

5-15-2013

# Late effects of childhood cancer : implications for child life specialists

Meghan Brewer

*Bank Street College of Education*

Follow this and additional works at: <http://educate.bankstreet.edu/independent-studies>

 Part of the [Child Psychology Commons](#), [Oncology Commons](#), and the [Pediatrics Commons](#)

---

## Recommended Citation

Brewer, M. (2013). Late effects of childhood cancer : implications for child life specialists. *New York : Bank Street College of Education*. Retrieved from <http://educate.bankstreet.edu/independent-studies/72>

This Thesis is brought to you for free and open access by Educate. It has been accepted for inclusion in Graduate Student Independent Studies by an authorized administrator of Educate. For more information, please contact [kfreda@bankstreet.edu](mailto:kfreda@bankstreet.edu).

Late Effects of Childhood Cancer:  
Implications for Child life Specialists

By  
Meghan Brewer

Mentor: Michelle Brauntuch

Submitted in partial fulfillment of the requirements of the degree of

Master of Science in Child Life  
Bank Street College of Education

2013

**Meghan Brewer**

**Title of Study: Late Effects of Childhood Cancer: Implications for Child Life Specialists**

**Abstract**

Due to an increasing rate of childhood cancer survivors, long term follow up for patients should include child life interventions addressing the educational, psychosocial, and emotional needs of children as they progress through school and developmental stages. The purpose of this paper is to discuss research findings on pediatric cancer diagnoses and treatments and their impact on a child's quality of life, schooling, coping and development. Research regarding current and future interventions to address these effects is explored. A discussion of possible implications of these findings for institutions to implement in order to meet the needs of the patients in regards to quality of life, coping, school and development is also presented. More specifically, research and theory are used to support the need for a child life specialist dedicated to school entry and long term follow up with patients, families and schools.

## Table of Contents

|  |    |
|--|----|
| Table of Contents.....   | 3  |
| Introduction.....  | 4  |
| Developmental Analysis of the School Age Child.....                | 6  |
| Child Life Profession.....   | 9  |
| Literature Review .....  | 12 |
| Future Recommendations.....  | 28 |
| Appendix   |    |
| A. Survey.....   | 34 |
| B. Data Collection Chart.....                                      | 35 |
| C. Chart.....  | 36 |
| D. Graph.....  | 36 |
| E. Job Description.....  | 37 |
| F. Sample School Transition and Long Term Follow Up Checklist..... | 41 |
| References.....  | 42 |

## **Introduction**

In the present paper, the effects of both a cancer diagnosis and treatments linked to cancer are investigated as they related to child development and school. It is hypothesized that school entry programs including long term follow up are necessary to address these possible problems successfully.

A new diagnosis of cancer and the treatments associated with it can have a significant effect on a patient's development, leading to the need for support in school entry during and after treatment. Psychosocial, emotional, cognitive and physical development can all be drastically affected in these patients. These patients may be at risk for problems related to growth and development including mastery and control as well as developing coping mechanisms. The communication between patients, families, schools and hospitals is imperative in providing these children with the consistent support that they need. In the present paper, the effects of both a cancer diagnosis and treatments linked to cancer are investigated as they relate to child development and school related issues. It is suggested that school entry programs including long term follow up are necessary to address these issues successfully and that a Certified Child Life Specialist should be included in this follow-up care.

### **Pediatric Cancer**

The most common type of childhood cancer, Leukemia, accounts for 34% of all cancers in children. Other common childhood cancers include central nervous system cancers, lymphoma and sarcoma (American Cancer Society, 2012c). It is projected by the American Cancer Society that approximately, "11,630 children in the United States under the age of 15 will be diagnosed with cancer in 2013" (2012c).

The American Cancer Society (2012a) explains that 8 out of every 10 children treated for cancers survive at least 5 years, with most of them being cured. It is stated that while most of the side effects of treatment disappear at the end of treatment, there are other problems labeled as, “late effects,” that may appear months or years after treatment. These “late effects” are caused by damage to the healthy cells in the body by chemotherapy, radiation and surgery. According to the American Cancer Society (2012a), these late effects depend on the type of cancer, age of child at diagnosis, overall health of the child before treatment and their genetic makeup. The impact of late effects on executive function is reported to lead to, “26 to 47% of childhood cancer survivors,” to be retained in school (Varni and Katz, 1997). Such functions include attention to tasks, difficulty planning and organizing, short-term memory problems and issues with processing information (Bradley-King & Sundman, 2010). Late effects are also proven to impact a child’s cognitive ability to interact socially, reduce a child’s ability to participate in physical interaction for socialization, and interfere with their ability to build social skills due to a lack of socialization with their peers (Bradley-King & Sundman, 2010). Cancer treatment can also have a drastic impact on the patient physically. Alopecia, or hair loss, can be very distressing on patients while, “Other physical effects from treatment include fatigue, physical limitations, scars, weight changes, decreased mobility, and muscle pain” (Bradley-King & Sundman, 2010). The American Cancer Society (2012a) adds that late effects of cancer treatment can impact a patient’s heart, lungs, growth and development, sexual development, reproductive organs, learning and development of secondary cancer. These effects should be considered in a patient’s long term follow-up care plan after treatment.

## **Developmental Analysis of the School Age Child**

To understand the impact that a cancer diagnosis can potentially have on a school age child's development, an understanding of school age children should be established. Children between the ages of 6 and 11 experience a variety of changes in regards to physical, cognitive, and psychosocial development. Piaget, Vygotsky, and Erikson developed theories that have become the basis for knowledge of child development.

### **Cognitive Development**

Piaget developed a cognitive-stage theory in which he believed, "children themselves actively construct," (Miller, 2002a) their knowledge. According to Piaget's theory, school age children are transitioning between the preoperational periods into the concrete operational period. Preoperational children's egocentrism is continuing to decline as they develop and begin to understand other's perspectives. Piaget explained that in the preoperational stage, "thoughts are often linked together in a loose way rather than in a logical relationship" (Miller, 2002a). These children's limited ability to use logic will also change as they enter future stages. It is also noted that Piaget theorized, "Their social conceptions are limited because they often are based on one or two concrete personal experiences" (Miller, 2002a). According to Piaget's theory, children between the ages of 7 and 11 enter into the Concrete operational stage. Miller defines an operation as, "an internalized mental action that is part of an organized structure," and that, "the ability to use operations, the child's representations are no longer isolated, rigid, or simply juxtaposed" (p. 52). Piaget felt that logic and mathematics were impacted by the child's cognitive structures which lead to his development of various types of thinking. Miller explains, "In summary of Piaget's stages to this point, children move from an

understanding of the world based on action schemes, to one based on representations, to one based on internalized, organized operations. Thought now is decentered rather than centered, dynamic rather than static, and reversible rather than irreversible. For the first time, the lawful nature of the world seems to be reflected in a logical system of thought... They deal with what 'is' rather than what 'could be' (p.56).

The school age child will eventually enter into a Formal Operational Period, typically between the ages of 11 to 15, in which they will be able to think more abstractly, rather than concretely. These stages that Piaget developed fall under the understanding that, "stages are structured wholes that emerge from and transform a previous stage, follow an invariant and universal sequence, and proceed from an unstable period of transition to a final stable period"(Miller, 2002a).

### **Social-Emotional Development**

According to Erikson and his theory on psychosocial development, children between the ages of 6 and 11 would land in the Industry vs. Inferiority stage. Crain interprets Erikson's theory to describe the child's development within this stage, paired with Freud's Latency stage. Crain explains that according to Freud's theory, "During this period, the sexual and aggressive drives, which produced crises at earlier periods, are temporarily dormant," and , "this is a period of calm and stability" (p. 255). Crain continues to explain how Erikson's theory shows , "this is the most decisive stage for ego growth"(p. 255) because of the social and cognitive skills that children develop within this time. He explains that despite Freud's theory, "The crisis is industry versus inferiority"(Crain, 2000). Erikson states, "danger, at this stage, lies in a sense of inadequacy and inferiority" (Erikson, 1963).It is within this stage that children are,

“asked to master more cerebral skills – reading, writing, and arithmetic,” while, “learning to do more meaningful work and are developing the ego strengths,” of attention and persevering (Erikson, 1963). Working and playing with peers is also an important aspect of this stage. Erikson explains the danger within this stage when he states, “Many a child’s development is disrupted when a family life may not have prepared him for school life, or when school life may fail to sustain the promises of earlier stages.” (Erikson, 1963). Children may not be adequately prepared for this stage because of unresolved issues in previous stages, or because of school or community attitudes that hinder the development of industry. Crain highlights Erikson’s focus on school by stating, “all too often schools fail to discover and encourage the individual’s special talent,” however, “good teachers (who often are those who feel trusted and respected by the community) can help children at this time” (p.256). The goal of this stage is to develop the “ego strength Erikson calls competence” (Crain, 2000). Failure to resolve issues within this stage can impact the child’s development in Erikson’s future stages of identity vs. role confusion and intimacy vs. isolation. In these stages, adolescents are uncertain about whom they are, and “the problem of identity reaches its crises at adolescence” (Crain, 2000). In regards to intimacy, it can only be attained when a sense of identity has been established. It is then that the adolescent is no longer preoccupied with whom he or she is, and can continue on to young adulthood. The issue in this stage, however, occurs when “people fail to attain genuine mutuality,” with a partner, and are at risk for a feeling of isolation. (Crain, 2000).

### **Socio-Cultural Development**

Lev Semyonovich Vygotsky developed a sociocultural theory in which the focus

is not on the individual child, but rather the child within a culture (Miller, 2002b). Culture, in this instance, includes social settings, including school. Unlike other theories, Vygotsky related the development of the child to their culture and believed that, “certain forms of social practice relate the child and her needs and goals to the environment and define what that environment means to the child,” and that, “social problem solving and communication one’s feelings and desires to other are not just “special cases” of predominantly “cold” cognition unrelated to personal needs; they are the fabric of everyday life and the essence of cognition”(Miller, 2002b). It is believed that changes in development are related to changes in which children participate in activities offered by their culture. For example, children participating in a group activity will gradually take on more responsibility, and “these developmental changes in participate are linked with changes in cognition”(Miller, 2002b). More specifically, Vygotsky’s, “Zone of Proximal Development” is the distance between a child’s actual development and their potential development, which is impacted by their interaction with adults and peers (Miller, 2002b). Vygotsky explained the importance of social interaction in regards to development by stating, “Learning awakens a variety of internal developmental processes that are able to operate only when a child is interacting with people in his environment in cooperation with his peers” (1978, p.90).

### **Child life Profession**

Child life began as a profession in the 1920’s, designed to improve experiences for hospitalized children through play therapy, education, and preparation for procedures within the hospital. Emma Plank, a leader in the field of child life, addressed the social, emotional and educational needs of hospitalized children (Thompson, 2009). Child life

experienced rapid growth within the 1970's and 1980's, creating new programs, as well as forming a committee within the Association for the Care of Children in Hospitals, or ACCH, officially becoming a study section in 1975. Through continuous development, "The Child Life Council (CLC) was established in 1982 to address the professional, programmatic and educational needs of child life practitioners" (Child Life Council, 2002c). The CLC had its own officers and developmental national conference. To further their success, the CLC created a professional certification exam in 1998 while reaching 1,500 members. Despite the health care crisis in the 1990's, the Child life profession continues to grow, along with their standards of being recognized as a certified child life specialist.

The CLC, along with scientific research, solidified that play can be used as a tool to address psychosocial issues of children within healthcare settings. The ACCH Child Life Research Project, supporting the justification for child life in hospitals, indicated , "children who received the experimental child life care showed significantly less emotional distress, more effective coping, greater understanding of hospital experiences, better overall adjustment in the hospital, and better post-hospital adjustment than control children who did not receive child life care" (Gaynard, 1998, p. 2). The results comparing physiological and psychosocial aspects of child life services, displayed that children participating in the experimental child life program scored significantly better in categories comparing physical, education, and emotional responses to the hospital (Gaynard 1998). This study was able to support the need for child life in a hospital setting and reinforce the profession's ideals by presenting a research-based rationalization. Other findings in research on child life found that to maximize effectiveness, child life must be

implemented soon after admission, must be ongoing, and must be individualized for each family. (Gaynard, Wolfer, Goldberger, Thompson, Reburn & Laidley, 1998).

In the Official Documents of Child Life, there are a set of competencies which are “the minimal level of acceptable practiced as defined by the Child Life Council...” (Child Life Council, 2002b). These competencies describe ideas of meaningful interactions, providing safe, therapeutic environments for patients and families, teaching these patients and families about their experiences and more. (Child Life Council, 2002b) When given the opportunity, child life specialists will also help the patient and their families’ transition back into home life by providing support in reentry to school. Child life begins when children enter the hospital, but there is no set “ending” for services.

The child life profession is an internationally recognized profession, supported by research and developmental theory. Present day, child life is present not only in hospital settings, but also in more nontraditional settings such as hospice care, camps, community settings and more. The variables that a child life specialist assesses include child variables, family variables, illness variables and medical experiences (Child Life Council, 2002a). More specifically, the child’s age, temperament, anxiety level, and coping style, parental anxiety, distress, characteristics, socioeconomic status, and presence are assessed. Illness variables assessed may include chronic vs. acute, as well as the length of hospital stay while medical experiences are assessed by variables such as exposure to invasive procedures and previous hospitalizations (Child Life Council, 2002a). These variables can be translated into these alternative settings, allowing child life to further their positive impact on the psychosocial development of these children.

## Literature Review

### Impact on Quality of Life

Barrera, D'Agostino, Gibson, Malkin, Wayland, & Weksberg (2003) completed a longitudinal study to compare preschool, school age and adolescent children's psychological adjustment and health-related quality of life, as well as to identify predictors of the two. These children were evaluated at 3, 9 and 15 months after diagnosis with questionnaires filled out by caregivers of patients. 29 girls and 40 boys with diagnoses including leukemia, sarcomas, Hodgkin's Lymphoma, brain tumors and malignancies were studied, with a mean age of diagnosis being at age seven. It was hypothesized that preschool children would express higher psychological adjustment difficulties and adolescents would demonstrate poorer HRQoL. It was also hypothesized that children's PA and HRQoL would increase with time while adolescents would experience more difficulty over time due to lack of autonomy and opportunity to socialize with peers. Researchers used the Child Behavior Checklist, The Play Performance Scale and multiple temperament questionnaires to evaluate the child's psychological adjustment, health related quality of life and temperament. The results suggested that there is a correlation between age and psychological adjustment, with preschoolers having more difficulties, supporting the hypothesis. These preschoolers also displayed more externalizing behavior problems, but higher HRQoL. The results also show that these preschoolers have a higher HRQoL than adolescents. Barrera et al. (2003) suggest, "Younger children may express their wants and feelings with their actions rather than with words because they may lack the cognitive maturity to understand the relationship between unpleasant procedures they are subjected to during

treatment and their health. They may also have fewer coping skills than older children. Older children may mask or repress their distress more easily than younger children.” (P. 227) Barrera et al. (2003) discuss the implications of these findings, suggesting, “Adolescents are still perceived as having worse HRQoL than younger children,” and that, “more needs to be done to specifically help them improve their quality of life”(p. 229). Based on development, it was highlighted “Being ill and dependent on parental support may inhibit adolescents from achieving the developmental tasks of establishing an autonomous identity” (Barrera et al., 2003).

Brons, Caron, Grootenhuis, Last, Maurice-Stam, & Oort (2009), completed a study to understand the health related quality of life (HRQoL) and anxiety in school aged cancer survivors in the first four years of remission, and to investigate the correlation of disease related coping with the HRQoL and anxiety. The study included 76 survivors, aged 8-15 years with a diagnosis of Leukemia Lymphoma. The participants completed questionnaires about HRQoL and anxiety as well as cognitive coping at 2 months, 1 year, 2 years and 4 years post diagnosis. TNO-AZL’s Children’s Quality of Life Questionnaire was used for the study. The State-Trait Inventory measured anxiety for Children, and the Cognitive Control Strategies Scale (CCSS) was used to measure the disease related cognitive coping in these children. The data collected was compared to data of the norm at each time frame. Researchers used a longitudinal mixed model analyses to investigate disease-related cognitive coping in correlation to HRQoL and anxiety over time. Brons et al. (2009) found that survivors reported worse motor functioning at 2 months after the end of treatment, but the issues were typically resolved by 1 year. It was also found that males reported lower levels of anxiety than females. Finally, researchers found that

patients that relied on physicians reported a better mental HRQoL than those who did not (Brons et al., 2009).

Katz & Varni (1997) conducted a study to investigate perceived stress and social support of school-aged children newly diagnosed with cancer. The study investigated predictors of negative affectivity in these patients. The study lasted 4 years, assessing these patients at one, six and nine months post diagnosis. Research teams in two major southern California pediatric cancer centers met 32 patients, aged 8 to 13 years old. Katz & Varni (1997) hypothesized that higher generic stress (non-disease related) would predict a higher negative affectivity, and higher perceived generic support would predict lower negative affectivity. They also predicted that the perceived stress effects would be mediated or moderated by higher perceived social support. Researchers used the Children's Hassles Scale, the Social Support Scale for Children, the Children's Depression Inventory Scale, and the State-Trait Anxiety Inventory for Children. Researchers found that age is significantly correlated with negative affectivity at six and nine months post diagnosis; however it is not correlated with perceived social support. However, gender is found to be related to perceived social support at one and nine months post diagnosis. The relationship between perceived social support and negative affectivity was significant at one and nine months post diagnosis. Katz & Varni (1997) explained that these results support the direct effects model of stress and social support. They also state , "The emotional trauma of being diagnosed with a life-threatening disease, the frightening meaning the term 'cancer' has to children and families, the profound physical changes and violation of body image that occurs, and the sheer extreme adversity of surgery, multiple invasive medical procedures, chemotherapy and

radiation therapy may take preeminence in these children's cognitive appraisals early in the diagnosis period over the daily hassles indigenous to normal childhood, "and that these findings, "have implications for primary and secondary prevention efforts in childhood cancer"(Katz & Varni,1997). Finally, it is suggested , "By focusing on the identification of potentially modifiable risk and resistance factors, cognitive-behavioral treatment interventions may be developed to enhance adaptation in children with newly diagnosed cancer who are evidencing maladjustment" (Katz & Varni, 1997).

Challinor, Hutter, Kaemingk, Matthay, Moore & Pasvogel (2003) researched the impact that cancer can have on behavioral adjustment and academic ability in pediatric patients. The study included 47 children with a diagnosis of acute lymphoblastic lymphoma that had been through a minimum of one year of treatment or had been off treatment for no more than three years. The parents and teachers of these patients are also included in the study. Challinor et al. (2003) assessed children, parents and teachers using a self-report behavioral assessment system used to measure behavioral adjustment. The Wechsler Intelligence Scale for Children – Revised (WISC-R) was used to measure cognitive abilities, and the Wide Range Achievement Test –Revised was used to measure academic ability. The study suggested , "Children and adolescents who are receiving or recently completed ALL treatment may be at risk for some behavioral adjustment problems," and that they, "appear to be particularly vulnerable to internalizing problems, specifically somatization, depression, anxiety and withdrawal" (Challinor et al., 2003). Specifically in regard to somatic problems, Mulhern, Wasserman, Friedman, and Fairclough (1989) found , "school problems and somatic complaints were increased fourfold relative to age and gender-adjusted rates for peer groups in the general

population,” and that, “somatic complaints could be related to other late effects of treatment” (as cited in Challinor et al, 2003, p. E89).

### **Impact on School**

In a study created to investigate the psychosocial adjustment, quality of life, and school experiences of pediatric cancer survivors post treatment, Bessell (2001) examined survivors’ adjustment to cancer and their views related to educational and psychosocial impacts of cancer treatment. 51 survivors 8-17 years were recruited from two pediatric cancer centers. Their diagnoses included pediatric cancers with the exception of brain tumors. The patients were required to be attending school, and to have had their last treatment at least six months prior to participation in the study. There was no control group in this study because the questions asked were not incomparable to those who had not experienced a cancer diagnosis. The Social-Anxiety Scale for Children – Revised and the Social-Anxiety Scale for Adolescents, the Self-Perception Profile for Children and the Self-Perception Profile for Adolescents were used to measure the results. The MPQOLQ is used with children that have cancer. Participants also took part in a School Experience Interview that was semi-structured. Bessell (2001) found that in regard to social anxiety, elementary students were socially anxious, with statistics stating that 42% reported >50 which suggests clinically significant social anxiety. Self-perception scales suggested that children reported higher global self worth, higher behavioral conduct, and lower athletic competence when related to the norm. According to the study, school placement after treatment impacted emotional stability, as well as school programs during treatment. Programs during treatment also impacted social competence. The study suggests that those who participated in a school program in their home reported lower emotional status

and social competence than those who remained in general school. The interviews about school experiences displayed that students retained reported more social difficulties. Students also reported poor communication between hospital home school and school-based teachers. According to Bessell (2001), the students expressed that being in the classroom with their peers provided them with a sense of normalcy, and “Lack of communication between doctors and teachers lead to frustration for those who experienced subtle difficulties in school” (p.354).

The impact of childhood cancer on the return to normal schooling was studied by Charlton, Jones, Lacombe, Meller, Mott and Walker (1990). Charlton et al. (1990) hypothesized that a liaison between the hospital, school and home should be available to help facilitate a smooth return to school for children with cancer. Parents and teachers of 117 children between the ages of 4 and 16 that returned to school after spending a significant amount of time in the hospital were studied. 51 children with a cancer diagnosis were involved, while the control groups included 34 children with chronic diseases and 32 with orthopedic conditions. Researchers interviewed parents with a structured questionnaire regarding physical, academic, psychological and behavioral problems on the child’s return to school, and results were analyzed by content analysis. Each child with a cancer diagnosis was matched with two children from the control group with similar age and same sex. The results from the study suggested that of the 117 patients, parents identified more problems than teachers, however, teachers of patients diagnosed with cancer and chronic conditions identified more problems than parents. Teachers reported that most of the problems at school were due to absenteeism, directly related to the cancer treatment. The study found that there were worries about teasing

because of hair loss within the school. Parents of children with cancer reported difficulty in obtaining assignments for missed school days, difficulty organizing home tutors, and trouble with guidelines issued by local education authority on the provision of home tutors. Both parents and teachers of children with a cancer diagnosis addressed the importance of planning a coordinated program of work to be followed on days children are absent. Within this study, only 13% of teachers reported that they were contacted by school health service before children with a cancer diagnosis returned to school, and suggested the need for more medical information to provide confidence in working with these children (Charlton, 1990).

Teachers of children with cancer have come to be a concern of those studying school reentries. Chekryn, Deegan & Reid (1987) conducted a study to describe dilemmas and feelings teachers face when a child with cancer returns to their classroom. The study was used to gain insight into the child, parent and teacher's perspective on the return to school of these children. Chekryn et al. (1987) wanted to demonstrate the need to include teachers as part of the health care team to ease the transition. The study involved nine children and their parents and teachers. These children were between the ages of 10 and 16. These patients had been diagnosed with Hodgkin's disease, lymphoma, leukemia or sarcoma. In depth, semi-structured interviews of these children, parents and teachers were completed 4-6 weeks after the child's return to school. Statements were compared within themes by investigators. One theme that emerged from the content analysis included "the dilemmas teachers faced as they attempted to normalize the school experience," such as, "balancing academic expectations with other aspects of the school experience, obtaining information versus respecting privacy, determining appropriate

discipline, and determining appropriate emotional support” (Chekryn et al., 1987). The other theme was, “the personal impact teachers experience from having a child with cancer in their classroom” (p.162). More specifically, “Teachers explicitly delineated their informational needs. They specified that they needed more than general information about cancer and its treatment,” and that they, “wanted guidelines as to how to deal with changes, especially emotional ones. Moreover, they wanted to know what the overall goals were for the child and what role school played in relation to those goals” (Chekryn et al. 1987).

Vance & Eiser (2001) reviewed literature discussing the school experience for children with cancer related to school absence, behavior problems and social relationships. They also reviewed possible interventions created to promote a positive school re-entry for these children. 42 papers focusing on children aged 5-18 at all stages of cancer treatment were reviewed. These studies addressed absences, behavior, social relationships and reported results of interventions. In their research of literature, Vance & Eiser (2001) found that school absence is a common problem for children at all stages of cancer as well as post treatment. It was stated , “the majority of evidence is suggesting that children with cancer miss more school than healthy controls or those with other chronic conditions. Although absences decline with time, they remain a problem long past the initial diagnosis” (Vance & Eiser, 2001). In regards to behavior, it was Deasy-Spinetta and Spinetta (1980) explained that children with cancer, “were judged to have less energy, and had more difficulty concentrating and completing tasks”(as cited in Vance & Eiser, 2001, p.13). Noll et. al (1997) published a series of studies to compare children with cancer and healthy children using the Revised Class Play (RCP) assessment

(as cited in Vance & Eiser, 2001, p.13). Based on this study, Vance & Eiser suggested, “The implications are that children with cancer differ from healthy children in key areas of social functioning, and have restricted leadership and social skills, at least according to teachers” (p.28). Using the same RCP, this study found that healthy peers often associated the children with cancer with more “sensitive-isolated roles,” in play than healthy peers (Vance & Eiser, 2001).

### **Interventions**

Kim and Yoo (2010) created a study to understand factors associated with resiliency of school age children with cancer. 74 children aged 10-15 that had been diagnosed with cancer at least 6 months prior to this study were included in an evaluation based on a self-reported questionnaire. Data collected included information regarding demographics, resiliency, family adaptability and relationship with friends and teachers. Based on results, it was found that, “school age children with cancer who reported higher family function, positive relationships with friends and positive relationships with teachers were more resilient than their counterparts. These results support the results of other studies using the resilience model that family support and social relationships such as friends are the important protective factors”(Kim & Yoo, 2010). It was also found that the teacher’s relationship with an attitude towards the child has a significant impact on the relationship with friends (Kim & Yoo, 2010). Kim and Yoo (2010) remind the reader that, “School is an important place where children learn social skills, and develop self identity and self esteem” (p. 434). Issues with friends can arise from friends being misinformed on the patient’s diagnosis. The importance of, “programs to help the children with cancer to build self-esteem, social skills and communication skills,” was

highlighted because of the risk of children's reported feelings of being isolated or bullied at school (Kim & Yoo, 2010).

Support from friends and class mates, has been show to help children deal with the cancer experience." Families were shown to be impacted by fear of the child's death, and demands regarding the length of treatment and finances, leading to negative psychosocial outcomes and impact the family function and resiliency in children (Kim & Yoo, 2010). In regards to family support, Kim & Yoo (2010) suggested that, "It is necessary to help family to receive adequate support such as correct information, emotional and physical support and financial aid" (p.434).

Bradley-King and Sundman suggest that measures currently taken to prepare children for school reentry are not adequately preparing children for reentry due to, "lack of quality instruction, limited time allotted for instruction, inadequate curricular materials and limited training of teachers to provide instruction"(p. 15). In their study of previous research and literature on the topic of childhood cancer survivors and school reentry, Bradley-King & Sundman found that, "childhood cancer survivors ranging in age from 8 to 17 years were interviewed to determine the impact of cancer on their adjustment," and they reported that, "school provided them with a sense of routine and an opportunity to rejoin their friends" (p.15). They found that students that had been retained, as well as those received special education services reported negatively on their reentry because they felt that there was a stigma setting them apart from their peers, in addition to their diagnosis. (p.15). For this reason, Bradley-King and Sundman suggested that retainment in school and special education should be, "replaced by careful assessment of a student's knowledge and skills, and matching that student's needs with the appropriate curriculum

and level of instruction,” and that because of late effects, “performance and progress across skill areas should be closely monitored to prevent negative outcomes” (16).

Accommodations in the classroom such as untimed testing, oral assessments and use of calculators were suggested based on impacts of treatment. A number of interventions for psychosocial late effects were also discussed in the article. Based on their research, Bradley-King & Sundman suggested that teachers and classmates keep in touch with the patient through their absence, informing and educating educational staff and classmates on illness, and teaching relevant social skills to the patient. These skills could include problem solving, coping techniques, and assertiveness.

Vance & Eiser (2001) reviewed literature on interventions that have been studied in regards to children with cancer and their entry into school after diagnoses or treatments. Tuffrey et al. (2003) “reported that teachers felt the information given to them was inadequate and should focus more on behavioral and psychological problems faced by these children”(as cited in Vance & Eiser, 2001, p.15). Multiple studies on programs aimed to help teachers with school re-entry for children with cancer were reviewed by Vance & Eiser that suggested that there was, “Increased knowledge of childhood cancer and confidence in dealing with these children”(p.15). A study conducted by Rynard, “reported the concerns of parents and teachers about school re-entry, including the need for open communication between home, hospital and school” (Vance & Eiser, 2001).

Vance & Eiser (2001) presented a study conducted by Katz, Rubenstein, Blew & Hubert (1988) that compared children receiving standard school entry care, and those receiving a four-part intervention programme. The program consisted of conferences about childhood cancer, presentations in the presence of the child for their peers, as well

as follow up support after the return to school (Vance & Eiser, 2001). This study, “reported that children in the intervention group had reduced depression, increased self-esteem, and their parents reported fewer problems (Vance & Eiser, 2001). Other interventions that Vance & Eiser reviewed included social skills training programmes to provide children with skills to deal with questions from others regarding their cancer, and workshops directed at classmates of children with cancer. Of the studies that were reviewed it was found that, “Classmates may benefit from short intervention sessions, discussing issues such as how cancer is caused and how it is treated. For teachers, it was reported that information about childhood cancer increases their confidence in dealing with school re-entry” (p.16).

Various studies have been conducted to investigate possible interventions and programs created to support patients, families and schools in the school entry process. Blew, Hubert, Katz, Rubenstein & Varni (1992) conducted a study to report children’s, parent’s and teacher’s evaluations on a comprehensive school reintegration intervention. 49 newly diagnosed cancer patients were selected from the Hematology-Oncology department at Children’s Hospital of Los Angeles. The children were between the ages of 5 and 17 with diagnoses including Acute Lymphoblastic Leukemia, lymphoma or solid tumors. Each patient that participated received school reintegration interventions. The interventions included supportive counseling, education presentations, systematic liaison between hospital and school, and periodic follow-ups conducted by a hospital based pediatric psychologist. The children, parents and teachers were then asked to rate their perceptions of the utility and value of each intervention by filling out questionnaires. It was found that parents and children questionnaires indicated that interventions were

important and supported a successful reintegration. Teacher questionnaires demonstrated “favorable ratings,” especially in regards to the knowledge gained by teachers and classmates (Blew et al., 1992).

Canter & Roberts (2012) conducted a systematic and quantitative review of interventions that have been created to support children with chronic health conditions in school reentry. They aimed to provide a summary of programs to indicate which types of interventions are more effective than others. Canter & Roberts (2012) hypothesized that “participation in school reentry program would be correlated with an increase in illness-specific knowledge,” and, “that school reentry programs would lead to positive attitudinal change among participants”(p. 1069). The comprehensive search of literature resulted in 12 studies being reviewed, involving 494 healthy classmates, 176 ill children and 443 school personnel. Canter & Roberts state, “According to Cohen’s interpretive guidelines... a large effect for increases in knowledge for teachers and a medium effect for increases in knowledge for peers,” (p.1069) was found. In regards to attitudinal change, Canter & Roberts state that, “According to Cohen’s interpretive guidelines... a large effect size for attitudinal change among teachers and a medium effect size for attitudinal change among/ healthy peers,”(p.1070) was indicated. These findings support the hypothesis of school entry programs increasing knowledge and enhancing positive attitudinal change. Canter & Roberts discuss that, “The previous literature has suggested that children as young as five can be taught specific factual information about certain health conditions,” and that, “Given these findings, it seems logical that participation in a school reentry intervention would be expected to correlate with large increase in

knowledge, particularly when the intervention program contains specific information about unfamiliar illnesses” (p.1071).

Chambers, Gray, Klinck and Rynard (1998) presented information they gained through researching literature on the topic of school support programs and their benefits. Chambers et al. (1998) hypothesized that children on treatment for cancer would display greater social and emotional problems than those who are not because of challenges they face in regards to behavior and academics. They also hypothesized that literature would show that parents of children would report a greater number of behavior difficulties than teachers because of the types of problems they would be exposed to. A thorough review of literature on pediatric cancer school support programs was completed. The present study, “presents the components of a school support program based on the available literature on school reintegration,” and an, “attempt at a consumer-oriented evaluation system” (Chambers et al., 1998). The study also was created to, “provide descriptive data on behavioral and academic functioning of children on and off treatment for childhood cancer” (Chambers et al., 1998). The objectives of the program created included providing school with relevant information regarding cancer, insight into emotional aspects of treatment, helping educators in providing support for patients and families, providing school with guidelines, resources and confidence in meeting needs of children, and to maintain communication for long-term school adjustment(Chambers et al., 1998). The team created included a psychologist, nurse, social worker, public health nurse and other hospital personnel. Goals included contacting families and schools to obtain consent and explain services. Information packets were distributed to schools regarding treatment, diagnosis and special need requirements. Meetings were held with staff to plan

accommodations, and information was continuously provided on a regular basis to school staff. To evaluate the program, questionnaires were completed by the teachers. Annual workshops were also conducted to provide networking opportunities and additional information (Chambers et al., 1998).

These goals were set to be maintained by a liaison between the hospital, home and school. This intervention was measured by consumer satisfaction questionnaires, absenteeism, child adjustment, and academic achievement. Results suggested, “all components of the program were perceived by teachers and parents as highly useful” (Chambers et al., 1998). The study supported Katz et al., 1992’s study that found, “teachers rated the school conference as the most useful component,” because of the need for, “face-to-face discussion and dialogue between school and hospital staff about the individual student...as opposed to generic, school intervention” (Chambers et al., 1998). Parents in the present study showed, “high ratings of the importance of communication between hospital and school,” and indicated their desire, “for open communication about their child’s illness with other important people in the child’s life” (Chambers et al., 1998).

A study surveying both United States and Japanese pediatric oncologists was conducted to gain insight into physician attitudes towards truth telling and information sharing in school reentry. The study was developed to understand how physicians, and oncologists’ communication was used handle school entry issues with children. The study compared members of both the US and Japanese pediatric oncology professional societies regarding patients aged 10-17. The survey involved general attitudes, patient factors, work cultures and respondent characteristics. It was found that 85% of US

physicians, “endorsed telling everyone (the school officials and classmates) about a child’s diagnosis and treatment to facilitate the transition back to school”(Hara, Iwata, Jeruss, Mayer, Nakagawa, Parsons, Saiki-Craighill, Terrin, Tighiouart, 2005), whereas only 25% of Japanese physicians supported the same actions. It was found that less than 2% of US physicians disagreed with telling patients about their diagnosis from the start. Lastly, 50% generally agreed, while 48.3 completely agreed, “that knowledge within community will enhance psychosocial support in US (Hara et al., 2005). It was suggested that the differences in US and Japanese results could be related to cultural differences as well as the average length of stay in the hospital and time of school reentry. Children in Japan typically stay in the hospital an average of 6 months and do not return to school until treatment is over and visible signs of treatment are gone, where children in the US spend less time in the hospital typically and return to school during treatment (Hara et al., 2005). The findings in this study suggest physicians’ positive attitudes regarding information sharing and truth telling in the United States.

### **Long Term Follow-Up**

To help increase awareness of late effects and improve follow-up care of childhood cancer survivors throughout their lives, the Children’s Oncology Group (COG) has developed a *Long Term Follow-Up Program Resource Guide* to support survivors of childhood cancers. These guidelines provide suggestions and resources for institutions to implement and take into consideration when developing long term interventions for patients. The guidelines discuss the importance of long term follow-up, models to use, potential barriers, program development, and delivery of care. Research is also included as an essential aspect of follow-up care that should be included in program development.

## **Survey**

A survey (Appendix A) was created to assess the amount of school entry support pediatric patients and families receive from institutions in the United States. The survey researched each institution and its available school related programs, team members involved, and their roles and responsibilities, salaries of coordinator positions, pediatric populations served, and number of patients assisted.

Results show that four out of the US News top five pediatric hospitals for oncology have a position specifically designed for school entry (Appendix B). These institutions report that they assist over 40 patients annually with their school entry program. The school entry positions at these institutions are designed to dedicate their time to coordinating interdisciplinary meetings, addressing educational concerns, scheduling school visits and facilitating communication between patients, families, hospitals and schools. This survey shows that institutions with school entry coordinators are able to assist in double the amount of patients in school entry each year when compared to institutions without these specific positions (Appendix B).

## **Future Recommendations**

With the increasing number of pediatric cancer diagnoses and long term survivors more support is needed within the hospitals (American Cancer Society, 2012a). As previously discussed, the long term impact of a cancer diagnosis and related treatments can significantly impact a child's school experience in relation to cognitive, social and emotional development (American Cancer Society, 2012a; Bradley-King and Sundman, 2010). These late effects can impact students' development several years post treatment. It is imperative to take a proactive stance and establish long term guidelines prior to end

of treatment to address any issues that may appear in the future. According to the Competencies and Standards of Clinical Practice set forth by the Child Life Council (2002c), Certified Child Life Specialists are educated and clinically experienced in developmental assessment. Certified Child Life Specialist can identify factors that may impact vulnerability to stress, describe coping behaviors specific to age groups and populations and explain immediate and long term coping styles and their effects on adjustment and behavior (Child Life Council, 2002b). The ability to anticipate future concerns is a key factor in a successful transition to school after a cancer diagnosis.

Communication between hospitals, school, patients and families should persist after the end of treatment to ensure that children continue to be supported after treatment ends. Psychosocial assessments of patients as well as support and education for school staff should be included in the long term follow up care plan to ensure successful school and developmental progress. As previously discussed, interdisciplinary teams are able to support children in entry to school based on the child's current needs and late effects proven by research (American Cancer Society, 2012a; Bradley-King and Sundman, 2010; Vance and Eiser, 2001). These late effects, which can appear months to years later (American Cancer Society, 2012a), are dependent upon the developmental stage in which the child receives treatment. Child Life Specialists are specifically educated and trained in child development, providing the ability to assess how a child's coping and understanding will change throughout the developmental stages and as new challenges present themselves (Child Life Council, 2002d). The ability to articulate this information to parents and teachers is necessary for successful long term care.

As the child progresses through school grades and developmental stages, new, unpredictable problems may arise. As discussed earlier, unsuccessful progression through previous developmental stages can lead to struggles in the future stages (Erikson, 1963; Miller, 2002a; Miller 2002b). School age children impacted by treatment may continue to develop cognitive, social and emotional issues into their adolescent years. For example, scars from treatment may lead to negative body image and low self-esteem in adolescent years and a lack of socialization in school age years can negatively impact peer relationships and self-confidence during subsequent developmental stages (Erikson, 1963; Miller, 2002a; Miller 2002b). If a child is not successful in school due to treatment, he or she may lack competence and self-esteem. If teachers are unaware of late effects, they may not understand why the child is struggling in school and set unrealistic academic expectations for him or her (Blew, Hubert, Katz, Rubenstein and Varni, 1992; Canter and Roberts, 2012). It is lack of understanding of appropriate curriculum and level of instruction needed that leaves these children at risk for school and feeling of incompetency (Bradley-King and Sundman, 2010). Teachers and classmates in the years following treatment may also lack education on late effects and specific ways to support these students academically and emotionally. Research has shown knowledge for school staff to be necessary in providing the confidence needed to support children post diagnosis (Blew, Hubert, Katz, Rubenstein and Varni, 1992; Canter and Roberts, 2012; Chambers, Gray, Klinck and Rynard, 1998). With knowledge of development and the ability to assess anticipated struggles of each individual patient, a Certified Child Life Specialist will be able to advocate for accommodations for patients within the IEP and 504 plans and provide patients, families and schools with the tools needed to address not

only current but future concerns.

According to a survey of pediatric hospitals in the United States, those with positions dedicated to school entry were able to support almost double the amount of patients than hospitals without a coordinating position (Appendix D). All hospitals that report having a position dedicated to school entry also report the ability to support over 30 patients annually. Although school entry teams and positions are present in some institutions, it does not imply the presence of long term follow-up care, or the quality and efficacy of the current program. Adding to the previously discussed skills that this job will require, the description for a school entry coordinator position (Appendix E) should include the need for data collection and research. Participation in evidence-based practice supported by continued research is included in the Standards of Clinical Practice of Certified Child Life Specialists to continually update and enhance the understanding of families, patients and clinical services (Child Life Council, 2002d). Using this information, the importance and efficacy of long term follow up and school entry interventions will be supported. The data collected should include statistics on number of patients served and interventions implemented as well as patient, family and school satisfaction. The school entry coordinator should maintain that each child is receiving all necessary interventions and means of support by keeping a record of services implemented. An example of a school entry long term follow-up checklist includes initial services as well as continued follow up care (Appendix F).

Communicating with patients, families and schools on their assessments of the program would allow a coordinator to adapt to each individual patient's experience. This requirement could be supplemented by a Certified Child Life Specialist's ability to

adapt to the culture and communication style of patients, families, and schools to maintain the effectiveness of interventions (Child Life Council, 2001c). Allowing the participation in the development of a classroom presentation for peers would provide the school age child with an opportunity to assert control, allowing the child to feel capable and avoiding future self-doubt (Crain, 2000). Research has shown that face to face interactions at school suggested reduced depression and anxiety for the patient, as opposed to standard, less personalized interventions (Katz et al., 1992). A Certified Child Life Specialist dedicated to school entry coordination could meet the emotional state and needs of the patient, while providing his or her classroom with developmentally appropriate information to address misconceptions and foster supportive peer relationships within the school (Child Life Council, 2002b).

While the Children's Oncology Group's *Long Term Follow-Up Program Resource Guide* suggests a multidisciplinary team approach to long term follow up, a Certified Child Life Specialist is not included in their suggested list of team members (Children's Oncology Group, 2007). Based on the Child Life Council's (2002c) Competencies, a Certified Child life Specialist will be able to use his or her skill set and knowledge base to best support children as they progress through their education and development. A Child Life Specialist's ability to continue to assess a patient's coping and anxiety, revisit diagnoses, educate staff annually, provide support in self-advocacy and maintain optimal psychosocial care is necessary to fully support these patients. Child Life involvement in long term follow up by anticipating future concerns through assessment and implementing age appropriate interventions is imperative as the children remains at

risk for struggle in their ability to cope with and understand their diagnosis and effects of treatment throughout development.

## Appendix A:

### School Entry Survey

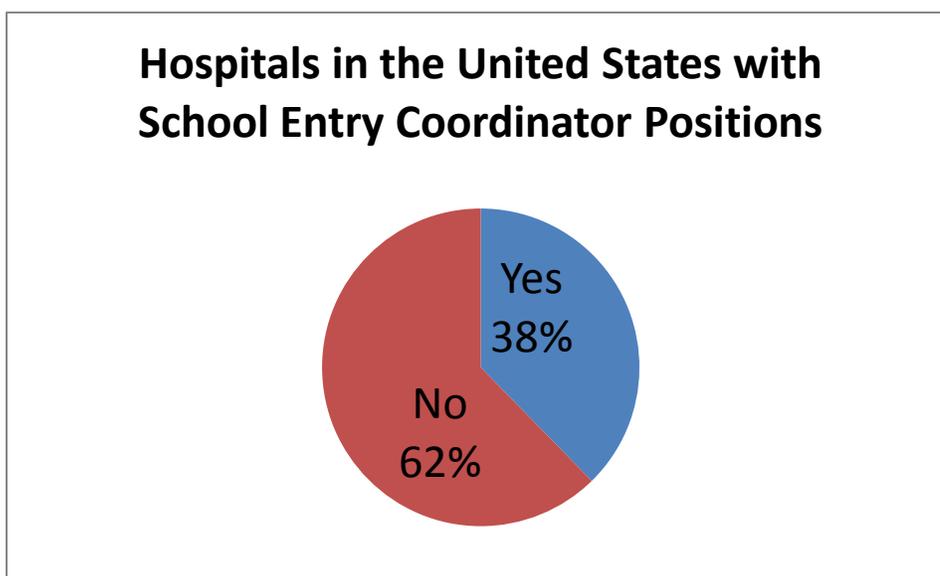
1. What is the name of your Institution?
2. What type of program do you have for school interventions? *(Check all that apply.)*
  - Hospital School
  - School Re-Entry Team
  - School Liaison
  - We don't have a school entry program.
3. What positions are involved in school interventions? *(Check all that apply.)*
  - Child Life
  - Social Work
  - Teachers
  - Psychologist
  - Nurse
  - Other(Please Specify)\_\_\_\_\_
4. What are the roles of each position in relation to school interventions? If you have a school entry/education coordinator, what roles are delegated to that position?
5. Are there positions designated specifically for school re-entry? If Yes, please specify.
6. Are there full time or part time positions for school re-entry?
7. What population is assisted in school re-entry at your institution? *(Check all that apply.)*
  - Oncology
  - Hematology
  - Cardiac
  - Other (Please Specify) \_\_\_\_\_
8. How many children do you typically assist in school re-entry each year?
  - 0-10
  - 10-20
  - 20-30
  - 30-40
  - 40+
9. What is the starting salary range for school re-entry positions?
  - Under \$30,000
  - \$30,000-\$40,000
  - \$40,000-\$50,000
  - \$50,000-\$60,000
  - \$60,000+
  - I would prefer not to share.
10. Is there any other information you would like to share regarding your program?

### Appendix B:

Collection of Data Based on Survey: Displaying Services Provided Annually at Hospitals throughout United States in 2012-2013

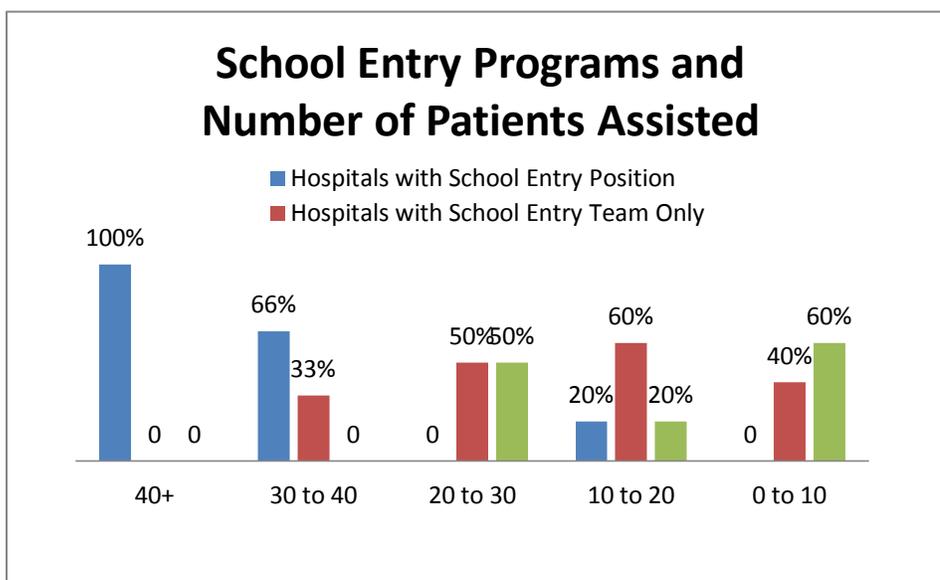
|            | Hospital School on Site | School Liason | School Entry Team | Support Hematology/Oncology Patients | Support Cardiac Patients | Support Other Populations | Assist over 30 Children a Year | School Entry Coordinator | School Visits |
|------------|-------------------------|---------------|-------------------|--------------------------------------|--------------------------|---------------------------|--------------------------------|--------------------------|---------------|
| Hospital A | ✓                       |               |                   | ✓                                    |                          |                           | ✓                              | ✓                        | ✓             |
| Hospital B |                         | ✓             | ✓                 | ✓                                    |                          |                           | ✓                              | ✓                        |               |
| Hospital C | ✓                       | ✓             | ✓                 | ✓                                    | ✓                        | ✓                         | ✓                              | ✓                        | ✓             |
| Hospital D | ✓                       | ✓             | ✓                 | ✓                                    |                          |                           | ✓                              | ✓                        | ✓             |
| Hospital E | ✓                       | ✓             |                   | ✓                                    |                          |                           | ✓                              |                          |               |
| Hospital F |                         |               | ✓                 | ✓                                    |                          |                           | ✓                              |                          | ✓             |
| Hospital G | ✓                       |               |                   | ✓                                    | ✓                        |                           |                                |                          | ✓             |
| Hospital H |                         |               | ✓                 | ✓                                    |                          |                           | ✓                              | ✓                        | ✓             |
| Hospital I | ✓                       |               |                   | ✓                                    | ✓                        | ✓                         |                                |                          | ✓             |
| Hospital J |                         | ✓             | ✓                 | ✓                                    |                          |                           |                                | ✓                        |               |
| Hospital K | ✓                       | ✓             | ✓                 | ✓                                    |                          |                           | ✓                              | ✓                        | ✓             |
| Hospital L | ✓                       |               |                   | ✓                                    | ✓                        |                           |                                |                          |               |
| Hospital M | ✓                       | ✓             | ✓                 | ✓                                    | ✓                        |                           |                                |                          | ✓             |
| Hospital N |                         |               | ✓                 | ✓                                    |                          | ✓                         |                                |                          | ✓             |
| Hospital O | ✓                       |               | ✓                 | ✓                                    |                          |                           |                                |                          | ✓             |
| Hospital P |                         |               | ✓                 | ✓                                    |                          | ✓                         |                                |                          | ✓             |
| Hospital Q |                         | ✓             | ✓                 | ✓                                    | ✓                        | ✓                         |                                |                          | ✓             |
| Hospital R | ✓                       | ✓             | ✓                 | ✓                                    | ✓                        | ✓                         |                                |                          | ✓             |
| Hospital S | ✓                       | ✓             | ✓                 | ✓                                    |                          |                           | ✓                              | ✓                        | ✓             |
| Hospital T | ✓                       |               |                   | ✓                                    | ✓                        | ✓                         |                                |                          |               |
| Hospital U | ✓                       | ✓             |                   | ✓                                    | ✓                        | ✓                         | ✓                              | ✓                        | ✓             |
| Hospital V |                         |               |                   | ✓                                    |                          |                           |                                |                          |               |
| Hospital W |                         |               | ✓                 | ✓                                    |                          |                           |                                |                          | ✓             |
| Hospital X |                         |               |                   | ✓                                    |                          |                           |                                |                          |               |

### Appendix C:



\*This chart displays percentage of hospitals reporting to have school entry coordinator positions (YES) and the percentage of those reporting no school entry coordinator position (NO).

### Appendix D:



\*This chart displays the percentage of hospitals with School Entry Positions, School Entry Teams Only and those that report having neither that support a specific number of patients each year. The results displayed include responses from 2012-2013.

## Appendix E:

### SAMPLE JOB DESCRIPTION

| 1. POSITION TITLE: School Entry Coordinator  |  |  |  |
|--|--|--|--|
| REPORTS TO: Director of Child Life DIVISION: Pediatrics<br>DEPARTMENT: Child Life  |  |  |  |
| 2. SUMMARY OF POSITION:<br>The School Entry Coordinator will provide support as part of an interdisciplinary team to efficiently deliver patient educational support, advocate for educational needs of patient and family, communicate with healthcare team and school system, and implement long term follow-up care plan. Using developmental assessment and knowledge, the School Entry Coordinator will anticipate potential risks in development and prepare all involved to prevent and address these concerns. |  |  |  |
| 3. QUALITATIVE DATA: Insert specific data to provide indication of the size of the area that this position will impact.  |  |  |  |
| 4. SPECIFIC DUTIES:  |  |  |  |
| ACTION   | REASON   | MEASUREMENT  | RELATED ACTION   |
| Assists in identifying education related problems for patient, family and school through maintaining evaluations from each member of psychosocial team.  | To identify effects of treatment and hospitalization.                  | Academic Performance of Patient.                       | Collaborate with multidisciplinary team to identify concerns and accommodations. |
| Is knowledgeable about child development and assesses patients prior to school entry and within long term follow up care.  | Ability to accurately assess will allow for appropriate interventions. | Decreased stress and anxiety related to school entry.  | Complete and document assessment completed by patient, family and school.        |
| Anticipate potential developmental risks and challenges children may face.   | To proactively address concerns before struggles develop.              | Successful progression through school and development. | Create intervention plans and educate families and staff on potential risks.     |
| Develop a family centered care plan with hospital staff, parents and school staff based on assessments of child's development,   | To improve patient behavior and performance.                           | Standards of Family Centered Care are implemented.     | Meetings with multidisciplinary team.  |

|  |  |   |   |
|--|--|---|---|
| temperament, coping style and support.   |  |   |   |
| Recognizes, addresses and utilizes therapeutic interventions to facilitate education and coping.               | To increase knowledge and reduce misconceptions of peers.<br>To reduce anxiety of patient related to school entry.       | Increased customer satisfaction.  | Conduct follow up assessments.                                |
| Understands Child Life, hospital and school policies and procedures pertinent to pediatric work.               | Maintain current policies and procedures for area, which are appropriate.<br>Collaborate with key appropriate personnel. | Policies and Procedures reflect current practice.                       | Comply with mandated trainings and reviews.                   |
| Makes clinical decisions based on theoretical knowledge of development and clinical experience.                | Assure best practice.  | Best Practice Standards are met through use of Child Life Competencies. | Collaborates with interdisciplinary team.                     |
| Facilitate meetings between psychosocial team, parents and school staff to discuss intervention plan.          | To maintain communication and consistency in regards to patient education.   | Consistent care plan for patient and family.                            | Attend meetings and provide proper documentation.             |
| Organize and implement administrative and classroom presentations.   | To educate school staff and peers on impact of late effects on patient/student.  | Increased understanding of effects of treatment.                        | Create presentations and transition books for classroom.      |
| Provide families and schools with proper documentation, and assist in completion.                              | To assure that paperwork is completed and understood.  | Paperwork completed in a timely manner.                                 | Maintain record of paperwork.                                 |
| Coordinate with family and school administration to attend IEP meetings with other members of psychosocial and | To ensure that all members are present at the meeting<br>To support families in advocating for patient                   | Proper accommodations included in 504 and IEP.                          | Provide family with proper information regarding IEP and 504. |

|   |  |  |  |
|---|--|--|--|
| medical team.   | accommodations.  |  |  |
| Coordinate with hospital, home bound and school teachers to maintain consistency in school work and expectations. | To assist parents in obtaining proper information.<br>To open the lines of communication between each member of educational team.      | Consistency in school work for patient.                                  | Follow up with patient, family and school teacher to ensure that needs are being met.                        |
| Conduct follow up evaluations with patient.   | To maintain that patient is receiving proper interventions<br>To evaluate the efficacy of the program and ensure patient satisfaction. | Increased patient satisfaction.  | Meet with family at follow-up meetings potential revisit to school.  |
| Collects clinical data to track.  | To provide data to prove efficacy of position.   | Proper documentation.  | Submits data to supervisor in a timely manner<br>Obtains data from other members of the team to add to data. |
| Support family in advocating for patients needs based on assessment and reported concerns.                        | To address family concerns in regards to school entry<br>To provide tools and education for family and patient to self advocate.       | Increased education and ability to self advocate.                        | Make proper referrals and provide resources.   |
| Acknowledges and adapts communication styles based on individual patient/family/school system needs.              | To ensure individual family needs are being met.   | Standards of Family Centered Care are implemented.                       | Adapts other aspects of interventions to patient and family communication style.                             |
| Participates in team meetings and/or discussions regarding patient care.  | To maintain consistency between team members to ensure each need is being met.   | Increased patient satisfaction<br>Increased communication between staff. | Schedule weekly meetings between interdisciplinary team.   |
| Provide topics for  | To provide   | Funding is   | Develop ideas for  |

|   |  |  |  |
|---|--|--|--|
| research, performance improvement.  | statistics and information to prove efficacy of program and expand department. | maintained and new opportunities are explored. | research<br>Participate in research and documentation. |
| <p>5. FREQUENT WORK CONTACTS AND PURPOSE:</p> <ul style="list-style-type: none"> <li>- Patients and Families: Support patients and families through treatment with assessment prior to intervention plan creation. Addressing concerns and anticipated risks related to development and education. Including patients and families maintains the family centered care approach. Patients and families will also assist in evaluating efficacy of program.</li> <li>- Physicians and Nursing: Support for teaching and treatment plan. Information provided by medical staff can assist in ability to assess future concerns. Medical staff can educate team and family on the diagnosis, treatment and side effects.</li> <li>- Interdisciplinary Team: Social work, teachers, psychologist, etc.: Treatment Plan Development based on assessments and evaluations of team.</li> <li>- Hospital School, Home School, Tutor etc.: To Coordinate and conduct meetings. To provide knowledge of development and late effects to reduce the impact of treatment on a child's school experience.</li> <li>-</li> </ul> |  |  |  |
| <p>6. OTHER INFORMATION: School Entry Coordinator must have BS/BA (Master's Preferred). Knowledge of child development is required. Must have ability to multi-task, work as member of inter-disciplinary team, time management skills, and strong customer service relations. Preferred Certified Child Life Specialist.</p>   |  |  |  |

### Appendix F:

| School Transition and Long Term Follow Up Checklist                         |                |          |
|---|----------------|----------|
|   | DATE COMPLETED | INITIALS |
| Release of information signed for school/hospital                           |                |          |
| School contacted to gather information/records                              |                |          |
| School contacted to schedule 504/IEP Meeting<br><br>SCHEDULED DATE: _____   |                |          |
| 504/IEP materials given to caregivers                                       |                |          |
| Meeting with caregivers to explain 504/IEP Process                          |                |          |
| School Recommendation Form  |                |          |
| Classroom Presentation  |                |          |
| Psychosocial Assessment   |                |          |
| PT/OT/SLP reports acquired  |                |          |
| Neuropsychology evaluation  |                |          |
| Neuropsychology report given to school                                      |                |          |
| 504/IEP Meeting at school   |                |          |
| Obtained copy of 504/IEP  |                |          |
| Administration Meeting with school and family                               |                |          |
| Program evaluations completed by School, Family and Patient (if applicable) | School         |          |
|   | Family         |          |
|   | Patient        |          |
| 1 month follow-up with assessment/concerns/recommendations                  |                |          |
| 3 month follow-up assessment/concerns/recommendations                       |                |          |
| 6 month follow-up assessment/concerns/recommendations                       |                |          |
| 9 month follow-up assessment/concerns/recommendations                       |                |          |
| 1 year follow-up assessment/concerns/recommendations                        |                |          |
| 2 year follow-up assessment/concerns/recommendations                        |                |          |
| 3 year follow-up assessment/concerns/recommendations                        |                |          |

## References

- American Cancer Society (2012a). Children Diagnosed with Cancer: Late Effects of Cancer Treatment. Retrieved from <http://www.cancer.org/treatment/childrenandcancer/whenyourchildhascancer/children-diagnosed-with-cancer-late-effects-of-cancer-treatment>.
- American Cancer Society. (2012a). Children Diagnosed With Cancer: Late Effects of Cancer Treatment. Retrieved from <http://www.cancer.org/treatment/childrenandcancer/whenyourchildhascancer/children-diagnosed-with-cancer-late-effects-of-cancer-treatment>.
- American Cancer Society. (2012b). Children Diagnosed with Cancer: Returning to School. Retrieved from: <http://www.cancer.org/treatment/childrenandcancer/whenyourchildhascancer/children-diagnosed-with-cancer-returning-to-school>
- American Cancer Society. (2012c). Children in Cancer. Retrieved from <http://www.cancer.org/acs/groups/cid/documents/webcontent/002287-pdf.pdf>
- Barrera, M., D'Agostino, N.M., Gibson, J., Malkin, D., Wayland, L., Weksberg, R. (2003). Developmental Differences in Psychological Adjustment and Health-Related Quality of Life in Pediatric Cancer Patients. *Children's Health Care*, 32(3), 215-232
- Bessell, A.G. (2001). Children Surviving Cancer: Psychosocial Adjustment, Quality of Life, and School Experiences. *The Council for Exceptional Children* 67(3), 345-359.
- Blew, B., Cherryl, L., Hubert, N., Katz, E.R., Rubenstein, L., Varni, J.W. (1992). Teacher, Parent, and Child Evaluative Ratings of a School Reintegration Intervention for Children with Newly Diagnosed Cancer. *Children's Health Care*, 21(2), 69-75
- Bradley-King, K.L., Sundman, A.N. (2010) Late Effects of Childhood Cancer: Implications for School Psychologists. *School Psychology Forum: Research in Practice*. 4(3), 13-24
- Brons, P.P.T., Caron, H.N., Grootenhuis, M.A., Last, B.F., Maurice-Stam, H., Oort, F.J. (2009). School-aged children after the end of successful treatment of non-central nervous system cancer: longitudinal assessment of health-related quality of life, anxiety and coping. *European Journal of Cancer Care* 18, 401-410.
- Challinor, J., Hutter, J., Kaemingk, K., Matthay, K., Moore, I.M., Pasvogel, A. (2003). Behavioral Adjustment of Children and Adolescents with Cancer. *Oncology Nursing Forum*, 30(5).
- Charlton, A., Jones, P.M., Lacombe, I.J., Meller, S., Mott, M.G., Walker, J. (1990). Impact of childhood cancer on return to normal schooling. 22, 378-382.

- Canter, K.S., Roberts, M.C. (2012). A Systematic and Quantitative Review of Interventions to Facilitate School Reentry for Children with Chronic Health Conditions. *Journal of Pediatric Psychology*.37 (10), 1065-1075.
- Chambers, A., Gray, J.D., Klinck, A.M., Rynard, D.W. (1998). School Support Programs for Chronically Ill Children: Evaluating the Adjustment of Children with Cancer at School. *Children's Health Care*.27 (1), 31-46.
- Chekryn, J., Deegan, M., Reid, J. (1987). Impact on Teachers When a Child with Cancer Returns to School. *Children's Health Care*, 15(3), 161-165.
- Child Life Council (2001a). Child Life Assessment: Variables Associated with a Child's Ability to Cope with Hospitalization. *Child Life Council Evidence-Based Practice Statement*. Rockville, MD: Child Life Council, Inc.
- Child Life Council (2001b). Child life competencies. In *Official Documents of Child Life* (pp.5- 8) Rockville MD: Child Life Council, Inc.
- Child Life Council (2001c). *Official Documents of Child Life*. Rockville MD: Child Life Council, Inc.
- Child Life Council (2002d). ). Standards for academic and clinical preparation programs. In *Official Documents of Child Life*. Rockville MD: Child Life Council, Inc.
- Children's Oncology Group (2007). Establishing and Enhancing Services for Childhood Cancer Survivors: Long Term Follow-Up Care Resource Guide. Retrieved from <http://www.survivorshipguidelines.org/pdf/LTFUResourceGuide.pdf>
- Crain, W. (2000). *Theories of development: Concepts and applications* (4<sup>th</sup> Ed.). Upper Saddle River, New Jersey: Prentice-Hall.
- Eiser, C., Vance, Y.H. (2001). The school experience of the child with cancer. *Child Care, Health & Development*, 28(1), 5-19.
- Erikson, E. (1963). *Childhood and society* (2<sup>nd</sup> Ed.). New York: W.W. Norton.
- Gaynard, L., Wolfer, J., Goldberger, J., Thompson, R., Redburn, L., & Laidley, L. (1998). Research Project. Rockville, MD: Child Life Council, Inc.
- Hara, J., Iwata, Y., Jeruss, S., Mayer, D.K., Nakagawa, K., Parsons, S.K., Saiki-Craighill, S., Terrin, N., Tighiouart, H. (2005). School re-entry after a cancer diagnosis: physician attitudes about truth telling and information sharing. *Child: Care, Health & Development*, 31(3), 355-263.
- Katz, E.R., Varni, J.W. (1997). Stress, Social Support and Negative Affectivity in Children with Newly Diagnosed Cancer: A prospective Transactional Analysis. *Psycho-Oncology*, 6, 267-785.
- Kim, D.H., Yoo, I.Y. (2010). Factors associated with resilience of school age children with cancer. *Journal of Paediatrics and Child Health*.46, 431-436.

- Miller, P.H. (2002a). *Theories of developmental psychology*. (4<sup>th</sup> ed., pp. 25-104). New York: Worth
- Miller, P.H. (2002b). *Theories of developmental psychology*. (4<sup>th</sup> ed., pp. 367-420). New York: Worth
- Thompson, R. (2009). *The handbook of child life: guide for pediatric psychosocial care*. Springfield, IL: Charles C Thomas Publisher, LTD.
- Vygotsky, L.S. (1978). *Mind in society*. Cambridge: Harvard University Press.