

THE SCHOOL REENTRY PROCESS IN NORTH CAROLINA SCHOOLS FOR CHILDREN  
WITH PEDIATRIC CANCER

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## TABLE OF CONTENTS

Abstract .....	iv
Chapter One: Introduction .....	1
Chapter Two: Literature Review .....	2
Overview of Pediatric Cancer and Treatment .....	2
Leukemia.....	2
Lymphoma .....	3
Brain and CNS Tumors.....	3
Other Childhood Cancers.....	4
Typical Effects of Pediatric Cancers .....	5
Cognitive and Academic Effects .....	6
Social, Emotional, and Behavioral Effects .....	9
The School Reentry Process for Students with Cancer .....	12
School Liaisons .....	12
Educational Workshops for School Personnel and Peers .....	14
Accommodations and School Supports .....	15
Targeting Absenteeism in Students with Pediatric Cancer .....	16
Statement of the Problem.....	18
Chapter Three: Methods .....	20
Participants .....	20
Materials and Procedures.....	20
Analysis .....	21
Chapter Four: Results .....	23
Services Provided to Students with Cancer .....	23
Parents' Perceived Helpfulness .....	24
Parents' Perception of Needed School Reentry Services .....	24
Chapter Five: Discussion.....	26
Limitations .....	27
Future Directions .....	28
Conclusions.....	28
References .....	31
Appendix A .....	35

## LIST OF TABLES

Table 1. Parents' perceptions of the helpfulness of accommodations provided .....	30
Table 2. Common themes regarding parents' perceptions of additional services needed.....	30

## ABSTRACT

### THE SCHOOL REENTRY PROCESS IN NORTH CAROLINA SCHOOLS FOR CHILDREN WITH PEDIATRIC CANCER

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Extensive research has been done looking at the cognitive, behavioral, and social/emotional effects of pediatric cancer and the impact these effects have on students' school performance.

The existing literature stresses the importance of schools having a school reentry plan in place for children when returning to school after treatment and/or extended stays in the hospital.

However, several studies have found that, often, parents of students with cancer report that their child's school did not have a reentry plan in place; or, that the plan was not an effective one.

This study will examine parents' perceptions of the accommodations North Carolina schools have provided to their children with cancer including the presence or absence of a reentry plan, if one is present, and any academic accommodations that are provided. Additionally, this study will gather information regarding parents' perceptions of how helpful services offered by the school were to their child and what additional services they believe would have been helpful, and wish had been offered to their child as they transitioned back into the school setting.

## CHAPTER ONE: INTRODUCTION

Approximately 1 out of every 285 school-aged children in the United States will receive a cancer diagnosis before the age of 20 (American Cancer Society, 2014). Whereas cancer is the second leading cause of death for children aged 5-14, the survival rate for pediatric cancer has vastly improved since the 1970s due to advancements in medical treatment. Currently, the five-year survival rate for these children is 80%, which has increased from 50% in 1977 (American Cancer Society, 2014). As a result, a significant number of children and adolescents will reenter the school environment following their cancer diagnosis and subsequent treatment. For this reason it is essential to understand how cancer and its treatment might affect the cognitive, emotional, and behavioral functioning of these students as well as the school's role in adequately serving the needs of these students.

This study will examine parents' perceptions of the accommodations North Carolina schools have provided to their children with cancer including the presence or absence of a reentry plan, if one is present, and any academic accommodations that are provided. Additionally, this study will gather information regarding parents' perceptions of how helpful services offered by the school were to their child and what additional services they believe would have been helpful, and wish had been offered to their child as they transitioned back into the school setting.

## CHAPTER TWO: LITERATURE REVIEW

### **Overview of Pediatric Cancer and Treatment**

The three most commonly diagnosed forms of pediatric cancer are Leukemia, Lymphoma, and brain and central nervous system (CNS) cancers (American Cancer Society, 2014). These cancers are typically treated using in a variety of methods including surgery, radiation, chemotherapy, and medications such as methotrexate, hydrocortisone, prednisone, and cyclophosphamide, which can have a variety of direct negative effects on school functioning (Armstrong & Horn, 1995).

#### **Leukemia**

Leukemia occurs in bone marrow blood cells and causes an abnormal increase in white blood cell production. There are two forms of Leukemia: Acute Lymphocytic Leukemia (ALL) and Acute Myeloid Leukemia (AML). ALL is the most common form of cancer diagnosed in children and is typically treated with chemotherapy and CNS prophylaxis in order to avoid re-occurrence of cancer in the CNS. Long-term difficulties typically related to ALL and its treatment can include growth delays and an increased risk of recurrence of other forms of cancer (American Cancer Society, 2014), as well as cognitive delays including significant decreases in IQ (6 to 7 points on average) and achievement scores four years after starting treatment (Mulhern & Palmer, 2003). Robison and Bhatia (2003) also found decreases in math skills and visual-motor abilities in children with ALL when compared to pretreatment functioning. AML has similar long-term associated effects. However, in AML cases, CNS prophylaxis is used less than it is in ALL treatment. This results in fewer long-term negative effects to cognitive functioning in children diagnosed with AML (American Cancer Society, 2014).

## **Lymphoma**

Lymphoma occurs in white blood cells known as lymphocytes. There are two forms of Lymphoma: Hodgkin Lymphoma (HL) and Non-Hodgkin Lymphoma (NHL). HL typically occurs in the lymph nodes in the chest, neck, and abdomen (American Cancer Society, 2014). It is more commonly diagnosed in adolescence than in early childhood. Treatment for HL usually includes radiation and chemotherapy. Long-term effects commonly associated with HL and associated treatments include heart disease, recurrence of a second cancer (especially breast cancer in girls who were treated with chest radiation), infertility, and thyroid problems (American Cancer Society, 2014).

NHL occurs in the jaw, abdomen, and areas around the eyes. It is more common in boys than girls and is typically treated with chemotherapy. Long-term effects include heart damage, infertility, and decreased bone density (American Cancer Society, 2014) as well as cognitive delays similar to those seen in Leukemia (i.e., deficits in expressive and receptive language skills, decrease in visual-motor skills, and difficulty concentrating (Robison & Bhatia, 2003).

## **Brain and CNS tumors**

Brain and CNS tumors are the second most common form of cancer diagnosed in childhood. There are three frequently diagnosed pediatric brain tumors: astrocytoma, medulloblastoma, and ependymomas. Astrocytomas are tumors made up of cells called astrocytes, which are in the supportive tissues of the brain (American Brain Tumor Association, 2014). These tumors are most typically found in the cerebellum, cerebrum, spinal cord and the brain stem. Common symptoms of the occurrence of astrocytomas are seizures, loss of memory, headaches, and behavior changes. Medulloblastomas are tumors that occur in the cerebellum and are associated with symptoms including changes in behavior and appetite, poor coordination,

abnormal eye movements, headaches, and nausea. Ependymomas are tumors consisting of ependymal cells, which are found in the brain ventricles and central spinal cord. Common symptoms of ependymomas include nausea, headache, fatigue, and irritability.

Treatment of CNS tumors often includes surgery, chemotherapy, and radiation. Benign (non-cancerous) and malignant (cancerous) CNS tumors and their treatment can be problematic in children. That is, the long-term effects associated with these tumors and their treatment include hearing loss and growth delays (American Cancer Society, 2014), as well as more general cognitive delays including deficits in working memory, a decrease in IQ scores over time, and problems with executive functioning skills (e.g., difficulties with sustained attention and abilities to plan and organize (Mulhern & Palmer, 2003).

### **Other childhood cancers**

While Leukemia, Lymphoma, and Brain and CNS tumors are the three most common forms of pediatric cancers diagnosed in childhood, they are not the only form of pediatric cancers. Other cancers experienced in childhood include embryonal tumors, bone tumors, soft tissues sarcomas, and gonadal germ cell tumors (American Cancer Society, 2014). While the body of research regarding these cancers is not vast in relation to those discussed above, it is still important to recognize the potential negative effects to school functioning they may represent when they do occur in students.

Embryonal tumors are made of cells from developing embryos (American Cancer Society, 2014). These tumors are typically diagnosed prior to 5 years old. The three most common embryonal tumors are neuroblastomas, Wilms tumors, and retinoblastoma. Neuroblastomas are commonly found in the sympathetic nervous system and can lead to a range of adverse outcomes in children including heart damage, infertility, and hearing loss. Wilms



tumors, often occurring in the kidneys, and their treatment can lead to spinal cord problems such as scoliosis and kyphosis, infertility, kidney failure, and the occurrence of a second cancer.

Retinoblastomas can be heritable as well as nonheritable. Side effects of the treatment of retinoblastomas can include vision problems and, similarly, an occurrence of a second cancer.

Bone tumors and soft tissues sarcomas are found in the form of osteosarcomas, ewing sarcomas, and rhabdomyosarcomas. Osteosarcomas occur in rapidly growing bone tissue and can lead to heart damage, kidney problems, infertility, the occurrence of second cancers, and hearing loss (American Cancer Society, 2014). Ewing sarcomas are typically found in bone and soft tissue with side effects ranging from heart damage and lung problems to larger musculoskeletal issues. Finally, Rhabdomyosarcomas are found in skeletal muscle tissue with reported side effects varying based on the different treatments received.

Gonadal germ cell tumors, another form of cancer sometimes diagnosed during childhood, are tumors occurring in the reproductive organs (American Cancer Society, 2014). These tumors are more commonly found in adolescents than in younger children. Ovarian germ cell tumors are often associated with stomach pains and weight gain. Treatments include surgical removal of the affected ovary and chemotherapy. Testicular germ cell tumors are often diagnosed after a lump on the testicle is discovered. Treatments include removal of the effected testicle and chemotherapy.

### **Typical Effects of Pediatric Cancer**

Leukemia, Lymphoma, brain tumors, and CNS cancers can all result in negative effects to cognitive, social/emotional, and behavioral functioning at school among students afflicted with these forms of cancer. Regarding cognitive effects typically experienced by these students, common difficulties reported include difficulties acquiring new information, working memory

deficits, slowed processing speed, and executive functioning difficulties including poor sustained attention as well as poor planning and organization skills (Mulhern & Palmer, 2003). Regarding specific academic deficits experienced by children with cancer as they return to school, decreases in math and written language abilities in particular are often indicated (Bonner, Hardy, Willard, & Gururangan, 2009). In reference to social and emotional concerns, peer relationship difficulties are most often reported (Bruce, Chapman, MacDonald, & Newcombe, 2008). Such difficulties often result in these students requiring accommodations and increased support from staff as they return to school following cancer treatment. It is also vital to understand the specific difficulties commonly experienced by students with cancer within these broader areas of school functioning.

### **Cognitive and Academic Effects**

In pediatric cancer patients experiencing CNS tumors, decreases in cognitive abilities and in turn, general school performance is common (Bruce, Chapman, MacDonald, & Newcombe, 2008; Mitby et al., 2003). The location of the brain tumor can often impact the extent of these effects. For example, a brain tumor located near the thalamus can affect memory in students making it hard for them to remember what they have learned in school (Armstrong & Horn, 1995). Other factors impacting how much of a decrease in cognitive functioning is experienced post diagnosis and treatment include the age at the time of treatment (i.e., children diagnosed at a younger age are more likely to experience more persistent negative effects to cognitive functioning) as well as the extent of radiation treatment received with those undergoing higher doses of radiation treatment and those receiving whole-brain radiation often experiencing greater cognitive difficulties (Armstrong & Horn, 1995).

According to researchers, 40 to 100% of brain tumor survivors have been found to experience some cognitive difficulties as a result of diagnosis and treatment (Mulhern & Palmer, 2003). These often include deficits in working memory, a decrease in IQ scores over time, and problems with executive functioning skills such as sustained attention and abilities to plan and organize. Students who have been diagnosed with CNS tumors also often struggle to acquire new knowledge learned at school due to treatment-induced impaired working memory and decreased processing speed (Mulhern & Palmer, 2003). Relatedly, it is important to note that decreases in IQ scores are most likely due to a slower rate of new learning in relation to peers rather than to a loss of previously acquired knowledge (Mulhern, Marchant, Gajjar, Reddick, & Kuh, 2004).

Similar cognitive effects are often experienced by children with Leukemia or Lymphoma as they return to school. CNS radiation and high doses of medications including methotrexate are typically related to declines in cognitive functioning for these students (Robison & Bhatia, 2003). Girls and children who began treatment at a younger age are particularly susceptible to these negative outcomes. Areas of cognitive functioning deficits often experienced by these students include attention and executive functioning deficits, slower processing speed and working memory deficits (Butler & Haser, 2006). Other studies have found decreases in Full Scale IQ scores (an average of 6 to 7 points) as well as decreases in verbal and nonverbal IQ scores, visual and motor skills, receptive and expressive language, and declines in math, reading, and language scores following diagnosis and treatment (Mulhern & Palmer, 2003; Robison & Bhatia, 2003).

Regarding more specific effects observed to cognitive functioning, the effects of CNS cancers and their treatments was examined using the Wechsler Abbreviated Scale of Intelligence

(WASI) and the Conners' Continuous Performance Test (CPT) (Butler et al., 2013). Results of this study indicated those who received cranial radiation therapy (CRT) were more likely to experience cognitive impairments and to demonstrate impulsive responding as well as delayed reaction times on these tests. In fact, the authors suggest treatment via CRT may serve as a major predictor of persistent cognitive impairment in children with CNS cancers. In addition, results of this study indicated that lower socioeconomic status (SES) also served as a significant predictor of greater impairment in attention and cognitive functioning. These results demonstrate the importance of considering the role of environmental influences as well when examining the cognitive effects of cancer in childhood.

It has been found that interventions can be helpful in improving those cognitive skills that may have been impacted by cancer. One study studied the effects a computer based cognitive training program had on executive functioning skills (Kesler, Lacayo, & Jo, 2011). Participants in the study were children aged 7 through 19 who had received radiation or chemotherapy following a diagnosis of Leukemia or a posterior fossa brain tumor. The Cognitive Rehabilitation Curriculum (CRC) was a computer based training program that used games to improve skills in the areas of cognitive flexibility, attention, processing speed, and working memory. Sessions were provided five times per week for eight weeks and lasted twenty minutes. Results showed that, at the end of the training program, participants experienced improvements in processing speed and cognitive flexibility. No improvements to working memory nor visual attention were demonstrated as a result of this program (Kesler, Lacayo, & Jo, 2011). Many cancer survivors who experience a decrease in sustained attention abilities are aided by stimulant medications such as methylphenidate (Ritalin) with the purpose of increasing attention (Mulhern & Palmer, 2003). These studies taken together demonstrate that, with intervention, cancer

survivors can see improvements in their cognitive skills that were impacted by their cancer and/or the treatments they received.

### **Social, Emotional, and Behavioral Effects**

Many studies have found children with cancer tend to report higher rates of depression and lower self-esteem in comparison to typically developing peers (Bonner, Hardy, Willard, Gururangan, 2009; Li, Lopez, Chung, Ho, & Chiu, 2013; Wolfe-Christensen, Mullins, Stinnett, Carpentier, & Fedele, 2009). One study examined self-reported depression (Center for Epidemiologic Studies Depression Scale for Children, CES-DC) and self-esteem (Rosenberg's Self-Esteem Scale, RSES) rating scales scores of children, ages 9 to 16 years, with cancer in conjunction with semi-structured interviews with these children (Li et al., 2013). Results demonstrated that participants with cancer had significantly higher levels of depression and significantly lower levels of self-esteem than their healthy peers.

More specifically, many children with cancer report feeling fearful of a second occurrence of cancer among other worries (Stegenga & Ward-Smith, 2009). Other concerns frequently voiced by these students include difficulties with peer relationships due to feelings they cannot relate because of their vastly different life experiences. Many also report it was hard to maintain relationships with friends when they were away from school. Relatedly, another study also found that many students with cancer report feeling misunderstood by their peers at school (Bruce, Chapman, MacDonald, & Newcombe, 2008).

The incidence of bullying also represents another problem for children with cancer as they return to school. Researchers report many students do not want to return to school because they fear being teased for the physical changes to their appearance (Prevatt, Heffer, & Lowe, 2000). Lähtenmäki, Huostila, Hinkka, and Salmi (2002) found that pediatric cancer patients

were bullied three times more often than their healthy peers. Moreover, most of this bullying is often due to changes in the appearance of students with cancer stemming from treatment (i.e., weight loss, hair loss) (Katz, Varm, Rubenstein, Blew, & Hubert, 1992). Researchers indicate peers are often not properly educated about cancer and will believe the disease is contagious (Prevatt, Heffer, & Lowe 2000). This can then result in peers purposefully isolating these students. In contrast, one study did not find any reports of bullying when examining students with cancer in schools (Sandeberg, Johansson, Bjök, & Wettergren, 2008). The authors suggested that this lack of bullying was due to the schools' provision of information about cancer and its treatment to peers, which perhaps aided in an increased understanding of the situation. In contrast to relationships with peers, family members often report that their relationships with children with cancer grew even stronger after going through the diagnosis and treatment of cancer together (Li, et al., 2013).

Researchers conducted interviews with brain tumor survivors in emerging adulthood and their families about their experiences after cancer (Boydell et al., 2008). Most survivors listed feeling anger, depression, and a lack of motivation. Furthermore, they reported that after treatments they were less agile than peers, impacting their ability to participate in sports along with peers and causing frustration. Concerns about their physical appearance (hair loss, scars, weight loss) had an impact on their self-esteem, confidence, and often led to feelings of rejection. Many reported that the lack of a normal social life while in treatment made it very important to them to have friends and feel included now. This study found that most survivors had great determination to succeed academically and socially in order to prove school and medical personnel wrong who told them they would experience many struggles due to the negative effects that come with cancer and treatment (Boydell et al., 2008).

Regarding behavioral effects of cancer, researchers examined parents' behavior ratings on the Behavior Assessment System for Children, Second Edition (BASC-2) for children with cancer in comparison to a control group of healthy peers (Wolfe-Christensen et al., 2009). They found that, while most scores still fell in subclinical ranges, children with cancer had significantly higher ratings than their healthy counterparts on the Depression, Somatization, Withdrawal, and Attention Problems scales. Furthermore, cancer patients were more likely to report somatic complaints and depression when compared to their healthy siblings (Robison and Bhatia, 2003). Similar results were found in reference to ASEBA Child Behavior Checklist (CBCL) ratings for childhood cancer patients (Bonner, Hardy, Willard, & Gururangan, 2009). That is, results showed significantly higher ratings for both internalizing (i.e., depression and anxiety) and social problems when compared healthy peers.

Researchers examined the CBCL and the Teacher Report Form of the ASEBA to examine perceptions of internalizing and externalizing behavior characteristics among children with cancer (Rynard, Chambers, Klinch, & Gray, 1998). Overall, the average scores for both parent and teacher ratings fell in the normal ranges. However, when parent ratings were compared to teacher ratings, it was found that parents consistently reported more problems with aggressive, depressed and hyperactive behaviors. The authors suggest two reasons for this. First, they suggest that, since parents spend more time with their child than his or her teachers they have a greater opportunity to observe these behaviors. Second, it may be that teachers attribute negative behaviors to situational causes such as their illness rather than to the child and underreport these behaviors as a result (Rynard, Chambers, Klinch, & Gray, 1998). Similarly, Fryer, Saylor, Finch, and Smith (1989) saw the same trend of teachers reporting fewer problems in student with cancer than their peers. They described this phenomenon as a "halo effect".

## **The School Reentry Process For Students With Cancer**

Following diagnosis and treatment, it is common for students with cancer to be out of school for an extended period of time. School reentry programs can assist children and their families with making the transition back to school smoother when it is time for the child to return. When these children return to school, they may be eligible for services mandated by federal legislation. Children whose school performance is negatively impacted by their diagnosis or treatment are eligible to receive services in the provision of an Individualized Education Program (IEP) as mandated by the Individuals with Disabilities Education Act (IDEA) (Prevatt, Heffer, & Lowe, 2000). Students who have not had their academic performance significantly impacted by their illness can still receive services, such as accommodations addressing multiple absences through Section 504 of the Rehabilitation Act and the Americans with Disabilities Act (ADA), which is designed to remove barriers to educational access for students requiring such support (Prevatt, Heffer, & Lowe, 2000).

This federal legislation states that students must receive any services that are deemed necessary and appropriate to benefit from the education provided by schools. There are a number of services that have been found to be particularly effective for these students as they return to school including school liaisons to aid in communication between the school, hospital, and family, educational workshops for school personnel and peers to promote understanding of the child's condition and the provision of accommodations and supports targeting any presenting cognitive deficits following diagnosis and treatment.

### **School Liaisons**

It is important for children with cancer to return to school as soon as possible following diagnosis and treatment. Returning to school helps to normalize the cancer experience for



students and their families by allowing the student to continue participating in activities with healthy peers (Katz et al., 1992). A delayed return to school can lead to adjustment problems, feelings of hopelessness, and greater overall difficulties in making the transition back to school (Katz et al., 1992). A common barrier to school re-entry is that schools often do not understand the needs of returning students with a current or past cancer diagnosis (Bruce, Chapman, MacDonald, & Newcombe, 2008). Perhaps as a result, several studies have stressed the importance of providing a school-hospital liaison that is able to communicate with the school about the unique needs of the returning student with cancer (Bruce, Newcombe, & Chapman, 2012; Katz et al., 1992; Lähteenmäki, Huostila, Hinkka, & Salmi, 2002; Moore, Kaffenberger, Goldberd, Mi Oh, & Hudspeth, 2009).

One such study implemented a school liaison program for students with brain tumors that provided support, helped advocate for students, and provided consultation for the parents, school, and health care professionals involved in students' care and education (Bruce, Newcombe, & Chapman, 2012). Reports from parents and teachers were overwhelmingly positive. That is, teachers reported having a liaison to help with communication among involved parties made them feel as if they were working as a team to achieve the same goals for the child. Teachers also reported that the liaison helped them understand the effects that the child's cancer and treatment may have had on student's current levels of academic and social skills. This made them feel better prepared to work with the student upon his or her return to school. Furthermore, parents involved in this study reported that the liaison was beneficial in advocating for their child's needs. In fact, many reported that, without the liaison, they would have been uncertain how to approach the school to discuss their child's needs. The liaison also monitored the student's progress and was able to change these plans to match the child's progress as he or she

settled back into the school environment. Despite the recognition of the potential usefulness of a liaison in this process, many schools and hospitals may not know who is responsible for providing this person. This often results in a lack of communication between involved parties in the school re-entry process (Moore, Kaffenberger, Goldberd, Mi Oh, & Hudspeth, 2009).

### **Educational Workshops for School Personnel and Peers**

School personnel have also reported a need for educational workshops regarding the child's condition before the child with cancer returns to school (Moore et al., 2009). These workshops can be provided to school personnel as well as the other students in the patient's classroom. Teachers can benefit from these workshops by learning what expectations (i.e., regarding school performance, attendance, attention, and behavior) they should realistically have for a student with cancer returning to school (Lähteenmäki, Huostila, Hinkka, & Salmi, 2002). Moreover, some teachers report that such educational workshops are often the most helpful part of a reentry program in preparing them for the student's return (Rynard, Chambers, Klinch, & Gray, 1998).

A common complaint from parents of children with cancer is that the school did not understand their child's needs upon return (i.e., staff would often not understand that academic and social problems were most likely related to cancer treatments (Bruce, Chapman, MacDonald, & Newcombe, 2008). Additionally, many parents may become frustrated with the school's lack of understanding for their child's needs and as a result transfer their child to another school that is more accommodating or even begin homeschooling their child as a result (Boydell, 2008). Educational workshops for school staff can then help to decrease this misunderstanding.

Educational workshops for classmates can also be beneficial; however, it should be discussed with the student with cancer first to confirm he or she is comfortable with this being

discussed with peers (Katz, Varm, Rubenstein, Blew, & Hubert, 1992; Moore, Kaffenberger, Goldberd, Mi Oh, & Hudspeth, 2009). Providing information to the other students in the classroom can also help prepare them for, and understand, the physical changes that the patient may have experienced. This in turn could help reduce the likelihood of bullying as the student reenters the school setting (Sandeberg, Johansson, Björk, & Wettergren, 2008). Educational workshops for peers should be developmentally appropriate (i.e., younger children may benefit most from a puppet show presentation rather than a lecture about the disease). Furthermore, it has been suggested that encouraging peers to make cards for the student when he or she is absent, or encouraging them to visit the hospital will help teach the other students how they can actively support the student with cancer (Prevatt, Heffer, and Lowe, 2000).

### **Accommodations and School Supports**

One notable change after the return to school of student with cancer is these children might require additional support that they did not require pre-diagnosis. Such services can include tutoring, special education placement and the establishment of an IEP and/or a 504 plan. Significantly more children with cancer (23%) require special education services when compared to their healthy siblings (8%) (Mitby et al., 2003). Additionally, other studies have found significantly more cancer patients (30%) require tutoring when compared to a control group of children without cancer (15%) (Lähteenmäki, Huostila, Hinkka, Salmi, 2002). Many different reasons can exist for such needs of students with cancer, including cognitive impairments (e.g., difficulty concentrating, deficits in working memory, problems learning new information), poor academic performance/lower academic test scores, and increased absences (Mitby et al., 2003). Children diagnosed at a younger age are often at a greater need of special education placement than those who were diagnosed later in their school careers (Mitby et al., 2003). The duration of

which these children remain in special education is often correlated with the type of treatment received. That is, those who received CRT were in special education for a longer time (5.7 years) than those who did not receive CRT (4.7 years) (Mitby et al., 2003).

Different accommodations have been found to be useful for students with cancer including the use of tape recorders during lectures, use of computers to type assignments rather than handwriting, allowing use of calculators on math assignments, unlimited time to complete assignments and exams, one on one tutoring, and allowing multiple absences (Armstrong & Horn, 1995; Boydell et al., 2008; Mitby et al., 2003). However, while many students may want the extra help, they often worry about feeling singled out in the classroom should they receive accommodations (Boydell et al., 2008).

### **Targeting Absenteeism in Students with Pediatric Cancer**

Frequent absenteeism is common in students with cancer. Cancer survivors will miss double the amount of school when compared to healthy students (on average, 7% of the school year) (French et al., 2013). Another study found a similar number of days missed in students who were no longer receiving treatment; however, a much higher number of days missed were reported in students who were currently receiving treatment (about 30% of the school year) (Rynard, Chambers, Klinch, Gray, 1998). Researchers also found a higher absenteeism rate in cancer patients who were a few years past diagnosis than other, healthy students (Prevatt, Heffer, and Lowe, 2000). There are many factors that influence the attendance rates of these children. First, cancer treatments such as chemotherapy and radiation can result in severe nausea and fatigue that make it nearly impossible for these children to attend school when experiencing such symptoms. Second, having cancer can cause the immune system to weaken, making it very easy for these children to get infections that may cause them to be hospitalized; therefore, missing

school. Third, these children can miss school due to ongoing in-patient treatments or for different follow-up doctors' appointments (Armstrong & Horn, 1995).

Health-related quality of life (HRQOL) is another factor that influences school attendance (Sandeberg, Johansson, Bjök, & Wettergren, 2008). This study examined the relationship between HRQOL, school attendance, and social interactions using self-reports of participants ages 7 to 16 years. Researchers found a significant positive correlation between HRQOL and school attendance. This may suggest that having a higher quality of life makes attending school easier. Alternatively, it may be that attending school more frequently helps these students with cancer have an overall higher quality of life. Results of this study further indicated that attendance increased within 5 months after diagnosis. The authors suggested two reasons for the higher rate of absences early in the course of cancer. First, the shock and trauma of the diagnosis made it challenging for children to attend school and, second, children who have time to adjust to the effects of the cancer and the treatment are better able to continue on in normal daily activities. Therefore, time away from school is often necessary.

Regular school attendance is extremely important for all students. Frequent absences have been shown to cause an increase in academic problems for the student and to make it more likely that a student will drop out (Prevatt, Heffer, & Lowe, 2000). Absences make keeping up with class assignments challenging and it becomes very easy for students to get behind their peers quickly. School attendance is important for a variety of reasons, not just for academic purposes. For example, school attendance provides a chance for socialization for students (particularly important in cancer patients whom often feel isolated), a chance to be successful at something, and to feel like a member of society or the community (Prevatt, Heffer, & Lowe, 2000). For students with chronic illnesses such as cancer, returning to school can allow them to

feel as if they, not their illness, are in control of their life. After a cancer diagnosis, regaining a sense of normalcy is vital, and returning to school is one of the most effective ways to do so (Prevatt, Heffer, & Lowe, 2000).

### **Statement of the Problem**

Late effects of pediatric cancer have a negative impact on many aspects of students' school experiences (Robison & Bhatia, 2003; Wolfe-Christensen et al., 2009; Boydell et al., 2008; Stegenga & Ward-Smith, 2009; Mitby et al., 2003; Lähteenmäki et al., 2002). These students will often require school reentry plans once they have returned after treatments or extended hospital stays. As mentioned previously, past research has found a number of components that should be included in school reentry plans such as a liaison to communicate between hospital, school and parents, educational workshops to prepare school personnel and student's peers for the student's return, and accommodations through an IEP or a 504 plan. However, past research has shown that many parents report their child's school did not have an effective school reentry plan in place and some reported that the school had no plan at all. The gap between what the literature states should be included in these school reentry plans, the nature of services schools are currently providing as reported by parents, and parents' perceptions of these services will be further examined in this study.

The current thesis will examine parent data collected from a survey created for this project. The survey focuses on parents' perceptions regarding their child's school performance after diagnosis, any academic difficulties experienced, elements of a school reentry plan implemented by their child's school, any academic accommodations received, and an overall rating of how helpful parents felt this reentry plan and accommodations were at addressing the

needs of their children following cancer diagnosis and treatment. The following research questions will be addressed:

1. According to parents, what are North Carolina schools offering to students with pediatric cancer in regard to a school reentry plan and/or academic accommodations?
2. According to parents, are the services provided by North Carolina schools consistent with what the existing literature states as best practices for serving the needs of these students?
3. What are parents' perceptions of the helpfulness of school reentry plans and/or academic accommodations provided to their children in North Carolina schools?

## CHAPTER THREE: METHODS

### **Participants**

Respondents consisted of parents of school-aged children (5 to 18 years) who have received a cancer diagnosis and are in the process of/have already made a transition back into the school setting in North Carolina. Between August 2015 and December 2015, a survey was distributed to support group leaders at Wake Forest Baptist Health Brenner Children's Hospital in Winston-Salem, NC and the Me Fine Foundation, Inc. in Princeton, NC. A total of 15 parents of children with a current or previous cancer diagnosis consented to completing the survey. The mean age of children included in the sample was 11.33 years of age ( $SD = 4.19$ ). Fifty-seven percent of the children of parents who completed the survey were male and 43% were female. The vast majority of the participant's children were White (93%) and 7% were reportedly Hispanic or Latino. About half of the children (57%) reportedly had a diagnosis of Leukemia, 7% had Brain or Central Nervous System Cancers, and 36% had other cancers including Wilm's Tumor, Rhabdomyosarcoma, and Osteosarcoma. Forty-three percent of the children of parents who filled out the survey were currently receiving chemotherapy and 57% were either no longer receiving treatment or were receiving a combination of chemotherapy and radiation.

### **Materials and Procedure**

The survey (found in Appendix A) developed for this research project focused on the perceptions of parents of children with cancer regarding their children's school performance (i.e., grades, retention rates, and attendance records) any school difficulties experienced (i.e., cognitive difficulties; reading, writing, and math deficits; inattention and/or hyperactivity; difficulties with peers; emotional difficulties, and fatigue), the components of a school reentry



plan as implemented by their child's school (i.e., providing a liaison, educational workshops for school staff and students, and/or schoolwork to complete while in the hospital), academic accommodations received (i.e., extended time for tests, use of computers to take notes, orally given exams, tutoring, etc.), and a rating of parents' perceptions of how helpful the reentry plan and accommodations provided to their child were upon return to school. The survey also asked parents to describe any other services they believed would have been helpful to their children as they returned to school. The survey consisted of 12 total items.

The survey was distributed to parents whose children were currently receiving or previously received treatment in the pediatric oncology hospitals in North Carolina mentioned above via Qualtrics, an online survey delivery tool. In order to protect confidentiality, support group leaders distributed the Qualtrics link to parents who then completed the survey anonymously online.

### **Analysis**

In order to examine what services and/or school reentry plans North Carolina schools are currently offering to students with pediatric cancer, frequency counts were examined. The current study examined the percentages of parents who reported their children with cancer were provided with each of the school services delineated on the survey (i.e., what percentage of parents reported their child was provided with a 504 plan). To examine whether the services being offered in North Carolina schools is consistent with what the previous literature states as best practices, qualitative comparisons were made using these frequency counts/percentages calculated for Research Question 1. In order to answer how helpful parents believed the services offered to their children were, frequency counts/percentages were examined to determine what percentage of parents found these services Not Helpful, A Little Helpful, Helpful, or Very

Helpful. The data collected from the responses to an open-ended question asking what other services parents believe would have been helpful, were examined qualitatively using the method of thematic analysis (Crowe, Inder, & Porter, 2015).

## CHAPTER FOUR: RESULTS

### **Services Provided to Students with Cancer**

In order to address the research questions regarding what services are typically provided to students with cancer and if these services are consistent with what research states is best practice to offer, a series of questions were posed to parents. First, parents were asked if their child was provided with a reentry plan by the school as he or she returned to school following a cancer diagnosis. According to parents, 71% of their children were not provided a reentry plan and 29% were provided with one (n = 14). Second, parents were asked if an informational session was provided to their child's teachers about cancer. Seventy-nine percent of parent responded that an information session was not provided to their child's teachers and 21% responded that one was provided (n = 14). Third, parents were asked if an informational session about cancer was provided to their child's peers about cancer. Fifty-seven percent of parents stated that their child's peers were not provided with an informational session and 43% responded that there was an informational session provided at their child's school (n = 14). Next, parents were asked if they were provided with a hospital-school liaison serving to aid communication between the school and hospital regarding their child's needs. Seventy-nine percent of parents stated that they were not provided with a liaison and 21% stated that they were provided with one (n = 14). Finally, parents were asked if their child was provided with an Individualized Education Plan (IEP), Section 504 Plan, Individual Health Plan, and/or any other plan to aid in their child's reentry to the school setting. Forty-two percent of children were reportedly provided with an IEP, 50% were provided with a Section 504 Plan, 25% were

provided with an Individual Health Plan, and 17% responded that they were provided with another type of plan (n = 12).

### **Parents' Perceived Helpfulness of School Accommodations**

In order to answer the question of how helpful parents view the services and accommodations provided to their children to be, parents were asked to rate the helpfulness of a variety of accommodations on a likert scale (1= Not Helpful; 2= A Little Helpful; 3= Helpful; 4= Very Helpful). Parents reported finding “Other” accommodations the most helpful with a mean score of 4.00. Other accommodations reported as being the most helpful were: frequent breaks as needed, flexible deadlines, dictation to scribe for test answers, and allowing frequent snacks. Mean scores and standard deviations for these ratings in response to each question are provided in Table 1.

### **Parents' Perceptions of Additional Needed School Reentry Services**

Parents were given the opportunity to complete the following free response question, “In order to assist your child in his/her return to school, is there anything you think your child’s school should offer/should have done differently in addition to the services they have already provided?” A total of ten respondents completed this question. The responses were examined using a thematic analysis approach. Five parents reported feeling frustrated by the lack of understanding among school staff about cancer and their child’s needs. Some examples parents provided were: “His teacher told us in meetings, ‘he does not seem sick to us’”, “When he developed bruising from treatment, the school reported us to child services. It was very embarrassing”, “Teachers should be more aware of the effects chemo has on children with cancer. They were very unaware”, “Teachers need to understand that after treatment, your child does not go back to normal and there are lasting effects of surgery and chemo that need to be

understood”, and “The teacher said, ‘I think he just does not want to do his work.’” Parents also generally were in consensus that better communication between schools and hospitals as well as educational sessions provided to their children’s schools regarding cancer would have been appreciated in facilitating their children’s reentry into the school setting. Six parents expressed frustration that schools made it difficult for their child to be absent when needed and that they had to enroll their children in a virtual public school or pay for a tutor in order to assist their child keep up with missed schoolwork. Some examples parents provided were: “The school did not prepare enough in advance and my daughter had a very difficult time adjusting the first few weeks back”, “I paid for a tutor to ensure my daughter could stay up with her class. We tried the mainstream classroom for high school, but had the best results with the NC Online High School”, and “I wish there had been online and summer options so that my son could have taken fewer courses at school or if there was the equivalent of an on-line live/skyping opportunity for days when he could have listened to a lecture but did not have the physical strength to get out of bed.” A summary of these common themes including how many parents addressed each theme in their response to this question is provided in Table 2.

## CHAPTER FIVE: DISCUSSION

Students with pediatric cancer often experience effects that impact their school functioning. It is important for these students to be provided with comprehensive school reentry services upon return to school in order to make this transition as helpful for the student as possible. This study aimed to provide information on the current state of these services in North Carolina as well as parents' perceptions of how effective these services are in the reentry process for their child.

Regarding results of the current study, parents reported that a majority of their children (71%) were not provided with a school reentry plan. Informational sessions provided to teachers were not common with only 21% of parents reporting that their children's teachers were provided with information about cancer. It was more common for parents to report that their children's peers were provided with an informational session about cancer with about 43% of parents reporting such a service was provided. Additionally, only 21% of parents reported being provided a hospital-school liaison in order to facilitate communication and understanding between their child's school and hospital/medical provider. In contrast, most parents reported that their children were provided services in the school upon reentry through some type of plan: 42% received services through an IEP, 50% received services through a 504 plan, 25% received services through an Individual Health Plan, and 17% received services through another type of plan.

Parents in this study reported that they found the following accommodations the most helpful: frequent breaks, flexible deadlines for assignments, dictation to scribes, and access to frequent snacks. Much of these accommodations have been reported by parents as particularly

helpful by a number of previous studies (Armstrong & Horn, 1995; Boydell et al., 2008; Mitby et al., 2003). Many parents expressed frustrations with the lack of understanding from teachers. This lack of understanding of the needs of students with cancer is consistent with the findings of Bruce, Chapman, MacDonald, and Newcombe (2008). Parents also reported that feeling an informational session for teachers would have been very helpful if one had been offered as an option. Parents additionally reported that they wished there was better communication between their child's school and doctors throughout the reentry process and felt that a liaison would have been helpful in facilitating this communication. This is consistent with the findings of Mitby et al. (2009). Boydell et al. (2008) has also suggested that parents often become frustrated with a lack of understanding by the school and will often change schools or homeschool their child as a result. This was seen in this current study as well as a number of parents described changing schools to a private school, an online school, and/or homeschooling their children.

### **Limitations**

Several limitations to the current study exist and must be addressed in interpreting the results with some caution. First, this study utilized a small sample size making it difficult to get an accurate representation of the perceptions of parents of children with pediatric cancers across the state of North Carolina. In addition, due to the small sample size, results of statistical analyses should be interpreted with caution. Moreover, participants were all recruited from the Piedmont and Eastern regions of North Carolina. Therefore, the sample of participants in this study does not offer a full representation of services offered across all school systems in the state. That is, services offered in a more rural region such as in mountain regions may vary from those offered to these participants.

### **Future Directions**

Future studies should gather information from a wider range of regions and child characteristics. Future studies would also benefit from utilizing larger sample sizes in examining the important issue of school reentry services provided to students with cancer. More research is also warranted into what should be included in an effective informational session provided to teachers and peers regarding cancer as these children return to school. Parents in the current study continued to express concerns with a lack of understanding among school staff even after their child's teachers had been provided with such an informational session. Therefore, it could be that a different approach to such sessions is needed. A number of parents in the current study also reported allowing their child to attend a virtual public school after unsuccessfully reentering their current school. Future studies should examine the outcomes of these students who attend such programs and compare to the outcomes of these students to those who remain in a mainstream public school setting.

### **Conclusions**

The results of this study provided information on the current state of these services in North Carolina as well as parents' perceptions of how effective these services are in the reentry process for their child. Majority of parents reported that their child was provided with a school reentry plan upon return to a North Carolina school. The parents who participated in this study provided their perceptions on the effectiveness on the various accommodations provided to their child following their return to school. Results of this study provided important parent feedback on their perceived areas of need in North Carolina school in regards to how to better support these students as their return to school. The parents in this study reported a need for improved communication between schools and hospitals specifically in increasing school staff



understanding on the needs of these students and what to expect a student to be able to do and what the student may struggle with upon their return to school. Future studies should explore how to better foster this communication between schools and hospitals in order to better serve these students upon return to school.

## TABLES

Table 1

*Parents' perceptions of the helpfulness of accommodations provided*

<u>Accommodation</u>	<u>Mean Helpfulness Score</u>	<u>SD</u>
Extended time for tests	2.82	0.98
Use of tape recorders to listen back on lectures.	3.67	0.58
Having tests read aloud to him/her.	2.50	1.05
Use of computers to take notes/write assignments	2.33	1.53
Use of audio books.	2.75	1.50
Modified physical education.	3.50	0.85
Approval for multiple absences.	3.80	0.63
Preferential seating in classroom	3.44	0.88
Use of a calculator in math.	3.20	0.84
Tutoring	3.25	1.16
Other.	4.00	0

Table 2

*Common themes regarding parents' perceptions of additional services needed*

<u>Theme</u>	<u>Number of parents addressing theme</u>
Lack of understanding of students' needs	5
Need for better communication between involved parties	8
Difficulties dealing with absences	6

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## APPENDIX A

### Parents Perspectives on the School Reentry Process for Children with Cancer Survey

1. How old is your child? \_\_\_\_\_
2. What is your child's sex?
  - a. Male
  - b. Female
3. What is your child's ethnicity?
  - a. White
  - b. Black or African American
  - c. American Indian/Alaskan Native
  - d. Asian/Pacific Islander
  - e. Hispanic or Latino
  - f. Multiracial
  - g. Other \_\_\_\_\_
4. What is/was your child's cancer diagnosis
  - a. Leukemia
  - b. Lymphoma
  - c. Brain or Central Nervous System cancers
  - d. Other \_\_\_\_\_
5. How many years/months has it been since he/she was first diagnosed?
  - a. Months \_\_\_\_\_
  - b. Years \_\_\_\_\_
6. What types of treatment(s) is your child receiving?
  - a. Surgery
  - b. Chemotherapy
  - c. Radiation
  - d. Other \_\_\_\_\_
7. Was your child provided with a reentry plan by the school as he/she returned to school following a cancer diagnosis?
  - a. No
  - b. Yes
8. Was an informational session provided to your child's teachers about cancer?
  - a. No
  - b. Yes
9. Was an informational session provided to your child's peers about cancer?
  - a. No
  - b. Yes
10. Were any of the following provided for your child after his/her return to school?  
Select all that apply.
  - a. Individualized Education Plan (IEP)
  - b. Section 504 Plan
  - c. Individual Health Plan
  - d. Other

11. Were you provided with a hospital-school liaison who helped to aid communication between the school and hospital regarding your child's needs?

- a. No
- b. Yes

12. How helpful do you think the accommodations provided to your child have been?

	<b>Not helpful</b>	<b>A little helpful</b>	<b>Helpful</b>	<b>Very helpful</b>	<b>N/A</b>
<b>Extended time for tests</b>					
<b>Use of tape recorders to listen back on lectures</b>					
<b>Having tests read aloud to him/her</b>					
<b>Use of computers to take/write notes</b>					
<b>Use of audiobooks</b>					
<b>Modified physical education</b>					
<b>Approval for multiple absences</b>					
<b>Preferential seating in classroom</b>					
<b>Use of a calculator in math</b>					
<b>Tutoring</b>					
<b>Other _____</b>					

13. In order to assist your child in his/her return to school, is there anything you think your child's school should offer/have done differently in addition to the services they already provided?

\_\_\_\_\_