arrived at the findings.

Low-inference descriptors. Direct quotations, a type of low-inference descriptor (i.e., descriptive information that requires minimal interpretation or a low degree of subjectivity by the reader), were used to highlight themes. The goal of using direct quotations was to allow the reader to experience the perspectives and unique viewpoints directly from the participants (Johnson & Christensen, 2004). This strategy also was used to minimize bias in the reporting of the findings.

Organization of Results Section

The results section includes a brief description of each individual case in table format and an in-depth synthesis of findings yielded from the cross case analysis (Stake, 2005, Yin, 2008). Findings are organized according to each research question. Themes found across cases are discussed, and direct quotes from the participants are used to illustrate a particular theme. Furthermore, preliminary assertions based on cross-case findings are discussed. Graphic illustrations are included to assist in summarizing the

cross-case findings and to depict how the findings of the study expand on the conceptual framework utilized in this study (Miles & Huberman, 1994; Stake, 2005).

CHAPTER FOUR:

RESULTS

The purpose of this chapter is to present the results of this multiple case study according to each research question delineated in Chapter Three. The data analyzed represent information provided by eight adolescent survivors of childhood cancer. First, demographic information on all the participants in the study is provided. Second, a description of each participant's cancer history is provided. Third, the themes yielded from the cross-case analysis are presented relative to each research question that includes representative quotes from participants. Fourth, tentative assertions are presented based on the cross-case analysis. Lastly, a summary of the principle investigator's (PI) personal journal is provided for the reader to gain an understanding of the PI's role in the research process. These data were analyzed using a combination of strategies including hand coding methods, word processing to organize and categorize data, case study worksheets and strategies adapted from Stake (2005) and Yin (2008), and multiple reflective discussions with qualified peer reviewers within the immersion/crystallization (I/C) data analysis method.

Participant Demographic Characteristics

A total of eight adolescent cancer survivors participated in the study. This particular sample size yielded rich information that helped answer the research questions (Guest, Bunce, & Johnson, 2006; Patton, 2002). Furthermore, thematic saturation was reached with the given sample size. Thematic saturation occurs when themes are

repeated or become redundant and subsequent interviews/other data collection methods do not reveal any new information or themes (Lincoln & Guba, 1985; Morse, 1994).

Demographic characteristics for each participant are reported in Table 1 and 2. These data were collected from the demographic survey that each participant was required to complete following the interview. The sample consisted of five male and three female adolescent survivors of childhood cancer. Participants were between the ages of 14 and 17 years and were all from Caucasian, non-Hispanic backgrounds. Although questionnaire data were not specifically collected on SES related variables, subjective observational data such as caregiver educational attainment, location of residence, and receipt of educational and social resources suggested that participants were from higher SES (n=4), middle SES (n=3), and lower SES (n=1) backgrounds. Five adolescents were diagnosed with leukemia, and the remaining participants received a diagnosis of lymphoma. Four participants received chemotherapy only, three had a combination of chemotherapy and radiation, and one had chemotherapy and a bone marrow transplant (BMT). For the purposes of providing context, a brief description of each type of cancer that is represented in this study is provided below from the National Cancer Institute website (<http://www.cancer.gov/dictionary/>).

Acute lymphoblastic leukemia (ALL): “An aggressive (fast-growing) type of leukemia (blood cancer) in which too many lymphoblasts (immature white blood cells) are found in the blood and bone marrow. Also called acute lymphoblastic leukemia and acute lymphocytic leukemia.”

Acute myeloid leukemia (AML): “An aggressive (fast-growing) disease in which too many myeloblasts (immature white blood cells that are not lymphoblasts) are found

in the bone marrow and blood. Also called acute myeloblastic leukemia, acute myelogenous leukemia, acute myeloid leukemia, acute nonlymphocytic leukemia, and ANLL.”

Hodgkin lymphoma: “A cancer of the immune system that is marked by the presence of a type of cell called the Reed-Sternberg cell. The two major types of Hodgkin lymphoma are classical Hodgkin lymphoma and nodular lymphocyte-predominant Hodgkin lymphoma. Symptoms include the painless enlargement of lymph nodes, spleen, or other immune tissue. Other symptoms include fever, weight loss, fatigue, or night sweats. Also called Hodgkin disease.”

Burkitt lymphoma: “An aggressive (fast-growing) type of B-cell non-Hodgkin lymphoma that occurs most often in children and young adults. The disease may affect the jaw, central nervous system, bowel, kidneys, ovaries, or other organs. There are three main types of Burkitt lymphoma (sporadic, endemic, and immunodeficiency related).”

At the time of the study, all of the participants attended high school and were in grades ranging from ninth through 12th. The participants had varied educational experiences during treatment and post-treatment including hospital-based, home-based, public school, and private school placements. These placements were primarily dictated by a combination of factors including type of cancer diagnosis, treatment regime, treatment side effects, and medical team recommendation.

Participant Descriptions

Descriptions for each of the eight adolescent cancer survivors are provided below. These descriptions include information that was gathered from the screener and

demographic questionnaires as well as transcribed interview and follow-up documents. Pseudonyms are used to protect the adolescents' identities.

Drew. Drew is a 16-year-old White male who lives in a rural community. He is in 10th grade at a public high school. Drew has two brothers ages eight and six. Drew resides with his mother and stepfather and has frequent contact with his biological father. His primary symptom prior to being admitted to the hospital included swelling in the nose. He was diagnosed with acute lymphoblastic leukemia (ALL) in April of 2007 at the age of 13. Drew's treatment began immediately after diagnosis and included chemotherapy and radiation over the course of two years. Drew shared that he experienced "the whole nine yards" (Drew, Interview line 40) and had treatment side effects such as body aches and pain, nausea, vomiting, and hair loss. He completed treatment in April of 2009 at the age of 15, is currently in remission, and has never experienced a relapse to date.

Regarding his school history, Drew did not return to the seventh grade after his diagnosis and missed the entire eighth grade school year. He was physically away from the regular school setting for approximately one and a half years. During this time, Drew received tutoring services at home. He returned to public school on the first day of ninth grade and attended on a fairly regular basis with the exception of missing school due to two bouts of pneumonia in the winter. While in the school setting, he did not receive special education services as a result of cancer or treatment (e.g., special education, school health services).

Table 1

Characteristics of Individual Cases (N=8)

Pseudonym	Gender	Age	Ethnicity	Race	Grade	Diagnosis	Treatment Received	School History
Drew	Male	16	Non-Hispanic	White	10 th	ALL	Chemo, Radiation	DT: Home PT: Public school CP: Public school
John	Male	14	Non-Hispanic	White	9 th	ALL	Chemo	DT: Public school, Home PT: Public school CP: Public school
Alexis	Female	17	Non-Hispanic	White	11 th	Hodgkin Lymphoma	Chemo, Radiation	DT: Private school PT: Private school CP: Private school
Luke	Male	16	Non-Hispanic	White	10 th	AML	Chemo	DT: Private school, Hospital, Home PT: Private school CP: Private school

Note. Chemo= chemotherapy, BMT= bone marrow transplant, ALL= acute lymphoblastic leukemia, AML= acute myeloid leukemia, DT= during treatment school placement, PT= post treatment school placement, CP= current school placement.

Table 1

Characteristics of Individual Cases (N=8) Continued

Pseudonym	Gender	Age	Ethnicity	Race	Grade	Diagnosis	Treatment Received	School History
Mark	Male	17	Non-Hispanic	White	12 th	ALL	Chemo	DT: Private school PT: Private school CP: Private school
Grace	Female	17	Non-Hispanic	White	12 th	Burkitt Lymphoma	Chemo	DT: Home, Internet PT: Public school CP: Public school
Kendall	Female	17	Non-Hispanic	White	12 th	Hodgkin Lymphoma	Chemo, Radiation	DT: Private school PT: Private school CP: Private school
Justin	Male	15	Non-Hispanic	White	10 th	AML	Chemo, BMT	DT: Hospital, Home PT: Home, Public school CP: Public school

Note. Chemo= chemotherapy, BMT= bone marrow transplant, ALL= acute lymphoblastic leukemia, AML= acute myeloid leukemia, DT= during treatment school placement, PT= post treatment school placement, CP= current school placement.

John. John is a 14-year-old White male who lives in an urban community. He is in the ninth grade at a public high school that specializes in preparing students for careers in the science, math, and health care fields. John resides with his mother, father, 16-year-old sister, and 17-year-old half brother. He also has a 20-year-old half brother and 19-year-old half sister. He has never met his half sister. His primary symptom prior to being admitted to the hospital included stomach pain on the evening of Halloween. John was diagnosed with acute lymphoblastic leukemia (ALL) in November of 2004 at the age of nine. John received chemotherapy over the course of approximately two and a half years. Some of his treatment side effects included decreased energy and stamina, dizziness, nausea, and hair loss. He completed treatment in May of 2007 at the age of 11, is currently in remission, and has never experienced a relapse to date.

Regarding his school history, John did not return to the school setting after receiving his diagnosis. He missed two months of school during his fourth grade year due to receiving treatment in the hospital. Subsequently, he returned to school and attended “on” and “off” throughout the course of treatment (John, screener questionnaire). John did not receive any formal Home/Hospital services when he was unable to physically attend school. However, John received tutoring services at home during the middle of his treatment. He also received school health services while on treatment (i.e., medication administration from the school nurse). He attended school on a regular basis in seventh grade.

Alexis. Alexis is a 17-year-old White female who lives in an affluent urban community. She is in 11th grade at a private high school. Alexis has an older brother who is 22 years old and attends college. She resides with her mother and father. Her

symptoms, which included a cough and fever, appeared the day before school started. Her fever did not resolve and her primary care physician referred her to the hospital. At the hospital, it was determined that Alexis had pneumonia and that she had a malignant tumor. Alexis was diagnosed with Hodgkin's lymphoma in September of 2006 at the age of 13. She missed the week of school following her diagnosis. Alexis's medical team indicated that it was not urgent for her to start treatment right away. Therefore, Alexis chose to attend a school trip and began treatment when she returned. Alexis started treatment approximately one month after her diagnosis in early October of 2006. Her treatment included chemotherapy and radiation after chemotherapy for two consecutive months. She was on treatment for approximately five months. Some of her treatment side effects included fatigue, weight loss, pale skin, minimal nausea, increased appetite, and hair loss. Alexis described her side effects as not that "drastic" (Alexis, Interview lines 113-115). She completed treatment in February of 2007 at the age of 14 and is currently in remission as evidenced by a sufficient shrinkage in her tumor size. She has never experienced a relapse to date.

Regarding school history, Alexis missed a week of school after her diagnosis but regularly attended during her eighth grade year throughout treatment. She periodically was absent from school secondary to hospital-based treatments but overall did not miss many days of school. She indicated that her side effects were minimal and that she did not feel very sick, therefore, she "didn't feel the need to miss" school (Alexis, Interview line 109). Alexis did not receive special education services at school as a result of cancer or treatment.

Luke. Luke is a 16-year-old Caucasian male who lives in a suburban community. He is in 10th grade at a private high school. Luke has three older siblings including a 21-year-old sister and 20-year-old twin brother and sister who all attend college. He resides with his mother and father. Luke's symptoms appeared during the first few weeks of his ninth grade school year. His primary symptom included physical exhaustion, which impacted his school activities such as completing homework and running cross-country. Luke was diagnosed with acute myeloid leukemia (AML) in October of 2008 at the age of 14. His treatment included chemotherapy, which started the day after he was diagnosed. Some of his treatment side effects included weight gain, hair loss, and memory impairment. Luke received his last chemotherapy treatment in April of 2009 at the age of 15. He was kept in the hospital after treatment was completed secondary to neutropenia and was formally discharged from the hospital in May of 2009. Luke is currently in remission and has never experienced a relapse to date.

Regarding school history, Luke attended the first month of his ninth grade year. After Luke was diagnosed, he missed the following month and a half of school secondary to receiving treatment in the hospital. Following this initial hospitalization, Luke attended a few days of school each month. He estimated that he physically attended school 12 days of his ninth grade school year while on treatment. Luke received hospital-based tutoring services during treatment. He did not return to school after his treatment was completed because there were only finals exams remaining for the school year. Luke received home-based tutoring from his school teachers during the summer. He then returned to the 10th grade and attended on a regular basis. He did not receive special education services at school as a result of cancer or treatment.

Mark. Mark is a 17-year-old White male who lives in a suburban community. He is in 12th grade at a private high school. Mark has two younger brothers who are nine and 15 years old. He resides with his mother, father, and two brothers. His symptoms first appeared in late June/early July of 2005 and included fatigue, feeling “drained”, pale/yellowish skin color, and changes in his eye appearance (Mark, Interview lines 9-10). Mark also had two bloody noses in early August which he indicated was a “tell tale” sign that something was not right (Mark, Interview lines 16-18). Mark was subsequently diagnosed with acute lymphoblastic leukemia (ALL) in August of 2005 at the age of 13. He received his diagnosis approximately two and a half weeks before the start of his eighth grade school year. Mark received chemotherapy the day after he was diagnosed. His treatment lasted a little over three years. Some of his treatment side effects included loss of appetite, pale skin completion, moodiness, weight loss, and hair loss. Mark was considered in remission in May of 2006; however, he continued to take chemotherapy in pill form until November of 2008. He officially completed treatment at this time and was 16-years-old. Mark is currently in remission and has never experienced a relapse to date.

Regarding school history, Mark attempted to go to the first day of eighth grade; however, he was only able to attend for 15 minutes because he became ill. He did not return to school until mid-September and attended when he was physically capable throughout treatment. By the end of the school year, Mark was able to attend school on a regular basis. He reported missing 96.5 days of school that year. He did not receive any special education services at school as a result of cancer or treatment.

Grace. Grace is a 17-year-old White female who lives in a suburban community. She is in the 12th grade at a public high school. Grace is an only child and resides with her mother and father. Her symptoms appeared in the beginning of October of 2007 and included a persistent dry throat, swollen tonsils, and a bump on her throat. Grace was subsequently diagnosed with Burkitt lymphoma in mid-October at the age of 15. She started chemotherapy the day after she was diagnosed. Grace received chemotherapy for six months during her 10th grade school year. Some of her treatment side effects included feeling sick, hair loss, and dry skin on her hands. She completed treatment in April of 2008 at the age of 15. Grace is currently in remission and has never experienced a relapse to date.

Regarding school history, Grace did not physically attend school during treatment. However, she was enrolled in the Home-Hospital program and had a home-based tutor. She also elected to take an online course. Grace returned to the 10th grade in the beginning of May 2008. She did not receive any special education services at school as a result of cancer or treatment.

Kendall. Kendall is a 17-year-old White female who lives in an urban community. She is in the 12th grade at a private high school. Kendall has two older brothers and resides with her mother, father, and one brother. Her primary symptom prior to diagnosis included lumps in her neck that went down to her neckline and into her arm. Kendall was diagnosed with Hodgkin's lymphoma in September of 2007 at the age of 14. She started treatment two weeks after her diagnosis. Kendall's treatment included chemotherapy over the course of three months followed by radiation for 10 days. Her side effects from chemotherapy included weight gain, negative emotions related to

weight gain, loss of appetite, and hair loss. Radiation side effects included weight loss, vomiting, and loss of all taste in her mouth. Kendall completed treatment in February of 2008 at the age of 14. She is currently in remission and has never experienced a relapse to date.

Regarding school history, Kendall returned to the ninth grade a week after she was diagnosed. She attended school when she did not have treatments and/or appointments and was physically capable. After Kendall completed treatment, she still missed many school days that year secondary to appointments and continued side effects of treatment such as fatigue. Overall, Kendall reported that she missed 76 school days during her ninth grade year. She began attending school on a regular basis in the 10th grade. Kendall did not receive any special education services at school as a result of cancer or treatment.

Justin. Justin is a 15-year-old White male who lives in a suburban community. He is in 10th grade at a public high school. Justin has an older brother who attends college and a younger sister. He resides with his mother, father, and sister. He experienced symptoms during the summer after his 6th grade school year. Some of his symptoms prior to diagnosis included headaches, nausea, vomiting, decreased appetite, urge but inability to belch, bruising, and pale skin. He was diagnosed with acute myeloid leukemia (AML) in September of 2007 at the age of 12. Justin started chemotherapy immediately after his diagnosis and stayed in the hospital for two months to receive treatment. Some of his treatment side effects included nausea, vomiting, physical weakness, and loss of stamina. He also participated in a clinical trial and experienced additional side effects. Justin received a bone marrow transplant in February

of 2008 and subsequently was discharged to hospital/respice housing near the hospital. He was discharged from the hospital/respice house and returned home in March 2008 at the age of 12. Justin is currently in remission and has never experienced a relapse to date.

Regarding school history, Justin attended school every other day during the first week of seventh grade prior to receiving his diagnosis. After his diagnosis, he was unable to return to the school setting secondary to his intense treatment regime. Justin received hospital-based tutoring services throughout treatment. Per medical team decision, he was not allowed to attend the remaining three months of seventh grade due to his weakened immune system and risk of infection. Therefore, Justin received home-based tutoring during those three months. Justin physically returned to the school setting on a regular basis during his eighth grade year. He did not receive special education services at school as a result of cancer or treatment.

Cross-case Analysis

Data were generated through five sources: (a) questionnaires; (b) typed notes taken during and after the interviews and follow-up meetings; (c) transcribed interviews and follow-up meetings; (d) documents; and (e) parent feedback. Data analysis was conducted using a combination of a template organizing style, immersion/crystallization (I/C) approach, and a multiple case study approach (Borkan, 1999; Crabtree & Miller, 1999, Stake, 2005; Yin, 2008). A cross-case analysis was conducted and results are presented relative to the six research questions. A specific goal during cross-case analysis was to treat each individual case fairly and honor the contributions of each case to the analysis (Yin, 2008). Cross-case themes related to each research questions are

discussed below, and participants' direct quotes and documents are used to illustrate and clarify a particular theme. All data were catalogued and are cited throughout the cross-case analysis findings. The terms "few" (one to two participants), "some" (three to four), "many" (five to six), and "majority" (seven to eight) are used to communicate how many adolescents endorsed a particular concept or topic. Lastly, the words "normal", "normalcy" and "normality" are placed in quotations to respect and honor each adolescent's personal definition.

Research Question 1: How do adolescent survivors of childhood cancer perceive their transition from off-treatment to post-treatment?

The following four themes were associated with the adolescents' perception of their transition from off-treatment to post-treatment: (a) it's not a transition, let's get back to "normal", (b) my approach to life after treatment, (c) signs that I'm making my way back to "normal", and (d) feeling more comfortable with time.

Theme 1: It's not a transition, let's get back to "normal"

All of the adolescents in the study perceived the completion of treatment as a time of mixed emotions. For example, two adolescents referred to completing treatment as "a double-edged sword" (Mark, Interview line 967) and "bittersweet" (Luke, Interview line 666). These adolescents experienced positive feelings such as happiness (n=4), excitement (n=3), and relief (n=2). They were looking forward to moving on with life (n=8), feeling physically better (n=4), having less restrictions (n=2), and gaining more freedom/independence (n=2). On the other hand, adolescents also described feeling uncomfortable emotions such as uncertainty and nervousness to return to "normal" life (n=4), sadness due to loss of health care team relationships (n=3), disappointment in no

longer experiencing the benefits of hospital life such as having ample free time and not following a set daily schedule (n=2), and vulnerability due to removal of treatment (n=1). One adolescent described a variety of feelings and thoughts he experienced after he completed treatment.

Um it was a nice feeling. I mean I don't know it's like a bad way to describe it cause it's not very explicit or anything. But it was kinda like just it was like a nice feeling. I was like, "Alright, I'm really done with this." Uh it was also a closure in a way. It was like, "Alright, I can move on in a way. This chapter is over and now we can just forget about all that and go on from there. Um so that was definitely one big positive thing that came out of it. I mean while on one hand it was kind of scary in a way cause like you sorta felt vulnerable without the drugs and stuff to help you like and keep you safe. On the other hand it was kinda like you didn't feel like you felt like you could do it on your own. It was a feeling of independence (Mark, Interview lines 931-941).

Another participant also described his state of mixed emotions during this time.

I was, it was kind of giddy. Um I was leaving it behind me, and I was happy that that was done with. And I was sort of happy for what's to come and a little bit nervous cause with school and everything else (Justin, Interview lines 1083-1085).

As illustrated by these quotes, treatment completion was not necessarily perceived as a cut and dry, straightforward event but rather a time characterized by mixed emotions and thoughts. The majority of adolescents in this study also had various types of formal

events to celebrate their treatment completion and signify that this phase of their cancer care had ended. The meaning and significance of these celebratory events differed among adolescents and was impacted by factors such as duration of treatment, how treatment ended (e.g., taking pills at home by oneself versus having last round of chemo in hospital), and the degree of personalization of the celebration (e.g., sharing a cake with two other cancer survivors versus a party at home with friends and family).

Furthermore, none of the adolescents in the study necessarily perceived their shift from off-treatment to post-treatment as a “transition.” Most adolescents (n=6) indicated that the word “transition” was not applicable because the word represented a more significant change than what actually happened in their lives. In fact, a few participants (n=2) suggested that a “transition” would be more like transferring from elementary or middle school to high school rather than the shift from off-treatment to post-treatment. Adolescents described this shift in a variety of ways including closing a chapter and moving on (n=2), moving on to the next stage (n=1), stepping back into the story or page of a book (n=1), and continuation of the journey (n=1). This shift from off-treatment to post-treatment was defined more in terms of ending treatment, looking forward to moving on with life, and returning to “normalcy.” It was not necessarily perceived as a huge change and the primary goal was to return to their lives as soon as possible. The main focus was not placed on all the potential challenges or worries that they could have faced but rather a goal-directed stance was taken to minimize confusion and maximize control by making efforts to get back to “normal” after treatment. For example, one adolescent described his approach to life after treatment: “It was also a closure in a way. It was like alright I can move on in a way this chapter is over and now we can just forget

about all that and go on from there” (Mark, Interview lines 935-937). Another adolescent shared her perception of her shift from off-treatment to post-treatment.

Like a good word to describe I don’t know I mean it really was just, it wasn’t transition because it was kind of like the same thing I had been doing before and so I didn’t feel like I had to transition back into my life. I feel like that would be weird. And so I feel like it was just kind of like stepping back into it like I like kind of stepped out of the story for a little bit and then I just kind of stepped back...like stepping back into like the page of a book or something (Grace, Interview lines 1380-1384, 1387).

Additionally, younger adolescents tended to provide less detailed and abstract descriptions of the shift from off treatment to post-treatment whereas older adolescents demonstrated greater insight and assigned more vivid, abstract meanings to this transition.

The majority of adolescents (n=7) described their participation in some type of familiar activity during treatment. For example, adolescents maintained some level of contact with friends (n=7), completed school work (n=7), attended school when possible (n=4), actively maintained a schedule/routine outside of school (n=3), and engaged alternative or modified activities (n=2). Modified participation in these activities kept adolescents actively engaged in age-appropriate activities during treatment and appeared to facilitate the shift from off-treatment to post-treatment. For example, two adolescents who played sports prior to their diagnoses made significant efforts to remain involved in their respective sports. One adolescent who played soccer decided to join a gym during treatment so she could remain physically active. She said that rather than feeling sorry

for herself, she made an active decision to get up and move in order to stay healthy. After treatment she was able to start running and eventually rejoined her community-based and school soccer teams.

As previously stated, the majority (n=7) of adolescents in this study perceived some sort of change during the shift from off-treatment to post-treatment. However, there was one adolescent who did not share the same experience. This adolescent, who was diagnosed with Hodgkin lymphoma, was keenly aware that her treatment differed in intensity and duration as compared to other cancer patients' diagnoses and associated treatment (e.g., leukemia). She expressed that her particular treatment regime coupled with her family-adopted strategy of keeping things as close to "normal" as possible during treatment created the optimal situation for a quick return back to "normal" life after treatment completion. This adolescent cited specific reasons why her life did not significantly change as a result of cancer and treatment.

Um it did in some ways. I guess not really just because a lot of stuff wasn't that different like after my family got over the shock like I was still going to school. I still went to ballet a lot. Um my parents like they were still like, "You're not allowed to be rude or whatever." So it wasn't like I got treated specially. It was just like um I guess everything was normal mostly or as close to normal as we could make it just cause I mean like I could walk and everything. But it wasn't like there was a need for anything to be different. So we mostly kept everything the same like everything that was possible to stay the same it just automatically went back to that (Alexis, Interview lines 158-164).

Interestingly, a few adolescents (n=2) also were aware of the differences in the intensity and duration of certain diagnoses and associated treatment regimens. These adolescents had the ability to not only compare themselves to others but to understand how these differences could have a distinct impact on life during and after treatment completion.

Overall, these adolescents experienced a variety of emotions at the time of treatment completion. The majority of adolescents did not think a great deal about what life would be like after they completed treatment or make a specific plan for the future. They focused more on the concrete goal of finishing treatment rather than how they were going to face the future and life as a cancer survivor. They tended to take things one day at a time and did not perceive this shift from off-treatment to post-treatment as a time of significant change.

Theme 2: My approach to life after treatment

The majority of adolescents (n=5) described how they approached returning to “normalcy” after treatment. They did not specifically endorse the word “approach” as it suggested something more formal and deliberate in nature. These adolescents indicated that they handled things as they came and did not necessarily think ahead of time about what life would be like after treatment or how they were planning to get back to “normalcy.” Rather, these adolescents faced challenges as they came and took one step at a time. There was an emphasis on getting through the present with hopes of the future but not necessarily specific ideas or plans on how to get back to “normalcy.” One participant described how he did not plan or look too far into the future.

I think um it was probably the majority of just taking it as it comes really.

I think that describes me better. I mean I thought about it a little bit. But I

mean I don't know it wasn't on my mind too much. I thought a lot about the day that I would get out. I thought about that day and that was always sort of I'd focus on that. But I mean I had never really thought too far past that and stuff. So I mean it was just a lot of you know taking it as it comes and stuff like that (Luke, Interview lines 852-857).

Another adolescent also took things as they came and waited for certain opportunities to present themselves that would help him return to "normalcy." This particular adolescent was not overly worried about whether or not things would be back to normal and took a more laid back approach to shifting from off treatment to post-treatment.

But I knew it was going to happen but I didn't really think much. I figured it would go back to normal. And I knew that I wasn't going to be in school the next year, so I sort of figured it would be like summer, like a long summer instead of school and everything else for a while. And besides that I didn't think too much about it cause it was just like, "You'll be done and I'll go back to school and life will be normal." (Justin, Interview lines 83-87)

One adolescent took a different approach than the other adolescents and actively planned ahead to help facilitate her shift from off-treatment to post-treatment. This particular adolescent thought about when she would complete treatment soon after she was diagnosed, planned out each week of treatment, and estimated when she would physically return to her school setting. She then set short-term (i.e., completing work/courses at home) and long-term academic goals (i.e., take exams at school) based on this information. She tracked her progress throughout treatment and eventually

accomplished all of these goals. She indicated that this planning helped to keep her on track during treatment and also made her transition to school and life after treatment smoother. She was able to return to her normal school activities with minimal disruption.

Overall, the majority of adolescents in the study did not engage in a tremendous amount of forethought or planning about what life would be like after they completed treatment. Instead, these adolescents tended to focus on more tangible, concrete events such as the event of completing treatment before shifting their focus to the future and life after treatment. Notably, one adolescent engaged in more preventative measures, which reflect the presence of individual differences among approaches to the shift from off-treatment to post-treatment.

Theme 3: Signs that I'm making my way back to "normal"

One important goal for all of the adolescents was to make their way back to "normalcy". Therefore, the question becomes how one knows whether they are making progress or not as they shift from off-treatment to post-treatment. The majority of adolescents in this study (n=7) described signs or indicators that they were improving and making it one step closer to achieving their definition of "normality." The improvement or absence of treatment residuals as well as re-engagement in activities and roles (which were facilitated by improvement/absence of treatment residuals) served as signs or indicators that life was getting back to "normal." The presence of these signs along the post-treatment journey was common among these adolescents; however, there were individual differences in the types of signs that were reported. Adolescents' perceptions of "I'm getting back to normal" were unique and influenced by their personal interests, motivations, and cancer history and treatment. These signs provided important

information regarding their progress toward achieving a more balanced, “normal” life. The signs provided feedback that helped these adolescents gauge their progress and, in some cases, modify their approach in order to move in a more positive direction. The signs were important milestones or individual markers that provided evidence of regaining “normalcy.”

Adolescents reported improvements in and/or absence of treatment residuals in areas such as decreased frequency and length of follow-up appointments (n=8), lessening or disappearance of treatment side effects (n=7), and port removal (n=7). In addition to treatment residuals, adolescents also described activity-based signs that life was getting back to “normal” including returning to school on a more regular basis (n=7), re-establishing social relationships and roles (n=7), returning to previous academic performance (n=6), and participating in extracurricular activities (n=5). Examples for the seven adolescents will be provided below to help gain a sense of each individual’s signs or indicators. Drew shared that he was able to re-engage in his daily routines, social activities, and work on the farm. He also noted that he no longer had to manage treatment side effects and go through medical-related procedures.

I saw my friends. I mean I could finally get back to a daily routine of life.

Not have to be all wouldn’t have to feel mixed up anymore, get back into my routine (Drew, Interview lines 237-238).

Um well I don’t do sports that much, but I’ve played them with my friends occasionally or stuff like that. I’m just glad to be back to the farm again.

I’m glad to be working again, picking corn, packing it, putting it up on a

pallet which is how I got a little bit stronger. Not a lot just a little and that's basically it (Drew, Interview lines 773-776).

All the side effects were gone. I didn't have any more to deal with. I wouldn't have to worry about the needles sticking anymore (Drew, Interview lines 538-539).

John indicated that improvement in his energy level enabled him to engage in a variety of activities that he previously enjoyed prior to treatment.

Um I decided that to go back to my regular life I could have my energy back and everything. Um it really made me happy that I could go out and hang with my friends again, stay at their houses and stuff. So we could go out and play basketball or like any kind of sport and everything (John, Interview lines 513-516)

Yeah. Well now I'm able to go to walk places either by myself or with someone else. Um I'm able to walk to the place where all my friends used to be. The school I used to go to, and I'm able to walk over there. I'm able to ride everywhere without getting sick and everything (John, Interview lines 299-301).

Luke shared that he was able to return to family, peer, and extracurricular activities. He also described how his follow-up appointments became farther apart and his physical status improved to the point where he now feels very close to "normal."

They were all home during the summer so we were all back together again you know four siblings and stuff like that. So it was you know still a really fun summer. I was still able to do a lot of stuff and hang out with

friends and all that. I wasn't just locked inside all summer. So um you know it was just really good. My family you know we all got back on track and all that (Luke, Interview lines 797-801).

I mean I had a couple kids over over the summer had some parties and stuff. But uh for the most part then I just started getting back into the swing of things and then started summer cross country in the summer. So I got back with all those guys and then got back into school in the fall (Luke, Interview lines 338-341).

Yeah, definitely think it's much closer to normal now. I mean like my monthly appointments are spread out to two months, and I'm not on any more medications or anything stuff like that. I'm physically able to do anything so I mean I think it's pretty much normal now (Luke, Follow-up meeting lines 16-18).

Mark shared how his high school attendance was no longer significantly disrupted by cancer and treatment.

Luckily, by the time I entered high school all the big drugs and treatments and all that they were gone. They ended in May with remission and stuff. I still went to the clinic at that point once at that point I think it may have been once, once every two weeks. But I mean after my last in-hospital stay was actually April of my eighth grade year. So I never had to miss any school for like an extended in the hospital stay during high school, which was really nice. It shocked the doctors. They couldn't believe it. It was different (Mark, Interview lines 565-570.)

Grace shared her experience returning to social and extracurricular activities and the sense of excitement and relief that those particular events brought to her life.

I was so excited. I was like, “Yes, I can finally like walk down to my friend’s house and like see her.” Like cause I used to like live there and I then like I had, like every day after school we’d like go over there and do homework together. And so it was nice to be able to go back to them. Like we studied for finals together and things like that like we used to. And so it was I don’t know it was like a big sigh of relief I guess (Grace, Interview lines 1039-1043).

Cause I was already like back in school and I was back to um I don’t know skating. Like I remember my first skating lesson back was like the best day ever like I was so excited to be back on the ice (Grace, Interview lines 979-981).

Kendall expressed that one of her biggest signs that she was returning to “normalcy” was when her hair grew back. Although she experienced positive feelings associated with completing treatment, this was not necessarily a defining moment that indicated to her that “normalcy” was soon to follow. Instead, growing her hair back was the main sign or indicator that her life was getting back to “normal.”

Yeah, like once I found out I was done yeah I was like relieved. I was excited like I felt like I just felt like one, one like chapter was over. It was just another chapter was getting my hair back and then normalcy would come back (Kendall, Interview lines 1179-1181).

I guess like I never really felt like I moved forward because I don't feel like I could move forward until I had my hair back. So I never, I don't think even though I was done with treatment, I was just going to school more. But I wasn't like playing soccer, like I wasn't really myself still. I couldn't go to the mall anytime and just hang out with my friends cause I looked different so. I still would rather just be at home. So I don't think I ever just moved forward until like once I started getting my hair back that's when like once my hair got long enough (Kendall, Interview lines 1169-1174).

Lastly, Justin shared that improvement in his physical status lead him to realize that he was able to move on with his life. He also described how returning to school was a big indicator that life was returning to "normal."

...but when I started not feeling sick, I started realizing I was kind of done and that I could move on to the next stage of my life and everything else which was nice (Justin, Interview lines 966-967).

Um I don't think it was like intentional like I wasn't really desperately trying to get back into normality. But it happened pretty quick like it was from getting out of the hospital it would seem gradually but what really happened was it basically stayed the same until school started. Then as soon as school started it went back to reality (Justin, Interview lines 1302-1305).

Notably, many adolescents (n=5) described their port removal as a significant event in their lives. In fact, some of the adolescents (n=3) identified port removal as more

memorable than completing treatment. For these adolescents port removal provided a sense of relief that treatment was really over and freedom as it allowed these adolescents to participate more fully in physical activities.

Overall, the majority of adolescents in this study had signs or indicators that provided information and feedback that they were on their way to achieving a sense of “normalcy.” These adolescents described a variety of observable activity and cancer-related signs/indicators that enabled them to continue to move forward as well as gain a sense of mastery and “normalcy.”

Theme 4: Feeling more comfortable with time

All of the adolescents (n=8) expressed feeling more comfortable with themselves as time since treatment completion increased. These adolescents developed an awareness that aspects of their life were improving and that they were on their way to returning to “normalcy.” This growing awareness developed at different points in time for these adolescents. Each adolescent experienced his/her own unique signs/indicators that life was starting to return to “normal” and, as a result, increased feelings of being comfortable with oneself. One adolescent shared how successfully participating in ice skating camp and returning to school promoted a sense of comfort.

I did not sit out of anything that entire week and so that was when I really started feeling like comfortable with myself. And then we like beginning of the fall season and winter season, I really started to pick it up and back to normal and like. I guess when I started school was when everything started like really back to normal so (Grace, Interview lines 1210-1214).

A few adolescents (n=2) also shared that they developed greater insight and general comfort with their status as time progressed. One adolescent described how over time he realized that physical symptoms experienced after treatment are not necessarily indicative of cancer.

Now I think now it has been a year I'm more able to have that time in between to realize this still happens in real life, people still get tired, people that doesn't mean that something is going wrong and things like that (Luke, Interview lines 894-897).

Some adolescents (n=3) also described increased comfort over time specifically related to attending follow-up appointments and having scans. One adolescent shared how she became increasingly comfortable with her follow-up appointments over time.

Um like the first few ones were kind of like nerve-racking for the fact like, "Oh, what if they find something?" But then as things started like to become clearer it was more like, I liked going because I got to see people that I haven't seen in a while. And then even like even more it just got to be like so routine. So now it's like go get blood drawn, everything is fine, and leave (Grace, Follow-up meeting lines 185-188).

Overall, these adolescents described feeling increasingly comfortable over time as they were able to re-engage in familiar activities, observe improvements in their physical appearance, develop insight about their physical status, and realize that follow-up appointments were becoming more manageable. The passage of time along with the presence of positive signs/indicators helped these adolescents become more comfortable

with themselves as well as facilitated meaningful movement during the shift from off-treatment to post-treatment.

Research Question 2: What are the challenges faced by adolescent survivors of childhood cancer during the transition from off-treatment to post-treatment?

The following two themes were related to the adolescents' perception of the challenges faced during the transition from off-treatment to post-treatment: (a) signs that life is not back to "normal" just yet, and (b) it is not the focus of life but the idea of relapse is there.

Theme 1: Signs that life is not back to "normal" just yet

Although ending treatment signified an important accomplishment, the majority of adolescents (n=7) expressed awareness that their journey was not over as many reported dealing with residuals of treatment such as continued disruption in their daily schedule due to follow-up appointments as well as lasting physical effects of treatment. The presence of treatment residuals served as signs or indicators that life was not quite back to "normal." They were not necessarily perceived or labeled as "challenges" by the adolescents. The difficulties they faced were often times dealt with in a matter of fact manner. These adolescents perceived that the end of treatment was not necessarily the "end all be all." One participant illustrated this idea: "I was the like getting out of the hospital I was really excited about it. But then it sort of it went from being like happy and I'm free but it still had like a lot of restrictions around it, a lot of um fine lines and yellow tape" (Justin, Interview lines 1110-1112). There were a variety of "fine lines and yellow tape" that these adolescents faced while moving away from a life of hospitalizations, treatment, side effects, and general unpredictability. Another adolescent

was very aware that her life was not back to “normal” as her physical appearance and ability to participate in activities was still comprised after treatment completion. Another adolescent shared the idea that even though treatment was over, she still had to deal with the possibility of relapse and monitor her health.

It was um like along with the whole, the celebration of being done it was also the talk about like, “Okay, now there’s still a 20% chance remember that this could come back.” But so I had to be like mindful of what I was doing and like paying attention to my body to make sure nothing was changing or if I was getting sick or something (Grace, Follow-up meeting lines 165-169).

Despite excitement for the future and moving on with life, the majority of adolescents (n=7) were challenged to juggle a complex combination of physical limitations and continued disruption in their daily lives. They shared that continued disruption, although on a more minor level, was still present in their lives. These adolescents provided examples of how their physical limitations secondary to cancer and treatment limited their lives in various ways. Specific examples of treatment residuals endorsed by adolescents included comprised immune function (n=4), decreased energy, endurance, and stamina (n=5), presence of port (n=7), attending appointments/having procedures (n=3), continuing to feel sick secondary to treatment side effects or medical procedures performed post-treatment (n=3) (e.g., scans, spinal taps), and “chemo brain” (n=1), which is a phenomenon thought to reflect deficits in memory, attention, and other cognitive functions (Staat & Segatore, 2005). The majority of adolescents (n=7) experienced some type of restrictions in their activities of interest secondary to these

particular treatment residuals. One adolescent commented on how her schedule and routine was still not back to “normal” after treatment was completed.

Um I’m not quite sure. I know I still missed a lot because although I was finished um like the treatments and stuff. I still had to go for like PT scans and CT scans and all like the other tests after that and I was still like tired and stuff. So I still missed a lot of days like I never really got into a routine of going back to school like every single day for like a week straight (Kendall, Interview lines 114-117).

Although these restrictions were not permanent for any of these adolescents, their presence required them to adapt and seek out alternative or modified activities throughout the shift from off-treatment to post-treatment. Notably, one adolescent did not discuss any specific treatment residuals. This particular adolescent was the individual previously mentioned who described her diagnosis and associated treatment regime as not significantly impacting her day-to-day life. Therefore, she perceived that her life after treatment was fairly close to normal and no treatment residuals or challenges were noted.

One adolescent’s viewpoint on life after treatment is noteworthy. This particular adolescent discussed the fact that just because treatment is over, it does not mean that cancer is completely out of someone’s life. In fact, she indicated that often times other people have a tendency (not deliberately or intentionally) to forget that the adolescent still must cope and live with residual effects of cancer and treatment.

No now like they forget like the stuff you have to live with that doesn’t ever really go away. Like I guess memories and like the things you miss out on like. It’s just like for people that only see that you lose your hair

and that you gone through treatment at the time. But like after you still like face a lot of problems like, like how it just like it affects like how I was saying how it affects when you go get to choose a college well at my age like it affects that but no one really sees that it affects other things down the road...It's not like it's their fault because it's just normal. But like it's just something that like affects kind of, it's like inside yourself that only like you can't expect other people to think about it cause it's just like other stuff that has nothing to do with you being sick at all (Kendall, Follow-up meeting lines 77-82, 94-96).

Overall, these adolescents were aware that they faced a variety of challenges after treatment was completed. They faced physical limitations, activity restrictions, and continued disruption in their daily schedules. These challenges provided signs that life was not back to “normal” just yet and that more time was needed to overcome these challenges. These types of signs or indicators also provided the adolescents with an important source of feedback on their progress in achieving “normalcy.”

Theme 2: It is not the focus of life, but the idea of relapse is there

All of the adolescents who were asked about relapse (n=6) expressed concerns related to potential relapse and the need for some reassurance that they were on their way to “normalcy.” Although thoughts associated with relapse were present, they tended not to be a central focus in their lives. Rather, the primary focus was on engaging in activities that would promote a sense of “normalcy” and an eventual return to “normal” life. One adolescent described his outlook on relapse and his focus on living a “normal” life.

I mean it's always going to cross your mind occasionally but for the most part it really doesn't. And I mean it's you know it's not how I want to live my life. I don't want to plan to have that ever happen again you know. I mean just you know I think everything is going to be fine. I'm just gonna go out and live a totally normal life. I'm not gonna have that affect me at all. I mean I obviously took lessons from the situation that happened but I'm not gonna say you know...not going to dwell on the fact that it could happen again (Luke, Interview lines 905-911).

For these adolescents, thoughts and concerns associated with potential relapse tended to be greater when treatment ended and lessened over time. Concerns were related to a variety of topics such as waiting to hear test results for continued reassurance (n=3), hoping that the cancer does not return (n=3), suspicion of symptoms post-treatment may be indicative of relapse (n=1), having a relapse and going through treatment all over again (n=1), and being vulnerable due to removal of treatment (n=1). One adolescent spoke about his suspicion of symptoms after treatment was completed: "It's always...I wouldn't say it's a big worry or anything but sometimes thinking of what your symptoms were beforehand and if you start you know if you're just tired even though you know it's for a different reason you start thinking about that or something" (Luke, Interview lines 890-893). Another adolescent shared some of her thoughts when she would wait for test results.

Well, I would always think, "Oh my god, I'm gonna have to go through chemo." And then like everything would play through my head of chemo. Like I could just see myself laying there getting chemo and losing my hair

again and then doing all that stuff all over again. Or just nothing ever worked and just keep going and going and going. I guess you just sit there and think the worse (Kendall, Interview lines 1382-1386).

Some adolescents adopted coping strategies such as avoiding excessive thoughts of relapse (n=3), citing positive information from the medical team or examples of peers who have survived (n=2), and avoiding cancer-related information that might induce anxiety (n=1). For example, one adolescent described his peers' positive outcomes and how this made him have a more favorable outlook on his own future.

Um but uh the other people that I knew um every person that had done well and that had never relapsed was kinda like something I that held onto cause it was one more thing on my side. It was one more number that was positive in my favor (Mark, Interview lines 1004-1007).

Notably, one adolescent expressed significant worry about test results and possible relapse as compared to the other adolescents. This particular adolescent identified feelings of distress, worry, and nervousness related to waiting for test results. She experienced many negative thoughts and pondered possible worst-case scenarios during these waiting periods, which sometimes impeded her daily functioning (e.g., not attending school). Although she indicated that these feeling and thoughts have decreased over time, she occasionally is reminded of her treatment experience during follow-up appointments and scans.

Um well, as time goes like I guess I forget, I try to forget about like ever like the chemo and like losing my hair again until like when I have a scan. I guess sometimes when I go to get a scan if I'm sitting in the chair then

that's what I think about and it just replays in my head over and over again...But like if you get a scan and it's a scare like they think it's something, then it's really, really bad. Like if they think they see something and they have to do like a bigger scan. Like for instance, I had to do like um, I had a CT scan they thought they saw something and then I had to a PT scan three months later or I think it was three weeks later. That whole three weeks was like kinda like a living hell cause I would go to the nur...I would just go to school and then go right to the nurse's office and just sit in there like still it was actually this year. And I'd just go sit with her and like talk to her and just miss class so (Kendall, Interview lines 1394-1397, 1402-1400).

Overall, adolescents expressed concerns related to relapse and experienced a variety of thoughts and emotions related to this possibility. There was some variability in the degree to which adolescents were concerned with relapse. Although these feelings and thoughts tended to lessen with time, they are still present in the minds of these adolescents. However, they actively chose not to let the fear of relapse rule their lives or consume an inordinate amount of their time. As previously noted, the primary focus of these adolescents is to move on with their lives and return to "normalcy."

Research Question 3: What are the beliefs of adolescent survivors of childhood cancer about the supports and/or services that were or would be beneficial during the transition from off-treatment to post-treatment?

The following four themes emerged that were associated with adolescents' beliefs about what supports and services would be beneficial during the transition from off-

treatment to post-treatment: (a) my need for supports and/or services (b) what my health care team told me, (c) it is beneficial to know others who have been through what I have been through, and (d) my advice on how to navigate the shift from off-treatment to post-treatment. Of note, the PI incorporated a question asking adolescents to provide advice on how to manage the shift from off-treatment to post-treatment. The hope was that the responses to these questions would yield relevant and relatable advice for other adolescents who may be experiencing similar situations.

Theme 1: My need for supports and/or services

The adolescents in this study varied in their perceived need for support as they made the shift from off-treatment to post-treatment. Some adolescents (n=3) welcomed the support they received and thought it was helpful and adequate whereas others (n=3) did not perceive a great need for support and preferred to make the shift on their own. One adolescent expressed how he thought the information provided by his health care team was helpful: “Yeah, I mean it was helpful. I mean I’m sure...I definitely appreciate that they told me that stuff that they gave me that advice” (Justin, Interview lines 1062-1063). In an example of the latter case, the adolescent wanted to get on with life and was not interested in hearing a great deal of information about potential late effects as it would have created unnecessary anxiety.

Um I didn’t want to hear those...Um I guess I don’t want to know like that I’m more likely to get this kind of cancer, I’m more likely to get that. I’d rather just live happily now and not have to think about like those things they would say. I guess that’s why...Yeah, they would just probably cause me to worry...Yeah, but I never wanted to hear like any side effects or any

of that kind of stuff (Kendall, Interview lines 1461, 1468-1470, 1474, 1482).

Another adolescent expressed that she was glad that there were no specific discussions about life after treatment because it suggested to her that this shift would not be a significant change. She indicated,

People might have been like, “Do you need to be part of a support group or something?” They offered that a lot. Um like stuff like that and I don’t really think I took anybody up on that offer. Um I don’t, I don’t really think anyone ever asked. And cause they didn’t ask, I just didn’t really think there would be that much of a change. Just cause like it was implied that there wouldn’t be just cause no one was really saying anything about it (Alexis, Interview lines 846-850).

She expanded on this comment during the follow-up meeting.

Um I think like you said it made it seem like it was not like not as big of a deal like the whole thing wasn’t um like it just wasn’t something that I needed to be like concerned about or anything and also I was very ready to be done with it and going back to life being normal and everything. So it was just like the sooner the better (Alexis, Follow-up meeting lines 100-103).

Another adolescent described her minimal need for discussion about the shift from off-treatment to post-treatment due to her pre-existing personality and general approach to facing challenges in life. She commented,

I feel like I was just the type of person that was just going to do it. Like I, like they would start bringing it up and I'd be like, "Yeah, I'm fine we don't need, like why are we..." I don't know. It wasn't, I feel like my doctors knew me well enough at that point that they knew it really wasn't an issue. And that like try not to get phased by it I guess. I just like tried to just go back to normal life (Grace, Interview lines 1366-1370).

Overall, adolescents indicated that they were content with the type and amount of information provided to them (or lack of information if that was their preference). None of the adolescents voiced concerns that they did not receive adequate information or support from their health care team.

Theme 2: What my health care team told me

Of the adolescents who were asked about this topic (n=6), all of them shared what type of information was given to them by their health care team to facilitate the shift from off-treatment to post-treatment. Information was conveyed verbally to adolescents and in one case hard copy materials were provided on survivorship. Physicians, nurses, and child life specialists were identified as those who provided information. Discussions pertained to topics including physical capabilities/limitations to be aware of post-treatment (n=3), engaging in healthy lifestyle behaviors like exercising, sleeping well, and minimizing risk of infection (n=3), pacing oneself during activities (n=3), follow-up schedule details (n=3), odds of relapse (n=2), and to have fun and enjoy life (n=1). As previously noted, adolescents had different perspectives about the necessity and value of such recommendations. Notably, two adolescents specifically cited appreciation when medical team members were "straight with me" and "honest and open" when presenting

information (Luke, Interview line 596; Mark, Interview line 1048). A notable instance occurred when one adolescent received information from a physician who was also a cancer survivor. It appeared that receiving this information from a source with these specific characteristics created a meaningful and relevant opportunity for discussion about life as a survivor. This adolescent shared,

Yeah. The doctors did, uh but I didn't have anybody that had personally...well no actually I did there was...no...I'm just thinking about it now there was one doctor who was doing a fellowship there who's actually a cancer survivor. And uh he wasn't my doctor or anything but he'd gotten in touch with me. Uh we just kinda hit it off and got along really well for the previous year and a half before that and as the time got closer I mean I expressed a couple of concerns to him about everything and he'd talk to me. And he was good because he didn't...there were a couple doctors and I think this is part of being a doctor for some people is they try to sugar coat things a little too much. And he I mean I remember talking to him and he gave it to me straight really and he said listen, "Yeah this could happen" um he said, "We don't I mean doctors in general we don't like to give a number um because it's just a number. I mean we could say one in a million and you could be that one. So the number really doesn't do a whole lot. It is just a number and doesn't mean anything." And he was honest he said, "I mean yeah there's a chance this comes back, we've seen it before, um but on the flip side there's also a chance that it doesn't. That is the better chance right now." Um so he was good

because he was really honest and open with me about everything and that really helped and he was talking from personal experience, which made it a lot easier. Cause I mean there are a lot of doctors who could just sit there and tell you whatever but they'd never gone through it. I mean indirectly they had with their own patients, but they personally had never experienced it. But for a doctor who obviously knows more about my situation than I do even and knows it from a personal level too that was...that was invaluable really (Mark, Interview lines 1033-1054).

As previously noted, one adolescent received hard copy materials to assist in facilitating the shift from off-treatment to post-treatment (Justin, Direct observation notes, lines 48-52). This adolescent and his mother shared that they were given a Lance Armstrong Foundation binder packed full with all types of cancer survivorship information. The adolescent and his mother indicated that he "used" the binder for school. The PI quickly surmised that there was a twist to the word "used" and inquired about the real use of this binder. He then went on to share that he never actually read the material inside and ended up using the binder to hold school-related materials. The binder essentially became a useful school supply rather than a helpful cancer survivorship resource. This is no surprise as they described this resource as cumbersome and not adolescent user friendly. This was a very telling example of how resources may be perceived as helpful and developed with all the best intentions but in actuality they do not provide a true benefit to the adolescent cancer survivor.

These adolescents indicated that their respective medical teams provided a wide range of information in hopes of facilitating the shift from off-treatment to post-

treatment. Some of this information was perceived as useful while others deemed it unnecessary or unwanted. Physician interpersonal characteristics that were seen as desirable include being open, honest, and providing up front information.

Theme 3: It is beneficial to know others who have been through what I have been through

The majority of adolescents (n=6) indicated that a source of support during life after treatment included fellow cancer survivors. Cancer survivors were accessed through a variety of ways including cancer camps (n=4), non-profit cancer organizations/adolescent support groups (n=2), at school (n=2), through relationships established during treatment (n=1), and reading about other cancer survivors' stories (n=1). Those two adolescents who did not endorse relationships with cancer survivors focused more on returning to their general peer group. One benefit identified by these adolescents was having the opportunity to share common life experiences and to talk to someone who has actually lived through cancer. Although sharing experiences was seen as beneficial, these adolescents described many other non-cancer related benefits such as participating in fun activities and just hanging out and talking about "normal", everyday topics. Those adolescents who attended camp indicated that they enjoyed participating in the variety of activities offered, seeing the same friends year after year, having opportunities to talk about cancer and non-cancer related topics, helping peers who are in treatment, escaping from everyday life, and being surrounded by people who understand their situation. They indicated that these camps offered a fun, supportive environment where they could feel at ease and relaxed.

One adolescent shared her cancer scrapbook with the PI that included pages devoted to describing her camp cancer experiences. She told her camp story through the use of pictures of friends and words such as “great friends”, “fun”, “life”, “inspire”, and the quote by Frank Crane, “a friend is someone with whom you dare to be yourself” (Kendall, Document pages 20-21). She indicated that camp provided her the opportunity to make close, lasting friendships with other people her age who shared a common experience. Based on the discussion between the PI and adolescent as well as the document review, it appeared that camp was a significant and meaningful aspect of this adolescent’s life and was something that she looked forward to year after year. Camp provided a consistent source of social support well after treatment was completed.

Those adolescents who attend the non-profit organization support group shared that it is beneficial to have a close-knit group of people who understand where there are coming from and are supportive of each other. One adolescent described how he began to attend the support group and his view on the benefits of participation.

We...I’m not sure how but this senior at my school, X student, um he had cancer. Um I’m not sure how I met him. I don’t know. But uh his mom I think his mom and my mom had been talking before I even met him. And so she said that he said that to tell me to come there and that it’s really cool. Even if you don’t like it, you don’t have to come back and stuff. So I was like “ugh” is like going to be like a sad, depressing group where everyone sorta tells all their sad cancer stories and stuff like that. And it’s just like totally the opposite. We all are sorta the same way. I mean if there is something going on in your life, we definitely want to be there and

talk about it. But if there's not, there's nothing that you know we have to talk about unless you want to. Unless you want to share your experiences or what you had experienced, or what you still are experiencing and stuff like that. It's just really good because other people no matter how close to you they are, there's always a level that they won't understand. That people who have gone through the same thing it's really good to have them. That's definitely a key that uh...that's really good I think between cancer patients is...that's really one of the best thing just knowing stuff like that they're going through the same thing (Luke, Interview lines 1001-1015).

In fact, another adolescent also referenced the importance of not focusing on sad cancer stories. He shared the following story about his first cancer camp attempt.

Well I went to at one point I went to this camp that was a cancer camp that's local and it was like a friends weekend to test out the camp. For a while it took me a long time to be persuaded to do any cancer camp because it sounds really depressing. Like it sounds like it's a bunch of people moping around saying, "Oh, you know I had cancer. Do you want to know about my experiences?" So I didn't want to go. And then the camp that I did, went to for like a weekend was like that and it was really bad camp and I didn't like it at all. And then this Jewish cancer camp tried to contact me. And I thought the same idea about the other camp that I thought which it turned out to be right. But before that I'd been contacted by this Jewish cancer camp. And so I said you know, "No"

cause I thought it was going to be like it was. And then after that I still didn't want to go the next year cause in between that time I had gone to the depressing camp. But then they were like, "Okay, we have this Orlando trip coming up. Do you want to come?" And what kind of kid says "No" to going to like Disney World and what not (Justin, Interview lines 1412-1423).

Overall, support from other cancer survivors was and continues to be a positive aspect of these adolescents' lives. The primary focus was placed on fostering meaningful relationships, engaging in fun activities, and being present in a comfortable environment that did not solely focus on cancer. These relationships provided an opportunity for these adolescents to be themselves and find comfort and support in knowing that there are others who can meaningfully relate to their experiences.

Theme 4: My advice on how to navigate the shift from off-treatment to post-treatment

All of the adolescents readily shared their advice related to navigating the shift from off-treatment to post-treatment. Their advice derived from their personal experiences and perceptions of what would be important for others to know who are about to make this shift. Much of the advice was related to having a positive outlook on life after treatment, enjoying/living life, and dealing with things as they come as opposed to worrying about things out of one's control. One adolescent specifically recommended it is beneficial to be aware that it may take some time to get back to one's regular activities due to treatment side effects but that eventually things will get better. Another topic of advice included regaining control over one's life by learning to adapt to limitations that present themselves post-treatment and not being afraid to go back to

previous situations and activities with confidence. Lastly, one adolescent highlighted the importance of exercising in order to begin regaining physical strength and endurance.

Examples of advice in these areas are presented below.

I'd say like just stay positive. Uh I mean everyday that you're not...everyday that something bad happens is automatically a good day. I mean so if you wake up the next day and you're still feeling fine don't worry then automatically about what if tomorrow is a bad...tomorrow is the day that something bad happens. I mean don't cause if you do that you're just going to drive yourself nuts and you're not going to be able to enjoy anything. So if something happens you cross that bridge when you come to it but don't sit there and tell yourself something bad is going to happen. I mean part of it is it's on your mind and it's going to be. I mean I'm not going to lie and say well get it off your mind because you're just not going to be able to do that (Mark, Interview lines 1072-1080).

Well, basically the way that you get back to everyday life. It might take time to get back to, like get back all your energy and stuff. But when you start getting it back you feel better and everything. You'll be able to go wrestle, or play around, or play sports, or hang out with all your friends again and everything without having to be at home feeling sick and everything (John, Interview lines 582-585).

Um I guess to not be afraid because then you're just gonna like miss out on all the stuff. And like to take like every day for what it is and like be excited about...I don't know. I tried to be so like every morning I was

excited to do something different and like to be out there in the world again. And like no to be afraid to go back to the situations because you're afraid of what people would think or things like that. I feel like you just gotta go for it and like have the confidence and then people won't be like, "Oh, she's just like she was before" like there's no big deal (Grace, Interview lines 1417-1423).

And then once you get to go out, I'd give some advice like to if you want to you probably should start exercising a lot more. I know I didn't and so like I never thought much about it. But now I'm stuck trying to get my stamina back to where it used to be and be a little stronger and stuff. And so I think that if you exercise like right out of the hospital and get cause I know a lot of kids are bedridden most of the time. So they lose a lot of muscle and stuff. So I think that it is good to go back into exercise really quick and sort of gain back anything that you lost. You'll definitely notice it. It's not unnoticeable (Justin, Follow-up meeting lines 109-115).

Collectively, these adolescents were more than happy to provide advice to others who may want to hear from someone who has experienced and lived through cancer. They were candid and thoughtful in their responses to this additional question presented by the PI. Advice centered around remaining confident that things will get better in spite of lingering effects of treatment, attempting to regain some sense of control, and attending to physical health.

Research Question 4: How do adolescent survivors of childhood cancer perceive their school reintegration experience?

The following three themes were associated with adolescents' perception of their school reintegration experience: (a) going back to school provided a sense of "normalcy", (b) here is what I was anticipating before going back to school, and (c) taking a matter of fact approach to going to school. The nature of school reintegration varied among these adolescents. Adolescents fell into one of two categories: (a) adolescent did not attend school during treatment and reintegrated on a full or half time basis after treatment was completed with clearance from medical team (n=3); or (b) adolescent was cleared by medical team to attend school during treatment, attended on an irregular basis, and returned to school for a full or half day after treatment was completed (n=5). Notably, one of the adolescents in the latter category did not perceive a great deal of change in her daily school life secondary to the nature of her cancer and treatment regime. Therefore, this particular adolescent attended school on a more regular basis as compared to other adolescents in the study. These differences will be noted if relevant to the theme under discussion.

Theme 1: Going back to school provided a sense of "normalcy"

For the majority of the adolescents in this study (n=7), attending school provided some sense of "normalcy" to their lives. In the midst of the unpredictability and decreased control over aspects of their lives, school was a familiar place (regardless of whether the adolescent enjoyed attending school or not) that they could return to either during throughout treatment or after treatment completion. School attendance was an important activity that provided an environment and avenue to begin to return to

“normal”, feel “normal,” and (for those who attended school during treatment) engage in social interactions that reaffirmed that there was still “normality” present in their lives. Many of these adolescents (n=5) specifically noted that there were excited to return to school for the social aspects such as being around their friends, teachers, and other familiar school staff members. One adolescent who sporadically attended school during his eighth grade year shared how returning to the social aspects of school life throughout his treatment provided him with a sense of “normalcy”

Oh yeah! I mean it was...it was being around my classmates and friends and stuff that's what really put everything back on the right track. I mean I sat there and I kinda felt like alright things are okay things are completely normal in a way (Mark, Interview lines 527-529).

Other adolescents (n=3) indicated that they were looking forward to returning to a “normal” routine at school. However, these adolescents’ reasons varied depending on their particular situation. One of these three adolescents attended school throughout treatment and shared that staying in her school routine helped her to “continue living” (Kendall, Interview lines, 163-164). She explained reasons why she believed it was beneficial that she continued to attend school throughout treatment.

Well, I think that it kinda helped me think that I was still living a normal life maybe. I mean although I hated every minute of getting up and going. I mean I would've rather had some like a person come to the house, but I think that it just helped me be around people and just continue living I guess (Kendall, Interview lines 161-164).

The other two adolescents did not attend school during treatment and returned after treatment completion. They experienced a prolonged period of time away from the school setting (i.e., one year to one and a half years of school missed). These adolescents expressed that attending school facilitated their return to normalcy and provided them the opportunity to get back on track with their lives.

Overall, attending school was perceived as a primarily positive activity with benefits such as reintegration into social activities/interactions and daily routines. School attendance and reintegration was a catalyst to regaining a sense of normalcy for these adolescents in the face of unpredictability, loss of control, and general disruption in their lives. The school environment presented opportunities for these adolescent to once again engage in developmentally appropriate activities and provide a sense of purpose and consistency to their daily lives.

Theme 2: Here is what I was anticipating before going back to school

Although this particular theme was not prevalent in all the adolescent's experiences, it is notable because it was present in the stories of all those adolescents who did not physically attend school during treatment (n=3). Each adolescent's situation was unique and influenced by his/her academic re-entry point. More specifically, one adolescent was entering middle school for the first time in eighth grade after approximately one year out of school, one was returning to high school in 10th grade after about an eight month hiatus, and the other was entering high school for the first time in ninth grade after a year and a half absence. These adolescents shared anticipatory thoughts and feelings that they had prior to school re-entry. These thoughts and feelings were positive, neutral, and more challenging (not necessarily negative) in nature. These

adolescents were generally concerned with getting back into their school routines after their prolonged absence. Other primary concerns included performance in academic subjects and the impact of physical side effects in the school setting (e.g., hair loss, less stamina). One of these adolescents specifically referenced worry about how school teachers and peers would react to her return to school. She did not want to be treated differently and did not know if people would look at her or say things about her. Another adolescent expressed concerns, which were indirectly related to his cancer and treatment. He was concerned about entering a new high school setting and not being familiar with the environment. Despite these concerns voiced by the adolescents, the overall sentiment about returning to school was happiness, excitement, and sense of comfort in returning to a familiar routine. For example, one of these adolescents was excited to enter middle school because he would be able to switch classes for the first time.

Overall, these adolescents had anticipatory thoughts and mixed feelings prior to school re-entry. Notably, the content of many of these thoughts and feelings was associated with their particular academic re-entry points. These adolescents were concerned about cancer and non-cancer related factors that could potentially impact them in their respective school environments. However, these adolescents conveyed an overall positive attitude and approach to school reintegration as it played an important part in facilitating their way back to “normalcy.”

Theme 3: Taking a matter of fact approach to going to school

The majority of adolescents (n=7) in this study did not describe any specific plans or strategies to facilitate school reintegration. Despite noted anticipatory thoughts, mixed emotions, and specific challenges (as described in research question five below), the

overall approach to returning to school was a matter of fact in nature with an emphasis on taking things as they came. As with the shift from off treatment to post-treatment, these adolescents did not necessarily describe going back to school as a transition. However, they recognized that returning to school was a change from their previous status. For example, adolescents were aware that their school attendance would be altered secondary to treatment, or they acknowledged that their upcoming reintegration after a prolonged absence from the school setting would be a change in routine and expectations. The magnitude of returning back to school was not necessarily perceived as commensurate with a transition. Rather, adolescents placed more of a focus on the idea that school would provide a sense of “normalcy” and that they would be required to return and re-acclimate to school-related activities with peers and other school staff given side effects and other cancer-related variables. They were aware of the potential and real life challenges but did not let that stand in the way of going back to school. One adolescent described that returning back to school after a year and a half was a “shock” at first due to a new high school environment and routines (Drew, Interview line, 299). However, he said that he dealt with school-related challenges and “just kinda went in head on faced it like a rock” (Drew, Interview line 164).

Another adolescent attended a very limited number of school days in ninth grade during treatment but returned full-time to the 10th grade after treatment completion. He shared that going back to school was challenging because he had to catch up on academic work and get back into a routine. However, he took things one thing at a time and was eventually able to get re-accustomed to school life and demands.

But um it was yeah I'm not I really don't know how I handled all that. I mean I guess I just sorta plugged through it all at once. You know I never really stopped to think about it all the stuff I was doing. Just took it one thing at a time. You know got all of it done...I mean that's definitely sort of a cancer patient motto like one thing at a time, one day at a time, just gotta get through this moment you know stuff like that (Luke, Interview lines 471-474, 484-485).

One adolescent described his overall attitude to school re-entry as “nonchalant” and did not have any specific expectations regarding school (Justin, Interview lines 873). He indicated that he wanted to get through the school year like any other school year.

Another adolescent who attended school during treatment indicated that her return to full time school status after treatment completion was relatively smooth as she had been going to school all along and had exposure to some sense of “normality.”

One adolescent who was previously mentioned created short- and long-term academic goals during treatment to help facilitate her return back to school. In addition to her planning and goal setting, this adolescent took a matter of fact approach in returning to school so she could meet her long-term goal (i.e., take exams with her peers). She expressed concerns about returning to school and taking exams. However, she faced them head on and was able to successfully achieve her goal. She described how setting and achieving academic goals facilitated a successful (rather than stressful) return back to school.

And it was great because like when I went back to school I just fit right in. So it wasn't like I was missing something or falling behind.

And so it gave me something that was like I don't know motivating me in a way so that I wouldn't be like, "Oh, that's the girl that didn't go to school. Where was she? And now she's behind." Like I wasn't that girl. I was like fine. I just kinda like fell right back in (Grace, Interview lines 480-484).

Notably, another factor that contributed to her successful school reintegration experience was attending school for a half day. This decision was made based on existing physical side effects that would impact her in the school setting (e.g., decreased energy) as well as the desire to gradually reintegrate into school and save some energy for other outside activities. She perceived that this was a beneficial decision because she was able to see her friends at school and complete academic work while not becoming too tired or worn out.

Adolescents also differed in the amount of time they perceived that it took to return to "normal" at school. For example, one adolescent shared that it took him a few days to adjust to his school routine and approximately one month to feel back to "normal" and comfortable at school. On the other hand, some adolescents (n=3) reported that they regained a sense of "normalcy" at school within approximately six months to a year. Multiple factors such as length of absence from the school setting, rate of improvement/absence of treatment residuals (e.g., physical side effects), and supports received prior to school reintegration (e.g., academic tutoring) contributed to individual differences in length of time to return to "normalcy" at school.

Overall, the adolescents in this study perceived their return to the school setting as a primarily positive experience that brought a sense of "normalcy" to their lives. Some

adolescents who were physically away from the school setting for an extended period of time expressed thoughts and feelings in anticipation to returning to the school. The majority of adolescents also took a matter of fact approach to school re-entry as they faced academic and social tasks in stride and focused on returning to “normalcy.” One adolescent specifically adopted a proactive planning strategy that helped her to achieve personal goals as well as take control over her school reintegration experience.

Research Question 5: What are the challenges faced by adolescent survivors of childhood cancer during school reintegration?

The following three themes were related to the adolescents’ perception of the challenges faced during school reintegration: (a) disruption of my school life; (b) my academic concerns, and (c) my social life concerns.

Theme 1: Disruption of my school life

The majority of adolescents (n=7) experienced significant disruption of their typical school schedule and routine. As previously noted, three adolescents did not return to school after their diagnosis secondary to their intense treatment regimes. One adolescent who was diagnosed with ALL missed his seventh and eighth grade school years. Another adolescent with AML missed the majority of his seventh grade year while the other adolescent with Burkitt lymphoma was absent for approximately seven months of her 10th grade year. Those adolescents who were able to attend school (n=4) attended on an irregular basis secondary to hospitalizations, treatment, side effects, and low immune function. Attendance was unpredictable and sporadic. To illustrate, some adolescents recalled the number of school days they missed which included estimates of 76, 96.5, and 140 days. One adolescent indicated that his attendance was spotty from

grades four through six. These adolescents attempted to go to school as much as possible but faced numerous limitations and barriers. A few adolescents (n=2) shared that they would arrive late and/or leave early to receive treatment or because they were not feeling well. One adolescent shared his daily struggles with school attendance.

...now all of a sudden it's like oh, you're not going to be there as much anymore. So the atmosphere was going to be a little different. Like I would wake up and I should be in school, no I'm just at home again. Some days even when I would feel fine, my blood counts wouldn't be ok. So I'd feel physically fine enough to go to school, but my blood counts wouldn't let me go to school or out in public for that matter. There were some days where it was like yeah you're fine to go and I just felt like there was no way I was going that day. So it was really irregular. One day I wake up and everything is fine and ready to go and I'd last the whole day and it's great and the next day I just crashed. Um so that was really different (Mark, Interview lines 102-110).

Notably, one adolescent in this study indicated that she did not experience significant disruption in her daily school life. She attributed various factors to her particular situation such as her type of diagnosis (e.g., Hodgkin lymphoma) as well as treatment regime, intensity, and duration.

Um no actually like I obviously wouldn't go when I had chemo. But I was never like, "Oh, I feel so sick" or anything like I never really felt sick. I think I threw up like once the whole time. So I really like it wasn't that dramatic how I felt um so I would only miss when I had chemo and other

than that I didn't really miss... Yeah, so like I didn't really feel sick. So I just didn't feel the need to miss (Alexis, Interview lines 102-105, 109).

Overall, the majority of these adolescents' daily lives were significantly altered as a result of cancer and treatment. Their schedules, routines, and roles were disrupted for a prolonged period of time, which made it difficult for them to continue to regularly participate in developmentally appropriate activities such as school and hanging out with friends. This disruption created a state of disequilibrium that these adolescents were challenged to manage and cope with on a daily basis. Even after treatment was completed, these adolescents still faced some level of disruption due to follow-up appointments, procedures, and unanticipated illnesses/hospitalizations.

Theme 2: My academic concerns

Adolescents expressed the following academic concerns: (a) falling behind/catching up with work (n=6), (b) motivation to do work (n=5), and (c) readjusting to school demands and routines (n=4). Adolescents who were at home as well as those who were able to attend school expressed concerns about falling behind and/or catching up with schoolwork. Irregular school attendance secondary to treatment played a large role in their inability to keep up with schoolwork. For example, one adolescent who inconsistently attended school from grades four through six indicated that it was difficult to stay on track: "Yeah, um I mean it was really hard trying to get to understand and uh um trying to get to understand most of the stuff that I missed" (John, Interview lines 130-131). He acknowledged that missing work and instructional time in the classroom had a long-term impact as he now has difficulty with high school academic work. He also shared that he wishes he could go back and re-learn some of the material he missed

during treatment. To further complicate his situation, he was challenged to cope with intrusive thoughts during school that would at times impede his productivity.

Well um I was thinking about like that I could die from everything. And like, like that I could have had seizures or just like pass out and all kind of stuff... Well yeah, sometimes it would make me I mean I was so like basically daydreaming that I wouldn't get my work done and sometimes when I started feeling bad and I thought something was going to happen, I would go to the nurse's office... Well, it wasn't daily, but it was like whenever I thought about having cancer. I would think about it.

Sometimes I would think about that stuff and sometimes I would just think about like how did I get into this stuff like that (John, Follow-up lines 8-9, 22-24, 29-31).

These adolescents were aware that they were not on par with their classmates. However, they varied in the degree to which this was a concern. For example, some adolescents felt overwhelmed or stressed and never felt like they would catch up while others were aware that they were behind their peers but did not perceive this as an overwhelming situation. Some of this variability may be attributed to factors such as type and quality of academic support received, grade level content standards, and level of difficulty of the academic content area. After his treatment was completed, one adolescent made up work over the summer in an attempt to catch up to his peers. He finished his entire second semester of ninth grade over the summer. He explained how Latin was a difficult subject for him to catch up in over the summer.

So I mean over the summer like one of the classes that really I got crammed in on was Latin. Like that one got really condensed. So I mean I was really shaky going into this year with Latin. That was probably my hardest transition subject. But I mean um there's definitely a dip you know catching back up still first semester of this year for sure (Luke, Interview lines 406-410).

Another adolescent who attended school during treatment described how she never felt caught up in one of her hardest classes, Western Civilization.

And for sixth period I kind, I missed sixth period a lot cause I, I guess I just hated going to that class so much because I guess because when you have something and you can't get caught up instead of going there and like, trying like cause you're so, you're so lost like you feel like you're never going to be caught up. Like it's kinda like, I can't really explain how it is. I guess when you're like, you're trying to get into something you have no idea what you're learning about. And it's kinda just, it's easier just to sit there in the nurse's office and try to catch up on work from the past and then keep getting further behind because you're doing work in September although it's November instead of going there and doing November's work, I was trying to do all September's work but then I was getting behind on November's work. So like I was always like trying to catch up for that class (Kendall, Interview lines 516-525).

Notably, some of these adolescents (n=3) took active steps to catch up with their academic work. For example, some catch up strategies included staying afterschool to

complete work, meeting with a teacher to better understanding academic material, or seeking out additional tutoring services.

Many adolescents (n=5) also cited lack of motivation as a challenge during treatment in the home and/or hospital setting. These adolescents indicated that they often times felt tired, sick, and just wanted to rest. They said it was difficult at times to gain the motivation to do work as they were facing so many physical limitations. One adolescent candidly shared that it was tempting to take advantage of the leniency of the teachers and just not do the work. This particular adolescent expressed this temptation and what he had to tell himself to get past those thoughts.

Staying motivated. That would be the biggest. There were a lot of points where I went against myself, um and I kinda went against my own will. Because I mean I'm lying in a hospital bed and I'm tired, and it's five in the afternoon and my friend just walked in and gave me work, I could have very easily been like screw this. I'm not going back, I'm not going back to school for the next week anyway, why would I waste my time doing this. The teacher they'll just discredit the assignment anyway, and I won't have to worry about it, so why would I even bother doing it. Uh that was my mentality and then I'd have to be like yeah or you could try to make yourself like another student there and stop sucking on this and really kinda I mean just kinda suck it up and do it anyway (Mark, Interview lines 799-808.)

An additional concern noted by some of the adolescents (n=4) included readjusting to their school demands and routines. These adolescents experienced either a

significant disruption in their school attendance during treatment or did not attend school during treatment. Again, adolescents reported varying lengths of time that it took them to make this readjustment (i.e., ranging from a couple days to a year). Concerns voiced by these adolescents included adjusting to increased homework and in school work demands, having assignment deadlines, multi-tasking, and the physical act of getting up early and going to school. Notably, one adolescent indicated that the grade one leaves and re-enters school is an important factor related to adjustment.

I mean I was a little stressed out cause the homework level goes up a lot from being like having a tutor to like middle school. And that's cause with like cause with the last school that I had, had which was like the elementary school. You're given one piece of homework maybe once a week or twice a week. Well there you getting like you have seven classes so you're getting maybe five pieces of homework from five different classes every week. So that at the first couple weeks that's like oh you know really stressful and stuff but then I just realized that's how it is (Justin, Interview lines 885-891).

Overall, these adolescents experienced a variety of academic-related challenges across home, hospital, and school settings. There was variability observed among the adolescents' perceptions of the intensity and duration of these challenges on their school life. Although it was difficult to manage and complete academic work, all of these adolescents maintained some level of involvement in these activities and retrospectively perceived a benefit in continuing to engage in educational tasks during treatment.

Theme 3: My social life concerns

The adolescents in this study faced challenges related to the impact of cancer and treatment on different aspects of their social lives. Adolescents coped with these challenges in and outside of the school setting. They had to manage various peer related situations including peer questioning (n=8), general peer discomfort/awkwardness (n=4), and peer reactions to physical side effects (n=3). Many adolescents also described how cancer and treatment impacted their ability to participate in social activities (n=5).

All of the adolescents shared that they answered questions posed by their peers and in some instances younger children in the community. Some of the more common questions included those related to treatment (n= 6) (e.g., “What’s treatment like?”, “What’s chemo like?”), physical side effects (n=4) (e.g., “When do you start losing your hair?”, “Why are you wearing a mask?”), school attendance (n=5) (e.g., “When are you coming back to school?”, “How much are you going to be in school?”), and mortality (e.g., “Are you going to die?”, “Did you die?”). Many adolescents (n=5) expressed that they were open and willing to answer questions and understood that their peers may be curious. In fact, these adolescents perceived benefits of telling others about their situation and candidly answering questions. They adapted and managed these questions despite having to repeatedly answer the same questions or respond to awkward questions. Some of the adolescents (n=3) perceived that it was beneficial to get information out in the open to minimize misinformation and potential rumors. Conversely, one adolescent who did not attend school during treatment preferred that minimal information was provided to school staff and classmates in order to protect her privacy and prevent unwanted attention. Adolescents reported directly answering peer questions during

informal conversations at school (n=4) and classroom-based discussions (n=1). Peer questions also were addressed through formal presentations and/or announcements conducted by principals and teachers such as school-wide announcements by the principal/teacher (n=3) and a letter distributed to the school (n=1). Additionally, caregivers provided information to peers and managed questions for some of the adolescents (n=3).

The majority of adolescents did not mention any negative repercussions of answering and managing peer questions. As previously stated, they took questions as they came and managed them to the best of their abilities. However, one adolescent reported an additional challenge related to answering peer questions. This adolescent indicated that responding to questions elicited some negative feelings and thoughts.

I mean it felt...it was okay to me, but it also hurt me and everything so...It made me feel like kinda depressed and everything so...Well, when I like it just made me think of a lot of stuff that I'd been though and everything. So it made me feel like depressed or something or sad, because I would have to remember all that by explaining it to them (John, Interview lines 196, 200, 204-206).

He shared that answering peer questions sparked difficult memories and served as reminders of what he had been through with cancer and treatment. Questions required him to, in some sense, relive moments or events that in turn conjured up uncomfortable emotions. This adolescent's experience provided a reminder that although one may be open to answering questions, they can trigger difficult memories and affirm the presence of lingering psychological side effects.

Another adolescent described her experience with peer questioning and management, which differed from the other adolescents. This particular adolescent shared that information about her diagnosis and treatment was conveyed by word of mouth during a high school social event and questions/comments were displayed on social networking sites. Peers at her high school were not sensitive to her situation and would often times ask intrusive and inappropriate questions over the Internet. The adolescent described much of this communication and information as gossip. She specifically noted that she was new to the high school, received her diagnosis at the beginning of the school year, and did not have time to establish a network of friends. Consequently, there was no one at the school or on the Internet to “have her back” or assist in appropriately conveying accurate information to peers. Although the gossip eventually subsided, this adolescent shared how difficult it was to manage peer questions and comments posted on the Internet. On the other hand, information was conveyed to peers at her former school in a more controlled fashion. Her mother went to the school and informed the school staff who then shared information with the students. She indicated that she had pre-established relationships with her former school as she attended from grades kindergarten through eighth. She indicated that she would have liked information about her cancer and treatment to be conveyed to her high school peers in a more appropriate way such as having the principal make an announcement.

Some adolescents (n=4) also were required to manage peer discomfort and/or awkwardness. They described peers at school as “touchy”, “scared”, “nervous”, and “on edge” when they attempted to approach them and ask questions related to their cancer, treatment, or side effects. These adolescents were aware of this peer discomfort and

attributed this behavior to the peer maybe not knowing how to handle or approach the situation. Generally, these adolescents were aware of this discomfort and attempted to adjust accordingly by reassuring the peer that they were open to answering questions and did not mind explaining their particular situation.

Some adolescents (n=3) also managed peer reactions to their treatment side effects. These reactions were not negative in nature but rather out of curiosity or just general commentary. These adolescents reported some looks and comments related to their physical side effects such as hair loss and port scars. One of these adolescents even noted a positive peer reaction to her wig. This peer asked the adolescent when she was going to lose her hair; however, the adolescent told her that she already lost her hair and was wearing a wig. She shared that this interaction made her think that her wig did in fact look realistic. In this instance, this particular peer reaction provided useful information to the adolescent that most likely instilled some confidence in her appearance at school.

Lastly, many adolescents (n=5) experienced limitations in their social interaction and activities in and outside of the school setting secondary to cancer, treatment regime, and side effects. These adolescents readily acknowledged that their social lives were altered. For example, some of these adolescents (n=3) expressed feeling socially out of the loop with friends due to hospitalizations, sporadic school attendance, or inability to physically attend school. One of these adolescents shared that she felt sad about missing out on social experiences at school. She described how her absence from school left her feeling out of the social loop when she returned to the school setting.

Related to school I guess um like I was kind of sad that I would like miss out. Like people do like talk now about like about a memory in sophomore year like something about something that happened at school and I'm like, "Oh yeah, I wasn't there" like it's kind of weird (Grace, Interview lines 499-502).

Another adolescent indicated that he could not engage in the fun activities during treatment that he and his friends once did together. However, he was able to reconnect with his friends when he attended school. In his case, attending school provided an important opportunity to engage in social interaction despite inconsistent school attendance. One adolescent shared that she did not want to hang out in public with her friends outside of school as much due to her hair loss. This hesitation to hang out and decline invitations lasted approximately a year and a half. She provided one reason why she did not want to go out in public: "How I looked. I didn't like, like I didn't like going out without hair cause I guess I was at the like you know beginning stages of you know finding boyfriends and stuff like that" (Kendall, Follow-up lines 199-200). However, once she thought about this situation in retrospect, she concluded that it may have been beneficial to explain to her peers why she declined their invitations to hang out.

Um I think if maybe if I would've told them more openly just like the other friend, like I had told my best friend but to like the other ones like maybe them understanding could've just helped them a little bit. Maybe like if they were sitting at home thinking like, "She never does anything", they would understand maybe inside they were mad but they never showed it (Kendall, Follow-up lines 214-217).

This same adolescent also shared the significant social difficulties she faced at her all girls high school. As a result of her intermittent school attendance and lack of pre-established social network at her high school, she shared that it was difficult for her to create lasting friendships. She indicated that peers at school would offer to provide help but not follow through once she returned to school or would provide support but then be too busy to continue to do so when she came back to school from a prolonged absence. She shared one particular story about the inconsistent and fleeting help and support she received at school.

I'd have to say like the people because you unless you expect them to understand. But like if you would, for instance, I made a friend. She helped me carry my books like all the time. And then I wasn't there for like two weeks and then I came back and she just like abandoned me. And another friend she, she like, she was my friend in eighth grade, but then in ninth grade I wasn't there for two weeks, so she was just like, "Well you haven't been in school for a long time so." That was like not having friends was the hardest part (Kendall, Interview lines 595-600).

This adolescent shared that it was difficult not having any close or true friends at school. She expressed that she felt betrayed by these peers and did not perceive them as real friends. Even after treatment was completed and she regained a sense of "normalcy", she indicated that she never made any close friendships or bonds at this particular school. The formation of "cliques" further compounded the situation as she expressed that this was not something she was interested in being a part of at school. This adolescent also explained how this particular life experience changed her outlook on social life.

Um I don't put up with like, I don't, I guess I don't really like, I don't care like about drama. Like if my school, like I don't, I guess maybe that's why I don't fit in because everyone there...a lot of girls just look for drama. They thrive on it. And I'm like it's stupid, it's petty. I mean there's people, like there's more serious stuff in life than like your boyfriend of your love letters you're going to write. So I guess, I guess I'm just, I'm more mature so I guess I just don't feel like I fit in with a lot of my, lot of people my age (Kendall, Interview lines 1200-1205).

In some capacity, all of these adolescents were challenged to manage peer related matters during and after treatment completion. They were required to answer peer questions, adjust to peer discomfort/awkwardness, manage peer reactions to their physical side effects, and cope with changes in their interactions with peers at school and in the community. Adolescents' social experiences and the degree to which they were disrupted or impeded varied among these adolescents.

Research question 6: What are the beliefs of adolescent survivors of childhood cancer about the supports and/or services that were or would be beneficial during school reintegration?

The following four themes were associated with adolescents' beliefs about what supports and services would be beneficial during school reintegration: (a) my academic support, (b) my social support, (c) these are the accommodations and modifications the school provided to me; and (d) my advice on how to navigate school reintegration.

Theme 1: My academic support

Adolescents received a variety of academic support to facilitate the school reintegration process. Academic support was provided by teachers, peers, family members, and outside tutors. Depending on the adolescent's situation, support was provided during treatment at school (for those adolescents who were still able to attend school), during treatment at home, in the hospital, or after school hours (for those who were unable to attend school), immediately after treatment was completed at home (for those who were unable to attend school), or post-treatment (for those adolescents who attended school during treatment and those who did not). Academic support was deemed at some level to be relevant and/or helpful in facilitating school reintegration regardless of when or in what setting the support was provided. For example, one adolescent in the study successfully completed treatment but did not attend the remaining three months of his seventh grade school year. During this time, he received home-based academic tutoring which helped him feel better prepared to reintegrate into the academic school environment. Therefore, supports provided away from the school setting will be included in the following discussion due to their direct relevance in facilitating these adolescents' school reintegration experiences.

All of the adolescents received some type of academic support and assistance from teachers at different points in time. Teachers provided support in and outside of the school setting. Specific types of teacher academic support included meeting afterschool to review work, teach/explain new material, and provide refresher sessions (n=3), meeting during school hours to review work (n=2), recommending outside tutors for additional help (n=2), providing opportunities to catch up with work/learn new content

during school hours (n=1), coming to the hospital to drop of assignments (n=1), and providing one-on-one tutoring to catch up on work (n=1). Overall, these adolescents described this academic support as helpful and needed as many of them were behind in their academic coursework as a result of cancer and treatment. Teachers also were perceived as willing to help and flexible in their ability to provide assistance based on the adolescent's physical status. One adolescent commented on her teachers' willingness to provide academic support and described her scheduling flexibility.

Yeah. It was the English teacher and my Math teacher did that like they were really helpful with that. What I would do is probably like once a month I would go back and check up on her like to get things straight and to make sure I was doing okay. And then like we have the occasional paper and so what she would do was on a day that I was feeling like we would scheduled it like for a day we knew I would be okay. And we would just go in and she would explain it to me so I would know how to write the paper (Grace, Interview lines 302-307).

Academic support was given through a variety of modes including, written notes/instructions (n=3), email (n=2), on-line courses (n=1), and audiovisual (n=1). A notable experience that one adolescent shared was that his teacher videotaped classes for him. This adolescent commented that one of the most exciting aspects of the videotaped classes was being able to see all his fellow classmates who interacted with him on the tape. He described his experience in detail.

...they would uh video tape a couple of my classes for me not every day but they made sure like the important classes stuff like that. They did that.

A couple teachers audio recorded their classes...Um well it wasn't webcam. It was just like recorded tape. So, um but I mean it was really, really helpful and you know....not even just the educational part but just the social inclusion part of it really and so um like I mean they'd videotaped a class. The first one the one teacher did he made it sorta like a feature film. He had like all the things before hand and stuff to make it sorta fun and like you know he'd walk in and you know he'd talk to the class for a while and then like talk to the camera and stuff like that and just like I was there and all that sorta stuff. So I mean it really gave a good aspect of you know staying with my class and all that. You know all the kids in the class would be waving at the camera and stuff so...it was really a good you know fun sort of thing and helped a lot (Luke, Interview lines 82-84, 102-110).

He went on to discuss some of his perceived benefits of the videotaping of classes.

Um it did help me to learn to a degree...But it definitely I would catch a few helpful hints and stuff on like that on there and like for things like book discussions and things like that, that definitely gave me a lot of ideas and helped me know what I should be doing and stuff. So I mean it was definitely very, very useful tool. If I wouldn't have had that there I'd definitely would have been missing a large portion of the education...Yeah, it definitely it was just a nice, good, helpful um sort of really it helped keep me on track (Luke, Interview lines 126, 134-139, 145-146).

A few adolescents (n=2) communicated with their teacher through email to receive and send back assignments as well as ask questions. Three adolescents received written instructions to complete assignments and notes for quizzes. One adolescent took an online class while she was on treatment and physically away from the school setting. Although she shared that the online teachers weren't very helpful, she did find numerous benefits in taking classes in this format. She was able to engage in self-directed learning and follow a structured assignment schedule. She described her online experience as well as long-term benefits of the experience.

Actually I really liked it. I actually ended up taking an online class my junior year and senior year because of it. Because I had found out, I was like, "Oh my gosh, there's more than just what my little school has to offer." And so um like taking it I really liked it because it had a pace set. And I knew what the due date was and knew exactly what was on it and how long it would take me. And so I could do it however far in advance or whatever. And I liked that everything was just like in one like the computer and I just did it all. I type up all my essays. I didn't like the subject. So that kind of changed my view on that particular course cause it wasn't really fun for me. It was just a lot of like reading and I don't really like that. And I didn't really like my teach...like the teachers aren't very helpful so if it was a class I would have needed help in, I feel like the online course wouldn't have been a good idea. But it did have or open up like I found out I was like cause I was looking at the course, like we were trying to figure out my next year. And they had me set up in this like

random course that was not going to help me at all and I was like, “Wait a minute like I can take an online course instead of taking a weird course through school.” It was like Graphic Design or something like something that’s not what I’m really interested in. And so I actually ended up taking AP Econ and then this year I took AP Stat and AP Civics online. So I got yeah so it was like I could take things that my school didn’t offer which was awesome. So that definitely was a benefit (Grace, Interview lines 415-432).

Adolescents also received academic support from their family members (n=5) and peers (n=2). Family members played an important and helpful role in the academic lives of these adolescents. Parents typically transported work to and from school, communicated with teachers, and taught/reviewed academic content.

Lastly, many adolescents (n=5) reported receiving academic support and/or assistance from outside home (n=5) and/or hospital-based (n=2) tutors. One adolescent received both home and hospital-based tutoring support from a professional outside of the school setting. All five adolescents received tutoring during treatment and two received services after treatment was completed. Tutors provided a wide range of services such as transporting work to and from school, teaching academic content, assigning and grading work, and reviewing/reinforcing content learned at school. Notably, tutoring experiences were highly variable in regard to frequency of receipt and quality. Some positive aspects of tutoring included learning relevant material to help catch up on missed content, reviewing/reinforcing content learned at school to promote a greater understanding and mastery, and attending to needs/capabilities of the learner (e.g., taking breaks when

needed). Adolescents who cited these positive outcomes perceived their tutors as qualified and knowledgeable of academic content. The aforementioned adolescent who completed treatment was unable to return for the remaining three months of seventh grade. Therefore, he received tutoring for those three months in core subject areas. He described his tutors as knowledgeable and adaptable as they took the initiative to introduce eighth grade content to help him be on par with his peers when he returned to school.

Alternatively, some tutors were not perceived as providing actual tutoring services. These tutors tended to provide non-academic assistance (e.g., transporting work, supervising while adolescent completed work independently). The two adolescents who received hospital-based tutoring cited reasons for the lack of quality of tutoring services. One adolescent shared that the tutor was responsible for providing support to pediatric patients in grades K through 12 which made it difficult for the tutor to be knowledgeable in all content areas across all grades.

So and she, I don't think she was like a bad tutor necessarily. I just think she wasn't cause she has to do all sorts of, she has to do like K through 12. So I mean you can only do so much of seventh grade so (Justin, Interview lines 242-244).

Another adolescent indicated that his hospital tutor worked primarily with younger children and was not knowledgeable in the content area of Latin in which he needed the most help.

That one I mean it was just it was just tough to teach when I was in the hospital and stuff. The guy who did help me a little bit, my tutor, but he

usually taught younger kids really so it was more me doing work and him reading a book and drinking his tea... He wasn't really able to help me with Latin. He didn't know it (Luke, Interview lines 415-418, 420).

On a related note, one adolescent was unable to receive the necessary home-based tutoring services because there was no tutor available who could teach pre-calculus. This particular adolescent was assigned a "tutor" who transferred work between school and her home. In these two cases, there were no tutors who could teach advanced high school subjects and, as a result, these adolescents did not receive adequate academic assistance and support. Additionally, some adolescents (n=3) reported that they engaged in a lot of self-teaching while they were on treatment.

Collectively, adolescents received different types of academic support from various individuals across home, hospital, and school settings. This support was offered during treatment and after treatment completion to help these adolescents catch up with work in hopes of being better prepared to enter the school setting. Tutoring services were variable in frequency, quality, and overall helpfulness in facilitating a successful return to academic life at school. Notably, these adolescents and their caregivers all elected to continue some sort of schooling during treatment suggesting that continuing education was a priority.

Theme 2: My social support

Adolescents received social support from peers, teachers, and other school staff that helped to facilitate school reintegration. All of the adolescents (n=5) who attended school during treatment received some type of social support from peers in the school setting. The adolescent males who attended school (n=3) indicated that their friends "had

their back”, helped them answer and manage questions, and looked out for them at school. They conveyed that their friends served as a consistent and reliable presence at school. One adolescent female shared that her friends were very supportive and made efforts to make her feel more comfortable when she started losing her hair. The other adolescent female (who as previously mentioned did not have the opportunity to establish a peer network at her new high school prior to diagnosis) indicated that she had specific individuals who she could relate to and enjoyed talking to at school. As her pre-existing network of friends did not attend her high school, she established these intimate peer relationships with these specific individuals as opposed to having a group of friends. One of these individuals also was a cancer survivor who provided an opportunity for meaningful conversation. She described her relationship with these two individuals.

Yeah, it was mainly, yeah well which well the one good part about my school is you have a big sister that’s a senior. Which she was, she was um her cousin was also a senior at my school and her cousin had cancer when she was little. And she’s the one who actually told me about camp which those two which I never really got to see them cause they’re seniors obviously. Like they um I guess cause they’re seniors they skip, they skip class a lot to go to the nurse’s office just to be in there. But like they would sit in there and talk to me. So I guess like them two at my school was like really helpful but no one like, like I didn’t really talk to any like 10th and 11th graders cause I don’t really know them and they’re not really gonna...but like my grade I didn’t really have anybody but actually having them two at my school did help (Kendall, Interview lines 696-704).

Adolescents who did not attend school during treatment (n=3) all reported that they received support from peers when they returned back to school. Support consisted of being generally supportive of their return, helping them make it through school, and treating them “normal.”

All of the adolescents in the study indicated that their teachers provided social support at school. Adolescents described their teachers as “understanding” (n=5), “helpful” (n=5), as treating them “normal”/not acting differently toward them (n=4), and “supportive” (n=2). Specific types of teacher support included offering extra help (e.g., making sure the adolescent received missed work) (n=3), being open and available to talk (n=2), and serving as a mediator between the adolescent and students to answer questions (n=1). In addition to teachers at school, some adolescents (n=4) identified other school staff as sources of social support including guidance counselors, a principal, a school nurse, and a cafeteria lady.

Two adolescents specifically noted that some of the most positive aspects of their relationships with peers and other school staff included the opportunity to talk about “normal” topics rather than the chance to discuss specific cancer-related or school reintegration concerns. One adolescent highlighted this aspect of his relationship with his guidance counselor.

... and he was good too at not making that the only thing that we talked about. That was his...that might have been his biggest asset really is that I could go down there and we would avoid...I mean now it really wasn't an issue...but like when I was first sick and when I was first still transitioning and we could go down there and avoid anything related to the hospital,

treatment, cancer, or whatever. We would just talk about how school was going, family, friends, sports, school work whatever. So that was really good he was able to...that wasn't the only thing. It wasn't like...and that made me more comfortable talking to him and talking to others really because it was like alright there is more to life and there is more in my life than just this. Where this doesn't have to be the sole focus...granted it was a big issue, but it wasn't *the* issue (Mark, Interview lines 770-780).

Another adolescent commented on how peers lightened up the mood while she was at school.

And being in the nurse's office I actually would like which kinda did help like if I was around older, like the older girls at my school like I don't have any friends. I guess if I would talk to a senior like sometimes they would like they would talk to me not really about my, not about cancer or anything just about they would tell me about their drama or their partying and stuff. And I'd just be there listening there would be like two seniors and they were talking about their partying and I could just sit there and just like listen to them be goofballs and stuff which kinda helped other people being in there talking about funny stuff. (Kendall, Interview lines 760-766).

Although teachers were primarily perceived in a positive light, two adolescents reported that they were treated somewhat differently by their teachers. They emphasized the importance of being treated "normally" at school and minimizing unnecessary

attention to their situation. These adolescents wanted to be viewed as competent individuals who were capable of participating in school. One adolescent described his desire to be treated “normally” by his teachers at school.

Uh I mean some of them you could tell in the beginning they were trying to go out of there way a little. They were kinda almost being like too helpful. Like they were constantly over my shoulder with, do you need help with this, can I help you with this, do you understand this. I was like after a while it was alright shut up back off. I have cancer I didn't get hit in the head. I'm perfectly competent to figure this stuff out my own. Um but I meant by that what I needed the most from them was I needed them to be there for me. Oh God, how do I put this without sounding selfish? On my own terms kinda of like when I need something they were there, but they did not by any stretch of the imagination have to be hovering over me waiting for me. If I needed something, if I had question they were there and they were easily accessible and I could go right to them. But they didn't have to be standing there ready and waiting for anything. It was kinda like if I have something here it is and if I don't, don't bring it up to me and act like I do in a way (Mark, Interview lines 385-397).

He also went on to describe how they figured each other out within the first few weeks of school.

In a way they were like kinda in the beginning and it got old and annoying really fast. Uh so luckily I mean we kinda figured each other out and just

how they acted after that was really good. It was like they realized what I needed and stuff and I realized what I needed from them. And that made the whole year just really smooth (Mark, Interview lines 411-414).

Lastly, two adolescents indicated that they did not perceive a need for support at school. They believed that the support from other sources (e.g., friends) was sufficient.

Overall, adolescents in this study reported receiving social support from peers, teachers, and other school staff during school reintegration. Adolescents perceived that their friends were consistent, helpful sources of support who treated them “normal.” Teachers and a variety of other school staff members were generally described as helpful and supportive during and after treatment completion. One valued aspect of these supportive relationships was that discussions and activities were not always centered on cancer-related topics which provided some needed relief and escape from the intense focus on cancer and treatment. Notably, differences existed among utilization of support in the school setting as some adolescents communicated with school staff whereas others did not perceive a great need for support in the school setting beyond their friends.

Theme 3: These are the accommodations and modifications the school provided to me

All of the adolescents reported receiving some type of school accommodations and/or modifications that were offered to facilitate their school reintegration. The most commonly endorsed accommodations and modifications included reducing the workload (n=4), sending work/assignments home to complete (n=4), requiring that only the essential work and not the “filler” work be completed (n=3), giving alternative or modified assignments (e.g., take home exams) (n=3), and modifying or providing alternative physical activities in gym class (n=3). These accommodations and

modifications were offered to these adolescents during treatment and after treatment completion. The majority of adolescents (n=7) utilized these accommodations and/or modifications across school and home settings as perceived them as helpful. There was one adolescent who was offered an accommodation but did not feel that it was necessary or very useful. Overall, these adolescents had a variety of accommodations and/or modifications available to ease the school reintegration experience and promote successful school-related outcomes.

Theme 4: My advice on how to navigate school reintegration

Of those adolescents who were asked (n=7), all of them offered advice on how to successfully navigate the school reintegration process and, more specifically, how to “make it at school.” One piece of advice that was given by some adolescents (n=3) included taking things one day at a time when one returns to school life. These adolescents expressed that it is important to stay motivated to do work, do as much as one can, but to take each day at a time so one does not overly stress out or push oneself too hard or to the point of exhaustion. Some adolescents (n=3) gave related advice to find a balance between pushing oneself too far and becoming complacent or lazy. Adolescents who gave advice related to this idea suggested that it is important to attempt to strike a balance and learn what one’s limits are after treatment. For example, one adolescent explained that one’s health should be a priority.

But then also don’t kill yourself for it. You are going through a lot. And so it’s like I mean you need to understand that your health is the bigger priority. Because you could physically make yourself worse if you stress yourself out too much worrying about work and stuff. But then again you

don't want to be on the other end of the spectrum and look at the guys who just don't care and sit in front of the TV and play Call of Duty all day long. So kinda have to find that balance between trying to do too much with your circumstances and then just not doing anything (Mark, Interview lines 831-837).

These adolescents also recognized that it may be easy to become overwhelmed with school work and trying to catch up with work. One adolescent who received tutoring services after his treatment was completed but before he returned to school indicated that tutors can be very helpful if one is having trouble with a specific academic subject.

An additional piece of advice endorsed by some adolescents (n=3) included to be comfortable with oneself and have confidence when returning to school as this can minimize attention and promote a positive school experience. A related strategy offered by a few adolescents (n=2) included to be the person one's always been and keep things as normal as possible to make returning back to school a smoother process. One of the adolescents explained why this particular strategy can be helpful.

But I think viewing yourself as or like not constantly thinking that you have cancer, just being not like pushing it away entirely, pushing the thought away entirely, but if you just view yourself as like how you always have been that anything will stay normal. And things stay normal is...I would say that's what you should aim for. I think it's easier cause like after your done things don't change that much if they've just stayed the same the whole time (Alexis, Interview lines 630-634).

Some adolescents (n=3) also indicated that people at school may not always understand the situation which can lead to being treated differently for a period of time. When providing this advice, these adolescents were empathetic and readily took the perspective of others. They conveyed an understanding that other people may not be knowledgeable or just curious about the situation and, as a result, may unintentionally be awkward or ask many questions. Other advice given by a few adolescents (n=2) was to try to stay positive and maintain a hopeful outlook even in the face of negative or discouraging situations. It was suggested that an emphasis be placed on trying to make the best of each situation with the knowledge that things will eventually improve over time.

Some adolescents (n=4) also offered advice related to social support at school. Advice focused on making friends or connecting to an existing peer network so that one has people who he/she can lean or count on at school. One adolescent described the importance of finding friends.

Socially um make sure you know find a couple of good friends to be you know your core you know rock to lean on and stuff. You know make sure you know you're around them and stuff and keep communicating with them though. Friends if they are really your friends will want to hear your problems and you know stuff that's going on. So if you're having a bad day let them know and stuff like that (Luke, Interview lines 647-651).

Other social advice included informing others at school of one's situation so they can acquire a better understanding of the situation and one's capabilities. Individual adolescents shared a few more pieces of insightful advice. One adolescent shared that one can take some control over his/her situation at school and take active steps to shape

the school experience and/or tailor the experience to one's preferences and needs. For example, this adolescent indicated that one can decide who he/she wants or does not want to provide cancer-related information to and can inform others of his/her preferences (e.g., wanting to talk about cancer versus wanting to keep to oneself). This adolescent shared his point of view on the degree of control one can have within the school setting.

Um no I mean you can make it go back to normal as fast or as slow as you want. You can immediately jump back into what you were doing before and your friends and everything else and act like nothing happened. Or you can take the other route and just let what they know be free and tell them about it if they want to know and stuff like I got asked a lot of questions the first few months and so that's normal. But I'm sure you can just tell people that you don't like to talk about it or anything. I wanted to talk about it, so I told people when they asked (Justin, Follow-up meeting lines 51-56).

Another adolescent who was unable to attend school throughout treatment shared her view on how never giving up on the possibility of the future can be an important motivator and something that should not be discounted or dismissed.

...and never I guess never take away the possibility of a future. Like even if like I feel like I still talked about it I was like, "I'm going to college" and I'm still like, I've wanted to go to X college since I was 10 years old. And that was like my biggest drive. And I feel like still having that goal and like people would like if someone were to ask me what I want to do with my life, I mean no one every did cause I feel like everyone thought it

was a touchy subject. But like where I wanted to go in college when I was going through it, I still would have answered and I still would have had like my whole life plan planned out. And I feel like some people may think about, “Oh well, there may not be a future” but I feel like that’s a terrible way to look at it. I mean there’s always going to be a future no matter what. And if you just look at it that way, then you’ll get yourself moving cause you’ll have something to look forward to (Grace, Interview lines 924-935).

Overall, adolescents provided a variety of advice on how to navigate the school reintegration process and increase the likelihood of having a positive school experience. This advice targeted personal, academic, and social-emotional domains and included strategies that could be used prior to or during school reintegration.

Additional Themes

Additional themes emerged from the data that are indirectly related to the research questions. These themes are discussed because they provide additional information that can help to further illuminate the research questions, individual cases, and quintain. The first theme that will be discussed is “pre-existing factors” followed by “outcome indicators of a healthy/unhealthy transition process.”

Theme 1: Pre-existing factors. The majority of adolescents (n=7) described the presence and/or absence of certain pre-existing factors prior to their cancer diagnosis and treatment. These factors were primarily protective in nature. Examples of pre-existing factors included pre-established school staff and student relationships, pre-existing peer support network(s), and pre-morbid

personality/attitude. One adolescent who attended the same catholic school since pre-school identified that his relationships with school staff were already in place prior to having cancer and that his teachers were aware of his academic work ethic.

Luckily for me I'd been pretty involved with the school and the parish in general for a long time probably, basically my whole life. So I knew a lot of the teachers before then pretty well and since the junior high teachers were all the same I knew them all from 7th grade already. So they all knew me. They all knew I was a good student and hard working and that I liked to get stuff done and if could anything I could do, I would do (Mark, Interview lines 346-350).

He also described how the presence of these pre-established teacher relationships was helpful while he attended school during treatment.

So there were all very sympatric and very helpful. Um they made it easier too because they were always willing to talk and always there for me or something. Which was that was what I needed most of all really from them. They were all really good. I accredit that really to how I'd known them beforehand (Mark, Interview lines 373-377).

Another adolescent also identified the presence of pre-established student relationships as something that was helpful. He was already familiar with some

of the students at school and had a good grasp on what to expect when he attended during treatment.

Like I mean I was I was there I was in school for about that first month, so I had a pretty good base. I knew all my teachers and a lot of kids in the classes and had the general idea of what was going on (Luke, Interview lines 74-76).

Two other adolescents also described pre-established school staff and peer relationships. One of these adolescents had prior relationships with teachers that significantly influenced her academic course while on treatment and beyond. This particular adolescent described that those teachers who previously had her in class and were keenly aware of her knowledge and skill level. She described how these teachers advocated for her academic needs and her ability to take on a challenging course load during treatment even in the face of doubt and dissention by other professionals unfamiliar with her background and prior academic performance. This adolescent indicated that if it were not for these teachers' efforts and advocacy she most likely would not have graduated with her class.

The majority of adolescents (n=7) reported having a pre-existing support network of friends prior to their diagnosis. These relationships were more intimate in nature and extended beyond acquaintances at school or in the community. These friendships were deemed as helpful and supportive during and after treatment. These adolescents were able to utilize these support networks during school reintegration and the shift from off-treatment to post-treatment. For example, one adolescent described how he got to know members of his cross-

country team the summer before his diagnosis and had some of his best friends in his homeroom. These pre-existing relationships were helpful when he attended school throughout treatment (e.g., close friends looked after him at school, supportive gestures from homeroom classroom) as well as when he returned full time the following school year (e.g., ran cross country that summer with friends, able to rejoin friends at school).

Another adolescent who was previously mentioned experienced the impact of simultaneously having a strong, pre-existing support network and a lack of a support network. More specifically, this adolescent had a close group of friends that attended her previous school. She was a grade ahead of her close friends and just started high school. Therefore, she entered a new school environment while her close group of friends remained at her former school. She received her diagnosis at the beginning of her ninth grade year, so she did not have a great deal of time to establish any close friendships. She described how one of her best friends who attended her former school helped her throughout treatment. She wished that this particular friend had attended her high school so that she could be there to provide support.

And so she could just, and she always like, she always like I guess she kinda felt like she protected me because people would say like, “Make sure you’re really nice to Kendall and stuff” and she’d be like, “No, you don’t treat her any different. She’s the exact same person. Don’t give her...she doesn’t want special treatment. She doesn’t want that kind of stuff.” And she would, she was always

like there and she even like came to chemo with me sometimes and like she always treated me like I was the same exact person. Like if I was, we would go kick the soccer ball if I could which was really good. And same with all like all six of them like I was just the same exact person which it was unfortunate that none of them went to my school (Kendall, Interview lines 277-285).

She also described how the lack of close relationships at her high school impacted her overall high school experience including news of her diagnosis being conveyed via gossip/social networking sites and lack of genuine support (e.g., peer would agree to help but not follow through on providing support). She indicated that she never truly formed any close friendships at her high school even after she completed treatment. There was a notable difference for this adolescent between the absence and presence of a pre-existing support network.

Lastly, some adolescents (n=3) described their personality/attitude prior to receiving their cancer diagnosis. They acknowledged that this is the way they have always been and that their unique personality characteristics played a role in how they managed and dealt with their cancer experience. Adolescents described themselves as independent, having positive attitude, and focused/goal-oriented. These personality characteristics were prevalent throughout each adolescent's cancer experience and in some cases reaffirmed to the adolescent that they possessed a particular characteristic. One adolescent described his positive attitude and outlook on life in general and how that carried throughout his diagnosis, treatment, and beyond.

A positive attitude that was...I mean that's sort of always been my nature but this whole experience has almost reassured that. I've always been a real positive person and even from the time of diagnosis I was just pretty positive. I mean that's just a really big thing in my life. Always stay positive (Luke, Interview lines 921-924).

Overall, pre-existing factors were identified in the adolescents' stories and primarily served a protective role or function throughout their cancer experience. These factors were related to social relationships and networks as well as personality characteristics/attitude. A few adolescents identified how these pre-existing factors were helpful to have in place prior to their cancer diagnosis and treatment.

Theme 2: Outcome indicators of a healthy/unhealthy transition process. As described in the conceptual framework used in this study, there may be outcomes that indicate whether a transition process has been "healthy" or "unhealthy" in nature. Although this was not a direct research question in the study, it is noteworthy as some adolescents' stories revealed examples of such outcomes. These outcomes differed from process indicators (i.e., signs or markers observed throughout the transition process as previously described). For the purposes of this study, outcome indicators were defined as long-term consequences of healthy/unhealthy transitions processes in which there was evidence of a lasting behavioral change that continued to impact the adolescent's life beyond diagnosis and treatment. As process indicators provide the adolescent with evidence or

feedback on their progress or lack thereof in making a transition, outcome indicators can provide the adolescent with information that cancer and treatment has made some significant, lasting change to their lives. In effect, process and outcome indicators are conceptualized as key pieces of feedback that the adolescent can internalize and use to assess their cancer experience and, more specifically, their ability to move from one phase of care to another (e.g., treatment to survivorship).

One example of a healthy outcome indicator endorsed by four adolescents in the study was increased strength and cohesion with certain family members. These adolescents shared descriptive stories that illustrated different ways that family members provided support as well as how being in close proximity facilitated growth in their relationship. These instances ultimately brought the adolescents and their particular family members(s) closer together and created a meaningful and lasting change in the relationship. Other healthy outcome indicators included having an appreciation for life and what was learned from the cancer experience (n=4), having and maintaining a generally positive outlook/approach to life (n=3), establishing future personal or professional goals (n=3), making lasting peer relationships at school (n=2), and returning to previous academic performance (n=2).

A notable outcome was appreciation for life and what was learned from the cancer experience. To highlight the individuality of each adolescent, each of the four unique perspectives will be shared. One adolescent shared that he was appreciative for all those things that he did not lose such as his friends. He also

expressed that he is grateful for the opportunity to meet new people and for all the friends he made during his cancer experience. Another adolescent shared the she has learned what is important in life and does not judge others who may be different.

Um I think I learned a lot. Like I think you learn more like important stuff in life because you like it kinda makes you mature really quickly and like focus on more important things in life than just, than just like you know girls who are being mean to you or just starting random drama. I think the biggest thing I learned was like judging people just like when you look at people and you judged them like no matter what it is, it's wrong whether they have a mental disability whether you know anything that's just different or unique about them. I just don't think I judge them at all. Like I just look at them or like I turn my head and don't stare if they have like one leg or anything about people that's different. I just don't judge people (Kendall, Follow-up meeting, 401-408).

Another adolescent shared that through his cancer experience he realized that life is valuable as a person has only one chance to live life. Therefore, he determined that life should be lived to the fullest extent possible because it cannot be reclaimed once it has been lost.

What I pretty much got out of it you only get one chance at life. You die you don't come back. So basically what I've learned is live life to the fullest because if you die, there's no coming back. I

mean you might get reincarnated into somebody another human form but it won't be you. So I've basically live by live life to the fullest. So far I've been doing that! (Drew, Interview lines 954-957).

Lastly, another adolescent expressed that she appreciates the “little things” in life such as going outside and breathing fresh air, being able to hang out with her friends with no restrictions, and even her hair as she has learned to take very good care of it now that it has grown back (Grace, Interview line 1032). She also shared that she is grateful for the new people she met, relationships she established with peers and hospital staff, increased closeness between her and her parents during treatment, and support received from friends, family, and her school. She described positive memories associated these individuals and indicated that she would have never had these memories if it were not for her having cancer.

Notably, one adolescent and his mother expressed a different view on the appreciation and lessons learned concept. This alternative viewpoint is being presented because it adds depth and richness to the study and serves as a reminder that there are multiple perspectives that warrant exploration and discussion. This particular adolescent was asked the following question: “What have you learned or got out of your cancer experience?” He replied that he did not learn anything in a spiritual or life changing sense as a result of having cancer. Rather, he learned technical information about his particular cancer and treatment from his medial team.

Honestly, nothing. I want to be 100% honest. I don't feel like I really learned anything from it. I mean through getting cancer, I learned information about other stuff. But I didn't learn anything about myself or have any like spiritual awakening or anything like that. So really that's a one-word answer for me (Justin, Interview lines, 1504-1507).

Following the interview, a debriefing session was conducted. This participant and his mother presented their views and thoughts related to this interview question (Justin, Direct observation notes lines 28-39). They indicated that these types of questions often times assume that something was or had to be learned as a result of having cancer. However, this is not always the case as not all cancer survivors have learned something, feel they have gained a greater sense of self, or are more appreciative of life. The PI, participant, and his mother then discussed how a "culture of cancer" exists in the United States which tends to emphasize or assume that the patient and family should "fight" and stay strong to "beat" cancer. Furthermore, this culture also can be perceived as imposing and may not be appropriate for all types of families. The participant's mother indicated that some individuals and their families may not want to fight cancer at all and just want to get through it, be done with it, and move on with their lives. Overall, this family expressed that having and surviving cancer does not always result in some type of learning experience or lesson learned. They suggested that to assume that this is the case for all cancer survivors would be misleading and misrepresent those who may not espouse those views.

Additionally, some (n=3) adolescents reported unhealthy outcome indicators. Of note, an unhealthy outcome can be attributed to multiple factors and should not be accredited to one individual, event, or situation. There is most likely a complex interplay among factors that lead to these particular outcomes. One adolescent who was a high performing student (i.e., honor roll, excellent attendance) prior to his cancer diagnosis indicated that he was unable to regain his academic productivity and performance after treatment completion. His schooling was disrupted from fourth to sixth grade and was finally able to regularly attend school in seventh grade. He was keenly aware of this change and identified some factors that may have contributed to his academic decline.

Well like in the 4th grade when I finished I missed a lot of stuff that I really didn't understand. Plus like 7th grade when it was all over, I started playing around and stuff. So since then I've been in high school all the work that I do is kinda hard and I kinda wish I could go back to 7th grade so I can actually redo it because I didn't know in 7th grade that the high schools look at that more than do look at the 8th grade. So, it would be better for me to go back to 7th grade and I could get into like a better school and everything like that (John, Follow-up lines 122-127).

He provided additional insight into his academic performance.

Well now since 7th grade, I mean I've been doing ok but I haven't been doing as much as I could have. That's cause um I think it's because either I didn't know how to do the stuff, or I was hanging

out with the wrong people. But I mean they didn't do anything bad. Just most of the time they didn't do their work or something and they was talking and everything (John, Interview lines 112-115).

Another adolescent shared how he did not maintain a healthy level of physical activity, ate unhealthy foods, and as a result gained weight during the year following treatment completion. He said that after treatment he did not feel like doing much and had lack of self-discipline and self-control despite the promise he made to himself that he would get into good shape once treatment was completed.

Well then that was one thing I told myself even during treatment. I was like alright and then this really hit me kinda after treatment too cause when I first got sick I was kinda like alright well I know I'm not going to be able to do anything now but once I'm finished with all this I'm just get myself into the best shape I possibly could.

Then, after treatment I did just the opposite. I really didn't care to do anything. Then it was a couple of months after treatment where I kinda looked at myself and I was like alright what are you doing like that promise you made to yourself three years ago, where is that (Mark, Interview lines 739-745)?

When asked for reasons why this weight gain occurred, he could not exactly pinpoint why this occurred but attributed it to a possible "teenage phase" (Mark, Follow-up line 215). However, he eventually turned this aspect of his life

around and “snapped out of the phase” as he realized that he was going into his senior year and wanted to look good and feel confident attending important school events and eventually college (Mark, Follow-up line 239). He made a concerted effort to lose weight and now continues to remain conscious of his health and overall well-being. Lastly, another adolescent shared how some aspects of her life have been impacted since her cancer diagnosis and treatment. This adolescent was candid about the changes she experienced and the long-term impact that they have had on her life and future. For example, this particular adolescent experienced derailment of her future plans to play soccer in college. Due to her cancer diagnosis and treatment, she was unable to play soccer for her entire year ninth grade year. Therefore, she got a late start with college planning which in turn negatively impacted her chance to be recruited to play soccer at a good college.

Well like with college planning like college soccer planning. Like I couldn't get started college coach like I started last year I started like after I started treatment. I guess I started back that February I stopped treatment then I didn't get to start back until like September. So that year I didn't really email college coaches to come watch me play cause I didn't understand how like, or didn't know how good of...I would be ready. So then I just started emailing them and now it's really late. So that kinda messed me up with getting a good college (Kendall, Interview lines, 1079-1084).

She shared that she continues to feel upset about this missed opportunity as well as missing out on her high school experience in general: “Um yeah cause I think it’s changed me a lot like with college and stuff just kind of upsetting a lot. I guess with school like I don’t feel like I got a high school experience (Kendall, Interview lines 1225-1226). This adolescent also experienced social life challenges that continue to impact her school life. She was the adolescent who did not have the opportunity to establish peer relationships prior to her diagnosis. When asked if she was able to make up social ground and establish new, meaningful friendships after treatment, she said that she has not developed a close relationship or bond with anyone at her high school. To further compound the situation, she also expressed that she feels more mature and now finds it difficult to relate to peers at school.

Lastly, this adolescent also indicated that she and her mother have observed changes in personality/outlook on life. She shared the following observation: “Um I don’t think I’m the same person. I’m not the same person as I was before (Kendall, Interview line 1195). Her mother has observed that she is at times angrier and more strong-willed than she was prior to her cancer diagnosis. She did not know exactly what her mother meant but provided some insight into these observations. She acknowledged that she no longer accepts certain behaviors (e.g., a person offers help but then does not follow through on providing it) and feels angry about missed opportunities (e.g., playing college soccer) and not having a typical high school experience. Notably, she did

recognize that there are positive and negative aspects to these changes in her personality.

Overall, adolescents in this study experienced a wide range of healthy and unhealthy outcomes associated with their cancer and treatment. Adolescents reported outcomes related to academic functioning, family and peer relationships, and personality/outlook on life. This particular theme provides preliminary information on the long-term outcomes that may result from healthy and unhealthy transition processes.

Tentative Assertions

Tentative assertions are presented due to the exploratory nature of this study. These assertions are based on a collective review of the data and reflect information yielded from the participants in this study. These are statements that reflect overarching main ideas that were constructed based on a holistic view of the findings.

Assertion 1: The shift from off-treatment to post-treatment and school reintegration were not necessarily perceived as transitions or times of significant change.

Generally, adolescents did not identify school reintegration and making the shift from off-treatment to post-treatment as transition processes. Elements of a transition according to the conceptual framework were present as adolescents recognized that there was *movement* from one phase of care to another and reported a sense of *disequilibrium* (i.e., facing challenges) during these times. However, they did not perceive that school reintegration and the shift from off-treatment to post-treatment were times of great confusion, discomfort, or anxiety. In fact, some adolescents commented that the word “transition” was an inaccurate representation or an exaggeration of what really happened.

They were more apt to describe going from middle to high school as an actual transition. The main focus was placed on feeling better, returning to “normal” life, and re-engaging in activities that they once enjoyed with friends and family. The prolonged state of unpredictability most likely served as an extremely powerful motivation to “get things back to the way they were” and to return to age-appropriate tasks and activities. There were many signs or *indicators* unique to each adolescent that helped them ascertain how they were progressing toward achieving a “normal” life. Again, the primary goal was to get back to “normal” as soon as possible and thinking about these times as “transitions” may have created an unnecessary and even maladaptive sense that there were additional hurdles to overcome or could have made it seem as though “normality” was not quite in reach.

Assertion 2: Returning to normalcy and regaining control over one’s life and environment are important goals guiding these “transitions”.

The theme of achieving a sense of “normality” was prevalent throughout the results of this study. On a more subtle level, adolescents also desired to regain a sense of control or mastery in the school setting and in their life after treatment. Examples of how these adolescents gained some control and/or mastery during these “transitions” included re-engaging in or catching up with academic work, meeting short-term and/or long-term academic goals, re-joining extracurricular activities that they were unable to participate in during treatment, advocating for themselves in school (e.g., determine how they wanted to present themselves/image at school, seeking out additional academic support to catch-up), and making new friends at school. In conjunction with these types of personal accomplishments, the improvement of treatment residuals also enabled these adolescents

to meet these goals. The improvement in physical and psychological treatment side effects appeared to set the stage for these adolescents to pursue personal goals and/or reclaim part of their life so they could begin to regain a sense of “normalcy” and/or control.

Assertion 3: The status of treatment residuals serve as signs/indicators which can provide feedback about the progression of the “transition” process and success in returning to “normality.”

The presence, improvement, or absence of treatment residuals served as signs or indicators that these adolescents’ lives were getting back to “normal” or that life was not back to “normal” just yet. Re-engagement in activities and roles (which were facilitated by improvement/absence of treatment residuals) also served as signs or indicators that life was returning to “normal.” These observable signs provided adolescents with information and feedback about their progress toward returning to “normality.” Each adolescent described unique signs and indicators that were related to their particular lifestyle, interests, and personal goals. These signs also could be conceptualized as each adolescent’s significant mile markers in their race to achieve “normalcy.” In fact, many adolescents were looking forward to meeting personal mile markers such as returning to certain activities and/or regaining their physical appearance. Similar to a marathon runner, the adolescent takes strides and eventually passes each individual mile marker. As each mile marker is passed, this brings a sense of accomplishment and reaffirms to the adolescent that his/her goal is achievable and within reach. The adolescent is aware that he/she is one mile closer to reaching the finish line. He/she pools internal and external

resources, continues to persevere through the aches and pain, and faces the challenge ahead by taking one stride at a time to finish the race.

Assertion 4: Adolescents receive support from multiple sources that indirectly facilitate the progression through these “transitions.”

Notably, adolescents in this study did not report receiving a great deal of advice or support specifically related to facilitating these transitions. With the exception of medical team advice, support was provided in general sense from family members, friends, and school staff that often times did not involve any direct discussion of ways or strategies to make these “transitions” smoother. In fact, many of the adolescents believed that they did not need specific advice related to these “transitions” and in some cases preferred that no discussion take place regarding this topic. Adolescents described receiving a variety of support (e.g., friends helping them manage questions, receiving encouragement and positive feedback others, teachers providing them additional academic support) from various people and identified that this was an important factor in facilitating their school reintegration and regaining a sense of “normalcy” after treatment completion. This support appeared to be more valuable and important in promoting a sense of “normalcy” than the information and advice specifically related to these “transitions.”

Assertion 5: Pre-existing factors play a role in the school reintegration and shift from off-treatment to post-treatment experience.

Adolescents identified a variety of factors such as pre-established relationships with teachers and peers at school, pre-existing peer networks, and pre-morbid personality characteristics/attitude. In the majority of cases, these pre-existing factors were

protective in nature and set the stage for positive cancer and, more specifically, “transition” experience. For example, one adolescent’s strong academic work ethic established prior to her cancer diagnosis played a role in her maintaining the motivation to do work during treatment and completing academic goals set during treatment. In turn, this help to facilitate a positive school re-entry experience as she was able to take and pass final exams in the school setting and was academically on par with her peers. Another example includes one adolescent who attended the same school since kindergarten and, as a result, had strong pre-established relationships with his teachers. His teachers provided a great deal of support and individualized attention and tailored their expectations and provision of support based on their knowledge of his prior academic performance and work ethic. Conversely, for another adolescent the lack of pre-existing protective factors (e.g., lack of an existing peer network at school) made certain social aspects of her school reintegration experience more difficult. In general, the presence and/or absence of pre-existing factors appeared to have an indirect impact on these “transition” processes. Although this was not a question directly asked by the PI, the majority of the adolescents described these pre-existing factors and, in some cases, recognized that they had a meaningful impact on their “transition” experiences.

Summary of the Principal Investigator’s Journal

I would like to take this opportunity to share my beliefs, relevant life experiences, and expectations with the reader in order to truthfully and candidly share my role in this research process. Before study conceptualization and data collection commenced, a fellow graduate student interviewed me to promote increased awareness and insight into my potential influence on study conceptualization as well as data collection, analysis, and

synthesis of findings. The interview revealed that I had numerous life experiences and strong personal beliefs that were undoubtedly going to impact the study on either a conscious or unconscious level. I knew there was no denying the fact that my perspectives, views, and background would influence the direction of the study. Another outcome of the interview included an increased openness and excitement to altering and/or reforming my perspectives. I had a renewed excitement to approach the study with an open mind, ears, and eyes. I was hoping that I would be thrown for a few loops because I knew it would result in tremendous personal and professional growth and insight. To say the least, I was thrown for quite a few loops, twists, and turns, and I learned a great deal from the adolescents in this study. I am truly grateful to them for making me a better researcher, critical thinker, and future psychologist.

As I was about to embark on data collection, I continued to identify and reflect on my own unique perspectives and beliefs. I realized that I possess strong beliefs regarding health care, quality of life, and programming to meet the needs of pediatric populations, especially childhood cancer survivors. For example, I believe that all children should have access to physical and mental health care and that one of my primary responsibilities as a future professional is to help improve the quality of life of children and their families with them being major partners in achieving such a goal. As a result, I want to be an advocate for adolescents and their families and help to provide more seamless school reintegration and survivorship care experiences and services. I also believe that the voices of childhood cancer survivors and their families should be heard if they feel comfortable doing so. Therefore, it was a very important goal for me to actively

listen to the experiences, viewpoints, and perspectives of the adolescents themselves so that I could gain a greater understanding of their lives.

Additionally, I learned that my experiences working in the hospital setting were extremely influential in conceptualizing the present study. First, I observed the educational experiences of adolescent cancer patients and how they and their families navigated this bumpy terrain throughout treatment. One patient and caregiver in particular struggled to navigate the complex web of home-hospital, online classes, and public school services. They had tremendous difficulty accessing quality educational services thus making school reintegration more difficult. I also worked with another adolescent who was not able to attend school secondary to treatment and associated side effects. I observed the social, academic, and emotional challenges this adolescent faced throughout treatment. I also had the opportunity to work with an adolescent and young adult who were transitioning back to high school and community college respectively. These individuals voiced many concerns and questions related to returning to their academic lives after treatment completion. There were very few services or supports available to these individuals despite their expressed need. It quickly became apparent to me that just because treatment had ended did not mean that their lives returned to “normal”. In fact, it appeared that for these particular individuals life was presenting new challenges along with a renewed hope to move forward with life. This also was one of the first times that I realized gaps in service delivery exist which can have a lasting impact on the lives of adolescent cancer survivors. Collectively, these professional experiences ignited a curiosity that inspired me to ask more questions and talk to

adolescents themselves about their lives, school experiences, and return to life after treatment.

In addition to my beliefs and professional experiences, I also had expectations about how the study would unfold and what information I might learn from the adolescents. For example, I expected that there would be a variety of challenges faced by adolescents during school reintegration and returning to life after treatment. I had a vision of struggle and awkwardness combined with feelings of happiness and excitement to return to “normalcy.” Challenges were identified during school reintegration and returning to life after treatment; however, they weren’t necessarily viewed as challenges but rather things that were approached in a matter of fact way. The “challenges” were not as overwhelming as I had envisioned or anticipated. The adolescents were quite resilient and approached many of these “challenges” head on and to the best of their abilities. Also, the combination of my beliefs and training background created an assumption that providing assistance and support to adolescent cancer patients and survivors would be a high priority and play a central role in their experience. I assumed that adolescents would express a need for support and services due to the challenges they faced. Effective service delivery is a concept that is engrained in my mind and admittedly this was something that I assumed from the start of the study. As the study progressed, I realized that my view or perception of what an adolescent cancer patient or survivor may benefit from can be vastly different from what the adolescent may want for him or herself. It became apparent that it was important for me to not assume what the adolescent would benefit from but rather to remain open to his/her expressed needs. I am

aware that this may seem obvious, but I think it had to hit me in the face in order for me to truly hear, understand, and process what the adolescents were telling me.

As a side note, I spoke with a few adolescent cancer survivorship programs across the country to find out more about their experiences working with this population of survivors. I spoke with a director from one site who shared his organization's approach to meeting the needs of adolescent cancer survivors. The director indicated that he heard adolescents in his organization mention concerns associated with experiences such as school reintegration (e.g., "Boy, it sucks that I have to go back to school"). The organization developed an initial program/support group that was developed primarily with adult input and focused on talking about cancer experiences and related content. As the director put it, the program "failed miserably" as the focus of sessions did not appear to hit home or appeal to the adolescents (J. Sellar, personal communication, February 2010). The director indicated that they changed their program, and it is now more focused on fostering social interactions and slowly developing rapport which has been much more successful than the previous program. A director at a different organization stated that adolescents are their own unique population that cannot be defined in child or adult terms and that they have specific developmental and cancer-specific needs (K. Maxwell, personal communication, February 2010). These conversations had an impact on my beliefs and expectations as well as the study progressed. They revealed the importance of incorporating the perspectives and needs of the adolescents into program development. This solidified my belief that the adolescents themselves are one of the greatest sources of information and insight.

Furthermore, I expected that adolescents would perceive the school reintegration and return to their everyday lives as a transition process. Despite my awareness that life is not straightforward, I found myself conceptualizing transition processes in a rather cut and dry, rigid manner. I held this view despite my awareness that life is complex with interaction among multiple variables that can yield various outcomes. As the study unfolded, I realized that the words “transition” and “process” were my chosen words that were a reflection of me attempting to impose adult structure and definitions on the experiences of these adolescents. It quickly became apparent that my adult focus required a serious check at the front door. As the study progressed, I became more and more open to the language, perspectives, and ideas of the adolescents themselves. I discovered a great appreciation for actively listening to the perspectives of the adolescents throughout the study to truly internalize what they were saying to me. I continuously evaluated my adult views and reminded myself that the goal of the study was to acquire an understanding of these adolescents’ experiences and the language in which they chose to describe them. The adolescents’ stories also enabled me to expand my original, overly simplistic view of a transition process. Their insights and perspectives undoubtedly served as an eye opener and challenged me to re-evaluate my perspectives and beliefs.

Overall, my beliefs, relevant life experiences, and expectations were shared with the reader in hopes of providing an honest appraisal of my role in this research process. My prolonged engagement in this study has yielded a wealth of personal knowledge, insight, and ultimately a greater perspective of the research process and the questions under study. I believe it was an extremely valuable exercise to conduct the self-interview

and continually reference it throughout the course of the study. Additionally, I found tremendous benefit in maintaining a personal journal as I was able to track my thought processes in relation to the progression of the study.

Summary

In summary, various sources of data were gathered from eight adolescent cancer survivors. A combination of a template organizing style, immersion/crystallization (I/C) approach, and a multiple case study approach were used to analyze these data (Borkan, 1999; Crabtree & Miller, 1999, Stake, 2005; Yin, 2008). A cross-case analysis was conducted and results were organized according to each of the six research questions. Tentative assertions also were developed based on a comprehensive examination of the findings.

Themes related to the first research question included “it’s not a transition, let’s get back to ‘normal’”, “my approach to life after treatment”, “signs that I’m making my way back to ‘normal’”, and “feeling more comfortable with time.” In general, adolescents perceived the shift from off-treatment to post-treatment as a time of change and disequilibrium but not as a transition. The word transition was not an accurate word to describe their experiences. Rather, this shift was described in more personalized terms that had meaning and significance to each adolescent. Primary goals during the shift from off-treatment were to return to a sense of “normalcy” and become more comfortable with oneself. The majority of adolescents did not have a specific approach or strategy as they went from being a cancer patient to survivor and did not necessarily think about the specifics of what life would be like or what they were planning to do after treatment completion. They faced challenges as they were confronted and approached life after

treatment by taking one day at a time. Additionally, improvement and/or absence of treatment residuals as well as re-engagement in activities and roles served as signs that life was getting back to “normal.” Adolescents described signs unique to their particular interests and goals. They also expressed feeling increasingly comfortable in their own skin and more confident in their ability to cope with life as a cancer survivor over time. Lastly, these adolescents developed awareness that aspects of their life were improving and that they were making progress toward achieving a sense of “normality.”

Two themes were associated with the second research question including “signs that life is not back to “normal” just yet and “it is not the focus of life, but the idea of relapse is there.” The presence of treatment residuals functioned as signs or indicators that life was not quite back to “normal” for these adolescents. These signs served as reminders that the effects and impact of cancer and treatment extended beyond treatment completion. Furthermore, it affirmed the idea that treatment completion does not necessarily equate to a life free of cancer and associated concerns. For the majority of the adolescents, treatment residuals continued to impact their daily lives and restricted participation in desired activities. They faced these challenges in a matter of fact fashion and adapted to their particular situation to the best of their abilities. Another prevalent concern after treatment completion included the fear of relapse. Adolescents shared a variety of emotions and thoughts related to the idea of relapse and variability existing among participants degree of concern of this possibility. They readily identified that relapse was a potential reality but actively chose not to let the thought of relapse control their lives. These concerns also lessened over time as adolescents became increasingly

comfortable with themselves and follow-up appointments. Adolescents were more concerned with moving on, living life, and returning to “normalcy.”

Themes related to the third research question included “my need for supports and/or services”, “what my health care team told me”, “it is beneficial to know others who have been through what I have been through”, and “my advice on how to navigate the shift from off-treatment to post-treatment.” Adolescents varied in their perceived need for services and/or supports specifically related to the shift from off-treatment to post-treatment. Some adolescents welcomed and were receptive to advice while others did not see the necessity of additional information/support. For those adolescents who reported receiving advice, the majority of advice came from their health care team. Some adolescents noted that it was valuable to have health care team members be honest and open when sharing information and making recommendations. Adolescents also received support from peer cancer survivors across school, community, hospital, and camp settings. They found numerous benefits in having these established relationships and many adolescents continue to stay in contact with friends made during treatment. Lastly, all of the adolescents offered valuable advice about how to successfully manage the shift from off-treatment to post-treatment.

Three themes were associated with research question four including “going back to school provided a sense of ‘normalcy’”, “here is what I was anticipating before going back to school”, and “taking a matter of fact approach to going to school.” Adolescents reported that attending school provided a sense of “normalcy” and allowed them to return to social activities and get back into a daily routine. They were able to once again participate in age-appropriate activities with a purpose. Regardless of whether or not

adolescents liked attending school, they reported that it was beneficial because it promoted a feeling of “normalcy” and provided the opportunity to be social. Those adolescents who did not physically attend school during treatment expressed a variety of anticipatory thoughts and mixed feelings prior to their school re-entry. These thoughts and feelings were associated with their academic re-entry points and their content was related to cancer as well as non-cancer topics. Adolescents also took a matter of fact approach to school reintegration despite facing academic and social challenges.

Although they acknowledged that going back to school represented a change in their lives, the majority of them did not have a specific plan of action to re-enter the school setting. They tended to focus on fitting in, hanging out with their peers, and returning to a general sense of “normalcy” at school. Notably, adolescents differed in the amount of time it took them to readjust and feel comfortable at school.

Themes related to research question five included “disruption of my school life,” “my academic concerns”, and “my social life concerns.” All of the adolescents in the study experienced some level of disruption in their school life secondary to cancer and treatment. The level of disruption varied among adolescents depending upon their specific diagnosis and treatment regime. The demands of cancer and treatment impeded these adolescents’ ability to regularly attend school and participate in school routines which made it difficult for them to maintain involvement in age-appropriate activities and tasks. Adolescents continued to experience this interference in their school life even after treatment was completed as they had to attend follow-up appointments, undergo scans and other hospital-based procedures, and manage unexpected illnesses. In addition to coping with unpredictable school attendance, adolescents also were required to manage a

variety of academic and social challenges in home, hospital, and school settings. Academic concerns included falling behind/catching up with work, maintaining motivation to do work, and readjusting to school demands and routines. Adolescents were also required to address peer-related situations such as answering questions, adjusting to peer awkwardness/discomfort, and managing peer reactions to their physical side effects. Notably, many adolescents were able to take the perspective of their peers and expressed an understanding of why their peers may have displayed these behaviors at school.

Four themes were associated with research question six including “my academic support”, “my social support”, “these are the accommodations and modifications the school provided to me”, and “my advice on how to navigate school reintegration.” Adolescents received many different types of academic and social support during treatment as well as after treatment completion. Teachers, family members, and peers provided academic support across home, hospital, and school settings. Teachers were a particularly important source of academic assistance both in and outside of school. Academic information was communicated between teachers and adolescents through different modes such as email, written instruction/notes, videotaping, and the Internet. Some adolescents also reported engaging in a good amount of self-teaching. Tutoring was another common type of academic support provided to adolescents. Tutoring services were highly variable in terms of frequency and quality, and some adolescents readily identified reasons for this variability. The majority of adolescents also received a great deal of social support from teachers, peers, and other school staff members. These sources of support helped adolescents feel increasingly comfortable and readjust to

school routines. Furthermore, adolescents reported receiving a variety of school accommodations and modifications to assist in their school reintegration and facilitate positive academic and social experiences. The majority of adolescents utilized these supports and found them to be beneficial. Lastly, adolescents provided advice on how to successfully navigate school reintegration.

The two additional themes of “pre-existing factors” and “outcome indicators of a healthy/unhealthy transition process” were also yielded from the data. Pre-existing factors that were identified in the adolescents’ stories included pre-established school staff and student relationships, pre-existing peer support network(s), and pre-morbid personality/attitude. These factors were mostly protective in nature and appeared to play a role in facilitating positive “transition” experiences. Additionally, healthy and unhealthy outcome indicators were identified related to academic functioning, family and peer relationships, and personality/outlook on life. These outcomes are most likely the result of the interplay among multiple factors both internal and external to the adolescent. Furthermore, tentative assertions were presented based on a comprehensive and in-depth review of the data. These assertions are general statements that represent a larger idea or concept that may provide further insight into the research questions and quintain. Finally, a summary of the principal investigator’s journal was summarized in order to provide the reader with an honest appraisal of her role throughout the research process.

CHAPTER FIVE

DISCUSSION

This chapter begins with a presentation of the findings associated with each research question. The conceptual framework used to guide this investigation will then be discussed, and modifications will be presented that integrate the findings of this study. This chapter will close with a presentation of the study limitations followed by suggestions for future research and practical implications.

Research Question 1: How do adolescent survivors of childhood cancer perceive their transition from off-treatment to post-treatment?

Themes related to the first research question included “it’s not a transition, let’s get back to ‘normal’”, “my approach to life after treatment”, “signs that I’m making my way back to ‘normal’”, and “feeling more comfortable with time.” Treatment completion was not perceived as a straightforward, cut and dry time for the adolescents in this study. Rather, they identified treatment completion as a time of mixed emotions and thoughts. It was a time of happiness and excitement with the ominous presence of worry and uncertainty about the future. Numerous studies also have found that adolescent, young adult, and adult cancer survivors experience a variety of emotions and thoughts at the time of treatment completion that can persist throughout survivorship (Arnold, 1999; Cantrell & Conte, 2009; Decker, 2007; Haase & Rostad, 1994; Hewitt et al., 2005; Karahalios et al., 2007; MacLean et al., 1996; Palmer et al., 2007; Sloper, 2000). For example, Haase and Rostad (1994) described treatment completion as having “two

faces—one of celebration and hope, and one of uncertainty and fear” (p. 1490). This finding accurately describes the perspectives of the adolescents in the present study.

Regarding the shift from off-treatment to post-treatment, adolescents in the current study perceived that change was occurring on some level after treatment completion but did not necessarily define this time as a “transition.” The term “transition” was not deemed an appropriate descriptor because it signified a large-scale change that did not accurately capture their actual experiences. Their descriptions reflected a smaller, subtler change and more attention was given to pursuing the future and a “normal” life. These adolescents wanted to return to a sense of “normalcy” and capitalize on opportunities to regain some control over one’s life. Overall, this time was described in more personalized terms that had meaning and significance to each adolescent.

The expressed desire to return to a sense of “normalcy” after treatment completion by adolescents and young adults has been found in the extant research literature (Duffey et al., 2006; Haase & Rostad, 1994; Miedema, Hamilton, & Easley, 2007; Weekes & Kagan, 1994). Findings have shown that adolescent cancer survivors are concerned with moving on with their lives and achieving a sense of “normalcy” but also are challenged to cope with lingering uncertainty about the future and residual effects of treatment (Adolescent and Young Adult Oncology Review Group, 2006; Decker et al., 2007; Woodgate, 1999). Although the general goal after treatment is to return to a “normal” life, research has shown that some adolescent and young adult cancer survivors desire to return to the lives they had prior to their cancer diagnosis while others believe that cancer has significantly altered life to the point that they must

establish a “new normal” (Cantrell & Conte, 2009; Haase and Rostad, 1994). The majority of adolescents in the current study wanted to return to their previous lives as soon as possible and did not express a need to reinvent or redefine themselves and establish a “new normal”. Notably, one adolescent did not perceive the need to return to “normal” because she experienced very minimal disruption to her daily life and, as a result, she was able to stay close to her typical routines and functioning throughout treatment. Rechner (1990) also found that adolescent cancer patients and survivors were primarily concerned with getting back to their normal lives as soon as possible. During treatment, they continued to perceive themselves as “normal” and engaged in typical activities to affirm their normality. Furthermore, some adolescents perceived that it was other people who behaved differently throughout treatment while they continued to be normal. Based on the findings of past research and the current study, a central goal for adolescent cancer patients and survivors includes returning to a sense of “normalcy.” These collective findings also suggest that it is important to consider the way in which “normality” is defined because some cancer survivors may desire to return to their prior activities and functioning while others feel it is necessary to establish a “new normal.”

Additionally, the majority of adolescents in the current study did not have a specific approach or strategy as they went from being a cancer patient to survivor. They did not necessarily think about the specifics of what life would be like or what they were planning to do after treatment completion. These adolescents tended to face challenges as they came and approached life after treatment by taking one day at a time. It is plausible that this particular approach to life after treatment may have served as protection against excessive worry and distress which could have impeded their return

back to “normalcy.” Previous research has shown that adolescent cancer patients’ and survivors’ individual perceptions, cognitive appraisals of their situation, and ways of making meaning have the potential to impact how they approach and manage life after treatment and even long-term psychological well-being (Weekes & Keegan, 1994; Glasson, 1995; Parry & Chesler, 2005). Thus, strategies employed by the adolescents in the present study such as in the moment thinking, not looking too far ahead in the future, and focusing on returning to “normalcy” may have been adaptive and promoted a healthy shift from off-treatment to post-treatment.

The improvement and/or absence of treatment residuals along with re-engagement in activities and roles also appeared to facilitate the return to “normalcy” for adolescents in the present study. Treatment residuals and re-engagement in activities and roles served as signs or indicators that life was getting back to “normal” after treatment. These signs were unique to each adolescent’s particular interests, goals, and motivations. There was diversity among each adolescent’s individual signs/indicators that made their shift from off-treatment to post-treatment qualitatively “look” different and/or progress at varying speeds. Research has supported this finding as studies have shown that the post-treatment journey is highly variable among cancer survivors and that residuals of treatment differ in type, severity, and duration (Eiser, 2004). Treatment residuals can manifest themselves in various ways over the course of a survivor’s lifespan. Interestingly, a few adolescents in the present study compared themselves to other cancer patients and survivors who received more intensive treatments. They extrapolated that differences in diagnoses and treatments received can potentially influence life after treatment and the return to “normalcy.”

These signs also provided information and feedback to the adolescents in the current study on their progress in shifting from life as a cancer patient to survivor. These adolescents developed awareness that aspects of their life were improving and that they were making progress toward achieving a sense of “normality.” The improvement and/or absence of treatment residuals, re-engagement in activities and roles, and general passage of time also made adolescents feel increasingly comfortable with themselves. They developed more confidence in their ability to cope with life as a cancer survivor over time. Haase and Rostad (1994) also found that the improvement and/or absence of treatment residuals (e.g., no longer having to take medications, attending checkup appointments that did not involve treatment, increased energy level) strengthened adolescents’ beliefs that treatment was over. Additionally, the authors reported that adolescents actively looked for these signs in order to obtain a greater sense of whether or not they were on the path to “normalcy.”

For the adolescents in the present study, these signs may serve a variety of purposes throughout the shift from off-treatment to post-treatment including the reaffirmation that treatment is over and the realization that progress is being made toward achieving a “normal” life. It is plausible that this ongoing feedback motivated adolescents in the present study to continue to move forward with their lives after treatment and may have provided hope that their lives would continue to improve and strengthen over time. These signs also could have provided family members, peers, and school personnel with information regarding the adolescent’s improving health status following treatment completion. In turn, these individuals could have offered adolescents

with feedback on their continued progress as well as encouragement to continue to engage in health promotion behaviors and meet their personal goals.

Research Question 2: What are the challenges faced by adolescent survivors of childhood cancer during the transition from off-treatment to post-treatment?

Two themes were associated with the second research question including “signs that life is not back to ‘normal’ just yet” and “it is not the focus of life, but the idea of relapse is there.” The presence of treatment residuals functioned as signs or indicators that life was not quite back to “normal” for these adolescents. These signs served as reminders that the effects of cancer and treatment extended beyond treatment completion. Furthermore, it affirmed the idea that treatment completion does not necessarily equate to a life free of cancer and associated concerns. For the majority of the adolescents, treatment residuals continued to impact their daily lives and restricted participation in desired activities. They had an awareness of these continued limitations and tended to face them in a matter of fact manner while adapting to the best of their abilities.

The idea that the effects of cancer and treatment persist beyond treatment has been widely cited in the research literature and extensively reported in national cancer publications. Research suggests that adolescent cancer survivors are keenly aware of the presence of long-term treatment side effects and recognize that it can negatively impact their life post-treatment (Haase & Rostad, 1994; Palmer et al., 2007; Woodgate & Degner, 2004). On a national awareness level, cancer is no longer seen as a onetime life event that begins with diagnosis and ends with death and/or the successful completion of treatment. In fact, the term “trajectory of childhood cancer care” has been used to describe the cancer experience and need for care beyond the completion of treatment

(Hewitt et al., 2003, p. 37). As one national cancer report stated, “the end of cancer treatment is not the end of the cancer experience” and “the end of treatment marks a new phase of life: living *beyond* cancer” (Rueben, 2004, p. 1). It also is plausible that the presence of treatment residuals and associated limitations in activities and roles experienced by adolescents in the current study provided information about their lack of progress or difficulties in returning to “normalcy.” This information, in conjunction with positive signs, could have provided the adolescents and others in their life with a holistic picture of their overall progress in returning to “normalcy.”

Adolescents in the current study also expressed a variety of emotions and thoughts related to the idea of relapse. Specific concerns included a general hope that cancer will not come back, waiting for test results, suspicion of symptoms post-treatment, having to go through treatment all over again, and being vulnerable due to removal of treatment. They identified that relapse was a potential reality but actively choose not to let the thought of relapse control their lives. They employed coping strategies such as avoiding excessive thoughts of relapse, citing positive information from the medical team or examples of peers who have survived, and avoiding cancer-related information that might induce anxiety. These concerns lessened over time as these adolescents became increasingly comfortable with themselves and follow-up appointments.

The fear of relapse also has been a documented concern among adolescent cancer survivors in the research literature. Studies have shown that adolescent cancer survivors experience underlying, recurrent fears that cancer might return (Haase & Rostad, 1994; Palmer et al., 2007). Regarding approaches to coping to with potential relapse, one study found that adolescent cancer survivors preferred not to discuss reoccurrence whereas

their parents outwardly expressed fear of relapse and had increased worry related to follow-up appointments (Duffey-Lind et al., 2006). Another study revealed that adolescent cancer survivors either preferred to not think/talk about relapse or felt comfortable but wanted to limit the amount of time devoted to thinking about the possibility (Haase & Rostad, 1994).

Adolescent cancer survivors also have been found to use avoidance strategies to deal with typical adolescent concerns after treatment completion (Bauld et al., 1998). The concept of “repressive style of adaptation” is a potentially useful and thought-provoking lens in which to view these findings. A “repressive style of adaptation” is a type of coping strategy that some pediatric cancer patients and survivors adopt to cope with cancer-related stressors (Phipps & Steele, 2002). This particular coping style reflects a tendency to minimize distress, report low levels of anxiety, and a desire to present oneself in a favorable light and protect their image while genuinely perceiving themselves as well-adjusted (Phipps & Steele, 2002). A growing body of research has suggested that this coping style is adaptive and associated with positive physical and psychological outcomes (Phipps, 2007). It is plausible that the strategies employed to cope with thoughts of relapse by adolescents in the current study were adaptive and enabled them to continue to progress through the shift from off-treatment to post-treatment. Many of these adolescents refused to let the fear of reoccurrence interfere with their post-treatment lives and actively chose to think about the positive aspects of their cancer experience as well as the future.

Research Question 3: What are the beliefs of adolescent survivors of childhood cancer about the supports and/or services that were or would be beneficial during the transition from off-treatment to post-treatment?

Themes related to the third research question included “my need for supports and/or services”, “what my health care team told me”, “it is beneficial to know others who have been through what I have been through”, and “my advice on how to navigate the shift from off-treatment to post-treatment.” Adolescents varied in their perceived need for services and/or supports specifically related to the shift from off-treatment to post-treatment. Some adolescents welcomed and were receptive to advice while others did not see the necessity of additional information or support. Two studies were found that investigated adolescent and young adult cancer survivors’ and their caregivers’ informational needs after treatment completion (Duffey-Lind et al., 2006; Palmer et al., 2007). Findings indicated that survivors and their caregivers believed they were not provided adequate information about late effects or how to manage this transition, had few resources to help them navigate life after treatment, and were unsure of who and where to discuss concerns. Notably, these concerns were primarily endorsed by the young adults and caregivers involved in these studies. Young adults and caregivers also were found to have a greater desire for information and to gain knowledge about aspects of cancer survivorship (e.g., late effects).

Conversely, adolescents in the current study did not report any concerns related to the information that they were given (or lack thereof) and did not express the need for any additional information. They were content with the discussions that did, or in some cases, did not occur with their health care team. Notably, a few adolescents did not want

any information because it would have created unnecessary anxiety or suggested that the transition was a “big deal.” This suggests that these particular adolescents may have wanted to preserve a neutral or positive state of mind as they made the shift from off-treatment to post-treatment. The avoidance or “blunting” of survivorship information among adolescent cancer survivors has been reported in the literature (Earle, Davies, Greenfield, Ross, & Eiser, 2005).

Many adolescents in the current study also received informal verbal information regarding their shift from off-treatment to post-treatment from health care team members. Discussions with medical team members centered around topics including awareness of physical limitations and capabilities, physically pacing oneself, engagement in healthy promotion behaviors (e.g., sleeping well, exercising), ways to minimize risk of infection, follow-up schedule details, odds of relapse, and how to enjoy life after treatment. Some adolescents noted that it was valuable to have health care team members be honest and open when sharing this information and making recommendations. Notably, adolescents did not report receiving any formal type of support such as a transition conference or a survivorship care plan as described by Beil et al. (2007). There is a chance that caregivers were the recipients of such information and services. The lack of formal supports or services to facilitate these adolescents’ shift from off-treatment to post-treatment is not surprising as research has suggested that limited transitional care planning and few interventions are typically offered during this time (Labay et al., 2004). One adolescent in the present study received an informational binder on cancer survivorship. He did not find this particular source of information useful. Numerous national cancer organizations offer written and audiovisual materials to cancer survivors

and their families; however, no research was found on the interest, ease of use, or efficacy of these survivorship materials. It most likely would be beneficial to develop informational resources that are adapted to the needs and interests of adolescents. For example, information can be presented in a socially engaging and visually stimulating manner using 21st century technology.

Bradlyn, Beale, and Kato (2003) conducted a systematic review of literature on pediatric cancer patients' informational needs and preferred modalities to receive information. The authors suggested that more research is needed to assess the effectiveness, acceptability, and patient outcomes related to various modes of communication and information sharing such as clinical consultations, print media, video, and interactive computer-based technology. Furthermore, they indicated that little research is available on the impact of print media. Print media is standardized in hopes of meeting the needs of the majority of recipients. However, it is not interactive and does not necessarily have a follow-up component such as discussion about content. Other avenues for communication and information dissemination may be more appropriate for adolescents given their developmental level. Interestingly, the authors went on to conclude that interactive media holds the most promise due to its potential for meaningful engagement and active learning. This type of media would seem to be more applicable and interesting to adolescent cancer populations as opposed to unidirectional, depersonalized modalities such as pamphlets and informational binders.

In addition to support and information from health care team members, the majority of adolescents in the present study also received support from peer cancer survivors across school, community, hospital, and camp settings. These relationships

provided these adolescents with the opportunity to relate and interact with peers who have experienced similar cancer-related events. Adolescents also derived non-cancer related benefits from these relationships such as hanging out with friends and engaging in fun activities. Many adolescents reported attending cancer camps where they could be themselves, have fun, and make meaningful friendships. Research has documented that adolescent cancer patients and survivors benefit from and value relationships with peer cancer survivors (Dunsmore & Quine, 1995; Enskar, Carlsson, Golsater, & Hamrin, 1997). Cancer camp attendance also has been found to yield psychosocial benefits for adolescents' cancer patients and survivors in the extant literature (Bluebond-Langner, Perkel, & Goertzel, 1991; Meltzer & Rourke, 2005). Meltzer and Rourke (2005) found that summer camp provided adolescent cancer survivors with an opportunity to make meaningful social comparisons with other cancer survivors, which promoted greater self-competence with their physical appearance, social acceptance, and global self-worth. The authors suggested that attending cancer camp provided these adolescents with the opportunity to continue to be a part of a community that understood their unique situation of being an adolescent cancer survivor. They also argued that even though the adolescents in this study had varying diagnoses, treatments, and side effects, they were able to relate and bond over the general aspects of the cancer experience such as facing a life threatening illness and undergoing medical procedures and tests.

Adolescents in the current investigation varied in the types of support they were interested in receiving after treatment completion. Two adolescents were members of a community-based teen group. They both indicated that this group provided a supportive social atmosphere that was focused on establishing friendships with other peer cancer

survivors and did not solely focus on talking about cancer. Other adolescents were uninterested and even declined participation in cancer-specific peer interactions or activities and returned back to their health peer group. On the other hand, many adolescents were referred to cancer camps by hospital staff and perceived benefits of attending camp during and post-treatment. This particular finding speaks to the importance of recognizing individual differences in support preferences. Lastly, all of the adolescents in this study offered valuable advice on how to successfully navigate the shift from off-treatment to post-treatment. To date, no research studies were found that described advice on this particular topic from the perspectives of adolescent cancer survivors.

Research Question 4: How do adolescent survivors of childhood cancer perceive their school reintegration experience?

Three themes were associated with research question four including “going back to school provided a sense of ‘normalcy’”, “here is what I was anticipating before going back to school”, and “taking a matter of fact approach to going to school.” Regardless of whether or not adolescents enjoyed attending school, they reported that going to school was beneficial because it provided a sense of “normalcy” and the opportunity to be in a social climate. They were able to get back into a daily routine and participate in age-appropriate activities with a specific purpose. This finding contributes to the existing literature base detailing the benefits of school attendance. There is consensus among researchers that attending school provides pediatric cancer patients and survivors with a sense of purpose and meaningful opportunities to participate in developmentally appropriate activities (Cabat & Shafer, 2002; DuHamel et al., 1999; Katz et al., 1988;

Lansky et al., 1983; Spinetta, 1982). Furthermore, research also has shown that adolescent cancer patients and survivors perceive school attendance as a normalizing experience in the midst of unpredictability and uncertainty (Bessell, 2001; Glasson 1995; Haase & Rostad, 1994; Katz & Madan-Swain, 2006).

Interestingly, some adolescents in the current study were given the option to discontinue school attendance due to their intense treatment regimes. All of these adolescents decided (a few with assistance from their caregivers) to engage in some level of academic work across home and hospital settings. A few of these adolescents commented that at the time they did not readily see the benefits of continuing to do school work but retrospectively perceived a variety of positive outcomes such as being academically on par with peers upon their return to the school setting and having something to keep them busy. Those adolescents who attended school throughout treatment looked forward to the social aspects of going to school because it kept them in the loop and allowed them to return to a familiar and supportive environment. In general, attending school and completing schoolwork provided these adolescents with the opportunity to continue to live their lives and accomplish important developmental tasks.

Those adolescents who did not physically attend school during treatment expressed a variety of anticipatory thoughts and mixed feelings prior to their school re-entry. The nature of these thoughts and feelings were related to cancer and non-cancer related topics as well as their specific academic re-entry points. Adolescents expressed cancer-related concerns such as being able to readjust to school routines, keeping up with academic work, and dealing with peer reactions to physical side effects. A few adolescents also shared non-cancer related concerns such as their ability to adjust to the

differences between middle and high school. Despite these specific concerns, the overall sentiment expressed by these adolescents was excitement and happiness to return to school. One adolescent even shared that he was excited to experience middle school life for the first time.

Previous research has also found that pediatric cancer patients and survivors have anticipatory school re-entry concerns related to their academic performance and readiness, keeping up with academic demands, and others' reactions to changes in their physical appearance (McCarthy et al., 1998; Searle et al., 2003). Notably, only two studies were found that examined the anticipatory thoughts and concerns prior to school re-entry. This is surprising given the numerous calls for preventative, proactive school reintegration planning and programming for pediatric cancer patients and survivors (Katz et al., 1988). For example, one adolescent in this study had a party prior to her school re-entry with family, friends, and school staff in attendance. Party attendees asked her questions and expressed their excitement that she would be returning to school. This experience helped to ease her concerns and feelings of uncertainty prior to her actual school re-entry. Furthermore, the type of school reintegration circumstance (e.g. attending school during treatment versus reintegrating after a prolonged absence) appeared to play a role in the report of these anticipatory thoughts and feelings. Adolescents in the current study who attended school throughout treatment did not express specific anticipatory thoughts or feelings but rather tended to focus on the idea that school attendance would provide a sense of "normalcy." Some of the adolescents also were concerned and/or curious about certain aspects of school reintegration that were

not directly related to cancer (e.g., what is it like going from having one teacher in elementary school to a group of teachers in middle school?).

Overall, anticipatory thoughts and feelings expressed by the adolescents in this study were not necessarily negative in nature and did not appear to elicit significant anxiety or distress. Woodgate (2000) suggested that the presence of uncomfortable thoughts and/or feelings does not necessarily imply significant distress or difficulties. In fact, it may be a healthy and necessary part of the adjustment process that can even provide an opportunity to acquire practice in managing uncomfortable situations and emotions.

In general, adolescents in the current study took a matter of fact approach to school reintegration despite facing academic and social challenges. Although they acknowledged that going back to school represented a change in their lives, the majority of them did not have a specific plan of action to re-enter the school setting. They tended to focus on fitting in, hanging out with their peers, and returning to a general sense of “normalcy” at school. This finding suggests that the adolescents approached school reintegration and the shift from off-treatment to post-treatment in similar ways. Interestingly, adolescents also differed in the perceived amount of time it took them to readjust and feel comfortable at school. It appeared that adolescents had unique perceptions and criteria that they used to determine when school was back to “normal.”

To date, no research studies were found that specifically examined adolescent cancer patients’ and survivors’ approach to re-entering the school setting. However, the disability-stress-coping model for pediatric adjustment to chronic illness may be useful in contemplating this particular finding (Varni & Wallender, 1988). Central components of

this model include risk and resistance factors. Risk factors include disease-related conditions (e.g., diagnosis, severity of treatment), level of functional independence, and psychosocial stressors (e.g., daily struggles, interpersonal problems). Resistance factors include intrapersonal (e.g., temperament, problem-solving skills), sociologic (e.g., family and peer support), and stress-processing (e.g., cognitive appraisal, coping strategies) factors.

Katz and Madan-Swain (2006) extended this model to reflect the experiences of pediatric cancer patients and survivors and suggested that school and social problems can be best understood through this framework. The authors indicated that minimizing risk factors while developing and fostering resistance factors can help to improve the school and social experiences of pediatric cancer patients and survivors. Stress-processing factors are of particular interest to this discussion. Perceived stress is defined as an individual's cognitive appraisal of stress surrounding a situation or event (Lazarus & Folkman, 1984 Varni & Wallender, 1988). This concept is rooted in the meaning that an individual assigns to the situation as well as their perception of the manageability or unmanageability of that situation. Research has shown that childhood cancer survivors who perceived higher stress regarding their cancer and treatment had increased psychological distress and lower self-esteem (Varni et al., 1994). It is plausible that the adolescents in the present study perceived school reintegration as a less stressful and more manageable situation. This type of cognitive appraisal, in addition to the presence of coping strategies (e.g., taking one day at a time), school reintegration support (e.g., effective tutoring, peer contact prior to reintegration), and demographic characteristics (e.g., age, socio-economic status) are all possible factors that may have contributed to

these adolescents' positive school adjustment. Overall, this model may be useful in further illuminating the school reintegration experiences, perceptions, and approaches of adolescent cancer patients and survivors.

Research Question 5: What are the challenges faced by adolescent survivors of childhood cancer during school reintegration?

Themes related to research question five included “disruption of my school life,” “my academic concerns”, and “my social life concerns.” All of the adolescents in the study experienced some level of disruption in their school life due to the demands associated with cancer and treatment. The level of disruption varied among adolescents depending upon their specific diagnosis and treatment regime. The demands of cancer and treatment impeded these adolescents' ability to regularly attend school and participate in school routines, which made it difficult for them to maintain involvement in age-appropriate activities and tasks. Adolescents continued to experience interference in their school life even after treatment was completed as they had to attend follow-up appointments, undergo scans and other hospital-based procedures, and manage unexpected illnesses. This disruption in school attendance and routines has been documented in the research literature (Larcombe et al., 1990; Prevatt et al., 2000; Upton & Eiser, 2006). Research has shown that absences are one of the biggest problems during the year after diagnosis but generally decrease with time after diagnosis (Rynard et al., 1998). The school attendance of adolescents in the current study generally improved over time secondary to receiving less intensive or time consuming treatments (e.g., hospital-based chemotherapy to maintenance therapy at home) and completion of treatment. Additionally, other studies have shown that children and adolescents with

certain types of cancer and treatments, such as CNS tumors and bone marrow transplants (BMT), have a greater number of absences than other cancer patients (Vannatta, Gartstein, Short, & Noll, 1998; Vannatta et al., 1998). This finding highlights the importance of type of diagnosis and treatment received as it can result in variable school attendance and subsequent outcomes.

Unpredictable school attendance also contributed to a variety of academic challenges across home, hospital, and school settings for adolescents in the present study. Academic concerns included falling behind/catching up with work, maintaining motivation to do work, and readjusting to school demands and routines. Notably, adolescents varied in their degree of academic motivation while on treatment. These academic-related challenges have been documented in the literature (Glasson, 1995; McCarthy et al., 1998). No research was found that specifically cited lack of or difficulties maintaining motivation to complete school work among adolescent cancer patients and survivors. However, Shaw and McCabe (2007) indicated that children and adolescents with chronic illness may experience decreased academic motivation as a result of multiple factors such as a poor prognosis, treatment side effects, and other mediating factors (e.g., poverty). The authors noted that limited research has examined predictors of academic motivation among chronically ill children and adolescent populations.

A few interesting findings emerged related to readjustment to school demands and routines. Adolescents reported varying lengths of time (i.e., a couple days to a year) that were needed to re-adjust to school. Many factors could have contributed to this finding including time physically away from the school setting, individual coping strategies, and

peer/teacher support at school. Additionally, one adolescent indicated that the grade one leaves and re-enters school can impact adjustment to school routines and demands. This is an important variable to consider given the different demands and expectations that correspond with various grade levels (Waber et al., 2003).

In addition to academic challenges, the literature has shown that some pediatric cancer populations may experience more severe academic limitations secondary to diagnosis and treatment. There is an extensive body of research on the neurocognitive deficits seen in patients diagnosed and treated for leukemia, and in particular ALL (Raymond-Speden et al., 2000; Upton & Eiser, 2006). Deficits have been observed in short-term memory, visual memory, auditory memory, attention, concentration, sequencing tasks, and non-verbal skills (Brown et al., 1998; Butler & Haser, 2006; Langer et al., 2002; Peckham et al., 1988). Five adolescents in the current study were diagnosed with leukemia (i.e., two with AML, three with ALL). Notably, one adolescent, who was diagnosed with AML, reported experiencing “chemo brain” after treatment completion. Chemo brain is a phenomenon believed to reflect deficits in memory, attention, and other cognitive functions (Staat & Segatore, 2005). This adolescent reported some changes in memory function that impacted his ability to perform certain academic tasks such as memorizing information for quizzes and tests. However, he explained that chemo brain did not significantly impact his overall academic functioning and performance. He indicated that his memory function has improved over time.

This particular adolescent and another adolescent diagnosed with ALL shared their experiences undergoing neuropsychological evaluations post-treatment. They indicated that they performed well on these tests and did not perceive any lasting effects

of chemotherapy on their academic functioning or performance. Research also has shown that not all pediatric cancer patients and survivors experience adverse neurocognitive deficits secondary to cancer and treatment; however, it should be noted that the presence of such deficits and subsequent delays in academic functioning may not be seen until years later (Bessell, 2001; Peckham et al., 1988). Overall, the majority of adolescents in the current study faced a variety of academic challenges during treatment and post-treatment. Notably, adolescents were often times able to adapt and, in some cases, implemented academic compensation strategies such as adopting new ways to memorize material, staying afterschool to complete work, and meeting with a teacher to gain better understanding of academic content. Adolescent cancer patients' use of active coping strategies in the school setting also has been documented in the literature (Glasson, 1995).

Adolescents in the current study also were required to address peer-related situations during school re-entry such as answering questions, adjusting to peer awkwardness/discomfort, and managing peer reactions to their physical side effects. The majority of adolescents were able to effectively cope with these peer-related situations and even utilized additional social support from peers and school staff. Notably, many adolescents were able to take the perspective of their peers and expressed an understanding of why their peers may have displayed these behaviors at school.

There is a sizable body of research on the school-based social experiences of pediatric cancer patients and survivors. The results of this current study are in alignment with previous research that has shown social concerns experienced by pediatric cancer patients and survivors are generally those that require adjustment and do not necessarily

cause significant social disruption or impairment. Examples of social concerns reported by adolescent cancer survivors in the research literature include coping with body image and hair loss during school re-entry, peer reactions to physical changes, fielding intrusive questions from peers, drawing unwanted attention from peers, and inability to participate in extracurricular activities (Glasson, 1995; McCaffrey, 2006; Pendley et al., 1997; Wallace et al., 2007). Furthermore, adolescent cancer patients and survivors also have been found to experience minimal distress during school re-entry and in some cases believed they received more support from school staff and peers than prior to their diagnosis (Searle et al., 2003). Other research has shown that adolescents may experience increased loneliness, social anxiety, and concerns with body image over time (Pendley et al., 1997). The results of the present study do not appear to support this particular finding as adolescents' worry and uncertainty about their school life seemed to decrease over time with improvement in treatment residuals and re-engagement in school activities and roles (e.g., hair re-growth, more regular school attendance, rejoining sports team). Notably, one adolescent in the study described how she had a difficult time relating to peers at school. As a result of her cancer experience, this particular adolescent felt that she was more mature than her peers and could no longer relate to them because she had a different outlook on life. This particular social concern has been documented in the literature (Labay et al., 2004).

Developmental level also has been found to play a role in the type of concerns reported by pediatric cancer patients and survivors. For example, one study found that individuals over the age of eight tended to be worried about their physical appearance and body image, peers' reactions to such changes, and whether they would still be accepted

(McCarthy et al. 1998). In a similar vein, the concerns described by adolescents in the present study emphasized social comparison, desire for social acceptance and not to be singled out, and physical appearance (in particular for the females in the study).

Lastly, adolescents in the current study experienced limited social interaction and activity in and outside of the school setting. They reported varying degrees of “being socially out of the loop” based on their treatment regime, side effects, and self-imposed restrictions (e.g., not wanting to go out with friends in public due to physical appearance). However, the majority of adolescents did not report long-term negative consequences of being isolated or unsocial. Social isolation among pediatric cancer patients and survivors also has been documented in the empirical literature (Glasson, 1995; Haase & Rostad, 1994; Searle et al., 2003). Collectively, the adolescents in this study experienced disruption in their school routines and were also required to face academic and social challenges throughout the school reintegration process. Adolescents adjusted to these challenges and established more regular school routines over time. Some adolescents employed compensatory strategies in an effort to actively address their academic and social concerns. The findings related to this research question corroborate previous research examining school re-entry challenges among adolescent cancer patients and survivors.

Research Question 6: What are the beliefs of adolescent survivors of childhood cancer about the supports and/or services that were or would be beneficial during school reintegration?

Four themes were associated with research question six including “my academic support”, “my social support”, “these are the accommodations and modifications the

school provided to me”, and “my advice on how to navigate school reintegration.”

Adolescents in the current study received many different types of academic support during treatment as well as after treatment completion. Teachers, family members, and peers provided academic support across home, hospital, and school settings. Teachers were a primary source of academic assistance in and outside of the school setting.

Teacher academic support varied in terms of frequency but was generally perceived as helpful. Notably, some caregivers took on the responsibility of teaching and/or helping explain academic content and also attempted to increase their child’s motivation to complete academic work. Academic information and instruction was communicated between teachers and adolescents through various modes such as email, written instruction/notes, videotaping, and the Internet. Technology-based modes such as email, video, and on-line learning all appeared to be beneficial and interactive ways to communicate, learn, and/or engage in social experiences with fellow classmates. One adolescent took an on-line course during treatment and discovered that there was a world of learning beyond the walls of her classroom. She was able to take more control over her learning and academic life. Even after she completed treatment, she continued to enroll in online classes because her school did not offer the courses she needed to be fully prepared to enter college. She also introduced her friends to online learning and they too have taken classes to supplement their school experience.

In regard to these findings, technological advances and the rise of global social networking have made it possible for pediatric cancer patients and survivors to engage in meaningful, interactive social and learning opportunities. Katz and Madan-Swain (2006) suggested that web-based resources and tools can be used to augment

homebound/hospital-based instruction. To date, no research has specifically examined the use of technology to create meaningful, interactive academic learning opportunities for pediatric cancer patients and survivors.

Tutoring was another common type of academic support provided across home and hospital-based settings to the adolescents in this study. Home-based tutoring was provided by school teachers, family acquaintances, and homebound teachers. Hospital-based academic instruction and/or assistance was provided by assigned tutors. Tutoring services were highly variable in terms of frequency of receipt and perceived quality. These adolescents reported more concerns with hospital-based instruction than homebound services. In fact, the majority of adolescents who received homebound tutoring perceived it as helpful. It should be noted that these particular tutors provided frequent, individualized services and were perceived as highly competent. Those tutors (whether home or hospital-based) that were deemed less helpful tended to not be knowledgeable about the subject matter and/or provided only non-academic assistance (e.g., transporting work, supervision). Interestingly, some adolescents identified possible reasons for the lack of appropriate tutoring services. For example, one adolescent explained that it was most likely difficult for his tutor to be knowledgeable in all kindergarten through 12th grade subject matter. These adolescents were able to extend their thoughts beyond whether their tutors were just “good” or “bad” and assess potential reasons for their less than optimal tutoring experiences. Another notable finding was that, in some cases, adolescents were not provided adequate services because there was no qualified tutor who could teach high school content. Consequently, these adolescents

reported engaging in a great deal of self-teaching to compensate for this lack of instructional support.

Research has documented that children and adolescents with cancer enroll in homebound and hospital-based programs in an effort to continue school (Glasson, 1995; McCaffrey, 2006; Searle et al., 2003). Although there is very limited research in the area of homebound and hospital-based instruction, a few studies have shown that adolescent cancer patients perceived homebound services as ineffective and less meaningful as compared to instruction received in hospital and community settings (Bessell, 2001; Searle et al., 2003). Furthermore, adolescents in these studies also have reported that homebound services did not adequately prepare them for school re-entry. Research also has demonstrated that adolescents who received hospital-based instruction were concerned whether they would be academically prepared to return to their school (Searle et al., 2003).

Homebound programs have been described as inflexible and fraught with administrative challenges resulting in inadequate service delivery to children and adolescents (Shaw & McCabe, 2007). Numerous limitations of homebound instruction have been identified in the literature such as lack of quality instruction, ineffective communication between parties (e.g., hospital, school, family, tutor), little time allocated to actual instruction, inadequate educational materials, limited training of teachers, poor match to instruction provided in the classroom, lack of opportunities to interact and benefit from classroom-based social learning, and high costs incurred to community school systems (Bessell, 2001; Gorin & McAuliffe, 2008; Searle et al., 2003; Shaw & McCabe, 2007). An additional barrier to quality instruction is that school districts vary in

the number of hours of homebound instruction they will allocate to medically ill students (Katz & Madan-Swain, 2006). Adolescents who receive inadequate home or hospital-based instruction and/or support and do not have other types of academic support in place would most likely be at greater risk for school reintegration difficulties. Conversely, the majority of adolescents in the current study received a great deal of academic support from family members, teachers, and school personnel which may have supplemented and even compensated for lack of quality instruction received in home and hospital settings. Overall, there is a dearth of research on the type, quality, and effectiveness of hospital and homebound services received by pediatric cancer patients and survivors (Bessell, 2001; Gorin & McAuliffe, 2008).

The majority of adolescents in the current study also received a great deal of social support from teachers, other school personnel, and peers. These sources of support helped these adolescents feel increasingly comfortable and readjust to school routines. These findings are consistent with the literature showing that children and adolescents receive and value social support from a wide variety of sources in and outside of the school setting (Haase & Rostad, 1994; Woodgate 2000). Specifically, research has shown that adolescents perceive teachers as helpful sources of social support during school reintegration but find that they are unable to relate and understand the implications of cancer in the school setting (Baskin et al., 1983; Chekryn, et. al., 1987; Greene, 1975; Glasson, 1995). Adolescents in the present study generally described their teachers and helpful and understanding with a few cases of teachers being inflexible or treating them different than other students. It was important for teachers to treat these adolescents “normally” while also being there to provide support when necessary. Other school

personnel also were cited as providing social support. Interestingly, many of these interactions were deemed positive and helpful because they involved discussion about non-cancer related topics. Again, this may reflect these adolescents' desire to feel "normal" and could have provided necessary reminders that not everything in their life has been consumed by cancer.

Healthy peers also have been cited in the literature as an important source of support for adolescent cancer patients and survivors (Glasson, 1995; Haase & Rostad, 1994; Ritchie, 2001; Suzuki & Kato, 2003). Adolescents in the present study perceived friends as consistent sources of support who they could go to for help and/or protection in distressing situations. A few adolescents specifically said that they preferred to seek out help from their friends at school as opposed to school personnel. One adolescent did not have a positive social experience upon her return to school after her diagnosis. As previously described, she was diagnosed at the beginning of ninth grade and did not have an opportunity to establish friendships. Sporadic school attendance during treatment exacerbated this concern. She shared that her classmates offered to help her with schoolwork. However, they were not there for her when she returned to school from a prolonged absence. This particular social experience also has been documented in the literature (Enskar et al., 1997). Overall, the majority of adolescents in this study were able to return back to the school setting and reintegrate with their friends. They perceived them as important sources of social support during school reintegration.

Additionally, adolescents in the current study reported that they received a variety of school accommodations and/or modifications to assist in their school reintegration and facilitate positive academic and social experiences. The majority of these adolescents

utilized these supports and found them to be beneficial. The receipt of school-based accommodations and/or modifications also has been cited in the research literature (Searle et al., 2003). However, no studies were found that described the nature of accommodations and/or modifications, their perceived usefulness, or impact on school-related outcomes. Accommodations and modifications have been a component of school reintegration programs but not systematically evaluated to determine if they facilitate the school reintegration process. Lastly, adolescents in the present study provided advice on how to successfully navigate school re-entry. Advice was related to personal, academic, and social-emotional topics that could be utilized prior to and during school reintegration. Again, no research was found that described advice given by pediatric cancer survivors regarding how to successfully manage and cope with school re-entry.

Two additional themes, “pre-existing factors” and “outcome indicators of a healthy/unhealthy transition process,” also were yielded from the data in the current study. Pre-existing factors that were identified in the adolescents’ stories included pre-established school staff and student relationships, pre-existing peer support network(s), and pre-morbid personality/attitude. These factors were mostly protective in nature and appeared to play a role in facilitating positive “transition” experiences. It may seem intuitive that pre-existing factors such as these could potentially moderate transition outcomes. However, this assumption is premature especially since research in this area has been inconsistent. For example, the role of pre-existing familial (e.g., parental psychological distress, maternal coping) and demographic variables (e.g. socioeconomic status, age) in predicting psychological outcomes has yielded mixed findings (Eiser, Hill, & Vance, 2000). There also is a dearth of research that has examined whether

psychological outcomes differ according to type of diagnosis. Furthermore, many research studies study have included heterogeneous samples, which makes it difficult to make any consistent empirical observations according to diagnosis. Although the identification of pre-existing factors was found in the present study, no clear links between such a factors and outcomes have been discerned in the literature to date.

Additionally, healthy and unhealthy outcome indicators were identified related to academic functioning, family and peer relationships, and personality/outlook on life. These outcomes are most likely the result of the interplay among multiple factors both internal and external to the adolescent. No studies were found that specifically examined outcome indicators associated with transition processes in pediatric oncology. However, healthy outcomes found among pediatric cancer survivors have included a greater appreciation for life, greater optimism, posttraumatic growth, increased self-esteem, and modified views of the self and the world (Barakat et al., 2006; Brennan, 2001; Eiser et al., 2000; Hollen, Hobbie, Finley, & Hiebert, 2001; Nelson et al., 2004; Woodgate, 1999). Conversely, unhealthy outcomes found among this population after treatment completion include long-term enduring worry and distress about the future, lower level of educational attainment, and posttraumatic stress symptoms (Bleyer, 2002; Hobbie et al., 2000; Kazak et al., 2001; Mitby et al., 2003). A notable observation in the current study included one adolescent's observation that cancer can have a long-term negative impact on life that may not be readily seen or observed by outsiders. These hidden losses of cancer are important to consider as not all outcome indicators may be observable. It then becomes important to assess what not only has been gained, but what may have been lost

through the eyes of the adolescent as it appears that some adolescents may be astutely aware of this loss.

Comparison between Findings and the Conceptual Framework

Wilkins and Woodgate (2006) developed a conceptual framework to describe the transition experiences of siblings of children with cancer. This framework was used in the current study to guide development of research and interview questions, revise the interview guide, and inform the data collection and analysis process. The framework included the following components: (a) antecedents to transitions; (b) key attributes or characteristics of a transition; (c) consequences related to a healthy transition process; and (d) consequences related to an unhealthy transition process. Each of these components will be discussed in relation to the findings of the study.

Antecedents to transitions. The completion of treatment was identified as a health-illness antecedent event in this study. Although this event unfolded at different times under various conditions for each adolescent, it was generally perceived as a phase of their life that was ending and completed. Despite adolescents' knowledge that cancer would still impact their lives after treatment, completing treatment was considered an observable change in their life. Adolescents were aware that they would no longer be required to do certain tasks and procedures due to removal of treatment. Additionally, some adolescents experienced situational events in tandem with treatment completion such as starting high school or middle school. The presence of multiple antecedents appeared to add an additional layer or complexity and helped to further define the "transition" process. The use of this conceptual framework component forced the PI to

look beyond treatment-related variables to address other types of situational antecedents that may have played a role in these “transition” experiences.

Key attributes of a transition. Key attributes of a transition including movement, disequilibrium, and individual perception were present in the adolescents’ personal accounts of their school reintegration and shift from off-treatment to post-treatment experiences. Adolescents perceived *movement* as they finished treatment and started to pursue the goal of returning to “normal.” Another example of movement included returning to school part-time or full-time. As adolescents moved through these “transitions”, they experienced a state of *disequilibrium*. Sources of disequilibrium present in the stories of the adolescents included feelings of uncertainty about the future, fear of relapse, and continued presence of treatment residuals or disruption in activities and/or roles (e.g., signs). Even in the face of these challenges, adolescents’ continued to move on with their lives and strived to achieve “normalcy.” Notably, the degree of disequilibrium experienced by adolescents was variable and appeared to be related to factors such as type of diagnosis, intensity of treatment regime, and severity/persistence of treatment residuals. The individual perception attribute was a hallmark of this study. The goal of this study was to listen to the unique perspectives and experiences of each adolescent in order to answer the research questions and in turn gain a greater understanding of these “transition” experiences. Each adolescent shared their perspective, assigned meaning to their experience, and was able to reflect on the impact (or lack thereof) that cancer had on their lives.

Conversely, adolescents did not necessarily identify the shift from off-treatment to post-treatment and school reintegration as a *process*. Rather, the majority of

adolescents focused on getting back to “normal” and observed signs or indicators along the way that life was heading in that direction. Some adolescents even had pre-establish signs or indicators that they were looking for which would let them know their life was returning back to “normal” (e.g., hair completely grew back, going back to school). These adolescents appeared to look out for these signs which may have taken the focus away from perceiving these times as processes. Although adolescents did not perceive a process per se, the passage of some amount of time was present in many of their stories. For example, some adolescents said that they regained a sense of “normalcy” at school within approximately six months to a year. Despite this observation, the perceptions of the adolescents themselves are honored. It also should be noted that one adolescent did not perceive that cancer and treatment significantly impacted her daily life; therefore, she did not have a great deal of readjustment post-treatment. In this case, the movement, disequilibrium, and process attributes would likely be represented on a smaller scale. Or a follow-up investigation may reveal that this particular framework is a poor fit for this type of post-treatment experience.

Consequences related to healthy and unhealthy transition processes. The presence of process and outcome indicators became apparent over the course of data collection and analysis. The emergence of these concepts was not immediately realized during preliminary review of the data and began to more fully develop over the course of the immersion/crystallization (I/C) process as well as ongoing discussion between the PI and peer coder. Process indicators were conceptualized somewhat differently in the current study. They were defined as observable, concrete signs that provided feedback to adolescents about their progress or lack thereof in returning to “normalcy.” One type of

sign or indicator was the presence, improvement, or absence of treatment residuals. These signs were physical, psychological, and situational in nature. Table 3 provides examples of different types of signs that suggested “I am on my way back to ‘normal’” or “I am not quite back to ‘normal’ yet.” Please note that physical and psychology domains are grouped together (e.g., complete hair re-growth signaled improvement in physical appearance while increasing self-confidence). Other signs were activity-based in nature and served as an additional source of information to adolescents about their progress toward achieving a “normal” life. These activity-based signs, facilitated by the improvement or absence of treatment residuals, yielded important information about not only their progress toward “normalcy” but also how they were engaging and/or participating in age-appropriate roles and activities compared to their peers. Table 4 provides examples of activity-based signs.

Regarding process indicators, the term “consequences of unhealthy and healthy transitions” has been replaced with “on my way to normal” and “not quite back to normal yet.” This change was made because process signs/indicators appeared to function more as information and feedback on the progression to “normalcy” rather than whether or not the transition process is healthy or unhealthy in nature. For example, an adolescent who is unable to fully participate in extracurricular activities due to the presence of treatment residual (e.g., fatigue, decreased stamina) does not necessarily reflect a negative or unhealthy situation as there may be many factors that are out of her control. Therefore, the aforementioned terms appeared to fit the data more appropriately than those offered in the original conceptual framework.

Table 2

Presence, Improvement, and Absence of Treatment Residual Signs

	On my way to “normal” Improvement (I) or Absence (A) in Treatment Residuals	Not quite back to “normal” yet Continued Presence (CP) of Treatment Residuals
Physical/Psychological	<ul style="list-style-type: none"> • Regaining strength and stamina (I) • Increased comfort with attending follow-up appointments (I) • Hair completely grown back (A) • Port removal (A) 	<ul style="list-style-type: none"> • Port (CP) • Post-treatment fatigue (CP) • Compromised immune function (CP) • Chemo brain (CP)
Situational	<ul style="list-style-type: none"> • Decrease in frequency and length of follow-up appointments and scans (I) 	<ul style="list-style-type: none"> • Attending follow-up appointments/scans/procedures that interfere with school attendance (CP)

Table 3

Activity-based Signs

	On my way to “normal” <i>Facilitated by the Improvement (I) or Absence (A) in Treatment Residuals</i>	Not quite back to “normal” yet <i>Facilitated by the Continued Presence (CP) of Treatment Residuals</i>
Activities	<ul style="list-style-type: none"> • Partial or complete participation in extracurricular activities • Return to previous academic performance 	<ul style="list-style-type: none"> • No or restricted participation in extracurricular activities • Disruption of school attendance secondary to appointments, procedures, or physical status
Roles	<ul style="list-style-type: none"> • Rejoining place in peer group at school and/or community • Regain family structure and functioning 	<ul style="list-style-type: none"> • Physical side effects impact desire to hang out with friends • Feeling out of the loop with family’s schedule and routine

Additionally, outcome indicators were identified in some of the adolescents’ stories. At the onset of the study, the PI did not specifically develop research questions or interview guide content with the goal of acquiring information on this particular aspect of the conceptual framework. However, the PI and peer coder started to identify certain

outcomes that had been reported by adolescents. In this particular case, the terms “consequences of healthy and unhealthy transitions” appeared to be an appropriate fit given the findings. Adolescents reported healthy and unhealthy outcomes that were related to academic functioning, family and peer relationships, and personality/outlook on life. These outcome indicators reflected long-term, lasting effects of cancer and treatment. Although the terms “healthy” and “unhealthy” are deemed appropriate, it also should be noted that these outcomes reported by adolescents are just one facet of their overall “transition” experiences. One “unhealthy” outcome indicator does not mean that the entire “transition” process was necessarily poor or unsuccessful.

Revised Conceptual Framework

A graphic illustration was created to assist in summarizing the cross-case analysis as well as to expand on the conceptual framework utilized in this study (see Figure 3) (Miles & Huberman, 1994; Stake, 2005). Pre-existing factors and cancer-related variables are presented first in this illustration because of their potential overarching impact on the school reintegration and shift from off-treatment to post-treatment experience. Throughout the adolescents’ stories, these factors seemed to have a noticeable role in shaping their “transition” experiences. Pre-existing factors found in the study included pre-established school staff and student relationships, pre-existing peer support network(s), and pre-morbid personality/attitude. These were protective factors in most cases that appeared to set the stage for more favorable school reintegration and shift from off-treatment to post-treatment experiences. Conversely, a few adolescents had pre-existing circumstances that may have placed them at risk for less favorable “transition” experiences.

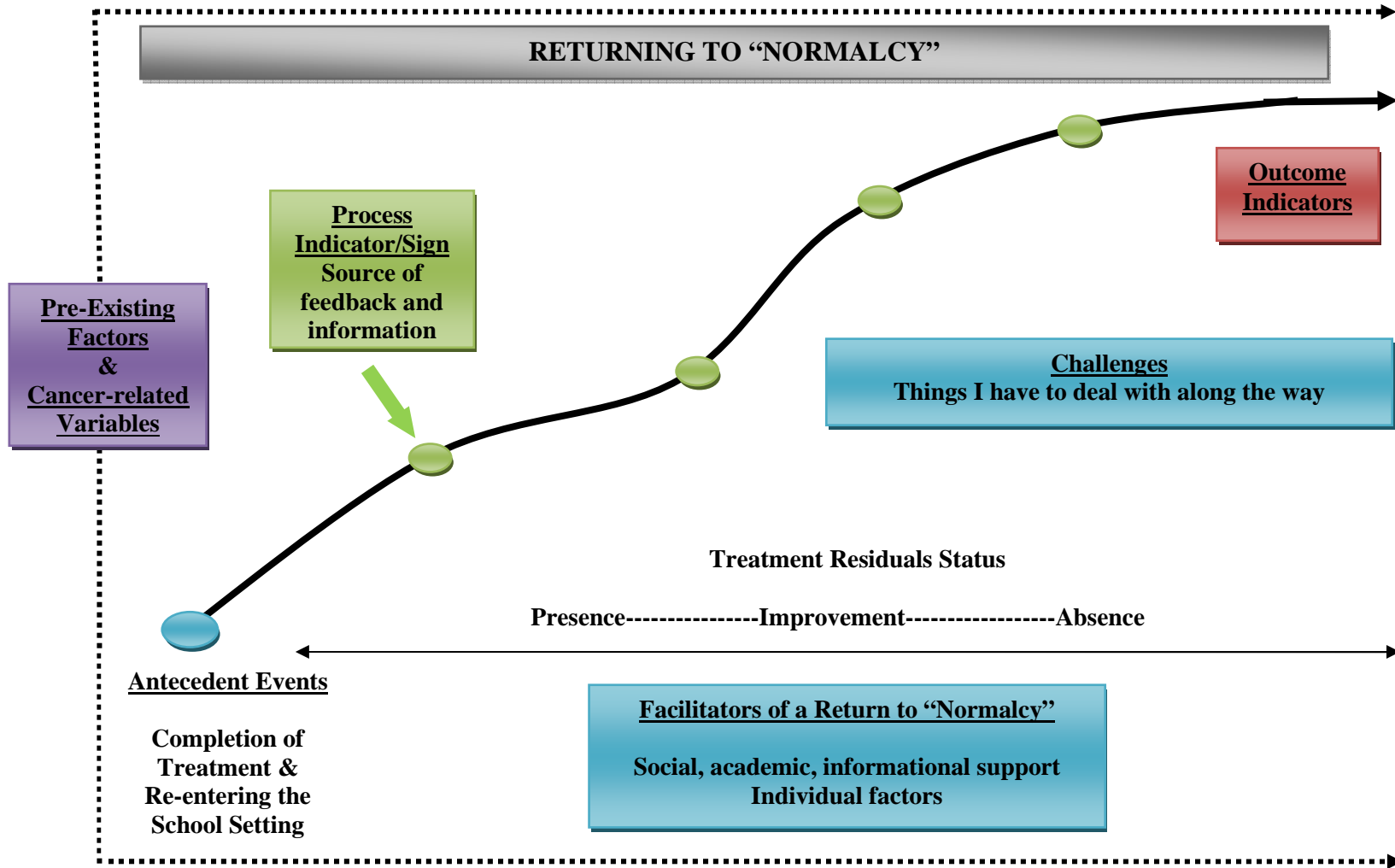


Figure 3. Revised Conceptual Framework

Cancer-related variables included type of diagnosis, treatment regime (i.e., duration, intensity), side effects, and timing of diagnosis (i.e., age/grade at diagnosis, time of the school year that diagnosis was received). The line shown in this illustration symbolizes the path or journey back to “normalcy” that adolescents embarked upon after treatment completion. The rate of progress toward achieving “normalcy” and regaining a sense of control varied among the adolescents in this study. The slope of these lines is not uniform and varies considerably based on each adolescent’s unique signs/indicators, meaning and significance assigned to those signs (e.g., hair re-growth was a milestone for some but not for others), and perception of “normalcy.” For example, adolescents reported varying amounts of time it took them to feel comfortable at school. These perceptions of time reflect such variability and would likely impact the appearance of the line in this illustration.

Next, the line begins with the antecedent events of completing treatment and/or returning back to school. Adolescents acknowledged that cancer would continue to impact their lives but their main focus was on moving forward with life and returning to “normalcy.” Dots along the line represent the unique signs/indicators that were experienced by each adolescent. Treatment residuals and return to activities/roles (facilitated by the improvement or absence of treatment residuals) functioned as signs/indicators that appeared to play a role in the movement or progression of an adolescent’s return to “normalcy.” Perhaps more importantly, these signs appeared to provide information and feedback to the adolescents about their progress (i.e., “I am on my way back to “normal”) or lack thereof in returning to “normalcy” (i.e., “I am not quite back to “normal” yet). The status of treatment residuals (i.e., presence, improvement, or

absence) facilitated the movement on the line. It appeared that for these adolescents progress, or becoming closer to “normalcy” and regaining control, occurred as treatment residuals gradually improved or completely went away.

Adolescents also experienced a variety of academic, social, and emotional challenges during the shift from off-treatment to post-treatment and school reintegration. Adolescents did not necessarily perceive these concerns as challenges but rather things that they had to deal with along the way to achieving a more “normal” life. Facilitators were identified that addressed these challenges as well as promoted movement along the line, or path to “normalcy.” Facilitators included academic, social, and informational support as well as individual factors such as cognitive appraisal (e.g., not perceiving these times as transitions or of significant change) and adopted coping strategies (e.g., avoidance of information, seeking out peers to provide support at school). Lastly, outcome indicators were present in some of the adolescent’s stories, which helped to describe their overall experiences after they completed the shift from off-treatment to post-treatment and school reintegration.

Limitations of the Study

There are several limitations to the current study that warrant discussion. One type of limitation was the threat to descriptive validity. Descriptive validity refers to the accurate reporting of descriptive information (Johnson & Christenson, 2004; Maxwell, 1992). A limitation related to this type of validity included that the PI was the only individual who collected data in the field. Therefore, it is possible that the PI may have misperceived interactions, behavior, or events that occurred during the interviews, follow-up meetings, and document review. The PI made every possible effort to address

this particular limitation throughout the research process. First, depending on the type of data collected, data were either audio recorded (e.g., interviews, follow-up meetings) or typed in a Word document immediately after data collection (e.g., direct observation notes, document review, parent feedback) to increase the likelihood that the information would be accurate and not fall prey to faulty recall of information. Furthermore, the PI frequently summarized information provided by the adolescents during interviews, follow-up meetings, and document reviews and directly asked the adolescent if the summary was accurate. This strategy assisted in minimizing miscommunication or inaccurate interpretations of verbal content. Additionally, a qualified transcriptionist transcribed the interviews and follow-up meetings and was instructed to transcribe them verbatim to ensure that no information was lost or subject to someone's else determination of what words or other behaviors (e.g., prolonged pauses, repeating of words) were relevant to include versus those that were not. The PI then followed-up by thoroughly reviewing all transcribed documents to assess accuracy and to make sure that subtle elements of the conversation were captured in written form. Lastly, the PI utilized the follow-up meetings to help clarify any descriptive information that was questionable or not fully understood upon further examination of the data yielded from that particular participant.

Another limitation includes the threat to interpretive validity. This type of validity is defined as the degree to which the research accurately depicts the meaning of the participants' statements or stories (Johnson & Turner, 2003). This particular type of validity is important within a constructivist paradigm because there is an emphasis on understanding and conveying participants' perceptions, beliefs, views, and how they

construct their reality (Patton, 2002). During this study, the PI's personal beliefs, biases, and preconceived notions may have inadvertently influenced how the data were interpreted and presented (Onwuegbuzie, 2002, 2003). Although it is recognized that all bias cannot be eliminated from this study, the PI took active steps to address this threat to the validity. The PI engaged in continually self-reflection and documentation of these reflective exercises throughout the duration of the study. Reflective exercises began prior to the start of the study as a peer conducted an interview with the PI to begin the process of raising her awareness of her role in the research process and how her particular set of beliefs, expectations, and biases may impact the study. After this initial interview, the PI continued to reflect on her thoughts, feelings, and behaviors and documented these observations in a personal journal (Patton, 2002). Perhaps more importantly, the PI summarized the contents of her interview and journal in this document so that the reader could be made aware of her role in the research process.

Additionally, follow-up meetings were used to conduct member checks with each participant. The purpose of these meetings was to have adolescents verify that their perspectives were accurately and fairly represented as well as to confirm accuracy in demographic information. These follow-up meetings were beneficial as they lessened the potential for data reporting errors and/or misrepresentation of information. Furthermore, case summaries were developed so the PI could obtain a solid grasp on the individual contributions of each case to the overall study. This within-case analysis facilitated the development of themes and assertions. Direct quotations also were used when presenting the results of the study to allow the reader to experience the unique perspectives of the adolescents first hand as well as to gain an accurate depiction of the language and format

of the adolescent's responses. Lastly, peer review sessions were conducted in order to gain another perspective and received feedback from those who were not directly involved in the study or data analysis.

An additional limitation is the threat to theoretical validity. Theoretical validity refers to the degree to which an explanation of a phenomenon "fits" the data, as well as the researcher's commitment to finding the best explanation (Johnson & Christensen, 2004). At the onset of the study, the PI identified a conceptual framework to guide the development of the research questions, create the interview guide, and inform the data collection and analysis process. This conceptual framework was assessed throughout the study for its continued validity and usefulness. The PI also engaged in theory triangulation and sought out other potential conceptual frameworks/theories to determine if they helped to better explain the findings of this study (Patton, 2002). However, there is a chance that not all options were explored or that some that may have been missed. Based on the PI's review of the literature, it was determined that a modified framework of the original was the most appropriate to communicate the findings to the reader and other interested parties.

Additionally, another limitation is the threat to internal validity. Internal validity, or credibility, refers to the degree to which the findings can be justified (Johnson & Christensen, 2004; Lincoln & Guba, 1985; Merrick, 1999). As previously noted, a limitation associated with this type of validity is that the PI was the only individual who conducted data collection, analysis, and interpretation. Although peer reviewers and the participants were involved in the research process, the PI was primarily responsible for these aspects of the study. In addition to data recording, reflexivity, theory triangulation,

member checking, and peer review strategies, the PI also engaged in methods triangulation in order to improve the creditability of the findings (Patton, 2002). The PI made a concerted effort to collect a variety of data including in-depth individual interviews and follow-up meetings, notes taken during and after the interviews and follow-up meetings, documents, parent feedback, and questionnaire data. Furthermore, the PI compared these sources of data associated with each case to check for consistency across different types of data. Additionally, the PI identified cases(s) that did not fit the observed themes in the data. These cases were highlighted in the results section to bring awareness to the reader and maintain the credibility of the findings. The presence of these cases was thought of as opportunities to refine themes and expand on the existing conceptual framework. Furthermore, possible explanations for these differences were addressed. Lastly, an audit trail was left for a peer reviewer so they could trace back the findings to their original sources (Lincoln & Guba, 1985, Stake, 2005). This audit trail included all collected data and a detailed description of the data analysis procedures.

Another limitation of the study included the threat to external validity (Lincoln & Guba, 1985). External validity, or transferability, is the degree to which findings can be generalized to other populations, situations, or settings (Johnson & Christensen, 2004; Maxwell & Loomis, 2004; Onwuegbuzie, 2003). This study investigated the experiences of adolescent cancer survivors who lived in specific geographic locations. The sample size was small, and there was no random selection of participants. Additionally, those individuals who volunteered for the study may have differed in their beliefs, perceptions, and experiences as compared to those who decline to participate or were unable to be reached by phone or email. Findings of the study may not be representative of the

experiences of adolescent cancer survivors from different geographic locations, and backgrounds. To address this particular limitation, the PI provided a detailed description of the methods used in this study so others can replicate procedures, if desired, and readers can make better informed decisions about the generalizability of the study. Despite these limitations, it is important to note that the primary goal of multiple case study research is to examine the cases, associated research questions, and phenomenon of interest (i.e., quintain). An inherent limitation of all qualitative research is the ability to generalize findings to other populations (Stake, 1994, 2005). Furthermore, the results are not meant to be generalizable to other populations but to show trends and convey meaning of experience within the populations specifically selected for the study.

A related limitation included the lack of cultural, ethnic, and socioeconomic (SES) diversity in the sample. It is recognized that much of the research literature on cancer survivorship is conducted with European American populations (Aziz & Rowland 2002; Kagawa-Singer, 2000). Furthermore, cancer care and programming has traditionally focused on this population and has even been described as a “Eurocentric paradigm for cancer care” (LaTour, 2009, p. 28). An effort was made to recruit adolescent cancer survivors from various different backgrounds. However, the final sample did not reflect these attempts. For example, two ethnically diverse adolescents were close to completing the recruitment process but unfortunately experienced a relapse prior to official enrollment in the study. Additionally, the majority of adolescents and their families appeared to be from high to middle SES backgrounds. Therefore, it was difficult to gain the perspectives of those adolescents and families from lower SES background whose experiences may have been different. Overall, a variety of factors

contributed to the lack of diversity in the sample. The PI readily acknowledges this particular limitation and recognizes the implications it has on the overall findings.

Social desirability was an additional threat present in this study. Social desirability bias is defined as “the tendency of individuals to deny socially undesirable actions and behaviors and to admit socially desirable ones” (Chung & Monroe, 2003, p. 291). To help proactively address this concern, The PI made a concerted effort to create a non-judgmental and comfortable environment for adolescents to share their perspectives. The PI also stressed to adolescents that one of the main goals of the research process was to listen and understand their unique experiences. Despite these efforts, adolescents in this study may have described their experiences in a socially desirable manner or withheld information to create/maintain a positive image or outlook during the interviews. Furthermore, adolescents may have felt the need to agree with the PI’s summary of their interview during the follow-up meetings. In an effort address this particular concern, the PI provided participants with the option to conduct the follow-up meeting in-person or over the phone. Most of the adolescents chose to conduct the follow-up meeting over the phone primarily for scheduling and convenience purposes. Other adolescents specifically requested an in-person follow-up meeting because they preferred this more personal mode of communication.

Another limitation of this study included the recall bias. The adolescents in the current study were asked to answer questions regarding their past experiences. There is a possibility of faulty recall of experiences, which could have skewed the data. Even with ample time to reflect and answer questions and follow-up meetings to verify information, adolescents still may have reported inaccurate information. Of note, data yielded from

the demographic and screener questionnaires was cross-checked with hospital records and/or caregiver report to verify the accuracy of the information.

Lastly, the final limitation of this study included time constraints that impacted the data collection and preparation process. As previously noted, the receipt of transcribed interviews and follow-up meetings from the transcriptionist were delayed secondary to logistics and time management concerns. Therefore, the PI was not always able to analyze transcribed documents soon after data collection. This may have interfered with the cyclical process of the qualitative research process and limited the ability of the PI to make timely modifications or changes to the interview guide based on the incoming data. To address this limitation, the PI listened to audiotapes and follow-up meetings as well as examined notes, documents, and questionnaires, which allowed continued engagement in the research process. This enabled the PI to make modifications/changes to the interview guide and continue to assess whether the being data collected were addressing the research questions.

Suggestions for Future Research

The findings of this study contribute to the literature base on the transition from off-treatment to post-treatment and school reintegration from the perspectives of adolescent cancer survivors. The qualitative research approach used rendered a rich, in-depth description and understanding of these transitions that can strengthen and add to the small body of existing research. Due to the exploratory nature of this study, there are many future areas of research to be recommended. First, it would be important to continue investigating adolescent cancer survivors' perceptions and approaches to school reintegration and the shift from off-treatment to post-treatment in order to determine if

the results of this study can be replicated and whether these perspectives are unique to the adolescent developmental stage. A developmental systems perspective is a critical framework to adopt when examining transition experiences and, more specifically, how cancer patients and survivors perceive, approach, and navigate transitions (Rey-Casserly & Meadows, 2008). Second, it would be useful to investigate the role that type of cancer diagnosis plays in the perception and trajectory of school reintegration and the shift from off-treatment to post-treatment. Each diagnosis carries unique features and treatment protocols, in addition to individual factors (e.g., type of side effects experienced), that could potentially yield qualitatively different transition experiences.

Third, an examination of the role that demographic, cancer-related, school-related, and pre-existing protective and risk factors play in predicting unhealthy and healthy transition outcomes would be a valuable area of research. Another interesting variable to investigate would be the role of prevention in facilitating healthy transition processes. For example, activities such as continued physical activity during treatment, ongoing communication with peers, and continued engagement in academic activities could feasibly promote a positive transition process and yield healthy outcome indicators such as greater self-efficacy, personal growth, and continued hope for the future. A fourth potential area of research includes examining how other conceptual and theoretical frameworks can be utilized to expand our preliminary understanding of transition experiences among pediatric cancer patients and survivors. For example, examination of the disability-stress-coping model and repressive style of adaptation concept in conjunction with the results of this study and other published research may lead to the development of a more accurate and meaningful understanding of the shift from off-

treatment to post-treatment and school reintegration that can then be empirically tested across pediatric cancer populations.

Finally, it would be important to conduct research to develop meaningful ways to assess and measure transition readiness, possible robust process indicators related to healthy and unhealthy transition processes, and the impact of facilitators (or absence of) on the transition process among pediatric cancer patients and survivors who make the shift from off-treatment to post-treatment and reintegrate back into the school setting (Pai & Schwartz, 2011). Furthermore, the use of health-related quality of life (HRQL) measures to assess transition processes and the effectiveness of transitional care and interventions would be another interesting area of future research. These future research directions will not only improve our understanding of transitions but also can lead to the design and implementation of effective, empirically based transitional care planning and interventions.

Practical Implications

The findings yielded from the current study have practical implications in hospital and school settings. Adolescents in this study had unique perspectives of the shift from off-treatment to post-treatment and school reintegration. Health care and school professionals can utilize this information to better understand and relate to cancer patients and survivors at this developmental level. This particular finding illuminates the importance of asking adolescent cancer patients and survivors to describe their own viewpoints and perspectives in order to guide conversations and inform intervention planning. Furthermore, it is critical to ascertain how developmental differences across early, middle, and late stage adolescence can influence the perception of these transitions.

It also was found that the type of diagnosis and treatment regime impacted the perception of these transitions. This finding suggests that these cancer-related variables may play an important role in the return to life after treatment as well as school reintegration. Health care and school professionals should utilize this information to gain a more comprehensive understanding of the adolescent's cancer experiences and, more specifically, how it may influence perceived and actual transition processes. Knowledge of this information also would be useful when conducting assessment to develop relevant transition-related interventions.

Additionally, process indicators (e.g., presence, absence, improvement of treatment residuals and activity-based signs) were identified among the adolescents' transition descriptions. Process indicators can serve as potentially useful sources of information for hospital and school personnel. This information can be utilized to assess transition progress, provide meaningful feedback and encouragement to adolescents, and increase awareness of family members of the transition process. The use of empirically derived transition measures also may be helpful in identifying robust process indicators and assessing overall transition progress. For example, the identification of indicators/signs of a difficult transition process (e.g., worsening of physical treatment residuals, significant decline in academic performance, or psychological distress) can inform intervention and guide transition care planning by professionals in their respective fields with the goal of providing appropriate and timely transition planning and care. Additionally, the identification of strengths and transition-related skills can be capitalized upon and integrated into intervention planning.

Adolescents in the current study also identified a variety of challenges associated with the transition from off-treatment to post-treatment and school reintegration. Although these challenges did not cause significant distress, they still resulted in discomfort and required adolescents to adapt and, in some cases, implement coping strategies. Identification of these challenges can provide information to hospital and school personnel on the potential sources of distress that adolescents may face during these specific transitions. Perhaps, more importantly, professionals across hospital and school settings can suggest interventions to promote active coping strategies to address concerns prior to and during transitions. One potential challenge endorsed by those adolescents who did not attend school during treatment included the presence of anticipatory thoughts and feelings associated with school reintegration. It would be useful for health care and school professionals to be aware of potential anticipatory concerns and to determine their nature based on the type of school reintegration circumstance (e.g., attend school during treatment versus reintegrating after a prolonged absence). Furthermore, it would be important to address these anticipatory thoughts and feelings in order to provide the necessary level of intervention to ease the transition process.

Additionally, the current study revealed that adolescents expressed varying needs for transition support and assistance. Again, this particular finding speaks to the importance of gaining the adolescent's perspective on their preferences for frequency, type, and intensity of transition support, planning, and care. Notably, adolescents identified a variety of academic and social supports that facilitated their transition experiences. Health care and school professionals can assist adolescents in identifying

potential sources of support and provide guidance on how to strategically utilize these supports to proactively manage and/or navigate transitions. Lastly, the adolescents shared advice on how to manage the shift from off-treatment to post-treatment and school reintegration. This advice may be useful to share and disseminate to other cancer patients and survivors across hospital and school settings in hopes of offering relevant, relatable information that can assist in coping with these particular transitions. Overall, there are numerous practical implications that can be utilized to promote positive transition experiences for adolescent cancer patients and survivors.

In addition to improving individual transition experiences, effective transitional care and planning efforts have the potential to yield large-scale positive outcomes such as prevention of secondary diseases, improved psychological adjustment, and greater quality of life. Targeted intervention and subsequent improvements in such areas have the potential to reduce future health care costs. To illustrate, it is estimated that in 2008 the annual costs of cancer were 228.1 billion dollars with direct medical costs at 93.2 billion, cost of lost productivity due to illness at 18.8 billion, and cost of lost of productivity due to premature death at 116.1 billion (American Cancer Society, 2009). Therefore, it is an imperative goal to provide cost effective care and interventions. For example, it is likely that adolescent cancer patients and survivors will vary in their perceived and actual need for transitional support and intervention. As such, not every adolescent would need intensive intervention, which is likely to be associated with high costs. Kazak (2006) presented the three-tiered Pediatric Psychology Preventative Health Model that describes different levels of psychosocial risk. This model specifically addresses subsets of children/adolescents and families that may experience significant distress and require

intervention. Levels of psychosocial risk that individuals and families may fall into include universal (i.e., distressed but resilient), targeted (i.e., acute distress and presence of psychosocial risk factors), and clinical (i.e., persistent/escalating distress with multiple psychosocial risk factors). Different types of supports and resources are needed to address concerns at each level. Those individuals and families at the targeted or clinical psychosocial risk level are in need of targeted intervention. This model may also be a useful and cost-effective framework for the provision of transition care and intervention.

Conclusion

In closing, the findings of the current study revealed that adolescent cancer survivors have unique perspectives of the shift from off-treatment to post-treatment and school reintegration; specific challenges associated with these times; varying needs for transitional support; and a variety of transition-related support from individuals across school, hospital, and community settings. Potential avenues of research were discussed that can expand the existing literature base and lead to a greater understanding of transitions from the perspectives of adolescents. Practical implications also were delineated relative to the findings of the current study. These practical implications have the potential to promote positive transition experiences for adolescent cancer patients and survivors across hospital and school settings.

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APPENDICES

Appendix A: Screener Questionnaire

Date: _____

Time: _____

Potential Participant Study ID #: _____

1. What is your date of birth? _____

2. Is English your primary language? Y N

3. Are you in foster care? Y N

4. What type of cancer were you diagnosed with? _____

5. At what age were you diagnosed with cancer? _____

6. When did you complete treatment? _____
(note: acquire specific month/year if possible so this information can be incorporated into the interview session i.e., using a time frame to put the transition from off-treatment to post-treatment in a context that adolescents can relate to)

7. Has your doctor said that you are in remission (i.e., disappearance of all signs of cancer in response to treatment)? Y N

8. Have you experienced a relapse (i.e., has your cancer returned or have you been diagnosed with a new cancer since you completed treatment)? Y N

Appendix A: (Continued)

9. Do you currently attend school? Y N

If YES, where? _____

(note: ineligible if home schooled or attending virtual school on the Internet)

10. Do you receive any special education services at your school? Y N

If YES, what type?

- a. Assistive technology
- b. Hearing/Vision
- c. Instructional support
- d. Mental health counseling
- e. Occupational therapy
- f. Physical therapy
- g. School health services
- h. Special transportation
- i. Speech/Language services
- j. Targeted academic/behavioral intervention
- k. Other: _____

(note: can be either in general or special education settings; IDEIA eligibility categories include: autism, deaf-blindness, emotional disturbance, hearing impairment, mental retardation, multiple disabilities, orthopedic impairment, other health impairment, specific learning disability, speech or language impairment, traumatic brain injury, visual impairment)

Appendix B: Demographic Questionnaire

Date: _____

Participant Study ID #: _____

Directions: Answer each question as best as you can.
You will not be asked to give your name.

1. Are you (circle one):

Male Female I do not identify with either male or female

2. How old are you? _____

3. What is your ethnicity (circle one)?
 - a. Hispanic
 - b. Not Hispanic
 - c. Prefer not to answer
 - d. I don't know

4. What is your race (circle one)?
 - a. American Indian/Alaskan Native
 - b. Asian/Pacific Islander
 - c. Black
 - d. White
 - e. Mixed
 - f. Other: _____
 - g. Prefer not to answer
 - h. I don't know

5. What kind(s) of treatment did you receive (you can circle more than one)?
 - a. Chemotherapy
 - b. Radiation
 - c. Surgery
 - d. Bone marrow transplant
 - e. Other: _____
 - f. I don't know

Appendix B: (Continued)

6. Where did you receive cancer treatment? _____
7. What grade in school are you in this year? _____
8. Where did you go to school while you received treatment (you can circle more than one)?
- a. Public or private school
 - b. In the hospital
 - c. At home
 - d. Took classes on the internet (virtual school)
 - e. Other: _____
 - f. I don't know
9. Where did you go to school after you completed treatment (you can circle more than one)?
- a. Public or private school
 - b. At home
 - c. Took classes on the internet (virtual school)
 - d. Other: _____
 - e. I don't know
10. Where do you go to school now (you can circle more than one)?
- a. Public or private school
 - b. At home
 - c. Take classes on the internet (virtual school)
 - d. It is summer and I don't go to school right now
 - e. Other: _____
 - f. I don't know

Appendix C: Final Semi-Structured Interview Guide

Pre-Interview

1. Welcome adolescent and caregiver(s) to the interview session.
 - *Hi! (Introduce self). Thank you for coming today. How are you doing? How was your weekend/week at school? Did you do anything fun/interesting this weekend?*
2. Give each adolescent/caregiver(s) two copies of assent/consent forms
 - Ask them to read the forms carefully
 - Interviewer will verbally review sections related to confidentiality and what they are agreeing to when they sign the form
 - Remind them that there will be two phases of the study (i.e., interview and follow-up session)
 - Ask if they have any questions and answer them accordingly
 - Collect the signed forms
 - Give adolescent one copy of the assent form; give caregiver(s) one copy of the consent form
 - Interviewer will retain the other copy of the assent/consent form for her records
 - Ask caregiver(s) to exit the room at this time
3. State purpose of the interview session
 - *First, I am going to ask you to give me a timeline of your cancer experience. For example, tell me about your symptoms leading up to your diagnosis, when you were diagnosed, your treatment schedule, your school schedule, and when you completed treatment. This can help us both have a good idea of your specific, unique experience and help organize the rest of the interview questions.*
 - *Second, I am interested in learning about two important experiences that kids your age who have survived cancer have gone through.*
 - *#1: I would like to learn more about what it was like going to school and what type of experiences you had with your teachers and other students your age (note: specify depending on situation of adolescent: going back to “regular” school after receiving a cancer diagnosis or after treatment was completed).*
 - *#2: I would like to learn more about your experience when you finished treatment and had to go back to your everyday life (note: use specific time frame recorded on screener questionnaire to put this into context for the adolescent).*
 - *Note: More time may be taken to explain/define this transition. This may include drawing pictures or Q/A between interviewer and adolescent*

Appendix C: (Continued)

4. Overview of Interview Session

- *To learn more about your experiences, I will be asking you some questions. . You also can share some of the things you brought to help me better understand what your experience was like (i.e., documents, audiovisual material). You may share these things during the interview or at the end of the interview when all the questions have been asked. For example, if I ask you a question, and you feel that sharing your (document/audiovisual material) will help you in answering the question, please feel free to share it at that time.*
- *Also, right after the interview you will answer a few questions about yourself (show adolescent the demographic questionnaire). This should take between 1-3 minutes to fill out. You can then ask any questions you have and/or talk about how the interview went. Then, you will receive a gift card for all your time and help.*
- *Remember, there are no right or wrong answers. I am looking forward to hearing what you have to say and learning more about your experiences. If at any time you feel uncomfortable, please let me know right away. You have can stop the interview at any time.*
- *The interview will last about 30 to 40 minutes. If you would like to keep talking more about your experiences that is okay too.*

5. Confidentiality

- Review general definition of confidentiality, purpose of audiotaping/note taking, and use of a pseudonym
 - *Everything we talk about today will be kept confidential. This means that what you say and do will not be shared with anyone or, in other words, it will be private and kept between just you and me. When I write up the report, I will do a summary of what all the kids who are participating in the study said. You will never be referred to by name. For example, I will say “the majority of kids said” or “a few kids said.”*
 - *We are tape recording this session so that I can look at it at a later time and remember exactly what we talked about. Also, I may write some notes down while we are talking. These are my notes and nobody else will see them.*
 - *If you would like, you can choose a fake name to use during the taped interview. Some people like to use a different name to keep their privacy while others do not mind if their real first name is recorded. This decision is up to you. Would you like to use a fake first name or your real first name?*
 - *Do you have any questions before we start the interview? Ok, let’s begin (turn on tape recorder)*

Appendix C: (Continued)

Interview

Organizing Question: Give me a timeline of your cancer experience. For example, tell me about your symptoms leading up to your diagnosis, when you were diagnosed, your treatment schedule, your school schedule, and when you completed treatment.

Topic Domain A: Experiences and Challenges Associated with School Reintegration (RQ4 & RQ5) (please note: questions related to school reintegration will be asked first because school is a familiar setting for most adolescents and deemed a more approachable starting point for questioning)

1. Tell me what it was like going to school (note: place this question in context for adolescent based on their specific schooling history/situation e.g., did not attend school during treatment, attended school while receiving treatment, mixture of home/hospital and regular school). (Lead-off question)

Probes:

- a.) Describe a typical day at school.
- b.) Did you feel different when you went back to school (either after diagnosis or completion of treatment)? In what ways did you feel different? Give an example.
- c.) Tell me what kind of feelings/emotions you had when you went to school (note: follow-up on specific emotions and ask for stories to illustrate feeling)
- d.) Describe what your _____ were like when you went back to school?
 - Teachers?
 - Other kids that you didn't know very well? (any teasing)
 - Other support staff (e.g., guidance counselor, principal, etc.)
 - Friends? (asking questions about your cancer)
- e.) Did you keep the same friends? Make new ones?
- f.) Did you feel that your teachers understood what you were going through?
- g.) How were your grades?
- h.) What did you think about the school work/assignments?
- i.) What kind of school work did you do?

Topic Domain B: Supports/Services to Improve the School Reintegration Process (RQ6)

Examples: Some kids your age may receive help/support from other people For example, some kids may have someone at the hospital (like a social worker) who calls the school and talks with their teachers to let them know what is going on. Others kids may have teachers at school who they can talk to. Some teachers will let kids take breaks if they are tired or give them an extra set of books to keep at home.

Appendix C: (Continued)

(other examples at SCHOOL: having someone to talk to at school like a guidance counselor or teacher, accommodations in the classroom like being able to take breaks or having an extra set of books at home; examples at HOSPITAL: having someone help plan your return to school like a social worker, talking with other kids in the hospital)?

2. What kinds of things do you think would have helped you at school? (Lead-off question)

Probes:

- a.) What kind of help/support do you think would have helped other kids your age go to school?
- b.) Did you receive any help like this when you went to school? If yes, tell me about it. Who helped you? What kind of help? How did you cope (or what was your strategy) for dealing with school stuff like other kids, teachers, and side effects of treatment?

Topic Domain C: Experiences and Challenges Associated with the Transition from Off-Treatment to Post-treatment (RQ1 & RQ2)

3. Describe for me what it was like when you finished treatment. (Lead-off question)

Probes:

- a.) Describe your last visit for treatment at the hospital
 - What did you feel like?
 - What did your mother/father/sibling say or do?
- b.) What was it like to hear the doctor say you were all done with treatments?
- c.) What was the best part of being finished with cancer treatment?
- d.) What was the worst part of being finished with cancer treatment?
- e.) Tell me a story about something that happened to you that would explain how you felt during treatment (or describe who you were). Now tell me a story about you that would explain how you felt after treatment (or would describe who you are).

4. Tell me what it was like for you when you finished treatment and had to go back to your everyday life?

(note: use specific time frame recorded on screener questionnaire to put this question into context for the adolescent). (Lead-off question)

Appendix C: (Continued)

Probes:

- a.) What things changed for you during this time (or specified time frame)?
- What was it like at home with your parents (mother, father, or other caregiver)
 - What was it like with your brother/sisters?
 - What was it like with your friends?
 - Were you able to return to doing activities that you couldn't do when you received treatment? What activities did you do?
(examples: playing sports, rejoining clubs/church organizations, getting a job for older adolescents, going to the movies)
 - What kinds of things were you not able to do?
 - What kinds of things did you want to do but couldn't?
 - How did you feel (or what emotions did you have) after treatment was completed and you returned to your everyday life?
 - When did you start thinking about what would happen after treatment (e.g., at time of diagnosis, last few weeks of treatment)
 - How would you describe this time (e.g., a transition, change)?
- b.) Did you have to deal with side effects of cancer treatment (examples: tired, low energy, weak muscles, dry mouth etc.)? Can you describe how your body felt (or how you felt physically)?
- Did (insert side effect/problem for example: being tired all the time) make it hard to (insert corresponding item for example: get through the day)? Can you give me an example of a day like this? What would happen? How did you get through the day?
- c.) Did your physical appearance change (examples: hair, weight loss/gain)? If so, what changed?
- How did your friends/family react?
 - Describe what you felt like having to deal with these changes

Topic Domain D: Supports/Services to Improve the Transition from Off-treatment to Post-treatment (RQ3)

**Examples: There are different kinds of help/support that are available to kids your age after they have finished treatment. Some kids who finish treatment may meet with their doctors and nurses to talk about important things they need to know about. For example, they may talk about side effects of treatment and what to expect at follow-up appointments. They also may talk with other kids who had cancer about what it was like to finish treatment or talk with an adult/professional about how they are feeling. (other examples at SCHOOL: having someone to talk to at school like a guidance counselor or teacher, accommodations in the classroom like being able to take breaks or*

Appendix C: (Continued)

having an extra set of books at home; examples at HOSPITAL: having someone help plan your return to school like a social worker, talking with other kids in the hospital)?

5. What kinds of things do you think would have helped you get back to your everyday life? (Lead-off question)

Probes:

a.) What kind of help/support do you think would have helped other kids your age after they finished treatment?

b.) Did you receive any help like this during or after you finished treatment? If yes, tell me about it. Who helped you? What kind of help? How did you cope (or what was your strategy) for getting through this time? (note: help should be specifically related to transition from off to post-treatment).

Closing Question(s):

- What did you learn or what did you “get out” of your cancer experience? (note: may provide information on outcomes of transition experiences)
- Is there anything else you would like to share or talk about?

At the end of the interview session, the interviewer will clarify and summarize (not interpret) information shared by the participant and may ask follow-up questions if clarification or elaboration on responses is needed.

(Stop tape recording)

Post Interview

6. Demographic Questionnaire (note: caregivers may re-enter the room at this time)
 - After the interview is completed, each adolescent will be asked to complete the demographic questionnaire (estimated time to complete=1-3 minutes).
 - Caregivers may assist the adolescent in completing the questionnaire.
 - The questionnaires will be collected and immediately assigned a number.

7. Debriefing

- Each adolescent/caregiver may ask any questions they have about their interview experience, and (if needed) the interviewer can provide more detailed information about the study and review confidentiality.
 - *Thank you for participating in this interview. I enjoyed talking with you and hearing about your experiences today. Please feel free to use this time to ask any questions or voice any concerns that you may have about the interview or the study in general. I would be happy to answer your questions.*

Appendix C: (Continued)

8. Conclusion of Interview Session

- Collect documents and/or audiovisual materials from the participants (note: participants were given the option to copy/scan documents and/or audiovisual material themselves and bring copies to the interview session OR give original copies to interviewer and allow her to copy/scan them).
- If the participant did not copy/scan their documents and/or audiovisual material themselves, they will be informed that each document and piece of audiovisual material will be copied/scanned by the interviewer. They will be informed that their original documents and/or audiovisual material will be returned to them at the follow-up meeting.
- All participants will be notified that their copied/scanned documents and/or audiovisual material will be assigned the same number that was written on the demographic questionnaire.
- Inform the adolescent/caregiver(s) that she will contact them within one month via phone to schedule a follow-up meeting.
- Thank adolescent and caregiver(s) for their time and participation.

Appendix D: Pilot Study Questions

1. Overall, what did you think about the interview?
2. What questions do you think I should keep?
3. What questions do you think I should get rid of? Why?
4. What other questions do you think I should ask?
5. Do you think the order of the questions should be changed? If so, why?
6. What did you think about the vignettes/stories?
7. Did you think that the vignettes/stories are/were helpful or not helpful? Why?
8. Do you think this study will be important/valuable/helpful? Why?
9. Do you have any other questions or comments about the interview?

Appendix E: Original Semi-Structured Interview Guide

Pre-Interview

Note: Asterisks denote that the content will only be included for those pre-test interviews using vignettes.

1. Welcome adolescent and caregiver(s) to the interview session.
 - *Hi! (Introduce self). Thank you for coming today. How are you doing? How was your weekend/week at school? Did you do anything fun/interesting this weekend?*
2. Give each adolescent/caregiver(s) two copies of assent/consent forms
 - Ask them to read the forms carefully
 - PI will verbally review sections related to confidentiality and what they are agreeing to when they sign the form
 - Remind them that there will be two phases of the study (i.e., interview and follow-up session)
 - Ask if they have any questions and answer them accordingly
 - Collect the signed forms
 - Give adolescent one copy of the assent form; give caregiver(s) one copy of the consent form
 - PI will retain the other copy of the assent/consent form for her records
 - Ask caregiver(s) to exit the room at this time
3. State purpose of the interview session
 - *I am interested in learning about two important experiences that kids your age who also have survived cancer have gone through. First, I would like to learn more about your experience during the first few months when you were no longer receiving treatment for your cancer (note: use specific time frame recorded on screener questionnaire to put this into context for the adolescent). The second experience I would like to learn more about is what it was like going back to school and what type of experiences you had with your teachers and other students your age (note: specify depending on situation of adolescent: going back to “regular” school after receiving a cancer diagnosis or after treatment was completed).*
4. Overview of Interview Session
 - *To learn more about your experiences, I will be asking you some questions. *Before I ask you these questions, I will share stories about what some other kids your age experienced or felt like. I met these kids while I was working at a hospital, and it may be helpful to hear about their experiences.* I also*

Appendix E: (Continued)

would like you to share some of the things you brought that will help me better understand what your experience was like (i.e., documents, audiovisual material). You may share these things during the interview or at the end of the interview when all the questions have been asked. For example, if I ask you a question, and you feel that sharing your (document/audiovisual material) will help you in answering the question, please feel free to share it at that time.

- *Remember, there are no right or wrong answers. I am looking forward to hearing what you have to say and learning more about your experiences. If at any time you feel uncomfortable, please let me know right away. You have can stop the interview at any time.*
- *The interview will last about 30 to 40 minutes.*

5. Confidentiality

- Review general definition of confidentiality, purpose of audiotaping/note taking, and use of a pseudonym
 - *Everything we talk about today will be kept confidential. This means that what you say and do will not be shared with anyone or, in other words, it will be private and kept between just you and me. When I write up the report, I will do a summary of what all the kids who are participating in the study said. You will never be referred to by name. For example, I will say “the majority of kids said” or “a few kids said.”*
 - *We are tape recording this session so that I can look at it at a later time and remember exactly what we talked about. Also, I may write some notes down while we are talking. These are my notes and nobody else will see them.*
 - *If you would like, you can choose a fake name to use during the taped interview. Some people like to use a different name to keep their privacy while others do not mind if their real first name is recorded. This decision is up to you. Would you like to use a fake first name or your real first name?*
 - *Do you have any questions before we start the interview? Ok, let’s begin (turn on tape recorder)*

Interview

Topic Domain A: Experiences and Challenges Associated with the Transition from Off-Treatment to Post-treatment (RQ1 & RQ2)

Vignette: I have talked with other kids your age who have survived cancer. I worked in a hospital and met many kids your age who were either going through treatment or had finished treatment. One kid I knew named Tim told me that he was happy that treatment was finished because he didn't have to worry about going to the hospital to receive treatment anymore, but a girl, Rachel, said she felt scared because she wasn't going to be able to see her doctor regularly anymore and was sad because she would miss all the doctors and nurses.

1. *Did you feel like Tim or Rachel when you finished treatment?* Describe for me what it was like when you finished treatment. (Lead-off question)

Probes:

- a.) Describe your last visit for treatment at the hospital
 - What did you feel like?
 - What did your mother/father/sibling say or do?
- b.) What was it like to hear the doctor say you were all done with treatments?
- c.) What was the best part of being finished with cancer treatment?
- d.) What was the worst part of being finished with cancer treatment?
- e.) Tell me a story about something that happened to you that would explain you during treatment. Now tell me a story about you that would explain you after treatment (or would describe who you are)

Vignette: After Tim finished treatment, the first few months after treatment were a big change because he went from being on treatment and always going to the hospital to going back to his normal routines (e.g., like seeing his friends again, doing schoolwork, doing chores around the house, etc.). Rachel said that she was excited because she was able to do things that she couldn't do while she was receiving treatment (like hang out with her friends, do fun activities like go to the movies) but she also was worried because she had to deal with side effects of cancer treatment (like feeling tired and changes in her appearance such as losing her hair).

Appendix E: (Continued)

2. *Did you feel like either of these kids during the first few months after treatment?* Tell me what it was like for you during the first few months after you completed treatment (note: use specific time frame recorded on screener questionnaire to put this question into context for the adolescent). (Lead-off question)

Probes:

a.) What things changed for you during these first few months (or specified time frame)?

- What was it like at home with your parents (mother, father, or other caregiver)
- What was it like with your brother/sisters?
- What was it like with your friends?
- Were you able to return to doing activities that you couldn't do when you received treatment? What activities did you do?
(examples: playing sports, rejoining clubs/church organizations, getting a job-for older adolescents, going to the movies)
- What kinds of things were you not able to do?
- What kinds of things did you want to do but couldn't?

b.) Did you have to deal with side effects of cancer treatment (examples: tired, low energy, weak muscles, dry mouth etc.)? Can you describe how your body felt (or how you felt physically)?

- Did (insert side effect/problem for example: being tired all the time) make it hard to (insert corresponding item for example: get through the day)? Can you give me an example of a day like this? What would happen? How did you get through the day?

c.) Did your physical appearance change (examples: hair, weight loss/gain)? If so, what changed?

- How did your friends/family react?
- Describe what you felt like have to deal with these changes

Topic Domain B: Supports/Services to Improve the Transition from Off-treatment to Post-treatment (RQ3)

Vignette: There are different kinds of help/support that are available to kids your age after they have finished treatment. Some kids who finish treatment may meet with their doctors and nurses to talk about important things they need to know about. For example, they may talk about side effects of treatment and what to expect at follow-up appointments. They also may talk with other kids who had cancer about what it was like to finish treatment or talk with an adult/professional about how they are feeling.

Appendix E: (Continued)

3. What kinds of things do you think would have helped you after you finished treatment? (Lead-off question)

(examples: support groups with same aged peers, talking with someone one-on-one, meeting with the doctors/nurses when you finish treatment so you know what to expect, talking with close friends, having information--like brochure/packet--on what to expect after treatment)

Probes:

- a.) Did you receive any help like this when you went back to school? If yes, tell me about it. Who helped you? What kind of help?

Topic Domain C: Experiences and Challenges Associated with School Reintegration (RQ4 & RQ5)

Vignette for adolescents who did not attend “regular” school while receiving treatment: I also knew a kid around your age, Bobby, who was getting ready to go back to school after he finished cancer treatment. He was excited to see his friends but also didn’t know how they would react to changes in his appearance (hair loss). He also was worried that he was behind in his classes and wanted to go back to school to catch up with his friends. When he got back to school his friends asked him questions about his cancer (what was “it like”, how do you feel?) and some kids he didn’t know teased (overheard them talking about) him. He went back to his regular classes and his teachers understood that sometimes he was tired and needed breaks.

Vignette for adolescents who attended school while receiving treatment: Rachel, the girl I told you about before, attended school while she was receiving her cancer treatment. She tried to go to school as much as possible, but it was hard because she was often times not feeling well enough and sometimes had a hard time concentrating in class (tired, experienced pain). She was absent a lot and she was worried that she would fall behind in her school work. She also started to lose her hair and had to deal with her friends asking her questions about her cancer. Although this was hard for her, her friends and teachers were helpful and understanding.

4. *Did you feel like Bobby/Rachel when you went back to school?* When you returned to school was anything different? Tell me about it. (Lead-off question)

Appendix E: (Continued)

Probes:

- j.) Can you describe a typical day at school?
- k.) Did you feel different when you returned back to school? In what ways did you feel different? Give an example.
- l.) Describe what your _____ were like when you went back to school?
 - Teachers?
 - Other kids that you didn't know very well? (any teasing)
 - Other support staff (e.g., guidance counselor, principal, etc.)
 - Friends? (asking questions about your cancer)
- m.) Did you keep the same friends? Make new ones?
- n.) Did you feel that your teachers understood what you were going through?
- o.) How were your grades?
- p.) What did you think about the school work/assignments?
- q.) What kind of school work did you do?

Topic Domain D: Supports/Services to Improve the School Reintegration Process **(RQ6)**

Vignette: Some kids your age may receive help/support from other people (like social workers at the hospital or teachers at school) when you go back to school (either after they were diagnosed or after they finished treatment). For example, some kids may have someone at the hospital (like a social worker) who calls the school and talks with their teachers to let them know what is going on. Others kids may have teachers at school who they can talk to. Some teachers will let kids take breaks if they are tired or give them an extra set of books to keep at home.

5. What kinds of things do you think would have helped you when you went back to school? (Lead-off question)

(examples at SCHOOL: having someone to talk to at school like a guidance counselor or teacher, accommodations in the classroom like being able to take breaks or having an extra set of books at home; examples at HOSPITAL: having someone help plan your return to school like a social worker, talking with other kids in the hospital)?

Probes:

- a.) Did you receive any help like this when you went back to school? If yes, tell me about it. Who helped you? What kind of help?

Appendix E: (Continued)

Closing Question: Is there anything else you would like to share or talk about?

At the end of the interview session, the PI will clarify and summarize (not interpret) information shared by the participant and may ask follow-up questions if clarification or elaboration on responses is needed.

(Stop tape recording)

Post Interview

6. Demographic Questionnaire (note: caregivers may re-enter the room at this time)
 - After the interview is completed, each adolescent will be asked to complete the demographic questionnaire (estimated time to complete=10 minutes).
 - Caregivers may assist the adolescent in completing the questionnaire.
 - The questionnaires will be collected and immediately assigned a number.

7. Debriefing
 - Each adolescent/caregiver may ask any questions they have about their interview experience, and (if needed) the PI can provide more detailed information about the study and review confidentiality.
 - *Thank you for participating in this interview. I enjoyed talking with you and hearing about your experiences today. Please feel free to use this time to ask any questions or voice any concerns that you may have about the interview or the study in general. I would be happy to answer your questions.*

8. Conclusion of Interview Session
 - Collect documents and/or audiovisual materials from the participants (note: participants were given the option to copy/scan documents and/or audiovisual material themselves and bring copies to the interview session OR give original copies to PI and allow her to copy/scan them).
 - If the participant did not copy/scan their documents and/or audiovisual material themselves, they will be informed that each document and piece of audiovisual material will be copied/scanned by the PI. They will be informed that their original documents and/or audiovisual material will be returned to them at the follow-up meeting.
 - All participants will be notified that their copied/scanned documents and/or audiovisual material will be assigned the same number that was written on the demographic questionnaire.
 - Inform the adolescent/caregiver(s) that she will contact them within one month via phone to schedule a follow-up meeting.
 - Thank adolescent and caregiver(s) for their time and participation.

Title of Study

Transition Experiences of Adolescent Survivors of Childhood Cancer: A Qualitative Investigation

Purpose of the Study

The purpose of this study is to conduct a qualitative investigation of two significant transitions experienced by adolescent survivors of childhood cancer and their perceptions of how these transitions impacted their lives. The two transitions that will be explored include the transition from off-treatment to post-treatment and school reintegration. Specifically, the study will explore adolescent cancer survivors' experiences of going through these transition processes, their perceptions of the impact of these transitions on their lives, challenges associated with these transitions, and their beliefs about what supports/services would be beneficial during these transitions.

Significance of the Study

The current study will contribute to the literature examining the transition from off-treatment to post-treatment and school reintegration from the perspectives of adolescent cancer survivors. The qualitative research approach used in this study will render a rich, in-depth description and understanding of these transitions which can strengthen and add to the small body of existing research. The findings generated from this study can provide health care professionals and school personnel with a better understanding of adolescent cancer survivors' transition experiences, the impact of these transitions on their lives, perceived challenges, and supports and/or services that would make the transition process smoother. Furthermore, knowledge of this information can help identify potential targets for intervention and improve service delivery in both health care and school settings.

Inclusion & Exclusion Criteria

Inclusion criteria:

- Chronological age between 12 and 17 years
- Diagnosis of cancer (other than brain tumor) received during childhood
- Diagnosis was received at age 5 years or older
- Has been off treatment for a minimum of six months and a maximum of five years
- Cancer is currently in remission
- No history of a relapse
- Currently attending school in the community (e.g., public, private, charter school)
- Willing and able to provide assent
- Caregiver(s) are willing to provide consent for participation
- Consent for Director to provide their contact information to co-investigator

Appendix F: (Continued)

Exclusion criteria:

- Lack of fluency in English
- In foster care
- Mental retardation
- Diagnosis of a brain tumor
- Below the age of five years at initial diagnosis
- Off treatment for less than one year or more than five years
- Home schooled or taking Virtual classes on the internet

Time Commitment for Participants

- Initial Telephone Contact (approximately 10 to 15 minutes)
 - Additional telephone contact if requested by adolescent and their caregivers (5 to 10 minutes)
- Interview Session (approximately 30 to 40 minutes)
 - Location of interview will be determined based on participant preference
- Follow-up meeting (approximately 20 to 30 minutes)
 - Location of follow-up will be determined based on participant preference
- Additional follow-up meeting if requested or needed (approximately 20-30 minutes)
 - Location of additional follow-up meeting will be determined based on participant preference

Appendix G: Johns Hopkins Hospital Letter of Support



Pediatric Oncology
Johns Hopkins Hospital
600 North Wolfe Street
CMSC 800
Baltimore, Maryland 21287
410.614.2457 / 410.955.0028 fax

April 6, 2009

Keith J Slifer, PhD
Director, Pediatric Psychology Consultation Program
Associate Professor, Department of Psychiatry,
Behavioral Sciences & Pediatrics
The Kennedy Krieger Institute & Johns Hopkins University
707 North Broadway Ave
Baltimore, MD 21205

RE: Alana Lopez

Dear Dr. Slifer,

I am writing in support of the above referenced PhD student. I am the coordinator of the Childhood Cancer Survivor Program at Johns Hopkins Hospital. I have met with Ms Lopez, reviewed her proposal and feel it is a feasible project for our program. I will be happy to assist her in identifying and recruiting potential patients.

If you have any questions about our program or my support of this project please contact me at rubleka@jhmi.edu or 410-614-5062. I look forward to working with Ms Lopez on this very interesting dissertation.

Sincerely,

Kathy Ruble, PhD, RN, CPNP, AOCN
Coordinator, Childhood Cancer Survivor Program
Johns Hopkins University



A Comprehensive Cancer
Center Designated by the
National Cancer Institute

Johns Hopkins Medicine

Transition Experiences of Adolescent Survivors of Childhood Cancer: A Qualitative Investigation

Volunteers Wanted for a Research Study

WHO: People who are cancer survivors between the ages of 12 and 17 (except survivors of brain tumors); diagnosed with cancer at age 5 or older; off treatment for at least 6 months and no more than 5 years; cancer is in remission; and no history of relapse.

WHY: To learn more about cancer survivors' experiences when they finished treatment and had to go back to their everyday life and what it was like going to school.

WHAT: A telephone call (10-15 minutes), interview (30-40 minutes), and a follow-up meeting or telephone call (20-30 minutes) will be required.

WHERE: At a location that is comfortable and convenient for the participant (example: home, hospital).

POTENTIAL RISKS: This research study presents minimal risk.

POTENTIAL BENEFITS: There is no direct benefit from being in this study. However, taking part in the research study may help others in the future. For example, information from this study may help provide more information on adolescent survivorship care and possibly be used to inform and improve survivorship care and practices in the community.

PAYMENT: Participants will be given a \$20 Target or Walmart gift card for their participation.

HOW: To learn more about this research, please call Alana Lopez, M.A. at (813-451-9425) or Keith Slifer, Ph.D. (443-923-2900).

This research is conducted under the direction of:

Keith Slifer, Ph.D.

Director, Pediatric Psychology Consultation Program

Associate Professor, Departments of Psychiatry, Behavioral Sciences, and Pediatrics

The Kennedy Krieger Institute & Johns Hopkins University School of Medicine

Appendix I: Johns Hopkins Hospital Telephone Screening for Participant Recruitment

- *Hello, my name is Alana Lopez, and I am a doctoral student who is conducting research at Johns Hopkins. I am part of a research team who is working with the Johns Hopkins Pediatric Oncology Outpatient and Long-Term Childhood Cancer Survivors Clinics to conduct a research study.*
- *I am calling because you expressed interest in learning more about this research study. Ms. Pat Williams/Dr. Kathy Ruble spoke with you and said I had permission to contact you directly. Thank you for your interest in this study.*
- *The purpose of this study is to learn more about (child's name) experience when he/she finished treatment and had to go back to his/her everyday life. I also would like to learn about what it was like for (child's name) going to school and what type of experiences he/she had with teachers and other students his/her age.*
- *Would you be interested in learning more about the study?*
 - *If NO: Thank you for your time.*
 - *If YES: Great. May I ask you some questions to see if (child's name) can be a part of the study? This will take between 5 to 10 minutes.*
 - *If YES: **Oral consent/assent will be obtained next (prior to asking any screener questions). The following script will be read to both the adolescent and his/her caregivers.***
 - *Before I ask you these questions, I'll read the informed assent/consent, which I want to read to make sure I clearly explain what the study is about and what you will be asked to do in the study.*
 - *You are invited to take part in a research study. Again, the purpose of this study is to learn more about your experience during the first few months when you were no longer receiving treatment for cancer. I also would like to learn about what it was like going back to school and what type of experiences you had with your teachers and other students your age.*
 - *You are being invited to join the study because you are a cancer survivor who is between the ages of 12 and 17. By taking part in this study, you will help us learn more about the experiences of cancer survivors your age.*
 - *As a part of the study, you will first be asked questions today to determine if you are eligible to participate in the study. If you meet the study requirements, then you will be asked to participate in an interview that will take about 30 to 45 minutes and will be audiotaped. We will ask you questions about your experience*

Appendix I: (Continued)

during the first few months when you were no longer receiving treatment and what it was like going back to school. You also can bring any documents (like journals, letters), or audiovisual material (like pictures, drawings, other artwork) if you believe it will help us better understanding your experiences. You can refuse to answer any specific question and you are free to stop the interview at any time. The audiotapes will be destroyed when you turn 23 years old (per Johns Hopkins policy).

- *After the interview is done, you will be asked to complete a questionnaire that includes some questions about yourself. The questionnaire will take about 8 to 10 minutes to complete. After you finish the questionnaire, you will be given a chance to ask questions about the interview or research study.*
- *You will be called to schedule a follow-up meeting within one month from the date you were interviewed. You will be mailed a copy of the results of your interview so you can review this information before the follow-up meeting. At the follow-up meeting, you will have a chance to share your feelings and thoughts about the results. If more information is needed or if you would like more time to discuss your experiences, an additional follow-up interview or a phone call may be scheduled.*
- *You can decide where you would like to meet to do the interview and follow-up sessions. They can be done at the hospital, at your home, or another place you choose. Please feel free to pick a convenient location where you feel most comfortable. Face-to-face interviews (in person) are preferred over phone interviews.*
- *Although we expect that there will be little to no risk involved in this study, there is a chance that some questions may bring up difficult feelings or memories. If you say that you are uncomfortable or upset, we will stop the interview or follow-up meeting. You will be able to decide whether you would like to keep going or not. You also may miss some school and/or work if you are a part of the study. However, you can schedule the interview and follow-up meeting at a time that works best for you so you do not miss any school or work.*
- *There is the risk for the loss of confidentiality of sensitive information (keeping your personal information private or secret). However, steps will be taken to prevent this loss. All responses will be protected using a code number and stored in a locked file cabinet and/or password protected computer. You may choose a fake name to use during the interview and follow-up meeting to maintain confidentiality (your privacy). If you do not choose a fake name, one will be given to you when writing up the results of the study. We try to make sure that everyone who needs to see your*

Appendix I: (Continued)

information uses it only for the study and keeps it confidential, but we cannot guarantee this.

- *We cannot promise that this study will be of direct benefit to you or your family. However, you may help others in the future. For example, information from this study may help provide more information on adolescent survivorship care and possibly be used to inform and improve survivorship care and practices in the community.*
- *There are no financial (money) costs to being part of this study.*
- *You will be given a \$10 Target or Walmart gift card for participating in the interview session and another \$10 Target or Walmart gift card for participating in the follow-up session. Therefore, you may receive up to \$20 for completing the interview and follow-up session. You will be paid at the end of each session.*
- *You do not have to join this study. It is up to you. You can say okay now, and you can change your mind later. All you have to do is tell us. No one will be mad at you if you change your mind. If you do not want to join the study, it will not affect your care at Johns Hopkins.*
- *Do you have any questions about the information I have read to you?*

- *Would you be interested in participating in this study?*

- *If NO: Thank you for your time.*
- *If YES: I will ask you to review and sign a written assent/consent form at the actual interview session. At this time, I will collect information about you to make sure you are eligible to take part in the study. You taking part in this meeting is completely voluntary. I will try to make sure that the information I collect from you is kept private and used only for the research study I am discussing. If you do not agree to continue the meeting at any time, it will not affect your care at Johns Hopkins. Note: Caregivers will be able to assist the adolescent in answering screener questions.*

Verbal consent YES NO Guardian's Name: _____

Verbal assent YES NO Child's Name: _____

Interviewer's Name

Date

Time

Appendix I: (Continued)

- Administer screener questionnaire
- The co-investigator (Alana Lopez) will check to make sure responses are correct/accurate. *Thank you for answering these questions. I will read your answers back to you to make sure they are correct.*
- Scenarios that may follow:
 - 1) Does not meet criteria: *Based on your answers, you will not be able to participate in the study because (co-investigator (Alana Lopez) will provide a specific reason based on the responses given). However, thank you for your time. It is greatly appreciated.*
 - 2) Meets criteria: *Based on your answers, you are able to participate in the study. Are you still interested in participating in the study?*
 - If YES: *Great. The information I have just collected from you will be stored in a database. If you agree to being included in the database, you can request at anytime that your name and information be removed. The database will be located on a computer that is password protected. Can I include you in the database?*
 - If NO: *Thank you for your time. It is greatly appreciated. All the information you provided during this meeting will be destroyed as you will not be participating in this study. Please feel free to contact us at (813)451-9425 if you choose to reconsider.*

THE FOLLOWING INFORMATION WILL BE GIVEN TO THOSE INDIVIDUALS WHO ARE ELIGIBLE TO PARTICIPATE AND ARE INTERESTED IN BEING PART OF THE STUDY.

- The co-investigator will ask them if they would like: (a) to schedule a day, time, and location for the interview now via phone; (b) additional time to make a decision and have the co-investigator contact them within a week via phone; or (c) to decline participation.
- Adolescents and their caregivers will be given ample time to ask questions, voice concerns, and think about whether they would like to participate in the study.
- *Would you like to A, B, or C?*
 - If A: *What days/times are best for you? Where would you like to do the interview? Confirm day, time, and location.*
 - At this time, potential participants will informed that they will be mailed/faxed/emailed an informational packet. *We will mail/fax/email*

Appendix I: (Continued)

you an informational packet that includes: (a) an introductory letter that briefly describes the purpose of the study and lists all documents in the informational packet; (b) consent and assent forms approved by the Johns Hopkins Medicine IRB for participant review; and (c) a quick guide for the interview and follow-up meeting.

- *Please feel free to call us at (813) 451-9425 if you have any questions/concerns or need to reschedule the interview. If you need to reschedule, please contact us at least 2 days before the scheduled interview. Thank you.*
 - *We will call you one week before the interview to review the informational packet and provide a reminder about the day, time, and location. Thank you for your time and participation in this study.*
 - *Note: For those potential participants who request a face to face meeting to further discuss the study/informational packet, a meeting will be scheduled. If you would like we can schedule a face to face (in-person) meeting to talk more about the study.*
- *If **B**: We will call you back in one week to see if you would like to schedule an interview. Please feel free to contact us at (813) 451-9425 if you have any questions or concerns in the meantime. Thank you for your time and interest in this study.*
 - *If **C**: Thank you for your time. It is greatly appreciated. All the information you provided during this meeting will be destroyed as you will not be participating in this study. Please feel free to contact us at (813)451-9425 or if you choose to reconsider.*

Telephone Contact for Participant Recruitment (for those who requested option B)

- *Hello, this is Alana Lopez calling from Johns Hopkins. I am calling to see if you have more questions about the research study we talked about last week. (Provide a brief summary of study if needed) and to see if you would like to schedule an interview.*
- *Would you like to schedule an interview?*
 - *If **YES**: What days/times are best for you? Where would you like to do the interview? Confirm day, time, and location.*
 - *At this time, potential participants will informed that they will be mailed/faxed/mailed an informational packet. We will mail/fax/email you an informational packet that includes: (a) an introductory letter that briefly describes the purpose of the study and lists all documents in the informational packet; (b) consent and assent forms approved by*

Appendix I: (Continued)

the Johns Hopkins Medicine IRB for participant review; and (c) a quick guide for the interview and follow-up meeting.

- *Please feel free to call us at (813) 451-9425 if you have any questions/concerns or need to reschedule the interview. If you need to reschedule, please contact us at least 2 days before the scheduled interview. Thank you.*
 - *We will call you one week before the interview to review the informational packet and provide a reminder about the day, time, and location. Thank you for your time and participation in this study.*
 - *Note: For those potential participants who request a face to face meeting to further discuss the study/informational packet, a meeting will be scheduled. If you would like we can schedule a face to face (in-person) meeting to talk more about the study.*
- *If **NO**: Thank you for your time. It is greatly appreciated. All the information you provided at the meeting will be destroyed as you will not be participating in this study. Please feel free to contact us at (813)451-9425 if you choose to reconsider.*

Telephone Contact a Week Prior to Interview

- *Hello, this is Alana Lopez calling from Johns Hopkins. I am calling to review the informational packet and provide a reminder about the day, time, and location.*
- *Information packet:*
 - *You and your parents will read and sign forms that say you understand the study and would like to participate before the interview starts. These are called assent and consent forms.*
 - *You can bring anything else like pictures, drawings, paintings, videos, music, journals, or anything else you think may help me understand your experience as a cancer survivor. You can bring things you have already made or you can make something to bring to the interview. It is your choice.*
 - *If you choose to bring something, I can collect it at the end of the interview so I can copy/scan it. I will return the originals to you at the follow-up meeting.*
 - *If you are uncomfortable leaving your original things with me, you can copy/scan them yourself and bring them to the interview.*
 - *You will be asked to fill out a questionnaire after the follow-up meeting. Your parents can help you with this if you want.*
 - *You will have a chance to ask any questions you want at the end of the interview.*

Appendix I: (Continued)

- *Please feel free to call us at (813) 451-9425 if you have any questions/concerns or need to reschedule the interview. If you need to reschedule, please contact us at least 2 days before the scheduled interview. Thank you.*
- *Do you have any questions?*
- *Thank you for your time.*
- *Please note: Pilot study participants requested an email reminder. If this is requested, an email will be sent with only the participant's first name.*

Appendix J: Johns Hopkins Hospital Introductory Letter

Dear _____,

This packet has been given to you because you said you are interested in participating in this study. The purpose of this study is to learn more about your experience when you finished treatment and had to go back to your everyday life. We also would like to learn about what it was like going to school and what type of experiences you had with your teachers and other students your age. You will find the following materials in this packet:

Assent Form

- The assent form is for you to look over. This form lets you know about the study and why you are being asked to take part in the study. This form will be explained in detail on the day of the interview and you will sign it at that time (if you choose to participate in the research study).

Consent Form

- The consent form is for your parents to look over. This form lets your parents know about the study and why you are being asked to take part in the study. This form will be explained in detail to your parents on the day of the interview and they will sign it at that time (if they are okay with you participating in the research study).

Quick Guide for the Interview and Follow-Up Meeting

- This sheet includes a list of important information to remember for the interview and the follow-up meeting.

Please feel free to contact us if you have any questions or concerns at (813) 451-9425. Thank you for taking the time to review this packet.

Sincerely,

Keith Slifer, Ph.D.

Kathy Ruble, Ph.D.

Alana Lopez, M.A.

Appendix K: Johns Hopkins Hospital Consent Form

Site of Research:

Johns Hopkins Medical Institutions

RESEARCH PARTICIPANT INFORMED CONSENT AND PRIVACY
AUTHORIZATION FORM

Protocol Title: Transition Experiences of Adolescent Survivors of
Childhood Cancer: A Qualitative Investigation

Application No.: NA_00024030

Principal Investigator: Keith Slifer, Ph.D.

1. What you should know about this study:

- Your child is being asked to join a research study.
- This consent and authorization form explains the research study and your child's part in the study.
- Please read it carefully and take as much time as you need.
- Please ask questions at any time about anything you do not understand.
- Your child is a volunteer. If your child joins the study, your child can change his/her mind later. Your child can decide not to take part or he/she can quit at any time. There will be no penalty or loss of benefits if your child decides to quit the study.
- During the study, we will tell you and your child if we learn any new information that might affect whether your child wishes to continue to be in the study.
- Ask your study doctor or the study team to explain any words or information in this informed consent and authorization form that you do not understand.

2. Why is this research being done?

- This research is being done to learn more about your child's experience when he/she finished treatment and had to go back to his/her everyday life. We also would like to learn about what it was like for your child going back to school and what type of experiences he/she had with teachers and other students his/her age.
- This study is designed to explore these experiences in-depth, your child's perceptions of the impact of these experiences on their lives, challenges associated with these experiences, and beliefs about what supports/services would have been beneficial during these experiences.

Appendix K: (Continued)

Who is eligible to participate in this study?

People who are cancer survivors, between the ages of 12 and 17, and patients of the Pediatric Oncology Outpatient Clinic or Long-Term Childhood Cancer Survivors Program (CCSP) at Johns Hopkins Hospital may join the research study.

How many people will be in this study?

Approximately 20 people are expected to take part in this study.

3. What will happen if your child joins this study?

Study Requirements

If you and your child agree to be in this study, we will ask your child to do the following things:

- Individual interview:
 - The interview will take about 30 to 40 minutes and will be audiotaped.
 - We will ask your child questions about his/her experience during the first few months when he/she was no longer receiving treatment and what it was like for your child going back to school. Your child also can bring any documents (like journals, letters), or audiovisual material (like pictures, drawings, other artwork) if he/she believes it will help us better understand his/her experiences.
 - At the end of the interview session, the interviewer will clarify and summarize (not interpret) information shared and may ask follow-up questions to clarify your child's responses.
 - After the interview is done, your child will be asked to complete a questionnaire. The questionnaire will take about 1 to 2 minutes to complete. You may help your child complete the questionnaire. After your child finishes the questionnaire, you and your child will be able to ask questions about the interview or research study.
 - Audiotapes will be retained at a minimum until your child reaches the age of 23. After your child turns 23 years of age, his/her audiotape(s) will be destroyed.
 - Follow-up meeting:
 - The follow-up meeting will take about 20 to 30 minutes.
 - You and your child will receive a phone call to schedule a follow-up meeting within one month from the date your child was interviewed.
 - You and your child will be mailed a copy of the results of their interview so your child can review this information before the follow-up meeting. You may help your child review this information if necessary.

Appendix K: (Continued)

- At the follow-up meeting, your child will have a chance to share his/her feelings and thoughts about the results.
- After follow-up meeting:
 - If more information is needed or if your child would like more time to discuss his/her experiences, an additional follow-up interview or a phone call may be scheduled.
- The total time length of time for participation in the study will be about 80 minutes.
 - Interview with demographic questionnaire = maximum of 50 minutes
 - Follow-up meeting = maximum of 30 minutes
- Interviews and follow-up meetings may be done at the hospital, at your home, or another location of you and your child's choice. Please feel free to pick a convenient location where you and your child feel most comfortable. Interviews and follow-up meetings over the phone are also permitted. Face-to-face interviews/meetings (in person) are preferred over phone interviews/meetings.
- It is preferable that you are not present in the room or area during the audiotaped portion of the interview session in order to allow your child maximum freedom and independence to answer questions. However, if your child expresses that he/she would feel more comfortable with you there, then you may sit in on the interview but will not be allowed to participate in the session (example: answer questions, elaborate on your child's responses).

How long will your child be in the study?

Your child will be in this study for approximately 2 to 3 months.

4. What are the risks or discomforts of the study?

- We expect that there will be little to no risk involved in this study. However, there is a chance that some questions may bring up difficult feelings or memories for your child. There may be other discomforts that are not yet known as well. If your child says that he/she is uncomfortable or upset or if we observe that your child is becoming distressed, the interview or follow-up meeting will be stopped immediately. You and your child will be able to decide whether if you would like to keep going or not. If you and your child choose to stop, then time will be taken to discuss the interview/follow-up session and ask questions. We also will provide you and your child with psychological services referral information if you would like.
- Your child may get tired or bored when he/she is answering questions or completing the questionnaire. Your child does not have to answer any question he/she does not want to answer.
- Your child may miss school and/or work if he/she participates in the study. However, you and your child can schedule the interview and follow-up meeting at a time that works best for him/her so no school or work is missed.

Appendix K: (Continued)

- Things that are said during the interview and follow-up meeting will be kept confidential (private, secret) to the maximum extent possible. However, there are a few times that we must tell appropriate authorities to keep someone safe. These include: (a) if someone says that they are going to hurt themselves; (b) if someone says that they are going to hurt someone else; (c) if someone says they have been hurt by someone.
- There is the risk for the loss of confidentiality of sensitive information. However, steps will be taken to prevent this loss. All responses will be protected using a code number and stored in a locked file cabinet and/or password protected computer. Your child also may choose a fake name to use during the interview and follow-up meeting to maintain confidentiality. If your child does not choose a fake name, one will be given to him/her when writing up the results of the study. Please see the “How will your child’s privacy be protected?” section below for more specific information on how your child’s sensitive information will be protected.

5. Are there benefits to being in the study?

- There is no direct benefit to your child from being in this study.
- If your child takes part in this study, he/she may help others in the future. For example, information from this study may help provide more information on adolescent survivorship care and possibly be used to inform and improve survivorship care and practices in the community.

6. What are the options if you or your child does not want to be in the study?

- An alternative is to not take part in the study.
- You and your child do not have to join this study. If you and your child do not join, care at Johns Hopkins will not be affected.

7. Will it cost you or your child anything to be in this study?

No.

8. Will your child be paid if he/she joins this study?

- Your child will get a \$10 Target or Walmart gift card for being part of the interview and \$10 Target or Walmart gift card for being part of the follow-up meeting. Your child will get the first gift card at the end of the interview and the second one at the end of the follow-up meeting.
- If your child leaves the study after the interview session, he/she will still receive a \$10 Target or Walmart gift card because he/she helped out with the study.

9. Can your child leave the study early?

- You and your child can agree to be in the study now and change your mind later.

Appendix K: (Continued)

- If you or your child wishes to stop, please tell us right away.
- If you or your child decides to leave this study, care at Johns Hopkins will not be affected.
- If you or your child leaves the study early, Johns Hopkins may use or give out your child's health information that it already has if the information is needed for this study.

10. Why might we take your child out of the study early?

- Your child may be taken out of the study if:
 - Staying in the study would be harmful.
 - The study is cancelled.
 - There may be other reasons to take your child out of the study that we do not know at this time.

11. How will your child's privacy be protected?

- Johns Hopkins has rules to protect information about your child. Federal and state laws also protect your child's privacy. This part of the consent and authorization form tells you what information about your child may be collected in this study and who might see or use it.
- Generally, only people on the research team will know that your child is in the research study and will see his/her information. However, there are a few exceptions that are listed later in this section of the consent and authorization form.
- The people working on the study will collect information about your child. This includes things learned from the procedures described in this consent and authorization form. They may collect other information including your child's name, address, date of birth, and other details.
- The research team will need to see your child's information. Sometimes other people at Johns Hopkins may see or give out your child's information. These include people who review the research studies, their staff, lawyers, or other Johns Hopkins staff.
- People outside of Johns Hopkins may need to see your child's information for this study. Examples include government groups (such as the Food and Drug Administration), safety monitors, other hospitals in the study, and companies that sponsor the study.
- We cannot do this study without your permission to use and give out your child's information. You do not have to give us this permission. If you do not, then your child may not join this study.
- We will use and disclose your child's information only as described in this form and in our Notice of Privacy Practices; however, people outside Hopkins who receive your child's information may not be covered by this promise. We try to make sure that everyone who needs to see your child's information keeps it confidential – but we cannot guarantee this.

Appendix K: (Continued)

- Specific ways that we will try to protect your child's privacy in this study include:
 - Your child's responses will be protected using a code number.
 - A code number will be given to your child as soon as the assent and consent/authorization forms are signed.
 - All of the following will have a code number and be stored in a locked file cabinet: (a) questionnaire, (b) notes, (c) audiotapes, (d) interview and follow-up transcripts, (e) documents, (f) audiovisual material; and (g) any information collected before consent/authorization and assent forms are signed (example: contact information).
 - Notes, transcribed interviews, documents, and audiovisual material also will be stored in password protected files on one research team member's computer.
 - These documents will be saved on a CD as a backup. The CD also will be in the locked file cabinet.
 - Also, your child may choose to use a fake name during the interview and follow-up meeting. If your child does not choose a fake name, one will be given to your child when writing up the results of the study. All records from the study will be destroyed in seven years.
- The use and disclosure of your child's information has no time limit. You can cancel your permission to use and disclose your child's information at any time by calling the Johns Hopkins Privacy Officer at 410-735-6509 or by sending a letter to:

Johns Hopkins Privacy Officer
5801 Smith Avenue
McAuley Hall, Suite 310
Baltimore, MD 21209
Fax: 410 735-6521
- Please be sure to include the name of the principal investigator, the study number, and your contact information.
- If you do cancel your permission to use and disclose your child's information, your child's part in this study will end and no further information about your child will be collected. Your cancellation would not affect information already collected in this study.

12. What other things should you and your child know about this research study?

a. What is the Institutional Review Board (IRB) and how does it protect you?

The Johns Hopkins Medicine IRB is made up of:

- Doctors
- Nurses
- Ethicists

Appendix K: (Continued)

- Non-scientists
- People from the local community

The IRB reviews human research studies. It protects the rights and welfare of the people taking part in those studies. You may contact the IRB if you have questions about your or your child's rights as a participant or if you think you or your child have not been treated fairly. The IRB office number is 410-955-3008. You may also call this number for other questions, concerns, or complaints about the research.

b. What do you do if you have questions about the study?

Call the principal investigator (Dr. Keith Slifer) at 443-923-2900 or team member (Alana Lopez) at 813-451-9425. If you cannot reach the principal investigator or team member and wish to talk to someone else, call the IRB office at 410-955-3008.

c. What should you do if your child is injured or ill as a result of being in this study?

Call Dr. Keith Slifer at 443-923-2900 if you think you are injured or ill because of this study.

d. What happens to data that are collected in the study?

The data collected from your child during this study are important to both this study and to future research.

If you join this study:

- You will not own the data given by your child to the investigators for this research.
- Johns Hopkins may study data provided by your child.
- If data are in a form that identifies your child, Johns Hopkins may use them for future research only with your consent and authorization or IRB approval.
- You will not own any product or idea created by the researchers working on this study.
- You will not receive any financial benefit from the creation, use, or sale of such a product or idea.

The results of this study may be published (put in a journal for others to read). However, your child's responses will be combined with other adolescent cancer survivors' responses in the publication. The published results will not include your child's name or any other information that would in any way identify you.

Appendix K: (Continued)

e. What are the Organizations that are part of Johns Hopkins?

Johns Hopkins includes the following:

- The Johns Hopkins University
- The Johns Hopkins Hospital
- Johns Hopkins Bayview Medical Center
- Howard County General Hospital
- Johns Hopkins Community Physicians

If The Johns Hopkins University School of Medicine IRB reviews a Kennedy Krieger Institute (KKI) study, “Johns Hopkins” also includes KKI.

13. Assent Statement

This research study has been explained to my child in my presence in language my child can understand. He/she has been encouraged to ask questions about the study now and at any time in the future.

14. What does your signature on this consent and authorization form mean?

Your signature on this form means that:

- You understand the information given to you in this form.
- You accept the provisions in the form.
- You agree to have your child join the study.
- You will not give up any legal rights by signing this consent and authorization form

WE WILL GIVE YOU A COPY OF THIS SIGNED AND DATED CONSENT FORM

Signature of Parent/Guardian	Date
Signature of Child Participant (optional unless IRB required)	Date
Signature of Person Obtaining Consent and Privacy Authorization	Date

NOTE: A COPY OF THE SIGNED, DATED CONSENT AND AUTHORIZATION FORM MUST BE KEPT BY THE PRINCIPAL INVESTIGATOR; A COPY MUST BE GIVEN TO THE PARTICIPANT; AND, IF APPROPRIATE A COPY OF THE CONSENT AND AUTHORIZATION FORM MUST BE PLACED IN THE PARTICIPANT ‘S MEDICAL RECORD.

Appendix L: Johns Hopkins Assent Form

Protocol Title: Transition Experiences of Adolescent Survivors of
Childhood Cancer: A Qualitative Investigation

Application No.: NA_00024030 NA

Principal Investigator: Keith Slifer, Ph.D.

Date: January 11, 2010

- ✓ We want to tell you about a research study we are doing. A research study is a way to learn information about something. We would like to find out more about your experience when you finished treatment and had to go back to your everyday life. We also would like to learn about what it was like going back to school and what type of experiences you had with your teachers and other students your age.
- ✓ You are being asked to join the study because you are a cancer survivor who is between the ages of 12 and 17.
- ✓ If you agree to join this study, you will be asked to do the following:
 - Individual interview: The interview will take about 30 to 40 minutes and will be audiotaped. We will ask you questions about your experience during the first few months when you were no longer receiving treatment and what it was like going back to school. You also can bring any documents (like journals, letters), or audiovisual material (like pictures, drawings, other artwork) if you believe it will help us better understanding your experiences. After the interview is done, you will be asked to complete a questionnaire that includes some questions about yourself. The questionnaire will take about 1 to 2 minutes to complete. After you finish the questionnaire, you will be given a chance to ask questions about the interview or research study. The tape that your interview is on will be kept until you turn 23 years old. After you turn 23 years old, your tape will be destroyed.
 - Follow-up meeting: The follow-up meeting will take about 20 to 30 minutes. You will receive a phone call to schedule a follow-up meeting within one month from the date you were interviewed. You will be mailed a copy of the results of your interview so you can review this information before the follow-up meeting. At the follow-up meeting, you will have a chance to share your feelings and thoughts about the results. You can do the follow-up meeting either in person or over the phone.

Appendix L: (Continued)

- After follow-up meeting: If more information is needed or if you would like more time to discuss your experiences, an additional follow-up interview or a phone call may be scheduled.
- ✓ Things that are said during the interview and follow-up meeting will be kept confidential (private, secret). However, there are a few times that I must tell others to keep someone safe. These include: (a) if someone says that they are going to hurt themselves; (b) if someone says that they are going to hurt someone else; (c) if someone says they have been hurt by someone.
- ✓ You will get a \$10 Target or Walmart gift card for being part of the interview and \$10 Target or Walmart gift card for being part of the follow-up meeting. You will get the first gift card at the end of the interview session and the second one after the follow-up meeting. If you decide to leave the study after the interview, you will still get a \$10 gift card because you helped out with the study.
- ✓ Possible risks: Although we expect that there will be little to no risk involved in this study, there is a chance that some questions may bring up difficult feelings or memories. If you say that you are uncomfortable or upset, we will stop the interview or follow-up meeting. You will be able to decide whether you would like to keep going or not. You also may miss some school and/or work if you are a part of the study. However, you can schedule the interview and follow-up meeting at a time that works best for you so you do not miss any school or work.
- ✓ Possible benefits: We do not know if you will be helped by being in this study. We may learn something that will help other adolescent cancer survivors some day.
- ✓ You do not have to join this study. It is up to you. You can say okay now, and you can change your mind later. All you have to do is tell us. No one will be mad at you if you change your mind.
- ✓ Before you say yes to being in this study, we will answer any questions you have.
- ✓ If you want to be in this study, please sign your name. You will get a copy of this form to keep for yourself.
- ✓ If you have any questions, please contact us at any time at (813) 451-9425.

I give my permission to take part in this study. I understand that this is research. I have received a copy of this assent form.

Sign your name here

Print your name here

Date

Appendix M: Johns Hopkins Hospital Quick Guide for the Interview and Follow-up Meeting

This sheet includes a list of important information to remember for the interview and follow-up meeting.

THE INTERVIEW (30-40 minutes)

Your interview is scheduled for:

- Date: _____
- Time: _____
- Place: _____

*We will call you one week before the interview to briefly review the informational packet and provide a friendly reminder about your interview date, time, and place.

What are some important things I need to remember for **the interview?**

- You will be asked to review and sign the assent form.
- One of your parents must be at the interview to review and sign the consent form.
- You can bring anything else like pictures, drawings, paintings, videos, music, journals, or anything else you think may help us understand your experience as a cancer survivor. You can bring things you have already made or you can make something to bring to the interview. It is your choice.
- If you choose to bring something, we will collect it at the end of the interview so we can copy/scan them. We will return the originals to you at the follow-up meeting. If you choose to do the follow-up meeting over the phone, then we will mail the originals to you within a few days after the interview.
- If you are uncomfortable leaving your original things with us, you can copy/scan them yourself and bring them to the interview.
- You will be asked to fill out a questionnaire after the follow-up meeting. Your parents can help you with this if you want.
- You will have a chance to ask any questions you want at the end of the interview.

Appendix M: (Continued)

- We will call you within one month to schedule a day/time for the follow-up meeting/phone call.
- We will write down what you talked about during the interview and send it to you in the mail or by email. It will say “My Interview”. We would like for you to read it and bring it to the follow-up meeting or have it with you during the phone call. Your parents can help you read it if you want.

THE FOLLOW-UP MEETING (20-30 minutes)

What are some important things I need to remember for the **follow-up meeting**?

- You can choose to have a follow-up meeting or phone call.
- Bring the paper that says “My Interview” to the follow-up meeting or have it with you during the phone call.
- We will talk about the interview so we can make sure that we understood what you told us. If you feel comfortable, we would like you to tell us about what you thought about the interview.
- If you would like to talk more about your experiences or if we need more information another short interview by phone or in-person may be scheduled.

Title of Study

Transition Experiences of Adolescent Survivors of Childhood Cancer: A Qualitative Investigation

Purpose of the Study

The purpose of this study is to conduct a qualitative investigation of two significant transitions experienced by adolescent survivors of childhood cancer and their perceptions of how these transitions impacted their lives. The two transitions that will be explored include the transition from off-treatment to post-treatment and school reintegration. Specifically, the study will explore adolescent cancer survivors' experiences of going through these transition processes, their perceptions of the impact of these transitions on their lives, challenges associated with these transitions, and their beliefs about what supports/services would be beneficial during these transitions. Various types of data will be collected to explore these transitions including individual interviews, direct observations during interviews, documents (journal entries, letters, short stories), and audiovisual material (artwork, photographs, videos).

Significance of the Study

The current study will contribute to the literature examining the transition from off-treatment to post-treatment and school reintegration from the perspectives of adolescent cancer survivors. The qualitative research approach used in this study will render a rich, in-depth description and understanding of these transitions which can strengthen and add to the small body of existing research. The findings generated from this study can provide health care professionals and school personnel with a better understanding of adolescent cancer survivors' transition experiences, the impact of these transitions on their lives, perceived challenges, and supports and/or services that would make the transition process smoother. Furthermore, knowledge of this information can help identify potential targets for intervention and improve service delivery in both health care and school settings.

Inclusion & Exclusion Criteria

Inclusion criteria:

- Chronological age between 12 and 17 years
- Diagnosis of cancer (other than brain tumor) received during childhood
- Diagnosis was received at age 5 years or older (preferably diagnosis received at age 11 or older)
- Has been off treatment for a minimum of six months and a maximum of five years
- Cancer is currently in remission

Appendix N: (Continued)

- No history of a relapse
- Currently attending school in the community (e.g., public, private, charter school)
- Willing and able to provide assent
- Caregiver(s) are willing to provide consent for participation

Exclusion criteria:

- Lack of fluency in English
- In foster care
- Intellectual disability
- Diagnosis of a brain tumor
- Below the age of five years at initial diagnosis
- Off treatment for less than six months or more than five years
- Currently home schooled or taking Virtual classes on the internet

Time Commitment for Participants

- Initial telephone call (approximately 10 to 15 minutes)
 - Potential follow-up telephone contact if adolescent and their caregiver(s) request more time to think about the study (5 to 10 minutes)
- Interview session (approximately 30 to 40 minutes)
 - Location of interview will be determined based on participant preference
- Follow-up meeting (approximately 20 to 30 minutes)
 - Location of follow-up will be determined based on participant preference
- Additional follow-up meeting if requested or needed (approximately 20-30 minutes)
 - Location of additional follow-up meeting will be determined based on participant preference

Appendix O: The Gathering Place Letter of Support

March 9, 2010

Division of Research Integrity & Compliance
University of South Florida
12901 Bruce B. Downs Blvd, MDC35
Tampa, FL 33612-4799

To Whom It May Concern:

I am writing in support of the dissertation project, “Transition Experiences of Adolescent Survivors of Childhood Cancer: A Qualitative Investigation”. I am a member of the clinical program staff at the Gathering Place, which is a non-profit cancer organization located near Cleveland, Ohio (<http://www.touchedbycancer.org/>). Specifically, I am the group leader for various children and teen programs. I have spoken with Ms. Lopez at length about her research and fully understand the purpose, inclusion/exclusion criteria, risks/benefits, and time commitment for participants. Based on this information, I believe that the Gathering Place is an appropriate site for Ms. Lopez to recruit participants for her study. There are adequate and appropriate resources available at the Gathering Place to conduct confidential interviews and follow-up meetings.

Furthermore, there are supports available for those participants who may experience an adverse or unanticipated event while participating in this study at the Gathering Place. The Gathering Place has a number of resources available for those participants who may experience distress during an interview or follow-up meeting. Additionally, Ms. Lopez also is prepared to provide a list of resources and/or emergency support to participants if necessary.

If you have any questions about our organization or pertaining to our support of this research project, please feel free to contact at me at (216) 595-9546 or kmaxwell@touchedbycancer.org.

Sincerely,

Kathy Maxwell, LISW-S
The Gathering Place
Clinical Program Staff Member

Appendix P: The Gathering Place Telephone Screening for Participant Recruitment

- Greeting. *Hello Mr. /Mrs. /Ms. _____.*
- *I am calling to briefly tell you about the research study and see if you and CHILD'S NAME may be interested in learning more about the study.*
- *The research study will include people who are cancer survivors between the ages of 12 and 17.*
- *The purpose of the research study is to learn more about cancer survivors' experiences when they finished treatment and had to go back to their everyday life and what it was like going to school.*
- *The study will require a telephone call (10-15 minutes), interview (30-40 minutes), and a follow-up meeting (20-30 minutes). The interview and follow-up meeting can be conducted at a location that is comfortable and convenient (example: home, hospital).*
- *Participants will be given a \$10 Target or Walmart gift card for completing the interview and another \$10 Target or Walmart gift card for completing the follow-up meeting....for a total of \$20.*
- *The research study presents minimal risk.*
- *There is no direct benefit from being in this study. However, taking part in the research study may help others in the future. For example, information from this study may help provide more information on adolescent survivorship care and possibly be used to inform and improve survivorship care and practices in the community.*
- Would you and CHILD'S NAME be interested in learning more about the study?
 - If YES: *I need your permission to provide the researcher, Alana Lopez, with your phone number so that she can contact you directly (note: parent and child must willingly provide a phone number).*
 - *Thank you for your contact information. Is there a time/day that would be best for your family to receive this phone call?*
 - *Alana Lopez will be calling you within one week (or at the preferred time/day stated by family) to talk more about the study.*
 - If NO: *Thank you for your time. It is greatly appreciated. Please feel free to contact Alana Lopez at (813)451-9425 if you choose to reconsider.*

Appendix P: (Continued)

Verbal Consent/Assent to Provide Contact Information

Date: _____

Time: _____

Verbal consent YES NO

Guardian's Name:

Verbal assent YES NO

Child's Name:

Phone Number: _____

Initials of Interviewer: _____

Follow-up Phone Call Information (if applicable)

Best day/time to reach family:

Appendix Q: The Gathering Place Introductory Letter

Dear _____,

This packet has been given to you because you said you are interested in participating in this study. The purpose of this study is to learn more about your experience when you finished treatment and had to go back to your everyday life. We also would like to learn about what it was like going to school and what type of experiences you had with your teachers and other students your age. You will find the following materials in this packet:

Assent Form

- The assent form is for you to look over. This form lets you know about the study and why you are being asked to take part in the study. This form will be explained in detail on the day of the interview and you will sign it at that time (if you choose to participate in the research study).

Consent Form

- The consent form is for your parents to look over. This form lets your parents know about the study and why you are being asked to take part in the study. This form will be explained in detail to your parents on the day of the interview and they will sign it at that time (if they are okay with you participating in the research study).

Quick Guide for the Interview and Follow-up Meeting

- This sheet includes a list of important information to remember for the interview and follow-up meeting.

Please feel free to contact us if you have any questions or concerns at (813) 451-9425 or (216) 595-9546. Thank you for taking the time to review this packet.

Sincerely,

Alana Lopez, M.A.

Parental Permission to Participate in Research

Information for parents to consider before allowing their child to take part in this research study

IRB Study # 107896

- The following information is being presented to help you and your child decide whether or not your child wants to be a part of a research study. Please read carefully. Anything you do not understand, ask the investigator.
- We are asking you to allow your child to take part in a research study that is called:
“Transition Experiences of Adolescent Survivors of Childhood Cancer: A Qualitative Investigation”
- The person who is in charge of this research study is Alana Lopez, MA. This person is called the Principal Investigator. However, other research staff may be involved and can act on behalf of the person in charge.
- The research will be done at The Gathering Place and Johns Hopkins Hospital.

1. Should your child take part in this study?

- This form tells you about this research study. You can decide if you want your child to take part in it. This form explains:
 - Why this study is being done.
 - What will happen during this study and what your child will need to do.
 - Whether there is any chance your child might experience potential benefits from being in the study.
 - The risks of having problems because your child is in this study.
- Before you decide read this form:
 - Have a friend or family member read it.
 - Talk about this study with the person in charge of the study or the person explaining the study. You can have someone with you when you talk about the study.
 - Talk it over with someone you trust.
 - Find out what the study is about.
- You may have questions this form does not answer. You do not have to guess at things you don't understand. If you have questions, ask the person in charge of the study or study staff as you go along. Ask them to explain things in a way you can understand.
- Take your time to think about it. It is up to you. If you choose to let your child be in the study, then you should sign this form. If you do not want your child to take part in this study, you should not sign the form.

Appendix R: (Continued)

2. What you should know about this study:

- Your child is being asked to join a research study.
- This consent and authorization form explains the research study and your child's part in the study.
- Please read it carefully and take as much time as you need.
- Please ask questions at any time about anything you do not understand.
- Your child is a volunteer. If your child joins the study, your child can change his/her mind later. Your child can decide not to take part or he/she can quit at any time. There will be no penalty or loss of benefits if your child decides to quit the study.
- During the study, we will tell you and your child if we learn any new information that might affect whether your child wishes to continue to be in the study.
- Ask the Principal Investigator to explain any words or information in this informed consent and authorization form that you do not understand.

3. Why is this research being done?

- This research is being done to learn more about your child's experience when he/she finished treatment and had to go back to his/her everyday life. We also would like to learn about what it was like for your child going back to school and what type of experiences he/she had with teachers and other students his/her age.
- This study is designed to explore these experiences in-depth, your child's perceptions of the impact of these experiences on their lives, challenges associated with these experiences, and beliefs about what supports/services would have been beneficial during these experiences.

Who is eligible to participate in this study?

People who are: (a) cancer survivors between the ages of 12 and 17 (except survivors of brain tumors); (b) diagnosed with cancer at age 5 or older; (c) off treatment for at least 6 months and no more than 5 years; (d) cancer is in remission; and (e) no history of relapse may join the research study.

How many people will be in this study?

- Approximately 20 people are expected to take part in this study.

4. What will happen if your child joins this study?

Study Requirements

- If you and your child agree to be in this study, we will ask your child to do the following things:
- Individual interview:
 - The interview will take about 30 to 40 minutes and will be audiotaped.
 - We will ask your child questions about his/her experience during the first few months when he/she was no longer receiving treatment and

Appendix R: (Continued)

- what it was like for your child going back to school. Your child also can bring any documents (like journals, letters), or audiovisual material (like pictures, drawings, other artwork) if he/she believes it will help us better understand his/her experiences.
- At the end of the interview session, the interviewer will clarify and summarize (not interpret) information shared and may ask follow-up questions to clarify your child's responses.
 - After the interview is done, your child will be asked to complete a questionnaire. The questionnaire will take about 1 to 2 minutes to complete. You may help your child complete the questionnaire. After your child finishes the questionnaire, you and your child will be able to ask questions about the interview or research study.
 - Follow-up meeting:
 - The follow-up meeting will take about 20 to 30 minutes.
 - You and your child will receive a phone call to schedule a follow-up meeting within one month from the date your child was interviewed.
 - You and your child will be mailed a copy of the results of their interview so your child can review this information before the follow-up meeting. You may help your child review this information if necessary.
 - At the follow-up meeting, your child will have a chance to share his/her feelings and thoughts about the results.
 - After follow-up meeting:
 - If more information is needed or if your child would like more time to discuss his/her experiences, an additional follow-up interview or a phone call may be scheduled.
- The total time length of time for participation in the study will be about 80 minutes.
 - Interview with demographic questionnaire = maximum of 50 minutes
 - Follow-up meeting = maximum of 30 minutes
 - Interviews and follow-up meetings may be done at the hospital, at your home, or another location of you and your child's choice. Please feel free to pick a convenient location where you and your child feel most comfortable. Interviews and follow-up meetings over the phone are also permitted. Face-to-face interviews/meetings (in person) are preferred over phone interviews/meetings.
 - It is preferable that you are not present in the room or area during the audiotaped portion of the interview session in order to allow your child maximum freedom and independence to answer questions. However, if your child expresses that he/she would feel more comfortable with you there, then you may sit in on the interview but will not be allowed to participate in the session (example: answer questions, elaborate on your child's responses).

Appendix R: (Continued)

- All records from the study (for example: audiotapes, questionnaires) will be destroyed in four years.

How long will your child be in the study?

- Your child will be in this study for approximately 2 to 3 months.

5. What are the risks or discomforts of the study?

- We expect that there will be little to no risk involved in this study. However, there is a chance that some questions may bring up difficult feelings or memories for your child. There may be other discomforts that are not yet known as well.
- If your child says that he/she is uncomfortable or upset or if we observe that your child is becoming distressed, the interview or follow-up meeting will be stopped immediately. You and your child will be able to decide whether if you would like to keep going or not. If you and your child choose to stop, then time will be taken to discuss the interview/follow-up session and ask questions. We also will provide you and your child with psychological services referral information if you would like.
- Your child may get tired or bored when he/she is answering questions or completing the questionnaire. Your child does not have to answer any question he/she does not want to answer.
- Your child may miss school and/or work if he/she participates in the study. However, you and your child can schedule the interview and follow-up meeting at a time that works best for him/her so no school or work is missed.
- Things that are said during the interview and follow-up meeting will be kept confidential (private, secret) to the maximum extent possible. However, there are a few times that we must tell appropriate authorities to keep someone safe. These include: (a) if someone says that they are going to hurt themselves; (b) if someone says that they are going to hurt someone else; (c) if someone says they have been hurt by someone.
- There is the risk for the loss of confidentiality of sensitive information. However, steps will be taken to prevent this loss. All responses will be protected using a code number and stored in a locked file cabinet and/or password protected computer. Your child also may choose a fake name to use during the interview and follow-up meeting to maintain confidentiality. If your child does not choose a fake name, one will be given to him/her when writing up the results of the study.

6. Are there benefits to being in the study?

- There is no direct benefit to your child from being in this study.
- If your child takes part in this study, he/she may help others in the future. For example, information from this study may help provide more information on

Appendix R: (Continued)

adolescent survivorship care and possibly be used to inform and improve survivorship care and practices in the community.

7. What are the options if you or your child does not want to be in the study?

- An alternative is to not take part in the study.
- You and your child do not have to join this study. If you and your child do not join, care at The Gathering Place will not be affected.

8. Will it cost you or your child anything to be in this study?

- No.

9. Will your child be paid if he/she joins this study?

- Your child will get a \$10 Target or Walmart gift card for being part of the interview and a \$10 Target or Walmart gift card for being part of the follow-up meeting. Your child will get the first gift card at the end of the interview and the second one at the end of the follow-up meeting.
- If your child leaves the study after the interview session, he/she will still receive a \$10 Target or Walmart gift card because he/she helped out with the study.

10. Can your child leave the study early?

- You and your child can agree to be in the study now and change your mind later.
- If you or your child wishes to stop, please tell us right away.
- If you or your child decides to leave this study, care at The Gathering Place will not be affected.

11. Why might we take your child out of the study early?

- Your child may be taken out of the study if:
 - Staying in the study would be harmful.
 - The study is cancelled.
 - There may be other reasons to take your child out of the study that we do not know at this time.

12. What will we do to keep your child's study records private?

- There are federal laws that say we must keep your child's study records private. This part of the consent and authorization form tells you what information about your child may be collected in this study and who might see or use it.
- Specific ways that we will try to protect your child's privacy in this study include:
 - a. Your child's responses will be protected using a code number.

Appendix R: (Continued)

- b. A code number will be given to your child as soon as the assent and consent/authorization forms are signed.
- c. All of the following will have a code number and be stored in a locked file cabinet: (a) questionnaire, (b) notes, (c) audiotapes, (d) interview and follow-up transcripts, (e) documents, (f) audiovisual material; and (g) any information collected before consent/authorization and assent forms are signed (example: contact information).
- d. Notes, transcribed interviews, documents, and audiovisual material also will be stored in password protected files on one research team member's computer.
- e. These documents will be saved on a CD as a backup. The CD also will be in the locked file cabinet.
- f. Also, your child may choose to use a fake name during the interview and follow-up meeting. If your child does not choose a fake name, one will be given to your child when writing up the results of the study. All records from the study will be destroyed in seven years.
- However, certain people may need to see your child's study records. By law, anyone who looks at your child's records must keep them completely confidential. The only people who will be allowed to see these records are:
 - Certain government and university people who need to know more about the study. For example, individuals who provide oversight on this study may need to look at your child's records. These include the University of South Florida Institutional Review Board (IRB) and the staff that work for the IRB. Individuals who work for USF that provide other kinds of oversight to research studies may also need to look at your child's records.
 - Other individuals who may look at your child's records include: agencies of the federal, state, or local government that regulates this research. This includes the Department of Health and Human Services (DHHS) and the Office for Human Research Protections. They also need to make sure that we are protecting your child's rights and safety.
 - People at The Gathering Place may look at the study records to make sure the study is done in the right way.
- We will use and disclose your child's information only as described in this form and; however, people outside of the University of South Florida who receive your child's information may not be covered by this promise. We try to make sure that everyone who needs to see your child's information keeps it confidential – but we cannot guarantee this.
- We may publish what we learn from this study. If we do, we will not let anyone know your child's name. We will not publish anything else that would let people know who your child is.
- We cannot do this study without your permission to use and give out your child's information. You do not have to give us this permission. If you do not, then your child may not join this study.

Appendix R: (Continued)

13. What happens if you decide not to let your child take part in this study?

- You should only let your child take part in this study if both of you want to. You or child should not feel that there is any pressure to take part in the study to please the study investigator or the research staff.
- If you decide not to let your child take part:
 - Your child will not be in trouble or lose any rights he/she would normally have.
 - You child will still get the same services he/she would normally have.
 - Your child can still get their regular services at The Gathering Place.
- **You can decide after signing this informed consent document that you no longer want your child to take part in this study.** We will keep you informed of any new developments which might affect your willingness to allow your child to continue to participate in the study. However, you can decide you want your child to stop taking part in the study for any reason at any time. If you decide you want your child to stop taking part in the study, tell the study staff as soon as you can.
 - We will tell you how to stop safely. We will tell you if there are any dangers if your child stops suddenly.
 - If you decide to stop, your child can go on getting his/her regular services at The Gathering Place.
- **Even if you want your child to stay in the study, there may be reasons we will need to take him/her out of it. Your child may be taken out of this study if:**
 - We find out it is not safe for your child to stay in the study. For example, your child's health may get worse.
 - Your child is not coming for the study visits when scheduled.

14. You can get the answers to your questions, concerns, or complaints.

- If you have any questions, concerns, or complaints about this study, please call Alana Lopez at 813-451-9425.
- If you have questions about your child's rights, general questions, complaints, or issues as a person taking part in this study, call the Division of Research Integrity and Compliance of the University of South Florida at (813) 974-9343.
- If your child experiences an adverse event or unanticipated problem, please call Alana Lopez at 813-451-9425.

15. Assent Statement

- This research study has been explained to my child in my presence in language my child can understand. He/she has been encouraged to ask questions about the study now and at any time in the future.

Appendix R: (Continued)

Consent for Child to Participate in this Research Study

- It is up to you to decide whether you want your child to take part in this study. If you want your child to take part, please read the statements below and sign the form if the statements are true.

I freely give my consent to let my child take part in this study. I understand that by signing this form I am agreeing to let my child take part in research. I have received a copy of this form to take with me.

Signature of Parent of Child Taking Part in Study

Date

Printed Name of Parent of Child Taking Part in Study

Signature of Parent of Child Taking Part in Study

Date

Printed Name of Parent of Child Taking Part in Study

The signature of only one parent was obtained because:

- The other parent is not reasonable available. Explain: _____
- The other parent is unknown.
- The other parent is legally incompetent.
- The parent who signed has sole legal responsibility for the care and custody of the child.

Signature of Witness

Date

Printed Name of Witness

Statement of Person Obtaining Informed Consent

I have carefully explained to the person taking part in the study what he or she can expect.

Signature of Person Obtaining Informed Consent

Date

Printed Name of Person Obtaining Informed Consent

Assent to Participate in Research

Information for Persons under the Age of 18 Who Are Being Asked To Take Part in Research

IRB Study # 107896

Title of study: Transition Experiences of Adolescent Survivors of Childhood Cancer: A Qualitative Investigation

- We want to tell you about a research study we are doing. A research study is a way to learn information about something. We would like to find out more about your experience when you finished treatment and had to go back to your everyday life. We also would like to learn about what it was like going back to school and what type of experiences you had with your teachers and other students your age.
- You are being asked to join the study because you are a cancer survivor who is between the ages of 12 and 17. If you take part in this study, you will be one of about 20 people in this study.
- The person in charge of this study is Alana Lopez a student at the University of South Florida. She is being guided in this research by Dr. Kathy Bradley-Klug. Other people who you may see while you are on the study include those who work at The Gathering Place.
- If you agree to join this study, you will be asked to do the following:
 - Individual interview: The interview will take about 30 to 40 minutes and will be audiotaped. We will ask you questions about your experience during the first few months when you were no longer receiving treatment and what it was like going back to school. You also can bring any documents (like journals, letters), or audiovisual material (like pictures, drawings, other artwork) if you believe it will help us better understanding your experiences. After the interview is done, you will be asked to complete a questionnaire that includes some questions about yourself. The questionnaire will take about 1 to 2 minutes to complete. After you finish the questionnaire, you will be given a chance to ask questions about the interview or research study.
 - Follow-up meeting: The follow-up meeting will take about 20 to 30 minutes. You will receive a phone call to schedule a follow-up meeting within one month from the date you were interviewed. You will be mailed a copy of the results of your interview so you can review this information before the follow-up meeting. At the follow-up meeting, you will have a chance to share your

Appendix S: (Continued)

feelings and thoughts about the results. You can do the follow-up meeting either in person or over the phone.

- After follow-up meeting: If more information is needed or if you would like more time to discuss your experiences, an additional follow-up interview or a phone call may be scheduled.
 - Things that are said during the interview and follow-up meeting will be kept confidential (private, secret). However, there are a few times that I must tell others to keep someone safe. These include: (a) if someone says that they are going to hurt themselves; (b) if someone says that they are going to hurt someone else; (c) if someone says they have been hurt by someone.
- You will be a part of this study for about 2 to 3 months.
 - No one, not even the people who are doing this study, will know that the information you give comes from you. All information from the study (for example: audiotapes of the interview, questionnaires) will be destroyed in four years.
 - You will get a \$10 Target or Walmart gift card for being part of the interview and a \$10 Target or Walmart gift card for being part of the follow-up meeting. You will get the first gift card at the end of the interview session and the second one after the follow-up meeting. If you decide to leave the study after the interview, you will still get a \$10 gift card because you helped out with the study.
 - Possible risks: To the best of our knowledge, the things you will be doing will not harm you or cause you any additional unpleasant experience. Although we expect that there will be little to no risk involved in this study, there is a chance that some questions may bring up difficult feelings or memories. If you say that you are uncomfortable or upset, we will stop the interview or follow-up meeting. You will be able to decide whether you would like to keep going or not. You also may miss some school and/or work if you are a part of the study. However, you can schedule the interview and follow-up meeting at a time that works best for you so you do not miss any school or work. In addition to the things that we have already talked about, listed above, you may experience something uncomfortable that we do not know about at this time.
 - Possible benefits: We do not know if you will be helped by being in this study. We may learn something that will help other adolescent cancer survivors some day.
 - You do not have to join this study. It is up to you. You can say okay now, and you can change your mind later. All you have to do is tell us. No one will be mad at you if you change your mind. If you do not want to be in the study, nothing else will happen.

Appendix S: (Continued)

- Before you say yes to being in this study, we will answer any questions you have. If you think of other questions later, you can ask them.
- If you have any questions, please contact us at any time at (813) 451-9425.

Assent to Participate

I understand what the person running this study is asking me to do. I have thought about this and agree to take part in this study.

Name of person agreeing to take part in the study

Date

Name of person providing information to subject

Date

Appendix T: The Gathering Place Quick Guide for the Interview and Follow-up Meeting

This sheet includes a list of important information to remember for the interview and follow-up meeting.

THE INTERVIEW (30-40 minutes)

Your interview is scheduled for:

- Date: _____
- Time: _____
- Place: _____

*We will call you one week before the interview to briefly review the informational packet and provide a friendly reminder about your interview date, time, and place.

What are some important things I need to remember for **the interview?**

- You will be asked to review and sign the assent form.
- One of your parents must be at the interview to review and sign the consent form.
- You can bring anything else like pictures, drawings, paintings, videos, music, journals, or anything else you think may help us understand your experience as a cancer survivor. You can bring things you have already made or you can make something to bring to the interview. It is your choice.
- If you choose to bring something, we will collect it at the end of the interview so we can copy/scan them. We will return the originals to you at the follow-up meeting. If you choose to do the follow-up meeting over the phone, then we will mail the originals to you within a few days after the interview.
- If you are uncomfortable leaving your original things with us, you can copy/scan them yourself and bring them to the interview.
- You will be asked to fill out a questionnaire after the follow-up meeting. Your parents can help you with this if you want.

Appendix T: (Continued)

- You will have a chance to ask any questions you want at the end of the interview.
- We will call you within one month to schedule a day/time for the follow-up meeting/phone call.
- We will write down what you talked about during the interview and send it to you in the mail or by email. It will say “My Interview”. We would like for you to read it and bring it to the follow-up meeting or have it with you during the phone call. Your parents can help you read it if you want.

THE FOLLOW-UP MEETING (20-30 minutes)

What are some important things I need to remember for the **follow-up meeting**?

- You can choose to have a follow-up meeting or phone call.
- Bring the paper that says “My Interview” to the follow-up meeting or have it with you during the phone call.
- We will talk about the interview so we can make sure that we understood what you told us. If you feel comfortable, we would like you to tell us about what you thought about the interview.
- If you would like to talk more about your experiences or if we need more information another short interview by phone or in-person may be scheduled.

Appendix U: Case Study Summary Worksheet

Case ID:

Analyst's Synopsis of Case (possibly identifying the case, the sites, the activity, key information sources, and context information):

Situational Constraints:

Uniqueness among Other Cases:

Prominence of Themes in This Case:

Expected Utility of This Case for Developing Themes:

Conceptual Factors:

Findings:

I.

II.

III.

IV.

Possible Excerpts for the Multicase Report (noting case report page number):

Commentary (sometimes noting case report page number):