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Parents' Perspectives on Children with Cancer and their Adjustment to School after Treatment

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Parents' Perspectives on Children with Cancer and their Adjustment to
School after Treatment

by

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MSW Clinical Research Paper

Presented to the Faculty of the
School of Social Work
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Master of Social Work

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The Clinical Research Project is a graduation requirement for MSW students at St. Catherine University/University of St. Thomas School of Social Work in St. Paul, Minnesota and is conducted within a nine-month time frame to demonstrate facility with basic social research methods. Students must independently conceptualize a research problem, formulate a research design that is approved by a research committee and the university Institutional Review Board, implement the project, and publicly present the findings of the study. This project is neither a Master's thesis nor a dissertation.

Abstract

When a child is diagnosed with cancer, it impacts every facet of their life including their school experience and peer relationships. This research explored parents' perspectives on how their child adjusted to school and peer relationships after a cancer diagnosis and treatment. This study distributed a survey that asked questions about the child's cancer diagnosis, treatment, return to school, and peer relationships through quantitative and qualitative questions. Fifteen parents of children diagnosed with cancer completed the survey. Results indicated that parents educated the school and child's class about their child's diagnosis and sought help from different school support programs. Parent respondents wrote how their children were able to maintain peer relationships and were supported by their classmates during and after treatment for cancer. The findings of this study are limited because of the convenience sampling method and small sample size. The strengths and limitations of the study, implications for social work practice, and directions for future research are also outlined.

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This research is dedicated to all the participants who were willing to share their stories of their children's school and peer experience, this research project would not be what it is without all of you. I sincerely thank you.

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Parents' Perspectives on Children with Cancer and their Adjustment to School after Treatment

Introduction

Chronic illness is used to explain a range of long-term health problems and conditions among children. Chronic illnesses are defined as a medical condition that lasts longer than three months and affects a child's normal activities (Compas et al., 2012). The illness is prolonged and very rarely is it they cured, rather children must live with and cope with the illness (Compas et al., 2012). Chronic illnesses can affect any person at any stage of his or her life. A brain injury, a serious infection, or a genetic disorder can cause many different types of chronic illness including pain syndromes, blood disorders, and cancer. Some chronic illness in children, like asthma or eczema, can be treated and children can grow up with few if any limitations in their daily lives. Other chronic conditions such as arthritis, cancer, lupus, and epilepsy can be debilitating and cause children to not be able to participate in normal childhood activities like school and sports (Gannoni & Shute, 2009). Medical advances have vastly improved in the last several decades, expanding medical treatment for children with chronic illnesses (Hopkins, 2010).

Chronic illnesses are usually present for the child's life, even as they enter adulthood (Compas et al., 2012). While medicine has extended the life expectancies of many chronic conditions; presently there are no cures for many childhood onset chronic illnesses. Even cancer, which can be treated and can go into remission, is still considered a chronic condition. Cancer necessitates life long treatment and can negatively effect the child's social, physical, and emotional development (Sansom-Daly et al., 2012). Spina

bifida, autoimmune disorders such as lupus, congenital heart problems, and cystic fibrosis are all chronic conditions, which children suffer from. In some chronic conditions, effective treatments can lead to remissions or periods of relief of some symptoms (Compas et al., 2012). However, the condition is something children and their families will have to endure for the majority of their lives. The condition will impact children's academic experience and adjustment to school, especially if school is missed for an extended period of time. Cancer diagnoses will also impact children's peer interactions and friendships both during treatment and when children return to school. The lasting nature of chronic illnesses and cancer is why more research needs to be completed to determine the impacts that the illnesses have on children's life, including family, school, and peer relationships.

Prevalence

The focus of this research paper will be children suffering from the chronic condition cancer. There are many different types of childhood cancers including leukemia and cancers of the brain and central nervous system (Cancer.gov, 2012). In 2007, around 10,400 children under the age of fifteen were diagnosed with cancer and of these 1,545, will die from cancer each year (Cancer.gov, 2012). The mortality rate of cancer has been declining and this means that more children are living with this chronic condition every day. Today, 89 percent of children are surviving cancer; although some cancers are more deadly than others, overall most survive (Comas et al., 2012). These statistics suggest that as more children survive cancer and research needs to focus on how the cancer diagnosis impacts the areas of children's life both during and post-treatment. Whether children are in remission or receiving treatment, the condition will remain with

them for their lifetime. While a cancer diagnosis is relatively unlikely for children, it is nonetheless important to study how the diagnosis impacts children in all areas of their lives. An increased understanding about the family dynamics after children are diagnosed with cancer and how the children's diagnosis impacts the social and academic aspects of the children's life is important to research.

The Child and Family

Chronic illnesses can impact children's life in many ways. Doctor's appointments, traveling for treatments, and hospitalizations all disrupt children's normal routine (Gannoni & Shute, 2009). Children can be absent from school for long periods of time and this can affect the relationship they have with their classmates and friends (Gannoni & Shute, 2009; Williams & Chapman, 2011). Most of children's time is spent in educational and leisure activities with peers and these relationships help children's social and emotional development (Williams & Chapman, 2011). Children's changed appearance and physical or other limitations can create negative social interactions with peers and can make children feel left out (Williams & Chapman, 2011). The illness may also cause children to feel angry, inadequate, helpless, and depressed (Durualp & Altay, 2012). Children's personality, family, school, and friend support is important and can help children cope with the diagnosis and treatment of a chronic illness (Compas et al., 2012).

When a childhood cancer diagnosis is given, parents often feel alone and terrified. They may grieve for the life they thought their child would lead and now worry about caring for a child who is sick. Parents can suffer from depression, anxiety, and social isolation because their focus is solely on the child and their chronic condition (Gannoni &

Shute, 2009; Ross & Scarvalone, 1982). Parents can experience different emotions from one another and this can ultimately affect their relationship. Other parents may feel guilty; that perhaps they did something wrong and now their child is sick. Parents may also be more overprotective and cause isolation to the child or the family (Ross & Scarvalone, 1982). However, parents are their children's best advocates and they have the power to create partnerships with doctors (Ross & Scarvalone, 1982).

Siblings are also deeply affected when their sister or brother is diagnosed with a chronic illness. The new health plan and doctors visit can disrupt the regular routine of the family and siblings may feel cast aside (Compas et al., 2012). Siblings may become angry or develop behavioral problems at home or in school because they lack the emotional maturity to understand their emotions (Cancer.net, 2012). Siblings may not know how to express their feelings so they often act out through their behavior (Cancer.net, 2012). Siblings may be scared of losing their brother or sister and may not understand what is happening to their loved one. Siblings may feel jealous because their parents may be spending more time and giving more attention to their brother or sister (Cancer.net, 2012). Siblings may also feel lonely and left out if the family activities are centered around their siblings' treatment and possible hospitalizations (Cancer.net, 2012).

Purpose of Study

Research has begun to include children with cancer into the same category as children with chronic illnesses such as diabetes, Spina bifida, and cystic fibrosis (Sansom-Daly et al., 2012). Children with cancer experience similar impacts on their daily activities as children with other chronic illnesses because of doctors' appointments and treatment. Children with cancer can have high rates of school absenteeism, changes

in social interactions, fear of going to school, and as a result of treatment some children may have decreased cognitive functioning (Rynard & Chambers, 1998). Currently there is no nation or statewide programs that help children reintegrate into school after cancer treatment (Rynard & Chambers, 1998). Research about how children adjust to school after treatment is from one or more decades ago. Now that research has grouped children with cancer with children with other chronic illnesses, cancer specific research has decreased. This research will study parents' perspectives on how children with cancer reintegrate into the social aspect of school after treatment. Children with cancer must reintegrate into peer relationships and academics for which they have been absent from for some time. It is important to understand how parents' feel their child is adjusting to school, in order to better understand how school staff and other professionals can help support children as they reintegrate into school.

Literature Review

Introduction

There is limited research investigating how children with cancer adjust to school during treatments. Research studying children with cancer and their school adjustment is not recent because children with cancer are now included in studies about children with chronic illness. Most of the research is focused on psychological adjustment to the diagnosis or is focused on the family and siblings' adjustment to the diagnosis. Research has shown mixed results when studying school adjustment in children with cancer because studies have not separated those children who are receiving treatment and those in remission. Research has not differentiated between children going through current cancer treatment and children who have been in remission for several years; although there could be great differences between the groups.

Recent research has grouped children with cancer into the overarching category of children with chronic illnesses (Sansom-Daly et al., 2012). While cancer is an ongoing disease even after remission, because of follow-up doctors appointment and long-term treatment effects, outcomes may be different for those children with cancer than for children with other chronic conditions such as cystic fibrosis or hemophilia. Another issue is that researchers have many studies focusing on the psychological impact cancer has on children, but it often overlooks the social impact of cancer (Durualp & Altay, 2012; Barrera et. al, 2003).

This literature review will have six parts to it. The first part will focus on children with chronic illnesses and how the diagnosis of a chronic illness impacts the child's daily functioning. This section will also discuss how children with chronic illnesses cope with

their illness and psychological adjustment to the diagnosis. The second part of the literature review will focus on children with chronic illness and the school and social issues they face. The third part will discuss the different types of childhood cancer and how a cancer diagnosis can affect the development of children. Psychological and social adjustment of children with cancer will be the next part of the literature review followed by a section focusing on school adjustment for children with cancer. The final section will discuss the importance of this current study and how this will be beneficial to social workers and other professionals working with children with cancer.

Children with Chronic Illnesses

As defined in the introduction, *chronic illnesses* are a medical condition that lasts longer than three months and affects children's normal developmental activities (Compas et al., 2012). Chronic illnesses impacts children for their lifetime; although medical advances have improved and provided intermittent remissions of the condition or relief of symptoms (Compas et al., 2012). Chronic illnesses, such as cystic fibrosis, can shorten children's lifespan, but for most illnesses the lifespan is comparable to that of healthy individuals (Compas et al., 2012). However, while medications and treatments are available to treat many conditions, such as asthma and diabetes, the illness is rarely cured and children must live with the condition for their lifetime (Comas et al., 2012).

More and more research has been focusing on children with chronic illnesses because it is estimated that 20-30% of adolescents in Western countries are living with many types of chronic illnesses (Sansom-Daly et al., 2012). Of those living with life-long illnesses, about 10-13% are significantly impacted in daily functioning, which means some need help in daily cares, others have physical limitations, and others have

cognitive deficits (Sansom-Daly et al., 2012). Researchers have completed small and medium size quantitative and qualitative studies of participants living with a chronic illness such as diabetes, cystic fibrosis, and asthma. The research has mostly studied psychological and social adjustment to the illness, but several studies have looked at school adjustment. However, researchers have now included cancer as a chronic illness because children must continue to deal with the possibility of the cancer reoccurring, continuing doctors' appointments, and possible long-term side effects of treatment (Sansom-Daly et al., 2012).

Children with chronic illnesses can be deeply affected by their diagnoses and the changes to their normal routines. Research has focused heavily on how adolescents' psychological and day-to-day functioning has changed because of an illness. Several studies have researched chronic illnesses across age groups, from elementary aged children to adolescents, but often times the researchers do not look at a single age group. Gannoni and Shute (2009) focused their study on 18 participants, ages seven through 14, with diabetes, cancer, and chronic renal failure. This study was unique because it interviewed children as well as their parents in order to understand how children and families adapted to chronic illness (Gannoni & Shute, 2009). Sansom-Daly and colleagues (2012) focused their meta-analysis of 25 studies, each containing between 12 and 375 participants, on adolescents living with cancer, diabetes, cystic fibrosis, sickle cell disease, asthma, and juvenile idiopathic arthritis.

Gannoni and Shute (2009) found that emotional reactions to children's diagnoses were similar, but subsequent worries about the diagnoses were different. Both parents and children reacted with sadness, fear, anger, and nervousness to their diagnosis

(Gannoni & Shute, 2009). Parents and children reported disruptive effects on the families' life including participating in activities and doing things spur of the moment. Both Gannoni and Shute (2009) and Sansom-Daly (2012) reported the disruptive nature of the illness in children's lives including more absences from school, not being able to participate in certain activities, not interacting as much with peers, and not being able to maintain relationships with peers.

In particular parents worried about their finances and medical bills and felt overwhelmed by doctors' visits and hospitalizations (Gannoni & Shute, 2009). Children worried about being absent from school, difficulty maintaining friendships, and not knowing how to handle peer's questions. Children also reported that they tried to provide support to their parents by reassuring them of their health and ability to do every day things. Gannoni and Shute (2009) found that children were able to use positive coping strategies and wanted to learn more about their illness from peers going through the same illness. The article concluded by giving suggestions for future interventions including the need for liaisons who can help in both the health care and school setting as well as more purposeful support groups such as father support groups and groups aimed for children in varying stages of treatment. Gannoni and Shute's (2009) study was important because it showed both positive and negative aspects of families and children when dealing with chronic illnesses.

Both Sansom-Daly (2012) and Comas (2012) conducted meta-analysis about different interventions and coping strategies for children and adolescents suffering from a chronic illness. Sansom-Daly (2012) reviewed psychological interventions for adolescents with chronic illnesses from peer-reviewed articles from journals from 1979 to

2010. Eight educational interventions for adolescents were studied and two, counseling by health care professionals and psychosexual health, had significant positive effects. Cognitive behavioral interventions that had significant effects included cognitive restructuring, problem solving, goal setting, and role-playing coping strategies (Sansom-Daly et al., 2012). Family interventions focused on a coping skills program had positive effects on adolescents; these positive effects increased when the family completed more than two sessions. Sansom-Daly (2012) reviewed several types of chronic illness programs and found that cancer programs were less successful than the diabetes intervention programs.

Compas (2012) studied how the time since diagnosis impacted the relationship between the different types of coping and adjustment the child had. Children diagnosed with cancer had poorer adjustment six months after the diagnosis compared with four years after the diagnosis. Most likely this is due to the stress that comes from beginning cancer treatments and the unknown about the future. Compas (2012) found that children with cancer had lower levels of depression and trait anxiety than healthy controls, but they had higher levels of avoidant coping strategies and defensiveness. Another study that Compas (2012) reviewed was about the difference between behavioral and cognitive control and self-reported depression. Behavioral control, such as deep breathing and holding a parent's hand, were significantly related to more self-reported depression symptoms and somatic complaints and nurses reported poorer adjustment of these patients (Worchel et al., 1987; Compas et al., 2012). Cognitive control, such as thinking or talking about the illness and treatment, was significantly related to nurses' reports of the children being withdrawn and passive behavior in children.

School and Social Issues for Children with Chronic Illnesses

Several recent studies have begun to examine how children with chronic illnesses adjust to school and the possible challenges they face in regards to the social aspect of school and the relationship between the family and school. School aged children spend most of their time in educational and other activities with peers and friends. Peer relationships are especially important because it helps the social and emotional development of children (Williams & Chapman, 2011). Support from peers and close friends can be especially important for children with medical conditions because friends can act as a protection against the stressors from the condition and can help a child adjust more easily to their new limitations (Williams & Chapman, 2011). However, several studies have found that negative reactions from peers and close friends can hinder the ability for a child with a medical condition to cope and can even make the condition worse (Williams & Chapman, 2011; Hopkins, 2010). Negative reactions can occur when children with medical conditions have physical activity restrictions or when their appearance has been altered (Williams & Chapman, 2011). Limitations, especially in physical and school activities can cause the child to have more difficulty establishing and maintaining peer relationships.

In one study by Williams and Chapman (2011), nine children, ages six to 13, who suffered from hemophilia were studied. Their study results emphasized different perceptions of social adjustment between parents and children. Specifically, children stressed that they could do things that normal children do; however, their parents reported that the child and family was not a normal family (Williams & Chapman, 2011). Children tried to minimize their health condition and tried to hide their illness from their

peers. Both children and their parents reported that the child's peers had difficulty understanding the illness, the severity, and the treatment needed. Williams and Chapman (2011) also found that children felt it was difficult to adhere to their health care plan while trying to be socially accepted by their classmates. Several parents reported their children had distanced themselves from his or her friends and as a result became socially isolated. Several parents reported that their children had one or two close friendships and were accepted by these friends regardless of their physical abilities and condition (Williams & Chapman, 2011). Parents and children reported that trying to educate peers about the medical condition was not always successful and did not end bullying by other peers. Thus it is important to discuss with children's teacher and school staff whether educating the classroom is needed or would it hinder the children's adjustment. This study will ask parents about their experiences with their children's peers and education.

Hopkins (2010) studied 42 mothers about their child's genetic conditions and how this condition had impacted their family and school relationship. Children studied were all in regular education classrooms and were all within two years of their expected grade in school. Overwhelmingly mothers in the study reported that their children were healthy compared with other children suffering from the same condition. "She's very healthy. If you saw her you would not know that she has any, any disease. She keeps up with the kids in the neighborhood.", one mother reported (Hopkins, 2010). When asked about children's adjustment to school and to the condition, half of mothers reported that their children had no adjustment problems when it came to school and 14 mothers reported some adjustment difficulties, but did not elaborate.

Hopkins (2010) found two themes, open, meaning the mother was open about the condition and treatment with school staff and selective, meaning the mother did not tell school staff everything about the child's condition and treatment when it came to school communication. Of the mothers interviewed, 32 reported talking with the teacher, nurse, and other school staff about the child's conditions; the mothers reported they wanted the staff to understand the child's condition and be supportive if the child was absent (Hopkins, 2010). Five mothers did not communicate with school staff because they felt the child was not displaying any symptoms of their condition and they did not want any issues with staff. Half of the mothers interviewed reported concerns about the child missing school, how well the child was doing academically and socially in school, and safety concerns. Several mothers also noted that they did not want the child to manipulate their teachers by using the condition as an excuse (Hopkins, 2010). Parents have different perspectives and experiences when their child returns to school with a diagnosis of a chronic illness, so this study will ask what is needed, helpful and not helpful when the child returns to school.

Cancer in Children, Child Development and Cancer

There are many different cancer diagnoses, but the two most common types of childhood cancer are leukemia and brain tumors although there are other types of cancer including those affecting the central nervous system (Semrud-Clikerman, 2009). While the prognosis of leukemia and brain tumors is different, the treatment involves chemotherapy and cranial irradiation (Semrud-Clikerman, 2009). Treatment can last for several years and this can greatly impact the family's routine and functioning. Long-term

effects from treatment in conjunction with absenteeism from school, can create academic and social issues for children (Semrud-Clikerman, 2009).

There are several different types of brain tumors and each has a different prognosis. Brain tumors are frequently diagnosed when the child is between the ages of three and nine and 50-60 percent are cancer free after five years, although this greatly depends on the type of tumor. Changes in cognition or personality, nausea, headaches, visual issues, and sensory or motor impairment are the typical manifestations of a tumor (Semrud-Clikerman, 2009). Medulloblastoma and astrocytoma are common types of malignant tumors and they have a 65 percent rate of survival (Semrud-Clikerman, 2009). Brain stem gliomas are less common and also have a less than 10 percent survival rate (Semrud-Clikerman, 2009).

Treatment interventions for brain tumors include whole-brain radiation, chemotherapy, and/or surgical interventions (Semrud-Clikerman, 2009). Treatment can cause decreases in intellectual and academic functioning. Cranial radiation therapy has been shown to have more declines in intellectual and academic functioning, especially in math (Semrud-Clikerman, 2009). Other problems from treatment include difficulty in memory, attention, and processing speed (Semrud-Clikerman, 2009). The younger the child is when they are diagnosed and treatment begins, the poorer the outcome in cognition can be (Semrud-Clikerman, 2009). Children with brain tumors have shown more depression and externalizing behaviors especially when they have a lower Intelligence Quotient (IQ), their family life is chaotic, and they live in a family with a low socio-economic status (Semrud-Clikerman, 2009). While the child can have deficits in

social skills, studies have found that emotional and social issues are not long lasting (Nortz, 2007; Semrud-Clikerman, 2009).

There are two types of leukemia; acute lymphocytic leukemia (ALL) and acute myelogenous leukemia (AML). Acute lymphocytic leukemia is the most common, accounting for 75-80 percent of leukemia cancers and it has a 95 percent survival rate (Semrud-Clikerman, 2009). Acute myelogenous leukemia accounts for 20-25 percent of cases and is not studied as thoroughly as ALL (Semrud-Clikerman, 2009). This section will focus on ALL as that is what the most recent literature discusses. The peak age of ALL is between three and five years and is more common among Hispanics and whites than African Americans (Semrud-Clikerman, 2009). The initial white blood count and age at diagnosis are good predictors for the length of remission and survival (Semrud-Clikerman, 2009). There are three stages of treatment and it can last between two and three years (Semrud-Clikerman, 2009). The first stage is called remission induction, where the goal is to use chemotherapy and other types of medications to induce remission; remission usually occurs within three to four weeks. The consolidation is where remission is strengthened through intense treatment (Semrud-Clikerman, 2009). The third and final stage is maintenance, where long-term, low doses of medication are used along with daily and weekly doses of cancer medication.

Long-term effects of treatment of acute lymphocytic leukemia can include difficulty with academics, attention, memory, fine motor skills, and speed of information processing (Semrud-Clikerman, 2009). Family difficulties were also discussed and included marital problems, financial difficulties because of medical bills, and sibling adjustment problems (Semrud-Clikerman, 2009). Mothers are at a higher risk of

depression, most likely because they are the child's primary caregiver and are responsible for the medical care (Semrud-Clikerman, 2009). While marital problems were reported, Manne (2001) found that 70 percent of couples reported stable and close marriages (Semrud-Clikerman, 2009). Poor adjustment for children can also happen if the family has a low socio-economic status, low education levels, and no medical insurance (Semrud-Clikerman, 2009).

Social and Psychological Adjustment Issues for Children with Cancer

Cancer in children can cause a number of psychological symptoms including depression, feelings of anger or inadequacy, decreased confidence, and hopelessness (Durualp & Altay, 2012). Some children with cancer experience difficulties adjusting to the diagnosis and treatment and others have mood changes and social withdrawal (Barrera & Wayland, 2003). Depressive symptoms among children can differ depending on the child's development level, whether they have physical limitations, changes in appearance, and many school absences which can lead to decreased social interactions. Durualp and Altay (2012) completed a study of 20 children with cancer and 20 healthy children ages six to 12 years old. Durualp and Altay (2012) found that children with cancer did not differ from healthy controls in relation to school achievement or self-confidence; however they suffered significantly more psychological problems such as depression and social isolation. Children who experienced decreased mobility and increased pain and isolation had greater depressive symptoms, which researchers attributed to the lack of sensory and emotional stimuli (Durualp & Altay, 2012). Children with cancer were also found to have more impulsivity, mistrust, and anger than the healthy controls. It was also noted that children with cancer have more anxiety and

shyness than those suffering either an acute health problem or those having no health issues.

Studies have found differing results about children and their psychological adjustment to being diagnosed with cancer. A 15-month study by Barrera and Wayland (2003) of 44 families found that children tend to focus on positive aspects of their lives where as their mothers report more issues with social isolation and academic achievement. Often studies combine children at different points in their treatment or who are finished with treatment, which can vary the results of studies (Barrera & Wayland, 2003). Several researchers have said that children who are diagnosed with cancer and begin treatment before the age of five may be at a higher risk of adjustment and psychological problems (Barrera & Wayland, 2003). This higher risk could be because of the lack of cognition needed to understand the diagnosis and treatment and because this is an important period of social development. Adolescents who are diagnosed with cancer are more aware of their illness and treatment and they may miss milestones such as autonomy. Adolescents might also have less enjoyment in life because they have more understanding about what their diagnosis means. Barrera and Wayland (2003) noted that children with difficult temperament might have more adjustment issues because of the high stress associated with treatment. Barrera and Wayland (2003) found that children with an easy temperament and whose mothers have adequate adjustment might suffer less negative experiences.

School Adjustment Issues for Children with Cancer

Research has shown that children with cancer are at a higher risk for school adjustment problems because of multiple absences, changes in social interactions,

possible school phobias (Rynard & Chambers, 1998). Some forms of cancer and cancer treatment may be linked to a decrease in cognitive functioning and learning difficulties (Rynard & Chambers, 1998). Social isolation due to treatment or hospitalizations, changes in the child's appearance, and peers not knowing how to respond to a classmate with cancer are all social issues a child faces when returning to school (Chesler & Barbarin, 1986).

Rynard and Chambers (1998) and Chesler and Barbarin (1986) had similar findings to the study completed by Ross and Scarvalone (1982). While in treatment and absent from school, children miss not only academic work, but also classroom events and peer interactions. If children fall behind their classmates in the first grade they are more likely to feel inferior towards their peers and dislike going to school (Ross & Scarvalone, 1982). Due to the cancer and treatment, children may have less stamina and coordination, which can impact the activities they are allowed to participate in and can harm their self-image. Ross and Scarvalone (1982) also reported that some children may refuse to go to school because they feel they are different than the other children. Whether children are accepted back into school by their peers or are faced with rejection, can be dependent on their confidence, self-worth, and previous standing in the group (Ross & Scarvalone, 1982). Peers, especially if they do not understand children's diagnosis, can be unkind to children who appear weak or is coddled by the teacher (Ross & Scarvalone, 1982).

Parents can positively or negatively affect children's readjustment to school. Parents may be concerned about sending their child back to school for fear of them contracting an infectious disease, lowered academic performance, or being stigmatized by

others (Chesler & Barbarin, 1986). Ross and Scarvalone (1982) surveyed 71 parents, 35 teachers, 40 nurses, and three principals about the helpfulness of a school workshop that focused on children with cancer. Parents were also concerned that the teacher may pity their children or show them preferential treatment (Ross & Scarvalone, 1982). Several parents reported that the teacher had lower expectations for their children and when children sense this they responded with helplessness and discouragement (Ross & Scarvalone, 1982). In Ross and Scarvalone's (1982) workshop study, while parents were not present during the workshop, they reported that the teachers and nurses were more comfortable when dealing with both them and their child following the workshop. "The teacher and nurse have more confidence in treating my child normally", one parent said in the interview (Ross & Scarvalone, 1982). Parents also told researchers that the teacher was better able to prepare the class for the return of their child and his or her changed appearance. Overall, parents expressed gratitude and relief because the school staff was better informed about the diagnosis (Ross & Scarvalone, 1982).

Teachers are not trained and may not be emotionally prepared to face children's illness or the questions that may ensue from other students (Ross & Scarvalone, 1982). Often teachers think that cancer is a terminal illness, and while cancer can be terminal, the survival rates have soared over the past decades because of treatment. In Ross and Scarvalone's study (1982), 56 percent of teachers and 65 percent of nurses indicated they wondered how to respond to questions from their students about the child's illness. Forty-four percent of teachers and 47 percent of nurses also wondered how to respond to questions from the child with cancer. After the workshop that Ross and Scarvalone (1982) organized, teachers and nurses reported feeling more comfortable when talking

with their students and with the child with cancer. “I don’t hesitate any longer to discuss her illness with her, I realize she is aware of what’s going on”, one teacher said (Ross & Scarvalone, 1982). Another teacher reported, “If questions arise from other students, I feel I can cope with them, I was scared I would say something wrong” (Ross & Scarvalone, 1982). Teachers and nurses reported wanting more information about the illness, treatment, and side effects and after the workshop, they felt more hopeful about their student with cancer (Ross & Scarvalone, 1982).

Rynard and Chambers (1998) studied the Pediatric Cancer Support Program of Ontario, which provided support to school personnel with medical information about cancer and the emotional impact that cancer can have on a child. It gave support to teachers and other schools staff and provided them with resources and guidelines for how to support the educational and emotional needs of the class and the student with cancer. The program stayed in contact with the school for several years after treatment to ensure long-term school adjustment.

In this study, the teachers answered questionnaires on 67 children and their parents answered questionnaires on 55 children; students were between the ages of five and 19, with a mean age of 10 years (Rynard & Chambers, 1998). The questionnaires included questions about academic achievement, child adjustment, absenteeism, and satisfaction of the program (Rynard & Chambers, 1998). Both teachers and parents rated the school support program as positive and reported that children with cancer were well adjusted to school, both behaviorally and academically (Rynard & Chambers, 1998). Parents rated their children, who had finished treatment, as lower in reading and the children scored significantly lower on standardized measure of reading and spelling than

those still receiving treatment (Rynard & Chambers, 1998). These lower scores could be because children missed many days of school during treatment or it could be long-term treatment effects (Rynard & Chambers, 1998). Parents reliably rated their children as displaying more aggression, depression, and hyperactivity as the teacher reported, although it was still not in the clinical range (Rynard & Chambers, 1998). Surprisingly teachers rated the child with cancer as having fewer behavioral, emotional, and learning problems than randomly selected peers. However, this could be because the children's teacher excuses the children from normal classroom work, may be ignoring problem behavior, wanting to maintain a positive outlook, minimizing problems, and attributing problems to the illness and not the children (Rynard & Chambers, 1998).

Researching the child's perspective can be difficult because children with cancer are considered a vulnerable population so studies are often completed with parents of children with cancer. Chesler and Barbarin (1986) studied 95 parents of children with cancer. The parents were interviewed about the school experiences of their child with cancer. Fifty-one percent of parents reported experiencing problems at school including 74 percent who reported peer teasing, 62 percent who reported the child missed school regularly, and 6 percent who reported problems with teachers (Chesler & Barbarin, 1986). When asked if parents thought school staff was helpful, 55 percent said the staff was helpful where as 45 percent said the school was not helpful (Chesler & Barbarin, 1986). Parents who responded that staff was helpful, reported that their child was doing similarly to before the cancer diagnosis and that they educated school staff about the child's diagnosis. Parents who responded that staff was not helpful reported that the

child was not doing well in school before the diagnosis and was having a more difficult time catching up in school.

Chesler and Barbarin (1986) also found that school staff had a difficult time deciding how much help they should offer to children and how to balance treating children as normal while knowing the children needed special arrangements. Parents reported that they felt better about sending their children to school when the teacher and staff were caring, treated their children as normal, gave academic help, and kept the parents informed about their children's academic progress and peer relationships (Chesler & Barbarin, 1986). When the teacher and staff were insensitive to children's diagnosis or were overprotective of children, the parents then reported problems (Chesler & Barbarin, 1986). The study concluded that good communication must be established with the teacher of the children with cancer as soon as possible in order to ensure smooth transitions. Accurate updates on the diagnosis and treatment, any special needs the children may have, and the prognosis, were requested by the teacher. Chesler and Barbarin (1986) also concluded that the parents must be proactive even if this is an added burden because it is important to keep the school informed so the transition back to school for children is easier.

Rynard and Chambers (1998) completed a review of the literature on pediatric cancer school support programs. Of the 37 cancer centers that were included, 84 percent offered programs to school staff and students. However, little formal evaluation of the programs have been completed to determine the effectiveness of the school interventions. The programs offered included both teacher and student workshops. The teacher workshops were found to be beneficial and teachers reported more confidence in dealing

with a child with cancer (Rynard & Chambers, 1998). Teacher workshops are cost-effective but no long-term follow-up has been completed to determine how the teacher continually interacts with their student with cancer. Student workshops encouraged understanding and acceptance of their peers with cancer. Students showed an increase in knowledge and desire to interact with their peer with cancer (Rynard & Chambers, 1998). While these workshops were found to be beneficial, it was difficult to present to multiple classrooms and they did not provide any long-term support to students.

Application to Professionals

Ross and Scarvalone (1982) implemented a program that educated teachers, school nurses, and principals about childhood cancer and its relation to school. The goal of the program was to increase knowledge of cancer and treatment, to be more confident in having a child with cancer at the school, manage classmate's questions about cancer, and to develop open communication between the treatment center and school (Ross & Scarvalone, 1982). The program was developed by social workers for school personnel. The social workers' responsibility when a child returns to school is to encourage the mastery of medical information, understand the goals of treatment, and also emotional concern for the child (Ross & Scarvalone, 1982). The social worker must stress the importance of thinking about the child in terms of the illness, as well as focusing on the child's relationship with classmates, allowing independence, and focusing on academic success (Ross & Scarvalone, 1982). The social worker also must include the family and ensure they are also receiving support. It is the social worker's responsibility to remember all the systems involved in the child's life including home, school, and medical (Ross & Scarvalone, 1982).

The teacher is also an essential part of the child returning to school. Teachers often have little knowledge of cancer and are not always prepared to face the illness or help their students understand what is going on with their classmate (Ross & Scarvalone, 1982). The teacher may not know how to talk with the parent for fear of upsetting them, they may not know how to talk with the class about the diagnosis, and they may avoid or pity the child with cancer (Ross & Scarvalone, 1982). After the program by Ross and Scarvalone (1982) teachers and nurses responded that the program helped eliminate the fear of having a child with cancer in the classroom. The teachers and nurses reported understanding how to talk with the families and children about the illness and how to help children cope with the illness in the classroom; they were also appreciative for more information about the types of cancer, treatment, and side effects, and were hopeful about the outcome for the child with cancer (Ross & Scarvalone, 1982). Parents also reported the increase in confidence among the teachers and reported the teachers were better able to facilitate their child's return to school (Ross & Scarvalone, 1982).

The program by Ross and Scarvalone (1982) brought to attention the need for teaching workshops for school personnel in order to better facilitate children's return to school. Rynard and Chambers (1998) noted that 84 percent of the 37 cancer centers they studied had programs for school personnel, but little formal evaluation has researched the effectiveness of these programs. The lack of programs to help children return to school and research evaluating these programs is a concern. Research has shown that teachers do not have the knowledge or confidence to help their class understand the child's diagnosis and to provide the children and family with added support (Ross & Scarvalone, 1982). Before these programs can be developed it is important to have input

from parents about the needs of their child when returning to school. This research will ask parents about the child's experience returning to school, their peer and teacher interactions, and what would have made the transition back to school easier.

Conclusion

Research studying children with cancer reintegrating into school was completed during the 1980s and 1990s, but recently empirical studies have not been published. Instead, current research focuses on children with chronic illnesses and includes children with cancer in this research (Sansom-Daly et al., 2012). More recent research has been completed about the psychological effects of a diagnosis of cancer on a child (Durualp & Altay, 2012; Barrera & Wayland, 2003). The impact of a child returning to school after cancer treatment can be a difficult adjustment. The child's appearance may have changed, the child may still be absent from school to attend doctors; appointment or maintenance treatment, and the child may have physical limitations (Rynard & Chambers, 1998; Ross & Scarvalone, 1982). The child has missed academic work, classroom events, and peer interactions that are important for a child's social and emotional development (Ross & Scarvalone, 1982). Current research needs to separately research children with cancer from children with other chronic health conditions because it is important to understand the specific needs a child with cancer has when returning to school. This study will focus on parent's perspectives of how their child reintegrates into school and peer relationships after treatment for cancer. This researcher hypothesizes that parents will feel that school staff was helpful, but that their child experienced negative peer interactions after the cancer diagnosis and treatment.

Theoretical Framework

The current study is informed by previous research, by clinical social work practice theories and by this researcher's personal and professional bias. The conceptual framework for this research study is grounded in Erik Erikson's psychosocial theory about stages of development.

Psychosocial Theory

Erikson's *Eight Stages of Man*. Erik Erikson created eight stages of psychosocial development. The stages were developed after Sigmund Freud created five stages about the development of the child from birth to puberty (Erikson, 1968). Freud's stages were about the development of personality. Freud's stages were set in a predetermined sequence and could result in either successful completion and a healthy personality or failure leading to an unhealthy personality (Erikson, 1968). Freud's stages were based on erogenous zones and if the child did not successfully complete the stage, they could become fixated on that particular area (Erikson, 1968).

Unlike Freud, Erikson's stages extended over the lifespan and each plays a major role in the development of personality and psychological skills (Erikson, 1968). Erikson described how during each stage a person searches for autonomy, which is "the quality or state of being self-governing, self-directing freedom, and moral independence" (Graves & Larkin, 2008). If the stage was not successfully achieved, the child's identity could not be formed. This study focuses on three stages that Erikson created.

The first stage that is relevant to the study is during the preschool years and is titled *Initiative vs. Guilt*. This is when young children assert control and power over their environment and this leads to either a sense of purpose or disapproval and guilt (Erikson,

1968). The next relevant stage is during the school age years and is *Industry vs. Inferiority*. School aged children are coping with new social and academic demands. Success of this stage leads to a feeling of competence and failure can lead to feeling of inadequacy among peers and problems with self-esteem (Sokol, 2009). The final stage that is relevant to this study is during adolescence and is *Identity vs. Identity Isolation*. During adolescence the teenager is developing a sense of self and personal identity (Erikson, 1968). The teenager has greater interactions with communities, schools, and peers because of newfound independence and autonomy (Sokol, 2009). Success of this stage leads to staying true to oneself and failure can lead to role confusion and a weak sense of self and isolation from family and friends (Sokol, 2009). These stages were created to be for normative development and the next section will discuss the stages applied to children with cancer.

Theory Applied to Development of Children during the Early, Latency and Adolescent Years

Early Years. Physical limitations from chronic illnesses, such as cancer, at an early age can affect the ability to maintain self-governance and self-direction (Graves & Larkin, 2008). Preschool children are busy exploring their physical and social world and are beginning to move away from their parents in order to seek out new experiences (Baum & Baum, 1990). When a young child is diagnosed with cancer, they may experience withdrawal, sadness, agitation, and panic over being away from their home and going through painful procedures (Baum & Baum, 1990). Hospitalizations can threaten the child's exploration of their world and lead to failure of the initiative vs. guilt

stage. It is important for the parent to be present, supportive, and reassuring that the child is not being punished for anything they did and this is temporary (Mattsson, 1972).

Children diagnosed with cancer at an early age may not be able to achieve Erikson's stage of *Initiative vs. Guilt*. A child may not be able to assert any control over their environment because they are going through intensive treatment. Without the ability to control and make some decisions in their life, the child may not feel they have a purpose in life. The child needs to feel a sense of purpose in their environment and doctors and parents may ignore this because they are more concerned about their child's treatment. The child may also feel guilt over the diagnosis and without the knowledge of how to express these emotions, the child will not communicate this to their parents and the child will not receive reassurance that the diagnosis is not their fault.

Latency years. Physical limitations can also impact school-aged children (ages seven to 11 years), who are at an age that is typically a developmental age where they would be experiencing more social interactions, competitions, and new accomplishments both at school and in other activities (Baum & Baum, 1990). Hospitalizations mean the child is separated from their home, friends, and school, which can lead to a lack of autonomy, mastery, and control, that had been achieved in previous stages of development (Baum & Baum, 1990). The child may blame him or herself for the diagnosis or may not fully understand what is happening and how to ask questions about their disease (Mattsson, 1972). The child may feel their control is being threatened and react with aggression or opposition or they may become passive and refuse to partake in decision-making (Baum & Baum, 1990). If the child's appearance has changed, they may refuse to attend school and may not want their friends to visit (Baum & Baum,

1990). The child may also participate in uncharacteristic tantrums, bed wetting, or cling to their parents (Baum & Baum, 1990). School aged children are relying more on school and peers for their learning and when this is threatened by a cancer diagnosis, the child may not successfully master this stage.

In contrast to children who are healthy, children diagnosed with cancer during the school age years (ages seven to 11 years) must now balance a difficult diagnosis and cope with new social and academic demands. A child may not be able to attend school during intensive treatments and hospitalizations. School is extremely important during these years and for children who miss many days or even months of school, they may begin to feel inferior when they return to school. Children desire to feel increasingly competent in academic and social interactions; however, when they miss school for long periods of time, this competence is not achieved. Children that maintain close friendships and continue with schoolwork may have an easier time adjusting to school after their treatment, because some feelings of competence have remained.

Adolescent Years. Adolescence is a time for separation and individuation from the family, while at the same time needing acceptance from peers (Baum & Baum, 1990). Adolescents are able to think more abstractly and therefore are able to understand their diagnosis of cancer and life, death, and quality of life. They can daydream about the future and are more concerned with their appearance and fitting in (Baum & Baum, 1990). The adolescent has a fragile self-image and if the cancer changes their abilities in any way, they may feel shame, humiliation, and loss of self-esteem (Baum & Baum, 1990). If their appearance has changed, even if temporary, it may make them feel unacceptable to themselves and then assume others will feel the same way and this can

lead to isolation and added distress (Baum & Baum, 1990). The adolescent may withdraw from family and friends, feel that life is no longer living, and may refuse treatment even when survival is great (Baum & Baum, 1990). During cancer treatment, adolescents may find it difficult to figure out their identity, which can lead to this stage being prolonged until the adolescent returns to a more normal life.

Adolescents diagnosed with cancer during middle or high school may suffer from not developing a sense of personal identity. Intensive treatment and hospitalizations separate the adolescent from social relationships leading to less contact with peers both inside and outside of school. The adolescent is not able to learn to explore their own identity without the help of peers and school and thus the adolescent may not achieve the Identity vs. Role Confusion stage. When returning to school after treatment, the adolescent may be unsure of their role in their own lives and they may not know how to explore their identity outside of the cancer diagnosis. It is important for adolescents to maintain contact with friends and their school in order to adjust more easily into this role after treatment.

Theory Applied to Children with Cancer during the Early Years, Latency Years, and Adolescent Years.

Cancer threatens the child with lasting physical impairment, shortened life expectancy, and interferes with school, activities, and time with family and friends (Mattsson, 1972). Mattsson (1972) found that there could be three outcomes for children and adolescents with poor adjustment due to a prolonged condition. The first is fearfulness, inactivity, and over dependency of family (Mattsson, 1972). The second is being overly independent, rebellious, and engaging in risky behavior (Mattsson, 1972).

The third is being shy, lonely, and having an identity as an outsider (Mattsson, 1972). However, positive results can come from being diagnosed with cancer. Learning from and associating with others who have overcome their illness can support the development of a positive self-image and can help the child become socially competent (Mattsson, 1972). If the child or adolescent experiences exhilaration when they master treatment or feel pride when they are able to handle problems successfully without the help of others, then positive adjustment is likely (Baum & Baum, 1990). If the family feels pride in their ability to cope and come together in support during difficult times, it shows the child and adolescent positive ways of coping and can help in successfully achieving Erikson's stages.

Professional and Personal Lens

The current study came about from my interest in childhood cancer and its affect on the social and academic aspects of children's lives. My interest in this topic grew from a volunteer experience at the Ronald McDonald house during college. During this time, I became more aware of the impact childhood cancer has on children and their families. I also learned about the impact of a cancer diagnosis on the ability of children to attend school and continue peer relationships. Interest also emerged when a close relative of mine was diagnosed with lung cancer. While the relative is an adult, the impact on the family and his career is great. Thus I wanted to learn more about the impact of childhood cancer.

It is through these personal and professional experiences that a research idea emerged. The purpose of the study is to learn about children with cancer readjustment to school after treatment from the perspectives of their parents. Through this investigation,

I hope to add to the current knowledge of childhood cancer in relation to school and academics.

Methodology

Research Design

The purpose of this study was to gain more insight into how children with cancer reintegrate into school after treatment as viewed from the perspective of their parents. In order to find answers to this question, this researcher employed a mixed method type of data collection by using a survey (see Appendix A). A mixed method design focused on collecting and analyzing quantitative and qualitative data within a single survey (National Institute of Health [NIH], 2012). Within this survey, quantitative methods emphasized known observable facts and included inferences of causality (NIH, 2012). An example of quantitative questions in this survey is demographics questions. Qualitative methods allow for explanations and can identify unknown information and processes (NIH, 2012). An example of qualitative questions in this survey is exploring parental experiences of their children adjusting to school after cancer treatment. Mixed method designs incorporate open-ended, (qualitative) and close-ended (quantitative) questions.

Sample

This researcher administered an online survey to 15 participants. To participate, each participant must have met three types of eligibility criteria. This was specified both when the survey was sent to participants and within the survey itself. First, participants must be parents of children diagnosed with any form of cancer. Second, they must be able to give consent. Third, the parents' children must have been between the ages of three to 17 years when they entered remission or the maintenance phase of treatment and returned to school. Finally parents' children must not be receiving any form of treatment

other than maintenance treatment. Those that will be excluded from taking the survey are those parents whose children were older than 17 when they returned to school after treatment. Parents of children who are still in intensive treatment, such as chemotherapy, will also be excluded. Those parents whose child passed away from cancer were also excluded because of the emotional risk of participating in the survey.

Recruitment

Participants for this study were recruited using a combination of snowball sampling and convenience sampling. *Snowball sampling* was used to identify one person for a study and then asking them to recommend others who meet the inclusion criteria (Research Methods, 2006). *Convenience sampling* is used when participants are chosen based on their easy access (Research Methods, 2006). This researcher had several contacts that agreed to send out email invites to their personal contacts, which is an example of snowball sampling. This researcher also recruited an agency that supports children and their families as they deal with a cancer diagnosis and treatment. The agency sent out emails to those families that participate in their summer programs and to their general listserves. Lastly, the researcher placed flyers (See Appendix C) in public places where parents with children with cancer have access to them (i.e. coffee shops), which is an example of convenience sampling. The flyers gave directions on how to contact the researcher for the link to the study. All participation in this study was voluntary and no compensation was provided.

Protection of Human Subjects

Those who participated in the survey were protected through several ways. Due to the sensitive nature of asking parents of children with cancer to answer highly personal

questions about their child's cancer and adjustment to school, care was taken to ensure the protection of human subjects during the project. Subjects were only allowed to participate if their child is finished with treatment. Parents of children receiving maintenance treatment will be allowed to participate. Subjects also were only allowed to participate if their child is living. A full review of this study was completed by the Institutional Review Board (IRB) at the University of St Thomas to ensure the utmost protection of human subjects.

Care was taken to further protect human subjects by ensuring complete anonymity and confidentiality in the survey process. This researcher had no knowledge of participants' answers, as the survey was completely anonymous. Open-ended questions with the option to not answer was used in the survey to minimize risk and hopefully this allowed participants to be more honest with their responses because there is a barrier between the researcher and participant. In efforts to minimize risk to participants, the researcher, her committee chair, and committee members reviewed the questions to ensure the questions are asked in a manner that is positive and recovery-focused, which hopefully minimized risk for participants. The participants must read the consent form (Appendix B) and electronically sign before entering the survey.

The consent form cautioned participants of potential emotional discomfort when answering the questions. The participants were also told in the consent form (Appendix B) that they would be able to discontinue the survey at any point and those answers would not be recorded in the survey. However, the consent form informed the subjects that once they submitted the survey, it could not be edited or deleted. At the end of the

survey, before the participant closed the survey, there will be a list of resources, including support groups, the participant can contact.

The research survey has been deactivated and all printed materials will be shredded within three years. Contact information for the researcher and the IRB at St Thomas was provided to subjects and if any questions arise while completing the survey, participants were encouraged to contact the researcher immediately.

Data Collection

The survey was created based on the findings from several studies, the researcher reviewed. A study by Hopkins (2010) focused on the family and school working relationship when a child has a chronic medical condition. The study assisted this researcher in creating questions about open communication between the school and parent. For example this survey asked parents how helpful school staff was during their child's diagnosis and treatment. Rynard and Chambers (1998) reviewed the literature on pediatric cancer school support questions. This study helped this researcher develop questions about school support programs and whether these programs were available for participants. For example this survey asked parents what school support programs were available to their children. A study by Chesler and Barbarin (1986) asked parents for their perspectives when their child with cancer returned to school. This study aided the researcher in formulating questions about how the child, child's peers, and child's teachers helped or hindered the child's return to school. For example this survey asked parents about how their children's peer relationships changed before and after a cancer diagnosis. These research studies helped this researcher create a study based on parents' experiences with school support systems, school staff, and their children's peer.

The survey was administered online through the online survey tool Qualtrics (Qualtrics.com, 2012). The survey was approximately 30 minutes, but may take shorter or longer depending on participant's responses. There were four sections to the survey. The first section asked about the child's age, gender, and race as well as the family's income and number of children. These questions were quantitative in nature. The second section regarded information about the child's diagnosis, treatment, and the family's reaction to the diagnosis. The third section asked questions about the child's school experience after begin diagnosed. Several questions asked about the support from the school as well as how long the child was absent from school. The final section asked parents about their child's peer interactions both during and after treatment. Several questions asked about the negative and positive aspects of the child's peer interactions. Sections two, three, and four asked more qualitative questions in order to gain understanding about the child's school experience.

Data Analysis Plan

Quantitative data analysis techniques were used to interpret participant answers to demographic and treatment questions. Descriptive statistics were collected by the survey software Qualtrics and were used to create categories, such as age of child when diagnosed, type of cancer and treatment, what grade the child is in school, and whether the family had access to support services at school. These categories will be used to compare the responses of the participants. The researcher will create charts for the age of the child and the type of cancer the child was diagnosed with. The researcher also created a chart of the support services offered by the school or the hospital for the family.

Qualitative data, or the open-ended questions on the survey, were analyzed using data reduction. Coding means to read the data and differentiate segments within it. A word or short phrase is developed to summarize a segment of the data. The researcher used content analysis, which is used to determine the presences of certain words, concepts, or themes within the interview (Roseborough, 2012). The researcher read through the answers of the open-ended questions and highlighted important words and phrases. The researcher looked for commonalities between the surveys and created possible concepts and themes based on the first read through of the surveys. During the next read through, the researcher used conceptual analysis, meaning the researcher marked how often the concepts and themes already chosen were mentioned (Roseborough, 2012). During the final read through, the researcher looked for themes that may have previously been missed. When using content analysis, the codes are used to make inferences about the meaning of what the participant said. After finishing the coding of all surveys, the researcher used the codes to construct themes that were most prevalent in the surveys. Charts were created to further display the themes and participants' responses.

Participants

There were 15 parents who completed the survey based upon their child's school experience after a cancer diagnosis. Of the 15 parents that responded, 12 had a male child and three had a female child. The parents were asked what the race of the child was and 12 said their child was white, one said their child was Hispanic, one said their child was white, African American and Native American, and one participant chose not to answer. The age at which the child was diagnosed with cancer was also asked and the

ages at time of diagnosis ranged from one to 16 years, with a mean age of seven to eight years. Parents reported that their child had between one and five siblings, with 67 percent ($n = 10$) reporting that the child had one to two siblings. The average household income that was reported by the parents was \$60,000, but the household income ranged between \$25,000 to above \$75,000.

Findings

Participants ($n = 15$) completed a mixed-method survey that asked them about their experiences as parents of children who had been diagnosed with cancer. Parents answered questions related to their impressions of their children's initial cancer diagnosis and subsequent treatment, of support their children received from their school's staff, and of how their children's peers treated them before and after their cancer treatment. Participants answered both quantitative and qualitative questions regarding their children's experiences in school. Qualitative questions were included to allow participants to write about their children's individual experiences. Furthermore, quantitative questions allowed for statistical significance to be determined to further understand how helpful school staff were to their children and whether their children's peer experiences changed after their cancer treatments.

Findings will be divided into three sections, each containing both quantitative and qualitative results. The first section will focus on children's diagnoses, parents and children's reactions to diagnosis, treatment, school absences, and children's limitations after treatment. The second section will focus on school support including whether the school staff in children's classes were educated about their diagnoses, what school support programs existed for children, and overall how helpful staff were in supporting their children. The final section will focus on each child's peer experience including the child's school experience before and after treatment, the peer support received by the child after treatment, any negative peer interactions that occurred during their child's treatment, and whether their child's peer relationships were similar or different after the cancer treatment was complete.

Quantitative

Cancer diagnosis. Participants ($n = 15$) were asked what type of cancer their child was diagnosed with and what types of treatment they subsequently endured. The most common type of cancer reported was Acute Lymphoblastic Leukemia (ALL), which was reported by 40% ($n = 6$) of participants. The next most common types of cancer reported were non-Hodgkin's Lymphoma and Astrocytoma or brain tumor, which were each reported by 13% ($n = 2$) of participants. Table One shows all cancer diagnoses that were reported and the frequency with which each was reported.

Table 1

Types of Cancer Diagnoses Among Children Discussed in the Survey Sample

Type	# ($n=15$)	%
Acute Lymphoblastic Leukemia	6	40%
Non-Hodgkin's Lymphoma	2	13%
Astrocytoma (brain tumor)	2	13%
Burkitt's Lymphoma	1	7%
Ganglioneuroblastoma	1	7%
Nephroblastoma	1	7%
Ewing's Sarcoma	1	7%
Yolk Sac Tumor	1	7%

Note: This table reflects respondents' answers to the question: What type of cancer was the child diagnosed with? Astrocytoma refers to cancer characterized by brain tumors. Yolk Sac Tumor is characterized by cancer with a type of germ cell tumor. Nephroblastoma refers to cancer of the kidneys. This form of Ewing's Sarcoma was in the ribs.

Length of treatment The next several questions focused on the type of treatments children had and the length of children's cancer treatments. Of the total respondents ($n = 14$), 71 percent ($n = 10$) had children who had undergone had chemotherapy, 7 percent ($n = 1$) had surgery and 21 percent ($n = 3$) had chemotherapy, radiation, and surgery. The length of treatment varied. The mean length of treatment was 2.93 years with a standard deviation of 1.39 years. Treatment length varied from less than one year to five years. Table Two illustrates the length of reported treatment.

Although all children in the study are no longer receiving active treatment, several participants reported that the child is on maintenance treatment.

Table 2

Length of Cancer Treatment Among Children Discussed in the Survey Sample

Length of Treatment	# (n=14)	%
Less Than 1 Year	3	20%
1 year	2	13%
2 years	5	33%
3 years	4	27%
4 years	0	0%
5 years	1	7%
6 or more years	0	0%

Note: This table reflects respondents' answers to the question: What was the length of treatment for the child? In this study treatment refers to chemotherapy, surgery, and radiation.

Absences from school. The type and length of treatment greatly affected how many days of school the child missed. Of the parents ($n = 15$) who responded, 47 percent ($n = 7$) of their children missed more than 60 days of school and 27 percent ($n = 4$) missed between 45-59 days of school. The mean length of school days missed was 45 days with a standard deviation of 1.25. Table Three shows how many absences the parents reported.

Table 3

Days Absent from School because of Treatment

Days Absent	# (n=15)	%
0-14 days	1	7%
15-29 days	1	7%
30-44 days	2	13%
45-59 days	4	27%
60 or greater days	7	47%

Note: This table reflects respondents' answers to the question: How many days was your child absent from school?

School limitations. Parents were also asked if their child had any limitations at school that may have impacted the child's school experience. Two-thirds of parents who

responded, or 67 percent reported that their child had limitations when they returned to school. Five parents or 33 percent reported that their child did not have any limitations when they returned to school. Of the parents who reported limitations, 90 percent reported that their child could not participate in recess or physical education class. Forty percent of the parents who reported limitations such as no recess or physical education said their child could not participate in activities that required endurance. One parent reported that their child could not participate in physical education due to a port in the child’s chest. One parent reported that their child had fatigue and anxieties that prevented their child from participating in every day school activities.

Table 4

Types of Limitations reported because of Cancer Diagnosis

Type	# of Children (n=10)
Could not participate in sports	4
Could not participate in physical education/recess	5
Could not participate because of endurance	3
Limitations caused by fatigue	2
Limitations caused by anxiety	1

Note: This table reflects respondents’ answers to the question: Did the child have any limitations at school that impacted his or her peer relationships? Participants could choose more than one option.

Qualitative

Response to diagnosis.

The participants (n = 15) were asked to write how the child and immediate family reacted to the diagnosis. Participants (n = 15) responded that they, as the parents, were very shocked and fearful about what was to come. Five parents reported that extended family came to town to help the family cope, especially during the beginning stages of diagnosis and treatment. One parent said, “As much as I feared the worst, when I actually heard the words that he had cancer it still was a shock”. Their child’s reaction

was greatly dependent on their age. All parents reported that their child was very brave throughout the diagnosis and treatment. If their child was younger the parents reported that their child’s understanding was limited. One parent wrote that their child “said he didn’t feel sick and then raised both arms and said I am going to beat this”. If their child was older, the parents reported their children were scared and were shocked. One parent wrote, “my child did a lot of mourning, especially at night when he was alone”.

Academics after diagnosis. Parents ($n = 15$) were asked whether their child was behind academically when the child returned to school. Forty-seven percent of parents ($n = 7$) stated their children were behind academically where as 53 percent ($n = 8$) stated their children were not behind academically after treatment. Table five illustrates reasons for their children being behind academically. Four of the seven parents wrote that the child was behind in reading. Of note, one parent reported that their child repeated kindergarten because of absences and difficulty with reading and letter recognition.

Table 5

Reasons why Children were Behind Academically

Theme	Sample Response
Behind in math	[Child] was behind in math...I’m not sure if it was simply a matter of needing to catch up or if the treatment affected his learning ability or brain function.
Behind in reading	[Child] ended up in reading support for many years. He never learned how to read or type or write cursive.
Missed assignments	[Child] still had work to complete and missed assignments [to make up].
Memory issues	Retention skills were lacking for about 2 years following the end of treatment.
Exhaustion	When [child] was at school [child] napped half of the day due to cancer treatment...It was decided to hold [child] back a year.

Note: This table reflects respondents’ answers to the question: In what ways was the child behind academically?

Education of school staff. The next section of the survey asked whether parents educated the school staff about the child’s cancer diagnosis. If the respondent answered “yes” than a follow-up question asked the participant to write how they educated the staff. Of the respondents, 87 percent ($n = 13$) answered that they did educate the school staff about their child’s diagnosis, seven percent ($n = 1$) answered that they did not educate the school staff, and seven percent ($n = 1$) did not remember. Parents who did educate school staff discussed their child’s needs with teachers, principals, nurses, or all three. Two parents created 504 plans--which included modifications and accommodations that their child will need to perform at the level of their peers--with school staff. Table Six explains how each parent educated school staff.

Table 6

How was Staff Educated About Child’s Diagnosis

Theme	Responses
Education of staff	<p>We maintained contact with [teachers] and school nurse...teachers and school nurses visited him at the hospital.</p> <p>Immediately started the conversation and provided information as we received it...Communication was a great tool in trying to help everyone understand what no one understands.</p> <p>Learned about the state mandated homeschool with teachers provided, educated [the school] about the program.</p> <p>I had someone from the Leukemia and Lymphoma Society go to the school to talk with the teachers.</p> <p>I talked with the school nurse and explained [child’s] condition and needs. I also talked to the teachers and school administrators so they would understand why [child] was missing so much school.</p> <p>I talked to the teachers, principal, and nurse.</p> <p>Gave [school] an information sheet that we typed with...things to watch for.</p>

Note: This table reflects respondents’ answers to the question: how was the staff educated about the child’s diagnosis?

Education of the child’s class. Parents were also asked if their child’s classes were educated about their child’s cancer diagnosis. Sixty-four percent ($n = 9$) of respondents reported that the class was educated where as 29 percent ($n = 4$) reported that

the class was not educated and 7 percent ($n = 1$) did not remember. The explanations regarding whether the class was educated or not showed that those who did educate the class used formal and informal ways of education.

Table seven explains how each child's class was formally or informally educated about each child's cancer diagnosis. Informal ways of educating the class included the child had to explain the diagnosis and the child's class became aware during fundraising events. Formal ways of educating the class included a child life specialist explaining the diagnosis to the class and the class watching the Charlie Brown video about cancer.

Table 7

How Children's Classes were Educated About the Child's Diagnosis

Theme	Response
Education of class	<p>The [class] was not educated and [child] had to tell everyone why he was losing his hair and not running anymore.</p> <p>Child life [specialist] and an oncology nurse also visited the class and talked with them.</p> <p>The principal let the entire class wear hats all year so the [child] would not feel he was the only one.</p> <p>Class became aware only during fundraising campaign for leukemia.</p> <p>Kindergarten class was shown the Charlie Brown video...in first grade the teacher talked to the class about [child] being in the hospital</p> <p>[Child] went to school that day and told the kids he had cancer and said he was going to be okay, they didn't think differently and accepted it.</p>

Note: This table reflects respondents' answers to the question: how was the child's class educated about the child's diagnosis?

School support programs. The next section of the survey asked parents ($n = 15$) if any school support programs were available to the child when they returned to school. Half of the participants ($n = 8$) answered that no support programs were available. Thirty-three percent ($n = 5$) of participants answered that there were support programs available and 13 percent ($n = 2$) did not remember.

When parents were asked to further explain what was or was not available to their child, their responses were divergent. Table eight further outlines all responses from parents about what was and was not available to the student. Two parents reported that the school did not offer anything and the parent was responsible for requesting resources. Four parents wrote that their children were given extra academic help and special accommodations. Two other parents wrote that school support programs were not available and they had to request additional assistance.

Table 8

School Support Programs Available to Children After Their Diagnosis

Theme	Response
Programs that were available	<p>Extra time for gym and physical activity. Extra academic help to help catch up.</p> <p>We were provided with in home tutoring...special accommodations, quiet rooms, extended test time IEP and 504 [plan].</p> <p>[Child was] home schooled.</p> <p>In the 504 plan we made sure he could go to the nurse's office to get whatever he needed...sensitive to noise so allowed to have an iPod in noisy situations.</p> <p>The counselor got us hooked up with Monkey in My Chair which opened up a way for class to stay in touch while he was gone, gave teacher an avenue to talk about it, and something fun when he had to leave for a day or miss a whole day.</p> <p>The staff at [medical center] offered to speak to school anytime to answer their questions.</p> <p>I was in constant communication with teacher, who helped convey messages to the students. We felt very supported at school.</p>
No support programs	<p>I had to request help and assistance, [child] was not offered anything.</p> <p>The school was very uninformed. I did all the running back and forth and was not only mother, nurse, but now teacher.</p> <p>We were the only parents enrolled who had gone through this type of event. Just having available connections to other parents would be helpful.</p>

Note: This table reflects respondents' answers to the question: What school support programs were or were not available to the child after the diagnosis?

Helpfulness of school staff. The final school experience section of the survey asked participants ($n = 15$) how helpful school staff (e.g. nurse, teacher, social worker, principal) were in supporting children when they returned to school. Sixty-seven percent ($n = 10$) of parents answered that school staff were very helpful, 27 percent ($n = 4$) answered that school staff were somewhat helpful, and 7 percent ($n = 1$) answered that school staff were not helpful.

Parents were then asked to further elaborate on how staff was or was not helpful. Table nine illustrates the responses of the parents of how staff was and was not helpful. Three parents reported that the nurse was helpful in administering medication and supporting their children. Six parents wrote that the teacher was very helpful and were willing to provide extra help to their children and to stay informed with the parent. The parents that reported the staff was not helpful said some teachers were supportive in providing homework or additional academic assistance.

Table 9

How was the School Staff Helpful or not Helpful when the Children Returned to School

Theme	Response
Helpful	<p>They asked how they could help. They gave my child extra attention and time to adjust.</p> <p>They wanted to be helpful, but this was new for [school staff]. We learned together...they always accommodated as best they could.</p> <p>Teacher would personally come and visit [child], bringing work that had been missed.</p> <p>Teacher and nurse could not have been more helpful. They were willing to do anything we needed.</p> <p>[Teachers] kept us informed on where [child] was and how that compared with the other kids in the class. Our school nurse was very good too.</p> <p>Made special accommodations in the class like having a hand sanitizer dispenser installed, allowing him to use the elevator, etc.</p> <p>Understand [child's] needs, being aware of possible side effects, making him feel welcomed when he return, teacher worked with classmates on helping [child] feel welcome after being absent for so long.</p>
Not helpful	<p>They did not help us or [child] at all.</p> <p>There was not ongoing support except academically with all the effort to get materials left up to me.</p> <p>We had some issues with the teachers. [Child] was in an accelerated program and those teachers weren't the most helpful in providing assignments and help when he had treatments or was hospitalized.</p>

Note: This table reflects respondents' answers to the question: How was the school staff helpful or not helpful after the child returned to school?

School experience before and after diagnosis. For the last section of the survey, parents were asked about their child's peer experience. Two questions asked how parents' children's school experience was before and after the diagnosis. The common theme in this section was that their children were doing well in school and were enjoying going to school. The answers after the child returned to school from treatment varied. Nine parents reported that the transition from treatment to school was difficult. Four parents wrote that their children struggled academically and their grades were lower. Three parents wrote that peer interactions changed and their children displayed some

social anxieties. Table 10 provides a list of the responses of parents about how their children’s school experience was after the diagnosis.

Table 10

Children’s School Experience After Their Diagnosis

Theme	Response
Positive experience	<p>The coaches from [child’s] three sports supported him.</p> <p>He ended up with many, many friends. I think every single person in the school knew who he was.</p> <p>[Child’s] attitude was great, but her physical state really wore her down.</p> <p>Made him appreciate what he missed and became more focused in doing well in school. Grades improved.</p> <p>It was still good- he qualified as a TAG (talented and gifted) student during treatment.</p>
Negative experience	<p>Somewhat a struggle academically.</p> <p>Felt very displaced socially when returned each time as kids had hooked up with new friend groups and each time she was starting over. Kids did not call much or show support when she was not around.</p> <p>Failing grades, not interested in much.</p> <p>[Child] displayed, and still displays social anxieties in certain situations.</p>

Note: This table reflects respondents’ answers to the question: what was the child’s school experience after the diagnosis?

Close friendships. The next survey question asked parents ($n = 15$) to explain whether their child maintained close school friendships while in treatment. Of the respondents, 73 percent ($n = 11$) reported that their children did maintain at least one close school friendship and 27 ($n = 4$) percent did not maintain any close school friendships during treatment. Most of the parents said their child was supported by his or her friends and classmates. The parents of the three female participants reported that their daughters did not maintain any close friendships. One parent of a male participant reported that their son did not maintain any close friendships. All 73 percent ($n = 11$) of those who reported that their children maintained close friendships were parents of males.

Parents were asked to elaborate on how their children maintained or did not maintain a close friendship. Table 11 further shows the respondents' answer to the question of whether their children maintained any close friendships during treatment. Parents that wrote that a close friendship was maintained said that friends visited the child in the hospital and home when the child was not able to attend school. Parents said that their children maintained the friendships that he or she had before the diagnosis. Of the four parents that said their children did not maintain a close friendship, one wrote that their child was too sick to participate socially and their child became socially isolated.

Table 11

Did Children Maintain Close School Friendships during Their Diagnosis or Treatment?

Theme	Response
Maintained close friendship	<p>His friends visited him in the hospital. He was able to see them few times outside of the hospital too.</p> <p>All friends were real supportive they would visit every day they could after school, weekends, and during chemo treatments. Even more than 6 years later he is still best friends with the people who got closer to him when he was diagnosed.</p> <p>Friends came to see him and one even shaved his head.</p> <p>Many friends supported him. A couple even came to a treatment with [child] because they wanted to support him.</p> <p>[Child] had his main circle of friends that were there for him. If kids made fun of him they were quick to step in and support him.</p> <p>He had friends visit him in the hospital. He had friends that would call him on the phone. Many times he received cards from friends/classmates at school. He also had friends visit at home.</p>
Did not maintain close friendship	<p>Initially no because during induction [child] rarely if ever made it to school and wasn't feelings good enough to hang out. This was the worst part. [Child] became very isolated.</p> <p>[Child] was an "everybody knows me" kid but never was close to any one child.</p>

Note: This table reflects respondents' answers to the question: Did the child maintain any close school friendships during the diagnosis and treatment?

Supportiveness of classmates. Parents ($n = 15$) were then asked if their child's classmates were supportive after their children returned to school. Fifty-three percent of ($n = 8$) the parents said their children's classmates were supportive, 33 percent ($n = 5$) said their children's classmates were somewhat supportive, and 7 percent ($n = 1$) said their children's classmates were not supportive. Three parents wrote that some of the children's classmates did not know how to react to their children. Three parents also wrote that their children's class was supportive by making cards and welcoming their children when he or she returned to school. Table 12 illustrates the ways in which their children's classmates were and were not supportive.

Table 12

Ways in Which Children's Classmates were and were not Supportive after their Diagnosis

Theme	Response
Were supportive	<p>[Classmates] showered him with good wishes, congratulations, and support.</p> <p>They were supportive, but the circumstances didn't allow for the support because of being immune suppressed. They were there for him when [child] could be there.</p> <p>They helped him carry his books in school. One of them even brought ice cream at home.</p> <p>They were all so young. They showed a genuine interest even at that age in his health and lack of hair.</p> <p>Those in [child's] class and closest to her were great.</p> <p>They helped him in the classroom. They made cards and videos for him when he was gone.</p>
Were not supportive	<p>Novelty of the situation wore off and the students got into their own busy high school lives.</p> <p>[Child] was constantly trying to find her group and place between each illness.</p> <p>The non-support came from other kids in the elementary school who whispered about her when she walked by, called her a boy, and acted like they could get cancer from her. The taunting and teasing really affected her.</p> <p>They were just so worried that they might hurt him.</p>

Note: This table reflects respondents' answers to the question: What were ways the child's classmates were and were not supportive after the diagnosis?

Negative peer interactions. Another survey question asked if their children had any negative peer interactions after returning to school that might have been related to the cancer diagnosis. Sixty-seven percent ($n = 10$) of parents reported that their children did not have negative peer interactions after returning to school, 27 percent ($n = 4$) reported that their children did have negative peer interactions, and 7 percent ($n = 1$) did not remember.

Parents ($n = 4$) that responded that their children had negative peer interactions were asked to explain the negative interactions. One parent reported that their child had trouble being attentive and following rules and structure. Three parents reported that their children had negative peer interactions due to their children's appearance: one child had lost his or her hair and had been teased and another had a scar that was noticeable. One parent reported their child desperately wanted friendships and because of this their child "became needy and tried too hard to make and keep friends".

Peer relationships. The final question in the survey related to children's school experience and asked if the child's relationships with peers are the same or different after the cancer diagnosis. Of the respondents, 13 percent ($n = 2$) said their children's relationships with peers are much different, 27 percent ($n = 3$) said their children's relationship is slightly different, 47 percent ($n = 7$) said their children's relationship is the same, 7 percent ($n = 1$) said their children's relationship is slightly better, and 7 percent ($n = 1$) said their children's relationship is much better.

Parents were then asked to write how their children's peer relationships changed. Table 13 illustrates the parent's explanations of how their children's relationships are different, the same, and better. Parents who reported their children's relationship is

different said that their child matured faster and was bullied. Parents who said their children's relationship is the same said their children did not lose any friends and were able to maintain friendships. Those parents who said their children's relationship is better wrote that their children has more friends after the diagnosis.

Table 13

Children's Relationship with Peers After Their Diagnosis

Theme	Response
Relationship is different	<p>[Child] matured faster than classmates. This caused change in many relationships.</p> <p>[Child] spent so much time with adults while he was ill, he seemed older and younger than his peers at the same time.</p> <p>[The teasing] continued until I finally took her out of school completely when some of the girls formed a club [against the child].</p> <p>He didn't go out as much.</p>
Relationship is the same	<p>The close group of friends he had in elementary school are still his close friends today.</p> <p>He didn't lose any friends.</p> <p>For the most part they were the same. He had a few close friends that didn't know how to handle the diagnosis and drifted away. Doctor had a conversation with [child] before school started so that he would be aware this might happen.</p> <p>He is still friends with the same group of kids.</p> <p>He wasn't treated any differently as far as we can tell.</p>
Relationship is better	<p>He went from a few close friends to many friends. Everyone wanted to help him. He always says that it is the one good thing that came out of all this.</p> <p>I think the kids opened up to him more after the diagnosis.</p> <p>Hard to distinguish if they are better after diagnosis or with age/maturity. This has been a long haul</p>

Note: This table reflects respondents' answers to the question: How was the child's relationships with peers after the diagnosis.

Conclusion

In summary, the survey illustrated how different and unique each child's experience with a cancer diagnosis was. More than half of respondents reported that the school staff was helpful, the child was able to maintain peer relationships, and the

classmates were supportive. The majority of parents wrote that their child's school experience after the diagnosis changed, although this change was not always for the worse. The discussion section will discuss the results of this study and how the results compare to the literature.

Discussion

Findings from this study begin to shed light on parent's perspectives of their children's school and peer experiences following their cancer diagnoses. Findings from this study reveal important information about their children's return to school, the helpfulness of school staff following this transition, and the children's interactions with their peers. Furthermore, the qualitative results highlight children's unique school and peer experience when returning to school after a cancer diagnosis. The following section will discuss the results of this study and compare these to the results from previous studies. The section will also discuss the limitations of this study, directions for future research, and implications for social work practice.

Results

Every family that has a child diagnosed with cancer has a unique experience during and after treatment, which is important to remember when studying the results of this study. While several conclusions will be drawn, it is always important to note that there are many factors present that will impact the children's school experience after a cancer diagnosis. These factors can include the age at which the child was diagnosed, the type of cancer and treatment, the family structure, the support given by school staff, and the child's school peers.

Diagnosis and treatment. Of the parents who completed the survey, the demographics were and were not representative of those diagnosed with cancer in childhood. Cancer affects boys slightly more than girls; boys have a one in 300 chance of being diagnosed with cancer and girls have a one in 333 chance of being diagnosed with cancer (Cancer.gov, 2012). In this study, respondents were parents to 12 male

children and to three female children, which is not representative of cancer diagnoses between genders. The types of cancer these children are diagnosed with are representative of cancer diagnoses, as six parents reported their child had Acute Lymphoblastic Leukemia, which is the most common form of childhood cancer (Cancer.gov, 2012). Brain tumors are the second most common form of cancer is also similar to findings from this study (Cancer.gov, 2013). Two parents in this study reported their children were diagnosed with a brain tumor. The other parents reported different forms of cancer including spinal cord tumor, kidney cancer, and cancer in the ribs. It is important to understand cancer types and frequency of the cancers diagnosed in order to know how the particular cancer may affect children's school functioning.

The type and length of cancer treatment is very different depending on the type of cancer. About three-fourths of the children of the parents in this study went through chemotherapy, while one-fourth went through chemotherapy, radiation, and surgery. The most common type of cancer treatment is chemotherapy and this study replicates the findings that chemotherapy is the most common cancer treatment (Semrud-Clikerman, 2009). About two-thirds of the children in this study were in treatment between two and five years. This is a common length of treatment, as Acute Lymphoblastic Leukemia has a treatment period of between two and three years, which was also represented in this study (Semrud-Clikerman, 2009). It is important to understand the type of treatment the child is going through because the treatment may cause the child to be absent from school for a long period of time and miss out on interactions with peers.

Treatment can cause a major disruption in the child's life, especially if the child is continually absent from school. As research literature suggests, these absences from

school can greatly impact the child because the child is missing academic work and classroom events (Ross & Scarvalone, 1982). While the child is absent, he or she may not be able to maintain relationships with peers and may have less interaction with peers (Gannoni & Shute, 2009; Sansom-Daly, 2012). Three-fourths of children in the current study missed more than 45 days of school and half of the children missed more than 60 days of school. The numbers of days missed is very dependent on the type of treatment. The current study asked how many days the child was absent because if a child is absent for long periods of time they will need additional support when returning to school.

This study also asked about limitations children experienced due to the cancer diagnosis. Limitations are common among those diagnosed with cancer and can greatly disrupt children's normal functioning (Sansom-Daly, 2012; Gannoni & Shute, 2009). Negative school experiences and peer reactions can result when children's physical activity is restricted (Williams & Chapman, 2011). Two-thirds of parents reported their children experienced limitations in their personal and school life because of the cancer diagnosis and treatment. The majority of those who responded said that their children had limitations said their children could not participate in sports, recess, and physical education. Other limitations included fatigue, loss of endurance, and anxiety. This study found that many children had limitations when returning to school, which is important for professionals to understand. School professionals need to be aware that children face limitations when they return to school and these can impact the child's school and peer experience.

In addition to physical limitations, about half of parents reported their children were behind academically, while half reported their children were not behind

academically. Findings from previous studies suggest two-thirds of children are behind academically because of school absenteeism (Chesler & Barbarin, 1986). Research on children who are diagnosed with brain tumors and Acute Lymphoblastic Leukemia indicate children experience difficulty with academics, attention, memory, and speed of information due to their treatment (Semrud-Clikerman, 2009). The current study finds most parents reported their child was behind in reading and others reported difficulty in memory issues. This study did show that almost half of children were behind in academics; however, the researcher would have thought more of the children would be behind due to absenteeism and treatment effects. These findings are important because it aligns with previous research that children with cancer diagnoses are behind academically when returning to school after treatment. School staff must be educated about this to help children succeed when they return to school and not fall further behind.

School experience. Parents of children diagnosed with cancer were asked if they educated the school staff about the cancer diagnosis. Educating school staff and opening lines of communication are important recommendations when children have diagnoses that may prompt absenteeism and possibly fall behind in academics. In previous studies, only about half of parents reported educating the school staff (Chesler & Barbarin, 1986; Hopkins, 2010). Although there was no statistical significance between educating the school staff and the helpfulness of the staff in the current study, a study completed by Chesler and Barbarin (1986) found that school staff were more helpful after the parents educated them. In this study, all but two of the participants, educated the school staff about their children's diagnosis and needs. The parents said that they talked with the teacher and school nurse about the child's medical and academic needs. Several parents

also responded that they kept in close contact with the teachers and school nurses about the child's treatment. It is important for parents to remember to keep their children's school informed in an effort to help the school staff better understand what their child is going through. These findings strengthen previous research findings that indicate it is important to educate the staff about the child's diagnosis and to continue to have open communication with the school about what is happening to the child, both medically and emotionally.

In this research study parents are asked whether they have educated their child's class about their child's cancer diagnosis. The previous research has not delved into the topic about the benefits of educating the class. However, if peers do not understand children's diagnosis, they may be unkind to children and not be supportive as children returns to school (Ross & Scarvalone, 1982). Chesler and Barbarin (1986), while they did not ask if the parent's child's class was educated, found that more than half experienced school problems and peer teasing. In this study, about two-thirds reported that they did educate the class. Several parents reported that a child life specialist talked with the class and answered questions. Two parents reported that their child's class watched an episode of Charlie Brown that was about cancer and then the teacher or parent answered the class' questions. Parents who reported the class was not educated said their children had to explain to peers reasons for appearance changes or physical limitations. Perhaps educating the class and answering their questions may help their class understand what is happening to the child and will prevent teasing and negative peer interactions. While previous research has not studied the importance of educating the

class, this study found that many parents educated the class to help their child's class understand what cancer is and how the cancer diagnosis may affect their child.

Support Programs can be very beneficial for children, diagnosed with cancer, when they return to school to ensure children are fully supported academically. Parents and schools benefit from being proactive about obtaining support for children. Some school support programs have been researched and have been found to be very helpful to children, parents, and school; yet these programs are not in most school districts (Rynard & Chambers, 1998; Ross & Scarvalone, 1982). Only one-third of parents who responded said that school support programs were available. One parent was set up with an outside program that assisted families and schools so children were able to stay in touch with his or her class while at his or her treatment. In this study, parent respondents reported that the other school programs that were available were 504 plans or homeschooling. Extra academic help and more communication were also noted, but these were not formal support programs. Parents that reported no support programs available said that the school was uninformed and the parent had to request further assistance. These findings demonstrated that many families had no additional support programs that helped children with cancer when returning to school. School support programs that are available to parents are not cancer-specific programs.

The final section in school experience asked whether school staff was or was not helpful. In Chesler and Barbarin's (1986) research study, they found a little more than half felt schools staff was helpful where as a little less than half felt school staff were not helpful. In the current research, two-thirds of parents thought schools staff were very helpful, while almost one-third thought school was somewhat helpful. Only one parent

felt school staff was not helpful. Further research about parents' perceptions of the helpfulness of school staff is needed as few studies have looked at this. In the current study, all but one parent felt school staff was at least somewhat helpful. The helpfulness of school staff is important as a child faces absences and falling behind in classwork due to treatments. School staff can help make the adjustment to a new cancer diagnosis easier for the family if they are helpful and supportive. This study found that more parents felt school staff was helpful than previous research had indicated. Perhaps more school staff are aware of the impact cancer has on children and are more willing to help children through this difficult time.

Peer experience. Parents were asked to discuss their child's school experience both before and after the diagnosis. Research has found differing results in relation to whether children had difficulty after a cancer diagnosis. If school support programs are in place, children may have more success when returning to school (Rynard & Chambers, 1998). The support of peers is very important in the child's adjustment as well. If the peers are not supportive and the child does not have close friends, it can hinder the child's adjustment to school (Williams & Chapman, 2011; Hopkins, 2010). Overall, the parent respondents reported that their children had a positive experience before the diagnosis. Upon diagnosis, 13 of 15 parents who responded said their children's experience changed. Several parents reported the school experience was positive after the diagnosis because of the support from teachers and friends. Two parents reported their child was doing better in school, especially academically, than before the diagnosis. However, parents did report some negative school experiences as well. Parents wrote their child struggled academically and felt socially displaced when he or she returned to

school. These findings are important because they show that for most children their school experience will change after a cancer diagnosis, but the findings also show the change is not always negative.

Peer relationships are very important for school-aged children because it helps children develop both socially and emotionally (Williams & Chapman, 2011). Ensuring that children maintains at least one friendship is very important because it can help children adjust more easily to the diagnosis and new limitations (Williams & Chapman, 2011). Not maintaining a relationship with a close friend increases the disruptive nature of the diagnosis and can further isolate the child (Gannoni & Shute, 2009; Sansom-Daly, 2012; Williams & Chapman, 2011). In the current study parents were asked if their child maintained any close relationships. Three-fourths of respondents said their child maintained a close relationship with at least one friend, while one-fourth did not maintain a close relationship. Parents, who said their child maintained a close friendship, wrote that friends visited their child in the hospital, helped their child when he or she returned to school, and their child and friends became closer as a result of the diagnosis. Those parents who reported their child did not maintain a close friendship wrote their child did not feel well enough to go out and became very isolated. The findings from this question suggest that most of the parents responded their children maintained a close relationship, which previous literature stresses is very important to help children through the diagnosis and treatment.

Due to the importance of peers in the school-aged children's lives, parents were also asked whether classmates were or were not supportive of the cancer diagnosis. Previous research studies found that children's peers were not always supportive and

children with cancer experienced more social isolation (Durualp & Altay, 2012; Chesler & Barbarin, 1986). Half of the parents reported classmates were very supportive, one-third said classmates were somewhat supportive, and only one parent reported classmates were not supportive. Parents who said classmates were supportive wrote that the classmates showed concern about their child, visited their child in the hospital, and helped their child when he or she returned to school. Those who said classmates were somewhat or not supportive wrote the classmates were busy with their own lives, their child was teased, and classmates were fearful they would hurt the child. This study found that more children experienced supportive peers than children that did not have supportive peers. This study's findings are important because it indicated children's classmates were supportive of the child during the cancer diagnosis and treatment.

Parents were also asked if their child had any negative peer interactions as negative experiences have been reported in previous research (Durualp & Altay, 2012; Chesler & Barbarin, 1986; Williams & Chapman, 2011). Absences and appearance changes can also negatively impact peer relationships (Williams & Chapman, 2011). The current study found two-thirds of children did not have negative peer interactions, while one-third did have negative peer interactions. Two of the three female children and one male child reported negative peer interactions that included teasing about appearance and not being able to find his or her place in a social group. This question yielded interesting results because most of the children in the study did not experience negative peer reactions as found in previous research studies (Durualp & Altay, 2012; Chesler & Barbarin, 1986; Williams & Chapman, 2011).

Overall, the current study sought to understand if peer relationships were better or worse after the cancer diagnosis. Previous research has focused largely on the negative peer interactions of the child, but perhaps future research should focus on children's perspective about peer relationships (Durualp & Altay, 2012; Chesler & Barbarin, 1986). The results of this question were very mixed, again highlighting the unique experiences each child faces. Slightly less than half said peer relationships became more negative because their child was forced to mature faster, their child was bullied, and their child became more isolated. Slightly less than half said the relationship with peers stayed the same because their child's friendships remained the same and he or she was not treated any differently. The other parents, about one-fifth, said the relationship improved because their child had more friends and more children wanted to help support the child.

Strengths and Limitations

This current study had several strengths. This study is a mixed methods design, which allowed for both quantitative and qualitative questions to be asked. This design allowed for descriptive statistics about the demographics of the participants and for a brief overview of the type of cancer and the treatment used. The qualitative section allowed for an in-depth and personal look into the participants' experiences. This section of the survey allowed the researcher to gather specifics into what helped and hindered the child's, with cancer, reintegration into school after treatment. Questions were designed from the previous literature about the experiences of parents of children with cancer returned to school and what was and was not helpful from the school staff. These questions were more meaningful because they were developed from the literature and are designed to understand personal experiences.

Four limitations of this study will be discussed: sample size and generalizability, recruitment, participation restrictions, and focusing only on parents' perspectives. The first and primary limitation of this study is the small sample size and, because of this, the generalizability of the findings is very limited. The sample consisted of 15 parents of children with a cancer diagnosis. Of 15 parents, 13 were Caucasian and 11 had a household income of more than \$50,000. The homogeneous nature of the participants in this study make it difficult to apply the results to the larger population of those children diagnosed with cancer. The sample also consisted of 12 male children and three female children, which is not an accurate representation of the gender of children diagnosed with cancer.

A second limitation of the current study is the way in which participants were recruited. The researcher used several personal contacts and an agency, which provides support to families with a child diagnosed with cancer, to recruit participants. The research survey was completely voluntary for the personal contacts and those in the agency and one can conclude that the participants were at a point in their experience in which they felt comfortable sharing their story. Those who did not feel comfortable sharing their story or who were not a part of the agency may have had different experiences, which could have affected the results.

The third limitation of this study is participation restrictions for the research survey. Those participants whose child is still receiving treatment or whose child had passed away were not able to participate in the survey. Due to the short length of the research study and potential emotional risk of completing the survey, the researcher felt including those participants whose child was still in treatment or whose child had passed

away was too great a risk. Also excluded from participating were participants whose child had been diagnosed with cancer in infancy or toddler years. While the cancer diagnosis may affect the child's school experience, the researcher wanted to learn about children's school experiences from those children who had been diagnosed while in school.

The fourth and final limitation in this study is the limited perspective resulting from solely researching parents' perspectives of their child's school experience. In order to fully understand a child's school experience after a cancer diagnosis, it is important to interview the child first hand, rather than use the interpretations of the parents. However, because of Institutional Review Board restrictions using child participants and the length of this project, the only way to complete this study was to have parents participate.

Directions for Future Research

Given that current research about children's school and peer experience after a cancer diagnosis is limited, additional research studies are needed to determine how best to support children as they return to school after cancer treatment. Future research should study both children's and parent's perspective of the children's school experience after their diagnosis of cancer. This would allow medical and school staff to better understand how the child and parent cope with the diagnosis and the return to school. Longitudinal research would also be beneficial because following children from the beginning of the diagnosis through their adult years would allow professionals to determine how best to support children and families as their needs change.

Previous research has also focused on the child's psychological well-being after cancer diagnoses and treatment. Researching children's peer experiences would be

beneficial in order to learn how to better support children's friendships when they return to school. Studying children's, parent's, and teacher's perspectives of children's peer interactions would be valuable to ensure children have the support of peers during their time of adjustment.

Implications for Professionals and Social Workers

Childhood cancer greatly affects not only children, but also their larger system of immediate family members, school experiences, and peer relationships. Children and families are part of a larger system and it is essential to remember this when working with families facing a child with a cancer diagnosis. It is important the school system understands the diagnosis and new needs of the child. Professionals must remember the child's illness impacts the family, school system, and peer relationships.

Teachers are essential to children's return to school system following their cancer treatment and are often the first point of contact for children and families at their schools. Teachers often have little knowledge of cancer and may feel under prepared to face the illness or help their students understand what is going on with their classmate (Ross & Scarvalone, 1982). Teachers may not know how to talk with parents for fear of upsetting them, may not know how to talk with their classes about chronic illnesses or cancer diagnoses, and may avoid or pity children with cancer (Ross & Scarvalone, 1982). However, when teachers have students diagnosed with cancer they must be proactive in understanding diagnosis and what the child may need. Parents are very overwhelmed during this time and having a teacher who is willing to support their child and family, while helping to ease the burden of their child's returning to school after treatment.

Social workers in schools and in medical settings also play a crucial role in helping children return to school after their cancer diagnosis and treatment. The school social worker must stress the importance of both thinking about children in terms of their illness, and also focusing on children's relationship with classmates, allowing independence, and focusing on academic success (Ross & Scarvalone, 1982). The medical social workers can help parents and children find resources to help children psychically, emotionally, and medically. It is beneficial for school and medical social workers to include the family and ensure they too are receiving support. It is important for social workers to have good communication between staff at school and families. This way parents understand the possible academic needs children have and how they are doing both academically and with peer relationships. While children are at school to learn, the social worker must remember peer relationships are very important during this time and to provide extra support to children if they are having a difficult time interacting with peers. School and medical social workers have the knowledge to help integrate all the systems involved in children's lives including home, school, and medical (Ross & Scarvalone, 1982).

Conclusion

The current study provides valuable insight into childhood cancer diagnoses and school adjustment after treatment. More research is needed to fully understand how children adjust to school and to peer relationships after a diagnosis. Social workers can help facilitate the return to school by integrating knowledge of children's medical, academic, and relationship needs into clinical work with children and families. Social workers can work with medical and school systems to ensure children and families

receive needed support. Social workers can also help the other school staff understand children's needs and ensure these needs are being met. Several parents in the current study said they are very proactive and ensure their child has everything they need both medically and academically. Social workers and other school professionals need to help families navigate this difficult time and work with families to guarantee all the child's needs are being met. Since social workers are aware of the impact cancer can have on the child and family, they must advocate for families in the medical and school systems.

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APPENDIX A

Survey

Demographics

1. What is the child's current age?

2. What is the child's gender?

Male Female Other

3. What is the race of the child?

White (not Hispanic)

Asian/Pacific Islander

African American

Hispanic

Other _____ (please specify)

4. What is the household income?

\$0-24,999 \$25,000-49,999 \$50,000-\$74,999 \$75,000 and above

5. How many siblings does the child have?

0 1-2 3-4 5+

Treatment Information

1. What best describes your child's diagnosis?

2 a. In general, what types of treatment did your child have?

Chemotherapy Radiation Surgery Other (please specify) _____

2 b. How long was the total time your child was in treatment?

Less than 1 year 1 year 2 years 3 years 4 years 5 years 6+ years

2 c. Was your child hospitalized during treatment?

3. Is your child currently on any form of maintenance treatment?

4. What was your child's age when he or she received a cancer diagnosis?

1-2 years 3-4 years 4-5 years 6-7 years 8-9 years 9-10 years 11-12 years 13-14 years 15-16 years

5. How did your immediate family (i.e. parents or siblings) react to his or her cancer diagnosis?

6. How did your child react to the cancer diagnosis?

School Information

1. What grade was the child in when diagnosed (if applicable)?

- Preschool
- Kindergarten-Grade 2
- Grade 3- Grade 5
- Grade 6- Grade 8
- Grade 9-Grade 12
- Not in School

2. How many days of school, on average, did your child miss for active treatments such as chemotherapy or radiation?

0-14 days 15-29 days 30-44 days 45-59 days 60+days

3. Did you educate the school staff on your child’s diagnosis? If yes, how did you educate staff? If no, was there a reason you did not? _____

Yes No I Don’t Remember

4. Were any school support programs available to you or the child when the child returned to school? If yes, what were they? _____

Yes No I Don’t Remember

5. When the child returned to school was he or she behind academically? If yes, please explain. _____

Yes No I Don’t Remember

6. How helpful was the school staff (i.e. teacher, nurse, social worker) when the child returned to school? Please circle one. If they were or were not helpful, explain how. _____

Not Helpful
1 2 3 4 5 Very Helpful

7. How was your child’s school experience before the diagnosis?

8. How was your child’s school experience after the diagnosis?

Peer Information

1. During the diagnosis and treatment, did your child maintain any close school friendships? Please further explain. _____

Yes No I Don't Remember

2. When your child returned to school was the class educated about the child's diagnosis or was the class not aware of the diagnosis? Please further explain.

Yes No I Don't Remember

3. Were your child's classmates supportive about your child's return to school? If supportive, in what ways were they supportive? _____

Not Supportive Very Supportive
1 2 3 4 5

4. Did your child have limitations at school that impacted his or her peer relationships, such as not being able to participate in gym class or go out for recess? If yes, what limitations did your child have? _____

Yes No I Don't Remember

5. Did your child have any negative peer interactions after returning to school that may have been related to the diagnosis? If yes, please explain. _____

Yes No I Don't Remember

6. Did your child have any positive peer interactions after returning to school that may have been related to the diagnosis? If yes, please explain. _____

Yes No I Don't Remember

7. Are your child's relationships with peers the same or different after the diagnosis? Please explain further. _____

Much Different
Slightly Different
The Same
Slightly Better
Much Better

8. Is there anything else that you would like to say about your child's experience at school or with peers after his or her diagnosis? _____

APPENDIX B

CONSENT FORM
UNIVERSITY OF ST. THOMAS
GRSW682 RESEARCH PROJECT

**Parents' Perspectives on Children with Cancer Readjustment to School
after Treatment**
IRB# 399633-1

I am conducting a study parents' perspectives on children with cancer and their adjustment to school after treatment. I am interested in the child's experiences at school and with peers after cancer treatment. I invite you to participate in this research. You were selected as a possible participant because you have a child with a cancer diagnosis. Please read this form and ask any questions you may have before agreeing to be in the study.

This study is being conducted by: Lauren Woppert, a graduate student at the School of Social Work, St. Catherine University/University of St. Thomas and supervised by Kari Fletcher, PhD, LICSW.

Background Information:

The purpose of this study is to explore and compare parent's perspectives of their child with cancer adjustment to school after treatment. The study will also explore and compare parent's perspectives of their child's peer relationships after cancer treatment.

Procedures:

If you agree to be in this study, I will ask you to participate in an online survey. The survey will ask a series of questions about the child's diagnosis and treatment, the child's school experience after treatment, the child's peer relationships after treatment, and other demographic questions. This survey should take you about 25-45 minutes to complete.

Risks and Benefits of Being in the Study:

There are no direct benefits to participating in this study. There is no compensation or other reward for your participation. However, sharing your story will add needed information to the field of research of children with cancer and school adjustment.

The study has some risk. You will be asked to share information about your child's diagnosis that is personal and may be potentially uncomfortable to discuss. It is possible that answering the questions on this survey may bring up memories and emotions related to your child's diagnosis. A list of resources and support services will be provided at the end of the survey.

Confidentiality:

The information collect in this study is completely anonymous. There will be no way to determine your identity or that of other participants. The only identifying information collected will be general demographic information you disclose in the survey. The

information collect in this study is completely anonymous. There will be no way to determine your identity or that of other participants. In the study all identifying information will be disguised.

The records of this study will be kept confidential. The online survey tool, Qualtrics, that the researcher is utilizing is locked and password protected. Information gathered from the survey in an Excel or Word document will also be locked and password protected on the principle investigator's personal computer. The only person who will have access to these anonymous survey responses are the principle investigator, Lauren Woppert, and the chair of the research, Dr. Kari Fletcher.

Voluntary Nature of the Study:

Your participation in this study is entirely voluntary. Your decision whether or not to participate will not affect your current or future relations with St. Catherine University, the University of St. Thomas, or the School of Social Work. If you decide to participate, you are free to withdraw at any time without penalty. Should you decide to withdraw, data collected about you will not be used. You may skip any questions you do not wish to answer and exit the survey at any time. However, once the survey is submitted, responses cannot be changed or eliminated.

Contacts and Questions

My name is Lauren Woppert. If you have questions, you may contact me at wopp2954@stthomas.edu. You can also contact the professor, Dr. Kari Fletcher, overseeing the project at 651-962-5807 or flet1660@stthomas.edu. You may also contact the University of St. Thomas Institutional Review Board at 651-962-5341 with any questions or concerns.

You will be given a copy of this form to keep for your records.

Statement of Consent:

I have read the above information and understand what is being asked of me in this survey. My questions have been answered to my satisfaction.

I give my full consent to participate in this study by clicking the YES button below.

YES _____

NO _____

APPENDIX C

Are you a parent of a child diagnosed with cancer?

Are you interested in being part of a study that explores parent's perspectives on children with cancer and their adjustment to school after treatment?

If so, you are invited to participate in a study.

The purpose of this study is to explore parent's perspectives of their child's school adjustment and peer relationships after cancer treatment.

Interested in participating?

Go To:

urlm.in/qvwg

Inclusions Criteria: **1)** child has a cancer diagnosis, **2)** child must have been between the age of 4-17 when they entered remission or began maintenance phase of treatment and returned to school, **3)** child must only be receiving maintenance treatment, **4)** child must be living

This study will be conducted by Lauren Woppert, graduate student at the University St Thomas/St Catherine University Master of Social Work Program. Contact if you have questions.

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APPENDIX D

List of Resources:

1. American Cancer Society

1599 Clifton Road NE Atlanta, GA 30329-4251 (800) ACS-2345 www.cancer.org

Has a national network of employees and volunteers who implement research, education, and patient service programs. Although programs differ according to state and province, some widely available programs are patient-to-patient visitation, transportation to appointments, housing near treatment centers, equipment and supplies, support groups, literature on a large variety of topics, summer camps for children with cancer, research and educational programs.

2. National Children's Cancer Society

The National Children's Cancer Society helps children with cancer and their families by providing financial assistance, advocacy, education, and emotional support.

The National Children's Cancer Society 1015 Locust, Suite 600 St. Louis, MO 63101 314.241.1600 (telephone) or 1-800-FAMILY 314.241.6949 (fax) www.children-cancer.com/

3. The National Brain Tumor Society

Main Offices: 617 924 9997

Provides telephone support, national and regional patient conferences, publications, free quarterly newsletter, caregiver programs, patient support network, support groups, and funds for research. The web site publishes the newsletter (and archives thereof) online, fact sheets, clinical trials, "ask the health professional", and helps for coping, including message boards and support groups. (Not peds specific; located in the San Francisco Bay Area.)

4. Friends of Scott

www.friendsofscott.org

Friends of Scott (San Diego, CA) provides emotional and financial support for young people with cancer and their families with face-to-face groups, a prom and other special events, scholarships, and a gas and grocery fund. See the web site for current details.