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Summer 2012

# The adolescent with cancer's school re-entry experience : exploration of predictors and successful outcomes

Chasity Brimeyer  
*University of Iowa*

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THE ADOLESCENT WITH CANCER'S SCHOOL RE-ENTRY EXPERIENCE:  
EXPLORATION OF PREDICTORS AND SUCCESSFUL OUTCOMES

by  
Chasity Brimeyer

An Abstract

Of a thesis submitted in partial fulfillment  
of the requirements for the Doctor of  
Philosophy degree in Psychological and Quantitative Foundations (School Psychology)  
in the Graduate College of  
The University of Iowa

July 2012

Thesis Supervisors: Associate Professor John Northup  
Professor Ann Marie McCarthy

## ABSTRACT

More adolescents are surviving cancer and being treated outside the hospital-setting, allowing them to return to typical activities of development like attending school. Effective preparation for school re-entry is an important aspect of easing the transition back-to-school following a cancer diagnosis. Previous research has used the terms school re-entry, school re-entry preparation, and school reintegration interchangeably. For the purposes of the current study, school re-entry refers to going back-to-school. School re-entry preparation or interventions refers to the preparatory process implemented for the *initial* return to school following a cancer diagnosis. Conversely, school reintegration refers to the ongoing or long-term adjustment of the child or adolescent with cancer to the school environment. Research in school re-entry preparation began in the late 1970s, but much is still not well understood about appropriate school re-entry preparation in terms of application, outcome, or the adolescent's needs. The adolescent with cancer's perspective has been grossly neglected in research. Furthermore, current research lacks an operational definition of "successful school re-entry" and knowledge of specific factors associated with positive school re-entry outcomes. Identifying variables that positively impact the school re-entry process is critical to improving and individualizing school re-entry interventions. The current study used an adaptation of the Disability-Stress Coping Model (DSC; Wallander & Varni, 1998) to both define school re-entry success and identify potential predictors that may impact school re-entry success. In addition, to obtain a more comprehensive picture of re-entry success, adolescents with cancer rated the success of their back-to-school experiences. The current study asked 85 adolescents with cancer (ages 11 - 19 years) to complete a web-based survey asking about their re-entry experiences and daily functioning. Results provided tentative support for a discrepancy between professional and adolescent re-entry needs/goals. Findings suggest that a subset of adolescents with cancer may be at risk for poor school re-

entry/reintegration outcomes, including females, being of lower SES, having certain types of cancer (brain tumors, leukemia), undergoing specific treatments (radiation, chemotherapy), being out of school for longer periods of time, having pre-morbid academic difficulties, and/or having poor social support. Adolescents who demonstrate these risk factors may warrant increased, specialized attention when preparing to return to school. In addition to systemic and within-person factors from the adapted DSC model, findings suggest that developmental characteristics of adolescence must be considered in planning re-entry intervention. Appropriate modifications to school re-entry preparation for adolescents may include utilizing electronic and social media, implementing peer mentors, focusing on reinforcing appropriate social circles, and emphasizing autonomy. More research is needed to understand how to best assist the adolescent with cancer in returning to school.

Abstract Approved:

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Professor Ann Marie McCarthy

Graduate College  
The University of Iowa  
Iowa City, Iowa

CERTIFICATE OF APPROVAL

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PH.D. THESIS

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This is to certify that the Ph.D. thesis of

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has been approved by the Examining Committee  
for the thesis requirement for the Doctor of Philosophy  
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In Memory of Sergio Wogomon,  
who started my journey and solidified my passion  
in pediatric oncology

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## ABSTRACT

More adolescents are surviving cancer and being treated outside the hospital-setting, allowing them to return to typical activities of development like attending school. Effective preparation for school re-entry is an important aspect of easing the transition back-to-school following a cancer diagnosis. Previous research has used the terms school re-entry, school re-entry preparation, and school reintegration interchangeably. For the purposes of the current study, school re-entry refers to going back-to-school. School re-entry preparation or interventions refers to the preparatory process implemented for the *initial* return to school following a cancer diagnosis. Conversely, school reintegration refers to the ongoing or long-term adjustment of the child or adolescent with cancer to the school environment. Research in school re-entry preparation began in the late 1970s, but much is still not well understood about appropriate school re-entry preparation in terms of application, outcome, or the adolescent's needs. The adolescent with cancer's perspective has been grossly neglected in research. Furthermore, current research lacks an operational definition of “successful school re-entry” and knowledge of specific factors associated with positive school re-entry outcomes. Identifying variables that positively impact the school re-entry process is critical to improving and individualizing school re-entry interventions. The current study used an adaption of the Disability-Stress Coping Model (DSC; Wallander & Varni, 1998) to both define school re-entry success and identify potential predictors that may impact school re-entry success. In addition, to obtain a more comprehensive picture of re-entry success, adolescents with cancer rated the success of their back-to-school experiences. The current study asked 85 adolescents with cancer (ages 11 - 19 years) to complete a web-based survey asking about their re-entry experiences and daily functioning. Results provided tentative support for a discrepancy between professional and adolescent re-entry needs/goals. Findings suggest that a subset of adolescents with cancer may be at risk for poor school re-

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## CHAPTER I

### INTRODUCTION

Pediatric cancer is a rare but complicated medical condition that remains the leading cause of disease-related death in children and adolescents. It impacts over 10,000 children under age fifteen each year. Leukemias, or blood cell cancers, and cancers of the brain and central nervous system (e.g., gliomas and medulloblastomas), account for over half of new diagnoses each year (National Cancer Institute [NCI], 2010). While the incidence of childhood cancers has remained relatively stable since the 1970s, the survival rate has dramatically increased. Five-year survival rates vary among types of childhood malignancies, but the overall survival rate has increased from 50% in 1977 to 80% in 2007 (American Childhood Cancer Organization [ACCO], 2007).

While the ultimate goal of eradicating the disease is often accomplished, surviving pediatric cancer is not without cost. Over two-thirds of childhood cancer survivors suffer from chronic health conditions, and one-fourth of survivors endure more severe consequences such as heart defects, secondary cancers, lung damage, infertility, and/or growth impairments (ACCO, 2007). Further, medical treatments can negatively impact the cognitive, academic, and social-emotional development of the surviving child or adolescent (Moore, 2005; Clay, 2004). A need to understand the psychosocial implications of pediatric cancer and treatment coincided with increased survival rates.

Research on the psychosocial consequences of pediatric cancer is contradictory. Many children and adolescents adjust well and do not experience psychosocial stress above and beyond what would be expected from having cancer (e.g., Spirito et al., 1990; Eiser, Hill, & Vance, 2000). However, evidence for adjustment problems, such as increased stress, separation anxiety, depression, PTSD, etc., has been found (Eiser, 1990; Pfefferbaum, 1978). Inattention, memory loss, poor executive functioning, and difficulty with handwriting in pediatric cancer survivors have been noted, (Moore, 2005; Butler &

Mulhern, 2005; Spencer, 2006; Daly & Brown, 2007), in addition to social difficulties (Clay, 2004). Other research suggests increased stress and adjustment difficulties are mostly observed in the initial stages of the disease, with improved coping seen over the course of the illness (Wallander & Varni, 1998). Finally, psychosocial consequences may not always be detrimental; Chesler (2000) described incidences of psychosocial growth in pediatric cancer patients. Variance in the way "adjustment" is defined is a likely contributor to differing outcome reports.

#### Adjustment: Back to Normal

Early on "adjustment" to pediatric cancer was defined as "functioning on par with peers" (van Eys, 1985, p. 160) or instilling normalcy in the child with cancer's daily life. The ability of the child or adolescent with cancer to obtain a level of normalcy through being involved in typical developmental experiences is an advantage of improvements in cancer treatment. Whereas children were once restricted to the hospital, they now more frequently return to their daily lives throughout treatment. Returning to school after being diagnosed is one way of facilitating normalcy during the cancer experience; in school, students with cancer can continue to take advantage of opportunities for social and academic growth (Clay, 2004; Katz, 2004). In fact, attending school has been called the "work of childhood" in research (Varni, Katz, Colegrove, & Dolgin, 1994, p. 24). Although barriers to attending school while ill exist, returning to pre-cancer activities has long been associated with better adjustment and adaptation to the disease (Katz et al., 1989). Effective preparation for school re-entry, then, is an important aspect of easing the transition back-to-school following a cancer diagnosis (Sexson & Madan-Swain, 1993).

#### Defining School Re-Entry, School Re-Entry Preparation, and School Reintegration

Previous research has used the terms school re-entry, school re-entry preparation, and school reintegration interchangeably. For the purposes of the current study, however,

distinctions are made to better understand the phases of adjusting to going back-to-school. "School re-entry" refers to going back-to-school. "School re-entry preparation" or interventions, however, refers to the preparatory process implemented for the *initial* return to school following a cancer diagnosis. Conversely, "school reintegration" refers to the ongoing or long-term adjustment of the child or adolescent with cancer to the school environment.

School re-entry preparation ranges from focusing on skill- and information-building, to more comprehensive approaches that include addressing the needs of a number of key individuals (e.g., student, family, school staff, and peers) to encourage the full participation of the student (DuPaul, Power, & Shapiro, 2009). Seminal research in school re-entry began in 1977 when Katz and colleagues investigated the needs of and interventions for pediatric cancer patients returning to school (Katz, Kellerman, Rigler, Williams, & Siegel, 1977). The researchers extended their work in 1989 by evaluating the effectiveness of a school re-entry program; this work represents the first and only empirically-based investigation on the effectiveness of school re-entry preparation.

Since the 1990s, research in school re-entry diverted from the work of Katz and colleagues and focused instead on identifying components of re-entry preparation, or the "how to." Such factors include multidisciplinary team cooperation, consideration of individual and family variables that may influence school performance, and comprehensive assistance with the child's unique medical, academic, cognitive, social-emotional, health, and behavioral needs (Prevatt, Heffer, & Lowe, 2000). Because research since the 1990s was largely descriptive and anecdotal, much less is known about how these variables relate to positive school re-entry outcomes in practice--or rather, much less is understood about the process of school re-entry. The ability of a student to re-enter the school environment may be impacted by his/her demographics, disease characteristics, premorbid psychosocial stressors, and/or the type of preparation for returning to school received (Die-Trill & Stuber, 1998; Varni et al., 1996). Further, the

adjustment of the student's family may impact the student's ability to successfully return to school (Vance & Eiser, 2002). To date, the relationship between these variables and school re-entry experiences and outcomes has not been examined.

Further, there is a paucity of research on outcomes and experiences of school re-entry interventions from a child with cancer's perspective, and even fewer from the adolescent with cancer's perspective. Most studies have examined school re-entry outcomes anecdotally from the viewpoint of parents and/or school staff (Clay, Cortina, Harper, & Cocco, 2004; Larcombe & Charlton, 1996; Notaras et al., 2002). Investigation of the student's perspective in terms of needs and outcomes in school re-entry have not been examined in over a decade (Varni, Katz, Colegrove, & Dolgin, 1994; McCarthy, Williams, & Plummer, 1998; Katz, Varni, Rubenstein, Blew, & Hubert, 1992). Lack of adolescent perspective, arguably one of the most important consumers of school re-entry interventions, limits our current understanding of what defines a successful school re-entry outcome or experience.

### Predictors of Successful School Re-Entry Outcomes

Theoretical models that explain general psychosocial adaptation to chronic illnesses are relatively recent (Brown, Daly, & Rickel, 2007). One prominent model that has been used to explain the relationship between child/adolescent and family adaptation to chronic illness is the Disability Stress Coping (DSC) model proposed by Wallander and Varni (1998).

The DSC model is an extension of systems or ecological theory, which posits a child's functioning is determined by the quality of interacting ecosystems (e.g. home, school, and child; Bronfenbrenner, 1979). Specifically, the DSC model attempts to explain variation in psychosocial outcomes of chronic conditions like pediatric cancer by examining risk and resilience variables that both mediate and moderate illness stress and adjustment (Brown et al., 2007). Increased stress is associated with poorer outcomes

(Wallander et al., 1989). Risk factors include illness parameters (e.g., duration of cancer, type of treatment, severity or visibility, etc.), impact on functional independence in daily activities (e.g., academic, behavioral, physical, or social functioning, etc.), and psychosocial stressors related to the cancer (Brown et al., 2007). Resistance, or resilience, factors include within-child or adolescent factors such as problem-solving capabilities, microsystemic factors such as socioeconomic status (SES), family functioning, etc., and stress-processing factors such as use of coping strategies (Brown et al., 2007).

Aspects of the DSC model were used to define predictors and outcomes of successful school re-entry in the current study. Specifically, the following facets of the DSC model were examined as potential predictors of school re-entry success: within-child variables, or demographic characteristics, illness characteristics, and premorbid functioning; and microsystemic factors such as school re-entry characteristics and family functioning. In addition, because the term “school re-entry success” is ill-defined in previous research, functional independence from the DSC model is posited as potential definition of school re-entry outcome. This adapted DSC model is presented in the current study as a way of understanding school re-entry interventions and outcomes to better inform future research.

#### Underlying Assumptions and Need

In summary, psychosocial consequences of childhood cancer have been addressed in research for several decades. More children and adolescents are surviving cancer and being treated outside the hospital-setting, allowing them to return to typical developmental activities such as attending school. Appropriate interventions for facilitating the student with cancer’s return to school are needed but not well understood in terms of application, outcome, or the adolescent's perspective. Furthermore, current research lacks an operational definition of “successful school re-entry” and knowledge of

specific factors associated with positive school re-entry outcomes. Identifying variables that positively impact the school re-entry process is critical to improving and individualizing school re-entry interventions. Using an adaption of the DSC model, intervention effectiveness is viewed as a combination of the “functional status of the child, the risk and resilience of the family, and the resources and collaborations existing among community-based systems” such as schools (Power, DuPaul, Shapiro, & Kazak, 2003, p. 40).

#### Purpose of the Current Study

The current study expanded research by identifying predictors that contribute to successful school re-entry from the adolescent with cancer’s perspective. It added to research by exploring systemic variables that may predict successful school re-entry outcomes. An adaptation of the DSC model was proposed as a definition of "school re-entry success," in addition to adolescent ratings of the success of their re-entry experiences. Accurately defining successful school re-entry may provide guidelines for future studies to investigate school re-entry effectiveness. Exploration of predictors associated with school re-entry success may also better inform school re-entry preparation. Specific research questions for the current study include:

1. Is there a relationship between demographic variables and successful school re-entry among adolescents with cancer?
2. Is there a relationship between illness characteristics and successful school re-entry among adolescents with cancer?
3. Is there a relationship between school re-entry characteristics and successful school re-entry among adolescents with cancer?
4. Is there a relationship between level of family adjustment/cohesion and successful school re-entry among adolescents with cancer?

5. Are there differences in functional independence and perceived school re-entry success among those who had school re-entry preparation and those that did not?

#### Definition of Key Terms

The following terms are defined to aid in understanding of the current study's aims and methodology.

*School Re-entry.* School re-entry is defined as the actual event of the student's initial return to school following a cancer diagnosis or relapse.

*School Re-entry Preparation/Interventions.* School re-entry preparation and school re-entry intervention are used interchangeably in the current study to describe the methods or activities used to assist the student with cancer, his/her peers, his/her family, and school staff with the student's initial return to school.

*School Reintegration.* School reintegration refers to the ongoing or long-term adjustment of the student with cancer to the school environment following re-entry. This phase may include modifications to initial school re-entry interventions used and/or more intensive measures.

*Demographic Characteristics.* Demographic characteristics are potential predictors of successful school re-entry outcomes, including the adolescent's current age, race or ethnicity, gender, and socioeconomic status (SES).

*Illness Characteristics.* Illness characteristics are potential predictors of successful school re-entry outcomes, including type of cancer, age when first diagnosed, type of treatment(s) received, presence of one or more relapses, and treatment duration.

*School Re-entry Characteristics.* Characteristics of the school re-entry experience are a potential predictor of school re-entry success and include time between diagnosis and return to school, age when the adolescent first returned to school, premorbid academic functioning, premorbid social functioning, premorbid emotional functioning, and type of re-entry preparation received.

*Premorbid functioning.* Refers to the adolescent with cancer's self-reported academic, social, and emotional functioning prior to being diagnosed or relapsing.

*Family Functioning.* Family functioning is a potential predictor of school re-entry success and is defined as the degree to which adolescents report their families are adaptable and cohesive (Olson, 2011).

*Functional Independence.* Functional independence is daily functioning or the degree to which an adolescent can function independently within physical, social, emotional, and academic domains; it serves as the outcome variable in the current study (Wallander & Varni, 1998).

*Perceived School Re-Entry Success.* The degree to which an adolescent felt his or her back-to-school experience was successful or not. In the current study, this was rated on a Likert scale (1 = Not Successful - 4 = Very Successful).

*Late Effects.* Difficulties with cognition, learning, and emotions resulting from abnormal changes in the child or adolescent's central nervous system (CNS) as a result of cancer and/or its treatment (Daly & Brown, 2007). Late effects may be acute or long term, occurring months or years after treatment has ended. The degree of impact depends upon the interaction of disease, child, and treatment factors (National Cancer Institute, 2012).

### Summary

Understanding predictors and outcomes of school re-entry research is needed. Chapter II provides an overview of the psychosocial impact of pediatric cancer and literature on school re-entry. An adaptation of the DSC model is presented as a theoretical framework for understanding school re-entry predictors and outcomes. Chapter III describes the study's design, participants, measures, and methodology for data analyses. Chapter IV presents results of statistical analyses. Chapter V discusses predictors of successful school re-entry from the modified DSC model and makes



recommendations for how school re-entry preparation may be adapted to fit the developmental needs of adolescents with cancer. The chapter concludes with discussion of the study's limitations and recommendations for future research. Appendix A contains figures, Appendix B includes focus group questions, Appendix C provides web-based survey questions (developed by the author), Appendix D contains a critique form for the former, Appendix E includes the Pediatric Quality of Life (Teen Report) form, and Appendix F provides the Family Adaptability and Cohesion Evaluation Scale-4<sup>th</sup> edition.

## CHAPTER II

### REVIEW OF LITERATURE

First, the psychosocial impact of pediatric cancer is reviewed. Challenges and benefits related to returning to school following a cancer diagnosis are examined. Second, results of a systematic literature search are presented, reviewing school re-entry research from its inception in the late 1970s to the present. Components and types of school re-entry preparation, including distinctions in school re-entry terminology, are highlighted. The third section discusses an adaption of the Disability Stress Coping model (DSC) as a theoretical framework for identifying variables that may predict successful school re-entry outcomes, emphasizing individual and systemic factors. The chapter concludes with a definition of “successful” school re-entry.

#### Pediatric Cancer: A Chronic Concern

Given increased survival rates, pediatric cancer is now more often considered a life-threatening chronic illness rather than an acute, terminal one (Naus, Ishler, Parrott, & Kovacs, 2009). This distinction has changed the way psychosocial adjustment is viewed in research and practice. Early research on psychosocial adjustment to pediatric cancer focused on issues of death and dying. With improved treatment, however, research began to emphasize “problems of living” (Pfefferbaum, 1978, p. 289). Issues faced by the child and his or her family during each phase of the illness (diagnosis, treatment, survivorship, and/or death and dying) were investigated. The potential chronicity of consequences associated with childhood cancer and its treatments, in addition to increased survival rates, underscore the importance of the child or adolescent’s adjustment when attempting to reintegrate back into “normal” life (Shaw & Páez, 2002). Accordingly, the psychosocial impact of childhood cancer has been of interest in research since the 1970s.

### Psychosocial Impact of Pediatric Cancers

You don't really get used to [cancer]...you adapt to it...I mean, you have to adapt because if you don't, you're going to die. And I don't think there's any way that you can totally prepare because there are no actual guarantees [sic]. (Woodgate & Degner, 2003, p. 484)

Typical developmental challenges of adolescence, such as forming an identity separate from one's family, acquiring social skills, and developing a sense of accomplishment or competence, can be distorted or made more difficult by a serious chronic illness (Weitzman, 1984). Ideal development is difficult even in the absence of a chronic or serious illness (van Eys, 1991), but adolescents with cancer are subjected to additional psychosocial stressors that have the potential to cause immediate and long-term problems in adjustment. The physical and psychosocial issues experienced throughout the disease can be immense, and the ambiguity of its course may cause additional stress (Sourkes, 1995). Frequent clinic and hospital visits, invasive procedures, home treatment regimens (such as port or central line care), and other disruptions of daily life become the new norm (Vannatta, Salley, & Gerhardt, 2009; Sloper, 2000). A cancer diagnosis and subsequent experiences introduce social, emotional, and cognitive challenges to overcome, reviewed below (Sourkes, 1995; Clay, 2004).

### Impact on Family and Peers

The child or adolescent with cancer must be viewed within the context of his or her family and social environment (Pfefferbaum, 1978). Family adjustment is one social aspect strongly linked to the child or adolescents' adjustment to cancer, as family members influence one another in development and adjustment to pediatric cancer (Wallander & Varni, 1998; Madan-Swain et al., 2006; Power, DuPaul, Shapiro, & Kazak, 2003). Early research on parental distress, for example, focused on adjustment to the child's diagnosis; but it is difficult to generalize these results across the course of the

child's cancer experience (e.g., Van Dolgen-Melman & Sanders-Woudstra, 1986). Examination of family adjustment at each phase of the illness and within each family member has been advocated (Kazak, 2005; Kazak, Simms, & Rourke, 2002). The majority of research on family adjustment, however, continues to focus on mothers.

Using a qualitative approach, Wallander and Noojin (1995) explored specific aspects of chronic illness that were most stressful to mothers over a period of 18 months. Medical and legal issues, difficulties with family functioning, and school issues were named most problematic. Barrera et al. (2004) compared the psychological adjustment of mothers of children with cancer and mothers of children with acute illnesses. Ninety-one mothers completed measures of depression, anxiety, coping, social support, and concurrent stressors. The researchers found that mothers of children with cancer reported more emotional difficulties, but also greater social support than mothers of children with acute illnesses. Increased social support has been implicated as a facilitator of family adjustment (Kazak, 2005). In a review of studies on the psychosocial impact of pediatric cancer, Wallander and Varni (1998) concluded that, much like children with cancer, their mothers are at increased *risk* for maladjustment. However, parental distress may decrease as the disease progresses from diagnosis to follow-up outpatient care (Dahlquist, Czyzewski, & Jones, 1996).

Anxiety, frustration, loneliness, feelings of uncertainty, and exhaustion are common reactions to attempting to maintain a semblance of pre-illness functioning (Kagen-Goodheart, 1977; O'Connor & Blesch, 1992; McDougal, 1997). Parents may feel torn between caring for a sick child while simultaneously carrying on day-to-day activities. Consequently, siblings of children and adolescents with pediatric cancer may experience feelings of resentment, jealousy, guilt, and/or fear (Kagen-Goodheart, 1977). Following a medical cure, the family may experience both joy and a sense of loss as they lose the supportive hospital community (O'Connor & Blesch, 1992). Fear of relapse and uncertainty may taint the family's degree of social involvement and daily lives.

Although family is an important factor in an adolescent's adjustment to cancer, his or her peer group becomes an integral part of adjusting to the disease. Pediatric cancer removes the adolescent from his/her environment of typical development, sometimes resulting in impaired social relationships and greater risk for social isolation and withdrawal (Kaffenberger, 2006; Spencer, 2006). Noll et al. (1990) found children with cancer were perceived by their teachers as less sociable and had fewer leadership qualities than age-matched peers. Children and adolescents at highest risk for peer difficulties are those with obvious physical changes (e.g., amputation) and those undergoing treatment impacting the central nervous system (Kazak, 2005). The need to be recognized by peers as independent, accomplished individuals is especially pronounced in adolescents with cancer given that having the disease often results in increased dependence (Weitzman, 1984).

#### Emotional Impact on Child with Cancer

Research on the emotional impact of having cancer in children is variable. Subtle psychosocial issues experienced by children and adolescents with cancer often include depression, anger (Brown et al., 2007), posttraumatic stress (Kazak et al., 2001; Vitulano, 2003), behavior problems (Spencer, 2006), and/or anxiety (Patenaude & Kupst, 2007). The adolescent may experience feelings of loss of control, dignity, and hopelessness (van Eys, 1985). Cuttini, Da Fre, Giovani, Baronci, and Tamaro (2003) found a higher prevalence of psychological distress in survivors of pediatric cancer when compared to their healthy siblings. Specifically, 14.2% of survivors expressed chronic symptoms of anxiety/depression versus 8.2% of their siblings. The authors hypothesized that using siblings as a control group may have actually underestimated the presence of psychosocial difficulties within the pediatric cancer survivors group, given that siblings themselves are at greater risk of psychosocial maladjustment. Zebrack, Zeltzer, Whitten, Berkow, and Chesler (2002) found young adult survivors of childhood cancers were 1.7

times more likely to report symptoms of depression and somatic stress than their healthy sibling counterparts.

Illness characteristics have been shown to impact adjustment. Higher levels of anxiety and lower self-concept were significantly correlated with the presence of relapse and extended duration of illness in a sample of children ages 6-13 ( $N = 44$ ) with cancer (Hockenberry-Eaton, Dilorio, & Kemp, 1995). These children also rated their experiences with cancer as significantly more stressful than those with higher self-concept and lower anxiety.

Conversely, Olson, Boyle, Evans, and Zug (1993) reported no differences in self-reported ratings of self-esteem, independence, social skills, and sense of control between cancer survivors (ages 6 – 16) and gender-matched school peers. More recently, Patenaude and Kupst (2007) summarized research on psychosocial issues of pediatric cancer and concluded most studies failed to find serious maladjustment in children and adolescents with cancer/cancer survivors. Moreover, adjusting to the emotional challenges of pediatric cancer may provide beneficial emotional maturation. Barakat, Alderfer, and Kazak (2006) provided evidence for the potential positive impact of pediatric cancer; adolescent cancer survivors and their parents reported experiencing posttraumatic growth, or positive psychological change following challenging life circumstances, one year after treatment.

Although discrepancy exists over the psychosocial consequences of pediatric cancer (Butler, Rizzi, & Bandilla, 2000), research suggests children and adolescents with cancer universally experience sub-clinical distress at the time of diagnosis, during treatment, and after the disease that may be associated with an increased *risk* for poor adjustment (Dowling, Hockenberry, & Gregory, 2003; Noll, Bukowski, Rosch, LeRoy, & Kulkarni, 1990). Kazak (1994) acknowledges:

The data are clear in stating that most childhood cancer survivors do not have clinically significant psychological difficulties and most function well. However, a troubling subset of

survivors do have significant difficulties, which we do not presently understand very well (p. 179).

### Cognitive and Academic Impact of Pediatric Cancers

Medical treatment for pediatric cancer may result in negative cognitive and academic consequences (Moore, 2005). Late effects, or chronic difficulty with learning, attention, and memory, are the result of abnormal changes in the child or adolescent's central nervous system (CNS) as a result of cancer and/or its treatment (Daly & Brown, 2007). Late effects are observed by changes in the child's behavior and functioning that may occur immediately or develop gradually (Mulhern & Butler, 2004; Daly, Kral, & Brown, 2008; Mulhern, 1994).

Neurologic outcomes are an accumulation of child and familial factors and how they interact with treatments, including experiences prior to the disease, preexisting conditions, and consequences associated with treatment and recovery. As a result, the degree of neurocognitive consequences will differ (Barrera, Atenafu, Andrew, & Saunders, 2008). Over 30% of pediatric cancer survivors demonstrate some level of cognitive impairment (Moore, 2005). Younger age at treatment, being female, receiving intrathecal chemotherapy (or chemotherapy delivered to the CNS), and/or having cranial radiation therapy (CRT), are all risk factors associated with development of late effects (Spencer, 2006).

The risk of cognitive difficulties faced by this population are well-researched but potentially not well understood by school staff (Spencer, 2006; Kazak, 2005). Deficits in executive functioning, reaction time, ability to learn new material, working memory, motor functions, and processing speed have been observed, in addition to decreases in a child or adolescent's ability to engage and persevere during tasks, sustain attention, and perform math and reading tasks (Butler & Mulhern, 2005; Daly & Brown, 2007; Mulhern & Butler, 2004). Research has shown that negative effects of treatment are often progressive and have a delayed onset (Moore, 2005; Butler & Mulhern, 2005; Spencer,

2006; Daly & Brown, 2007). Because of changes in brain structure that impact the way a student encodes information, declines in cognitive, and later academic, performance are most likely due to failure to learn new information rather than a loss of previously-learned material (Moore, 2005; Taylor et al., 2007).

Treatments may immediately impact the student's ability to benefit from school (Spencer, 2006; Mulhern & Butler, 2004). Poor cognitive functioning due to fatigue or malaise may cause decreased motivation to complete challenging tasks at school (Butler et al., 2008). Difficulties with attention and focus may be responsible for declines in school performance and social interaction (Butler & Mulhern, 2005; Palmer, Reddick, & Gajjar, 2007). Children and adolescents with cancer have been shown to utilize special education services more frequently (Daly, Kral, & Brown, 2008; Mitby et al. (2003), including homebound instruction, health-related services, transportation, counseling, and academic interventions (Baird, Ashcroft, & Dy, 1984). Students who do not receive necessary special education services are more likely to drop out of school (Mitby et al., 2003).

An interesting but often overlooked subset of children impacted by late effects includes those students who continue to perform within the average ranges, but were once above-average before cancer treatment (Deasy-Spinetta, 1993). Differences experienced by these students must also be acknowledged, as any loss of ability can be devastating to the student. Acute difficulties in school may impede a student's productivity as an adult (Butler et al., 2008). Learning problems may persist even after they are considered medically-cured (Upton & Eiser, 2006).

Late effects are especially common among children with brain malignancy; these individuals may be at risk for declines in intellectual functioning regardless of the type of treatment received (Moore, 2005; Taylor et al., 2007). The presence of the tumor itself presents a risk to the child; the foreign body can push on important brain structures causing changes in functioning. Similarly, surgical procedures used to remove the tumor



may cause changes in the child's functioning (Moore, 2005; Daly & Brown, 2007). Complications from surgery, such as difficulty with anesthesia, hydrocephaly (or swelling), and seizures may also contribute to a negative outcome (Moore, 2005; Butler & Mulhern, 2005).

In summary, although research regarding the adjustment of children with cancer and their families is equivocal, it is clear a heightened risk for poor adjustment in many domains of functioning exists. Even when an individual's cancer is medically cured, lasting concerns often emerge in the psychosocial consequences of the disease. O'Connor and Blesch (1992) stated, "the ongoing effects of having had cancer, a life-threatening disease, and the potential late effects associated with therapies used to eradicate cancer are still present" (p. 176). Koocher (1996) and van Eys (1985; 1991) suggested we must now tend to the psychosocial consequences of successful medical treatment. The interaction of mediating variables such as severity of illness, compounding life stressors, level of functional independence, coping skills, resources, and socio-ecological issues may account for some of the variability in adjustment outcomes (Brown & DuPaul, 1999). Further, methodological issues, including the emphasis on descriptive and correlational studies, vacillating interest in risk versus resiliency outcome variables, or failure to adequately operationalize and assess "adjustment" provide additional explanation for differences in results.

#### Return to Normalcy

The importance of re-establishing normalcy for children and families impacted by pediatric cancer coincided with increased interest in psychosocial adjustment in the late 1970s (Kagan-Goodheart, 1977). Re-entrance into life, or "the business of the child, must be ongoing, not in spite of the cancer, but with the cancer" (van Eys, 1991, p. 91). Resuming, to the extent possible, life as it was before cancer provides the adolescent optimism and a sense of control (O'Connor & Blesch, 1992; Ross, 1984). Because the

adolescent's school attendance, peer relationships, and academic achievement are closely related to his or her overall adjustment to the disease, effective school re-entry preparation is needed (Sexson & Madan-Swain, 1993). The importance of returning to school following a cancer diagnosis or treatment is well-supported in research (e.g., Madan-Swain & Brown, 1991; Sexson & Madan-Swain, 1995; McCarthy, Williams, & Plumer, 1998; Stuart & Goodsitt, 1996; Kapelaki et al., 2003; Vance & Eiser, 2002; Deasy-Spinetta, 1993; Ross & Scarvalone, 1982; Larcombe et al., 1990; Prevatt et al., 2000; Cleave & Charlton, 1997).

School has been called the business of childhood (Varni, Katz, Colegrove, & Dolgin, 1994; Harris, 2009); returning to school following a cancer diagnosis is symbolic of the student's diminished identity as "the sick kid." Ultimately, a well-adjusted child or adolescent is one who is developmentally on course with peers academically, socially, emotionally, and physically (van Eys, 1991). It may be argued that schools serve as the primary venue for academic, cognitive, social, and emotional development during childhood and adolescence: "ongoing participation and success in school are essential for positive health outcomes in young people" (Katz & Madan-Swain, 2006, p. 313). Attending school provides a sense of academic mastery and competency (Bessell, 2001) that may extend to other domains within the adolescent's self-image. Further, attending school and engaging in developmentally-appropriate activities may prevent learned helplessness or hopelessness while improving a child's ability to cope (Katz, Varni, Rubenstein, Blew, & Hubert, 1992).

Although clearly important for overall adjustment, barriers to attending school with cancer exist. Students with cancer often experience extended absences due to medical treatments, pain, nausea, fatigue, and the threat of catching other illnesses, resulting in the interrupted social relationships and academic skills previously reviewed (see Clay, 2004; Ross, 1984). Being unprepared to respond to peers' questions about cancer can increase feelings of social isolation or discomfort at school. Cancer and

treatment-related learning difficulties, as well as worry over falling behind academically, may result in school avoidance (Clay, 2004; Prevatt, Heffer, & Lowe, 2000; Kapelacki et al., 2003; Katz et al., 1989).

Systemic factors such as parental overprotection and school personnel's lack of confidence in educating a student with cancer also make regularly attending school difficult (Katz et al., 1989). Parents may fear or undervalue the importance of returning to school (Clay, 2004). Consequences of cancer treatments (e.g., alterations in physical appearance, cognitive ability, and/or mobility) can result in negative attitudes and reactions from school staff and peers (Katz et al., 1989). The relative infrequency of pediatric cancer may contribute to misunderstanding the student's social, emotional, and academic functioning or needs. Both previous and more recent research suggests teachers may feel largely unprepared for the academic, behavioral, and emotional challenges associated with having a student with cancer in the classroom, in addition to having a lack of knowledge about the disease itself (Tuffrey, Muir, Coad, & Walker, 1993; Clay et al., 2004).

Even when able to attend school during treatment, students with cancer may experience psychosocial exclusion from school life and peers (Power, DuPaul, Shapiro, & Kazak, 2003). Environmental constraints to returning to school are also present, such as the student's need for a clean environment to prevent infection or the need for medical care during school (Notaras et al., 2002). Administratively, inadequate funding, need for accommodations, staff shortages, and/or poor interdisciplinary collaboration have served as barriers to providing services for students with cancer (Baird et al., 1984).

In summary, given the importance of the school experience on a child or adolescent's psychological development, interest in psychosocial adjustment to pediatric cancer has extended to the school environment. Specifically, school re-entry preparation may be an important tool for easing the transition back-to-school following a cancer diagnosis (Brown, 2004).

### School Re-Entry Defined

Previously, the term “school re-entry” has had multiple meanings in research, referring to the specific program or method used to facilitate a student’s return to school, and/or used synonymously with the phrase, “back-to-school.” Further, the terms “school re-entry” and “school reintegration” have been used interchangeably in prior research to describe programs or interventions meant to facilitate the student’s return to school. Inconsistency in terminology across studies in school re-entry have somewhat limited our understanding of the back-to-school experiences and outcomes of children and adolescents with cancer. Clearer distinctions of school re-entry are needed and are best described in different categories or phases. The current study defines “school re-entry preparation” as the preparatory process, programs, or interventions used to facilitate the student’s transition back to the school. School re-entry preparation attempts to facilitate full participation of the student with cancer in school activities by preparing the child or adolescent with cancer, the family, and school staff for transition back into the routine of school (Katz & Madan-Swain, 2006). It is synonymous with "school re-entry intervention." “School re-entry,” conversely, refers to the actual act of returning to school following a cancer diagnosis, relapse, and/or treatment. The point of re-entry varies according to the type of cancer and treatment received, and ideally occurs following preparation. School re-entry is synonymous with "back-to-school." Finally, “school reintegration” describes the ongoing or long-term adjustment of the child or adolescent with cancer to the school environment. Each distinction, when considered together, forms a more comprehensive picture of the school re-entry process and serves as the focus of the current investigation. Madan-Swain, Katz, and LaGory (2004) aptly summarize:

School re-entry is a dynamic, ongoing process that requires continuous cooperation and commitment among the medical team, family, and school from initial hospitalization through follow up contact. Regardless of whether the chronic illness follows a constant, progressive, or relapsing course, the child’s return to

school poses a significant stressor. Yet, re-entry to school is imperative. (p. 651)

Literature supports both the preventative advantage of re-entry preparation and the reintegration of students in school to address academic, cognitive, and social-emotional issues of pediatric cancer (e.g., Katz et al., 1989; Madan-Swain & Brown, 1991; McCarthy, Williams, & Plumer, 1998). School re-entry preparation helps to instill confidence in schools to provide the specialized care needed to facilitate the student's adjustment (Stuart & Goodsitt, 1996). Deasy-Spinetta (1993) argues school re-entry interventions may even be cost-effective in that they prevent social problems while encouraging the development of adaptive behaviors necessary for a productive adulthood.

#### School Re-Entry for Children and Adolescents with Cancer

A systematic literature review of school re-entry for adolescents with cancer was conducted to establish a knowledge base of school re-entry preparation and outcomes. The following databases were used: CINAHL Plus, PubMed, PsycInfo, ERIC, Academic Search Elite, and Social Work Abstracts. The following search terms were used: cancer, neoplasms, school re-entry (reentry), and school reintegration. Because of an interest in the history of school re-entry programs, lower limits on dates were not established. Inclusion criteria included peer-reviewed papers written in English that focused on children aged 6-18 years. Age range was not limited to adolescence given the paucity of research in this area. 136 papers were identified. Several references from the initial review were eliminated, including non-peer reviewed, non-English papers, and references with that were more medically-based in subject matter, yielding 65 papers. Subsequent references were obtained from reference lists of articles yielded through the systematic review and information from cancer organization websites for a total of 141 articles and books on school re-entry. One was an empirical evaluation of school re-entry preparation, 47 were anecdotal or qualitative evaluations, and 93 were descriptive in nature (e.g., exploring roles, attitudes, components, etc.).

Seminal School Re-entry Research. Katz et al.'s (1977) study served as an initial effort to understand the back-to-school experiences of children and adolescents with cancer. In a sample of 26 children and adolescents (ages 5-16), the researchers found anxiety about hair loss, extensive absences, parental overprotection, and the need for special education placements were common worries about going back-to-school. Katz et al. highlighted the range of differences found in post-diagnosis school participation. Variation in pre-cancer school adjustment and development, parent and physicians attitudes about the importance of school, and reactions of school personnel and peers were conjectured to be influential factors in how participants adjusted. The need for individualized school re-entry interventions, such as counseling, assistance with special education processes, and preventative psycho-education for peers, was emphasized. The school re-entry interventions implemented in this study were largely unstructured and narrow in focus (e.g., providing counseling for the child but not education for peers).

A more structured approach to school re-entry was provided by the landmark investigation of Katz et al. in 1989. Expanding upon their preliminary study, Katz et al. developed the first systematic school re-entry intervention package for a sample of 49 children and adolescents with cancer to investigate how to best facilitate school re-entry. Thirty-six children and adolescents with cancer who did not receive school re-entry preparation served as a control group. Both groups completed assessments of competence, depression, and behavioral checklists. The intervention group completed these measures twice: pre- and post-participation in the school re-entry intervention. Control group participants reported more problematic school and social adjustment, but group differences were not exhibited in grades or attendance. In addition to empirical evidence of effectiveness, the intervention was perceived as successful by parents, patients, and teachers, and increased classmate understanding was reported.

The study by Katz et al. (1989) represents the first and only empirical investigation of the effectiveness of early school re-entry preparation intervention to date.

It was limited by lack of randomization and failing to control for possible effects of variability in disease duration, but nevertheless illustrated the importance of providing comprehensive, collaborative services to students with cancer returning to school. The authors stressed the importance of ongoing follow-up and use of a liaison between disciplines. Contrary to educator fears at the time, discussing cancer did not increase classmate fears but rather helped to reduce misperceptions and social isolation (Katz et al., 1989; Katz et al., 1977). Finally, the study by Katz et al. (1989) suggested that students with cancer were capable of achieving successful school re-entry despite a lack of differences in number of absences or improvement in grades, common outcomes variables used in subsequent research in school re-entry.

Katz and colleagues further extended their research by examining the social validity of the comprehensive intervention described above (Katz et al., 1992). A sample of 49 newly-diagnosed children and adolescents, their parents, and their teachers rated the utility of the school re-entry intervention. Students and parents alike rated the intervention as both successful and important. Further, teachers in this study indicated the preparation was effective in increasing knowledge and social acceptance of the student. Katz et al. (1992) concluded that in addition to therapeutic effectiveness, their school re-entry intervention demonstrated contextual value or efficacy. The importance of providing school re-entry preparation was further solidified, eventually resulting in a standardized manual of school re-entry intervention.

Interestingly, despite early recommendations by Katz et al. (1989, 1992) to continue to empirically investigate school re-entry preparation effectiveness, subsequent research moved away from this and instead became more descriptive and anecdotal in nature. School re-entry intervention components, or the “how to” of school re-entry preparation, were emphasized. For example, a large number of studies focused on the professional roles of teachers, counselors, psychologists, or school nurses (Kaffenberger,

2006; Wodrich & Landau, 1999; McDougal, 1997; Prevatt et al., 2000; Wallinga, 1990; Power, Heathfield, McGoey, & Blum, 1999; Rabin, 1994).

Emphasis on Components. Emphasis on re-entry preparation components beginning in the 1990s may have coincided with changes in special education legislation, such as the reauthorization of Education of the Handicapped Act in 1990 (IDEA). IDEA is federal legislation that provides eligible chronically ill students in elementary and secondary schools to receive educative assistance. IDEA requires “that assessment services and the development of interventions be tailored to the needs of the child through the use of multidisciplinary teams in the diagnostic and intervention planning process” (Lee & Janik, 2006, p. 34). This is particularly important for chronically ill students whose needs not only vary according to different types of health conditions, but also within the same disease. Academic and psychological services are provided within the least restrictive environment so that students can “adapt to age-appropriate academic and social challenges and have the opportunity to learn from normally developing peers” (Power & Blom-Hoffman, 2004, p. 41). Very specific services or interventions were mandated by IDEA that likely contributed to the increased value placed on individual school re-entry interventions.

Components of School Re-entry Preparation. Seminal efforts by Katz and colleagues provided a foundation for the structure of school re-entry interventions, although subsequent efforts vary in scope and approach. Generally, components of school re-entry preparation emphasize a combination of (a) education for school personnel and classmates about cancer and related treatments, (b) the importance of attending school, (c) provision of counseling to address psychosocial effects (Harris, 2009), (d) an expedited return to school, (e) multidisciplinary involvement and collaboration, (f) use of a communication liaison, (g) multiple intervention targets (e.g., parents, school staff, student, classmate, etc.), and (h) the need for ongoing adjustments in services based on changing needs (Katz et al., 1992, 1989). While a paucity of



literature exists on the effectiveness of school re-entry interventions, the components of preparing for a child or adolescent with cancer's return to school are well-established (Prevatt, Heffer, & Lowe, 2000).

Power, DuPaul, Shapiro, and Kazak (2003) suggested that integration back-to-school is a continuous process facilitated by use of multiple components. They, along with other researchers (Katz & Madan-Swain, 2006; Madan-Swain, Katz, & LaGory, 2004), proposed a model that outlined school re-entry preparation based on Bronfenbrenner's (1979) ecological theory. This systems-based theory encouraged conceptualizing school re-entry as a comprehensive, interactive process between many people and settings. The following is a summary of major facets of school re-entry preparation that have been proposed in literature. Suggestions that address the major systems that impact children and adolescents, mainly the family and school setting, are provided.

*Phase one: planning.* The first step to school re-entry preparation involves preparing the family and student for consultation with school and medical staff. Pre-re-entry efforts or preparation serve to improve attitudes and address misconceptions that may exist about the process (Katz & Madan-Swain, 2006). This phase strengthens the family to maintain cohesion and encourage adaptation, which is associated with school success (Power et al., 2003). Families are prepared to collaborate with the school, which typically includes establishing a preferred mode of communication. Parent needs are addressed, such as reluctance or fear associated with allowing the student to return to school. As Katz et al. (1989, 1992) encouraged, the importance of returning to school to facilitate normalcy should be emphasized.

Efforts to sustain academic progress throughout hospitalization may be negotiated (e.g., homebound instruction, tutoring) to prevent the student from falling behind. To do so, information on the student's premorbid academic and behavioral functioning is obtained for education planning. In addition, the adolescent may need

neuropsychological assessment to address cognitive effects of cancer and its treatment, and/or social-emotional assessment. The adolescent may also undergo individual counseling and/or receive assistance in developing a plan for facing peers.

Similarly, school staff needs are addressed. Teachers, school nurses, and other personnel receive education about the student's condition, treatment, and side effects, and how they may impact school performance. Staff should be made aware of accommodations that are needed and provided an opportunity to process personal reactions to the student's diagnosis (McDougal, 1997; Clay, Cortina, Harper, & Cocco, 2004). School staff also require direction on how to answer questions of other students (Power et al., 2003; Katz & Madan-Swain, 2006).

*Phase two: returning to school.* This stage involves actual implementation of school re-entry interventions, including presentations to school staff and classmates, provision of medical care at school, and application of necessary academic and social-emotional accommodations. Goodell (1984) advocated for the use of a peer-education program to prevent and ameliorate classmate fears. The adolescent may participate (if desired) in classroom presentations to inform his or her peers about the illness, which may include an age-appropriate informative presentation (e.g. puppet show or video), and a question-and-answer session.

Vital to the success of this phase is regular communication and collaboration among the school, family, and medical systems (Katz & Madan-Swain, 2006; Power et al., 2003). In order to effectively discuss the logistics and expectations of a school re-entry program, however, communication needs to be conducted in a manner that is free of jargon to avoid miscommunication. Each profession must become familiar with the other discipline's vocabulary, goals, and obstacles to work together successfully; often a heterogeneous view of the adolescent's needs exists when inter-agency collaboration and communication is absent (Shaw & Paez, 2002).

Consulting with the adolescent's family about communal goals and providing a liaison to facilitate multidisciplinary communication is helpful (Prevatt, Heffer, and Lowe, 2000). Parents are often overwhelmed by their adolescent's diagnosis and the logistics of transitioning back to school; they need to develop a trustworthy relationship with at least one professional that is able to advocate and help them coordinate services to transition to independence following the hospital stay—someone with whom they can discuss uncomfortable questions (Stuart & Goodsitt, 1996). School staff should take the lead in creating a “context for a mutually supportive family-school collaboration (Power et al., 2003, p. 86). A number of professionals may fill the role of liaison, such as a school psychologist, social worker, nurse, school counselor, or someone from the hospital staff. The consultant must be knowledgeable in many areas, such as childhood cancer, education methods and the school environment, child development and adjustment, and family dynamics. A structure or well-defined process to delineate the liaison's role often adds to the re-entry process (Shields & Herron, 1995).

*Phase three: follow up.* This phase encourages the student with cancer's continued reintegration into the school environment. Because of the variable nature of the disease, continued communication and modification to any accommodations and interventions is necessary (Madan-Swain et al., 2004). A working liaison that coordinates communication among each system may also facilitate follow up (Katz et al., 1989; Katz & Madan-Swain, 2006).

This phase may include more intensive and/or ongoing services, such as social skills training, assertiveness training, counseling, special education, and/or transition planning as needed (Katz & Madan-Swain, 2006). The school nurse may care for the child's special health needs to ensure the adolescent's health plan is closely followed at school (Dahlheimer, 2005). The school nurse may monitor side effects from chemotherapy or radiation and update parents and healthcare providers, as well as inform parents of the presence of school-wide illnesses that may be detrimental to the

adolescent's health. Individual and family counseling services and peer support for classmates are often provided by school psychologists (McDougal; Prevatt, Heffer, & Lowe). Periodic academic, behavioral, and social-emotional assessments throughout an adolescent's illness may be necessary to determine whether additional intervention (and what type of intervention) are needed (Nessim & Katz, 1995, as cited in McDougal, 1997). Given the progressive nature of late effects, regular neuropsychological evaluations are recommended to monitor any declines in performance so that accommodations can be adjusted as needed (Armstrong & Briery, 2004).

Unfortunately, an additional component to the follow-up phase may include services that address grief, disease progression, and death (Katz et al., 1989, 1992). A relapse following several years may require school re-entry preparation to begin at Phase One. However, school participation continues to be important for students of declining health or terminal disease. Flexible scheduling, realistic expectations, and systemic assistance with bereavement are needed to address issues of death and dying (Katz & Madan-Swain, 2006).

Types of School Re-entry Preparation. While the former represents a summary of ideal school re-entry interventions, research varies regarding the content and structure of services that are implemented (Katz & Madan-Swain, 2006). For example, in a review of school re-entry practices, Prevatt, Heffer, and Lowe (2000) concluded interventions provided differ per school district, hospital, and coordinating professional (e.g. nurse, Child Life worker, school psychologist, etc.). School re-entry preparation ranges from comprehensive, ongoing interdisciplinary collaboration or reintegration (Katz et al., 1989, 1992), to short-term, restricted interventions largely focused on the initial return to school. Examples of restricted interventions includes those that solely emphasize psycho-education or target audience (Larcombe & Charlton, 1996; Duboway, 2006).

The continuum of school re-entry preparation can be categorized. Many students return to school without any type of preparation for anyone. Conversely, "informal"

school re-entry preparation includes interventions developed locally by school and medical personnel to reintroduce the child back to school. Informal school re-entry preparation is typically restricted in scope and audience. Examples include structured workshops, meetings, presentations, and/or web tutorials (Treiber, Schramm, & Mabe, 1986; McCarthy, Williams, & Plumer, 1998; Dubowy, 2006) for classmates, students with cancer, his/her family, and/or school staff, etc. Finally, “formal” or manualized school re-entry preparation features intervention guidelines developed by organizations like the American Cancer Society or the Leukemia & Lymphoma Society. This category typically provides materials such as videos, activities, props, and/or books. Examples of formal school re-entry preparation interventions include the Trish Greene Back to School Program (Leukemia & Lymphoma Society, 2008) and the Cancervive Back to School Kit (Education Services for the Child with Cancer, 2008).

Lack of Intervention. A surprising and somewhat troublesome trend was found regarding the lack of school re-entry preparation being implemented (Brimeyer & McCarthy, 2009). Despite enactment of Public Law 94-142, which includes “Other Health Impaired” as a qualifier for school accommodations, considerable variability remains in available services and their implementation (Lynch, Lewis, & Murphy, 1992). Many students with cancer are returning to school without preparation even though resources on school re-entry interventions are widely available from organizations such as Candlelighters, American Cancer Society, and Beyond the Cure. School staff have reported a need for more training and preparation regarding having students with cancer in the classroom (e.g., Clay et al., 2004).

More comprehensive, systems-based re-entry interventions recommended in research may have been viewed as laborious and time-consuming during a time of special education reform. The lack of more comprehensive programs being implemented may have contributed to the paucity of research on more comprehensive school re-entry outcomes. In addition, organizational barriers and lack of funding within hospitals have

created a barrier to providing any type of school re-entry preparation. Without interventions being conducted in schools, it is difficult to conduct empirically-sound evaluations.

Nevertheless, all students with cancer should be allowed access to school re-entry services despite appearing well-adjusted. Some adolescents with cancer may have sub-clinical difficulties that may lead to later maladjustment (e.g. dropping out, anger, etc.) (Deasy-Spinetta, 1993). Research suggests providing a structured school re-entry experience can lead to an overall positive experience for children, families, and school personnel by caring for the ill child's needs in one arena (Katz, Kellerman, Rigler, Williams, & Siegel, 1977; Tesauero, Rowland, & Lustig, 2002; Shaw & Paez, 2002). Deasy-Spinetta (1993) accurately proposes the challenge in school re-entry research is to "make school intervention efforts an integral part of psychosocial care in all pediatric hematology/oncology centers" (p. 3261); this challenge remains today.

Anecdotal Support for School Re-entry. In addition to a descriptive focus on school re-entry components, several studies following Katz et al. (1989, 1992) anecdotally evaluated school re-entry interventions. These studies were limited by target population (e.g., school staff only, peers only, etc.), target intervention (e.g., social skills training), and/or approach (e.g., a workshop on cancer and treatments). Teachers, for example, are a frequent target for intervention. Larcombe & Charlton's (1996) education-based intervention increased the self-reported confidence of elementary teachers in managing school-related issues of pediatric cancer. More recently, Duboway (2006) utilized a web-based training intervention to prepare teachers for school re-entry ( $N = 41$ ). Participants reported increased knowledge of cancer. In both studies, classmates, the student with cancer, and other school staff were not included in the intervention. Further, psychosocial issues related to pediatric cancer were not addressed, which likely limited the teachers' ability to fully address the student with cancer's needs.

School re-entry interventions have also been limited in scope through a narrow definition of outcomes. For example, studies have commonly used school absences or grades as an indicator of school re-entry success (Vance & Eiser, 2002). However, Katz et al. (1989) suggested school re-entry may be perceived as successful despite many absences or poorer grades. A broader scope to identifying and investigating school re-entry outcomes is needed.

Lack of Adolescent Perspective. Research to date has emphasized ratings of school re-entry effectiveness from limited perspectives (Notaras et al., 2002), such as school staff and/or parents (e.g., Lynch et al., 1992; Chekryn, 1986; Moore et al., 2009; Rynard, Chambers, Klinck, & Gray, 1998). Very few studies have reported outcomes and experiences of school re-entry interventions from a child's perspective, and no published studies were found from the adolescent's perspective (Varni, Katz, Colegrove, & Dolgin, 1994). Those studies that included the perspective of children with cancer typically gathered information about the problems experienced when returning to school versus facilitating factors or outcome ratings (e.g., Larcombe et al., 1990; Upton & Eiser, 2006; Deasy-Spinetta, 1993). The lack of adolescent perspective is particularly troubling given their increased ability to provide insight into their experiences (versus school-age children). Labay, Mayans, & Harris (2004) commented "little is known about the unique experiences of pediatric oncology patients during this specific time period" (p. 168).

Two studies have addressed the need for obtaining the child with cancer's perspective on re-entry outcomes in research. Using qualitative measures, McCarthy, Williams, & Plumer (1998) explored the back-to-school experiences of ten children and adolescents with cancer following a school re-entry intervention by interviewing the student, parent, and teacher. Children and adolescents in the study (ages 5 – 13) worried about keeping up with school activities, while parents were concerned with the child's safety. Teachers were concerned with the child's academic and physical progress. The authors concluded school re-entry preparation should address a range of concerns. The

study by McCarthy et al. illustrated the importance of obtaining outcome reports from a variety of sources, as each person involved had unique concerns regarding the student's return to school. Their conclusions are corroborated by other research; Lynch et al. (1992) found families of chronically ill children commonly focus on social-emotional and health issues while school staff are concerned about absences and academic work.

Similarly, Katz, Varni, Rubenstein, Blew, & Hubert (1992; previously described) used retrospective, anecdotal ratings of a comprehensive school re-entry intervention from children, parents, and teachers. The authors concluded school re-entry interventions were positively viewed by child participants. Both Katz et al. (1992) and McCarthy et al. (1998) rated school re-entry outcomes globally; specific factors contributing to the success of the intervention were not evaluated.

In summary, research following Katz and colleagues' empirical evaluation of re-entry effectiveness contributed to knowledge of school re-entry components (or the "how to"); barriers, facilitators, particular aspects of school re-entry interventions, programs, and/or roles were emphasized. Consequently, although the importance and descriptions of school re-entry interventions are now well-established (Madan-Swain & Brown, 1991; McCarthy et al., 1998; Katz et al., 1989, 1992, etc.), much less is known about the variables associated with positive re-entry outcomes, or how outcomes should be defined. Research in school re-entry has reached a plateau. The piecemeal nature of school re-entry research has strayed from the systematic approach proposed two decades ago. Research in school re-entry must return to its early roots to gain insight into outcome variables and predictors. Assessing school re-entry outcomes more comprehensively, in addition to identifying predictors of successful outcomes, would better inform future studies on the effectiveness of school re-entry interventions. This may begin to once again move the research agenda forward. Current school re-entry preparation remains mostly limited in scope, making it difficult to identify generalizable predictors of success and/or outcomes. The lack of feedback on re-entry experiences from the student with



cancer (particularly the adolescent), perhaps the most important consumer of school re-entry interventions, is an additional notable gap in research.

A theoretical framework for understanding school re-entry outcomes is needed to better hypothesize predictors and outcomes. Varni, Blount, and Quiggins (1998) and Butler, Rizzi, and Bandilla (2000) criticized the lack of theory-based examination of correlates of general adjustment to chronic illnesses like cancer. It follows that a similar criticism can be made regarding school re-entry outcomes; current literature in school re-entry preparation lacks a predictive model of successful re-entry outcomes. Examination of outcomes was recently recommended as a future direction of school re-entry research (Katz & Madan-Swain, 2006). Exploring potential predictors of school re-entry success is necessary to clarify school re-entry outcomes. A potential starting point is the widely-accepted Disability Stress Coping model first introduced by Wallander and Varni (1992, 1998).

#### The Disability Stress Coping Model: Framework for Identifying Predictors of School Re-entry Success

The Disability Stress Coping model (DSC; Wallander & Varni, 1998) represents broader, more comprehensive efforts to conceptualize the impact of chronic illnesses on children/adolescents and their families and psychosocial adjustment (Eiser, 1990). Variability in adjustment outcomes for children and families impacted by pediatric cancer may be partially explained by the differential impact of risk and resiliency in this model. Research by Katz et al. (1989; 1992) lends support to using the DSC model to assess child survivors' overall adjustment to pediatric cancer by emphasizing how within-child variables (in this case, motivation and personal competency) and social-ecological or systemic variables (e.g., social support) interact, resulting in differences in adjustment.

It is argued the DSC model of adjustment to chronic illnesses provides a foundation for potentially identifying predictors and outcomes of successful re-entry in

the current study. Brown (2004) posits “school and social difficulties in children and adolescents with cancer can best be understood within the disability, stress, and coping theoretical model...proposed by Varni and Wallender” (p. 313). The DSC model encourages a systemic approach to facilitating psychosocial adjustment that is commensurate with recommendations in school re-entry preparation (e.g., coordinating consultation between families and professionals). Additionally, Worchel-Prevatt et al. (1998) modeled a school re-entry program based on this model to address systemic needs.

Facets of the DSC model that interact to inhibit or facilitate general adjustment are easily applied to school re-entry outcomes and potential predictors of success. These include illness characteristics, the child’s level of functioning (e.g., social, cognitive, etc.), the presence or absence of compounding stressors, and social factors (e.g., social support, family adjustment, etc.). Finally, there is a considerable link between overall adjustment and attending school. Die-Trill and Stuber (1998) suggested school re-entry and reintegration is an important indicator of successful general adjustment to pediatric cancer.

Model Overview. The DSC model is an extension of systems or ecological theory, which posits a child’s functioning is determined by the quality of interacting ecosystems (e.g. home, school, and child; Bronfenbrenner, 1979). An ecological or systems perspective is useful for framing the process that links the home, school, and medical settings to facilitate school re-entry, as the adolescent’s potential is often heavily dependent on his or her environment (van Eys, 1991; 1985). In addition, the quality of school re-entry interventions depends on the ability of each system to collaborate with one another (Power et al., 2003).

Interacting facets of the model include illness parameters (e.g., duration of cancer, type of treatment, severity or visibility), child adjustment (e.g., social-emotional, academic), psychosocial stress (e.g., illness-related difficulties, additional life stressors), stress appraisal (e.g., coping strategies), intrapersonal factors (e.g., temperament,

problem-solving skills), and social-ecological factors (e.g., family environment, parental adjustment, social support). Please see Figure 1. The DSC model attempts to explain variation in psychosocial adjustment outcomes of pediatric cancer by examining risk and resilience variables that mediate and moderate adjustment to illness stress (Brown, Daly, & Rickel, 2007).

The level of risk or resiliency within each facet exists on a continuum, or, the degree to which a facet is present or absent. For example, risk factors from this model may entail having a type of cancer or treatment that causes highly visible side effects, being from a chaotic family environment, or exhibiting poor academic performance. Conversely, resistance factors may include undergoing treatments not associated with cognitive or academic declines, having social support, or appropriate family adjustment.

Functional independence or health-related quality of life. The degree of risk and resiliency among the interacting facets of the DSC model ultimately results in the child or adolescent's ability to independently carry out daily activities (e.g., academic, behavioral, physical, or social functioning, etc.). An important variable within the DSC model is the child or adolescent's functional independence. Defined in developmental terms, functional independence is demonstrated in normative, healthy, age-appropriate behavior that typically results in higher quality of life (Wallander & Varni, 1998; van Eys, 1985). Functional independence appears particularly important for adolescents with pediatric cancer, as developing autonomy is integral to developmentally-appropriate adjustment (van Eys, 1985). Positive adjustment to cancer has been associated with functional independence in school, social, emotional, and physical domains (Varni, et al., 1996).

A promising construct in examining the functional independence of children and adolescents with chronic diseases is health-related quality of life (Wallander & Varni, 1998). The concept of quality of life is comprehensive, incorporating the degree to which a child or adolescent functions academically, socially, emotionally, and physically. Quality of life has a tradition of use in research (e.g., Berrin et al., 2007; Varni,

Burwinkle, & Seid, 2006) and may be an appropriate outcome assessment of school re-entry: Ross (1984) found school re-entry interventions are associated with increased quality of life or functional independence. To the author's knowledge, however, it has not been investigated as an outcome variable for school re-entry.

### Model of School Re-Entry Success: An Adaptation of the DSC Model

There is no existing model that attempts to describe the relationship between specific predictors and outcomes of school re-entry. While a review of school re-entry literature anecdotally suggests variables correlated with general adjustment may also be linked to successful school re-entry, specific variables that facilitate positive school re-entry outcomes have not yet been identified. Further, variables that facilitate positive school re-entry outcomes from the perspective of the adolescent are lacking. Thus, the current study proposes a model of school re-entry success adapted from the DSC model to illustrate potential predictors and outcomes specific to school re-entry (see Figure 2). Exploratory investigation of the relationship between hypothesized predictors and outcomes may better tailor school re-entry interventions while informing future research on their effectiveness.

### Predictors

Demographics. The DSC model suggests social-ecological factors impact adjustment. The current model similarly suggests demographic characteristics, including age, race/ethnicity, gender, and socioeconomic status (SES) may have a relationship with successful school re-entry outcomes. Lower SES is consistently named a potential contributor to increased adjustment difficulties (e.g., Lavigne & Fraier-Routman, 1993; Brown & DuPaul, 1999), and is an important variable to consider in pediatric psychology research (Maloney, Clay, & Robinson, 2005).

Illness Characteristics. Illness characteristics such as type of cancer, type of treatment, age at diagnosis, experiencing relapses, and treatment duration may also impact successful school re-entry outcomes. Kazak, Segal-Andrews, and Johnson (1995) noted illness characteristics directly impact the adolescent with cancer. As noted previously, treatments or cancers impacting the CNS often have academic implications. Relapses or extended treatment time result in increased absences, which may impact both social-emotional and academic functioning (Clay, 2004; Henning & Fritz, 1983).

School Re-entry Characteristics. Premorbid academic, social, and/or emotional difficulties can be exacerbated by pediatric cancer and impact the school environment (Brown & DuPaul, 1999). School re-entry interventions thought to prevent these concerns and encourage positive outcomes were previously discussed. To briefly review, Prevatt, Heffer, & Lowe (2000) summarized five domains that should be targeted when implementing school re-entry intervention: the child/adolescent with cancer, the parents and family members, teachers and other school staff, classmates, and medical staff. Further, interventions unique to systemic needs are warranted (e.g., education, counseling, accommodations, etc.). The presence or absence of these interventions may have an impact on school re-entry outcomes.

Family adjustment and functioning. A growing body of research emphasizes investigating the impact of pediatric cancer on the child or adolescent's family (e.g., Brown, 2004; Alderfer, Navsaria, & Kazak, 2009). Family adjustment mediates child adjustment, which indirectly impacts functional independence. Family adaptability and cohesion have been shown to serve as protective factors that facilitate better outcomes through increased collaboration (Carlson, Kubiszyn, & Guli, 2004; Kazak, Simms, & Rourke, 2002). Poor family adjustment, however, can disrupt a family's ability to work with schools during school re-entry preparation, which may have implications on its outcome (Ewing-Cobbs & Bloom, 2004; Power, DuPaul, Shapiro, & Kazak, 2003; Christenson & Sheridan, 2001). Family difficulties may disrupt the adolescent's ability

to carry out daily activities such as school and social relationships (Brown, 2004). Power et al. (2003) aptly stated, “the capacity...to address the health needs of the child and family depends upon the functional status of the child, the risk and resilience of the family, and the resources and collaborations existing within school” (p. 40). To the author’s knowledge, the specific impact of family functioning on successful school re-entry outcomes has not been well studied.

#### Definition of “Successful” School Re-entry: Outcomes

van Eys (1991, 1985) argues that a “truly cured child” is one who has both medically and psychologically eliminated the disease and is “functioning on par with peers” (1985, p. 160). Brown and DuPaul (1999) described within-child factors (including social-emotional development, cognitive functioning, and age at diagnosis) and systemic variables (including SES, family adjustment, and social support) that are associated with successful school re-entry preparation. The current study specifically applied hypotheses of general adjustment to school re-entry. *Successful school re-entry* was defined as the degree of functional independence or quality of life exhibited by the adolescent with cancer within physical, academic, social, emotional domains.

Additionally, given the relative lack of adolescent perspective in research on school re-entry, successful school re-entry was defined by participants using a Likert scale (1 = *Not Successful*, 2 = *A Little Successful*, 3 = *Successful*, 4 = *Very Successful*).

#### Summary and Statement of Problem

A review of literature on psychosocial adjustment to pediatric cancer and school re-entry/reintegration leads to several conclusions. Despite being investigated over several decades, school re-entry preparation remains a burgeoning area of research with several literature gaps. The importance of returning to school to facilitate adjustment is well established, as are descriptions of recommended components of school re-entry interventions. However, knowledge of successful school re-entry outcomes, in addition

to associated predictors of those outcomes, is lacking. One potential barrier to empirically-based research in re-entry outcomes is the lack of an operationalized, measurable definition of school re-entry success. Taking what is known from research on general psychosocial adjustment, functional independence is proposed as a possible definition of successful school re-entry in the current study because school re-entry interventions appropriately emphasize independent or normative functioning in school, social, emotional, and physical domains. Quality of life, an assessment of functional independence, may be an appropriate outcome measure of functional independence (and thus, school re-entry success). Similarly, the perspectives of adolescents are largely neglected in literature. Feedback from adolescents on perceived school re-entry success is warranted. Anecdotal research on the effectiveness of specific school re-entry interventions is limited in scope, making it difficult to identify generalizable predictors of success and/or outcomes. A model adapted from the DSC model is proposed as a way to better investigate variables associated with successful school re-entry experiences.

The current study attempts to expand current research by identifying predictors that contribute to successful school re-entry from the adolescent with cancer's perspective. It adds to research by exploring systemic variables that may predict school re-entry outcomes. A theoretical framework is proposed in an attempt to define successful school re-entry outcomes. Accurately defining successful school re-entry may provide guidelines for future studies to examine school re-entry effectiveness. Exploration of predictors associated with school re-entry success may inform interventions. Similarly, the current study adds to literature by obtaining the adolescent with cancer's perspective on school re-entry. Specific research questions for the current study include:

1. Is there a relationship between demographic variables and successful school re-entry among adolescents with cancer?

2. Is there a relationship between illness characteristics and successful school re-entry among adolescents with cancer?
3. Is there a relationship between school re-entry characteristics and successful school re-entry among adolescents with cancer?
4. Is there a relationship between level of family adjustment/cohesion and successful school re-entry among adolescents with cancer?
5. Are there differences in functional independence and perceived school re-entry success among those who had school re-entry preparation and those that did not?



## CHAPTER III

### METHODS

The goal of the current study was to identify predictors that contribute to successful school re-entry from the adolescent with cancer's perspective. A descriptive approach with several quantitative measures was used. Given the paucity of research on the school re-entry experiences of adolescents with cancer, a focus group was also used to facilitate survey development (Hanson, Creswell, Clark, Petska, & Creswell, 2005).

This chapter describes the research design and methodology. First, the study design is described followed by presentation of participants and setting. Next, the investigator-developed portion of the web-based survey is discussed and predictor variables from this section are defined. Predictor variables from commercial measures are then offered. Outcome variables and measures are then presented. Next, outcome variables and measures are described. Procedures for each phase of recruitment are then presented, followed by description of data analyses for each research question.

#### Design

An exploratory, descriptive design was employed. Given the lack of research in predictors of successful school re-entry outcomes, an exploratory approach was utilized to identify variables that warrant future, more in-depth research. The general class of design was correlational and most appropriate for the study as predictor variables were analyzed according to functional independence. Although the current study is quantitative, a semi-structured focus group was used to obtain contextually-valid information from the point of view of adolescent cancer survivors to inform instrument development (Stewart, 1990; Marshall & Rossman, 2006) and pilot the survey. Acquiring the assistance of the subject matter experts (in this case, adolescent cancer survivors) helped to ensure the accuracy of the construct being studied (Morgan, 1996; Hanson et al., 2005; Creswell & Clark, 2007).

### Participants/Setting

Adolescents (ages 11 to 19) who were diagnosed with cancer or who had relapsed within the last five years were recruited to complete the web-based survey. A convenience sample from several institutions (described below) was necessary given the rarity of pediatric cancer. Inclusion criteria included (a) current age of 11 --19 years, (b) diagnosis or relapse between Jan 2008 to November 2011 (c) English-speaking, and (d) a return to a private or public school setting at least once following their cancer diagnosis and/or treatment. Exclusion criteria included non-English speaking adolescents and those with pre-cancer developmental delays (per parent or self-report of previous diagnoses). Those with developmental delays as a result of cancer/cancer treatments were included if parents deemed them capable of answering survey questions independently.

A total of 88 participants from several institutions participated in the study (overall response rate: 16.4%). Of these participants, 3 were removed from analysis for missing data on the outcome measure (PedsQL™). In addition, 3 participants who responded "Don't Know" when asked about use of free and reduced lunch (FRL), and 3 participants who received radioactive iodine treatment were removed from statistical analyses involving SES and treatment (respectively) due to insufficient numbers for comparisons.

Participants had a mean age of 14.98 years ( $SD = 2.60$ ). Fifty-five percent were female ( $n = 46$ ). Participants were primarily Caucasian ( $n = 78$ ; 93.9%) and did not receive Free and Reduced Lunch ( $n = 66$ ; 79.5%). The most common diagnosis was leukemia ( $n = 24$ ; 28.2%). The majority of participants underwent treatment for less than one year ( $n = 35$ ; 41.2%), with the most common treatment being chemotherapy ( $n = 73$ ; 85.8%). The average age at diagnosis was 11.34 years ( $SD = 3.35$ ). Most participants did not relapse ( $n = 75$ ; 88.2%). (Complete participant demographics are found in Tables 2 and 3 of Chapter IV).

### Measures

A web-based survey consisting of three sections was used: a) questions on demographic, illness, and re-entry characteristics developed by the investigator (19 items; see Appendix C), b) a standardized assessment of functional independence (Pediatric Quality of Life Scale 4.0; 23 items; see Appendix E), and c) an assessment of family functioning (Family Adaptability and Cohesion Scale-IV; 42 items; see Appendix F). A pre-existing measure that specifically addressed all purposes of this study was not available. Please see Table 1 for a description of all variables, measures, and psychometric properties.

Instrument Development. Content validity of the portion of the survey developed by the investigator regarding demographic, illness, and re-entry characteristics was first established via comprehensive review of the literature on school re-entry and consultation with experts in nursing and education who have pediatric oncology experience. Content validity was further established through consultation with adolescent cancer survivors during the focus group.

Focus group participants were asked about the characteristics of their school re-entry preparation (if any), academic, physical, and social experiences, school re-entry needs, barriers, and facilitators, and what made their school re-entry successful or unsuccessful (See Appendix B). Focus group participants also piloted an initial draft of the entire web-based survey at the conclusion of the focus group to verify its content and feasibility (i.e., completion time). Participants provided written feedback on the Demographic, Illness, and Re-entry Characteristics questions developed by the investigator (see Appendix D). Information from the focus group was then used to verify, develop, and edit the content in the Demographic, Illness, and Re-entry Characteristics portion of the web-based survey.

The initial draft contained 17 items. Based on themes from the focus group, two questions were added asking about the nature of social support during the transition back-

to-school. Survey questions were also re-ordered according to categories to facilitate ease of completion (i.e., the questions asking about illness and treatment were grouped together). The final version of this section of the survey had 19 items. Question content included demographics (4 items), illness/treatment characteristics (5 items), school re-entry characteristics (6 items), perceived social support (2 items), and perceived re-entry success (2 items).

The final version of the total survey contained 84 items, including the portion developed by the principle investigator, the PedsQL, and FACES-IV. The survey was developed using the Qualtrics survey program (Qualtrics Labs, 2009) to address the specific aims of the study. Item response formats included multiple choice, fill-in-the-blank, and Likert scale ratings. Please see Appendixes C, E, and F for all survey items.

Predictor variables defined. Demographic, Illness, and Re-entry characteristic variables originated from the investigator-developed section of the web survey. 1) *Demographic* variables included: current age, race or ethnicity (Caucasian/non-Caucasian), gender, and socioeconomic status (SES; defined by self-reported use of free and reduced lunch). 2) *Illness Characteristics* variables included: type of cancer, age when first diagnosed, type of treatment(s) received, presence of one or more relapses, and treatment duration (years). 3) *Re-entry Characteristics* variables included: time between diagnosis and return to school (months), age when the adolescent first returned to school, premorbid academic functioning (defined through self-reported use of special education assistance prior to having cancer), premorbid social functioning (defined by Likert scale ratings of social difficulties experienced prior to having cancer), premorbid emotional functioning (defined by Likert scale ratings of emotional difficulties experienced prior to having cancer), and type of re-entry preparation received, 4) *Family adjustment* was defined as the degree to which adolescents report their families are adaptable and cohesive. For the purposes of this study, family functioning can be healthy or unhealthy as assessed by the Total Circumplex Ratio of the FACES IV assessment.

*Family adjustment.* The Family Adaptability and Cohesion Scale-IV (FACES-IV; Olson, 2011) is a 62-item, self-report instrument that has been recommended as an assessment of family dynamics in previous research (Power, et al., 2003; Olson, 2011). Items are assessed on a 5-point Likert scale (Marsac & Alderfer, 2010; Franklin, Streeter, & Springer, 2001). Permission was obtained to create a web-based version of this measure (E. Bailey, personal communication, September 28, 2010). The FACES-IV yields six scales of family characteristics (a total of 42 items): Cohesion (7 items), Flexibility (7 items), Disengaged (7 items), Enmeshed (7 items), Rigid (7 items), and Chaotic (7 items). There were two additional scales (Family Communication, 10 items, and Family Satisfaction, 10 items) on the FACES-IV that were not utilized in this study as they do not contribute to the Total Circumplex Ratio calculation. The Total Circumplex Ratio was used for data analyses in the current study. The Total Circumplex Ratio score represents the degree of function or dysfunction within a family system (Olson, 2011). It is obtained by dividing the average of the Cohesion and Flexibility (balanced or healthy) scales by the average of the remaining four unbalanced or unhealthy scales. “Balanced” families are considered well-functioning. Conversely, “unbalanced” families are considered poor-functioning. Ratio scores of one indicate an equal amount of balance versus unbalance in the family system. The higher the ratio score above one, the more balanced or healthy the family system. Conversely, unhealthy families have a ratio score below one. Scoring was completed by an Excel program created by the publisher (Olson, 2011).

Adequate internal consistencies for the FACES-IV have been reported: Disengaged ( $\alpha = 0.87$ ), Enmeshed ( $\alpha = 0.77$ ), Rigid ( $\alpha = 0.83$ ), Chaotic ( $\alpha = 0.85$ ), Balanced Cohesion ( $\alpha = 0.89$ ), and Balanced Flexibility ( $\alpha = 0.80$ ; Gorall et al., 2006). In a sample of 162 families with a child with cancer, Marsac and Alderfer (2010) found evidence for construct validity with moderate correlations between parent ratings and other measures of family functioning. Similarly, Olson (2011) reported high levels of

discriminant validity of the Balanced Cohesion and Flexibility scales (percent accuracy in discriminating problem versus non-problem families = 74 - 89%) and Unbalanced Disengaged and Chaotic scales (80 - 86%), but weaker correlations on the Rigid and Enmeshed scales (54 - 64%). The Flexibility and Cohesion scales were shown to highly correlate with other assessments of family functioning, including the Family Satisfaction Scale (FSS;  $r = .89$  and  $.91$ , respectively), Self-Report Family Inventory (SFI,  $r = .98$  and  $.99$ , respectively), and the Family Assessment Device (FAD;  $r = .95$  and  $.95$ , respectively; Olson, 2011). Finally, the FACES IV has been recommended for use in pediatric psychology research (Brown, Daly, & Rickel, 2007), and specifically recommended for use with adolescents (Franklin, Streeter, & Spring, 2001). Kim and Yoo (2010) recently used the FACES-IV to identify resiliency factors in school age children with cancer.

Outcome Variables Defined. *Successful school re-entry* was the outcome variable; defined two ways. First, successful school re-entry was described as functional independence (or quality of life) within physical, academic, social, emotional domains (see Chapter 2). It was assessed via adolescent self-report on the Pediatric Quality of Life Scale (PedsQL™; Varni et al., 2002). Second, adolescents rated the perceived success of their re-entry experiences via Questions 18 on the Demographic, Illness, and Re-entry Characteristics portion of the survey.

Functional independence. The PedsQL™ (Varni et al., 2002) is a widely-used assessment of multidimensional adolescent adjustment or functional independence (Barrera et al., 2004; Porgorzala et al., 2010). The PedsQL™ is a 23-item measure of both generic core scales and health-related scales within physical (8 items), emotional (5 items), social (5 items), and school functioning domains (5 items). The Teen (ages 13-18) and Child (ages 11-12) Self-Report forms were used in this study (See Appendix E). Permission from the author to use this paper-and-pencil measure on the web was obtained (M. Sidonie, personal communication, March 10, 2011). The PedsQL™ yields individual

scale scores within each domain and summary scores of Total Scale, Physical Health, and Psychosocial Health (Varni et al., 2002). Adolescents rate each item in terms of problematic functioning on a 5-point Likert scale (0 = *Never* to 5 = *Almost Always*). Items are reverse-scored and linearly transformed to scores ranging from 0-100, with higher scores associated with better health-related quality of life (HRQL; Varni et al., 2002). The Psychosocial Health and Physical Health domain scores were used as indicators of successful school re-entry instead of the Total score to prevent potentially masking individualized effects in functioning (Varni, Burwinkle, & Seid, 2006). Standardized cut-off scores are not available for this measure.

The PedsQL™ has been used as an indicator of school functioning in children with cerebral palsy and related pain (Berrin et al., 2007). It has also been recommended for use as an outcome measure for school interventions (Varni, Burwinkle, & Seid, 2006). Internal consistency reliability coefficients of .80 for the Physical Domain and .83 for the Psychosocial Domain have been shown (Varni, Seid, & Kurtin, 2001). PedsQL™ scales differentiated between quality of life ratings of healthy children and adolescents and those with chronic and acute illnesses. Further, construct validity was demonstrated by small to medium negative correlations on the self-report form with indicators of illness burden (e.g., number of absences, care needed, etc.), ranging from -0.11 to -0.27 (Varni, Seid, & Kurtin, 2001). When used as an outcome measure of school health policies, the PedsQL™ demonstrated internal consistency reliability coefficients ranging from 0.72 to 0.89 on the individual scales of the adolescent self-report form. In addition, the school functioning scale significantly correlated with academic achievement as assessed by the Stanford 9 ( $r = 0.26, p < 0.001$ ; Varni, Burwinkle, & Seid, 2006). The PedsQL™ is the only pediatric measure of health-related quality of life (or functional independence) that is empirically validated and reports item and scale consistency (Varni, Seid, & Kurtin, 2001).

Adolescent perception of successful re-entry. Social support was an important characteristic of successful re-entry described by the focus group participants. It was translated into a question on the investigator-developed portion of the survey (Items 16 and 17), asking participants to rate the degree to which they felt supported via a Likert scale, in addition to ranking individuals they felt were most to least supportive. Survey participants also ranked the extent they felt their school re-entry experience was successful using a Likert scale ( $1 = \text{Not Successful at All} - 4 = \text{Very Successful}$ ; Item 18).

### Procedures

#### Recruitment.

Focus Group (Pilot). The focus group for instrument development was conducted in the Lindquist Center at the University of Iowa. Adolescents (18 – 21 years) who are pediatric cancer survivors (defined as those in remission, who have completed all treatment, or have No Evidence of Disease) were recruited for the focus group and initial piloting of the survey. Following approval from the University of Iowa Hospital and Clinics institutional review board, adolescents known to the author who were previous attendees of the 2010 Children's Cancer Connection's oncology summer camp ([childrenscancerconnection.org](http://childrenscancerconnection.org)) were contacted to participate using the camp address book. Inclusion criteria included (a) male and female adolescents between the ages of 18 to 21 who were treated for any type of cancer, (b) adolescents who were English-speaking, and (c) adolescents who returned or attempted to return to a private or public school setting following their cancer diagnosis and/or treatment. Exclusion criteria included non- English speaking adolescents and those with pre- and/or post-cancer developmental delays. Five adolescents were invited to participate (two males, three females). Three adolescents participated in the focus group ( $N = 3$ ). Two did not respond to requests to participate. Focus group participants were all female, had a mean age of 19 years, and were survivors of ALL ( $n = 1$ ) and non-Hodgkin's Lymphoma ( $n =$



2). A semi-structured interview was used to obtain information on the school re-entry experiences of adolescents with cancer and their perception of its success (see Appendix B).

One ninety-minute, semi-structured focus group was conducted. Group size was limited to allow for meaningful discussion (Stewart, 1990). The principle investigator served as group moderator and the meeting was audio-recorded. Each participant was reimbursed with their choice of one \$20 gift card from amazon.com, iTunes, Best Buy, Barnes and Noble, or Starbucks at the conclusion of the session. Focus group/pilot participants were not recruited again to participate in the final survey.

Web-based Survey (Study). The web-based survey was completed by participants from three states: Iowa, Ohio, and Utah. Because the survey was anonymous, information reported on participation rates from individual institutions was estimated based on time of recruitment. Recruitment occurred in two phases.

Phase One. Recruitment at the first two institutions occurred simultaneously. Support (via letter) from the interim oncology clinic director at the University of Iowa Children's Hospital (UIHC) was obtained. Following approval from the institutional review board, the names, addresses, and phone numbers of adolescents meeting inclusion criteria from the oncology clinic database were provided to the author. Two recruitment letters (verifying support from the director of the oncology clinic) were mailed to the parents of 73 adolescents who met inclusion criteria inviting them to participate in the study. Parents were asked to provide their email address for minor adolescents, and adult-aged adolescents were asked to provide personal email addresses. Parents and/or adolescents (if age 18 or over) were provided the link to the web survey in addition to information on the study's purpose, confidentiality, risks, and benefits. One adolescent passed away and three letters were returned undeliverable. Forty adolescents did not respond to the invitation; the families of those adolescents were then called once about participating in the study. Twenty-eight families provided parent email addresses and

were emailed the link to the survey so that parents could allow their adolescents access to the survey; adult-aged adolescents were emailed directly.

Potential participants were also recruited from the Children's Cancer Connection oncology summer camp attendee list ( $N = 45$ ). Participants were cross-referenced with the UIHC oncology database to prevent duplication. Recruitment occurred similarly to that of UIHC. Names and addresses of eligible participants were provided to the author. Four letters were returned undeliverable; 36 families did not respond. Nine families provided parent email addresses; the link to the survey was emailed to parents so that they may allow their adolescent access to the survey. Adult-aged adolescents were emailed directly. Thirty-seven families from both institutions provided email addresses. A total of 17 adolescents (out of a possible 118) from UIHC and Children's Cancer Connection completed the web-based survey (survey completion rate: 14.4% ).

Phase Two. Given the inadequate response rate from these institutions, additional participants were contacted through other oncology organizations known to the investigator, including Primary Children's Medical Center (Salt Lake City, UT), Central Ohio Leukemia and Lymphoma Society (Columbus, OH), and Blank Children's Hospital (Des Moines, IA). Additional approvals from the institutional review boards of Primary Children's Medical Center and Blank Children's Hospital were obtained. Research through the Central Ohio Leukemia and Lymphoma Society was overseen by the University of Iowa's institutional review board. Appropriate IRB modifications were made. Recruitment occurred as follows:

Primary Children's Medical Center. Following approval from their institutional review board, the names and addresses of families with adolescents meeting inclusion criteria were provided to the author. Letters providing the direct link to the web survey and information on the study's purpose, confidentiality, and risks/benefits were mailed to 284 families. Parents were asked to allow minor adolescents access to the survey; adult-aged adolescents were asked to access the survey directly. Eight letters were returned

undeliverable and four adolescents passed away. Forty-one adolescents from this institution completed the survey (response rate: 14.4%).

Central Ohio Leukemia and Lymphoma Society. Per this organizations request, the names and addresses of potential participants were kept anonymous from the principle investigator. Two rounds of letters inviting 115 families with adolescents meeting inclusion criteria were mailed directly from this organization to potential participants. The direct link to the web survey and information on the study's purpose, confidentiality, and risks/benefits was provided in the letter. The organization also sent letters indicating their support of the study. Parents were asked to allow minor adolescents access to the survey; adult-aged adolescents were asked to access the survey directly. A total of 16 adolescents participated from this institution (response rate: 13.9%).

Blank Children's Hospital. Following approval from this institution's review board, two rounds of letters requesting parent/adult-aged adolescent emails were mailed to 20 families with adolescents meeting inclusion criteria. These letters included information on the study's purpose, confidentiality, and risks/benefits. Per this institution's request, names and addresses of potential participants were kept anonymous from the investigator. Oncology clinic staff members sent the letters. Participants were cross-referenced by Blank Children's staff to avoid duplication with Children's Cancer Connection. Fourteen parents responded to the letters and were emailed the link to the web survey. Fourteen adolescents completed the survey from this institution (response rate: 70%).

Data Collection. Following recruitment from each institution, parents of minor adolescents provided access to the survey (or adult-aged adolescents accessed the survey directly). Parents providing access to minors served as implied consent; submission of the survey served as adolescent consent/assent. Participants completed the survey online; average completion time was 15 minutes.

Participants could elect to receive their choice of one \$10 gift card to iTunes, amazon.com, Best Buy, or Barnes and Noble. Participants who wished to be reimbursed were provided a link to a separate survey to provide their contact information at the end of the survey; this information could not be linked to any responses on the web-based survey.

Data Management. Contact information from each institution (when applicable) was stored in secure, password-protected databases and remained confidential. The Central Ohio Leukemia and Lymphoma Society and Blank Children's Hospital managed their own contact information. Hard copies of returned letters (when applicable) were shredded upon receipt. Emails exchanged between the principle investigator and the recruiting institutions were also deleted upon receipt.

Survey data were collected within the secure, password-protected Qualtrics (Qualtrics Labs, 2009) database through the University of Iowa. Information is stored within this program for one year and then deleted by the University. Survey responses were anonymous and contained no personal identifying information that could be linked to responders, even those responders for which the investigator had contact information. All survey data and contact information (when applicable) was managed by the principle investigator.

#### Data Analyses

Demographic, illness, school re-entry characteristics (as assessed through the web-based survey), and family adjustment (as assessed through the Circumplex Total Ratio on the FACES IV) were independent variables in analyses. School re-entry success, defined as functional independence assessed through the Psychosocial and Physical Health scores on the PedsQL<sup>™</sup>, and perceived success re-entry success ratings, were dependent variables (see Table 1). Analysis comparing potential differences between responders and non-responders was not possible since information on non-

responders was not available. Similarly, analysis between groups of responders from each institution was not possible since the survey was anonymous.

For each test, the probability of a Type I error was set at .05 ( $\alpha = .05$ ). However, given the large number of tests conducted, the familywise Type I error in this study is very high. In order to restrain the familywise Type I error, a lower alpha level or a correction factor (e.g., Bonferroni) could have been employed. Given the lower power of the current study due to the nature of the sample, however, a Bonferroni or similar correction was not used due to the risk of having masked effects (i.e., Type II errors). This methodology is appropriate because the nature of the current study is exploratory; the aims are to investigate an under-researched phenomenon, so strong conclusions will not be made. Instead, variables identified that warrant further investigation will inform future research. Analyses for each research question are described below.

*Question 1: Is there a relationship between demographic variables and successful school re-entry among adolescents with cancer?* Descriptive statistics were used to explain the demographic characteristics of the sample. Current age, race/ethnicity (Caucasian and non-Caucasian), gender (male/female), and free and reduced lunch (FRL; Yes or No) were independent variables in analyses (see Table 1). School re-entry success, defined as Physical and Psychosocial Functional Independence on the PedsQL™ and the adolescents' perceived school re-entry success, were the dependent variables. First, Pearson correlations (age) and t-tests (race/ethnicity, gender, and FRL) were used to describe the relationship between the demographic variables and the PedsQL™ Psychosocial Health and Physical Health scores and perceived school re-entry success ratings. Second, separate multiple regressions were used to explore the relationship between the set of demographic independent variables and the outcome variables. The regression analysis was conducted three times, once for Psychosocial Health, once for Physical Health, and once for perceived school re-entry success ratings.

*Question 2: Is there a relationship between illness characteristics and successful school re-entry among adolescents with cancer?* Descriptive statistics were used to depict illness characteristics of the sample. Given the large number of predictors and relatively low power, predictor variables within Cancer and Treatment types were reduced to those most commonly found within the sample for multiple regressions. Cancer type (Leukemia, Hodgkin's Lymphoma, Brain Tumor), age at diagnosis, treatment type (radiation, chemotherapy, and surgery), presence of relapse (Yes or No), and time in treatment (years) served as independent variables in analyses. School re-entry success (defined as functional independence as assessed through the Psychosocial and Physical Health scores on the PedsQL™ and the adolescents' perceived school re-entry success) were dependent variables (see Table 1). First, Pearson correlations (age at diagnosis, time in treatment), t-tests (all treatment types, presence of relapse), and Analysis of Variance (ANOVA) were used to describe the relationship between the illness variables and the outcome variables. ANOVA could not be used to assess differences among treatment types because participants typically underwent more than one type of treatment at a time (e.g., radiation and chemotherapy). Second, separate multiple regressions were used to explore the relationship between the set of illness characteristic independent variables and the outcome variables. The regression analysis was conducted three times, once for Psychosocial Health, once for Physical Health, and once for perceived school re-entry success ratings.

*Question 3: Is there a relationship between re-entry characteristics and successful school re-entry among adolescents with cancer?* Descriptive statistics were used to illustrate school re-entry characteristics. Time between diagnosis/relapse and initial return to school, age at re-entry, premorbid academic functioning, premorbid social functioning, premorbid emotional functioning, and whether school re-entry preparation was received (Yes or No) were the independent variables in analyses. School re-entry success (defined as functional independence as assessed through the Psychosocial and

Physical Health scores on the PedsQL™ and the adolescents' perceived school re-entry success) were the dependent variables (see Table 1). First, Pearson correlations (time between diagnosis and re-entry, age at re-entry, premorbid academic, social, and emotional functioning) and t-tests (whether school re-entry preparation was received) were used to describe the relationship between the demographic and outcome variables. Second, separate multiple regressions were used to explore the relationship between the set of school re-entry independent variables and outcome variables. The regression analysis was conducted three times, once for Psychosocial Health, once for Physical Health, and once for perceived school re-entry success.

*Question 4: Is there a relationship between level of family adjustment/cohesion and successful school re-entry among adolescents with cancer?* Descriptive statistics were used to describe characteristics of family adjustment. Separate t-tests were used to examine group differences in family adjustment among those adolescents who reported receiving school re-entry preparation and those who did not. Family adjustment (defined by the Circumplex Total Ratio score) was the independent variable in analyses. School re-entry success (defined as functional independence as assessed through the Psychosocial and Physical Health scores on the PedsQL™ and the adolescent's perceived school re-entry success) were the dependent variables (see Table 1). A Pearson correlation was used to describe the relationship between family adjustment and the outcome variables.

*Question 5: Are there differences in functional independence or perceived school re-entry success among those who had school re-entry preparation and those who did not?* Descriptive statistics were used to explain the percentage of adolescents who perceived their re-entry experience as successful. A t-test was used to examine group differences in functional independence scores (as assessed by the Psychosocial Health and Physical Health scores on the PedsQL™) among those adolescents who reported receiving school re-entry preparation and those who did not. Pearson correlation was

used to examine relationships between how successful they rated their school re-entry experience and Psychosocial and Physical Health ratings on the PedsQL™.



Table 1

*Variables, Measures, Psychometrics, and Research Questions*

Variable	Research Question	Measure	Psychometrics
<b>Predictors</b>			
<i>Demographics</i> Age Caucasian/Non-Caucasian Gender SES	Question 1	Survey (items 1- 4)	4 items: multiple choice, fill-in-blank; Content validity from focus group (adolescent cancer survivors; $N = 3$ ), review of literature, and colleagues in nursing and education fields
<i>Illness Characteristics</i> Cancer Type Age at Diagnosis Treatment Type Relapse(s) Time in Treatment (years)	Question 2	Survey (items 5-9)	5 items: multiple choice, fill-in-blank; Content validity from focus group (adolescent cancer survivors; $N = 3$ ), review of literature, and colleagues in nursing and education fields
<i>Re-Entry Characteristics</i> Time Between Diagnosis and initial Re-Entry Age at Re-Entry Premorbid Academic Functioning Premorbid Social Functioning Premorbid Emotional Functioning Reentry Preparation Received	Question 3, 5	Survey (items 10-17)	6 items: fill-in-blank, Likert scale, multiple choice; Content validity from focus groups (adolescent cancer survivors), review of literature, and colleagues in nursing and education fields
<i>Family Functioning</i>	Question 4	FACES IV Total Circumplex Ratio	42 items: Likert scale

Table 1—continued

Cohesion	$\alpha = 0.89^a, r = .95^b$
Flexibility	$\alpha = 0.84^a, r = .95^b$
Disengaged	$\alpha = 0.87^a, r = -.93^b$
Enmeshed	$\alpha = 0.77^a, r = -.31^b$
Rigid	$\alpha = 0.82^a, r = -.25^b$
Chaotic	$\alpha = 0.86^a, r = -.71^b$
CircumplexTotal Ratio <sup>c</sup>	--

### Outcome

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<i>Functional Independence</i>	Questions 1-4	PedsQL™	23 items: Likert Scale
Psychosocial Health		Psychosocial and	$\alpha = 0.83^c; r = -.27^d$
Physical Health		Physical Health Scale	$\alpha = 0.80^c; r = -.18^d$
		Scores	
<i>Perceived Reentry Success</i>	Question 18		1 item: Likert Scale

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*Note.* FACES IV = Family Adaptability and Cohesion Evaluation Scales; <sup>a</sup>Cronbach's alpha from Olson (2011); <sup>b</sup>Convergent construct validity with the Family Assessment Device (FAD) from Olson (2011). Negative correlations on some scales are expected given high extremes on the FACES IV coincide with low functioning on the FAD; <sup>c</sup>Cronbach's alpha from Varni, Seid, & Kurtin (2001); <sup>d</sup>Construct validity with level of care needed from Varni, Seid, & Kurtin (2001); <sup>e</sup> Reliability and validity information is currently unavailable for this ratio given it is only used in research and a new addition from previous versions of the FACES.

## CHAPTER IV

### RESULTS

Descriptive statistics for the measure of successful re-entry, the outcome of interest in this study, are presented first. This section is followed by the analyses for questions one through four, which investigated clusters of independent variables and their impact on successful school re-entry. Descriptive statistics and results of independent-samples t-tests, Pearson correlation coefficients, and multiple regressions are presented for each of the categories of independent variables from the modified DSC-model: demographics, illness characteristics, school re-entry characteristics, and family adjustment. Finally, the analyses for question five are presented, which examined school re-entry preparation.

#### Outcome Variables

The outcome of interest for this study was successful school re-entry. The Psychosocial and Physical Domain scores of the PedsQL™ were used as measures of this outcome in the study; these scores approximated functional independence, or the degree to which the participant independently functioned within physical, academic, social, and emotional arenas at the time of his/her return to school. It assesses typical or normative daily functioning, which is the proposed goal of school re-entry preparation and reintegration. According to Varni, Burwinkle, and Seid (2006), Physical Health scores between 61.17 - 95.53 and Psychosocial Health scores between 50.54 - 85.46 are indicative of average quality of life ratings for children and adolescents with chronic medical conditions. The average rating of physical quality of life in this sample was 50.69 ( $SD = 23.03$ ), and the average psychosocial rating was 59.94 ( $SD = 19.96$ ). Participants in the current study reported a mean level of independent physical functioning lower than the normative range presented by Varni et al. (2006), while the mean level of independent psychosocial (academic, emotional, and social) functioning

was within the normative range. Given that a relatively large proportion of participants received substantial treatments such as radiation and surgery, it is not unexpected that they reported lower levels of physical functioning than children and adolescents with more general chronic illnesses (such as diabetes) in Varni and colleague's study.

Given the lack of research on the adolescent perspective of school re-entry, participants were also asked to rate the perceived success of their school re-entry experience (1 = *Not Successful*, 2 = *A Little Successful*, 3 = *Successful*, 4 = *Very Successful*). The majority of adolescents in this study indicated their school re-entry experience was "Successful" ( $M = 3.07$ ,  $SD = .910$ ). The PedsQL™ Physical, PedsQL™ Psychosocial, and adolescent ratings of school re-entry success were used as separate outcome measures in analyses, described below. Please see Table 4 for description of outcome variables.

Separate Pearson product-moment correlation coefficient revealed a large, positive correlation between perceived re-entry success and psychosocial functional independence ( $r = .520$ ,  $p < .001$ ). A small, positive correlation was found between perceived re-entry success and physical functional independence ( $r = .250$ ,  $p = .021$ ).

Question 1: Is there a relationship between demographic variables and successful school re-entry among adolescents with cancer?

Descriptive Statistics (see Tables 2 and 3). The relationship between demographic variables (current age, ethnicity, gender, and SES) and successful school re-entry was examined among adolescents in the current sample, as follows:

Current Age. The relationship between the participants' current age and functional independence (as measured by the PedsQL™ Physical and Psychosocial Domains and adolescent school re-entry success ratings) was investigated using separate Pearson product-moment correlation coefficient. Preliminary analyses were performed to

ensure no violation of the assumption linearity. There were very small, negative, nonsignificant correlations between current age and physical ( $r = -.082$ ;  $p = .463$ ) and psychosocial ( $r = -.083$ ;  $p = .458$ ) functional independence at the time of school re-entry. Similarly, a small, nonsignificant relationship was found between participant age and ratings of perceived school re-entry success ( $r = .202$ ;  $p = .067$ ).

Ethnicity. Separate independent-samples t-tests were conducted to compare ratings of physical and psychosocial functional independence and perceived school re-entry success for Caucasian and non-Caucasian (or minority) participants. Assumptions of equal variance were met. There were no significant differences in ratings of physical functioning, psychosocial functioning, or perceived school re-entry success among minority and non-minority participants. See Table 5.

Gender. Separate independent-sample t-tests were also used to compare differences in ratings of physical functioning, psychosocial functioning, and perceived school re-entry success among males and females. Assumptions of equal variance were met. Males endorsed significantly higher independent physical functioning ( $M = 56.59$ ,  $SD = 23.06$ ) than females ( $M = 43.03$ ,  $SD = 20.83$ ),  $t(83) = 2.82$ ,  $p = .006$ . The magnitude of differences in the means (*mean difference* = 13.56, 95% CI: 4.00 - 23.12) was moderate (*eta squared* = .088).

Males also rated higher independent psychosocial functioning ( $M = 63.88$ ,  $SD = 19.81$ ) than females ( $M = 55.09$ ,  $SD = 19.54$ ),  $t(83) = 2.05$ ,  $p = .043$ . The magnitude of the differences in the means (*mean difference* = 8.79, 95% CI: .267 - 17.32) was small (*eta squared* = .048).

Finally, no significant differences were found in ratings of perceived school re-entry success among males and females in the sample. See Table 5.

SES. SES was assessed by self-reported use of FRL at the time of school re-entry. Separate independent-samples t-tests were conducted to investigate differences in physical functioning, psychosocial functioning, and perceived school re-entry success

among those who had FRL and those who did not. No significant differences were found among ratings of independent physical or psychosocial functioning among those of differing SES. Similarly, no significant differences in ratings of perceived school re-entry success were found. See Table 5.

Relationship Between Demographic Variable Set and Physical Functional Independence. Standard multiple regression was used to examine how well this set of demographic variables (age, ethnicity, gender, and SES) predicted physical functional independence among adolescents with cancer/cancer survivors in the sample. Preliminary analyses were conducted to ensure no violation of the assumptions of normality, linearity, multicollinearity and homoscedasticity. Results of the regression indicated this set of variables did not significantly predict physical functional independence ratings ( $R^2 = .107$ ,  $F(4, 73) = 2.198$ ,  $p = .078$ ). However, it was found that gender made a statistically significant, unique contribution to physical functional independence ( $\beta = -.303$ ,  $p = .010$ ), explaining 8.5% of the variance. See Table 6.

Relationship Between Demographic Variable Set and Psychosocial Functional Independence. Standard multiple regression was again used to explore whether the set of demographic variables predicted psychosocial functional independence. Results indicated that this model significantly predicted psychosocial functional independence in adolescents with cancer/cancer survivors ( $R^2 = .126$ ,  $F(4, 73) = 2.62$ ,  $p = .042$ ), explaining 12.6% of the variance. Specifically, gender made the strongest unique contribution ( $\beta = -.278$ ,  $p = .017$ ), explaining 7.7% of the variance, suggesting being female predicted poorer psychosocial functioning. SES also made a statistically significant unique contribution ( $\beta = -.262$ ,  $p = .029$ ), explaining 5.9% of the variance. Lower SES predicted poorer psychosocial functioning. See Table 6.

Relationship Between Demographic Variable Set and Perceived School Re-entry Success. Finally, standard multiple regression was used to explore how well these demographic variables predicted perceived school re-entry success. Results indicated

this set of variables did not significantly predict perceived school re-entry success ( $R^2 = .113$ ,  $F(4, 73) = 2.32$ ,  $p = .065$ ). However, it was found that gender made a statistically significant, unique contribution ( $\beta = -.229$ ,  $p = .049$ ), uniquely explaining 4.9% of the variance. See Table 7.

Question 2: Is there a relationship between illness characteristics and successful school re-entry among adolescents with cancer?

Descriptive Statistics. The average age of diagnosis was 11.34 years ( $SD = 3.35$ ). The most common diagnoses were leukemia ( $n = 24$ ; 28.2%), brain tumor ( $n = 13$ , 15.3%), and Hodgkin's Lymphoma and Sarcoma (both  $n = 12$ , 14.1%). The majority of participants underwent treatment for less than one year ( $n = 35$ ; 41.2%), with the most common treatments being chemotherapy ( $n = 73$ ; 85.8%), surgery ( $n = 50$ , 58.8%), and radiation ( $n = 36$ , 42.4%). Many participants had a combination of treatments. Most participants did not relapse ( $n = 75$ ; 88.2%). Please see Tables 1 and 2 for a complete description of illness characteristics. The impact of illness characteristics on successful school re-entry in the current sample was examined by the following:

Age at Diagnosis. The relationship between the participants' age at diagnosis and physical functional independence, psychosocial functional independence, and perceived school re-entry success was investigated using separate Pearson product-moment correlation coefficient. Preliminary analyses were performed to ensure no violation of the assumption of linearity. None of the correlations between age of diagnosis and the outcome variables reached significance. See Table 8.

Time in Treatment. The relationship between time in treatment and physical functioning, psychosocial functioning, and perception of school re-entry success was examined with separate Pearson product-moment correlation coefficients. Small, negative, nonsignificant correlations were found between time in treatment and physical

( $r = -.081$ ,  $p = ns$ ), psychosocial ( $r = -.130$ ,  $p = ns$ ) functioning and perceived re-entry success ( $r = -.120$ ,  $p = ns$ ). See Table 8.

Cancer Type. Separate univariate analyses of variance (ANOVAs) were conducted to explore the impact of cancer type on ratings of physical functional independence, psychosocial functional independence, and perceived school re-entry success. Given the large number of cancer types that were explored with respect to the current sample size, cancer types were reduced and grouped according to similar type for analysis. This created five groups used in analysis: brain tumor ( $n = 13$ ), solid tumor ( $n = 23$ ), leukemia/blood ( $n = 24$ ), Hodgkin's ( $n = 12$ ), and Non-Hodgkin's ( $n = 11$ ). No significant differences in ratings of physical functional independence were found among the different cancer types ( $F(4, 78) = .412$ ,  $p = .800$ ). Similarly, no significant group differences were found in psychosocial ratings ( $F(4, 78) = 1.72$ ,  $p = .154$ ). Finally, no significant differences between groups were found in perception of school re-entry success ( $F(5, 79) = 1.32$ ,  $p = .266$ ).

Treatment Type. Separate independent-samples t-tests were conducted to compare physical and psychosocial functional independence and perceived school re-entry success for each type of treatment: chemotherapy, surgery, radiation, and bone marrow transplant. Assumptions of equal variance were met. There were no significant differences in functional independence (physical or psychosocial) among those who received any type of treatment versus those who did not. There were also no differences in ratings of perceived school re-entry success among those who received chemotherapy, surgery, BMT, and those who did not. However, those participants who did not receive radiation therapy ( $M = 3.33$ ,  $SD = .828$ ) reported significantly more successful school re-entry experiences than those who did receive radiation ( $M = 2.88$ ,  $SD = .927$ ),  $t(83) = 2.34$ ,  $p = .022$ . The magnitude of differences in the means (*mean difference* = .456, 95% CI: .069 - .083) was moderate (*eta squared* = .062). See Table 9.



Relapse. Separate independent-samples t-tests were used to compare ratings of physical and psychosocial functional independence and perceived school re-entry success among those participants who relapsed and those who did not. Assumptions of equal variances were met. There were no significant differences found in functional independence (physical or psychosocial) or perceived school re-entry success among the groups. See Table 10.

Relationship Between Set of Illness Characteristics and Physical Functional Independence. Standard multiple regression was used to examine how well this set of illness characteristics predicted physical functional independence among adolescents impacted by cancer in the sample. Given the number of participants relative to the number of illness predictors, only those types of cancers and treatments most commonly found in the sample were entered in the regression: leukemia, brain tumor, Hodgkin's Lymphoma, surgery, radiation, and chemotherapy. Years in treatment, age at diagnosis, and presence of relapse were also included in regression analyses. Preliminary analyses ensured no violation of assumptions. Results of the regression indicated this variable set did not significantly predict physical functional independence ratings ( $R^2 = .117$ ,  $F(9, 75) = 1.11$ ,  $p = .078$ ). No individual predictors uniquely contributed to physical functional independence. See Table 11.

Relationship Between Set of Illness Characteristics and Psychosocial Functional Independence. Standard multiple regression was again used to examine how well this set of reduced illness characteristic variables predicted psychosocial functional independence (see Table 11). Assumptions were met. Results indicated this model as a whole significantly predicted psychosocial functional independence ( $R^2 = .217$ ,  $F(9, 75) = 2.31$ ,  $p = .024$ ), explaining 21.7% of the variance. Several individual predictors provided significant unique predictive power, including leukemia ( $\beta = -.268$ ,  $p = .050$ ), brain tumor ( $\beta = -.251$ ,  $p = .042$ ), chemotherapy ( $\beta = -.262$ ,  $p = .031$ ), surgery ( $\beta = -.320$ ,  $p = .015$ ), and years in treatment ( $\beta = -.344$ ,  $p = .016$ ). Having leukemia and undergoing

chemotherapy explained the largest amounts of unique variance (4.1% and 5.1%, respectively). See Table 11.

Relationship Between Set of Illness Characteristics and Perceived School Re-entry Success. Finally, standard multiple regression was used to investigate how well this set of illness characteristics predicted perceived school re-entry success.

Assumptions were met. This model did not reach statistical significance ( $R^2 = .155$ ,  $F(9, 75) = 1.52$ ,  $p = .155$ ). However, undergoing radiation ( $\beta = -.291$ ,  $p = .016$ ) and having leukemia ( $\beta = -.283$ ,  $p = .046$ ) uniquely contributed to 6.8% and 4.6% of the variance in perceived school re-entry success, respectively. See Table 12.

Question 3: Is there a relationship between school re-entry characteristics and successful school re-entry among adolescents with cancer?

Descriptive Statistics. Most participants were average to higher functioning overall, reporting higher levels of pre-diagnosis social ( $M = 87.7$ ;  $SD = 15.3$ ) and emotional ( $M = 89.29$ ;  $SD = 13.0$ ) functioning. Similarly, most participants did not receive pre-morbid special education services (90.6%,  $n = 77$ ). Participants were an average age of 12.49 years ( $SD = 2.99$ ) at the time of re-entry and took an average of 2.5 months to return to school ( $SD = 1.38$ ) after being diagnosed. The majority of participants reported receiving some type of school re-entry preparation (83.5%;  $n = 71$ ). Preparation included talking with the school nurse (41.1%,  $n = 35$ ), teachers (76.4%,  $n = 65$ ), and classmates (32.9%,  $n = 28$ ). Approximately one-quarter of participants indicated re-entry preparation included developing an IEP or 504 plan (25.9%;  $n = 22$ ). Please see Tables 1 and 2 for a complete description of school re-entry characteristics. The impact of school re-entry characteristics on successful school re-entry was investigated in the current sample, as follows:

Time to Re-Entry, Age at Re-Entry, Pre-morbid Social, Emotional Functioning.

The relationships between these variables and physical functioning, psychosocial functioning, and perception of school re-entry success was examined with Pearson product-moment correlation coefficient. Preliminary analyses were performed to ensure no violation of the assumption of linearity. No significant relationships were found between these variables and perceived school re-entry success or physical functional independence. However, several small, significant relationships were found involving psychosocial functional independence. First, time to re-entry ( $r = -.24, p = .024$ ), with greater time out of school associated with poorer psychosocial functioning. Second, pre-morbid social functioning ( $r = .27, p = .012$ ), with better pre-morbid social functioning associated with better psychosocial functional independence. Finally, pre-morbid emotional functioning ( $r = .228, p = .037$ ), with better pre-morbid emotional functioning associated with higher psychosocial functional independence. See Table 13.

Pre-morbid Academic Functioning. Separate independent-sample t-tests were used to compare differences in ratings of physical and psychosocial functional independence and perceived school re-entry success among those who received pre-morbid special education services and those who did not. Assumptions of equal variance were met. Those participants who did not receive special education rated significantly higher psychosocial independence ( $M = 61.96, SD = 19.16$ ) than those who received special education ( $M = 42.50, SD = 19.60$ ),  $t(80) = 2.72, p = .008$ . The magnitude of differences in the means (*mean difference* = 19.46, 95% CI: 5.24 - 33.68) was small (*eta squared* = .085). No significant differences were found in ratings of physical functional independence or perceived re-entry success. See Table 14.

Perceived Social Support. The majority of participants indicated they felt very supported (72.9%,  $n = 62$ ) or somewhat supported (22.4%,  $n = 19$ ) by others when going back to school. Ninety percent ( $n = 77$ ) of participants indicated their parents were most supportive, as were friends (40%;  $n = 34$ ), teachers (31.8%;  $n = 27$ ), and classmates

(23.5%;  $n = 20$ ). Participants also listed church groups, medical staff, and cancer organizations as sources of social support.

The relationship between social support and physical/psychosocial functional independence and perceived school re-entry success was examined using Pearson product-moment correlation coefficient. A medium, positive correlation was found between social support and school re-entry success ( $r = .471, p < .001$ ), as well as psychosocial functional independence ( $r = .429, p < .001$ ). No statistically significant relationship was found between social support and physical functioning.

To further explore the impact of social support, separate independent-samples  $t$ -tests were used to investigate differences in psychosocial functional independence, physical functional independence, and perceived school re-entry success among those who rated higher and lower social support. Participants were grouped according to ratings of perceived social support using median split. Assumptions of equal variance were met. No significant differences in physical functional independence were found among those who rated higher or lower social support. However, those who endorsed higher social support reported significantly better psychosocial functional independence ( $M = 64.91, SD = 15.83$ ) than those who endorsed lower social support ( $M = 49.93, SD = 22.95$ ),  $t(82) = 3.45, p = .001$ . Similarly, those who endorsed higher social support perceived their school re-entry experiences as significantly more successful ( $M = 3.34, SD = .757$ ) than those who reported lower social support ( $M = 2.52, SD = .918$ ),  $t(82) = 4.25, p < .001$ . See Table 15.

Relationship Between Set of School Re-Entry Characteristics and Psychosocial Functional Independence. Standard multiple regression was used to investigate how well this set of re-entry characteristics (Premorbid social, emotional, and academic functioning, time from diagnosis to re-entry, age at re-entry, and no school re-entry preparation) predicted ratings of psychosocial functional independence. Assumptions were met. The model as a whole significantly predicted psychosocial functional

independence ( $R^2 = .491$ ,  $F(7, 72) = 9.91$ ,  $p < .005$ ), explaining 49.1% of the variance.

Several predictors made significant, unique contributions to the prediction, including age at re-entry ( $\beta = -.187$ ,  $p = .036$ ), receiving pre-morbid special education services ( $\beta = -.275$ ,  $p = .004$ ), and not having school re-entry preparation ( $\beta = .252$ ,  $p = .005$ ).

Receiving pre-morbid special education services served as the largest unique predictor, explaining 4.2% of the variance. See Table 16.

Relationship Between Set of School Re-Entry Characteristics and Physical Functional Independence. Standard multiple regression was used to explore how well this set of re-entry characteristics predicted physical functional independence.

Assumptions were met. This model was found to significantly predict physical functioning ( $R^2 = .227$ ,  $F(7, 72) = 3.03$ ,  $p = .008$ ), explaining 22.7% of the variance.

Exploration of individual predictors suggested receiving pre-morbid special education services ( $\beta = -.229$ ,  $p = .047$ ) and not receiving school re-entry preparation ( $\beta = .289$ ,  $p = .009$ ) significantly predicted unique variance, with no school re-entry preparation being the largest predictor (6.7%). See Table 16.

Relationship Between Set of School Re-Entry Characteristics and Perceived School Re-Entry Success. Finally, standard multiple regression was used to investigate this model's ability to predict perceived school re-entry success. Assumptions were met. Results indicated this set of characteristics significantly predicted perceived re-entry success ( $R^2 = .156$ ,  $F(6, 73) = 2.24$ ,  $p = .049$ ), explaining 15.6% of the variance. Not having school re-entry preparation again made a significant, unique contribution, predicting 8.2% of the variance ( $\beta = .298$ ,  $p = .009$ ). Age at re-entry approached, but did not reach, statistical significance as an individual predictor ( $\beta = .224$ ,  $p = .051$ ). See Table 17.

Question 4: Is there a relationship between family adjustment/cohesion and successful school re-entry among adolescents with cancer?

Family Adjustment/Cohesion. Most participants reported a high level of family adjustment and cohesion on the FACES-IV ( $M = 2.75$ ;  $SD = 1.18$ ). On the FACES-IV, The higher the Total Circumplex ratio score above one, the more balanced or healthy the family system. Participants' were grouped according to family adjustment ratings using median split. Separate independent-samples t-tests were used to compare differences in physical and psychosocial functional independence and perceived school re-entry success among those participants who rated lower family adjustment and those who rated higher family adjustment. Assumptions were met. No statistically significant differences were found in ratings of physical functional independence. Differences in ratings of perceived school re-entry success approached, but did not reach, statistical significance. However, those participants who reported higher family adjustment also reported significantly higher psychosocial functional independence ( $M = 65.33$ ,  $SD = 15.47$ ) than those who rated lower family adjustment ( $M = 53.77$ ,  $SD = 22.11$ ,  $t(81) = -2.76$ ,  $p = .007$ ). The magnitude of differences in the means (*mean difference* = -11.55, 95% CI: -19.88 - -3.22) was moderate (*eta squared* = .085). See Table 18.

Pearson product-moment correlation coefficient was used to describe the relationship between family adjustment/cohesion and the outcome variables. Assumptions were met. A medium, positive correlation was found between family adjustment and psychosocial functional independence ( $r = .413$ ;  $p < .001$ ), with higher family adjustment associated with better psychosocial functional independence. A small, positive correlation was found between family adjustment and physical functional independence ( $r = .250$ ;  $p = .022$ ), with higher family adjustment associated with better physical functional independence. Finally, a small, positive correlation was found

between family adjustment and perceived school re-entry success ( $r = .267$ ;  $p = .015$ ), with higher family adjustment associated with greater perceived success.

Question 5: Are there differences in functional independence and perceived school re-entry success among those who had school re-entry preparation and those that did not?

Participants who did not receive re-entry preparation ( $n = 14$ ) were mostly males (71.4%,  $n = 10$ ) with solid tumors (28.6%,  $n = 4$ ). They were in treatment for a shorter period of time (less than one year; 50%,  $n = 7$ ), but otherwise qualitatively similar to the overall sample.

Separate independent-samples t-tests were used to compare differences in ratings of physical and psychosocial functional independence and perceived school re-entry success among those participants who received any type of school re-entry preparation and those who did not. Assumptions were met. There were no statistically significant differences between groups among psychosocial and physical functional independence. Interestingly, those who did not receive school re-entry preparation ( $M = 3.18$ ;  $SD = .816$ ) rated significantly higher perceived school re-entry success than those who did ( $M = 2.50$ ;  $SD = 1.16$ ),  $t(83) = 2.66$ ,  $p = .009$ . The magnitude of differences in the means (*mean difference* = .683, 95% CI: .172 - 1.19) was moderate (*eta squared* = .079). See Table 14.

Table 2

*Means, Standard Deviations, and Ranges for Continuous Demographic, Illness Characteristics, School Re-Entry, and Family Adjustment Variables (N = 85)*

Variable	N	Mean	SD	Minimum	Maximum
Demographic Variables					
Current Age	83	14.98	2.60	11	19
Illness Variables					
Age at Diagnosis	85	11.34	3.35	6	17
Years in Treatment	85	2.06	1.05	1	3
School Reentry Variables					
Months to Reentry	85	2.56	1.38	1	5
Age at Reentry	84	12.49	2.99	6	18
Premorbid Emotional	84	89.29	13.04	50	100
Premorbid Social	84	87.70	15.28	25	100
Family Functioning					
Circumplex Ratio	83	2.75	1.18	0.66	5.82

*Note.* SD = Standard Deviation. Premorbid Emotional = emotional functioning on a scale of 1 - 100, with higher scores associated with better functioning. Premorbid Social = social functioning on a scale of 1 - 100, with higher scores associated with better functioning. Circumplex Ratio = assessment of family adjustment from FACES - IV.



Table 3

*Categorical Demographic, Illness Characteristics, School Re-Entry, and Family Adjustment Variables*

Variable	<i>N</i>	Percentage
<b>Demographic Variables</b>		
Caucasian	78	93.9
Non-Caucasian	7	8.4
Male	39	46.9
Female	46	55.4
FRL - Yes	18	21.7
FRL - No	66	79.5
FRL - DK	1	1.2
<b>Illness Variables</b>		
Leukemia	24	28.2
Solid Tumor	9	10.6
Brain Tumor	13	15.3
Hodgkin's Lymphoma	12	14.1
Non-Hodgkin's Lymphoma	11	12.9
Neuroblastoma	2	2.4
Sarcoma	12	14.1
Wilms' Tumor	2	2.4
Rhabdomyosarcoma	1	1.1
Retinoblastoma	2	2.3
Chemotherapy	73	85.8
Radiation	36	42.4
Surgery	50	58.8
BMT	8	9.4
Relapse - Yes	4	4.7
Relapse - No	75	88.2

Table 3—continued

## School Re-Entry Variables

Premorbid Academic	8	9.4
Teachers Prepared	65	76.4
School Nurse Prepared	35	41.1
Classmates Prepared	28	32.9
IEP/504	22	25.9
None	14	16.5

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*Note.* FRL = free and reduced lunch. BMT = bone marrow transplant. IEP = individualized education plan. 504 = 504 plan.

Table 4

*Means, Standard Deviations, and Ranges for Outcome Variables (N = 85)*

Variable	<i>N</i>	Mean	<i>SD</i>	Minimum	Maximum
PedsQL™					
Psychosocial	85	59.94	19.96	8.33	96.67
Physical	85	50.69	23.03	3.13	100
Perceived Success	85	3.07	0.91	1	4

*Note.* *SD* = Standard Deviation. PedsQL™ = Pediatric Quality of Life Scale 4.0. Perceived School Re-Entry assessed by Likert scale ratings (1 = *Not Successful*, 2 = *A Little Successful*, 3 = *Successful*, 4 = *Very Successful*).

Table 5

*Means, Standard Deviations, and T-Test Analyses for Categorical Demographic and Outcome Variables (N = 85)*

Variable	N	Mean	SD	T	Df
<b>PedsQL™ Psychosocial</b>					
Male	46	63.88	19.81	2.05*	83
Female	39	55.09	19.54		
FRL - Y	18	53.15	23.28	2.05	82
FRL - N	66	62.45	17.84		
Caucasian	72	59.99	20.54	-.445	82
Non-Caucasian	9	63.15	14.42		
<b>PedsQL™ Physical</b>					
Male	46	56.59	23.06	2.82**	83
Female	39	43.03	20.83		
FRL - Y	18	45.49	23.56	2.81	82
FRL - N	66	52.18	22.61		
Caucasian	72	50.26	23.28	-.405	82
Non-Caucasian	9	53.82	22.14		
<b>Perceived Re-Entry Success</b>					
Male	46	3.15	.842	-.897	83
Female	39	2.97	.986		
FRL - Y	18	2.78	.878	-1.63	82
FRL - N	66	3.17	.904		
Caucasian	72	3.06	.948	.848	79
Non-Caucasian	9	3.33	.707		

*Note.* Means reflect Scaled Scores on the PedsQL™ domains, with higher scores representing higher functional independence. Perceived School Re-Entry assessed by Likert scale ratings (1 = *Not Successful*, 2 = *A Little Successful*, 3 = *Successful*, 4 = *Very Successful*). FRL - Y = use of free and reduced lunch. FRL - N = did not use free and reduced lunch. \* $p < .05$ . \*\* $p < .01$ .

Table 6

*Multiple Regression Analyses: Demographic Characteristics as Predictors of Physical and Psychosocial Functional Independence (N = 85)*

Variable	Physical					Psychosocial				
	<i>B</i>	SE( <i>B</i> )	<i>B</i>	<i>t</i>	<i>p</i>	<i>B</i>	SE( <i>B</i> )	$\beta$	<i>t</i>	<i>P</i>
Age	-.731	1.03	-.083	-.703	.484	-.991	.872	-.133	-1.14	.260
Ethnicity	6.52	8.02	.092	.812	.419	6.28	6.74	.104	.933	.354
Gender	-13.8	5.23	-.303	-2.64	.010*	-10.7	4.39	-.278	-2.45	.017*
SES	-9.59	6.66	-.171	-1.44	.155	-12.5	5.59	-.262	-2.23	.029*
$R^2$	.107					.126				
<i>F</i>	2.19					2.62*				

*Note.* Physical and Psychosocial Functional Independence assessed by the PedsQL™ 4.0. *B* = unstandardized beta coefficient. SE(*B*) = standard error of *B*;  $\beta$  = standardized beta coefficient. *t* = t-statistic. *p* = p-value;  $R^2$  = multiple correlation squared. *F* = F-statistic. \**p* < .05.

Table 7

*Multiple Regression Analyses: Demographic Characteristics as Predictors of Perceived School Re-Entry Success (N = 85)*

Variable	Perceived School Re-Entry Success				
	<i>B</i>	SE( <i>B</i> )	$\beta$	<i>T</i>	<i>P</i>
Age	.066	.041	.192	1.63	.11
Ethnicity	.290	.315	.104	.921	.360
Gender	-.410	.205	-.229	-2.00	.049*
SES	-.385	.261	-.174	-1.47	.145
$R^2$	.113				
<i>F</i>	2.32				

*Note.* Perceived School Re-Entry assessed by Likert scale ratings (1 = *Not Successful*, 2 = *A Little Successful*, 3 = *Successful*, 4 = *Very Successful*). *B* = unstandardized beta coefficient. SE(*B*) = standard error of *B*.  $\beta$  = standardized beta coefficient. *t* = t-statistic. *p* = p-value.  $R^2$  = multiple correlation squared. *F* = F-statistic. \**p* < .05.

Table 8

*Pearson Correlations for Age at Diagnosis, Time in Treatment, and Outcome Variables.  
(N = 85)*

Variables	1	2	3	4	5
1. Age at Diagnosis	---				
2. Time in Treatment	-.45**	---			
3. PedsQL™ Psychosocial	.000	-.13	---		
4. PedsQL™ Physical	-.043	-.08	.65**	---	
5. School Re-Entry Success	.12	-.12	.52**	-.31**	---

*Note.* Time in Treatment is in years. PedsQL™ = Pediatric Quality of Life Scales (Psychosocial Domain and Physical Domain). Perceived School Re-Entry assessed by Likert scale ratings (1 = *Not Successful*, 2 = *A Little Successful*, 3 = *Successful*, 4 = *Very Successful*). \* $p < .05$ . \*\* $p < .01$ .

Table 9

*Means, Standard Deviations, and T-Test Analyses for Treatment Type and Outcome Variables (N = 85)*

Variable	N		Mean		SD		t
	Yes	No	Yes	No	Yes	No	
<b>Physical Functional Independence</b>							
Chemotherapy	73	12	49.61	54.95	23.04	22.94	.744
Radiation	36	49	48.44	60.42	23.03	23.05	.662
Surgery	50	35	47.13	55.00	22.83	22.68	1.57
BMT	8	77	38.67	51.58	24.43	22.63	1.53
<b>Psychosocial Functional Independence</b>							
Chemotherapy	73	12	58.54	68.33	20.22	17.45	1.60
Radiation	36	49	60.42	59.42	19.19	20.87	-.225
Surgery	50	35	56.77	64.24	21.80	16.60	1.71
BMT	8	77	57.29	60.10	13.51	20.67	.376
<b>Perceived School Re-Entry Success</b>							
Chemotherapy	73	12	3.07	3.08	.903	.996	-.052
Radiation	36	49	2.88	3.33	.927	.828	2.34*
Surgery	50	35	3.02	3.14	.958	.845	-.610
BMT	8	77	3.50	3.03	.756	.917	1.41

*Note.* Means reflect scaled Physical and Psychosocial PedsQL™ Domain scores, with higher scores representing higher functional independence. Mean from perceived school re-entry success reflect Likert scale ratings (1 = *Not Successful*, 2 = *A Little Successful*, 3 = *Successful*, 4 = *Very Successful*). BMT = bone marrow transplant. t = t-statistic. \*  $p < .05$ .



Table 10

*Means, Standard Deviations, and T-Test Analyses for Relapse and Outcome Variables*

Variable	N	Mean	SD	T
Physical Functional Independence				
Relapse	10	40.94	26.74	1.39
No Relapse	75	51.63	22.32	
Psychosocial Functional Independence				
Relapse	10	58.33	16.78	.252
No Relapse	75	60.04	20.55	
Perceived School Re-Entry Success				
Relapse	10	3.10	1.1	.108
No Relapse	75	3.07	.890	

*Note.* Means reflect scaled Physical and Psychosocial PedsQL™ Domain scores, with higher scores representing higher functional independence. Mean from perceived school re-entry success reflect Likert scale ratings (1 = *Not Successful*, 2 = *A Little Successful*, 3 = *Successful*, 4 = *Very Successful*). \* $p < .05$ .

Table 11

*Multiple Regression Analyses: Illness Characteristics as Predictors of Physical and Psychosocial Functional Independence (N = 85)*

Variable	Physical					Psychosocial				
	<i>B</i>	SE( <i>B</i> )	$\beta$	<i>t</i>	<i>p</i>	<i>B</i>	SE( <i>B</i> )	$\beta$	<i>t</i>	<i>P</i>
Leukemia	5.85	7.25	-.115	.807	.422	11.85	13.64	-.268	1.99	.050*
Brain Tumor	12.39	8.19	-.195	1.51	.135	13.94	6.74	-.251	2.07	.042*
Hodgkin's	-1.52	8.18	-.023	-.185	.854	1.02	6.73	-.018	.152	.879
Years Tx	-4.01	3.26	-.183	-1.23	.222	-6.58	2.68	-.344	-2.46	.016*
Surgery	-11.67	6.36	-.251	-1.84	.070	-12.98	5.23	-.320	-2.48	.015*
Radiation	-.463	5.56	-.010	-.083	.934	3.76	4.57	-.093	.823	.413
Chemo	-7.40	8.30	-.113	-.891	.376	-14.99	6.83	-.262	-2.20	.031*
Age Dx	-1.18	.872	-.173	-1.36	.179	-.786	.717	-.131	-1.10	.278
Relapse	-8.85	9.59	-.125	-.923	.359	4.19	7.90	-.068	.531	.597
$R^2$	.117					.217				
<i>F</i>	1.11					2.31*				

*Note.* Physical and Psychosocial Functional Independence assessed by the PedsQL™ 4.0. Hodgkin's = Hodgkin's Lymphoma. Years Tx = total years in treatment. Chemo = chemotherapy. Age Dx = age at diagnosis. *B* = unstandardized beta coefficient. SE(*B*) = standard error of *B*.  $\beta$  = standardized beta coefficient. *t* = t-statistic. *p* = p-value.  $R^2$  = multiple correlation squared. *F* = F-statistic. \* $p < .05$ . \*\* $p < .01$ .

Table 12

*Multiple Regression Analyses: Illness Characteristics as Predictors of Perceived School Re-Entry Success (N = 85)*

Variable	Perceived School Re-Entry Success				
	<i>B</i>	SE( <i>B</i> )	$\beta$	<i>T</i>	<i>P</i>
Leukemia	.570	.281	-.283	2.03	.046*
Brain Tumor	.130	.318	-.052	.410	.683
Hodgkin's	.165	.317	-.063	.520	.605
Age Dx	.023	.034	.085	.681	.498
Chemo	-.301	.322	-.116	-.936	.352
Radiation	.533	.215	-.291	2.47	.016*
Surgery	-.052	.247	-.028	-.211	.834
Years Tx	-.207	.126	-.238	-1.64	.106
Relapse	.218	.372	.078	.586	.560
$R^2$	.155				
<i>F</i>	1.52				

*Note.* Perceived School Re-Entry assessed by Likert scale ratings (1 = *Not Successful*, 2 = *A Little Successful*, 3 = *Successful*, 4 = *Very Successful*). *B* = unstandardized beta coefficient. SE(*B*) = standard error of *B*.  $\beta$  = standardized beta coefficient. *t* = t-statistic. *p* = p-value.  $R^2$  = multiple correlation squared. *F* = F-statistic. \*  $p < .05$ .

Table 13

*Pearson Correlations for Time to Re-Entry, Age at Re-Entry, Premorbid Social Functioning, Premorbid Emotional Functioning, and Outcome Variables (N = 85)*

Variables	Physical	Psychosocial	Re-Entry Success
Time to Re-Entry	-.193	-.244*	-.136
Age at Re-Entry	-.107	-.019	.154
Premorbid Social Fx	.050	.274*	.106
Premorbid Emotional Fx	-.046	.228*	.065

*Note.* Time to Re-Entry is in months. Age at Re-Entry is in years. Premorbid Social Fx = perceived social functioning pre-diagnosis from 1 (*Not Problematic*) - 4 (*Problematic*). Premorbid Emotional Fx = perceived emotional functioning pre-diagnosis from 1 (*Not Problematic*) - 4 (*Problematic*). PedsQL™ = Pediatric Quality of Life Scales (Psychosocial Domain and Physical Domain). School Re-Entry Success = participant ratings from 1 (*not successful*) - 4 (*successful*). \* $p < .05$ .

Table 14

*Means, Standard Deviations, and T-Test Analyses for Premorbid Academic Functioning, School Re-Entry Preparation, and Outcome Variables (N = 85)*

Variable	N	Mean	SD	t
<b>Physical Functional Independence</b>				
No Special Education	74	51.27	23.16	1.63
Premorbid Special Education	8	37.50	18.14	
Re-entry Prep - Y	71	48.59	23.21	-1.62
Re-entry Prep - N	14	59.39	20.06	
<b>Psychosocial Functional Independence</b>				
No Special Education	74	61.96	19.16	2.72*
Premorbid Special Education	8	42.50	19.60	
Re-entry Prep - Y	71	59.55	19.24	-.298
Re-entry Prep - N	14	61.31	24.60	
<b>Perceived School Re-Entry Success</b>				
No Special Education	74	3.13	.926	.168
Premorbid Special Education	8	3.07	.835	
Re-entry Prep - Y	71	2.50	1.16	2.66**
Re-entry Prep - N	14	3.18	.816	

*Note.* Means reflect scaled Physical and Psychosocial PedsQL™ Domain scores, with higher scores representing higher functional independence. Mean from perceived school re-entry success reflect Likert scale ratings (1 = *Not Successful*, 2 = *A Little Successful*, 3 = *Successful*, 4 = *Very Successful*). \* $p < .05$ . \*\* $p < .01$ .

Table 15

*Means, Standard Deviations, and T-Test Analyses for Social Support and Outcome Variables (N = 85)*

Variable	N	Mean	SD	t
Physical Functional Independence				
Higher Support <sup>a</sup>	59	53.18	22.69	1.62
Lower Support	25	44.38	23.12	
Psychosocial Functional Independence				
Higher Support	59	64.92	15.83	3.45**
Lower Support	25	49.93	22.95	
Perceived School Re-Entry Success				
Higher Support	59	3.34	.757	4.25**
Lower Support	25	2.52	.918	

*Note.* Means reflect scaled Physical and Psychosocial PedsQL™ Domain scores, with higher scores representing higher functional independence. Mean from perceived school re-entry success reflect Likert scale ratings (1 = *Not Successful*, 2 = *A Little Successful*, 3 = *Successful*, 4 = *Very Successful*). Social support ratings occurred on a Likert scale (1 = *Not Supported*, 2 = *A Little Supported*, 3 = *Supported*, 4 = *Very Supported*). \* $p < .05$ . \*\* $p < .01$ . <sup>a</sup> groups of family adjustment ratings created using median split.

Table 16

*Multiple Regression Analyses: School Re-Entry Characteristics as Predictors of Physical and Psychosocial Functional Independence (N = 85).*

Variable	Physical					Psychosocial				
	<i>B</i>	SE( <i>B</i> )	$\beta$	<i>t</i>	<i>p</i>	<i>B</i>	SE( <i>B</i> )	$\beta$	<i>t</i>	<i>p</i>
Re-Entry Time	-1.04	1.76	-.063	-.589	.558	-1.26	1.26	-.087	-1.00	.321
Re-Entry Age	-1.58	.806	-.211	-1.96	.054	-1.23	.576	-.187	-2.14	.036*
Premorbid Aca	-18.3	9.05	-.229	-2.022	.047*	-19.29	6.48	-.275	-2.98	.004*
Premorbid Soc	.065	.227	.039	.287	.775	.099	.162	.068	.612	.542
Premorbid Emo	-.086	.244	-.047	-.353	.725	.220	.175	.135	1.26	.211
No Re-Entry Prep	17.61	6.60	.289	2.67	.009*	13.57	4.72	.252	2.88	.005*
$R^2$	.227					.491				
<i>F</i>	3.03*					9.91**				

*Note.* Physical and Psychosocial Functional Independence assessed by the PedsQL™ 4.0. Re-Entry Time assessed in months. Re-Entry Age = age at first re-entry. Premorbid Aca = use of special education service prior to diagnosis. Premorbid Soc = Likert scale ratings of social difficulties prior to diagnosis (1 = *No Problems* - 4 = *Many Problems*). Premorbid Emo = Likert scale ratings of emotional difficulties prior to diagnosis (1 = *No Problems* - 4 = *Many Problems*). Re-Entry Strategies assessed by endorsing preparation or not. *B* = unstandardized beta coefficient. SE(*B*) = standard error of *B*.  $\beta$  = standardized beta coefficient. *t* = t-statistic. *p* = p-value.  $R^2$  = multiple correlation squared. *F* = F-statistic. \**p* < .05. \*\**p* < .01.

Table 17

*Multiple Regression Analyses: School Re-Entry Characteristics as Predictors of Perceived School Re-Entry Success (N = 85)*

Variable	Perceived School Re-Entry Success				
	<i>B</i>	SE( <i>B</i> )	$\beta$	<i>t</i>	<i>p</i>
Re-Entry Time	-.107	.074	-.160	-1.45	.153
Re-Entry Age	.068	.034	.224	1.99	.051
Premorbid Aca	.446	.380	.137	1.17	.245
Premorbid Soc	.016	.010	.230	1.62	.110
Premorbid Emo	-.003	.010	-.039	-.287	.775
No Re-Entry Prep	.368	.138	.298	2.66	.009*
$R^2$	.156				
<i>F</i>	2.24*				

*Note.* Perceived School Re-Entry assessed by Likert scale ratings (1 = *Not Successful*, 2 = *A Little Successful*, 3 = *Successful*, 4 = *Very Successful*). Re-Entry Age = age at first re-entry. Premorbid Aca = use of special education service prior to diagnosis. Premorbid Soc = social difficulties prior to diagnosis. Premorbid Emo = emotional difficulties prior to diagnosis. Re-Entry Strategies assessed by endorsing preparation or not. *B* = unstandardized beta coefficient. SE(*B*) = standard error of *B*.  $\beta$  = standardized beta coefficient. *t* = *t*-statistic. *p* = *p*-value.  $R^2$  = multiple correlation squared. *F* = *F*-statistic. \**p* < .05. \*\**p* < .01.



Table 18

*Means, Standard Deviations, and T-Test Analyses for Family Adjustment and Outcome Variables (N = 85)*

Variable	N	Mean	SD	<i>t</i>
Physical Functional Independence				
Higher Adjustment <sup>a</sup>	42	53.20	21.15	-1.29
Lower Adjustment	41	46.73	24.53	
Psychosocial Functional Independence				
Higher Adjustment	42	65.33	15.47	-2.76*
Lower Adjustment	41	53.77	22.12	
Perceived School Re-Entry Success				
Higher Adjustment	42	3.27	.867	-1.98
Lower Adjustment	41	2.88	.916	

*Note.* Means reflect scaled Physical and Psychosocial PedsQL™ Domain scores, with higher scores representing higher functional independence. Mean from perceived school re-entry success reflect Likert scale ratings (1 = *Not Successful*, 2 = *A Little Successful*, 3 = *Successful*, 4 = *Very Successful*). Family adjustment was assessed via the FACES-IV Circumplex Ratio, with higher scores over one associated with greater positive family adjustment. \* $p < .05$ . <sup>a</sup> groups of family adjustment ratings created using median split.

## CHAPTER V

### DISCUSSION

The purpose of this study was to identify predictors that contribute to successful school re-entry from the adolescent with cancer's (or cancer survivors) perspective. Given the paucity of research from this point-of-view, the present study added to existing literature by identifying concerns of adolescents with cancer in order to capture a more accurate picture of school re-entry and promote more relevant outcomes. Using an adaptation of Wallander and Varni's (1998) Disability-Stress Coping Model (DSC), the impact of a variety of factors on functional independence and perceived school re-entry success were examined. Functional independence (as assessed via the PedsQL™) and ratings of the adolescent's perceived school re-entry success were outcome variables in the study.

First, predictors of successful school re-entry are discussed (research questions one through four). Next, unexpected findings regarding school re-entry preparation are discussed (research question five). Recommendations for how school re-entry preparation might be modified to fit the developmental needs of adolescents with cancer are made. The study's limitations are then conferred. The chapter concludes with recommendations for future research.

#### Predictors of Successful School Re-Entry Success

School re-entry preparation has not been examined empirically in research, possibly because predictors of school re-entry success are currently not well understood. In the present study, research questions one through four identified several within-child and microsystemic predictors among demographic, illness, school re-entry, and family adjustment/social domains that had small to medium influence on functional independence and/or perceived school re-entry success. These predictors may help to improve re-entry services by identifying those adolescents in particular need of services.

Demographics. Gender was found to predict differential school re-entry outcomes. Females in the current study rated lower psychosocial and physical functional independence as well as lower perceived school re-entry success, consistent with previous research in adjustment to cancer. For example, Kazak, Christakis, Alderfer, and Coiro (1994) found female adolescent cancer survivors reported significantly higher levels of hopelessness, depression, and anxiety than male adolescents. The authors surmised differences in ratings were due to potential developmental differences in self-image, disparities in the way male and female adolescent cancer survivors were socialized, and/or the differential impact of the cancer experience on the adolescents' development and memories. In addition, females have also been shown to be at greater risk for cognitive and academic difficulties following chemotherapy with methotrexate than males (Armstrong & Briery, 2004). Greater risk for poor school performance and internalization problems may lead to higher risk for school re-entry difficulties in female adolescent cancer survivors.

Lower SES also negatively impacted psychosocial functional independence in the current study. Having more financial resources may provide the adolescent with cancer additional opportunity to better prepare for returning to school. For example, adolescents with cancer often complained of the poor quality of tutors available through homebound instruction in a qualitative study by Lopez (2011). Adolescents from families with higher financial means may pursue private options and compensate for such difficulties. Being of higher SES may also reduce extraneous psychosocial stressors, such as family conflict, parental job stress, etc., resulting in less stress when returning to school.

Illness Characteristics. Having leukemia, a brain tumor, and chemotherapy predicted both poorer functional independence and lower perceived school re-entry success, the risk for which has long been shown in previous research (see Daly, Kral, & Brown, 2008; Brown & DuPaul, 1999; Butler et al., 2008; Reeves et al., 2007). Late effects negatively impact the way adolescents learn and perform in school, in turn

influencing daily functioning. Adolescents at greatest risk for late effects are those treated for leukemia and brain tumors (Armstrong & Briery, 2004). Because leukemic cells can cross the blood-brain barrier, chemotherapy is sometimes administered into the spinal fluid of the central nervous system (intrathecally) to prevent CNS disease, occasionally resulting in late effects (Armstrong & Briery, 2004). Similarly, the severity of late effects associated with brain tumors depend upon the areas of the brain impacted and whether healthy brain tissue is damaged during treatment or surgery.

In terms of the impact of cancer treatment on school re-entry success, undergoing chemotherapy regularly disrupts school attendance. Adolescents in prior qualitative school re-entry studies stated the most beneficial aspect of returning to school was being able to re-establish normalcy (Lopez, 2011; Fochtman, 2010). Not being able to regularly attend school may signal to the adolescent that life is not yet back to normal, which could diminish the success of the re-entry process from the adolescent's point of view.

Having surgery predicted poorer psychosocial functional independence, but not perceived re-entry success. For adolescents with brain tumors, this may be associated with the late effects discussed above. For those with other solid tumors, having surgery may limit their ability to navigate the school environment independently (Clay, 2004). In addition, surgery may result in permanent changes in physical appearance, such as limb amputations. Significant changes in physical appearance may lead to fear of what peers may think or say, potentially lowering the quality of social interactions over time (Clay; Vance & Eiser, 2002; Noll, Vannatta, Koontz, Kalinyak, Bukowski, & Davies, 1996; Fuemmeler, Mullins, & Carpentier, 2006). Decreased cognitive function, limited mobility, and changes in physical appearance place adolescents who have had surgery at risk for poor school reintegration outcomes, or adjustment back-to-school over time.

It is unclear why having surgery did not also negatively impact ratings of perceived school re-entry success, particularly given the potential for undesirable social

consequences that may result. Previous qualitative research suggests adolescents enjoy returning to school to re-establish normalcy (Lopez, 2010). Having surgery may not have disrupted perceived success as much as functional independence because simply going back to school may have been enough for the adolescent to achieve re-entry success, regardless of the impact on functioning. As one study participant noted: "I went back to school and felt normal and happy again."

Undergoing radiation predicted poorer perceived school re-entry success, but not psychosocial or physical functional independence. Having radiation might influence school re-entry success by impeding the quality of social interaction adolescents experienced when they returned to school. Radiation treatment has been linked to social and behavioral difficulties due to problems with appropriately perceiving social cues or minimizing behavioral impulses (see Dennis, Hetherington, & Spiegler, 1998; Armstrong & Briery, 2004). Similarly, students who have had radiation may utilize special education more frequently given increased risk for neurocognitive deficits (Mulhern & Butler, 2006). The social stigma associated with receiving special education services may result in teasing or feeling different from peers, therein decreasing re-entry success. Finally, undergoing radiation disrupts regular school attendance. Multiple absences from fatigue, not feeling well, and frequent doctor's appointments may pose challenges to school re-entry success.

The fact that radiation did not also impact ratings of functional independence is surprising, particularly given that the social and academic difficulties described above would also be expected to impact functional independence. Lower power may have failed to detect potential effects in functional independence. Similarly, participants may have failed to detect potential difficulties in their functioning. Having multiple informants may have improved the study's ability to detect any deficits in functional independence due to radiation.

Finally, extended time in treatment predicted lower psychosocial functional independence, but did not impact perceived re-entry success. This is consistent with extant research (Clay, 2004; Prevatt, Heffer, & Lowe, 2000; Ross, 1984). Being away from school due to treatment and hospital admissions limits normative opportunities to develop academically, socially, and emotionally, potentially decreasing functional independence, which may result in later difficulties when returning to school. However, technology has allowed adolescents to keep in touch with friends much more easily. Perceived success may have been impacted less than functional independence if adolescents maintained consistent contact with peers throughout their treatment, facilitating normalcy throughout their treatment. In this way, returning to school may have been less of a transition socially for adolescents in the current study. However, adolescents may have still faced academic, physical, and emotional challenges, impeding functional independence.

Further, returning to school after a lengthy treatment may represent victory and recovery to adolescents with cancer. Adolescents in Lopez' (2011) study felt returning to school felt like a "safe haven" regardless of the amount of time spent away, and going back was a signal that things in their lives were realigning after their diagnoses (p. 147). Adolescents felt "normal" simply by returning to school regardless if they were still in treatment; as one participant in the current study noted: "It helped me when I came back to school and people treated me like nothing happened, it makes me feel like a normal person."

School Re-Entry Characteristics. Results of regression analyses suggested that returning to school as soon as medically feasible was associated with better psychosocial functional independence, re-emphasizing the benefits of returning to pre-cancer activities on adjustment noted in existing research (Clay, 2004; Prevatt, Heffer, & Lowe, 2000; Ross, 1984; Katz, 2004).

In addition, older age at re-entry was a risk factor for poorer psychosocial functional independence in the current study. When considering adolescent development, early adolescence (11 - 13 years) is marked by initial development of independent decision making and autonomy, but a large degree of dependence on others remains as the young adolescent continues to negotiate social roles (Wallander, Eggert, & Gilbert, 2004). Late adolescence (17 - 19 years), on the other hand, is characterized by independence, self-sufficiency, and taking on more adult roles. From a developmental perspective, having to depend on others because of cancer and its treatment likely has a greater impact on older adolescents when returning to school than younger adolescents, resulting in poorer functional independence in this age group.

Not having school re-entry preparation predicted both better psychosocial and physical functional independence and school re-entry success. This unexpected finding may be attributed to differences in who received school re-entry preparation in the current study. It may be that the adolescents who received school re-entry preparation were more negatively impacted by their cancer or cancer treatment (e.g., suffered more cognitive or academic changes, were absent longer, etc.) and were more frequently targeted for school re-entry preparation than those less severely impacted. Even though these students' preparation may have been beneficial, their return to school may have been difficult regardless given the severity of their disease. Disease severity or treatment visibility has been shown to be related to adjustment in previous research (Koocher & O'Malley, 1981; Zebrack & Zeltzer, 2002). In addition, this study focused on the adolescent perspective; if multiple informants had been included, such as teachers or parents, perceptions of the impact of school re-entry preparation may have differed. Finally, ineffective or inappropriate school re-entry preparation may also offer explanation (see Implications section for further explanation).

Premorbid academic, emotional, and social functioning were also important predictors of re-entry outcomes. As expected, better pre-cancer functioning predicted

higher psychosocial functional independence. Adolescents in the current study who used special education services prior to being diagnosed endorsed lower functional independence at school re-entry. Pre-existing academic difficulty, combined with increased stress of frequent absences, social isolation, and fatigue, may place students at risk for school re-entry difficulties.

Family Adjustment and Peer Support. Previous research suggests social support is beneficial for facilitating adolescent coping with chronic illness (Varni, Katz, Colgrove, & Dolgin, 1994; Brown, 2004; Alderfer, Navsaria, & Kazak, 2009; Carlson, Kubiszyn, & Guli, 2004; Kazak, Simms, & Rourke, 2002). Results of the current study suggest those adolescents who rated higher levels of both family and peer support had greater psychosocial functional independence. Peer support moderately correlated with psychosocial functional independence and perceived school re-entry success, while family support moderately correlated with psychosocial functional independence but correlated less with perceived school re-entry success.

Research has shown specific parenting behaviors have the potential to impact an adolescent's emotional, behavioral, and social functioning. Issues of parental overprotection or the inability to appropriately allocate medical care responsibilities may lead to decreased autonomy, sporadic school attendance, or limited interactions with peers. In a study of children with spina bifida, Holmbeck and colleagues (2004) found parental overprotection contributed to greater internalizing and externalizing behavior problems. Thus, adolescents with less appropriate forms of family support may be at risk for poorer school re-entry outcomes.

Interestingly, higher family adjustment did not impact perceived school re-entry success in this study. Although the family remains an important coping resource during adolescence, peers begin to take on a much greater influence (Wallander et al., 2004). Results suggest that peer support may have been more salient to adolescents during re-entry. As one participant noted, "Getting back to school with my friends" was what made



her back-to-school experience successful. Peer support was a consistent theme in re-entry success in the current study, and is similarly uniform with the importance of friendships and social relationships in adolescent development (Wallander et al., 2004). When participants described their re-entry experience as unsuccessful, responses were overwhelmingly due to lack of peer support: "I wish kids were nicer;" "Having more support from friends, they didn't understand;" "everyone was nice and didn't tease me until I moved to a different school [sic]."

Summary. Overall, the predictors identified in the current study lend tentative support to suggest a subset of adolescents may be at risk for poor school re-entry outcomes, including being female and of lower SES, having certain types of cancer and treatment, undergoing treatment for a longer time period, having premorbid adjustment difficulties, and being older when returning to school. Having social and family support, no re-entry preparation (or perhaps inappropriate re-entry preparation), and returning to school quickly after being diagnosed were associated with better re-entry outcomes (see Figure 3). These predictors were consistent with extant research on general adjustment to pediatric chronic illness (see Wallander & Varni, 1992; Wallander & Varni, 1998; Eiser, Hill, & Vance, 2000; Patenaude & Kupst, 2005). Adolescents who may be at increased risk for problematic school re-entry outcomes may warrant individualized interventions; further research is needed on how school re-entry preparation may better address these needs.

### Implications

Defining School Re-Entry Outcomes. Research question five examined differences in the outcome variables among those adolescents who received re-entry preparation and those who did not. It was hypothesized that level of functional independence may be an appropriate outcome measure for school re-entry as it assesses similar goals: normative, developmentally-appropriate adjustment within academic,

social, emotional, and physical domains (Varni et al., 1996; Varni, Burwinkle, & Seid, 2006). In the current study, however, results of regression analyses suggested *not* having school re-entry preparation predicted better psychosocial and physical functional independence. Equally as unexpected, *not* having re-entry preparation was the largest unique predictor of perceived school re-entry success. Interestingly, no differences were found in psychosocial or physical functional independence between those who had received re-entry preparation and those who did not. However, those adolescents who did *not* receive re-entry preparation perceived *higher* school re-entry success than those who received preparation prior to returning to school.

Several explanations are offered for these unanticipated findings. First, despite being widely used in general coping and adjustment in chronic illness research (Wallander & Varni, 1998; van Eys, 1985; Varni, et al., 1996), the PedsQL™ may be too general of a measure of functional independence to assess school re-entry outcomes. A measure of functional independence specific to the aims of school re-entry may be more suitable, but has not yet been developed. Functional independence was highly correlated with perceived re-entry success and thus a potential re-entry outcome construct worthy of further exploration. Aspects of functional independence specific to school re-entry preparation may include within-child factors (emotional adjustment, changes in cognitive functioning, age at diagnosis, etc.), disease factors (time in treatment, type of treatment, prognosis, etc.) and systemic variables (SES, family adjustment, social support, etc.) that are associated with successful school re-entry preparation (Brown & DuPaul, 1999; see Figure 3 for further suggestion).

Second, differences in ratings of perceived re-entry success versus functional independence may suggest the two constructs are capturing different aspects of the school re-entry/reintegration experiences. The professional's goal of re-entry (described in literature) may be to restore, to the extent possible, the student's pre-diagnosis functioning. van Eys (1991, 1985) argues that a “truly cured child” is one who is

“functioning on par with peers” (1985, p. 160). In this way, functional independence may be an appropriate assessment of the professionals', rather than the adolescents', re-entry goals. (Further research is needed on this, as the ratings from school and medical staff were not obtained in the current study). There were no differences in functional independence among those who received re-entry preparation and those did not. From a professional standpoint, this may suggest the goal of school re-entry was met. The adolescent's re-entry goal may be different, however. As previously discussed, prior qualitative research has suggested adolescents simply want to return to normal (see Lopez, 2010; Fochtman, 2011). Adolescents in the current study similarly defined successful school re-entry by being "treated like I didn't [sic] have cancer," "having lots of friends to help me," and "being excited to be able to go back to school." Interestingly, multiple illness characteristics significantly predicted functional independence (where greater illness severity was associated with more limitations), but they did not impact perceived school re-entry success. Instead, simply resuming pre-cancer activities and being allowed a facet of normalcy was beneficial to adolescents, a definition of success or goal yet to be investigated in school re-entry research or practice.

Discrepancy in how adolescents and professionals define successful school re-entry is a critical finding, as it has important implications for how re-entry preparation is constructed. A final explanation for the unexpected results is that the current re-entry interventions being used are not meeting adolescents' needs when returning to school. Adolescents who received re-entry preparation rated their experience as less successful, indicating that, from an adolescent standpoint, their re-entry goal was not met by their preparation. This may be in part because we do not yet fully understand what the adolescents' re-entry goals are.

Failing to meet the adolescent with cancer's school re-entry needs may be due to lack of individualization of re-entry preparation. This may occur from failure to consider the developmental needs of the adolescent when preparing for his/her return to school.

Differences in Needs/Goals. Much of what is known about school re-entry intervention is based on research done with school-aged students (Madan-Swain, Katz, & LaGory, 2004). School and medical staff do not appear to have altered their re-entry goals to fit the developmental needs of adolescence; as such, current re-entry preparation being provided for adolescents with cancer may be inappropriate and ineffective. Power, DuPaul, Shapiro, and Kazak (2003) assert that professionals have failed to consider the potential negative consequences of school re-entry interventions, including social isolation or self-consciousness.

School and medical professionals focus on providing instrumental support (e.g., workshops, providing information/education, etc.). Fuemmeler et al. (2006) further define this as "support in the form of tangible aid or services" (p. 100). Adolescents, on the other hand, may prefer more emotional-based support. In the current study, adolescent's main goal was to re-establish normalcy when returning to school. As one participant commented, "It [returning to school] was successful because I got to be with my friends again." Open-ended survey responses suggest that, more than anything else, adolescents in the current study wanted to re-establish a sense of normalcy and belonging upon returning to school. This notion has received preliminary support in recent qualitative studies of adolescent cancer survivors returning to school (see Lopez, 2011; Fochtman, 2010). Sourkes (1995) adds, "For the child, facets of 'normal' include being regular (not special), ordinary (not exceptional), and fitting in (not being different)" (p. 82).

School and medical professionals must resist the urge to blindly provide re-entry interventions just because they are available in a manualized program or worked for a previous student in the past. In some instances, school re-entry efforts have been found to decrease the likelihood of peer acceptance for adolescents with cancer and other chronic illnesses (La Greca & Bearman, 2000; Bell & Morgan, 2000). In the current study, preparation for school re-entry neither facilitated independent functioning nor a

more successful perception of going back to school. Instead, professionals must consider the individual student's needs in terms of risk and resilience factors (i.e., from the adapted DSC model), developmental needs, personality factors, and staff/classmate needs to create a re-entry plan. Consideration must be made for both professional and adolescent "definitions" of school re-entry success to achieve a balance of functional independence while facilitating normalcy.

Although school re-entry has been investigated since the late 1970s, psychology and nursing professionals are just beginning to approach adolescent cancer survivors to ask them what they need to effectively return to school. Currently these studies are qualitative dissertations with small *Ns* that are not largely disseminated (see Lopez, 2011; Fochtman, 2010; Banko, 1999). Results of the current study suggest there is much about adolescent re-entry needs and goals we do not yet fully understand, which is troubling in terms of designing school re-entry preparation. It is professionally irresponsible to provide interventions without first fully understanding these needs. Further research is needed so that we may better understand how to best design school re-entry preparation for adolescents with cancer. Several suggestions from the current study are offered as a potential beginning point.

Special Considerations for Adolescents. The range of re-entry needs are partially a product of how variables within the adapted DSC model interact, but may also result from the developmental characteristics of adolescence. As Madan-Swain et al. (2004) suggest, characteristics of development interact with re-entry interventions but have not yet been well investigated. Currently, research on how to adapt re-entry interventions to address the developmental needs of adolescents with cancer is lacking. Given the range of needs from both a systemic and developmental perspective, an individualized approach to re-entry is recommended for adolescents with cancer.

School re-entry preparation *must* be individualized for adolescents. Adolescents with cancer in the current study benefitted from social support (e.g., "Having supportive

parents and teachers and friends helped a lot."). However, while school-age children often benefit from having their classrooms or schools attend presentations about their cancer experience (Varni et al., 1994), adolescents may not similarly benefit.

Adolescence is a period characterized by the importance of fitting in with peers; thus, being the topic of a presentation outlining all of the reasons in which the adolescent is different from his or her classmates may not be the best approach. In one study, Banko (1999) found that peer introductions of students with chronic illnesses did not have an impact on their willingness to interact with that student; the authors concluded that adolescents may not have the same difficulty accepting peers with medical concerns that younger children appear to have.

In the current study, the need for classmate support varied. Some participants appreciated having their peers understand their experiences while others preferred to maintain privacy. It is important to be mindful of how re-entry preparation is used and of the advantages/disadvantages for using specific components of re-entry interventions for individual students. In balancing the need to ensure the student, staff, and classmates are prepared while respecting the adolescent with cancer's need for privacy, professionals may seek alternative ways to garner social support, such as having discussions with close friends only, sending a general letter from the school principal, or limiting presentations to those peers with whom the adolescent has frequent contact (e.g., the band or orchestra, sports teams, etc.).

The risks/benefits to disclosure should be discussed with the adolescent, including risks associated with managing rumors, gossip, and misinformation in this age of social media. As one participant in Fochtman's (2010) qualitative study experienced, attempting to manage online rumors after the fact was more troublesome than not originally disclosing information to her peers. Fochtman recommended assisting the adolescent in identifying, reinforcing, and expanding his or her existing support systems

in preparation for going back to school. The methodology used to do this is dependent upon the adolescent's preference, personality, and school and family contexts.

Adolescents' need for autonomy and control was serviced by returning to school; they felt that "getting back to normal" or staying engaged in activities throughout their treatment was beneficial. As one participant noted, "just getting back in the school routine" made his re-entry experience successful. This may limit an adolescent's need for a more formal "re-entry" during phase two of re-entry preparation, such as a presentation prior to his or her return, but may require more planning during phase one (see chapter II for a review). Helping the adolescent to stay engaged may include arranging for the student to attend school half a day, preparing to "attend" courses via the web, or problem-solving alternate ways to participate in extracurricular activities. It is also important to address transitions that may have occurred during treatment, such as moving from middle school to high school, which will impact re-entry preparation. These transitions are typically not a consideration for school-aged children and thus not included in manualized re-entry preparation programs.

Adolescents in the current study enjoyed having a peer and/or professional to talk to about both cancer and non-cancer related events in their lives upon returning to school. This may suggest that including mentors, such as survivors who have undergone the re-entry and reintegration process, may be a helpful addition to re-entry preparation as well as facilitating overall coping. Being able to discuss their fears and excitement with a peer may be a nice addition to re-entry interventions given the importance peers have in adolescent development.

Finally, peers and adolescents with cancer alike may benefit from electronic re-entry preparation through social media, websites, online discussion groups, cell phone and tablet apps, etc. Electronic resources may be a culturally relevant resource for adolescents to provide information to peers non-intrusively, to allow adolescents to

connect with other peers with cancer, demonstrate social support, and/or stay in touch with classmates throughout treatment.

Overall, the need for individualized school re-entry preparation for the adolescent can be addressed by including him or her in the process. The adolescent should be invited to be an active participant in planning his or her re-entry preparation, including how much information to disclose, how to disclose, and to whom. In this way, the adolescent's needs are identified, the intervention can be uniquely tailored to those needs, and developmentally-appropriate goals of autonomy and independence can be supported.

### Limitations

Several limitations are noted. The current study is cross-sectional, so changes in reintegration across time could not be assessed. While participants with relatively recent cancer diagnoses were recruited, respondents may have been subject to retrospective bias. The sample is overwhelmingly Caucasian which greatly reduced generalizability of results. Similarly, given the nature of the recruitment sites, participants with leukemia and lymphoma may have been overrepresented. The current study was subject to difficulty with recruitment noted in online survey research (Hamilton, 2003). In addition, study findings may also speak to difficulties with recruitment with this population; several adolescents wished to return to normal, perhaps participating in a study asking them to discuss their cancer experiences was perceived as aversive and contrary to this goal. This may have limited the range of perspectives obtained. Only data from adolescents were collected, and adolescents may have failed to detect problems in their functioning at the time of re-entry. Gathering information from multiple informants (such as parents and teachers) may have provided a more comprehensive picture of their school re-entry experience. Finally, lower power may have inhibited the ability to fully capture potential statistical effects in the current sample, in addition to potentially limiting generalizability. A goal sample size of 108 participants was deemed sufficient to



obtain a power of 0.80 and a medium anticipated effect size (0.15) with an alpha of 0.05 for up to eight predictors for analysis. However, the study's actual sample size was not large enough to ensure adequate power for tests involving a medium effect.

### Future Research

Identifying variables from the adapted DSC model that impacted the school re-entry process is critical to improving and individualizing school re-entry interventions. As Fuemmeler et al. (2006) summarize, "It appears that considerable individual variability exists in the adjustment process, and that only a small subset of these children experience consistent difficulties" (p. 105). It is important to continue to empirically evaluate how these predictors interact or moderate one another, and impact school, home, and community systems, to better understand their influence on school re-entry. Along these lines, it would be interesting to investigate how social support mediates and/or moderates both school re-entry and reintegration outcomes. School re-entry effectiveness should be studied using control groups and longitudinal designs, particularly examining the efficacy of interventions among different age groups. In addition, further qualitative studies, and perhaps needs assessments, with adolescents with cancer are warranted to better understand their school re-entry and reintegration needs and goals. Finally, further investigation of the appropriateness of functional independence as an outcome measure of school re-entry should be considered.

### Summary

The current study added to extant literature by obtaining the adolescent with cancer's perspective on school re-entry. The study provided tentative support for a discrepancy between professional and adolescent re-entry needs and goals. Findings suggest that a subset of adolescents with cancer may be at risk for poor school re-entry/reintegration outcomes, including females, being of lower SES, having certain types of cancer (brain tumors, leukemia), undergoing specific types of treatments

(radiation, chemotherapy), being out of school for longer periods of time, having pre-morbid academic difficulties, and/or having poor social support. Adolescents who demonstrate these risk factors may warrant increased attention when preparing to return to school. In addition to systemic and within-person factors identified through the adapted DSC model, developmental characteristics of adolescence must be considered in planning re-entry intervention. Appropriate modifications to school re-entry preparation for adolescents may include utilizing electronic and social media, implementing peer mentors, focusing on reinforcing appropriate social circles, and emphasizing autonomy. Much more research is needed to understand how to best assist the adolescent with cancer in returning to school.

APPENDIX A  
FIGURES

Figure A1. Disability Stress Coping Model Adapted from Wallander & Varni (1998).

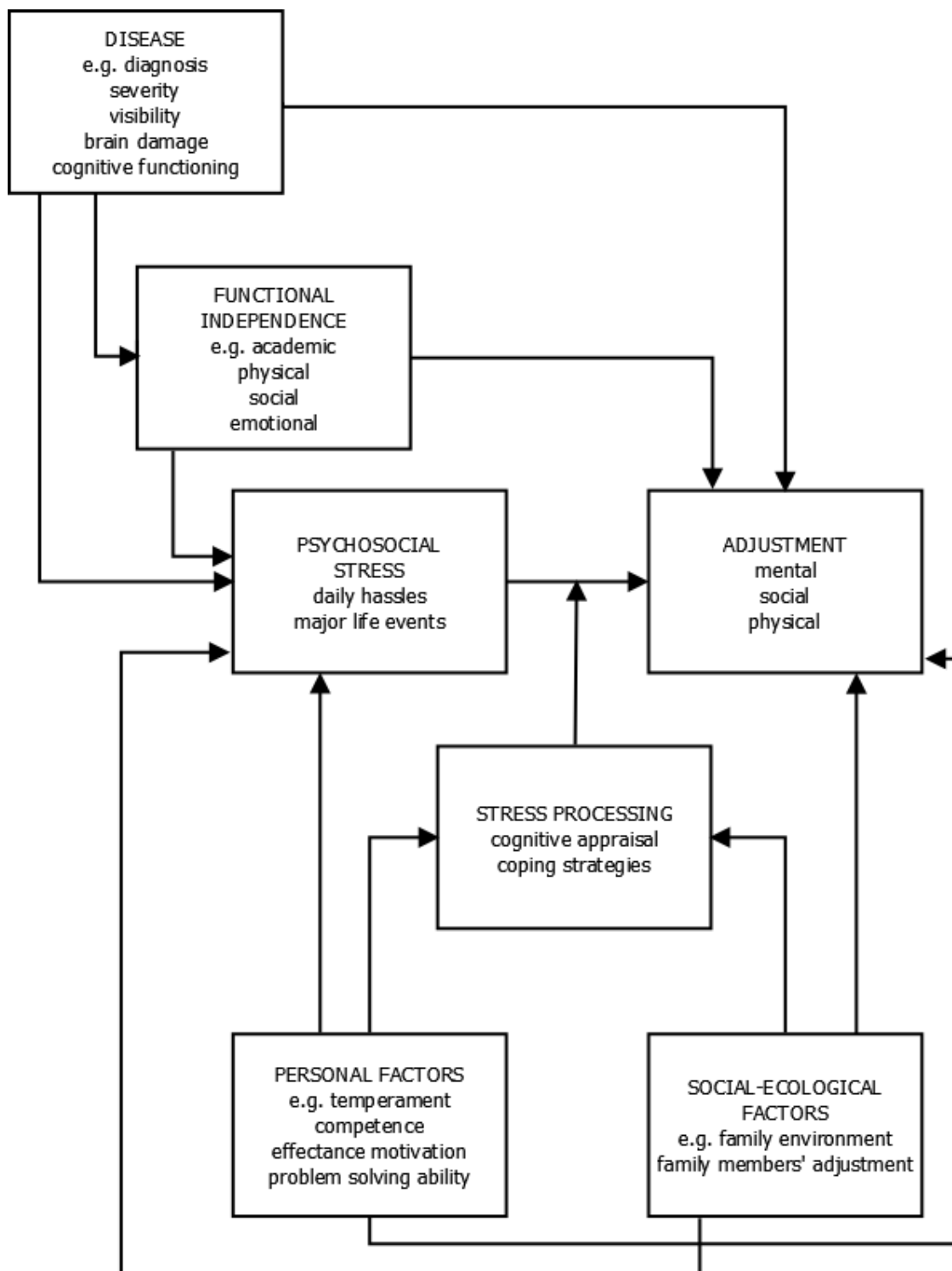


Figure A2. Adaptation of DSC Model for School Re-Entry Outcomes and Predictors.

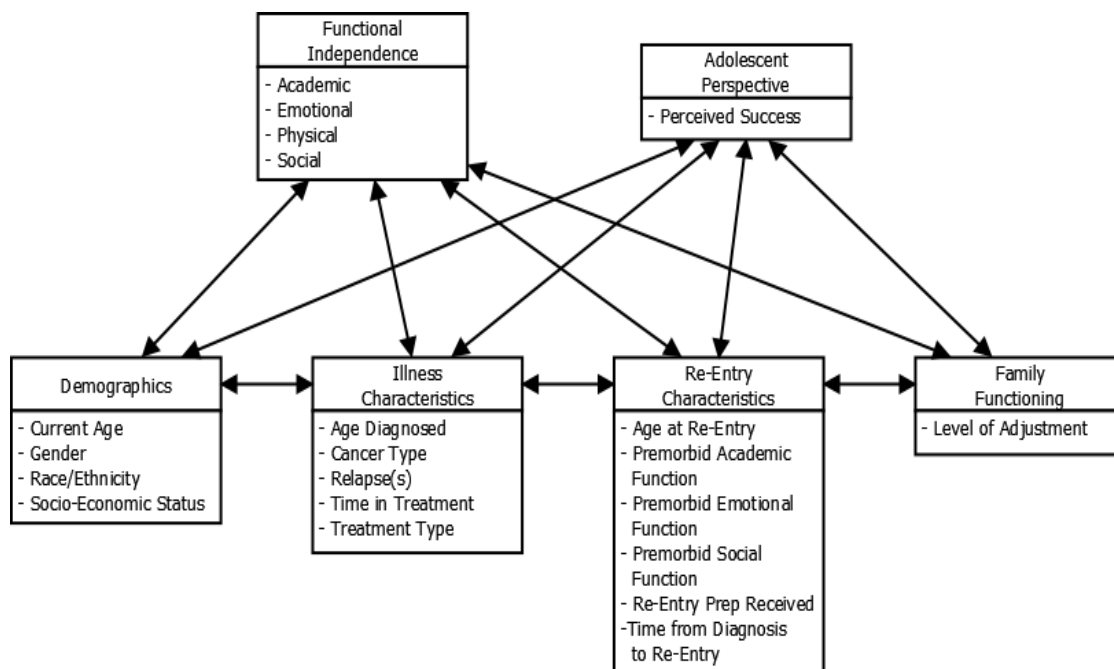
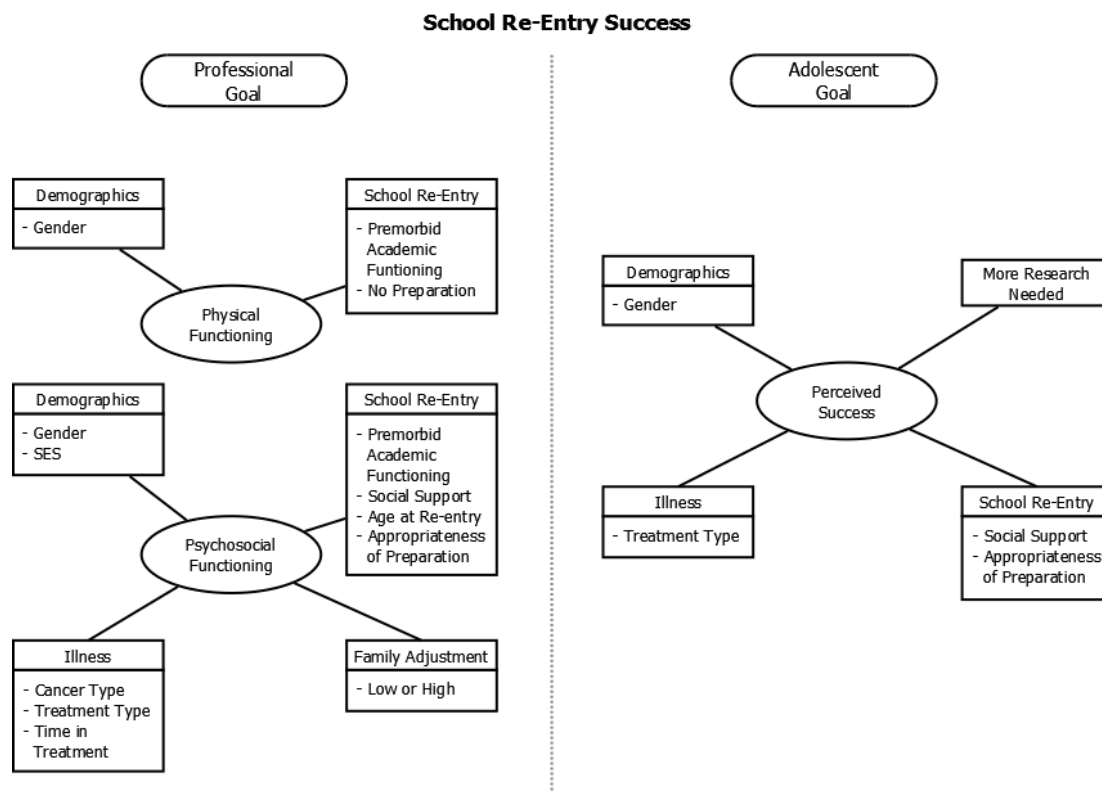


Figure A3. School Re-Entry Success: Significant Predictors of Outcomes.



APPENDIX B  
FOCUS GROUP QUESTIONS

1. What happened before you went back to school for the first time? For example, did someone come talk to your classmates, did you receive testing, did you see a counselor?
2. What was it like for you academically?
3. What was it like for you socially?
4. What was it like for you physically?
5. Do you consider your return to school successful? Why or why not?
6. What helped you get back to school?
7. What made it difficult for you to get back to school?
8. What did you need to return to school?



APPENDIX C  
WEB-BASED SURVEY QUESTIONS

1. How old are you?

-Response (0-100)

2. What is your race or ethnicity? Select all that apply.

-American Indian or Alaska Native  
-Black or African American  
-Caucasian (Non-Hispanic)  
-Hispanic or Latino/a  
-Native Hawaiian or Pacific Islander  
-Other  
-Unknown  
-Multiple ethnicities

3. What is your gender?

-Male  
-Female

4. Did you receive free or reduced lunch at school?

-Yes  
-No  
-I don't know

5. What type of cancer were you diagnosed with?

-Leukemia (ALL or AML)  
-Solid Tumor  
-Brain Tumor  
-Hodgkin's Lymphoma  
-Non-Hodgkin's Lymphoma  
-Neuroblastoma  
-Retinoblastoma  
-Sarcomas  
-Rhabdomyosarcoma  
-Wilms' Tumor  
-Other

6. How old were you when you were first diagnosed with cancer?

-Fill in blank (0-100)

7. What type(s) of treatment have you received? Please select all that apply.

-Chemotherapy  
-Radiation  
-Surgery  
-Other (please explain):

8. Have you experienced a relapse?

-Yes, one relapse  
-Yes, more than one relapse  
-No

9. How many **total** years were you in treatment? Please include time you spent inpatient and outpatient.

-Less than one year  
-1 year  
-2-3 years  
-4 or more years

10. Did you receive special education services **before** you had cancer?

(Examples: you had an IEP, you had a special reading teacher, you went to resource room, etc.)

-Yes  
-No  
-I don't know

11. How often did you have problems getting along with kids your age **before** you were diagnosed with cancer?

-I never had problems  
-I had a few problems  
-I had many problems  
-I had problems almost every day

12. How often did you have problems with your feelings or emotions **before** you were diagnosed with cancer?

- I never had problems
- I had a few problems
- I had many problems
- I had problems almost every day

13. How old were you when you first went back-to-school after being diagnosed or relapsing? (Please answer based on your most recent return to school).

-Response: (0-100)

14. How many **months** did it take you to go back-to-school after being diagnosed or relapsing? Provide your best estimate.

- Less than one month.
- 1 - 3 months
- 4 - 6 months
- 7 - 11 months
- One year or more

15. This is a list of strategies sometimes used to help students with cancer get ready to go back-to-school after being diagnosed. Please check all the strategies that were used for you when you went back-to-school.

- Someone came to my school and talked to my classmates about cancer before I went back
- Someone talked with my teacher(s) about my cancer before I went back
- Someone talked with my school nurse about my cancer before I went back
- I had a 504 plan or IEP to help with school work and/or getting around school
- I don't know
- None of these strategies were used before I went back to school.
- Other:

16. Social support may be an important part of making going back-to-school easier for students. Please check how supported you felt by other people when you went back-to-school after being diagnosed or relapsing.

- Very supported by others
- Sometimes supported by others
- Not very supported by others
- Not at all supported by others

17. Who was most supportive of you when you went back to school? Drag the names up or down the list to put them in order of most supportive to least supportive, with "1" being Most Supportive and "7" being Least Supportive.

Options: Parents, Teachers, Friends, Other Classmates, My Community, Hospital Staff, Other

18. How successful was your back-to-school experience after being diagnosed or relapsing overall?

- 1 = Not successful at all
- 2 = A little successful
- 3 = Successful
- 4 = Very Successful

19. What was most helpful in making your back-to-school experience a success? If it was not successful, what do you think would have made it better?

- Open-ended Answer

APPENDIX D  
SURVEY CRITIQUE FORM

### Survey Critique

Thank you for your time and expertise to review the survey. Your feedback about the survey will guide survey revisions before the final survey is launched. **Please write your comments on this form and return it to me at the end of the group.**

#### **Style & Structure**

1. Have you ever completed a web based survey prior to the *School Re-Entry* survey?

\_\_\_\_yes      \_\_\_\_no

2. Estimate the number of minutes it took you to complete just the survey (do not include the time it takes to write comments on critique form) \_\_\_\_ minutes

3. Was the survey too long? \_\_\_\_yes\_\_\_\_no

Comments:

4. Are there aspects of the survey (such as length, electronic format, etc) that you think

would discourage respondents from completing the survey? \_\_\_\_yes

\_\_\_\_no

Comments:

5. Was the style or design of the survey (such as color, font, font size, page breaks, etc.) problematic?

\_\_\_\_yes      \_\_\_\_no

Comments:

**Content**

6. Do you think the survey questions about current school re-entry practices were

insulting or offensive? yes no

Comments:

7. Did the words used in the survey seem clear and appropriate? yes no

Comments:

8. Are there other questions you think should be asked? yes no

Comments:

9. Are there questions you think should be deleted? yes no

Comments:

10. Please add any additional comments here and on the back:



APPENDIX E  
PedsQL QUESTIONNAIRE

The following questions are things that might be a problem for you. There are not right or wrong answers. Please tell me **how much of a problem** each one has been for you during the **past ONE month** by circling:

- 0** if it is **never** a problem
- 1** if it is **almost never** a problem
- 2** if it is **sometimes** a problem
- 3** if it is **often** a problem
- 4** if it is **almost always** a problem

#### **About My Health and Activities (problems with...)**

1. It is hard for me to walk more than one block
2. It is hard for me to run
3. It is hard for me to do sports activity or exercise
4. It is hard for me to lift something heavy
5. It is hard for me to take a bath or shower by myself
6. It is hard for me to do chores around the house
7. I hurt or ache
8. I have low energy

#### **About my Feelings (problems with...)**

1. I feel afraid or scared
2. I feel sad or blue
3. I feel angry
4. I have trouble sleeping
5. I worry about what will happen to me

#### **How I get Along with Others (problems with...)**

1. I have trouble getting along with other kids/teens
2. Other kids/teens do not want to be my friend
3. Other kids/teens tease me
4. I cannot do things that other kids/teens my age can do
5. It is hard to keep up with my peers

#### **About School (problems with...)**

1. It is hard to pay attention in class
2. I forget things
3. I have trouble keeping up with my schoolwork
4. I miss school because of not feeling well
5. I miss school to go to the doctor or hospital

APPENDIX F  
FACES-IV QUESTIONNAIRE

**Directions to Family Members:**

1. All family members over the age 12 can complete *FACES IV*.
2. Family members should complete the instrument independently, not consulting or discussing their responses until they have been completed.
3. Fill in the corresponding **number** in the space on the provided answer sheet.

<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>Strongly Disagree</b>	<b>Generally Disagree</b>	<b>Undecided</b>	<b>Generally Agree</b>	<b>Strongly Agree</b>

1. Family members are involved in each others lives.
2. Our family tries new ways of dealing with problems.
3. We get along better with people outside our family than inside.
4. We spend too much time together.
5. There are strict consequences for breaking the rules in our family.
6. We never seem to get organized in our family.
7. Family members feel very close to each other.
8. Parents equally share leadership in our family.
9. Family members seem to avoid contact with each other when at home.
10. Family members feel pressured to spend most free time together.
11. There are clear consequences when a family member does something wrong.
12. It is hard to know who the leader is in our family.
13. Family members are supportive of each other during difficult times.
14. Discipline is fair in our family.
15. Family members know very little about the friends of other family members.
16. Family members are too dependent on each other.
17. Our family has a rule for almost every possible situation.

18. Things do not get done in our family.
19. Family members consult other family members on important decisions.
20. My family is able to adjust to change when necessary.
21. Family members are on their own when there is a problem to be solved.
22. Family members have little need for friends outside the family.
23. Our family is highly organized.
24. It is unclear who is responsible for things (chores, activities) in our family.
25. Family members like to spend some of their free time with each other.
26. We shift the household responsibilities from person to person.
27. Our family seldom does things together.
28. We feel too connected to each other.
29. Our family becomes frustrated when there is a change in our plans or routines.
30. There is no leadership in our family.
31. Although family members have individual interests, they still participate in family activities.
32. We have clear rules and roles in our family.
33. Family members seldom depend on each other.
34. We resent family members doing things outside the family.
35. It is important to follow the rules in our family.
36. Our family has a hard time keeping track of who does various household tasks.
37. Our family had a good balance of separateness and closeness.
38. When problems arise, we compromise.
39. Family members mainly operate independently.
40. Family members feel guilty if they want to spend time away from the family.
41. Once a decision is made, it is very difficult to modify that decision.
42. Our family feels hectic and disorganized.

***Thank you for Your Cooperation***

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