THE RELATIONSHIP BETWEEN POST-TREATMENT INTELLECTUAL FUNCTIONING AND LONG-TERM SOCIAL FUNCTIONING IN SURVIVORS OF PEDIATRIC CANCER

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Ann Arbor, MI

2001

Submitted to the Faculty of the Graduate College of the Oklahoma State University in partial fulfillment of the requirements for the Degree of MASTER OF SCIENCE May, 2007

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ACKNOWLEDGEMENTS

I would first like to thank my primary advisor and mentor, Dr. Larry L. Mullins, for his ongoing support and encouragement. You have changed the person I want to become both personally and professionally and have showed me by example that it is completely possible to be successful in your career while still maintaining a balanced life. You have taught me so much about myself and have helped to strengthen any weaknesses I have felt during graduate school. I do not think I could ever really thank you for all you have done! I would also like to extend a special thank you to the other members of my committee, Drs. Jennifer L. Callahan and John M. Chaney. Thank you both for your support and guidance throughout my graduate school experience. I have relied on you so much and I truly appreciate you "giving me a home" at OSU.

At this time, I would also like to thank my family for their love and encouragement. Mom, Dad, and Jordan, I would not be where I am today without the three of you. You all loved me and believed in me when I did not believe in myself.

Although many miles separate us, I know you are all only a phone call or plane ride away.

Most of all, I would like to thank Kyle for his patience and love. No one else truly knows what the past 2 ½ years have been like, and you have been there every step of the way. You have been my "rock" and my source of unconditional love and encouragement. I love you very much and I cannot wait to see what the future has in store for us!

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CHAPTER 1

INTRODUCTION

Pediatric cancer is the leading cause of death by disease in children ages 1 – 14 (National Cancer Institute [NCI], 2005). It is estimated that in the United States alone, approximately 9,500 children will be diagnosed with cancer and about 1,560 will die from the disease in 2006 (American Cancer Society [ACS], 2006). Notably, five-year survival rates for pediatric cancer have dramatically improved over the past three decades, increasing from less than 50% before the 1970s to 79% currently for all pediatric cancers combined (ACS, 2006). However, this increase in survivorship has resulted in greater numbers of children and adolescents being at risk for the long-term effects of their illness.

Although there are 12 major types of childhood cancer, leukemia and brain malignancies account for more than half of the newly diagnosed cases (NCI, 2005). It is well documented that brain tumors and leukemia in childhood are associated with long-term cognitive, neurobehavioral, and psychosocial deficits; however, the contributing factors for these consequences are not well understood (Carpentieri, Mulhern, Douglas, & Fairclough, 1993; Lannery, Marky, & Ollsom, 1990; Mulhern, 1994). Since the five-year survival rate for childhood brain tumors has dramatically increased to 60%, and the survival rate for childhood leukemias is approximately 80% (Ries, et al., 1999), research on the long-term effects of these diseases is critical for improving the quality of life for childhood cancer survivors. The extant literature on childhood cancer suggests that over

time, the majority of pediatric cancer survivors typically exhibit emotional, behavioral, and psychosocial functioning relatively comparable to that of their peers (Noll, Bukowski, Davies, Koontz, & Kulkarni, 1993; Noll, Bukowski, Rogosch, LeRoy, & Kulkarni, 1990; Noll, et al., 1999), at least when assessed by broadband measures of adjustment. However, research has identified sub-groups of survivors with higher chances of adverse psychological sequelae of their illness. Children with brain tumors and those who experience insult to their central nervous system (CNS) as a result of cancer, or as a consequence of the treatment for cancer, have been shown to be at considerably higher risk for adverse psychosocial outcomes (e.g., Mulhern, 1994). Specifically, studies have documented lower levels of social competence in childhood brain tumor survivors when compared to survivors of other types of pediatric cancer as well as healthy controls (Carpentieri, Mulhern, Douglas, & Fairclough, 1993; Foley, Barakat, Herman-Liu, Radcliffe, & Molloy, 2000). Other research has consistently demonstrated deficits in social functioning, including increased social isolation in brain tumor survivors compared to healthy controls (Mulhern, Carpentieri, Shema, Stone, & Fairclough, 1993; Mulhern, Hancock, Fairclough, & Kun, 1992).

Although deficits in the social competence of childhood survivors of cancer with CNS-involvement have been replicated in several studies, the majority of this research has utilized parent-reported levels of social competence and has neglected the use of self-report measures. Additionally, social competence has typically been assessed in broad terms, with studies frequently neglecting to assess specific dimensions of social functioning, such as loneliness, social dissatisfaction, perceived social competence, and social support. Thus, the current study will combine both parent and self-report data to

address perceptions of overall emotional, behavioral, and social functioning, including loneliness, perceived social support, and social competence in survivors of pediatric cancer with and without CNS-involvement. For purposes of the current study, the group of survivors of pediatric cancer with CNS-involvement was comprised solely of children who were diagnosed with brain tumors, while the non CNS-involvement group was comprised of all other pediatric diagnoses.

The current study is guided by two specific aims:

Aim 1 - To determine whether deficits in post-treatment intellectual functioning are related to current ratings of: a) self-reported loneliness and social dissatisfaction, b) perceived social competence, c) perceived social support, d) parent-report of emotional and behavioral functioning, and e) self-report of emotional functioning and personal adjustment in survivors of pediatric cancer

Aim 2 - To determine whether survivors of childhood cancer with CNS-involvement differ from survivors of childhood cancer without CNS-involvement on measures of self-reported loneliness and social dissatisfaction, perceived social competence, and social support.

To address Aim 1, it was hypothesized that children and adolescents who evidence greater deficits in post-treatment intellectual functioning, as measured by verbal IQ and performance IQ, would be rated by their parents as having higher levels of later emotional, behavioral, and psychosocial difficulties, and would self-report higher levels of loneliness and social dissatisfaction, lower levels of social support and social competence, and more emotional and behavioral distress.

With regard to Aim 2, it was hypothesized that survivors of childhood cancer with CNS-involvement would self-report higher levels of loneliness, and lower levels of social competence and social support as compared to survivors of cancer without CNS-involvement.

An additional research question that was explored in the current study was an examination of whether child self-reports of loneliness and social dissatisfaction were consistently associated with parent-report of the child's loneliness and social dissatisfaction.

CHAPTER II

REVIEW OF THE LITERATURE

Chapter Overview

The following is a review of the extant literature relevant to the proposed project. This review is divided up into four major sections. The first section will focus on the nature of pediatric cancer and will include a discussion of the classification of childhood cancer, incidence, prevalence, and mortality rates, treatments, and specific types of brain tumors and leukemia. The second section will provide a brief overview of the literature on psychosocial functioning, including a discussion of the constructs of peer relationships, peer acceptance, and loneliness in childhood. The third section will focus on the specific impact of cancer on psychosocial functioning, including social adjustment, social competence, and social support. Finally, the chapter will conclude with a brief overview of the cognitive and neuropsychological effects of childhood cancer and treatment.

The Nature of Pediatric Cancer

<u>Classification.</u> Childhood cancer is not a single disease, but rather a spectrum of different malignancies, which can vary by type of histology, site of disease origin, race, sex, and age (Ries, Percy, Bunin, 1999). In contrast to the classification of cancer in adults, childhood cancer is classified by morphology, rather than by primary site (Steliarova-Foucher, Stiller, Lacour, & Kaatsch, 2005). Although the majority of

childhood cancers follow this pattern, brain tumors are often classified differently. They can be described based on histology (e.g., astrocytoma, glioma), site (e.g., supratentorial, infratentorial), or a combination of the two (e.g., brainstem gliomas) (Ris & Noll, 1994). This discrepancy in nomenclature led to the development of the International Classification of Childhood Cancer (ICCC-3), which standardizes the classification of cancer for purposes of international comparison (Steliarova-Foucher et al., 2005). The ICCC-3 is based on the International Classification of Diseases for Oncology (ICD-O) and categorizes childhood cancer in a hierarchical manner. The main classification table contains levels 1 (12 main diagnostic groups) and 2 (47 diagnostic subgroups). The extended, optional, classification is contained in level 3, where selected diagnostic subgroups are further differentiated. Please refer to Appendix A for an illustration of the current classification system.

<u>Incidence</u>, <u>Prevalence</u>, and <u>Mortality</u>:

Cancer is the leading cause of death by disease in children ages 1 – 14 (National Cancer Institute [NCI], 2005). It was estimated that in 2005, approximately 9,510 children would be diagnosed with cancer and about 1,585 would die from the disease within the United States (American Cancer Society [ACS], 2006). Furthermore, although there are 12 major types of childhood cancer, leukemia and brain malignancies account for more than half of the newly diagnosed cases (NCI, 2005).

Over the past two decades, it appears that CNS cancer incidence in children has increased slightly, although explanations for this trend are unclear. It has been suggested that exposure to environmental toxins may explain this increase, although evidence from epidemiological studies is scant (Gurney, Smith, & Bunin, 1999). Other researchers have

proposed that this increase in incidence rate can be attributed to better diagnostic technology, which would suggest that cases previously overlooked are now being detected.

Leukemia Incidence and Prevalence.

Leukemia is the most frequently diagnosed cancer of childhood, accounting for 31% of all cancers in children younger than 15 years old and 25% of cancer cases in people younger than 20. There are approximately 3,250 children diagnosed with leukemia every year in the United States; of these cases 2,400 are of the Acute Lymphoblastic Leukemia (ALL) subtype. ALL accounts for nearly 75% of all leukemia cases in children younger than 15, and Acute Myeloid Leukemia (AML) accounts for an additional 16%.

Based on the data collected by the Surveillance, Epidemiology and End Results Program (SEER) of the National Cancer Institute between 1986 and 1994, the incidence of leukemia varies considerably by age. The incidence of ALL peaks between 2 and 3 years of age (80 per million), but then declines to 20 per million between the ages of 8 and 10. This drastic increase between 2 and 3 years of age is four times greater than the incidence of ALL in infancy, and 10 times greater than the incidence at 19 years old. In contrast, the incidence of AML peaks during the first 2 years of life (12 per million), then declines during the school age years and slowly increases during adolescence. With regard to sex differences, in children younger than 15, ALL occurs in males 20% more often than in females. Between 15 and 19, this difference increases dramatically, with males' incidence of ALL twice that of females.

Brain Tumor Incidence and Prevalence

Malignancies of the Central Nervous System (CNS) account for 16.6% of all malignancies in childhood and adolescence. Annually it is estimated that in the United States, 2,200 children and adolescents under the age of 20 are diagnosed with invasive CNS tumors. CNS cancers are the second most frequent malignancy of childhood (after leukemia), accounting for the most solid tumors. Specifically, 52% of CNS malignancies are accounted for by astrocytomas, 21% by primitive neuroectodermal tumors (PNET), 15% by other gliomas and 9% are accounted for by ependymomas.

Based on the SEER data collected between the years of 1986-1994, the incidence rate of CNS malignancies with regard to age at diagnosis was stable between infancy (36.2 per million) and 7 years of age (35.2 per million), decreased by 40% between the ages of 7 and 10 (21.0 per million), remained fairly consistent between the ages of 11 and 17, and decreased dramatically at age 18. With regard to sex differences, males suffered from PNET and ependymomas significantly more than females; no differences in incidence rates between sexes were seen for the other types of tumors.

In contrast to older children and adults, young children have a higher occurrence of malignancies in the brainstem and cerebellum. Specifically, for children under the age of 10, the occurrence of brainstem malignancies was almost as common as cerebral malignancies, and malignancies of the cerebellum were much more common than malignancies of the cerebrum.

Mortality.

Although increases in childhood cancer incidence occurred between 1975 and 1995, mortality rates of childhood cancer decreased dramatically during this time. There

were significant declines in each of the five age groups (<5, 5-9, 10-14, and 15-19) for all cancers combined. Overall, between 1975 and 1995, deaths from leukemia declined nearly 50% and mortality rates from brain and other CNS cancers declined 32%.

Currently, the 5 year survival rate for all pediatric cancers combined is approximately 75% (NCI, 2002).

Treatment for Pediatric Cancer

The dramatic increase in survival rates for childhood cancer that has occurred over the past four decades is a direct result of clinical research. Originally, this research was conducted by four primary pediatric research groups in North America: the Children's Cancer Group (CCG), the Pediatric Oncology Group (POG), the National Wilms' Tumor Study Group (NWTSG), and the Intergroup Rhabdomyosarcoma Study Group (IRSG). In 2000, the four groups officially merged to form the Children's Oncology Group (COG), a single organization for clinical trials of pediatric cancer (COG, 2005). The COG is comprised of pediatric surgeons and oncologists, neurologists, radiation oncologists, psychologists, researchers, and nurses who work together to develop the worldwide standard of care for pediatric cancer patients, in addition to conducting new studies to discover more effective therapies (Shiminski-Maher, Cullan, & Sansalone, 2002). To facilitate the development of new treatments, all sites participating in COG trials submit diagnostic, treatment, and follow-up data to the COG research center, where they are combined with patients from other sites to create larger samples of homogenous diagnoses. The COG (2005) notes that this coordination of data collection allows new therapies to be developed "hundreds of times faster" than they could be developed in individual cancer centers.

In general, when a child is diagnosed with pediatric cancer, the family is given the choice to participate in a clinical trial sponsored by COG, or to receive the current standard care for the diagnosis. The COG (2005) reports that there are currently over 40,000 pediatric cancer patients enrolled in 150 clinical trials in more than 230 participating medical institutions. The purpose of these clinical trials is to compare new treatments with the standard therapy for a particular diagnosis. Therefore, each patient is randomized into either the *standard care arm* or *experimental arm* of a specific trial with the hope that the experimental arm will prove to be either more effective or less toxic than the current standard care. Once enrolled in a clinical trial, each patient receives a treatment protocol, called a *roadmap*, which serves as a timeline for the therapy and provides the patient with information regarding all of the drugs, dosages, and tests involved in each segment of the trial and follow-up. If at any point during the trial it becomes apparent that one treatment is significantly better than the other, the trial is terminated and all enrolled patients receive the superior treatment.

Types of Treatment:

The most common types of treatment for pediatric cancer include surgery, radiation, chemotherapy, and stem cell transplantation. Various aspects of some or all of these therapies are combined for the treatment of a specific diagnosis. The typical therapy combinations for different types of brain tumors and leukemia will be discussed in the next section. Importantly, the actual treatment for a particular diagnosis depends on a wide variety of factors, including: the histology, stage, and location of the malignancy, and the child's age at diagnosis. These treatments will be briefly summarized below.

Surgery. Surgery plays a vital role in the treatment of solid tumors and tumors of the CNS, since the ultimate goal of these malignancies is the total removal of the tumor mass (Shochat & Hayes-Jordan, 2000). There are a variety of surgical techniques that can be employed throughout the course of treatment. Some of the most common include biopsy, debulking, surgical resection, and surgical treatment of hydrocephalus.

A biopsy involves removing a piece of the tumor through a small incision.

Biopsies can be used to help diagnose a tumor when it is located deep within the brain or brainstem and because of its location relative to vital functions, more aggressive surgery is not possible. The piece of the tumor that has been removed is then used to diagnose and stage the tumor.

Surgical debulking involves removing a portion, usually 40% to 70%, of the tumor (Shochat & Hayes-Jordan, 2000). Debulking is used when the tumor is located either: 1) deep within the brain; 2) close to a blood vessel; or 3) growing from the brainstem. In these instances, a total removal of the tumor would be too dangerous; thus, the goal of the surgery is to reduce symptoms, such as intracranial pressure, that are being caused by the tumor (Shiminski-Maher, Cullen, & Sansalone, 2002).

Maximal surgical resection is the ultimate goal of treatment of brain tumors of the CNS and involves the complete removal of the tumor. Shiminski-Maher and colleagues (2002) point out that unlike tumors in other areas of the body, such as the intestines, tumors in the CNS cannot be removed with wide margins because of the vital structures throughout the brain and in the spinal cord. Therefore, while maximal surgical resection is optimal, it is not always possible.

Finally, surgery can be used to reduce the intracranial pressure that results from hydrocephalus. Hydrocephalus occurs when a tumor blocks the normal flow of cerebrospinal fluid (CSF) causing the fluid to build up in the brain. In order to treat this condition, the surgeon inserts a ventriculostomy into the brain, which shunts the excess CSF from the brain into a bag located outside of the body. The ventriculostomy is usually removed a few days after it is placed (Shiminski-Maher, Cullen, & Sansalone, 2002).

Radiation Therapy. Radiation therapy is one of the oldest and most effective treatments for cancer. Over 100 years ago, it was discovered that radiation had the ability to destroy both cancerous and healthy tissue. Therefore, it was used to destroy tumors as well as the normal tissue that surrounds them. In contrast to the tumor cells, the normal tissue was able to repair itself after it had been damaged (Merchant, 2000). Radiation therapy was developed long before chemotherapy and continues to be an integral part of pediatric cancer therapies, playing a vital role in the treatment of CNS tumors as well as leukemia. Radiation therapy directs high-energy x-rays at specific areas of the body to destroy tumor cells. It is extremely effective in both reducing the size of the tumor as well as decreasing pain, but can also cause short-term side effects and sometimes permanent damage (Shiminski-Maher, Cullen, & Sansalone, 2002). Specifically, one of the most severe complications of radiation therapy is radiation-induced brain injury, which is most pronounced during the early childhood years and is the major limitation in using high-dose radiation (Strother et al., 2002). One of the most difficult aspects of using radiation therapy is determining the smallest amount of radiation that can be used without jeopardizing the cure rate.

Prior to beginning radiation therapy, the child will undergo *simulation*, a process that includes taking precise measurements and using technical x-rays to determine the exact area to be treated. With regard to the treatment of tumors in the CNS, radiation therapy consists of a particular dose of whole-brain radiation combined with an increased dose, or *boost*, to what is referred to as the tumor bed. The dose of radiation is measured in centrigrays (cGy) and is usually administered daily, excluding weekends, for a specified length of time. For example, in the treatment of medulloblastoma, the current COG protocol requires 2340 cGy of craniospinal radiation and doses between 5400 and 5550 cGy to the posterior fossa tumor bed, while the standard care for sPNET involves 3600 cGy of craniospinal irradiation and a boost of 5400 cGy to the area of the primary tumor (Strother et al., 2002).

In contrast to radiation therapy for CNS tumors, the therapy for leukemia often involves craniospinal irradiation for ten days. Additionally, males with leukemic cells in the testes will receive 2400 cGy to both testes, administered in 200 cGy doses for 12 days. Finally, total body irradiation (TBI) is occasionally employed prior to bone marrow transplantation.

<u>Chemotherapy.</u> The goal of typical pharmacotherapy is symptom reduction, not necessarily curing the underlying disease; however, this conventional approach cannot be applied to childhood cancer (Balis, Holcenberg, & Blaney, 2002). Instead, as described by the *killing paradigm*, anticancer drugs are developed with the ability to differentiate between normal host cells and cancer cells; once they have identified the cancer cells, they *kill* those cells throughout the body (Schipper, Goh, & Wang, 1995). The use of these anticancer drugs is referred to as *chemotherapy*. Although chemotherapy can

consist of a single drug, research clearly demonstrates that the combined use of several drugs, given in a specific order, results in much higher cure rates (Strother, 2002).

There are seven groups of chemotherapy drugs (e.g., alkylating agents, antimetabolites, antibiotics, alkaloids, hormones, enzymes, and anti-angiogenesis agents) that all affect cancer cells in very different ways (Shiminski-Maher, Cullen, & Sansalone, 2002). However, for purposes of brevity, only the most commonly used drugs for the treatment of brain tumors and leukemia will be mentioned. The reader is directed to Strother et al. (2002) for a complete review of current chemotherapy treatments. Alkylating agents (e.g., Cytoxin, Cisplatin, and Carboplatin) destroy cancer cells by interacting with DNA to prevent cell reproduction; whereas antimetabolites (e.g., Methotrexate) replace essential cell nutrients that are necessary for the synthesis phase of reproduction, therefore starving the cell. Additionally, alkaloids (e.g., Vincristine) are derived from plants and interrupt cell reproduction in a variety of ways, including interfering with DNA synthesis and weakening of the cell membrane to cause cell death. Finally, hormones (e.g., Prednisone) create an uncomfortable environment, which slows cell growth.

Chemotherapy can be administered in a variety of ways, including intravenous, intramuscular, intrathecal injections, or by mouth. Unlike surgery and radiation, chemotherapy has the ability to immediately affect cancer cells throughout the entire body since it travels via the circulation system. Although exposing the entire body to these drugs can be very beneficial, chemotherapy puts the child at risk for neurotoxicity and various other side effects including excessive nausea and vomiting, hair loss, shaking

or chills, and pain or swelling at the injection site (Shiminski-Maher, Cullen, & Sansalone, 2002).

Stem Cell Transplantation. Stem Cell Transplantations (i.e., Bone Marrow Transplants) are frequently used to treat children who have relapsed following the standard treatment, which included chemotherapy and/or radiation. These transplants are most frequently used in the treatment of leukemia, although they can be beneficial for children with brain tumors as well as other forms of pediatric cancer. In a stem cell transplant, the child undergoes intensive high-dose chemotherapy and/or radiation, which can permanently damage the bone marrow. To counteract this damage, the child can be infused with their own healthy stem cells (i.e., Analogous Transplant), or healthy stem cells from a donor (i.e., Allogeneic Transplant). These transplanted cells will travel to the child's bone marrow and begin to produce normal blood cells.

There are a wide range of side effects that can occur after a stem cell transplant. Specifically, patients who undergo stem cell transplants are highly susceptible to infection since their immune system has been destroyed by the chemotherapy and radiation. Until the transplanted stem cells engraft and begin to produce large numbers of healthy white blood cells, the child is at high-risk for infection; which is most frequently caused by bacteria inside the body (Keene, 2002). One if the most serious side effects of stem cell transplants is the development of *Graft-versus-Host Disease (GVHD)*, which occurs when the transplanted cells from the donor (i.e., *graft*) attack the tissues and organs of the transplant recipient (i.e., *host*).

Types of Brain Tumors

Due to the heterogeneity of childhood brain tumors, the International Classification of Childhood Cancer (ICC-3) has developed six sub-categories of *CNS and miscellaneous intracranial and intraspinal neoplasms* (Steliarova-Foucher, Stiller, Lacour, & Kaatsch, 2005). A complete review of each of these categories is beyond the scope of this project, and the reader is directed to Strother et al., 2002 for this information. For purposes of the current project, the four most common types of brain tumors (i.e., *astrocytoma*, *primitive neuroectodermal tumor* (*PNET*), *ependymoma*, and *brain stem glioma*) will be discussed.

Astrocytomas are the most common type of childhood brain tumors, accounting for 52% of CNS malignancies (Gurney, Smith, & Bunin, 1999). Seventy to seventy-five percent of cerebellar astrocytomas occur in childhood (Campbell & Pollack, 1996), mostly during the first decade of life. Additionally, boys are more often affected than girls; the average age at diagnosis ranges from 6.5 to 9.0 years (Smoots, Geyer, Lieberman, & Berger, 1998).

Astrocytomas arise from astrocyte cells, as either slow-growing (i.e., low-grade) or fast-growing (i.e., high-grade) tumors, and can develop anywhere in the brain and spinal cord (Shiminski-Maher, Cullen, & Sansalone, 2002). Approximately 80% of astrocytomas develop as slow growing, low-grade tumors (LGA), such as *juvenile pylocytic astrocytomas (JPA)*, *oligodendrogliomas*, *mixed gliomas*, and *gangliogliomas*. These slow-growing tumors arise supratentorially in the cerebral hemispheres and infratentorially in the cerebellum of the brain, in addition to the spinal cord. In general, LGA are generally histologically more benign than high-grade tumors and are treated

with surgery alone when they are located in the cerebral hemispheres or cerebellum. In contrast, LGA that are deep within the brain (e.g., *optic pathway* or *hypothalamic gliomas*) are treated with chemotherapy and radiation because surgery is not possible due to their location. Additionally, LGA comprise 75% of all childhood spinal cord tumors. Tumors in the spinal cord are usually treated with multiple surgeries, followed by radiation for tumors that continue to grow after surgery. Neuroaxial spread of LGA is very uncommon, and occurs in less than 5% of cases (Gajjar et al., 1997).

The remaining 20% of astrocytomas arise as fast-growing, high-grade tumors such as *anaplastic astrocytomas*, *glioblastoma multiforme*, and *gliomatosis cerebri*. They occur most often in the brainstem or cerebrum and infrequently occur in the spinal cord. These high-grade tumors are highly malignant and are difficult to cure. They are treated with aggressive therapies including surgery followed by multiagent chemotherapy and radiation. The chemotherapy prescribed for high-grade astrocytomas might include high-dose chemotherapy followed by a peripheral blood stem cell transplant (PBSCT) (Strother et al., 2002). In contrast to low-grade astrocytomas, neuroaxial dissemination of high-grade tumors occurs in 25% - 50% of cases (Marchese & Chang, 1990).

Based on the most recent SEER data, the 5-year survival rate for astrocytomas as a whole is 78.6% (NCI, 2002). However, the survival rates vary drastically depending on the type and location of the tumor, with LGA with incomplete resection and high-grade tumors having dramatically lower rates of survival than LGA with complete resection (Strother et al., 2002).

Primitive neuroectodermal tumor (PNET) is the broad name given to embryonic tumors of the CNS. Great controversy has surrounded the classification of these tumors

because all PNETs are histologically similar, but are named differently based on location. This is in direct contrast to the usual classification of pediatric tumors of the CNS, which is generally based on histology. Thus, PNET that occur supratentorially are classified as sPNET, and those that arise in the cerebellum (posterior fossa) are given the diagnosis of *medulloblastoma*, even if the tumors are histologically similar. Overall, sPNETs are rare in childhood, only accounting for 2.5% to 6.6% of CNS tumors (Pollack, 1994; Yang, Nam, Wang, Kim, Chi, & Cho, 1999). Standard therapy for sPNET includes surgical resection followed by craniospinal radiation. Chemotherapy has been added to the treatment for sPNET in several studies, but the results have been inconclusive with regard to its effectiveness (Strother et al., 2002). The 3-year survival rate for children with sPNET is approximately 61% for pineal tumors, but 33% for tumors in all other areas, regardless of the treatment employed (Dirks, Harris, Hoffman, Humphreys, Drake, & Rutka, 1996).

The most frequently occurring PNET is medulloblastoma, which is the most common malignant brain tumor of childhood and alone accounts for approximately 20% of primary pediatric tumors of the CNS (Strother et al., 2002) and 40% of posterior fossa lesions (Shiminski-Maher & Wisoff, 1995; Heideman, Packer, Albright, Freeman, & Rorke, 1997; Strother et al., 2002). Although medulloblastomas usually arise in the vermis of the cerebellum, they can quickly grow and extend into the cerebellar hemispheres, fourth ventricle, and brainstem, causing secondary complications such as hydrocephalus (Shiminski-Maher, Cullen, & Sansalone, 2002; Strother, 2002). The peak age of incidence for medulloblastoma is between 3 and 4 years old, with the majority arising within the first decade of life. With regard to sex differences, males are one-and-a

half to two times more likely to develop medulloblastomas than females (Gurney, Smith, & Bunin, 1999). Additionally, medulloblastoma has the greatest tendency for extraneural spread of all pediatric CNS neoplasms. Some studies from smaller institutions report this spread in 25-30% of cases, although larger studies have reported it in less than 4% of cases (Tarbell et al., 1991). When metastasis does occur, bone is the most common site, accounting for 80% of such cases, with bone marrow, lymph nodes, liver and lungs as other common sites (Strother et al., 2002).

Medulloblastomas are categorized into two groups: standard-risk and high-risk (Shiminski-Maher, Cullen, & Sansalone, 2002). Tumors that have undergone complete surgical resection and have not spread to other parts of the CNS are considered *standard-risk*. The treatment for standard-risk tumors includes surgery followed by chemotherapy and craniospinal radiation. In contrast, *high-risk* tumors are those that either: 1) have not been completely resected; 2) have spread to other parts of the CNS; or 3) are diagnosed in a child younger than 3 years old. High-risk medulloblastoma are treated with surgery, followed by craniospinal radiation and aggressive chemotherapy, and in some cases may include a PBSCT (Shiminski-Maher, Cullen, and Sansalone, 2002). The 5-year survival rate for children with medulloblastoma is 59.6% (NCI, 2002).

Ependymomas account for 9% of primary childhood tumors of the CNS (Gurney, Smith, & Bunin, 1999) and most often arise within or next to the ependymal lining of the ventricular system or within the central canal of the spinal cord (Strother et al., 2002). Ninety percent of ependymomas are intracranial, with nearly two-thirds arising in the posterior fossa. The highest incidence of these tumors occurs in the first seven years of life (Gurney, Smith, & Bunin, 1999); recent studies have found a 1.3-2.0 male-to-female

ratio in occurrence. Ten percent of ependymomas occur in the spinal cord, where they account for 25% of all spinal cord tumors. In contrast to intracranial tumors, spinal cord tumors rarely occur before the age of 12 (Heideman, Packer, Albright, Freeman, & Rorke, 1997). Although systemic metastasis of ependymomas is uncommon, tumors in the posterior fossa will frequently invade the brainstem, and a third of those cases will involve the medulla and upper spinal cord (Strother, 2002).

Ependymomas, like other types of CNS neoplasms, can occur as either low-grade (i.e., ependymoma) or high-grade (i.e., anaplastic ependymoma) tumors. The treatment for ependymomas usually includes surgery followed by radiation. Chemotherapy has been used in some cases, with platinum agents appearing to have the most effect, but does not appear to greatly affect overall survival rates (Bouffet & Foreman, 1999). Children with ependymomas have a 5-year survival rate of 62.8%, although this rate is lower for anaplastic ependymomas (NCI, 2002).

Finally, 15% of CNS malignancies are accounted for by brain stem gliomas (Gurney, Smith, & Bunin, 1999). The median age of occurrence for brain stem gliomas is 6 to 7 years old, with males and females equally affected (Strother, 2002). Notably, brain stem gliomas appear to occur more frequently in people with neurofibromatosis type 1 (NF-1). The term *brain stem glioma* encompasses a wide range of neoplasms, which are often subclassified based on either histology or location (e.g., *pontine glioma*, *diffuse glioma*) (Barkovich et al., 1991). Generally, brain stem gliomas can be categorized as either diffuse or focal, with the former have a poorer prognosis. *Diffusely infiltrative brainstem gliomas* are highly malignant, most often arising in the ventral pons and surrounding the basilar artery, which renders them ineligible for surgical resection

(Fisher et al., 2000). Thus, these tumors are frequently treated with radiotherapy, although this usually does not result in long-term survival (Strother et al., 2002). The median survival for children with diffusely infiltrative brainstem gliomas is less than 1 year, even with increased doses of radiation and the addition of chemotherapy (Freeman et al., 1998; Freeman & Perilongo, 1999). Focal brainstem tumors, on the other hand, are well-circumscribed without evidence of infiltration. They occur most frequently in the midbrain or medulla, rather than in the ventral pons. For these types of tumors, the treatments vary and depend on both the histology and location of the particular tumor. In general, treatment may include radiotherapy alone, surgery followed by radiotherapy, or the possibility of cerebrospinal fluid (CSF) diversion with observation (Strother et al., 2002). To date, there is no evidence that the inclusion of either single or multiagent chemotherapy will improve long-term survival of children with focal brainstem gliomas. Overall, focal brainstem gliomas have a 5-year survival rate of 58.5% (NCI, 2002); with the survival rate of children with diffusely infiltrative brainstem gliomas significantly lower, as previously discussed.

Types of Leukemia

Based on the International Classification of Childhood Cancer (ICC-3), there are six subtypes of *Leukemia*, *myeloproliferative diseases*, and *myelodysplastic diseases*. Leukemia can be broadly classified as acute, which has a fast progression (e.g., *Acute Lymphoblastic Leukemia* and *Acute Myelogenous Leukemia*) or chronic, which has a slower progression (e.g., *Chronic Myeloid Leukemia* and *Juvenile Myelomonocytic Leukemia*). Since chronic leukemia accounts for less than 5% of all childhood cancers (Keene, 2002), the current project will focus on children with diagnoses of acute

leukemia. Leukemia arises in the bone marrow and is considered a disease of the blood in which immature white blood cells, referred to as *blasts*, rapidly reproduce without the ability to develop into normal white cells. In a healthy body, blasts account for less than 5% of blood cells in the bone marrow and do not enter the bloodstream, but a child with leukemia can have a trillion blasts in both their bone marrow and bloodstream (Margolin, Steuber & Poplack, 2002).

Acute Lymphoblastic Leukemia (ALL) develops when lymphoblasts are excessively reproducing and are unable to mature into lymphocytes. It is the most common malignancy of childhood, accounting for one quarter of all childhood cancers and approximately 75% of all cases of childhood leukemia (Pui, 2000). In the United States, ALL is more common in Caucasians than African-Americans, and males suffer higher rates of incidence than females (Smith, Ries, Gurney, & Ross, 1999). Currently, the 5-year survival rate for ALL is 79.9% (SEER, 2005). Although the precise etiology of ALL remains unknown, both genetic and environmental factors have been implicated in the development of the disease. Notably, rates of ALL are 15 times greater in children with trisomy 21 (i.e. Down's syndrome) (Dordelmann et al., 1998), suggesting a strong link between ALL and chromosomal abnormalities. Additionally, increased frequency of leukemia has been documented in families, with siblings of children with leukemia having a two-fold to four-fold greater risk than unrelated children of developing the disease (Draper, Heaf, Kennier-Wilson, 1977). With regard to environmental factors, exposure to ionizing radiation and chemical toxins increase the likelihood of developing ALL. For example, it is well-documented that survivors of the atomic bomb explosions during World War II in Japan had a much higher incidence of leukemia than the general

population (Moloney, 1955). Other factors, including exposure to viral infection in utero, and congenital immunodeficiency diseases may predispose children to leukemia (Margolin, Steuber, & Poplack, 2002).

The current treatments for ALL are 2 to 3 years in duration and occur in phases, including: *Induction, Central Nervous System (CNS) Prophylaxis, Consolidation, Reinduction, Reconsolidation,* and *Maintenance*. The primary treatment for ALL is chemotherapy, although craniospinal radiation is used for high-risk patients (Keene, 2002). The specific types of treatment and type and dosage of chemotherapy agents administered in each stage are dependent on the child's subtype of ALL (e.g., *Early Pre-B, Pre-B, B cell,* or *T cell*).

Induction is the initial phase of treatment. Induction involves administration of chemotherapy, lasts for approximately four weeks, and usually involves inpatient care. The goal of induction is to kill as many leukemic cells possible in the shortest period of time; thus, putting the child into remission (Margolin, Steuber, & Poplack, 2002). Induction is followed by CNS Prophylaxis, a preventative measure used to eradicate ALL cells in the cerebrospinal fluid (CSF) before they can reproduce, causing CNS relapse. The incorporation of CNS prophylaxis in treatment has reduced the rate of CNS relapse from 65% to 5%, which has played a large role in the overall improvement in cure rates for ALL (Keene, 2002). In the Consolidation phase, new combinations of chemotherapy agents are used to destroy any cells that had survived induction. It includes high doses of new or previously used chemotherapy drugs and CNS prophylaxis. The Reinduction and Reconsolidation phases are not included in all treatment protocols and are most likely used for children who had a slow response to the initial induction. These phases

essentially mimic the induction and consolidation phases, but involve different combinations of chemotherapy drugs. The final phase of ALL treatment is *Maintenance*, which lasts for two to three years and involves low doses of chemotherapy to destroy any remaining leukemic cells. If the child relapses at any point during treatment, especially within 18 months of going into remission, a bone marrow transplant (BMT) is likely the next stage of therapy.

Acute Myelogenous Leukemia (AML) accounts for only 16% of cases of childhood leukemia (Smith, Ries, Gurney, & Ross, 1999), but accounts for 30% of deaths from leukemia (Golub & Arceci, 2002). With regard to etiology, environmental factors have been implicated in the development of AML. For example, exposure to ionizing radiation causes a ten-to-twenty fold increase in the incidence of AML (Golub & Arceci, 2002). Other environmental factors that increase the incidence of AML include prenatal exposure to maternal cigarette smoking and exposure to environmental chemical toxins. Unlike ALL, AML does not appear to have a strong genetic link and most frequently occurs in children without familial histories of cancer (Golub & Arceci, 2002).

The differentiating factor between ALL and AML is the type of white blood cell that is being affected. While ALL involves lymphoblasts, the cancer cells in AML are either myeloblasts or monoblasts; which, under normal conditions, would develop into granulocytes and monocytes, respectively. It is estimated that 500 children in the United States are diagnosed with AML each year; with equal rates of occurrence in males and females (Smith, Ries, Gurney, & Ross, 1999).

The treatment for AML resembles the treatment for ALL, but more frequently requires stem cell transplantation. Treatment for AML occurs in either two or three

phases: Induction, Postremission Consolidation, and/or Postremission Intensification, based on the specific subtype of AML. The goal of the first phase of treatment, *Induction*, is the same as in the treatment for ALL; to put the child into remission. The induction phase is the most intense part of therapy, with the child receiving a combination of two or three chemotherapy agents. Research has demonstrated that induction therapy for AML is most effective when the treatments are given on a timed basis, therefore not allowing the child to completely recover from one treatment before giving the next (Keene, 2002). Due to this intense schedule, AML induction usually requires long stretches of inpatient hospitalization. During induction, children with highrisk subtypes of AML may also receive craniospinal radiation in conjunction with the chemotherapy. As in the treatment of ALL, CNS Prophylaxis is used to prevent cancer cells present in the CSF from reproducing. Following induction, even if a child is in complete remission, residual cancer cells are still present in the body. Therefore, Postremission Therapy is used to destroy those remaining cells. During this phase of treatment children will receive a bone marrow transplant if a donor can be identified; but if a donor is unavailable, the child will receive postremission chemotherapy (Smith, Ries, Gurney, & Ross, 1999). The duration of treatment for AML is usually six to twelve months. Although the treatment for AML is shorter than that for ALL, the therapy is much more intense (Keene, 2002).

In summary, the Children's Oncology Group (COG) has developed a multitude of successful treatment protocols for pediatric cancer. Although there are four primary treatments for pediatric cancer, these therapies are used in a variety of combinations depending on several variables, including the specific type and stage of cancer, age at

diagnosis, and long-term prognosis. Currently, the five-year survival rate for all pediatric cancers combined is approximately 79%, which is a 30% increase since the 1950s (ACS, 2006). These statistics indicate that large numbers of children are surviving pediatric cancer, therefore necessitating further research on long-term effects of this disease and its treatment.

Social Functioning

It has been well-documented in the child psychology literature that social relationships play an integral part in a child's psychological well-being (Erdley, Nangle, Newman, & Carpenter, 2001). It is important that we understand the psychosocial functioning of typical children in order to recognize possible differences that exist for children with chronic illnesses. The construct of psychosocial functioning includes a wide variety of topics, many which are beyond the scope of this paper. Thus, a brief overview of the literature on typical peer relationships, peer acceptance, and loneliness will be discussed below, followed by a more detailed discussion of the impact of pediatric cancer on psychosocial functioning.

Peer Relationships. The overarching theme of *peer relationships* encompasses a wide variety of social experiences, and refers to both group and dyadic relationships.

Peer relationships are particularly important for children and adolescents because they are not only a measure of current social competence, but are also predictive of future psychological adjustment (Parker & Asher, 1987; Ruben, Hymel, & Mills, 1989; Hymel, Ruben, Rowden & LeMare, 1990).

<u>Peer Acceptance or Sociometric Status.</u> Peer acceptance or sociometric status is one way of assessing the social relationships of children by investigating the peer group's

perception of individual children (Gifford-Smith & Brownell, 2003). The most commonly used sociometric method is Coie and Dodge's (1983) version of peer nominations, in which children are given a class roster and are asked to circle the names of the three children they most like (i.e. like ratings), and the three children they least like (i.e. dislike ratings). These ratings are compiled and are used to compute scores of social impact and social preference for each child. Social impact refers to the degree to which the child is noticed by his or her peers, and is calculated as the sum of all "like" and "dislike" nominations. Social preference, on the other hand, is calculated as the number of "like" nominations minus the number of "dislike" nominations. These scores are then used to further categorize the children into five sociometric categories: popular, rejected, controversial, neglected, and average (Coie & Dodge, 1983; Bukowski & Hoza, 1989), which are briefly described below.

Popular. Children who are categorized as popular by their peers receive many "like" nominations and few "dislike" nominations. Thus, these children have high social impact and social preference scores and are perceived to have many positive qualities. They are often viewed as kind, cooperative, and trustworthy people (Parkhurst & Asher, 1992) who are socially competent and exhibit prosocial problem-solving skills (Nelson & Crick, 1999). In the classroom, popular children approach their peers frequently (Dodge, Coie, & Brakke, 1982) and are perceived by their teachers to be more helpful than other students (Wentzel & Asher, 1995).

Rejected. Rejected children are those who receive few "like" nominations and many "dislike" nominations from their peers. Thus, children in this category have the lowest social preference scores. Notably, Rubin and colleagues (1990) have further

categorized rejected children into two distinct behavioral groups: those who exhibit aggressive and disruptive behavior (i.e., *aggressive-rejected*), and those who are socially withdrawn (i.e., *submissive-rejected*). In general, rejected children are at greater risk for poorer psychological and psychosocial outcomes than children in the other status groups (Ollendick, Weist, Borden, & Greene, 1992). Specifically, *aggressive-rejected* children display more hostile behaviors and emotional reactivity, and *submissive-rejected* children demonstrate socially awkward behaviors (Bierman, Smoot, & Aumiller, 1993) and report higher levels of loneliness and worry than their peers (Parkhurst & Asher, 1992). Surprisingly, *rejected* children approach their peers as often as popular children, although they are much more likely to receive negative responses (Dodge et al., 1982).

Controversial. Children categorized into the controversial group demonstrate qualities consistent with both popular and rejected children; therefore, receiving high numbers of both "like" and "dislike" peer nominations. These children are perceived as leaders by their peers; but are also seen as aggressive (Newcomb, Bukowski, & Pattee, 1993). They often have an increased number of negative peer interactions, but an average number of positive interactions (Parkhurst & Asher, 1992). This combination of leadership ability and physical aggression can lead to controversial children having a greater negative effect on their peers, especially during adolescence (Bagwell, Coie, Terry, & Lochman, 2000); and might account for teachers rating controversial children as less preferred and more likely to start fights than average students (Wentzel & Asher, 1995).

Neglected. Children who receive few "like" or "dislike" nominations are categorized as neglected. In the classroom, neglected children often go unnoticed

because they typically exhibit few socially inappropriate or aggressive behaviors, and infrequently approach their peers (Dodge et al., 1982). Interestingly, *neglected* children report higher levels of school motivation than other students and are more likely to be preferred by teachers who rate them as more independent than average children (Wentzel & Asher, 1995).

Average. Almost half of the children involved in sociometric studies are considered average and therefore are not categorized into any of the previously mentioned groups. In contrast to the other categories, average children function well, do not show clinically significant elevations of behavior problems, and are not at increased risk for adverse psychological or psychosocial adjustment (Fuemmeler, Mullins, & Carpentier, 2006).

An interesting result of research involving sociometric status is the difference in the emotional and behavioral functioning between children in the *neglected* and *rejected* groups. Although children in both groups receive few "like" nominations from their peers, *rejected* children are more likely to display either hostile or socially awkward behaviors, while *neglected* children actually report the highest levels of academic motivation. It is suggested that these differences in behavior are a direct result of the child's perception of his/her social relationships. For example, children in the *neglected* group might fail to realize that they have few friends, or report being satisfied with their social relationships because they prefer to be alone. In contrast, children in the *rejected* group are aware that they are not accepted by their peers, which results in feelings of sadness and loneliness. Although short periods of loneliness throughout childhood are

normal, children who suffer from chronic loneliness are at greater risk for maladjustment in adolescence and adulthood (Asher & Paquette, 2003).

Loneliness in Childhood. Loneliness is defined by researchers as "the cognitive awareness of a deficiency in one's social and personal relationships, and the ensuing affective responses of sadness, emptiness, or longing" (Asher & Paquette, 2003, p. 75). Loneliness is exclusively a subjective experience that does not necessarily reflect observations in the external environment. For example, a child can be well accepted by a peer group, appearing to have many friends, but still feel lonely. Similarly, a child who is poorly accepted by peers might not evidence any feelings of loneliness. Therefore, the most important aspect of loneliness is the child's perception of his/her peer relationships and satisfaction with those relationships.

The majority of studies assessing peer relationships to identify children who are experiencing social problems have relied on teacher ratings, sociometric procedures, and/or behavioral observations. Asher et al. (1984) argued that these assessments should be combined with self-report measures of satisfaction in peer relationships, given that loneliness is such a subjective experience. Thus, in an effort to understand the relationship between peer acceptance (i.e., sociometric status) and individual feelings of social acceptance, Asher and colleagues (1984) developed a specific measure of loneliness and social dissatisfaction using sociometric nominations and self-report data from 506 third through sixth grade children. In their initial sample, 10% of the children reported increased feelings of loneliness and social dissatisfaction, which were significantly related to their sociometric status in the classroom.

In a subsequent study, Asher and Wheeler (1985) investigated differences in loneliness between children who are sociometrically categorized as *rejected* or *neglected* to determine whether being in one of these categories puts the child at greater risk for feelings of loneliness or increased social dissatisfaction. Data from 200 third through sixth grade students indicated that *neglected* children did not differ in loneliness from higher status peers. In contrast, *rejected* children significantly differed from all other sociometric groups and reported the highest levels of loneliness. This pattern of *rejected* children being lonelier than other groups has been demonstrated in numerous age groups; from kindergarten through middle-school (Asher, et al., 2003, as cited in Asher & Paquette, 2003).

These results suggest that although children in the *rejected* and *neglected* sociometric groups are both poorly accepted by their peers, they may have different perceptions of their peer relationships. For example, despite being poorly accepted by their peers, children in the *neglected* group may not perceive their social relationships as unsatisfying and thus, fail to report high levels of loneliness. In contrast, children in the *rejected* group are probably aware that they are not accepted by their peers, which puts them at greatest risk for internalizing problems including loneliness and social dissatisfaction. Based on this data, it stands to reason that the relationship between social relationships and loneliness depends solely on the child's perception of such relationships.

In summary, it would appear that *rejected* children are at increased risk for longterm adverse psychosocial outcomes. There are a wide variety of reasons that children can be rejected by their peers, including inappropriate behavior, physical disfigurement, and impaired cognition. This is extremely worrisome in the context of children who may evidence cognitive or physical deficits as a result of their illness or treatment.

The Impact of Cancer on Social Functioning

Much of the research on childhood cancer survivors suggests they will exhibit emotional, behavioral, and psychosocial adjustment comparable to that of their peers (Noll, Bukowski, Davies, Koontz, & Kulkarni, 1993; Noll, Bukowski, Rogosch, LeRoy, & Kulkarni, 1990; Noll, et al., 1999). However, extant research has identified various sub-groups of pediatric cancer survivors with substantially adverse psychological sequelae of their illness. Children with brain tumors and those who experience insults to their CNS as a result of cancer or cancer treatment have been shown to be at *considerably higher risk for adverse psychosocial outcomes* (Mulhern, 1994). A discussion of the specific impact of childhood cancer on psychosocial functioning will be addressed below.

Previous research involving chronically ill children has identified nine categories of possible risk factors for psychosocial dysfunction: demographic variables (e.g., age, sex, socioeconomic status), type of disease, degree of impairment (e.g., severity), visibility of disease, predictability of disease process, age of onset and duration, individual susceptibility and resilience, social environmental factors, and medical environmental factors (Pless & Nolan, 1991). This large number of potential risk factors, coupled with the heterogeneity of pediatric cancer, and small sample size has led to mixed results regarding the psychological and social adjustment in survivors of childhood cancer.

The extant literature on psychological functioning of survivors of childhood cancer is mixed, with some studies reporting that these children are at an increased risk

for internalizing problems such as depression and anxiety. A full discussion of this body of literature is beyond the scope of this paper, and the reader is directed to Patenaude and Kupst (2005) for a review. For purposes of the current study, results from studies of children with brain tumors will be briefly discussed below.

Early studies of the emotional and behavioral functioning of survivors of childhood brain tumors found that these children evidenced various difficulties, including depression, social isolation, aggression, and emotional lability (Bamford, et al., 1976; Hirsch et al., 1979). However, it should be noted that the participants in these studies experienced far less sophisticated treatments than are currently used with to treat brain tumors today. In contrast to these findings, Lannering, Marky, Lundberg, and Olsson (1990) reported emotional dysfunction (e.g., depression, anxiety, and concentration difficulties) in only 14% of 48 survivors of various types of tumors in the posterior fossa and supratentorial regions. Furthermore, a study of 80 survivors of various childhood brain tumors conducted by Carpentieri and colleagues (1993) found that children with brain tumors exhibited lower levels of internalizing problems than children with non-CNS cancer.

However, problematic emotional and behavioral functioning in survivors of childhood brain tumors has been found in studies utilizing teacher ratings. In a study assessing teacher-rated quality of life, children with brain tumors (n = 27), were compared to their siblings (n = 21), and matched healthy control groups (n = 25; n = 20). Children in the brain tumor group were more often rated as having higher levels of worry and emotional problems (Glaser, Nik Abdul Rashid, Walker, & Walker, 1997), while

their siblings were rated as less likely to show concern for others, compared to the healthy control groups.

The study of social functioning in childhood survivors of cancer incorporates a variety of constructs, including social adjustment, social competence, and social support; all three of these domains are at risk for being negatively affected by the child's illness.

Social adjustment refers to the child's overall ability to exist and perform in a wide range of social contexts, especially with regard to peer relationships (Welsh & Bierman, 1997).

Social competence, on the other hand, refers to the child's mastery of skills necessary for social acceptance (Welsh & Bierman, 1997). The relationship between social adjustment and social competence can be influenced by social support; whereby children who perceive closer relationships to family and friends (i.e. social support) are more likely to evidence higher levels of social adjustment and competence (Welsh & Bierman, 1997).

Social Adjustment. Peer relationships play an extremely important role in the emotional development and subsequent well-being of children of all ages. Oftentimes, children with chronic medical conditions face increased pressure due to worry that their illness will negatively affect such relationships (LaGreca, Bearman, & Moore, 2002). Overall, children with conditions such as sickle cell disease, cancer, and diabetes do not appear to evidence increased social difficulties as a group (Noll, Vannatta, Koontz et al., 1996; Noll, Bukowski, Rogosch, et al., 1990). However, children with illnesses that involve the central nervous system (CNS) do appear to have more difficulty developing age-appropriate peer relationships. Nassau and Drotar (1997) suggest that these difficulties for children with CNS-related conditions can result from cognitive

impairment, physical handicap, limited social opportunities, or a combination of any of these factors

In several studies that have investigated the social relationships of children with cancer, Noll and colleagues used a modified sociometric approach in addition to soliciting information from teachers and peers regarding the social functioning of the children with cancer in their classrooms. Initially, Noll and colleagues (1990) collected ratings from teachers of 24 children with cancer and compared them to classroom control groups on three dimensions of interpersonal style: sociability-leadership, aggressive-disruptive, and sensitive-isolated. The results indicated that the children with cancer were more likely to be rated as sensitive and isolated and less likely to be rated as sociable and leaders when compared to their peers.

Noll and colleagues (1991) subsequently conducted an examination involving self-report of 23 children with cancer and peer-report from their classmates. Child participants with cancer were compared to classroom controls on measures of: 1) overall popularity; 2) feelings of loneliness; 3) mutual friendships; 4) self-concept; and 5) peer and self perceptions of sociability, aggression, and social isolation. Results suggested that children with cancer were more likely to be perceived by their peers as socially isolated compared to their healthy counterparts. In contrast, no differences between the children with cancer and the comparison control children were found with regard to popularity, number of mutual friends, loneliness, depression, self-worth, and self-concept. This tendency for children with cancer to be perceived as more socially isolated persisted over time, as reported in a 2-year longitudinal investigation by Noll et al. (1993).

In a subsequent investigation, Noll and colleagues (1992) assessed the social reputations of children with either brain tumors, malignancies without primary CNS-involvement, or sickle cell disease. Results of teacher ratings of sociometric status showed that children with cancer were more often nominated for sociability-leadership roles and less frequently for aggressive-disruptive roles compared to healthy peers in their class. Additionally, children with brain tumors were more frequently nominated for sensitive-isolated roles, while children with sickle cell disease did not significantly differ from their peers.

Social Competence. Social competence is a term used to identify a wide range of skills that are necessary for social acceptance. Although a strict definition has yet to be developed, social competence is often assessed based on the child's ability to: 1) initiate and maintain friendships; 2) be socially accepted; and 3) develop the skills necessary to interact with peers (Rose-Krasnor, 1997). The development of social competence is a critical aspect of childhood adjustment, as deficits in social competence have been linked to feelings of low self-worth in adolescence and psychopathology in adulthood (Bagwell, Newcomb, & Bukowski, 1998). The construct of social competence has been frequently studied within the context of childhood chronic illness. For example, Nasssau and Drotar (1997) reported that children with specific types of CNS-related health conditions (e.g., cerebral palsy, spina bifida, epilepsy) have greater deficits in social competence than both children with non-CNS related health conditions and healthy children.

Carpentieri and colleagues (1993) investigated the differences in social competence and behavioral problems between 40 survivors of childhood brain tumors and 40 survivors of other childhood cancers without CNS-involvement. Based on parent-

reported data, results showed that although both groups deviated from the normative sample, children with brain tumors exhibited significantly lower levels of social competence than the cancer controls. Notably, in contrast to their hypotheses, the groups did not differ with regard to levels of behavioral problems. Although not formally evaluated, the researchers suggested that the increased psychosocial support services offered to children with brain tumors may have decreased the risk for potential behavior problems.

In another study comparing survivors of childhood cancer with and without CNS-involvement, Fossen, Abrahamsen, and Storm-Mathisen (1998) investigated the differences between 16 children with brain tumors and 15 children with Acute Lymphoblastic Leukemia (ALL) on measures of teacher- and parent-reported psychosocial functioning. Their data demonstrated that children with brain tumors evidenced increased behavior problems, lower social competence, and poorer adaptive functioning compared to those with ALL. These results again support the notion that cancer with CNS-involvement plays a critical role in subsequent psychosocial functioning.

In a longitudinal study investigating possible risk factors for poor behavioral and social adjustment, Kullgren and colleagues (2003) used data collected at Time 1 (one to two years post diagnosis) to predict functioning at Time 2 (three to four years post diagnosis) in 40 children with brain tumors. Consistent with the findings from Carpentieri et al. (1993), parents in this study rated their children lower than average across areas of social competence at both time points when compared to the normative sample. Additionally, this sample evidenced more significant school difficulties than

have been reported in previous studies (Mulhern et al., 1993; Carpentieri et al., 1993). Further investigation of demographic and treatment related variables indicated that multiple treatment modalities were associated with poorer social competence, while socioeconomic status was related to increased behavior problems.

Social Support. Social support refers to relationships with friends, family members, and acquaintances and has been proposed to be a protective factor in the adaptation to a chronic pediatric condition (Varni, Katz, Colegrove, & Dolgin, 1994; LaGreca, Bearman, & Moore, 2002). Although Barrera (1986) has distinguished three types of social support (i.e., perceived social support, social embeddedness, and enacted support), perceived social support is the most frequently studied construct, and has consistently shown a negative relationship to psychological distress.

In an early study of the relationship between social support and adjustment in childhood cancer, Kazak and Meadows (1989) compared a sample of young adolescent cancer survivors to a healthy control comparison group. Their results indicated that the groups did not significantly initially differ in terms of levels of social support, perceived self-competence, and family adaptability and cohesion. However, seven months after the first assessment, the cancer survivors reported lower levels of perceived support from family and friends.

Varni and colleagues (1994) conducted additional research on the relationship between perceived social support and adjustment in children newly diagnosed with cancer. In a sample of 30 children between the ages of 8 and 13 years, their results indicated that perceived classmate support was the most reliable predictor of psychological functioning, significantly predicting both depressive symptoms and

anxiety. In contrast, perceived support from teachers only predicted externalizing behavior problems, while perceived support from parents and friends failed to predict any of the criterion variables.

In a subsequent study, Varni and Katz (1997) investigated the effects of perceived social support and stress on negative affectivity in a sample of newly-diagnosed children with cancer. The children were evaluated within one month of diagnosis, six months post-diagnosis and nine months post-diagnosis. The results revealed that higher perceived social support was predictive of lower negative affectivity at each of the three time points. Additionally, the researchers discovered that the relationships between perceived social support, perceived stress, and negative affectivity changed throughout the nine months. Thus, they suggested that the adjustment of children with cancer should be carefully monitored at various points throughout their treatment and well as throughout survivorship.

In summary, previous research clearly demonstrates that survivors of childhood cancer with CNS-involvement are at high risk for deficits in social functioning however, the exact cause of this risk remains unknown. It stands to reason that damage to brain tissue or underlying brain structures could be responsible for impairments in a child's ability to perceive social situations, and that some brain areas are more vulnerable than others. Unfortunately, because research incorporates small sample sizes, various types and locations of pediatric brain tumors, and several different treatment protocols, our ability to detect and understand subtle differences between children is greatly reduced.

Neuropsychological Functioning

Although the research regarding social competence in survivors of childhood cancer is mixed, there is evidence that survivors of cancer with CNS-involvement are at greatest risk for deficits in the area of neuropsychological functioning. As previously mentioned, the multitude of cognitive impairments that can result from the damage to brain tissue in cancer and cancer treatment places these children at great risk for an array of psychosocial deficits. A full discussion of the neuropsychological deficits associated with childhood brain tumors is beyond the scope of the current paper; thus, the reader is directed to reviews by Ris and Noll (1994) and Butler and Mulhern (2005) for this information. For our purposes, we will briefly discuss the effects of cancer on cognitive and neuropsychological functioning, as well as the relationship between these deficits in these domains and subsequent psychosocial functioning.

In summary, the most commonly reported cognitive effect of childhood brain tumors is a decrease in intellectual functioning. Numerous studies have found evidence of declines in Full Scale IQ, Verbal IQ, and Performance IQ, although each of these scores may be affected differently. For example, in a series of studies, Radcliffe and colleagues found that children with malignant brain tumors who were treated with craniospinal radiation evidenced decreases of 10 - 15 points in all three IQ scores 2 years post-diagnosis. In contrast, children who were treated with only surgical resection did not demonstrate such changes (Radcliffe et al., 1992; Radcliffe, Bunin, Sutton, Goldwein, & Phillips, 1994; Packer et al., 1989). In an extension of this study, Radcliffe and colleagues (1994) tested these same children 3 and 4 years post-diagnosis, and contrary to expectations, the IQ scores were not significantly different. The researchers concluded

that deficits in intellectual functioning that resulted from the treatment of brain tumors were evident within 2 years of diagnosis, and that intellectual functioning did not continue to decline after this time.

In addition to decrements in intelligence, survivors of childhood brain tumors are at risk for impairments in other aspects of neuropsychological functioning. Specifically, these children often evidence long-term deficits in fine motor coordination as well as declines in perceptual-motor, visual-constructive, and memory abilities (Dennis et al., 1991; Ris & Noll, 1994). In an early study of neuropsychological effects of survivors of childhood medulloblastoma, Packer and colleagues (1987) found that despite average intellectual functioning, these children showed significant deficits in manual dexterity, memory, verbal fluency, and mathematical ability. In a subsequent study, Packer et al (1989) observed that these children also evidenced deficits in visual-motor and visual-spatial skills. Consistent with these findings, Lannering and colleagues (1990) found persistent deficits in cognitive, motor, visual, and psychological/emotional functioning as late as 16 years post-diagnosis for long-term survivors of childhood brain tumors. Again, it should be noted that these children were treated with protocols considered more "neurotoxic" than those administered in the last five years.

Although the existence of neuropsychological deficits secondary to cancer treatment is well documented, little is known about the relationship between these impairments and emotional, behavioral, and psychosocial functioning. In a longitudinal study of 98 children with either brain tumors or Acute Lymphoblastic Leukemia (ALL), Holmquist and Scott (2002) found that deficits in long-term verbal memory functioning significantly predicted internalizing problems in this population. Additionally, learning

problems and verbal fluency were highly predictive of social withdrawal, such that children who evidenced more learning problems and lower verbal fluency were more likely to withdraw from social situations than those who did not experience these difficulties. Finally, the researchers observed that lower overall intellectual functioning and verbal fluency were related to disturbances in attention, inhibition, and social functioning.

Chapter Summary

In summary, childhood cancer is the leading cause of death in children ages 1 -14 (NCI, 2005). However, survival rates have dramatically increased over the past two decades, leaving greater numbers of children and adolescents at risk for the long-term effects of their illness. Survivors of childhood cancer, especially those with CNS-involvement, are at increased risk for problems in psychosocial functioning. The effects of cancer and its treatment can lead to physical disfigurement, inappropriate behavior, and impaired cognition, which all have the ability to result in increased psychological distress (e.g., loneliness) and/or maladaptive psychosocial functioning (e.g., poor peer relationships, lower social competence).

CHAPTER III

THE PRESENT STUDY

The preceding literature review clearly demonstrates that although the majority of pediatric cancer survivors appear to evidence adjustment comparable to that of their peers, survivors of cancer with central nervous system (CNS) involvement are at high risk for difficulties in social functioning. Although deficits in the social competence of childhood survivors of cancer with CNS-involvement have been replicated in several studies, the majority of this research has utilized parent-reported levels of social competence and has neglected the use of self-report measures. Additionally, social competence has been assessed in broad terms, with the majority of the research utilizing the Achenbach Child Behavior Checklist (CBCL) as the only measure of social competence. Drotar and colleagues (1995) have cautioned that the CBCL has psychometric shortcomings when used in chronically ill populations; the CBCL is not sensitive to minor adjustment problems, and it may provide an incomplete assessment of social competence.

Thus, the present study will addressed the gaps in the literature by investigating a more thorough and sensitive assessment of functioning by combining both parent and self-report data of social competence, as well as emotional and behavioral functioning. Survivors of pediatric cancer with CNS-involvement are at great risk for deficits in neuropsychological functioning; and it is suggested that damage to brain tissue as a result

of the cancer and treatment may affect the child's perception of both the physical environment as well as interpersonal relationships. Therefore, the current study compared data from previous neuropsychological evaluations to parent- and self-report of current emotional, behavioral, and psychosocial functioning.

Additionally, previous research suggests that parents of survivors of childhood cancer with CNS-involvement rate their children as evidencing deficits in social competence. However, the current study sought to also understand the child's perception of his/her social relationships, because it is this perception of the social environment that ultimately leads to feelings of loneliness and social dissatisfaction. As discussed in the previous chapter, loneliness is a subjective construct, which may appear to be inconsistent with the external environment. It is possible that even though parents rate their children as having low social competence, the children do not have the same perception, and therefore do not report feelings of loneliness. The construct of loneliness has yet to be studied within the population of pediatric cancer survivors; notably, chronic loneliness in childhood has been associated with maladjustment in adolescence and adulthood (Asher & Paquette, 2003). Thus, it is critical to identify children at greatest risk for such feelings at the earliest time possible.

The present study was guided by the following aims:

<u>Aim 1.</u> To determine whether post-treatment deficits in intellectual functioning are related to current ratings of: a) self-reported loneliness and social dissatisfaction, b) perceived social competence, c) perceived social support, d) self-report of emotional and behavioral functioning, and e) parent-report of emotional and behavioral functioning in survivors of pediatric cancer with and without CNS-involvement.

Hypothesis: It was hypothesized that children and adolescents who evidence greater deficits in intellectual functioning, as measured by verbal IQ and performance IQ, would be rated by their parents as having higher levels of later emotional, behavioral, and psychosocial difficulties, and would self-report higher levels of loneliness and social dissatisfaction, lower levels of social support and social competence, and more emotional and behavioral distress.

<u>Aim 2.</u> To determine whether survivors of childhood cancer with CNS-involvement differed on measures of self-reported loneliness and social dissatisfaction, perceived social competence, and social support from survivors of childhood cancer without CNS-involvement.

Hypothesis: We hypothesized that survivors of childhood cancer with CNS-involvement would self-report higher levels of loneliness, and lower levels of social competence and social support as compared to survivors of cancer without CNS-involvement

An additional research question addressed in the current study was:

Research Question 1. Are the child and adolescents' self-reports of loneliness and social dissatisfaction consistently associated with parent-report of their child's loneliness and social dissatisfaction?

In order to test these hypotheses and explore the additional research question, survivors of pediatric cancer were recruited from the Jimmy Everest Cancer Center in Oklahoma City, Oklahoma. All participants had previously undergone a full neuropsychological assessment following the completion of their cancer treatment, and completed measures of current psychological and psychosocial functioning, as well as

measures of loneliness, perceived social competence, and perceived social support.

Additionally, parents of the participants were asked to complete a demographic form as well as measures of the child's current psychological and psychosocial functioning. The information for each of these measures in addition to a detailed explanation of the present study's procedures will be addressed in the next chapter.

CHAPTER IV

METHOD

Participants

Participants for the present study included 30 children and adolescents (20 M, 10 F) currently between the ages of 7 and 21 (M=13.97, SD=4.18), who underwent treatment for cancer diagnosed in childhood, and their parents (26 mothers, 3 fathers, 1 custodial grandparent). With regard to race, 80% of the sample self-identified as Caucasian, 10% as Native American, 3.3% as African American, 3.3% as Hispanic, and 3.3% as Asian. Parent participants ranged in age from 28 to 60 years old (M=4.37, SD=6.93), their educational attainment ranged from 12 to 20 years (M=14.30, SD=1.99), and the majority reported being married (80%). With regard to annual family income, 16.9% of the sample reported an income less than \$20,000, 16.7% between \$20,000 and \$39,999, 26.6% between \$40,000 and \$59,999, 33.3% over \$60,000, and 6.7% did not report an income.

The most common cancer diagnosis was Medulloblastoma (n = 12), followed by Acute Lymphoblastic Leukemia (ALL; n = 6) (See Table 1). The children's age at cancer diagnosis ranged from 3 to 17 years of age (M = 7.49, SD = 3.85) and duration of illness, which was calculated by subtracting the "date of diagnosis" from the "date off treatment", ranged from 1 to 47 months (M = 16.16, SD = 12.52). The majority of

participants (70%) received a combination of 2 or more treatments (e.g., surgery, chemotherapy, radiation), while the remaining 30% received a single treatment.

Additionally, all youth participants had previously received a post-treatment comprehensive neuropsychological evaluation at the University of Oklahoma Health Sciences Center (OUHSC). The neuropsychological evaluations were conducted at an average of 18.53 months post-treatment (range 5 - 71, SD = 15.77). The length of time between the neuropsychological assessment and participation in the current study ranged from .25 to 12.25 years (M = 4.02, SD = 3.57).

Measures: (See Appendix B)

<u>Demographic Information.</u> A demographic form was created to collect information from the parents including: the child's current age and grade, child's race, the ages and educational levels of the child's parents, and annual household income.

<u>Medical Chart Review.</u> A medical chart review was conducted by a trained psychology graduate student to obtain information regarding the child's diagnosis, age at diagnosis, treatment protocol (i.e., length of treatment, type and dosage of chemotherapy drugs, radiation dosage), and secondary complications.

Intellectual Functioning. The child's intellectual functioning was assessed during the neuropsychological evaluation using the appropriate version of the Wechsler Intelligence Scales, based on the child's age. The majority of the participants (n = 27) received the Wechsler Intelligence Scale for Children – 3^{rd} Edition (Wechsler, 1991; WISC-III), 2 participants received the Wechsler Pre-Primary Scale of Intelligence – Revised (Wechsler, 1989; WPPSI-R), and the remaining participant received the Wechsler Adult Intelligence Scale – 3^{rd} Edition (Wechsler, 1997; WAIS-III). The Wechsler Intelligence

Scales are widely-used measures of intelligence and have all demonstrated solid psychometric properties. Each scale yields a full scale IQ (FSIQ), verbal IQ (VIQ), performance IQ (PIQ), and 4 composite scores. In the current study, the VIQ and PIQ will be used as measures of verbal and nonverbal intellectual functioning. All of the Wechsler scales have demonstrated excellent psychometric properties. For the WPPSI-R, reliabilities for the three IQ scores range from .90 to .97 for ages 3 to 6 ½ years, although the reliabilities for the VIQ, PIQ, and FSIQ for the age of 7 are slightly lower (r = .85, .86, .90, respectively) (Sattler, 2001). For the WISC-III, internal consistency coefficients were .89 or higher for the verbal, performance, and full scales across all age groups (Sattler, 2001). Finally, on the WAIS-III internal consistency coefficients are .93 and above for the three intelligence scores across the entire standardization sample (Sattler, 2001). Criterion validity has been established for all three Wechsler scales by correlating them with the Stanford-Binet: Fourth Edition (Thorndike, Hagan, & Sattler, 1986), other intelligence tests, and measures of achievement and school grades (Sattler, 2001). Internal reliability for the current sample was excellent for the VIQ scale ($\alpha = .90$) and good for the PIQ scale ($\alpha = .84$). In the current study, FSIQ was not utilized, as it would cause problems with multicollinearity given it's strong relationship to the VIQ and PIQ. <u>Emotional and Behavioral Functioning</u>. The youth's current emotional and behavioral functioning was assessed using the Behavior Assessment System for Children -2^{nd} Edition (BASC-2; Reynolds & Kamphaus, 2004). The BASC-2 is a multidimensional approach to evaluating the behavior and self-perceptions of children and adolescents. For purposes of the current project, both the Parent Rating Scale (BASC-2-PRS) and the Self Report of Personality (BASC-2-SRP) were utilized. For children ages 5 – 12, the BASC-

2-PRS Child version, containing 160 items was administered, and for children ages 13-21, the BASC-2-PRS Adolescent version, containing 150 items was administered. For each item, the parent was asked to read each description and to rate how often their child exhibited that behavior on a 4-point Likert scale ranging from "never" to "almost always." The BASC-2-PRS yields 10 clinical subscales and 5 composite scales, with higher scores indicative of more problems. In the current study, three composite scores: Externalizing Problems, Internalizing Problems, and The Behavioral Symptoms Index score were used as measures of parent-rated psychological and behavioral adjustment of their child/adolescent. Internal consistency for the child version was excellent.

Cronbach's alpha coefficients were .95 for both the EP and IP subscales, and .96 for the BSI subscale. On the adolescent version, Cronbach's alpha coefficients were .87 on the EP subscale, .88 on the IP subscale, and .84 on the BSI subscale.

The BASC-2-SRP is similar to that of the PRS, but incorporates several items that are answered using a "true/false" format in addition to the Likert scale described above. The BASC-2-SRP has three versions, Child (ages 8-11), Adolescent (ages 12-21), and College (ages 18-25), which were all utilized in the current study based on the age of the participant. The BASC-2-SRP yields 18 clinical subscales and 5 composite scales, with higher scores indicative of more problems. In the current study, the Emotional Symptoms Index and Personal Adjustment composite scores were utilized as measures of current self-reported emotional and behavioral functioning. The BASC-2 has excellent psychometric properties (α = .80s to low .90s).

<u>Loneliness and Social Dissatisfaction.</u> The child's level of loneliness and social dissatisfaction was assessed by the Loneliness and Social Dissatisfaction Questionnaire

(LSDQ: Asher, Hymel, & Renshaw, 1984). The LDSQ is a 24-item self-report scale, containing 16 primary items assessing four areas: a) children's feelings of loneliness (e.g., "I'm lonely), b) children's appraisals of their current peer relationships (e.g., "I have nobody to talk to"), c) children's perceptions of the degree to which important relationship needs are being met (e.g., "I feel left out of things"), and d) children's perception of their social competence (e.g., "It's easy for me to make new friends at school"). The additional 8 items refer to hobbies or interests (e.g., "I like to read") and were demonstrated to be unrelated to the measured construct. Respondents were asked to rate each statement based on the degree to which the statement is a true description of themselves on a 5-point scale ranging from "not at all true" to "always true." The LSDQ yields a total score between 16 and 80, with higher scores being indicative of greater loneliness and social dissatisfaction. The LSDQ total score was used as the measure of loneliness and perceived social dissatisfaction in the current project. The LSDQ has demonstrated excellent psychometric properties ($\alpha \ge .90$). Cronbach's alpha for the LSDQ self-report in the current sample was high ($\alpha = .85$).

Additionally, a parent-report LDSQ was developed for the current project by modifying the child version to read "my child" instead of "I." The total score from the parent form was compared to the total score from the self-report measure to determine whether discrepancies existed between raters. Cronbach's alpha for the LDSQ parent-report in the current sample was excellent ($\alpha = .93$).

<u>Perception of Social Competence.</u> The child's perception of social competence was assessed by the Self Perception Profile (SPP; Harter, 1985; 1988; Neemann & Harter, 1986). The SPP is a self-report scale that taps into domain-specific judgments of

competence. For purposes of the current study, only the Global Self Worth subscale from the *child, adolescent,* and *college student* versions, was used as the measure of perceived social competence. Each item requires the respondent to compare themselves to one of two types of people (e.g., "some students are often disappointed with themselves" or "other students are usually quite pleased with themselves") and then to rate how true that description is of themselves (e.g., "really true for me" or "sort of true for me"). Each scale yields an independent score, with higher scores being indicative of higher competence in that area. The scores from the Global Self Worth subscale were used as the measure of perceived global competence, which is an important component for navigating social interactions (Harter, 1985). The Self-Perception Profile demonstrates adequate psychometric properties with reliabilities of the scales ranging from .76 to .92 across the three versions. Internal consistency across all three versions (i.e., child, adolescent, college student) were excellent in the current sample ($\alpha = .86$; .92; .94, respectively).

Perceived Social Support. The child's perceived social support was assessed using the Social Support Scale for Children (SSS; Harter, 1985). The Social Support Scale for Children is a 24-item self-report measure for children and adolescents that assesses the perceived support and regard from 4 types of significant others: 1) parent, 2) classmate, 3) teacher, and 4) close friend. The college student report contains 20-items and yields scores on similar scales. Each item requires the respondent to compare themselves to one of two types of people (e.g., "some kids often spend recess being alone" or "other kids spend recess playing with their classmates") and then to rate how true the description is of themselves (e.g., "really true for me" or "sort of true for me"). The measure yields a

score for each type of support with higher scores indicating more perceived support and regard. Given the necessity to collapse scores across versions due to the small sample size, only the close friend subscale was utilized in the current study, as the other scales did not overlap. The Social Support Scale for Children demonstrates adequate psychometric properties ($\alpha = .74$ to .88). In the current sample, Cronbach's alpha coefficients were consistent with those reported in previous studies (child/adolescent: $\alpha = .81$; college student: $\alpha = .80$).

Procedures

Potential participants for this study were first identified in the neuropsychology database based on their referral by pediatric oncologists for testing after the completion of their cancer treatment. Once eligible participants had been identified, recruitment letters were sent to their homes to solicit their interest in participating in the current study (See Appendix C). The participants were provided with a brief summary of the project as well as a phone number and e-mail address for which to contact the research staff. Participants who expressed interest in the project were given the choice to: 1) receive the measures via mail; or 2) complete the measures during their next scheduled clinic visit. For those who chose to receive the measures by mail, an appointment was scheduled for the graduate research assistant to travel to the family's home to collect the data and answer any questions. Informed consent was obtained by a graduate research assistant trained in HIPAA research guidelines, in conformity with standards of the OUHSC and Oklahoma State University (OSU) Institutional Review Boards (IRB). All families received a \$20.00 Wal-Mart gift card as a thank you for their participation. Recruitment letters were sent to a total of 65 families and follow-up phone calls were made to 51 of

the families (78.5%). The phone numbers for the remaining 14 families had been disconnected and new phone numbers were not available through medical records at OUHSC. Of the 51 families who were contacted by phone, 6 did not return our messages, 6 children were deemed ineligible for the study due to comorbid medical conditions, and 36 families consented to participate in the study (92.3%). Finally, 30 families actually completed the study (83.3%). The majority of the families who consented and did not complete the study reported that they felt the measures were too long, especially for the child

Once measures were completed by and collected from the participants and double-checked for completeness by a psychology graduate student, the data was entered into a database created in SPSS. Additionally, a review of the patient's medical chart was conducted to obtain the medical data described above. Finally, once data had been collected from all participants, a list of names was sent to the Psychiatry and Behavioral Sciences department, where a database of their neuropsychological data was created. The 2 databases were merged and all identifying information was removed prior to conducting statistical analyses. All raw data was identified by a subject number and was stored in a locked filing cabinet in the research office, with consent forms, HIPAA privacy forms, and demographic forms removed and stored separately to insure confidentiality of the participants.

CHAPTER V

RESULTS

Preliminary Analyses to Identify Covariates

First, descriptive statistics were calculated for all predictor (i.e., Verbal Intelligence Quotient [VIQ], Performance Intelligence Quotient [PIQ]) and outcome variables (i.e., parent-rated loneliness [LSDQ-P], self-rated loneliness [LSDQ-S], perceived social competence [SC], perceived social support [SS], emotional symptoms index [ESI], personal adjustment [PA], behavioral symptoms index [BSI], internalizing problems [IP], and externalizing problems [EP]). The descriptive statistics were calculated for the entire sample, as well as separately for the two groups of cancer survivors (i.e., with central nervous system [CNS] involvement, without CNS-involvement) (See Table 2).

Next, a series of chi-square tests of association and independent t-tests were conducted to determine whether survivors of cancer with and without CNS-involvement differed on a variety of demographic variables and illness parameters (i.e., gender, age at diagnosis, current age, length of time since diagnosis, duration of illness, length of time off treatment, and length of time between neuropsychological evaluation and current psychological/social evaluation). Results indicated that the groups differed on age at diagnosis (t(28) = -2.77, p = .01) and duration of illness (t(28) = 3.50, t(28) = 3.50, t(28)

and had significantly greater illness duration (See Table 3). No other comparisons were significant (all p's > .05).

To determine whether demographic variables (i.e., child age, gender, annual family income, parent age, and parent education) were related to any of the outcome variables (i.e., LSDQ-P, LSDQ-S, SC, SS, ESI, PA, BSI, IP, EP), a series of bivariate correlations were conducted (See Table 4). Results revealed that child age (r(25) = -.64, p < .01) and gender were both related to perceived social support (r(25) = .41, p < .05), such that younger children and males reported higher levels of social support. Additionally, annual family income was related to parent-report of global behavioral functioning and parent-rated externalizing problems (r(28) = -.51, p < .01; r(28) = -.54, p < .01, respectively), such that higher annual family income was related to better parent-reported global behavioral functioning (i.e., less behavior problems) and less externalizing problems in their child. Furthermore, parent education was related to child self-report of loneliness (r(29) = -.37, p < .05), such that greater parent education was related to lower levels of self-reported loneliness in their child. Therefore, these demographic variables were used as covariates in the appropriate analyses.

To examine the relationship between illness parameters (i.e., age at diagnosis, disease group, duration of illness, time off treatment, time between tests) and the outcome variables (i.e., LSDQ-P, LSDQ-S, SC, SS, ESI, PA, BSI, IP, EP), a series of bivariate correlations were conducted (See Table 5). Results revealed that disease group was related to both the emotional symptoms index and personal adjustment (r(28) = -.42, p < .05; r(29) = .39, p < .05, respectively), such that survivors of brain tumors reported lower levels of emotional symptoms and higher (i.e., better) levels of personal adjustment.

Finally, time off treatment and time between tests were both related to perceived social support (r(25) = -.45, p < .05; r(25) = -.40, p < .05, respectively), such that less time off treatment and less time between tests were both related to higher levels of perceived social support. Thus, these illness parameters will be used as covariates in all appropriate analyses. No other correlations were significant (all p's > .05).

To examine the relationships between the predictor variables (i.e., Verbal Intelligence Quotient [VIQ], Performance Intelligence Quotient [PIQ]) and the outcome variables (i.e., LSDQ-P, LSDQ-S, SC, SS, ESI, PA, BSI, IP, EP) a series of bivariate correlations were conducted (See Table 6). Results revealed that VIQ was significantly related to both the behavioral symptoms index and externalizing problems (r(29) = -.45, p < .05; r(29) = -.43, p < .05, respectively), such that higher verbal intelligence was associated with lower levels of behavior problems. In contrast, PIQ was unrelated to any of the outcome variables (all p's > .05).

Primary Analyses

Although the current project included several hypotheses, and thus several statistical tests, no corrections were made to address alpha inflation, given the preliminary nature of the work. It is argued that although not adjusting for alpha inflation could potentially result in significant spurious relationships, these results are preferred over possibly overlooking an important relationship (Cohen, 1988). Such significant relationships can be investigated in future studies, whereas those that are overlooked would forever be left out of subsequent research.

<u>Hypothesis 1a:</u> Children and adolescents who evidence greater deficits in posttreatment intellectual functioning will self-report higher levels of current loneliness. To determine whether deficits in post-treatment intellectual functioning were related to current levels of self-reported loneliness, hierarchical regression analysis was utilized. Covariates were chosen statistically, based on significant correlations from the preliminary analyses. Guided by Thompson and Gustafson's (1996) model, parent education (i.e., a demographic variable) was entered on Step 1, and VIQ and PIQ were simultaneously entered as predictor variables on Step 2. Self-reported loneliness (LSDQ-S) served as the dependent variable. Results revealed that after controlling for parent education, the overall model was not significant (F(3,23) = 2.10, p > .05, $f^2 = .07$, power = .19). Further, post-treatment intellectual functioning was unrelated to current levels of self-reported loneliness (both p's > .05; See Table 7).

<u>Hypothesis 1b:</u> Children and adolescents who evidence greater deficits in post-treatment intellectual functioning will self-report lower levels of perceived social competence.

To determine whether deficits in post-treatment intellectual functioning were related to current levels of self-reported perceived social competence, multiple regression analysis was utilized. The preliminary analyses did not identify any significant correlations with regard to perceived social competence, thus no covariates were used in the regression equation. Verbal IQ and PIQ were simultaneously entered as predictor variables while perceived global self-worth (SC) served as the dependent variable. Results revealed that the overall model was not significant (F(2,20) = .03, p > .05, $f^2 = .003$, power = .05). Further, neither post-treatment VIQ nor PIQ significantly predicted current level of perceived social competence (both p's > .05; See Table 8).

<u>Hypothesis 1c:</u> Children and adolescents who evidence greater deficits in posttreatment intellectual functioning will self-report lower levels of perceived social support.

To determine whether deficits in post-treatment intellectual functioning were related to current levels of self-reported perceived social support, hierarchical regression analysis was utilized. Covariates were identified statistically based on significant correlations from the preliminary analyses. Guided by Thompson and Gustafson's (1996) model, demographic variables (i.e., child current age, child gender) were entered on Step 1, illness parameters (i.e., time off treatment, time between tests) were entered on Step 2, and VIQ and PIQ were simultaneously entered as predictor variables on Step 3. Perceived social support from close friends (SS) served as the dependent variable. Results revealed that after controlling for demographic variables and illness parameters, the overall model showed a trend toward significance (F(6,16) = 2.55, p = .06, $f^2 = .21$, power = .40). However, neither post-treatment VIQ nor PIQ significantly predicted current levels of perceived social support from close friends (both p's > .05; See Table 9).

<u>Hypothesis 1d:</u> Children and adolescents who evidence greater deficits in posttreatment intellectual functioning will self-report poorer current emotional functioning and personal adjustment.

To determine whether deficits in post-treatment intellectual functioning were related to current levels of self-reported emotional functioning or personal adjustment, hierarchical regression analysis was utilized. Covariates were chosen based on statistically significant correlations identified in the preliminary analyses. Guided by Thompson and Gustafson's (1996) model, disease group (i.e., an illness parameter) was entered on Step 1, and VIQ and PIQ were simultaneously entered as predictor variables

on Step 2. Self-report of emotional functioning (ESI) and personal adjustment (PA) served as the dependent variables in separate equations. Results revealed that after controlling for disease group, the overall model for ESI was not significant (F(3,25) = 1.63, p > .05, $f^2 = .001$, power = .05; See Table 10). However, the overall model for PA showed a trend toward significance (F(3,22) = 2.52, p = .08, $f^2 = .22$, power = .49; See Table 11). Further, neither post-treatment VIQ nor PIQ significantly predicted current levels self-reported emotional functioning or personal adjustment (all p's > .05).

<u>Hypothesis 1e:</u> Children and adolescents who evidence greater deficits in posttreatment intellectual functioning will be rated by their parents as evidencing poorer current global behavioral functioning, and greater current emotional and behavioral difficulties.

To determine whether deficits in post-treatment intellectual functioning were related to current levels of parent-reported global behavioral functioning, emotional, or behavioral difficulties, hierarchical regression analysis was utilized. Covariates were chosen statistically based on significant correlations from the preliminary analyses. Guided by Thompson and Gustafson's (1996) model, annual family income (i.e., a demographic variable) was entered on Step 1, and VIQ and PIQ were simultaneously entered as predictor variables on Step 2. Parent-rated current global behavioral functioning (BSI), current internalizing problems (IP), and current externalizing problems (EP) each served as the dependent variable in separate equations. Results revealed that after controlling for annual family income, the overall model for IP was not significant $(F(3,22) = 1.39, p > .05, f^2 = .08$, power = .20; See Table 12). In contrast, the overall models for both BSI and EP were significant $(F(3,22) = 5.98, p < .01, f^2 = .02$, power =

.08; F(3,22) = 5.62, p < .01, $f^2 = .01$, power = .06, respectively; See Tables 13 and 14). Further examination of the models revealed that after controlling for annual family income, post-treatment intellectual functioning was unrelated to current levels of parent-reported global behavioral functioning and externalizing problems (all p's > .05); however, annual family income significantly predicted both BSI and EP (t(25) = -2.89, p < .01; t(25) = -3.00, p < .01, respectively).

Hypothesis 2a: Survivors of pediatric cancer with CNS-involvement will self-report significantly higher levels of current loneliness and social dissatisfaction compared to survivors of pediatric cancer without CNS- involvement.

To determine whether survivors of pediatric cancer with and without CNS-involvement differed with regard to self-reported current levels of loneliness and social dissatisfaction, a one-way ANCOVA (CNS-involvement vs. non-CNS involvement) was utilized, with illness duration and age at diagnosis entered as covariates and self-report of loneliness and social dissatisfaction (LSDQ-S) entered as the dependent variable. Results revealed that after controlling for illness duration and age at diagnosis, survivors of cancer with CNS-involvement (M = 30.21, SD = 6.36) did not significantly differ from survivors of cancer without CNS-involvement (M = 32.80, SD = 12.23) (F(1,25) = .59, p > .05, partial eta-squared = .02, power = .11).

<u>Hypothesis 2b:</u> Survivors of pediatric cancer with CNS-involvement will selfreport significantly lower levels of current perceived levels of social competence compared to survivors of pediatric cancer without CNS- involvement.

To determine whether survivors of pediatric cancer with and without CNS-involvement differed with regard to self-reported current levels of perceived social

competence, a one-way ANCOVA (CNS-involvement vs. non-CNS involvement) was utilized with illness duration and age at diagnosis entered as covariates, and global self-worth (SC) entered as the dependent variable. Results revealed that contrary to expectations, after controlling for illness duration and age at diagnosis, survivors of cancer with CNS-involvement (M = 19.94, SD = 4.26) reported significantly higher levels of perceived social competence than survivors of cancer without CNS- involvement (M = 17.22, SD = 4.32) (F(1,22) = 4.97, p = .04, partial eta-squared = .18, power = .57).

<u>Hypothesis 2c:</u> Survivors of pediatric cancer with CNS-involvement will selfreport significantly lower levels of current perceived social support from classmates compared to survivors of pediatric cancer without CNS-involvement.

To determine whether survivors of pediatric cancer with and without CNS-involvement differ with regard to self-reported current levels of perceived social support, a one-way ANCOVA (CNS involvement vs. non-CNS involvement) was utilized with illness duration and age at diagnosis entered as covariates, and perceived social support from close friends (SS) entered as the dependent variable. Results revealed that after controlling for illness duration and age at diagnosis, survivors of cancer with CNS-involvement (M = 17.80, SD = 5.37) did not significantly differ from survivors of cancer without CNS-involvement (M = 20.00, SD = 4.22) (F(1,21) = .22, p > .05, partial eta-squared = .01, power = .07).

Exploratory Analyses

Research Question 1: To investigate the relationship between levels of current self- and parent- reported loneliness and social dissatisfaction.

To determine whether the child's self-report of loneliness and social dissatisfaction was related to parent-report of the child's loneliness and social dissatisfaction, a bivariate correlation was conducted for the entire sample. Results revealed that self- and parent-report were significantly related (r(29) = .51, p = .001). However, when this relationship was examined within the two disease groups (CNS-involvement vs. non-CNS involvement), the results indicated that self- and parent-report of loneliness and social dissatisfaction were significantly correlated for survivors of pediatric cancer without CNS-involvement (r(10) = .73, p = .02), but were not significantly related for survivors of pediatric cancer with CNS-involvement (r(19) = .25, p > .05).

CHAPTER VI

DISCUSSION

The purpose of the present study was three-fold. First, both parent- and self-report measures were utilized to obtain a comprehensive, multi-informant assessment of the emotional, behavioral, and social functioning of pediatric cancer survivors. Second, the present study attempted to identify whether deficits in post-treatment intellectual functioning were predictive of the child's current emotional, behavioral, and social functioning. Finally, the study investigated differences in levels of loneliness, perceived social competence, and perceived social support in survivors of pediatric cancer with and without central nervous system (CNS)-involvement. The present study was guided by two hypotheses and an additional research question.

Hypothesis one stated that children and adolescents who evidenced greater deficits in post-treatment intellectual functioning, as measured by verbal IQ and performance IQ, would be rated by their parents as having higher levels of later emotional, behavioral, and psychosocial difficulties, and would self-report higher levels of loneliness and social dissatisfaction, lower levels of social support and social competence, and more emotional and behavioral distress. Results revealed that after controlling for significant demographic variables and illness parameters, post-treatment intellectual functioning was not predictive of current levels of emotional, behavioral, or social difficulties in the current sample. Thus, the hypothesis was not supported. It should

be noted however, that the overall models for the social support and personal adjustment outcome variables both showed trends toward significance in the predicted direction, and evidence of medium to large effect sizes for both equations. Additionally, the overall regression models for the global behavioral functioning and externalizing problems outcome variables were both significant, yet the effect was driven by the strong relationship between annual family income and the outcome variables, rather than the relationships between post-treatment intellectual functioning, global behavioral functioning, and externalizing problems.

The second hypothesis stated that survivors of childhood cancer with CNS-involvement would self-report higher levels of loneliness, and lower levels of social competence and social support as compared to survivors of cancer without CNS-involvement. Results revealed that although the groups did not differ on levels of loneliness or perceived social support, they significantly differed on level of perceived social competence. Specifically, survivors of cancer with CNS-involvement reported significantly higher levels of perceived social competence than survivors of cancer without CNS-involvement. This finding was in contrast to what was expected, as previous research has demonstrated that CNS-involvement is a risk factor for poorer social outcomes in survivors of pediatric cancer (Mulhern, 1994; Nassau & Drotar, 1997). Notably, examination of the range of scores on the social competence measure identified a number of individuals whose scores appeared to influence the mean score of this group. Thus, it may be that sampling bias influenced these specific results.

Finally, the research question investigated whether the survivor's level of selfreported loneliness and social dissatisfaction was consistent with parent-report of their

child's loneliness and social dissatisfaction. Interestingly, when the entire sample was examined, parent- and self-reported levels of the child's loneliness and social dissatisfaction were significantly correlated. However, when this relationship was investigated within the two disease group subtypes (i.e., CNS-involvement vs. non CNSinvolvement), it was found that the reports between survivors of pediatric cancer with CNS-involvement were not significantly related to their parent's rating of their loneliness and social dissatisfaction. Specifically, the parents rated their child as having higher levels of loneliness and social dissatisfaction than were reported by the children. Although a clear explanation for this discrepancy cannot be identified, it is suggested that treatment effects, such as cognitive deficits, which are more likely to occur in survivors of cancer with CNS-involvement, may cause the child to misperceive his/her social environment. In other words, it is quite possible that outside observers (i.e., parents) perceive that the child is lonely, but data from the current study suggest that survivors of cancer with CNS-involvement are not reporting this same level of loneliness. As mentioned previously, the construct of loneliness is completely subjective and does not necessarily correlate with an objective assessment of the social situation.

Although not a focus of the current study, it should be noted that two of the demographic variables (i.e., parent education, annual family income) were strongly correlated with some of the outcome measures (i.e., global behavioral functioning, parent-reported externalizing problems, and parent-rated loneliness and social dissatisfaction). The data indicated that higher family income was significantly correlated with less externalizing problems and better global behavioral functioning (i.e., less behavior problems). Additionally, higher parent education was related to lower levels of

self-reported loneliness and social dissatisfaction. Consistent with other research using other populations of both healthy and chronically ill children, select demographic factors appear to provide resilience against poor psychosocial outcomes (Pless, 1991).

Strengths and Limitations

Although the current study is indeed preliminary in nature, there are several strengths that should be highlighted. First, the present study utilized a longitudinal design, which is somewhat rare in pediatric cancer research. In fact, previous longitudinal studies have typically focused on the reassessment of specific variables over time and have frequently neglected interrelationships between variables from different domains which may lead to identifying risk factors for maladaptive adjustment. For example, instead of assessing changes in intellectual functioning over time, we chose to investigate whether intellectual deficits evidenced during post-treatment neuropsychological evaluations were predictive of the child's later emotional, behavioral, and social adjustment. A second strength of the current study is that it assessed children and adolescents at different points in survivorship. Although these differences added variability to the data, they allowed us to investigate whether "time-related" variables, such as time off treatment, time between the neuropsychological evaluation and the psychosocial functioning assessment, and duration of illness played a role in the child's current functioning. Finally, although the small sample size resulted in low power, which potentially precluded us from detecting significant effects, several of the effect sizes for the regression equations fell in the small-to-medium range, while the effects for the relationships between post-treatment intellectual functioning, global behavioral functioning and externalizing problems were indeed medium-to-large effects. Thus, such

data suggests that these relationships be examined in future investigations of survivors of pediatric cancer.

In addition to the aforementioned strengths of the current study, several limitations should also be addressed. First, the present study included a relatively small sample size, which as mentioned above, resulted in low power and reduced our ability to detect significant effects. Second, the neuropsychological evaluations were from an archival database, which unfortunately contained considerable missing data for many of the subjects. The combination of missing data and the small sample size precluded us from examining other aspects of neuropsychological functioning (e.g., verbal fluency) and their relationships to current levels of emotional, behavioral, and social functioning. Third, the current sample included a wide age range of children and adolescents, which necessitated the utilization of several versions of the psychosocial measures. Although the different versions are assumed to measure the same constructs across age groups, it is quite possible that some differences exist. Finally, given that the recruitment procedures for participants involved sending letters to eligible families and following up with phone calls, it is quite possible that the current study includes a sampling bias. Unfortunately, no data was collected on families who did not respond to the research solicitations or on those who consented to participate but did not complete the study. Thus, no conclusions can be made with regard to differences between these groups and those families who completed the study.

Future Directions

The present study is indeed preliminary in nature, and although few significant relationships emerged within the context of the current sample, the findings support the

need for future research in identifying predictors of maladaptive adjustment in survivors of pediatric cancer. Future studies should attempt to identify such predictors by assessing a range of variables, including cognitive functioning (e.g., deficits in intellectual functioning, verbal fluency, and working memory), demographic variables (e.g., low annual family income, younger age at diagnosis, and parent age and education), and illness parameters (e.g., duration of illness, type of treatment, time off treatment). Once significant predictors of maladaptive functioning have been identified, interventions can be tailored to address the specific needs of survivors of pediatric cancer. Further, these interventions can then be implemented early in survivorship in an attempt to ameliorate future difficulties. As discussed previously, advances in medicine and the treatment of pediatric cancer have resulted in a 75% 5-year cure rate of all pediatric cancers combined (NCI, 2002). Although huge strides have been made in saving these children's lives, future research should be directed at improving their quality of life in survivorship.

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APPENDICES

$\label{eq:Appendix A} \mbox{INTERNATIONAL CLASSIFICATION OF CHILDHOOD CANCER, THIRD}$ $\mbox{EDITION}$

International Classification of Childhood Cancer, Third Edition

- I. Leukemias, myeloproliferative diseases, and myelodysplastic diseases
 - a. Lymphoid leukemias
 - b. Acute myeloid leukemias
 - c. Chronic myeloproliferative dieases
 - d. Myelodysplastic syndrome and other myeloproliferative diseases
 - e. Unspecified and other specified leukemias

II. Lymphomas and reticuloendothelial neoplasms

- a. Hodgkin lymphomas
- b. Non-Hodgkin lymphomas (except Burkitt lymphoma)
- c. Burkitt lymphoma
- d. Miscellaneous lymphoreticular neoplasms
- e. Unspecified lymphomas

III. CNS and miscellaneous intracranial and intraspinal neoplasms

- a. Ependymomas and choroids plexus tumor
- b. Astrocytomas
- c. Intracranial and intraspinal embryonal tumors
- d. Other gliomas
- e. Other specified intracranial and intraspinal neoplasms
- f. Unspecified intracranial and intraspinal neoplasms

IV. Neuroblastoma and other peripheral nervous cell tumors

- a. Neuroblastoma and ganglioneuroblastoma
- b. Other peripheral nervous cell tumors

V. Retinoblastoma

VI. Renal tumors

- a. Nephroblastoma and other nonepithelial renal tumors
- b. Renal carcinomas
- c. Unspecified malignant renal tumors

VII. Hepatic tumors

- a. Hepatoblastoma
- b. Hepatic carcinomas
- c. Unspecified malignant hepatic tumors

VIII. Malignant bone tumors

- a. Osteosarcomas
- b. Chondrosarcomas
- c. Ewing tumor and related sarcomas of bone
- d. Other specified malignant bone tumors
- e. Unspecified malignant bone tumors

IX. Soft tissue and other extraosseous sarcomas

- a. Rhabdomyosarcomas
- b. Fibrosarcomas, peripheral nerve sheath tumors, and other fibrous neoplasms
- c. Kaposi sarcoma
- d. Other specified soft tissue sarcomas
- e. Unspecified soft tissue sarcomas

X. Germ cell tumors, trophoblastic tumors, and neoplasms of gonads

- a. Intracranial and intraspinal germ cell tumors
- b. Malignant extracranial and extragonadal germ cell tumors
- c. Malignant gonadal germ cell tumors
- d. Gonadal carcinomas
- e. Other and unspecified malignant gonadal tumors

XI. Other malignant epithelial neoplasms and malignant melanomas

- a. Adrenocortical carcinomas
- b. Thyroid carcinomas
- c. Nasopharyngeal carcinomas
- d. Malignant melanomas
- e. Skin carcinomas
- f. Other and unspecified carcinomas

XII. Other and unspecified malignant neoplasms

- a. Other specified malignant tumors
- b. Other unspecified malignant tumors

CNS; central nervous system

Appendix B

MEASURES

Demographic Questionnaire

Medical Chart Review

Loneliness and Social Dissatisfaction Questionairre – Self Report (LSDQ-S)

Loneliness and Social Dissatisfaction Questionairre – Parent Report (LSDQ-P)

Behavior Assessment System for Children – 2nd Edition: Parent Rating Scales – Child (BASC-2: PRS-C)

Behavior Assessment System for Children – 2nd Edition: Parent Rating Scales – Adolescent (BASC-2: PRS-A)

Behavior Assessment System for Children – 2nd Edition: Self Report Profile – Child (BASC-2: SRP-C)

Behavior Assessment System for Children – 2nd Edition: Self Report Profile – Adolescent (BASC-2: SRP-A)

Behavior Assessment System for Children – 2nd Edition: Self Report Profile – College Student (BASC-2: SRP-COL)

Self-Perception Profile for Children (What I Am Like – C)

Self-Perception Profile for Adolescents (What I Am Like – A)

Self-Perception Profile for College Students (What I Am Like – CS)

Social Support Scale for Children and Adolescents (People in My Life – C/A)

Social Support Scale for College Students (People in My Life – CS)

DEMOGRAPHIC INFORMATION

Today's Date:		_	Subject Nun	nber:	
Child's Name: Mother's Name: Father's Name:): 		Child's Ger	nder:	
Name of persor	n filling out this f	form and relat	ionship to child (e.	g., mother):	
	the child and age	(e.g., brother elation to chil	u and your child? I - 15 months, steppa d	arent-36 yea A	
What is your ag		What w	as <i>your age</i> when ild was diagnosed?		
What is your spouse's age?			as <i>your spouse's ag</i> ild was diagnosed?		_
What is your child's age?			as <i>your child's age</i> vas diagnosed?	when	_
What grade is y	our child in?				
What is your ra Caucasian A		Hispanic 3	Native American 4		Other 6
Parent's Marita Married		Remarried	Never Married	Other	
1	2	3	4	5	
Parent's Highes	st Level of Educa	tion: Mother	:Fa	ther	
Parents' Occup	ations: Mother_		Father _		
			ne: 0-4,999		

 	15,000-19,999
 20,000-29,999	30,000-39,999
 40,000-49,999	50,000-59,999
60,000 or greater	

FORM FOR MEDICAL CHART REVIEW

Subject Number:		
Child's Diagnosis:		
Date of Diagnosis:		
Current Date:		
Date off Treatment:		
Medical Interventions Reco		oined)
Procedure Procedure	Received (check to indicate)	Approx. Number of Times
Surgery		
Biopsy		
Shunts		
Radiation		
Chemotherapy		
Bone Marrow Transplant		
Spinal Tap		
Bone Marrow Aspiration		
Other (describe)		
Other (describe)		
Other (describe)		
Complications Secondary t	to Diagnosis and/or Treatment:	'

LSDQ-S

INSTRUCTIONS:

Please read each statement and put an "X" in the box that describes how true the statement is about you.

	Always True	True Most of the Time	True Sometimes	Hardly Ever True	Never True at All
1) It's easy for me to make new					
friends at school					
2) I like to read					
3) I have nobody to talk to					
4) I'm good at working with other					
children					
5) I watch TV a lot					
6) It's hard for me to make new					
friends					
7) I like school					
8) I have lots of friends					
9) I feel alone					
10) I can find a friend when I					
need one					
11) I play sports a lot					
12) It's hard to get other kids to					
like me					
13) I like science					
14) I don't have anyone to play					
with					
15) I like music					
16) I get along with other kids					
17) I feel left out of things					
18) There's nobody I can go to					
when I need help					
19) I like to paint and draw					
20) I don't get along with other					
children					
21) I'm lonely					
22) I am well-liked by the kids in					
my class					
23) I like playing board games a					
lot					
24) I don't have any friends					

LSDQ - P

INSTRUCTIONS:

Please read each statement and put an "X" in the box that describes how true the statement is about your child.

	Always True	True Most of the Time	True Sometimes	Hardly Ever True	Never True at All
1) It's easy for my child to make new					
friends at school					
2) My child likes to read					
3) My child has nobody to talk to					
4) My child's good at working with					
other children					
5) My child watches TV a lot					
6) It's hard for my child to make new					
friends					
7) My child likes school					
8) My child has lots of friends					
9) My child feels alone					
10) My child can find a friend when					
he/she needs one					
11) My child plays sports a lot					
12) It's hard to get other kids to like					
my child					
13) My child likes science					
14) My child doesn't have anyone to					
play with					
15) My child likes music					
16) My child gets along with other					
kids					
17) My child feels left out of things					
18) There's nobody my child can go					
to when he/she needs help					
19) My child likes to paint and draw					
20) My child doesn't get along with					
other children					
21) My child is lonely					
22) My child is well-liked by the					
kids in his/her class					
23) My child likes playing board					
games a lot					
24) My child doesn't have any friends					
Irienas					

BASC-2: PRS-C

INSTRUCTIONS:

On the pages that follow are phrases that describe how children may act. Please read each phrase, and mark the response that describes how this child has behaved recently (in the last several months).

Circle **N** if the behavior **never** occurs.

Circle **S** if the behavior **sometimes** occurs.

Circle **O** if the behavior **often** occurs.

Circle A if the behavior almost always occurs.

Please mark every item. If you don't know or are unsure of your response to an item, give your best estimate.

	Never	Some- times	Often	Almost Always	Remember: N – Never S – Sometimes O – Often A – Almost Always
1)	N	S	О	Α	Shares toys or possessions with other children
2)	N	S	О	A	Eats too much
3)	N	S	О	A	Has trouble following regular routines
4)	N	S	О	A	Gives good suggestions for solving problems
5)	N	S	О	A	Worries
6)	N	S	О	A	Cannot wait to take turn
7)	N	S	О	A	Is easily annoyed by others
8)	N	S	О	Α	Teases others
9)	N	S	О	Α	Has a short attention span
10)	N	S	О	Α	Is easily upset
11)	N	S	О	Α	Does strange things
12)	N	S	О	A	Worries about what teachers think
13)	N	S	О	A	Is too serious
14)	N	S	О	A	Recovers quickly after a setback
15)	N	S	О	A	Disobeys
16)	N	S	О	A	Makes friends easily
17)	N	S	О	A	Pays attention
18)	N	S	О	A	Complains about being teased
19)	N	S	О	A	Joins clubs or social groups
20)	N	S	О	A	Is unable to slow down
21)	N	S	О	A	Refused to join group activities
22)	N	S	О	A	Has seizures
23)	N	S	О	A	Babbles to self
24)	N	S	О	A	Bullies Others
25)	N	S	О	A	Will change direction to avoid having to greet someone
26)	N	S	О	A	Hits other children
27)	N	S	О	A	Eats things that are not food
28)	N	S	О	A	Cries easily
29)	N	S	О	A	Steals
30)	N	S	О	A	Expresses fear of getting sick
31)	N	S	О	A	Congratulates other when good things happen to them
32)	N	S	О	A	Worries about making mistakes
33)	N	S	О	A	Is easily soothed when angry
34)	N	S	О	A	Provides own telephone number when asked
35)	N	S	О	A	Acts in a safe manner
36)	N	S	О	A	Is a "self-starter"
37)	N	S	О	A	Worries about what parents think

	Never	Some- times	Often	Almost Always	Remember: N – Never S – Sometimes O – Often A – Almost Always
38)	N	S	0	A	Disrupts other children's activities
39)	N	S	O	A	Organizes chores or other tasks well
40)	N	S	О	A	Argues with parents
41)	N	S	О	A	Listens to directions
42)	N	S	0	A	Says, "Nobody understands me"
43)	N	S	О	A	Acts confused
44)	N	S	О	A	Worries about schoolwork
45)	N	S	0	A	Is fearful
46)	N	S	О	A	Adjusts well to changes in routine
47)	N	S	О	A	Breaks the rules
48)	N	S	О	A	Avoids competing with other children
49)	N	S	О	A	Pays attention when being spoken to
50)	N	S	О	Α	Complains about not having friends
51)	N	S	О	Α	Is good at getting people to work together
52)	N	S	О	A	Acts out of control
53)	N	S	О	A	Is chosen last by other children for games
54)	N	S	O	A	Complains of pain
55)	N	S	О	A	Repeats one thought over and over
56)	N	S	О	A	Argues when denied own way
57)	N	S	О	A	Is shy with other children
58)	N	S	О	A	Threatens to hurt others
59)	N	S	О	A	Has stomach problems
60)	N	S	0	A	Says, "Nobody likes me"
61)	N	S	О	A	Lies to get out of trouble
62)	N	S	О	A	Says, "I think I'm sick"
63)	N	S	О	A	Encourages others to do their best
64)	N	S	О	A	Tries too hard to please others
65)	N	S	О	A	Adjusts well to new teachers
66)	N	S	О	A	Speaks in short phrases that are hard to understand
67)	N	S	О	A	Sets realistic goals
68)	N	S	О	A	Is creative
69)	N	S	О	A	Is nervous
70)	N	S	О	A	Fiddles with things while at meals
71)	N	S	О	A	Volunteers to help clean up around the house
72)	N	S	О	A	Annoys others on purpose
73)	N	S	О	A	Is easily distracted
74)	N	S	О	A	Is negative about things
75)	N	S	О	A	Seems out of touch with reality
76)	N	S	О	A	Answers telephone properly
77)	N	S	О	Α	Worries about things that cannot be changed
78)	N	S	О	A	Adjusts well to changes in family plans
79)	N	S	О	A	Deceives others
80)	N	S	О	A	Quickly joins group activities
81)	N	S	О	A	Is unclear when presenting ideas
82)	N	S	О	A	Says, "I don't have any friends"
83)	N	S	О	A	Is usually chosen as a leader
84)	N	S	О	A	Is overly active
85)	N	S	О	A	Offers to help other children
86)	N	S	0	A	Has headaches
87)	N	S	0	A	Acts as if other children are not there
88)	N	S	0	A	Seeks revenge on others
89)	N	S	O	A	Shows fear of strangers
90)	N	S	O	A	Loses temper too easily
91)	N	S	O	A	Complains about health
92)	N	S	O	A	Says, "I want to die" or "I wish I were dead"
93)	N	S	O	A	Sneaks around
94)	N	S	O	A	Gets Sick
	·				1

	Never	Some- times	Often	Almost Always	Remember: N – Never S – Sometimes O – Often A – Almost Always
95)	N	S	О	A	Compliments others
96)	N	S	О	A	Seems unaware of others
97)	N	S	О	A	Is cruel to animals
98)	N	S	О	A	Has difficulty explaining rules of games to others
99)	N	S	О	A	Attends to issues of personal safety
100)	N	S	О	A	Will speak up if the situation calls for it
101)	N	S	О	A	Says, "I'm afraid I will make a mistake"
102)	N	S	О	A	Interrupts others when they are speaking
103)	N	S	О	A	Has trouble fastening buttons on clothing
104)	N	S	O	A	Calls other children names
105)	N	S	O	Α	Listens carefully
106)	N	S	O	Α	Says, "I hate myself"
107)	N	S	O	Α	Hears sounds that are not there
108)	N	S	O	A	Is able to describe feelings accurately
109)	N	S	O	A	Says, "I'm not very good at this"
110)	N	S	O	Α	Is a "good sport"
111)	N	S	O	A	Lies
112)	N	S	O	A	Avoids other children
113)	N	S	O	Α	Tracks down information when needed
114)	N	S	O	Α	Is sad
115)	N	S	O	Α	Has a hearing problem
116)	N	S	O	Α	Acts without thinking
117)	N	S	O	A	Tries to bring out the best in other people
118)	N	S	O	A	Has fevers
119)	N	S	O	A	Stares blankly
120)	N	S	O	A	Sleeps with parents
121)	N	S	O	A	Has trouble making new friends
122)	N	S	O	A	Responds appropriately when asked a question
123)	N	S	O	A	Is afraid of getting sick
124)	N	S	O	A	Seems lonely
125)	N	S	O	Α	Breaks the rules just to see what will happen
126)	N	S	O	A	Complains of being sick when nothing is wrong
127)	N	S	O	A	Volunteers to help with things
128)	N	S	O	A	Says things that make no sense
129)	N	S	O	A	Throws up after eating
130)	N	S	O	A	Is clear when telling about personal experiences
131)	N	S	O	A	Needs to be reminded to brush teeth
132)	N	S	O	A	Makes decisions easily
133)	N	S	O	A	Says, "It's all my fault"
134)	N	S	O	A	Interrupts parents when they are talking on the phone
135)	N	S	О	A	Has toileting accidents
136)	N	S	0	A	Is cruel to others
137)	N	S	0	A	Falls down
138)	N	S	0	A	Says, "I want to kill myself"
139)	N	S	O	A	Sees things that are not there
140)	N	S	0	A	Accurately takes down messages
141)	N	S	О	A	Worries about what other children think
142)	N	S	0	A	Is stubborn
143)	N	S	0	A	Sets fires
144)	N	S	O	A	Prefers to be alone
145)	N	S	O	A	Has trouble getting information when needed
146)	N	S	O	A	Eats too little
147)	N	S	O	A	Runs away from home
148)	N	S	O	A	Has poor self-control
149)	N	S	O	A	Shows interest in others' ideas
150)	N	S	O	A	Vomits
151)	N	S	O	A	Shows feelings that do not fit the situation

	Never	Some-	Often	Almost	Remember: N - Never S - Sometimes O - Often A - Almost
		times		Always	Always
152)	N	S	O	A	Has eye problems
153)	N	S	О	A	Is shy with adults
154)	N	S	О	A	Communicates clearly
155)	N	S	О	A	Wets bed
156)	N	S	О	A	Changes mood quickly
157)	N	S	О	A	Gets into trouble
158)	N	S	О	A	Complains of shortness of breath
159)	N	S	О	A	Says, "please" and "thank you"
160)	N	S	O	A	Acts strangely

BASC-2: PRS-A

INSTRUCTIONS:

On the pages that follow are phrases that describe how children may act. Please read each phrase, and mark the response that describes how this child has behaved recently (in the last several months).

Circle **N** if the behavior **never** occurs.

Circle **S** if the behavior **sometimes** occurs.

Circle **O** if the behavior **often** occurs.

Circle A if the behavior almost always occurs.

Please mark every item. If you don't know or are unsure of your response to an item, give your best estimate.

	Never	Some- times	Often	Almost Always	Remember: N – Never S – Sometimes O – Often A – Almost Always
1)	N	S	О	A	Adjusts well to new teachers.
2)	N	S	О	A	Accurately takes down messages.
3)	N	S	О	A	Volunteers to help clean up around the house.
4)	N	S	О	Α	Calls other adolescents names.
5)	N	S	О	Α	Pays attention.
6)	N	S	О	Α	Compliments others.
7)	N	S	О	Α	Is creative.
8)	N	S	О	Α	Cries easily.
9)	N	S	О	Α	Complains of being sick when nothing is wrong.
10)	N	S	О	Α	Annoys others on purpose.
11)	N	S	О	Α	Has eye problems.
12)	N	S	О	Α	Worries about making mistakes.
13)	N	S	О	A	Uses foul language.
14)	N	S	О	A	Makes friends easily.
15)	N	S	О	Α	Cannot wait to take turn.
16)	N	S	О	A	Has stomach problems.
17)	N	S	О	Α	Joins clubs or social groups.
18)	N	S	О	A	Adjusts well to changes in plans.
19)	N	S	О	A	Steals.
20)	N	S	О	Α	Acts without thinking.
21)	N	S	О	Α	Seems unaware of others.
22)	N	S	О	Α	Complains about being teased.
23)	N	S	О	Α	Is nervous.
24)	N	S	О	Α	Encourages others to do their best.
25)	N	S	О	Α	Is cruel to animals.
26)	N	S	О	Α	Is unclear when presenting ideas.
27)	N	S	О	Α	Sees things that are not there.
28)	N	S	О	Α	Says, "I'm not very good at this."
29)	N	S	О	Α	Drinks alcoholic beverages.
30)	N	S	О	Α	Says, "Nobody understands me."
31)	N	S	О	A	Adjusts well to changes in routine.
32)	N	S	О	Α	Communicates clearly.
33)	N	S	О	A	Acts in a safe manner.
34)	N	S	О	A	Teases others.
35)	N	S	О	A	Has a short attention span.
36)	N	S	О	A	Congratulates others when good things happen to them.
37)	N	S	О	A	Is good at getting people to work together.
38)	N	S	О	A	Is negative about things.

	Never	Some-	Often	Almost	Remember: N – Never S – Sometimes O – Often A – Almost
		times		Always	Always
39)	N	S	О	A	Complains of shortness of breath.
40)	N	S	О	A	Threatens to hurt others.
41)	N	S	О	A	Has a hearing problem.
42)	N	S	О	A	Worries about what teachers think.
43)	N	S	О	A	Sneaks around.
44)	N	S	O	A	Refuses to join group activities.
45)	N	S	O	A	Has poor self-control.
46)	N	S	0	A	Says, "I think I'm sick."
47)	N	S	0	A	Will speak up if the situation calls for it.
48)	N	S	0	A	Is a "good sport."
49)	N	S	0	A	Smokes or chews tobacco.
50)	N	S	O	A	Interrupts parents when they are on the phone.
51)	N	S	0	A	Stares blankly.
52)	N	S	0	A	Says, "I hate myself."
53)	N	S	0	A	Tries too hard to please others.
54)	N	S	0	A	Says, "please" and "thank you."
					1 1
55)	N	S	0	A	Has headaches.
56)	N	S	O	A	Tracks down information when needed.
57)	N	S	O	A	Has strange ideas.
58)	N	S	О	A	Says, "I get nervous during tests" or "Tests make me nervous."
59)	N	S	О	A	Is in trouble with the police.
60)	N	S	O	A	Says, "I want to kill myself."
61)	N	S	О	A	Recovers quickly after a setback.
62)	N	S	О	Α	Is effective when presenting information to a group.
63)	N	S	О	A	Needs help from others to get up on time.
64)	N	S	О	A	Argues when denied own way.
65)	N	S	О	A	Listens to directions.
66)	N	S	О	A	Tries to bring out the best in other people.
67)	N	S	О	A	Works well under pressure.
68)	N	S	О	A	Changes moods quickly.
69)	N	S	O	A	Complains about health.
70)	N	S	O	A	Hits other adolescents.
71)	N	S	0	Α	Repeats one activity over and over.
72)	N	S	0	A	Worries about things that cannot be changed.
73)	N	S	O	A	Breaks the rules.
74)	N	S	0	A	Is shy with other adolescents.
75)	N	S	0	A	Acts out of control.
76)	N	S	0	A	Pays attention when being spoken to.
77)	N	S	O	A	Makes decisions easily.
78)	N	S	0	A	Adjusts well to changes in family plans.
79)	N	S	0	A	Lies.
80)	N	S	0	A	Interrupts others when they are speaking.
81)	N	S	0	A	Needs to be reminded to brush teeth.
82)	N	S	0	A	Is easily upset.
83)	N	S	0	A	Worries about what other adolescents think.
84)	N	S	0	A	Shows interest in others' ideas.
85)	N	S	0	A	Complains of chest pain.
86)	N	S	0	A	Is able to describe feelings accurately.
87)	N	S	0	A	Says things that make no sense.
88)	N	S	0	A	Prefers to be alone.
89)	N	S	0		Gets into trouble.
90)	N N	S	0	A	
				A	Says, "I want to die" or "I wish I were dead."
91)	N	S	0	A	Complains when asked to do things differently.
92)	N		0	A	Is clear when telling about personal experiences.
93)	N	S	0	A	Organizes chores or other tasks well.
94)	N	S	0	A	Bullies others.
95)	N	S	О	Α	Eats things that are not food.

	Never	Some- times	Often	Almost Always	Remember: N – Never S – Sometimes O – Often A – Almost Always
96)	N	S	О	A	Volunteers to help with things.
97)	N	S	O	A	Is a "self-starter."
98)	N	S	O	A	Seems lonely.
99)	N	S	O	A	Complains of pain.
100)	N	S	О	A	Loses temper too easily.
101)	N	S	O	A	Hears sounds that are not there.
102)	N	S	O	A	Is fearful.
103)	N	S	O	A	Uses illegal drugs.
104)	N	S	O	A	Quickly joins group activities.
105)	N	S	О	A	Fiddles with things while at meals.
106)	N	S	O	A	Listens carefully.
107)	N	S	О	A	Has difficulty explaining rules of games to others.
108)	N	S	О	A	Is stubborn.
109)	N	S	0	A	Breaks the rules just to see what will happen.
110)	N	S	0	A	Falls down.
111)	N	S	0	A	Sets realistic goals.
112)	N	S	0	A	Says, "Nobody likes me."
113)	N	S	0	A	Worries.
114)	N	S	0	A	Sleeps with parents.
115)	N	S	0	A	Gets sick.
116)	N	S	0	A	Responds appropriately when asked a question.
117)	N	S	0	A	Babbles to self.
118)	N	S	0	A	Is chosen last by other adolescents for games.
119)	N	S	0	A	Deceives others.
120)	N N	S S	0	A	Attends after-school activities.
121) 122)			0	A	Sets fires.
122)	N N	S S	0	A	Writes messages that are unclear or incorrect. Attends to issues of personal safety.
123)	N N	S	0	A A	Seeks revenge on others.
124)	N N	S	0	A	Throws up after eating.
126)	N N	S	0	A	Offers help to other adolescents.
120)	N	S	0	A	Gives good suggestions for solving problems.
128)	N	S	0	A	Says, "I don't have any friends."
129)	N	S	0	A	Is afraid of getting sick.
130)	N	S	0	A	Is cruel to others.
131)	N	S	0	A	Seems out of touch with reality.
132)	N	S	0	A	Eats too little.
133)	N	S	0	A	Disobeys.
134)	N	S	0	A	Has trouble making new friends.
135)	N	S	0	A	Disrupts other adolescents' activities.
136)	N	S	O	A	Is easily distracted.
137)	N	S	O	A	Answers telephone properly.
138)	N	S	O	A	Eats too much.
139)	N	S	O	A	Lies to get out of trouble.
140)	N	S	O	A	Runs away from home overnight.
141)	N	S	O	A	Picks out clothes that match the weather.
142)	N	S	0	A	Is sad.
143)	N	S	O	A	Says, "I'm afraid I will make a mistake."
144)	N	S	О	A	Is easily annoyed by others.
145)	N	S	O	A	Expresses fear of getting sick.
146)	N	S	О	A	Has trouble getting information when needed.
147)	N	S	O	A	Acts strangely.
148)	N	S	О	A	Avoids other adolescents.
149)	N	S	О	A	Has seizures.
150)	N	S	О	A	Is usually chosen as a leader.

BASC-2: SRP-C

INSTRUCTIONS:

On the pages that follow are sentences that tell how some boys and girls think or feel or act. Read each sentence carefully. For the first group of sentences, you will have two answer choices: T or F.

Circle **T** for **True** if you agree with a sentence.

Circle **F** for **False** if you do not agree with a sentence.

For the second group of sentences, you will have four answer choices: N, S, O, and A.

Circle **N** if the sentence **never** describes you or how you feel.

Circle **S** if the sentence **sometimes** describes you or how you feel.

Circle **O** if the sentence **often** describes you or how you feel.

Circle A if the sentence almost always describes you or how you feel.

Please mark every item. Give the best answer for you for each sentence, even if it is hard to make up your mind. There are no right or wrong answers. Please do your best, tell the truth, and answer every sentence,

	TRUE	FALSE	Remember: T – True F – False
1)	T	F	Things go wrong for me, even when I try hard.
2)	T	F	I can't wait for school to be over
3)	T	F	I like everyone I meet.
4)	T	F	Nothing ever goes right for me.
5)	T	F	I think I am a good person.
6)	T	F	My parents are always telling me what the do.
7)	T	F	I have some bad habits.
8)	T	F	I worry about little things
9)	T	F	People tell me I should pay more attention
10)	T	F	Sometimes, when alone, I hear my name
11)	T	F	I always go to bed on time
12)	T	F	My classmates don't like me
13)	T	F	I tell the truth every single time
14)	T	F	I used to be happier
15)	T	F	I never get into trouble
16)	T	F	I have never been in a car
17)	T	F	Nothing goes my way
18)	T	F	My parents are always right
19)	T	F	I have too many problems
20)	T	F	I wish I were different
21)	T	F	I tell my parents everything
22)	T	F	I have never been to sleep
23)	T	F	If I have a problem, I can usually work it out
24)	T	F	I never seem to get anything right
25)	T	F	My friends have more fun then I do
26)	T	F	I have never been mean to anyone
27)	T	F	I get mad at my parents sometimes
28)	T	F	I am not very good at anything
29)	T	F	Nobody ever listens to me
30)	T	F	My parents blame too many of their problems on me
31)	T	F	I don't like thinking about school

	TR	UE	FA	LSE	Remember: T – True F – False
32)		T		F	My teachers understands me
33)		T		F	Nothing is fun anymore
34)		T		F	I feel good about myself
35)		Т		F	I can't seem to control what happens to me
36)		T		F	I never break the rules
37)		T		F	I often worry about something bad happening to me
38)		T		F	I think I have a short attention span
39)		T		F	Sometimes I want to hurt myself
40)		T		F	I often do things without thinking Other children don't like to be with me
42)		T		F	I think I am very creative
43)		T		F	I don't seem to do anything right
44)		T		F	I don't care about school
45)		T		F	I like who I am
46)		T		F	Nothing about me is right
47)		Т		F	I have attention problems
48)		T		F	I just don't care anymore
49)		T		F	I wish I were someone else
50)		T		F	I have no teeth
51)		T		F	I always do what my parents tell me
	Never	Some-	Often	Almost	Remember: N - Never S - Sometimes O - Often A - Almost
52)	N	times S	0	Always A	Always I am good at schoolwork
53)	N	S	0	A	When I take tests, I can't think
54)	N	S	0	A	People say bad things to me
					1 3 6
55) 56)	N N	S	0	A	I am bothered by thoughts about death I see things that others cannot see
57)	N	S	0	A	It is hard for me to keep my mind on schoolwork
58)	N	S	0	A	My parents expect too much from me
59)	N	S	0	A	I feel like I want to quit school
60)	N	S	0	A	Teachers make me feel stupid
61)	N	S	0	A	I feel depressed
62)	N	S	0	A	I like the way I look
63)	N	S	О	A	I am blamed for things I don't do
64)	N	S	О	A	My teacher is proud of me
65)	N	S	О	A	I am afraid I might do something bad
66)	N	S	О	A	I forget things
67)	N	S	0	A	I feel like people are out to get me
68)	N	S	0	A	I have trouble standing still in lines
69)	N	S	0	A	Other kids hate to be with me
70)	N	S	0	A	I can solve difficult problems by myself
71)	N	S S	0	A	No one understands me I hate school
72)	N N	S	0	A	My looks bother me
74)	N	S	0	A	I feel sad
75)	N	S	0	A	I listen when people are talking to me
76)	N	S	0	A	I feel like my life is getting worse and worse
77)	N	S	0	A	I get upset about my looks
78)	N	S	0	A	Someone else controls my thoughts
79)	N	S	O	A	I am lonely
80)	N	S	0	A	I am a dependable friend
81)	N	S	О	A	I am disappointed with my grades
82)	N	S	О	A	I am left out of things
83)	N	S	О	A	I get nervous
84)	N	S	0	A	I drink 50 glasses of milk every day
85)	N	S	0	A	Even when I try hard, I fail
86)	N	S	0	A	I am bothered by not getting enough sleep
87)	N	S	О	A	My school feels good to me

	Never	Some- times	Often	Almost Always	Remember: N - Never S - Sometimes O - Often A - Almost Always
88)	N	S	0	A	My teacher gets mad at me for no good reason
89)	N	S	О	A	My mother and father help me if I ask them to
90)	N	S	О	A	I have trouble sitting still
91)	N	S	О	A	I get blamed for things I can't help
92)	N	S	0	A	If I get a bad grade, it's because the teacher doesn't like me
93)	N	S	0	A	I am afraid of a lot of things
94)	N	S	О	Α	I have trouble paying attention to what I am doing
95)	N	S	0	A	I see weird things
96)	N	S	О	A	People tell me that I'm stubborn
97)	N	S	О	A	My classmates make fun of me
98)	N	S	0	A	I am good at making decisions
99)	N	S	0	A	People tell me that I am too noisy
100)	N	S	0	A	My parents are easy to talk to
101)	N	S	0	A	My mother and father like my friends
102)	N	S	0	A	I fail at things
103)	N	S	0	A	I get into trouble for not paying attention
104)	N	S	0	A	Little things bother me
105)	N	S	0	A	I sleep with my schoolbooks
106)	N	S	0	A	I hear things that other cannot hear
107)	N	S	0	A	I feel out of place around people
107)	N	S	0	A	I am someone you can count on
					ý .
109)	N	S	0	A	I am proud of my parents
110)	N	S	0	A	I am bothered by teasing from others
111)	N	S	0	A	I worry but I don't know why
112)	N	S	0	A	My parents are proud of me
113)	N	S	0	A	I get mad at others
114)	N	S	0	A	I worry when I go to bed at night
115)	N	S	0	A	School is boring
116)	N	S	О	A	My teacher trusts me
117)	N	S	О	A	My parents trust me
118)	N	S	О	A	I talk while other people are talking
119)	N	S	О	A	People get mad at me, even when I don't do anything wrong
120)	N	S	O	Α	Teachers are unfair
121)	N	S	O	A	I get so nervous I can't breathe
122)	N	S	О	A	I give up when learning something new
123)	N	S	О	Α	I give up when learning something new
124)	N	S	О	Α	People tell me to be still
125)	N	S	0	A	I feel nobody likes me
126)	N	S	О	A	I am dependable
127)	N	S	0	A	I talk without waiting for others to say something
128)	N	S	0	A	I like going to bed at night
129)	N	S	0	A	My parents like to help with my homework
130)	N	S	0	A	I want to do better, but I can't
131)	N	S	0	A	I have trouble paying attention to the teacher
132)	N	S	0	A	I worry about what is going to happen
133)	N	S	0	A	My parents listen to what I say
134)	N	S	0	A	I hear voices in my head that no one else can hear
135)	N	S	0	A	Other people find things wrong with me
136)	N	S	0	A	Other people make fun of me
137)	N	S	0	A	I like going places with my parents
	N	S	1		People act as if they don't hear me
138)			0	A	
139)	N	S	O	A	I get nervous when things do not go the right way for me

BASC-2: SRP-A

INSTRUCTIONS:

On the pages that follow are sentences that young people may use to describe how they think or feel or act. Read each sentence carefully. For the first group of sentences, you will have two answer choices: **T** or **F**.

Circle **T** for **True** if you agree with a sentence.

Circle **F** for **False** if you do not agree with a sentence.

For the second group of sentences, you will have four answer choices: N, S, O, and A.

Circle **N** if the sentence **never** describes you or how you feel.

Circle **S** if the sentence **sometimes** describes you or how you feel.

Circle **O** if the sentence **often** describes you or how you feel.

Circle A if the sentence almost always describes you or how you feel.

Please mark every item. Give the best answer for you for each sentence, even if it is hard to make up your mind. There are no right or wrong answers. Please do your best, tell the truth, and answer every sentence,

	TRUE	FALSE	Remember: T – True F – False
1)	T	F	I like who I am
2)	T	F	I hate taking tests
3)	T	F	Nothing goes my way
4)	T	F	My muscles get sore a lot
5)	T	F	People tell me I should pay more attention
6)	T	F	Things go wrong for me, even when I try hard
7)	T	F	I get mad at my parents sometimes
8)	T	F	I used to be happier
9)	T	F	I often have headaches
10)	T	F	I don't care about school
11)	T	F	I can never seem to relax
12)	T	F	I always go to bed on time
13)	T	F	My classmates don't like me
14)	T	F	I worry about tests more than my classmates do
15)	T	F	My parents are always right
16)	T	F	If I have a problem, I can usually work it out
17)	T	F	I never break the rules
18)	T	F	I have not seen a car in the last 6 months
19)	T	F	What I want never seems to matter
20)	T	F	I worry about little things
21)	T	F	Nothing is fun anymore
22)	T	F	I never get into trouble
23)	T	F	I tell the truth every single time
24)	T	F	I never seem to get anything right
25)	T	F	I have never been mean to anyone
26)	T	F	My friends have more fun than I do
27)	T	F	I like loud music
28)	T	F	I always do what my parents tell me
29)	T	F	No matter how much I study for a test, I am afraid I will fail
30)	T	F	I cover up my work when the teacher walks by
31)	T	F	I wish I were different

	TR	UE	FA	LSE	Remember: T – True F – False
32)		T		F	I have just returned from a 9-month trip on an ocean liner
33)		T		F	Nobody ever listens to me
34)		T		F	Often I feel sick in my stomach
35)		T		F	I think I have a short attention span
36)		T		F	My parents have too much control over my life
37)		T		F	My teacher understands me
38)		T		F	I just don't care anymore
39)		T		F	Sometimes my ears hurt for no reason
40)		T		F	I don't like thinking about school
41)		T		F	I worry a lot of the time
42)		T		F	I get along well with my parents
43)		T		F	Other children don't like to be with me
44)		T		F	I wish I were someone else
45)		T		F	I tell my parents everything
46)		T		F	I can handle things on my own
47)		T		F	I like to take chances
48)		T		F	I am sometimes jealous
49)		T		F	My parents are always telling me what to do
50)		T		F F	I often worry about something bad happening to me
52)		T		F	I don't seem to do anything right
		T		F	I like everyone I meet I have attention problems
53) 54)		T		F	Most things are harder for me than for others
55)		T		F	I have some bad habits
		T		F	Other children are happier than I am
56) 57)		T		F	I would rather be a police officer than a teacher
58)		T		F	I always do homework on time
59)		T		F	I take a plane trip from New York to Chicago at least twice a week
60)		T		F	I never quite reach my goal
61)		T		F	I feel good about myself
62)		T		F	Sometimes, when alone, I hear my name
63)		T		F	Nothing ever goes right for me
64)		T		F	I get sick more than others
65)		T		F	I give up easily
66)		T		F	My parents blame too many of their problems on me
67)		Т		F	My teacher cares about me
68)		Т		F	Nothing about me is right
69)		T		F	My stomach gets upset more than most people's
	Never	Some-	Often	Almost	Remember: N – Never S – Sometimes O – Often A – Almost
		times		Always	Always
70)	N	S	O	A	My school feels good to me
71)	N	S	О	A	I get so nervous I can't breathe
72)	N	S	O	A	I am proud of my parents
73)	N	S	О	A	Other kids hate to be with me
74)	N	S	О	A	I like the way I look
75)	N	S	O	A	People say bad things to me
76)	N	S	О	A	I am dependable
77)	N	S	0	A	I like it when my friends dare me to do something
78)	N	S	0	A	When I get angry, I can't think about anything else
79)	N	S	0	A	I get blamed for things I can't help
80)	N	S	0	A	I worry when I go to bed at night
81)	N	S	0	A	I feel like my life is getting worse and worse
82)	N	S	0	A	School is boring
83)	N	S	0	A	I forget things
84)	N	S	0	A	Even when I try hard, I fail
85)	N	S	0	A	My teacher trusts me
86)	N	S S	0	A A	People as if they don't hear me I like to play rough sports
87)	N				

	Never	Some- times	Often	Almost Always	Remember: N – Never S – Sometimes O – Often A – Almost Always
88)	N	S	O	A	I have trouble standing still in lines
89)	N	S	О	A	I can't seem to turn off my mind
90)	N	S	О	A	I am disappointed with my grades
91)	N	S	О	A	I get upset about my looks
92)	N	S	О	A	I feel like people are out to get me
93)	N	S	О	A	I feel depressed
94)	N	S	О	A	I sleep with my schoolbooks
95)	N	S	O	A	I listen when people are talking to me
96)	N	S	O	A	I stay awake for 24 hours without getting tired
97)	N	S	O	A	Teachers make me feel stupid
98)	N	S	O	A	No one understands me
99)	N	S	О	A	I feel dizzy
100)	N	S	О	A	Someone wants to hurt me
101)	N	S	0	A	I feel guilty about things
102)	N	S	0	A	I like going places with my parents
103)	N	S	0	A	I feel nobody likes me
104)	N	S	0	A	I am good at things
105)	N	S	0	A	I am lonely
106)	N	S	0	A	I can solve difficult problems by myself
107)	N	S	0	A	I like to experiment with new things
108)	N	S	0	A	I get nervous
109)	N	S	0	A	My parents expect too much from me
110)	N	S	0	A	I worry but I don't know why
111) 112)	N N	S S	0	A A	I feel sad
112)	N N	S	0		I get bored in school
113)	N N	S	0	A A	I have trouble paying attention to the teacher When I take tests, I can't think
114)	N N	S	0	A	Teachers look for the bad things that you do
116)	N	S	0	A	I am left out of things
117)	N	S	0	A	I like to ride in a care that is going fast
118)	N	S	0	A	I talk while other people are talking
119)	N	S	0	A	Even when alone, I feel like someone is watching me
120)	N	S	0	A	I want to do better, but I can't
121)	N	S	0	A	My looks bother me
122)	N	S	0	A	I hear voices in my head that no one else can hear
123)	N	S	0	A	I am good an making decisions
124)	N	S	0	A	I have trouble sitting still
125)	N	S	O	A	I pay attention when someone is telling me how to do something
126)	N	S	О	A	My parents are easy to talk to
127)	N	S	0	A	Teachers are unfair
128)	N	S	О	A	I have a hard time slowing down
129)	N	S	О	A	I like going to bed at night
130)	N	S	0	A	I see weird things
131)	N	S	О	A	I get nervous when things do not go the right way for me
132)	N	S	О	A	My mother and father like my friends
133)	N	S	О	A	People think I am fun to be with
134)	N	S	О	A	I feel like I have to get up and move around
135)	N	S	О	A	Other people find things wrong with me
136)	N	S	О	A	I like to make decisions on my own
137)	N	S	0	A	I like to be the first one to try new things
138)	N	S	O	A	Little things bother me
139)	N	S	O	A	I am blamed for things I don't do
140)	N	S	O	A	I worry about what is going to happen
141)	N	S	O	A	My mother and father help me if I ask them to
142)	N	S	O	A	I feel like I want to quit school
143)	N	S	О	A	I have trouble paying attention to what I am doing
144)	N	S	О	A	I fail at things

	Never	Some- times	Often	Almost Always	Remember: N – Never S – Sometimes O – Often A – Almost Always
145)	N	S	О	A	My teacher is proud of me
146)	N	S	О	A	I feel out of place around people
147)	N	S	О	A	I like to dare others to do things
148)	N	S	О	A	I talk without waiting for others to say something
149)	N	S	О	A	Someone else controls my thoughts
150)	N	S	О	A	I quit easily
151)	N	S	О	A	I am slow to make new friends
152)	N	S	О	A	I do things over and over and can't stop
153)	N	S	О	A	My friends come to me for help
154)	N	S	О	A	People tell me to be still
155)	N	S	О	A	My parents listen to what I say
156)	N	S	О	A	I like to be close to my parents
157)	N	S	О	A	My teachers want too much
158)	N	S	О	A	When I get angry, I want to break something
159)	N	S	О	A	I get phone calls from popular movie actors
160)	N	S	О	A	I hear things that others cannot hear
161)	N	S	О	A	I get mad at others
162)	N	S	О	A	I have trouble sleeping the night before a big test
163)	N	S	О	A	I am liked by others
164)	N	S	О	A	People tell me that I am too noisy
165)	N	S	О	A	I feel that others do not like the way I do things
166)	N	S	О	A	I am someone you can rely on
167)	N	S	О	A	When I get angry, I want to hurt someone
168)	N	S	О	A	When I start talking, it is hard for me to stop
169)	N	S	О	A	People get mad at me, even when I don't do anything worng
170)	N	S	О	A	I am afraid of a lot of things
171)	N	S	О	A	My parents trust me
172)	N	S	O	A	I hate school
173)	N	S	О	A	My parents are proud of me
174)	N	S	О	A	Ideas just race through my mind
175)	N	S	О	A	My teacher gets mad at me for no good reason
176)	N	S	О	A	Other people are against me

BASC-2: SRP-COL

INSTRUCTIONS:

On the pages that follow are sentences that young adults may use to describe how they think or feel or act. Read each sentence carefully. For the first group of sentences, you will have two answer choices: T or F.

Circle **T** for **True** if you agree with a sentence.

Circle **F** for **False** if you do not agree with a sentence.

For the second group of sentences, you will have four answer choices: N, S, O, and A.

Circle **N** if the sentence **never** describes you or how you feel.

Circle **S** if the sentence **sometimes** describes you or how you feel.

Circle **O** if the sentence **often** describes you or how you feel.

Circle A if the sentence almost always describes you or how you feel.

Please mark every item. Give the best answer for you for each sentence, even if it is hard to make up your mind. There are no right or wrong answers. Please do your best, tell the truth, and answer every sentence,

	TRUE	FALSE	Remember: T – True F – False
1)	T	F	I like who I am
2)	T	F	I never break the rules
3)	T	F	The am a healthy person
4)	T	F	My parents are always telling me what to do
5)	T	F	I think I have a short attention span
6)	T	F	I like everyone I meet
7)	T	F	I like to take chances
8)	T	F	I used to be happier
9)	T	F	No matter how much I study for a test, I am afraid I will fail
10)	T	F	I never get into trouble
11)	T	F	Sometimes, when alone, I hear my name
12)	T	F	I never seem to feel like working on school assignments
13)	T	F	Most things are harder for me than for others
14)	T	F	I tell the truth ever single time
15)	T	F	Nobody ever listens to me
16)	T	F	I can never seem to relax
17)	T	F	Other people are happier than I am
18)	T	F	I get mad at my parents sometimes
19)	T	F	I hate taking tests
20)	T	F	I often have headaches
21)	T	F	I think that I am going to school for the wrong reasons
22)	T	F	I have never been mean to anyone
23)	T	F	I never stay out too late
24)	T	F	I often worry about something bad happening to me
25)	T	F	I never stay out too late
26)	T	F	I often worry about something bad happening to me
27)	T	F	I have some bad habits
28)	T	F	I tell my parents everything
29)	T	F	Nothing ever goes right for me
30)	T	F	I am sometimes jealous
31)	T	F	I am tired of going to school

	TR	UE	FA	LSE	Remember: T – True F – False
32)		T		F	I wish I were someone else
33)		T		F	I always do what my parents expect of me
34)		T		F	I get sick more than others
35)		T		F	What I want never seems to matter
36)		T		F	People tell me I should pay more attention
37)		T		F	I go to the doctor's office more than most people
38)		T		F	I am more daring than my friends are
39)		T		F	Nothing feels good to me
40)		T		F	I always do assignments on time
41)		T		F	I get along well with my parents
42)		T		F	I cannot stop myself from doing bad things
43)		T		F	My parents are pressuring me to go to school
44)		T		F	I never seem to get anything right
45)		T		F	If I have a problem, I can usually work it out
46)		T		F	I just don't care anymore
47)		T		F	I worry a lot of the time
48)		T		F	My friends have more fun than I do
49)		T		F	I like to stretch the rules
50)		T		F	I wish I were different
51)		T		F	My stomach gets upset more than most people's
52)		T		F	I am attending school because I want to
53)		T		F	I have just returned from a 9-month trip on an ocean liner
54)		T		F	I never really feel in control of my life
55)		T		F	I don't seem to do anything right
56)		T		F	I never quite reach my goal
57)		T		F	I worry about little things
58)		T		F	I get into trouble because of my drinking
59)		T		F	Other people don't like me
60)		T		F	Nothing goes my way
61)		T		F	I can never really do what I want to do
62)		T		F	I am bored with school
63)		T		F	I feel good about myself
64)		T		F	Nothing about me is right
65)		T		F	My muscles get sore a lot
66)		T		F	Things go wrong for me, even when I try hard
67)		T		F	I have attention problems
68)		T		F	Often I feel sick in my stomach
	Never	Some-	Often	Almost	Remember: N – Never S – Sometimes O – Often A – Almost
(0)	N	times	0	Always	Always
69)	N	S	0	A	I do things that my friends are afraid to do
70)	N	S S	0	A	I feel sad
71) 72)	N N	S	0	A	I have trouble sleeping the night before a big test
	N N	S	0	A	My parents are proud of me I feel like people are out to get me
73)		S		A	1 1 5
74)	N N	S	0	A	I feel like quitting school When I take tests, I can't think
75) 76)	N N	S	0	A A	I am dependable
	N	S	0		I feel depressed
77) 78)	N N	S	0	A A	I get so nervous I can't breathe
79)	N N	S	0		People say bad things for me
80)	N	S	0	A A	I like it when my friends dare me to do something
81)	N	S	0	A	I am good at things
82)	N	S	0	A	I feel dizzy
83)	N	S	0	A	I enjoy doing schoolwork
84)	N	S	0	A	Someone else controls my thoughts
85)	N	S	0	A	I get blamed for things I can't help
86)	N	S	0	A	No one understands me
87)	N	S	0	A	I quit easily
0/)	1 N	ે	U	Α	i quit easily

	Never	Some- times	Often	Almost Always	Remember: N – Never S – Sometimes O – Often A – Almost Always
88)	N	S	О	A	I have trouble making up my mind
89)	N	S	0	A	I drink alcohol when I am by myself
90)	N	S	0	A	I feel close to others
91)	N	S	О	A	I feel like my life is getting worse and worse
92)	N	S	О	A	My life seems out of control
93)	N	S	О	A	I wonder why I am going to school
94)	N	S	О	A	My looks bother me
95)	N	S	О	A	I study the right things when I get ready for a test
96)	N	S	0	A	I feel better after a couple of drinks of alcohol
97)	N	S	O	A	I have trouble standing still in lines
98)	N	S	O	A	I forget things
99)	N	S	O	A	I stay awake for 24 hours without getting tired
100)	N	S	O	A	I like to ride in a car that is going fast
101)	N	S	O	A	When I get angry, I want to break something
102)	N	S	O	A	I do things over and over and can't stop
103)	N	S	O	A	I like going places with my parents
104)	N	S	0	A	Someone wants to hurt me
105)	N	S	0	A	I feel overwhelmed by demands of school
106)	N	S	0	A	I am disappointed with my grades
107)	N	S	0	A	I can solve difficult problems by myself
108)	N	S	0	A	I get mad at others
109)	N	S	0	A	I worry when I go to bed at night
110)	N	S	0	A	I am lonely
111)	N N	S S	0	A	I like to play rough sports
112)	N N	S	0	A	I like the way I look
113)	N N	S	0	A	People tell me to be still My mother and father like my friends
114)	N N	S	0	A	I hear things that others cannot hear
116)	N	S	0	A A	I am blamed for things I don't do
117)	N	S	0	A	I finish my work on time
118)	N	S	0	A	Even when I try hard, I fail
119)	N	S	0	A	I am afraid of a lot of things
120)	N	S	0	A	I drink alcohol to feel better
121)	N	S	0	A	I am slow to make new friends
122)	N	S	0	A	I feel like I belong at my school
123)	N	S	O	A	My parents expect too much from me
124)	N	S	O	A	I sleep with my schoolbooks
125)	N	S	0	A	I have trouble paying attention to lectures
126)	N	S	О	A	I get nervous when things do not go to the right way for me
127)	N	S	О	A	I drink alcohol so I can be at ease around other or at a party
128)	N	S	О	A	I have trouble sitting still
129)	N	S	О	A	I listen when people are talking to me
130)	N	S	О	A	I feel that nobody likes me
131)	N	S	O	A	I like to be the first one to try new things
132)	N	S	O	A	Other people find things wrong with me
133)	N	S	O	A	Even when alone, I feel like someone is watching me
134)	N	S	O	A	My parents are easy to talk to
135)	N	S	O	A	I see weird things
136)	N	S	0	A	When I get angry, I want to hurt someone
137)	N	S	0	A	I want to do better, but I can't
138)	N	S	0	A	I am good at making decisions
139)	N	S	0	A	I think about when I can do drinking again
140)	N	S	0	A	I feel guilty about things
141)	N	S	0	A	People act as if they don't hear me
142)	N	S	0	A	I like to experiment with new things
143)	N	S	0	A	I get upset about my looks
144)	N	S	O	A	I feel like I have to get up and move around

	Never	Some- times	Often	Almost Always	Remember: N – Never S – Sometimes O – Often A – Almost Always
145)	N	S	O	A	My parents trust me
146)	N	S	O	A	I enjoy meeting others
147)	N	S	O	A	People get mad at me, even when I don't do anything wrong
148)	N	S	O	A	I get into trouble for not paying attention
149)	N	S	O	A	I like to make decisions on my own
150)	N	S	O	A	I get nervous
151)	N	S	O	A	I drink more alcohol than I plan to drink
152)	N	S	O	A	I am liked by others
153)	N	S	О	A	I feel that others do not like the way I do things
154)	N	S	O	A	I am proud of my parents
155)	N	S	О	A	When I start talking, it's hard for me to stop
156)	N	S	О	A	When I get angry, I can't think about anything else
157)	N	S	O	A	I worry about what is going to happen
158)	N	S	О	A	I miss classes because of drinking or having a hangover
159)	N	S	O	A	I talk while other people are talking
160)	N	S	О	Α	I have trouble paying attention to what I am doing
161)	N	S	О	A	People think I am fun to be with
162)	N	S	О	Α	I like excitement
163)	N	S	О	A	I am left out of things
164)	N	S	О	A	Ideas just race through my mind
165)	N	S	О	A	My mother and father help me if I ask them to
166)	N	S	О	A	I hear voices in my head that no one else can hear
167)	N	S	О	A	I take a plane trip from New York to Tokyo at least twice a week
168)	N	S	О	A	I fail at things
169)	N	S	О	Α	My friends come to me for help
170)	N	S	О	Α	I drink alcohol to calm down
171)	N	S	О	Α	Little things bother me
172)	N	S	О	Α	I feel out of place around people
173)	N	S	О	Α	I like to dare others to do things
174)	N	S	О	Α	I have a hard time slowing down
175)	N	S	О	A	People tell me that I am too noisy
176)	N	S	О	A	My parents listen to what I say
177)	N	S	О	A	Other people hate to be with me
178)	N	S	О	A	I can't seem to turn off my mind
179)	N	S	О	A	I pay attention when someone is telling me how to do something
180)	N	S	О	A	I am someone you can rely on
181)	N	S	О	A	I worry but I don't know why
182)	N	S	О	A	People tell me I drink alcohol too much
183)	N	S	О	A	Others have respect for me
184)	N	S	О	A	Other people are against me
185)	N	S	O	A	I like to be close to my parents

WHAT I AM LIKE - C

- 1. First, read the descriptions of the two types of kids and decide which one is most like you
- 2. Now that you have decided which kind of kids are most like you, you need to decide whether it is "sort of true for you" or "really true for you" and put an "X" in the box
- 3. For each sentence, you will only mark one box. Sometimes it will be on one side of the page and other times it will be on the other side. You don't need to mark both sides, just the side that is most like you.

Really	Sort of				Sort of	Really
True	True				True	True
for Me	for Me				for me	for Me
		Some kids would rather		Other kids would		
		play outdoors in their	BUT	rather watch T.V.		
		spare time				
		Some kids feel that the		Other kids worry		
		are very <i>good</i> at their	BUT	about whether they		
		school work		can do the school		
				work assigned to		
				them.		
		Some kids find it <i>hard</i> to		Other kids find it's		
		make friends	BUT	pretty <i>easy</i> to make		
				friends.		
		Some kids do very well at		Other kids <i>don't</i> feel		
		all kinds of sports	BUT	that they are very		
				good when it comes to		
				sports.		
		Some kids are <i>happy</i> with		Other kids are <i>not</i>		
		the way they look	BUT	happy with the way		
				they look.		
		Some kids do <i>not</i> like the		Other kids usually <i>like</i>		
		way they behave	BUT	the way they behave.		
		Some kids are often		Other kids are pretty		
		<i>unhappy</i> with themselves	BUT	pleased with		
				themselves.		
		Some kids fell like they		Other kids aren't so		
		are just as smart as other	BUT	sure and wonder if		
		kids their age		they are as smart.		
		Some kids have <i>a lot</i> of		Other kids <i>don't</i> have		
		friends	BUT	very many friends.		
		Some kids wish they		Other kids feel they		
		could be a lot better at	BUT	are good enough at		
		sports		sports.		
		Some kids are <i>happy</i> with		Other kids with their		
		their height and weight	BUT	height or weight were		
				different.		

Really	Sort of				Sort of	Really
True	True				True	True
for Me	for Me				for me	for Me
		Some kids usually do the		Other kids often <i>don't</i>		
		right thing	BUT	do the right thing.		
		Some kids <i>don't</i> like the		Other kids <i>do</i> like the		
		way they are leading their	BUT	way they are leading		
		life		their life.		
		Some kids are pretty <i>slow</i>	DIVE	Other kids can do		
		in finishing their school	BUT	their school work		
		work		quickly.		
		Some kids would like to	DIT	Other kids have as		
		have a lot more friends	BUT	many friends as they		
		Some kids think they		want. Other kids are afraid		
		could do well at just	BUT	they might <i>not</i> do well		
		about any new sports	ВОТ	at sports they haven't		
		activity they haven't tried		ever tried.		
		before		ever tried.		
		Some kids wish their		Other kids <i>like</i> their		
		body was different	BUT	body the way it is.		
		Some kids usually <i>act</i> the		Other kids often don't		
		way they know they are	BUT	act the way they are		
		supposed to		supposed to.		
		Some kids are <i>happy</i> with		Other kids are often		
		themselves as a person	BUT	<i>not</i> happy with		
				themselves		
		Some kids often forget		Other kids can		
		what they learn	BUT	remember things		
				easily.		
		Some kids are always	DIE	Other kids usually do		
		doing things with a lot of	BUT	things by <i>themselves</i> .		
		kids Some kids feel that they		Other kids <i>don't</i> feel		
		Some kids feel that they are <i>better</i> than others their	RIIT	they can play as well.		
		age at sports	DUI	mey can play as well.		
		Some kids wish their		Other kids <i>like</i> their		
		physical appearance (how	BUT	appearance the way it		
		they look) was different.		is.		
		Some kids usually get in		Other kids usually		
		trouble because of things	BUT	don't do things that		
		they do		get them in trouble.		
		Some kids <i>like</i> the kind of		Other kids often wish		
		person they are	BUT	they were someone		
				else.		
		Some kids do very well at		Other kids <i>don't</i> do		
		their classwork	BUT	very well at their		
				classwork.		

Really True for Me	Sort of True for Me				Sort of True for me	Really True for Me
		Some kids wish that more people their age liked them	BUT	Other kids feel that most people their age do like them.		
		In games and sports some kids usually <i>watch</i> instead of play	BUT	Other kids usually play rather than just watch.		
		Some kids with something about their face or hair looked different	BUT	Other kids <i>like</i> their face and hair the way they are.		
		Some kids do things they know they <i>shouldn't</i> do	BUT	Other kids <i>hardly ever</i> do things they know they shouldn't do.		
		Some kids are very <i>happy</i> being the way they are	BUT	Other kids wish they were <i>different</i> .		
		Some kids have <i>trouble</i> figuring out the answers in school	BUT	Other kids almost always can figure out the answers.		
		Some kids are <i>popular</i> with others their age	BUT	Other kids are <i>not</i> very popular.		
		Some kids <i>don't</i> do well at new outdoor games	BUT	Other kids are <i>good</i> at new games right away.		
		Some kids think that they are good looking	BUT	Other kids think that they are not very good looking.		
		Some kids behave themselves very well	BUT	Other kids often find it hard to behave themselves.		
		Some kids <i>are not</i> very happy with the way they do a lot of things	BUT	Other kids think the way they do things is <i>fine</i> .		

WHAT I AM LIKE - A

- 1. First, read the descriptions of the two types of teenagers and decide which one is most like you
- 2. Now that you have decided which kind of teenagers are most like you, you need to decide whether it is "sort of true for you" or "really true for you" and put an "X" in the box
- 3. For each sentence, you will only mark one box. Sometimes it will be on one side of the page and other times it will be on the other side. You don't need to mark both sides, just the side that is most like you.

Really	Sort of				Sort of	Really
True	True				True	True
for Me	for Me				for me	for Me
101 1/10	101 1110	Some teenagers like to go		Other teenagers would	101 1110	101 1/10
		to movies in their spare	BUT	rather go to sports		
		time	201	events.		
		Some teenagers feel that		Other teenagers aren't		
		they are just as smart as	BUT	so sure and wonder if		
		others their age	DOI	they are as smart.		
		Some teenagers find it		For other teenagers		
		hard to make friends	BUT	it's pretty easy.		
		Some teenagers do very	DUI	Other teenagers don't		
		well at all kinds of sports	BUT	feel that they are very		
		well at all killes of sports	DUI	good when it comes to		
				sports.		
		Some teenagers are not		Other teenagers are		
		happy with the way they	BUT	happy with the way		
		look	DUI	they look.		
				· ·		
		Some teenagers feel that	DIT	Other teenagers feel		
		they are ready to do well	BUT	that hey are not quite		
		at a part-time job		ready to handle a part-		
		0 1.1		time job		
		Some teenagers feel that	DIVE	Other teenagers worry		
		if they are romantically	BUT	that when they like		
		interested in someone,		someone romantically,		
		that person will like them		that person won't like		
		back		them back.		
		Some teenagers usually		Other teenagers often		
		do the right thing	BUT	don't do what they		
				know is right.		
		Some teenagers are able		Other teenagers find it		
		to make really close	BUT	hard to make really		
		friends		close friends.		

Really True	Sort of True				Sort of True	Really True
for Me	for Me				for me	for Me
		Some teenagers are pretty		Other teenagers can		
		slow in finishing their	BUT	do their school work		
		school work		more quickly.		
		Some teenagers have a lot		Other teenagers don't		
		of friends	BUT	have very many		
				friends.		
		Some teenagers think		Other teenagers are		
		they could do well at just	BUT	afraid they might not		
		about any new athletic		do well at a new		
		activity		athletic activity.		
		Some teenagers wish their		Other teenagers like		
		body was different	BUT	their body the way it		
				is.		
		Some teenagers feel that		Other teenagers feel		
		they don't have enough	BUT	that hey do have		
		skills to do well at a job		enough skills to do a		
				job well.		
		Some teenagers are not		Other teenagers are		
		dating the people they are	BUT	dating those people		
		really attracted to		they are attracted to.		
		Some teenagers often get		Other teenagers		
		in trouble for the things	BUT	usually don't do		
		they do		things that get them in		
				trouble.		
		Some teenagers do have a		Other teenagers do not		
		close friend they can	BUT	have a really close		
		share secrets with		friend they can share		
				secrets with.		
		Some teenagers don't like		Other teenagers do		
		the way they are leading	BUT	like the way they are		
		their life		leading their life		
		Some teenagers do very		Other teenagers don't		
		well at their classwork	BUT	do very well at their		
				classwork.		
		Some teenagers are very		Other teenagers are		
		hard to like	BUT	really easy to like.		
		Some teenagers feel that		Other teenagers don't		
		they are better than others	BUT	feel they can play as		
		their age at sports	Der	well.		
		Some teenagers wish the		Other teenagers like		
		their physical appearance	BUT	their physical		
		was different	Der	appearance the way it		
		was different		is.		
		Some teenagers feel they		Other teenagers do not		
		are old enough to get and	BUT	feel they are old		
		keep a paying job		enough, yet, to really		
		keep a paying joo	1	handle a job well.		
	<u> </u>	1	l	nandic a job well.	L	l

Really True	Sort of True				Sort of True	Really True
for Me	for Me				for me	for Me
		Some teenagers feel that		Other teenagers worry		
		people their age will be	BUT	about whether people		
		romantically attracted to		their age will be		
		them		attracted to them.		
		Some teenagers feel		Other teenagers don't		
		really good about the way	BUT	feel that good about		
		they act	201	the way they often act.		
		Some teenagers wish they		Other teenagers do		
		had a really close friend	BUT	have a close friend to		
		to share things with	DOI	share things with.		
		Some teenagers are happy		Other teenagers are		
		with themselves most of	BUT	often not happy with		
		the time	DUI	themselves.		
			DIT			
		Some teenagers have trouble figuring out the	BUT	Other teenagers		
				almost always can		
		answers in school		figure out the answers.		
		Some teenagers are	DIE	Other teenagers are		
		popular with others their	BUT	not very popular.		
		age				
		Some teenagers don't do		Other teenagers are		
		well at new outdoor	BUT	good at new games		
		games		right away.		
		Some teenagers think that		Other teenagers think		
		they are good looking	BUT	that they are not very		
				good looking.		
		Some teenagers feel like		Other teenagers feel		
		they could do better at	BUT	that they are doing		
		work they do for pay		really well at work		
				they do for pay.		
		Some teenagers feel that		Other teenagers		
		they are fun and	BUT	wonder about how fun		
		interesting on a date		and interesting they		
				are on a date.		
		Some teenagers do things		Other teenagers hardly		
		they know they shouldn't	BUT	ever do things they		
		do		know they shouldn't		
				do.		
		Some teenagers find it		Other teenagers are		
		hard to make friends they	BUT	able to make close		
		can really trust		friends they can really		
				trust.		
		Some teenagers like the	1	Other teenagers often		
		kind of person they are	BUT	wish they were		
		kind of person they are	DUI	someone else.		
		Some teanagers feel that	1			
		Some teenagers feel that	BUT	Other teenagers		
		they are pretty intelligent	DUI	question whether they		
	<u> </u>	<u> </u>	1	are intelligent.		

Really True for Me	Sort of True for Me				Sort of True for me	Really True for Me
		Some teenagers feel that they are socially accepted	BUT	Other teenagers wished that more people their age accepted them.		
		Some teenagers do not feel that they are very athletic	BUT	Other teenagers feel that they are very athletic.		
		Some teenagers really like their looks	BUT	Other teenagers wish they looked different.		
		Some teenagers feel that they are really able to handle the work on a paying job	BUT	Other teenagers wonder if they are really doing as good a job at work as they should be doing.		
		Some teenagers usually don't go out with the people they would really like to date	BUT	Other teenagers do go out with the people they really want to date.		
		Some teenagers usually act the way they know they are supposed to	BUT	Other teenagers often don't act the way they are supposed to.		
		Some teenagers don't have a friend that is close enough to share really personal thoughts with	BUT	Other teenagers do have a close friend that the can share personal thoughts and feelings with.		
		Some teenagers are very happy being the way they are	BUT	Other teenagers wish they were different		

WHAT I AM LIKE - CS

- 1. First, read the descriptions of the two types of college students and decide which one is most like you.
- 2. Now that you have decided which kind of college students are most like you, you need to decide whether it is "sort of true for you" or "really true for you" and put an "X" in the box
- 3. For each sentence, you will only mark one box. Sometimes it will be on one side of the page and other times it will be on the other side. You don't need to mark both sides, just the side that is most like you.

Really True for Me	Sort of True for Me				Sort of True for me	Really True for Me
		Some students like the kind of person they are	BUT	Other students wish that they were different.		
		Some students are not very proud of the work they do on their job	BUT	Other students are very proud of the work they do on their job.		
		Some students feel confident that they are mastering their coursework	BUT	Other students do not feel so confident.		
		Some students are not satisfied with their social skills	BUT	Other students think their social skills are just fine.		
		Some students are not happy with the way they look	BUT	Other students are happy with the way they look.		
		Some students like the way they act when they are around their parents	BUT	Other students wish they acted differently around their parents.		
		Some students get kind of lonely because they don't really have a close friend to share things with	BUT	Other students don't usually get too lonely because they do have a close friend to share things with.		
		Some students feel like they are just as smart or smarter than other students	BUT	Other students wonder if they are as smart.		
		Some students often question the morality of their behavior	BUT	Other students feel their behavior is usually moral.		

Really True for Me	Sort of True for Me	Some students feel that		Other students worry	Sort of True for me	Really True for Me
		people they like romantically will be attracted to them	BUT	about whether people they like romantically will be attracted to them.		
		When some students do something sort of stupid that later appears very funny, they find it hard to laugh at themselves	BUT	When other students do something sort of stupid that later appears very funny, they can easily laugh at themselves.		
		Some students feel they are just as creative or even more so than other students	BUT	Other students wonder if they are as creative.		
		Some students feel they could do well at just about any new athletic activity they haven't tried before	BUT	Other students are afraid they might not do well at athletic activities they haven't tried before.		
		Some students are often disappointed with themselves	BUT	Other students are usually quite pleased with themselves.		
		Some students feel they are very good at their job	BUT	Other students worry about whether they can do their job.		
		Some student do very well at their studies	BUT	Other students don't do very well at their studies.		
		Some students find it hard to make new friends	BUT	Other students are able to make new friends easily.		
		Some students are happy with their height and weight	BUT	Other students wish their height or weight was different.		
		Some students find it hard to act naturally when they are around their parents	BUT	Other students find it easy to act naturally around their parents.		
		Some students are able to make close friends they can really trust	BUT	Other students find it hard to make close friends they can really trust.		
		Some students do not feel they are very mentally able	BUT	Other students feel that they are very mentally able.		

Really True for Me	Sort of True for Me	Some students usually do		Other students	Sort of True for me	Really True for Me
		what is morally right	BUT	sometimes don't do what they know is morally right.		
		Some students find it hard to establish romantic relationships	BUT	Other students don't have difficulty establishing romantic relationship.		
		Some students don't mind being kidded by their friends	BUT	Other students are bothered when friends kid them.		
		Some students worry that they are not as creative or inventive as other people Some students don't feel	BUT	Other students feel they are very creative and inventive. Other students feel		
		they are very athletic	BUT	they are athletic. Other students reel Other students often		
		Some students usually like themselves as a person	BUT	don't like themselves as a person		
		Some students feel confident about their ability to do a new job	BUT	Other students worry about whether they can do a new job they haven't tried before.		
		Some student have trouble figuring out homework assignments	BUT	Other students rarely have trouble with their homework assignments.		
		Some students like the way they interact with other people	BUT	Other students wish their interactions with other people were different.		
		Some students wish their body was different	BUT	Other students like their body the way it is.		
		Some students feel comfortable being themselves around their parents	BUT	Other students have difficulty being themselves around their parents.		
		Some students don't have a close friend they can share their personal thoughts and feelings with	BUT	Other students do have a friend who is close enough for them to share thoughts that are really personal.		
		Some students feel they are just as bright or brighter than most people	BUT	Other students wonder if they are as bright.		

Really True for Me	Sort of True for Me				Sort of True for me	Really True for Me
		Some students would like to be a better person morally	BUT	Other students think they are quite moral.		
		Some students have the ability to develop romantic relationships	BUT	Other students do not find it easy to develop romantic relationships.		
		Some students have a hard time laughing at the ridiculous or silly thing they do	BUT	Other students find it easy to laugh at themselves.		
		Some students do not feel that they are very inventive	BUT	Other students feel that they are very inventive.		
		Some students feel they are better than others at sports	BUT	Other students don't feel they can play as well.		
		Some students really like the way they are leading their lives Some students are	BUT	Other students often don't like the way they are leading their lives. Other students are		
		satisfied with the way they do their job	BUT	quite satisfied with the way they do their job.		
		Some students sometimes do not feel intellectually competent at their studies	BUT	Other students usually do feel intellectually competent at their studies		
		Some students feel that they are socially accepted by many people	BUT	Other students wish more people accepted them		
		Some students like their physical appearance the way it is	BUT	Other students do not like their physical appearance		
		Some students find that they are unable to get along with their parents	BUT	Other students get along with their parents quite well		
		Some students are able to make really close friends	BUT	Other students find it hard to make really close friends		
		Some students would really rather be different	BUT	Other students are very happy being the way they are		
		Some students question whether they are very intelligent	BUT	Other students feels they are intelligent		

Really	Sort of				Sort of	Really
True	True				True	True
for	for Me				for me	for
Me						Me
		Some students live up to		Other students have		
		their moral standards	BUT	trouble living up to		
				their moral standards		
		Some students worry that		Other students feel that		
		when they like someone	BUT	when they are		
		romantically, that person		romantically interested		
		won't like them back		in someone, that		
				person will like them		
				back		
		Some students can really		Other students have a		
		laugh at certain things	BUT	hard time laughing at		
		they do		themselves		
		Some students feel they		Other students		
		have a lot of original	BUT	question whether their		
		ideas		ideas are very original		
		Some students don't do		Other students are		
		well at activities requiring	BUT	good at activities		
		physical skill		requiring physical skill		
		Some students are often		Other students are		
		dissatisfied with	BUT	usually satisfied with		
		themselves		themselves		

PEOPLE IN MY LIFE – C/A

- 1. First, read the descriptions of the two types of kids and decide which one is most like you
- 2. Now that you have decided which kind of kids are most like you, you need to decide whether it is "sort of true for you" or "really true for you" and put an "X" in the box
- 3. For each sentence, you will only mark one box. Sometimes it will be on one side of the page and other times it will be on the other side. You don't need to mark both sides, just the side that is most like you.

Really True for Me	Sort of True for Me				Sort of True for me	Really True for Me
		Some kids like to do fun things with a lot of other people	BUT	Other kids like to do fun things with just a few people		
		Some kids have parents who <i>don't</i> really understand them	BUT	Other kids have parents who really <i>do</i> understand them		
		Some kids have classmates who like them the way they are	BUT	Other kids have classmates who wish they were <i>different</i>		
		Some kids have a teacher who <i>helps</i> them if they are <i>upset</i> and have a problem	BUT	Other kids <i>don't</i> have a teacher who helps them if they are upset and have a problem		
		Some kids have a close friend who they can tell problems to	BUT	Other kids <i>don't</i> have a close friend who they can tell problems to		
		Some kids have parents who <i>don't</i> seem to want to hear about their children's problems	BUT	Other kids have parents who <i>do</i> want to <i>listen</i> to their children's problems		
		Some kids have classmates that they can become friends with	BUT	Other kids <i>don't</i> have classmates that they can become friends with		
		Some kids <i>don't</i> have a teacher who <i>helps</i> them to do their very best	BUT	Other kids <i>do</i> have a teacher who <i>helps</i> them to do their very best		
		Some kids have a close friend who really understands them	BUT	Other kids <i>don't</i> have a close friend who understands them		

Really True for Me	Sort of True for Me				Sort of True for me	Really True for Me
		Some kids have parents who <i>care</i> about their feelings	BUT	Other kids have parents who don't seem to care very much about their children's feelings		
		Some kids have classmates who sometimes make fun of them	BUT	Other kids <i>don't</i> have classmates who make fun of them		
		Some kids <i>do</i> have a teacher who <i>cares</i> about them	BUT	Other kids <i>don't</i> have a teacher who cares about them		
		Some kids have a close friend who they can talk to about things that bother them	BUT	Other kids <i>don't</i> have a close friend who they can talk to about things that bother them		
		Some kids have parents who treat their children like a personal who really matters	BUT	Other kids have parents who don't usually treat their children like a person who matters		
		Some kids have classmates who pay attention to what they say	BUT	Other kids have classmates who usually don't pay attention to what they say		
		Some kids <i>don't</i> have a teacher who is <i>fair</i> to them	BUT	Other kids <i>do</i> have a teacher who is fair to them		
		Some kids <i>don't</i> have a close friend who they like to spend time with Some kids have parents	BUT	Other kids <i>do</i> have a close friend who they like to spend time with Other kids have		
		who like them the way they are	BUT	parents who wish their children were different		
		Some kids <i>don't</i> get asked to play in games with classmates very often	BUT	Other kids <i>often</i> get asked to play in games by their classmates		
		Some kids <i>don't</i> have a teacher who cares if they feel bad	BUT	Other kids <i>do</i> have a teacher who cares if they feel bad		
		Some kids <i>don't</i> have a close friend who really listens to what they say	BUT	Other kids <i>do</i> have a close friend who really listens to what they say		

Really	Sort of				Sort of	Really
True	True				True	True
for Me	for Me				for me	for
						Me
		Some kids have parents		Other kids have		
		who <i>don't</i> act like what	BUT	parents who do act like		
		their children do is		what their children do		
		important		is important		
		Some kids often spend		Other kids spend		
		recess being alone	BUT	recess playing with		
				their classmates		
		Some kids have a teacher		Other kids <i>don't</i> have		
		who treats them like a	BUT	a teacher who treats		
		person		them like a person		
		Some kids <i>don't</i> have a		Other kids do have a		
		close friend who cares	BUT	close friend who cares		
		about their feelings		about their feelings		

PEOPLE IN MY LIFE - CS

- 1. First, read the descriptions of the two types of college students and decide which one is most like you
- 2. Now that you have decided which kind of college students are most like you, you need to decide whether it is "sort of true for you" or "really true for you" and put an "X" in the box
- 3. For each sentence, you will only mark one box. Sometimes it will be on one side of the page and other times it will be on the other side. You don't need to mark both sides, just the side that is most like you.

Really True for Me	Sort of True for Me				Sort of True for me	Really True for Me
		Some students have a close friend who wants to hear about their problems	BUT	Other students don't have a close friend who wants to hear about their problems		
		Some students have a mother who doesn't really understand them	BUT	Other students have a mother who really does understand them		
		Some students feel the people in their organizations treat them like a person who matters	BUT	Other students feel like the people in their organizations do not treat them like a person who matters		
		Some students have a father who doesn't seem to want to hear about their problems	BUT	Other students have a father who does want to listen to their problems		
		Some students do feel they have the support of their instructors	BUT	Other students feel they do not have the support of their instructors		
		Some students don't have a close friend who really understands them	BUT	Other students do have a really close friend who understands them		
		Some students have a mother who likes them the way they are	BUT	Other students have a mother who wishes they were different		
		Some students feel that people in their campus organizations don't take what they say seriously	BUT	Other students feel that people in their campus organizations do take what they say seriously		
		Some students feel their father is pleased with the way they are	BUT	Other students feel that their father is disappointed with the way they are		

Really True for Me	Sort of True for Me				Sort of True for me	Really True for Me
IVIE		Some students have instructors who don't really listen to what they say	BUT	Other students have instructors who do really listen to what they say		IVIE
		Some students have a friend they can confide in about things that bother them	BUT	Other students don't have a friend they can confide in about things that bother them		
		Some students have a mother who really cares about how they feel	BUT	Other students have a mother who doesn't really care how they feel		
		Some students feel they have the support of people in campus organizations to which they belong	BUT	Other students do not feel they have the support of people in campus organizations to which they belong		
		Some students have a father who doesn't really care how they feel	BUT	Other students have a father who really does care how they feel		
		Some students have instructors who are understanding when you tell them about a problem	BUT	Other students have instructors who are not very understanding about their problems		
		Some students don't have a close friend who really cares about how they feel	BUT	Other students do have a close friend who really cares about how they feel		
		Some students have a mother who doesn't seem to want to hear about their problems	BUT	Other students have a mother who does want to hear about their problems		
		Some students feel that the people in campus organizations would prefer them if they were different	BUT	Other students feel that the people in campus organizations like them the way they are		
		Some students have a father who likes them the way they are	BUT	Other students have a father who wishes they were different		
		Some students have instructors who do not take what they say seriously	BUT	Other students have instructors who usually do take what they say seriously		

Appendix C RECRUITMENT LETTER

«Date»

Dear «Parent Name»,

We are contacting you because your child, «Child_Name», is a survivor of pediatric cancer who was treated at the Jimmy Everest Center for Childhood Cancer and Bleeding Disorders (JEC). Additionally, «Child_Name» received a neuropsychological evaluation at the University of Oklahoma Health Sciences Center (OUHSC) on «date_of_evaluation». At the time of «Child_Name»'s evaluation, you consented to «hisher» data being used for research purposes, and Dr. Larry Mullins is currently conducting a study that is investigating whether «Child_Name»'s scores on «hisher» neuropsychological assessment are related to «hisher» current emotional, behavioral, and social functioning, and you and «Child_Name» are eligible to participate.

Your participation in this study is voluntary and would require that you and your child complete questionnaires regarding «hisher» current functioning. The study would last for 45 minutes to 1 hour and your participation would end as soon as the questionnaires are completed. There are two options for participating in this study. You may either 1) complete the measures during your next clinic visit at the JEC, or 2) have a research assistant travel to your home so you can complete the measures.

Although there is no direct benefit to you or your child, your participation would allow us to begin to identify survivors of pediatric cancer who are at greatest risk for poor emotional, behavioral, and social functioning. These survivors could be targeted for intensive interventions to attempt to reduce the long-term effects of their disease.

This study is being funded by the OU College of Medicine Alumni Association, which allows us to provide you with a \$20.00 gift card as a thank you for your participation.

If you and your child are interested in participating, please contact Cortney Wolfe by phone at (405) 271-5830 or via e-mail at cortney.wolfe@okstate.edu. If we do not hear from you within 10 days of the date of this letter, we will contact you by phone to identify whether or not you are interested in participating. If you are not interested in participating or do not wish to be contacted, please feel free to leave a message at (405) 271-5830. Your participation is greatly appreciated.

Sincerely,

James Scott, Ph.D., ABPP-CN

Professor

Department of Psychiatry and Behavioral Sciences

Appendix D

TABLES

Table 1

Breakdown of Diagnoses

Diagnosis	Frequency	% of Total
Acute Lymphoblastic Leukemia (ALL)	6	20.0 %
Astrocytoma	1	3.3 %
Ependymoma	1	3.3 %
Low Grade Astrocytoma	1	3.3 %
Low Grade Glioma	1	3.3 %
Medulloblastoma	12	40.0 %
Neuroblastoma	2	6.7 %
Non-Hodgkin's Lymphoma	2	6.7 %
Oligodendroglioma	1	3.3 %
Optic Pathway Glioma	2	6.7 %
Wilms' Tumor	1	3.3 %

Table 2

Descriptive Statistics for Predictor and Outcome Variables

Variables	Entire Sample (N = 30)	CNS- Involvement	Non CNS- Involvement (N =
		(N = 19)	11)
VIQ	93.10 (16.95)	93.42 (17.77)	92.50 (16.18)
PIQ	88.85 (17.34)	85.29 (17.85)	94.90 (15.44)
LSDQ-P	33.80 (10.24)	34.74 (8.60)	32.18 (12.91)
LSDQ-S	31.10 (8.70)	30.21 (6.36)	32.80 (12.22)
SC	19.00 (4.40)	19.94 (4.26)	17.22 (4.32)
SS	18.68 (4.97)	17.80 (5.37)	20.00 (4.22)
ESI	48.86 (9.75)	45.61 (5.88)	54.70 (12.68)
PA	50.59 (10.35)	54.00 (6.53)	45.00 (13.12)
BSI	51.27 (12.01)	49.79 (7.73)	53.82 (17.30)
IP	54.37 (12.45)	53.47 (10.17)	55.91 (16.10)
EP	47.93 (9.31)	46.63 (6.39)	50.18 (13.01)

Note: VIQ = Verbal Intelligence Quotient; PIQ = Performance Intelligence Quotient; LSDQ-P =

Loneliness and Social Dissatisfaction Scale - Parent Report; LSDQ-S = Loneliness and Social

Dissatisfaction Scale - Self Report; SS = Social Support Scale for Children; SC = Self-Perception Profile

(Social Competence); BSI = Behavioral Symptoms Index; IP = Internalizing Problems; EP = Externalizing

Problems; ESI = Emotional Symptoms Index; PA = Personal Adjustment

Table 3

Descriptive Statistics for Demographic Variables and Illness Parameters for CNS vs. non

CNS-involvement

Demographic Variable/Illness Parameter	CNS-Involvement (N = 19)	Non CNS- Involvement $(N=11)$
Gender	8 F, 11 M	2 F, 9 M
Age at Diagnosis (years)*	8.66 (4.15)	5.45 (2.19)
Current Age (years)	15.02 (4.25)	12.16 (3.51)
Time Since Diagnosis (years)	6.44 (3.32)	7.14 (5.25)
Illness Duration (years)**	2.09 (0.93)	0.92 (0.86)
Time Off Treatment (years)	4.44 (3.29)	6.23 (5.45)
Time Between NP Eval. and Current Eval. (years)	2.83 (1.88)	4.71 (4.15)

Note: * *p* < .05; ** *p* < .01

Table 4

Zero-Order Correlations Between Demographic Variables and Outcome Variables

Variable	1	2	3	4	5	6	7	8	9	10	11	12	13	14
4 (21.21.1														
1. Child														
Age		37*	.07	.58**	.08	.09	.04	64**	28	29	.03	30	07	.34
2. Child														
Gender			.12	14	.07	02	09	.41*	12	.16	06	.14	.25	19
3. Family														
Income				.35	.51**	33	31	09	.10	51**	25	54**	.01	.12
4. Parent					• 0		• •							
Age					.29	01	20	01	14	35	09	27	03	.33
5. Parent								• 0	0.6	•				
Education						07	37*	.28	.06	29	11	22	11	.34
6.														
LSDQ-P							.53**	31	52**	.64**	.53**	.50**	.46*	18
7.									40.1					
LSDQ-S								44*	40*	.46*	.35	.32	.64**	81**
8. SS									.18	09	22	01	24	07
9. SC										45*	40*	37	65**	.32
10. BSI											.78**	.92**	.53**	41*
11. IP												.66**	.55**	25
12. EP													.43*	29
13. ESI														79**
14. PA														

Note: LSDQ-P = Loneliness and Social Dissatisfaction Scale - Parent Report; <math>LSDQ-S = Loneliness and Social Dissatisfaction Scale - Self Report; <math>SS = Social Support Scale for Children; SC = Self-Perception Profile (Social Competence); BSI = Behavioral Symptoms Index; <math>IP = Internalizing Problems; EP = Externalizing Problems; ESI = Emotional Symptoms Index; <math>PA = Personal Adjustment; *p < .05, **p < .01

Table 5

Zero-Order Correlations Between Illness Parameters and Outcome Variables

Variable	1	2	3	4	5	6	7	8	9	10	11	12	13	14
1. Age at														
Diagnosis 2. Disease		.45*	36	34	.43*	08	.01	21	17	16	.02	12	15	.26
Group			62**	.13	.20	.08	07	20	.30	22	16	28	42*	.39*
3. Illness			02	.13	.20	.08	07	20	.30	22	10	28	42	.39
Duration				34	21	08	.04	.22	03	.22	.05	.21	.27	36
4. Time off														
Treatment					.79**	.23	.12	45*	01	21	07	23	02	.15
5. Time b/t														
Tests						.28	.01	40*	.01	20	01	30	03	.20
6.														
LSDQ-P							.53**	31	52**	.64**	.53**	.50**	.46*	18
7. LSDQ-S								4.45	40*	4.64	2.5	22	C d about	0.1.44
LSDQ-S								44*	40*	.46*	.35	.32	.64**	81**
8. SS									.18	09	22	01	24	07
9. SC										45*	40*	37	65**	.32
10. BSI											.78**	.92**	.53**	41*
11. IP												.66**	.55**	25
12. EP													.43*	29
13. ESI														79**
14. PA														

Note: Illness Duration = Date off treatment – Date of Diagnosis; Time off Treatment = Date of Participation – Date off Treatment; Time b/t Tests = Date of Participation – Date of Neuropsychological Evaluation; LSDQ-P = Loneliness and Social Dissatisfaction Scale – Parent Report; LSDQ-S = Loneliness and Social Dissatisfaction Scale – Self Report; SS = Social Support Scale for Children; SPP = Self-Perception Profile (Social Competence); BSI = Behavioral Symptoms Index; IP = Internalizing Problems; EP = Externalizing Problems; ESI = Emotional Symptoms Index; PA = Personal Adjustment; * p < .05, ** p < .01

Table 6

Zero-Order Correlations Between Predictor and Outcome Variables

Variable	1	2	3	4	5	6	7	8	9	10	11
1. VIQ		.72**	38*	29	.01	.30	11	.17	45*	28	43*
2. PIQ 3.			30	02	.02	.37	.05	17	36	36	35
LSDQ-P 4.				.51**	48*	31	.43*	16	.64**	.53**	.50**
LSDQ-S					40*	44*	.64**	81**	.46*	.35	.32
5. SS						.18	65**	.32	45*	40*	37
6. SC							24	07	09	22	01
7. ESI								79**	.53**	.55**	.43*
8. PA									41*	25	29
9. BSI										.78**	.92**
10. IP											.66**
11. EP											

Note: VIQ = Verbal Intelligence Quotient; PIQ = Performance Intelligence Quotient; LSDQ-P = Loneliness and Social Dissatisfaction Scale – Parent Report; LSDQ-S = Loneliness and Social Dissatisfaction Scale – Self Report; SS = Social Support Scale for Children; SPP = Self-Perception Profile (Social Competence); BSI = Behavioral Symptoms Index; IP = Internalizing Problems; EP = Externalizing Problems; ESI = Emotional Symptoms Index; PA = Personal Adjustment; PA = Personal Problems; P

Table 7

Hierarchical Regression Analyses of Post-Treatment Intellectual Functioning on Current

Levels of Self-Reported Loneliness

Step	Variable	Standardized β	t for within- step predictors	R ² Change for step	Cumulative R^2	F Change for Step
1	Parent Education	40	-2.19*	.16	.16	4.81*
2	VIQ	33	-1.06	.05	.22	.78
	PIQ	.32	1.21			

Note: VIQ = Verbal Intelligence Quotient; PIQ = Performance Intelligence Quotient; p < .05; ** p < .01

Table 8

Hierarchical Regression Analyses of Post-Treatment Intellectual Functioning on Current

Levels of Self-Reported Perceived Social Competence

Step	Variable	Standardized β	t for within- step predictors	R ² Change for step	Cumulative R^2	F Change for Step
	VIQ	.07	.21	.001	.001	.03
	PIQ	03	10			

Table 9

Hierarchical Regression Analyses of Post-Treatment Intellectual Functioning on Current

Levels of Self-Reported Perceived Social Support

Step	Variable	Standardized β	t for within- step predictors	R ² Change for step	Cumulative R^2	F Change for Step
1	Child Age	58	-2.68	.37	.37	5.94**
	Child Gender Time Off	.05	.25			
2	Treatment Time Between	10	38	.01	.38	.91
	Tests	.06	.29			
3	VIQ	.23	.81	.11	.49	1.72
	PIQ	.13	.45			

Note: VIQ = Verbal Intelligence Quotient; PIQ = Performance Intelligence Quotient; p < .05; ** p < .01

Table 10

Hierarchical Regression Analyses of Post-Treatment Intellectual Functioning on Current

Levels of Self-Reported Emotional Symptoms

Step	Variable	Standardized β	t for within- step predictors	R ² Change for step	Cumulative R^2	F Change for Step
1	Disease Group	44	-2.84*	.19	.19	5.68*
2	VIQ	14	48	.01	.20	.17
	PIQ	.05	.16			

Table 11

Hierarchical Regression Analyses of Post-Treatment Intellectual Functioning on Current

Level of Self-Reported Personal Adjustment

Step	Variable	Standardized β	t for within- step predictors	R ² Change for step	Cumulative R^2	F Change for Step
1	Disease Group	.36	1.89	.13	.13	3.55
2	VIQ	.55	1.90	.13	.26	1.89
	PIQ	51	-1.73			

Note: VIQ = Verbal Intelligence Quotient; PIQ = Performance Intelligence Quotient; *p < .05; **p < .01

Table 12

Hierarchical Regression Analyses of Post-Treatment Intellectual Functioning on Current

Levels of Parent-Reported Internalizing Problems

Step	Variable	Standardized β	t for within- step predictors	R ² Change for step	Cumulative R^2	F Change for Step
	Annual Family					
1	Income	31	-1.58	.09	.09	2.50
2	VIQ	.01	.03	.07	.16	.85
	PIQ	29	-1.02			

Table 13

Hierarchical Regression Analyses of Post-Treatment Intellectual Functioning on Current

Levels of Parent-Reported Global Behavioral Functioning

Step	Variable	Standardized β	t for within- step predictors	R ² Change for step	Cumulative R^2	F Change for Step
1	Annual Family Income	66	-4.31**	.44	.44	18.55**
2	VIQ	10	35	.01	.45	.26
	PIQ	06	26			

Note: VIQ = Verbal Intelligence Quotient; PIQ = Performance Intelligence Quotient; *p < .05; **p < .01

Table 14

Hierarchical Regression Analyses of Post-Treatment Intellectual Functioning on Current

Levels of Parent-Reported Externalizing Problems

Step	Variable	Standardized β	t for within- step predictors	R ² Change for step	Cumulative R^2	F Change for Step
	Annual Family					
1	Income	65	- 4.23**	.43	.43	17.92**
2	VIQ	01	05	.01	.43	.13
	PIQ	08	35			

Appendix E

INSTITUTIONAL REVIEW BOARD APPROVAL LETTERS



The University of Oklahoma

Health Sciences Center

INSTITUTIONAL REVIEW BOARD

IRB Number: 12866

Meeting Date: June 19, 2006 Approval Date: July 27, 2006

July 27, 2006

Larry Mullins, Ph.D. Dept of Pediatrics 940 N. E. 13th, CHO 3B3308 Oklahoma City, OK 73104-5066

RE: Neuropsychological Predictors of Long-Term Social Functioning of Pediatric Cancer Survivors

Dear Dr. Mullins:

The University of Oklahoma Health Sciences Center's Institutional Review Board (IRB) reviewed the above-referenced research protocol at its regularly scheduled meeting on June 19, 2006. It is the IRB's judgement that the rights and welfare of the individuals who may be asked to participate in this study will be respected; that the proposed research, including the process of obtaining informed consent, will be conducted in a manner consistent with the requirements of 45 CFR 46 or 21 CFR 50 & 56, as amended; and that the potential benefits to participants and to others warrant the risks participants may choose to incur.

On behalf of the IRB, I have verified that the specific changes requested by the convened IRB have been made. Therefore, on behalf of the Board, I have granted final approval for this study.

This letter documents approval to conduct the research as described:

SRC Appr Ltr Dated: May 17, 2006 IRB Application Dated: May 01, 2006 Protocol Dated: February 16, 2005

Other Dated: May 01, 2006 Appendix A: Measures
Consent form - Subject Dated: April 24, 2006 Revised
Priv - Research Auth 1 Dated: January 06, 2005

Other Dated: May 01, 2006 Appendix B: Recruitment Letter

Assent Form Dated: July 12, 2006 Revised

As principal investigator of this protocol, it is your responsibility to make sure that this study is conducted as approved by the IRB. Any modifications to the protocol or consent form, initiated by you or by the sponsor, will require prior approval, which you may request by completing a protocol modification form.

It is a condition of this approval that you report promptly to the IRB any serious, unanticipated adverse events experienced by participants in the course of this research, whether or not they are directly related to the study protocol. These adverse events include, but may not be limited to, any experience that is fatal or immediately life-threatening, is permanently disabling, requires (or prolongs) inpatient hospitalization, or is a congenital anomaly, cancer or overdose. For multi-site protocols, the IRB must be informed of serious adverse events at all sites.

The approval granted expires on May 31, 2007. Should you wish to maintain this protocol in an active status beyond that date, you will need to provide the IRB with an IRB Application for Continuing Review (Progress Report) summarizing study results to date. The IRB will request a progress report from you approximately three months before the anniversary date of your current approval.

If you have questions about these procedures, or need any additional assistance from the IRB, please call the IRB office at (405) 271-2045 or send an email to irb@ouhsc.edu. Finally, please review your professional liability insurance to make sure your coverage includes the activities in this study.

Kardy Vacana

Sincerely your

Chair, Institutional Review Board



The University of Oklahoma

Health Sciences Center

INSTITUTIONAL REVIEW BOARD

IRB Number: 12866

Amendment Approval Date: August 08, 2006

August 16, 2006

Larry Mullins, Ph.D. Dept of Pediatrics 940 N. E. 13th, CHO 3B3308 Oklahoma City, OK 73104-5066

RE: IRB No. 12866: Neuropsychological Predictors of Long-Term Social Functioning of Pediatric Cancer

Dear Dr. Mullins:

On behalf of the Institutional Review Board (IRB), I have reviewed your protocol modification form. It is my judgement that this modification allows for the rights and welfare of the research subjects to be respected. Further, it has been determined that the study will continue to be conducted in a manner consistent with the requirements of 45 CFR 46 or 21CFR 50 56 as amended; and that the potential benefits to subjects and others warrant the risks subjects may choose to incur.

This letter documents approval to conduct the research as described in:

Amend Form Dated: July 31, 2006 Protocol Dated: July 31, 2006

Letter Dated: July 31, 2006 Parent letter - contact Consent form - Subject Dated: July 31, 2006

Amendment Summary:

Received funding from OU College of Medicine Alumni Assoc. for study. Submit revised Protocol, Consent Form and Parent letter to provide reimbursement for participation in study.

This letter covers only the approval of the above referenced modification. All other conditions, including the original expiration date, from the approval granted July 27, 2006 are still effective.

If consent form revisions are a part of this modification, you will be provided with a new stamped copy of your consent form. Please use this stamped copy for all future consent documentation. Please discontinue use of all outdated versions of this consent form.

If you have any questions about these procedures or need additional assistance, please do not hesitate to call the IRB office at (405) 271-2045 or send an email to irb@ouhsc.edu.

Chair, Institutional Review Board

Ltr_Amend_Final_Appv_Exp

Sincerely your

Post Office Box 26901 • 1000 S.L. Young Blvd., Room 176 Oklahoma City, Oklahoma 73190 • (405) 271-2045 • FAX: (405) 271-1677

Oklahoma State University Institutional Review Board

Date: Monday, January 22, 2007 IRB Application No AS06139

Proposal Title: Neuropsychological Predictors of Long-Term Social Functioning of Pediatric Cancer

Survivor

Reviewed and

Processed as: Expedited (Spec Pop)

Status Recommended by Reviewer(s): Approved Protocol Expires: 5/31/2007

Principal Investigator(s):

Cortney Wolfe-Christensen

215 N. Murray

Stillwater, OK 74078

Larry L. Mullins

OUHSC 940 NE 13th St.

Okla. City. OK 73104

Jennifer L. Callahan

215 N. Muray

Stillwater, OK 74078

The IRB application referenced above has been approved. It is the judgment of the reviewers that the rights and welfare of individuals who may be asked to participate in this study will be respected, and that the research will be conducted in a manner consistent with the IRB requirements as outlined in section 45 CFR 46.

The final versions of any printed recruitment, consent and assent documents bearing the IRB approval stamp are attached to this letter. These are the versions that must be used during the study.

The reviewer(s) had these comments:

Please note that this protocol has been approved for less than one year. The expiration date has been chosen to match that of the the OUHSC IRB approval. OSU IRB renewal can be applied for at that time.

Additionally, any modifications to this research project must also be reviewed and approved by the OSU IRB.

As Principal Investigator, it is your responsibility to do the following:

- Conduct this study exactly as it has been approved. Any modifications to the research protocol
 must be submitted with the appropriate signatures for IRB approval.
- Submit a request for continuation if the study extends beyond the approval period of one calendar year. This continuation must receive IRB review and approval before the research can continue.
- Report any adverse events to the IRB Chair promptly. Adverse events are those which are unanticipated and impact the subjects during the course of this research; and
- 4. Notify the IRB office in writing when your research project is complete.

Please note that approved protocols are subject to monitoring by the IRB and that the IRB office has the authority to inspect research records associated with this protocol at any time. If you have questions about the IRB procedures or need any assistance from the Board, please contact Beth McTernan in 219 Cordell North(phone: 405-744-5700, beth.mcternan@okstate.edu).

Sincerely,

Institutional Review Board

VITA

Cortney Wolfe-Christensen

Candidate for the Degree of

Master of Science

Thesis: THE RELATIONSHIP BETWEEN POST-TREATMENT INTELLECTUAL FUNCTIONING AND LONG-TERM SOCIAL FUNCTIONING IN SURVIVORS OF PEDIATRIC CANCER

Major Field: Psychology

Biographical:

Education: Graduated from West Bloomfield High School, West Bloomfield, Michigan in June 1997; received Bachelor of Science degree, in Biopsychology and Cognitive Science from the University of Michigan, Ann Arbor, Michigan in May 2001. Completed the requirements for the Master of Science degree with a major in Clinical Psychology at Oklahoma State University in May 2007.

Experience: Research – Acting Graduate Research Assistant for the Neuropsychological predictors of long-term social functioning in survivors of pediatric cancer, a grant funded by the University of Oklahoma College of Medicine Alumni Association from August 2006 to present. Previously employed as a Graduate Research Assistant in the department of pediatrics, section of hematology/oncology at the University of Oklahoma Health Sciences Center, from July 2005 to August 2006; Research Assistant in the Neuropsychology Department at the Children's Hospital of Michigan, August 2002 to May 2004; Research Assistant in the Neuropsychology Department at the University of Michigan Medical Center, May 2001 to July 2002. Clinical – Acting Psychological Associate at the Oklahoma State University Psychological Services Center, August 2004 to present; Practicum Student at the A Better Chance Clinic, July 2006 to present.

Professional Memberships: American Psychological Association; Division 40, Clinical Neuropsychology; Division 54, Society of Pediatric Psychology

Name: Cortney Wolfe-Christensen Date of Degree: May, 2007

Institution: Oklahoma State University Location: Stillwater, Oklahoma

Title of Study: THE RELATIONSHIP BETWENN POST-TREATMENT
INTELLECTUAL FUNCTIONING AND LONG-TERM SOCIAL
FUNCTIONING IN SURVIVORS OF PEDIATRIC CANCER

Pages in Study: 147 Candidate for the Degree of Master of Science

Major Field: Clinical Psychology

Scope and Method of Study: The purpose of the current study was threefold. First, both parent and self-report measures were included to obtain a comprehensive, multiinformant assessment of the emotional, behavioral, and social functioning of pediatric cancer survivors. Second, we sought to examine whether deficits in posttreatment intellectual functioning were related to long-term emotional, behavioral, and social functioning in survivors of pediatric cancer. Finally, differences in social functioning between survivors of cancer with and without central nervous system (CNS) involvement were explored. Participants included 30 children and adolescents ranging in age from 7 to 21 years old (M = 13.97, SD = 4.18), who underwent treatment for cancer diagnosed in childhood, and received a posttreatment comprehensive neuropsychological evaluation. With regard to diagnosis, 19 of the children (63%) were survivors of pediatric brain tumors, while the remaining 37% were survivors of other types of pediatric cancer. The child/adolescent participants completed the Behavior Assessment System for Children, 2nd Edition (BASC-2), the Loneliness and Social Dissatisfaction Questionnaire (LSDQ), the Social Support Scale for Children, and the Self-Perception Profile. The parent participants rated their child's current functioning using the BASC-2, and a revised version of the LSDQ.

Findings and Conclusions: Results revealed that although several demographic variables and illness parameters were related to the outcome variables, post-treatment intellectual functioning was unrelated to the child's current emotional, behavioral, or social functioning. Further, deficits in post-treatment IQ scores were not related to the child's current perceived level of social support or social competence. Surprisingly, in contrast to previous findings, survivors of cancer with CNS-involvement reported significantly higher levels of perceived social competence than survivors of cancer without CNS-involvement. Finally, for survivors of cancer without CNS-involvement, the parent and self-report scores on the LSDQ were significantly correlated (p < .001). However, the parent and self-report scores on the LSDQ for survivors of cancer with CNS-involvement were not correlated.

ADVISER'S APPROVAL: Jennifer L. Callahan, Ph.D.