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THE EFFECTS OF PEDIATRIC ACUTE LYMPHOBLASTIC LEUKEMIA ON
SOCIAL COMPETENCE: AN INVESTIGATION INTO THE
FIRST THREE MONTHS OF TREATMENT

by

Rachel L. Duchoslav

A thesis submitted in partial fulfillment
of the requirement for the degree

of

MASTER OF SCIENCE

in

Psychology

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2010

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ABSTRACT

The Effects of Pediatric Acute Lymphoblastic Leukemia on Social Competence:
An Investigation into the First Three Months of Treatment

by

Rachel L. Duchoslav, Master of Science

Utah State University, 2010

Major Professor: Clinton E. Field, Ph.D.
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Childhood cancer is the leading cause of death by disease for children under 15 years of age. Despite a growing survival rate for childhood cancer, psychological research of this population has lagged behind medical advances in treatment. The research that does exist in the psycho-oncology literature is plagued with inconsistency in conclusions and methodological limitations. Focus has been given to measuring maladaptive symptoms with few firm conclusions. Conclusions in the area of social competence of children with cancer have been considerably more reliable than in other domains. Previous research suggests that children with cancer exhibit significant difficulties in the areas of social competence (peer relationships, social functioning) when compared with healthy peers. Although this phenomenon has been consistently demonstrated, it had not been investigated longitudinally or with a focus on pre- and postdiagnosis differences in functioning. This project investigated individual change in

social competence in children with acute lymphoblastic leukemia (the most common form of childhood cancer) during their first 3 months of treatment compared to normally developing controls.

(83 pages)

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I am fortunate to have a tight community of friends and loved ones in graduate school. I thank each of them for what I have learned from them, and for how we have grown together. Finally, I am blessed with the unwavering support of a loving family; for them I will be forever grateful. I thank them for everything.

Rachel L. Duchoslav

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CHAPTER I

INTRODUCTION

Cancer is currently the leading cause of death by disease in the US for children under the age of 15. However, medical advances in treatment for childhood cancer have made impressive strides in increasing survival rates, which currently approach 80% 5 years post diagnosis (Vannatta & Gerhardt, 2003). Unfortunately, research on the psychosocial effects of childhood cancer has lagged in comparison. With an increasing population of childhood cancer survivors experiencing peer reintegration, school adjustment, and health transformation, there is a critical need for investigation of this phenomenon.

Research considering the effects of childhood cancer on psychosocial health has revealed inconsistent results. The majority of research has indicated that children with cancer are not significantly different than healthy controls across many areas; this may be a result of a tendency to focus on measures of maladaptive functioning such as depression, anxiety, and posttraumatic stress. There have not been consistent findings regarding these maladaptive symptoms (Eiser, Hill, & Vance, 2000). Further research is needed in the investigation of positive measures of functioning (i.e., social competence, self-esteem), and is warranted due to the consistent lack of evidence that children with cancer possess clinical problems such as post traumatic stress disorder (PTSD), depression, and anxiety (Eiser et al., 1997; Phipps, Larson, Long, & Rai, 2006; Stuber & Shemesh, 2006; Van Dongen-Melmen, 1995). Some general psychosocial research has concluded that children with cancer have significant difficulties with school adjustment,

internalizing problems, externalizing problems, and quality of life. Research has also suggested that long-term survivors of childhood cancer experience significant difficulties in multiple domains compared to healthy peers (Eiser et al., 2000). Although these findings are neither consistent nor without methodological error, they warrant further investigation to deepen understanding of the childhood cancer experience.

The social effects of childhood cancer have been more widely researched than other psychosocial domains, although the primary use of cross-sectional design reflects a consistent methodological weakness. Nonetheless, this research has yielded interesting and consistent results. The available evidence has suggested that children in treatment and children who have survived cancer suffer significant social deficits (Vance & Eiser, 2002). This can be described in terms of decreased social competence as well as problems in social functioning that have detrimental effects on peer relationships.

General conclusions from social competence research in childhood cancer are consistent in the domains of peer relationships, social functioning, and social competence. As mentioned previously, this research is primarily cross-sectional, while the only longitudinal studies rely heavily on qualitative data. Considering the scope of the issue and the increasing size of this population, there is a surprising lack of longitudinal research in the area of childhood cancer and social competence. In addition to the dearth of longitudinal data and overrepresentation of qualitative data, studies have often failed to incorporate healthy peers as a control group. Despite the limitations of the current literature, social competence is an area that yields consistent, although sparse, conclusions (Vance & Eiser, 2002). These conclusions include significantly lower social

competence (Olson, Boyle, Evans, & Zug, 1993; Van Dongen-Melman, 1995), less satisfaction with peer relationships (Vannatta et al., 1998), less popularity (Sloper, Larcombe, & Charlton, 1994), and significantly more social isolation (Vannatta et al., 1998) in children with cancer when compared to healthy controls or population norms. Such findings combine to paint a vague image of the diverse long-term social effects possible for survivors of childhood cancer and warrant critical empirical attention.

Despite the consistency of these conclusions, there are important gaps in the literature that need to be addressed. First, there have been no studies to date that measure prediagnostic functioning of children with cancer. Although it is impossible to predict which children will develop cancer, and therefore improbable to collect data prior to diagnosis, it is an absolute possibility to retrospectively collect data on prediagnostic social functioning. The current state of the research suggests that children with cancer are qualitatively different from healthy peers, but there exists no data confirming that this was not the case before the cancer diagnosis was made. Although it is unlikely that children with cancer are qualitatively different than healthy children prior to diagnosis, this remains an unanswered empirical question. It also may be possible that prediagnostic baseline functioning is predictive of the course and severity of social competence deficits during treatment. To conclude that cancer or its treatment decreases a child's social competence, without a prediagnostic measure of social competence, is illogical.

There is also a significant lack of longitudinal research in the field. True longitudinal research focused on children with cancer has been conducted few times in

the literature. Additional longitudinal research is needed to understand individual patterns of functioning across the cancer experience. Although cross-sectional research has demonstrated that children with cancer have lower social competence than healthy peers, longitudinal data would provide details regarding pre- and postdiagnosis differences, patterns, and points of risk during and after treatment. This research limitation prevents the full understanding of a child's cancer experience over time (Eiser et al., 2000; Patenaude & Kupst, 2005).

Finally, the longitudinal research that is available has used large numbers of participants, and has analyzed data in a group format. By investigating individual change in social competence over time, a clear picture of progression, severity, and patterns of social competence could be more clearly assessed.

In sum, there is a surprisingly small amount of research that has been conducted in this critically important area of pediatric psycho-oncology. Longitudinal research that investigates individual pre- and postdiagnosis differences is desperately needed. The population of pediatric cancer survivors is growing steadily, yet with marked differences in social competence. Further investigation of this phenomenon to appropriately address the needs of this growing population is paramount.

This study attempted to diminish current gaps in the literature by addressing the following research questions:

1. Do children with acute lymphoblastic leukemia (ALL) function similarly to healthy controls in the social domain, prior to diagnosis?
2. Following diagnosis and during treatment, do children with ALL display

diminished levels of social competence?

3. Do children with ALL display patterns of social interaction that are different relative to control children?

CHAPTER II

REVIEW OF LITERATURE

Introduction to Childhood Cancer

Prevalence and Survival

Cancer is currently the leading cause of death by disease for children under the age of 15 in the United States. Each year up to 10,000 children in the United States receive a new cancer diagnosis, making the overall prevalence rate .3%, or one out of every 330 children under the age of 19 (Vannatta & Gerhardt, 2003). While the prevalence rate for childhood cancer has remained stable, the survival rate for childhood cancer has increased rapidly from a 5- year survival rate of 55% in 1975 to 79% in 2002. Due to significant advances in medical treatment, the majority of children with cancer can expect to go into long-term remission (Patenaude & Kupst, 2005). This reduction in mortality has greatly increased the number of childhood cancer survivors in the US population and yielded an increased need for pediatric psychologists to focus on research and psychosocial treatments for the child with cancer. In response to these demands, pediatric psycho-oncology developed as a field focused on enhancing understanding of a full picture of childhood cancer and its immediate and long-term emotional, behavioral, and psychosocial effects.

Essential to understanding the full picture of childhood cancer is a basic understanding of the disease itself. Cancer can be defined in simple terms as cells that continue to grow, divide, and thrive when they normally should not. Cancerous cells can

damage nearby healthy tissue and spread quickly throughout the body. Also, with cancerous cell growth, genetic changes can occur that hinder healthy cell functions related to cell growth and death.

There are currently 12 identified types of childhood cancer. Leukemias are the most common category of childhood cancers, with over 33% of childhood cancers classified as some type of leukemia. Acute lymphoblastic leukemia (ALL) is the most common form of all childhood cancers and is associated with an exceptional survival rate of approximately 83%. Children diagnosed with ALL are the focus of this study. However, the review of the literature will include studies of various types of childhood cancer due to the relatively limited size of pediatric psycho-oncology research literature. First, a brief overview of ALL is given to provide a basis for understanding the physical disease. Second, the general psychosocial effects of childhood cancer are summarized to highlight areas of current knowledge in the field. Third, social competence will be considered from a general developmental perspective as well as how it has been measured in the pediatric psycho-oncology literature. Finally, the specific effects of childhood cancer on social functioning will be discussed in detail, providing a rationale for the current study.

Acute Lymphoblastic Leukemia

ALL is a disease in which too many stem cells in the blood and bone marrow develop into lymphocytes, a specific type of white blood cell. This overabundance of lymphocytes decreases the available space for healthy, white blood cells, platelets, and red blood cells, and lowers overall immune system functioning. Symptoms preceding

ALL include fever, bruising, joint pain, weakness, loss of appetite, and small painless lumps in the lymph nodes (Pui, Campana, & Evans, 2001)

While the causes of ALL are largely unknown, there are etiological theories based on genetics, chromosomal abnormalities, and environmental factors (i.e., prenatal exposure to x-rays or low levels of radiation). Diagnostic procedures for ALL vary in invasiveness and range from less invasive diagnostic procedures such as simple physical exam, blood sample, and chest x-ray to more invasive diagnostic procedures such as bone marrow biopsies. Using a sample of blood, a complete blood count (CBC) is conducted, which assesses the amount of red blood cells, white blood cells, and hemoglobin. Chromosomes in the lymphocytes may also be evaluated in a cytogenetic analysis of the blood sample. A chest x-ray allows for evaluation of the bones and organs within the torso. In most cases, a biopsy of the bone marrow is conducted and a needle is inserted into the hipbone or breastbone to collect a sample of bone marrow to study microscopically. Cancerous cells can be identified by their abnormal size, shape, or rapid growth. A lumbar puncture may also be performed to assess the stage of cancer development (Pui et al., 2001). These invasive diagnostic procedures can be painful and stressful for both the child and parents.

Out of all children with ALL, those below the age of 1, above the age of 9, or of any age with a white blood cell count of over 50,000 are considered to be at high risk. Children between the age of 1 and 9, who have a white blood cell count below 50,000 are considered to be in the standard-risk group. Treatment for ALL is consistent with the treatment of most childhood cancers, is extremely rigorous, and may include three

components: chemotherapy, radiation, and chemotherapy with stem cell transplant.

Chemotherapy is the administration of drugs that kill cancerous cells. However, chemotherapy drugs also harm healthy cells. Common side effects of chemotherapy include hair loss, fatigue, nausea, vomiting, diarrhea, and mouth pain. It is common for healthy cells to recover when chemotherapy treatment ends. Radiation therapy is a treatment in which high-energy radiation rays are focused on affected areas of the body through the use of a machine, catheter, injection, or temporary implant. Although the treatment itself is painless, side effects can include weakness, fatigue, and a weakness in immune system functioning due to a lowered white blood cell count. Chemotherapy with stem cell transplant involves chemotherapy in addition to the replacement of donor stem cells (immature blood cells) that replace cells destroyed by the disease and cancer treatment. Typically, treatment for ALL lasts 2-3 years (Pui et al., 2001)

General Psychosocial Effects of Childhood Cancer

Although the increased survival rate for children with cancer is encouraging, this growing population will encounter complications. As medical treatment has become more intense and effective, the severity of the physical side effects (hair loss, amputation, appetite reduction, weakness, etc.) has increased. In addition, as a result of an increased survival rate, it is necessary to fully evaluate the psychological effects of this disease.

Psychosocial Effects of Childhood Cancer During Treatment

The research on the effects of childhood cancer on psychosocial health reveals

inconsistent results. Eiser and colleagues (2000) conducted a systematic review of the literature in this area and concluded that the majority of research indicates that children with cancer are not significantly different than healthy controls across most domains.

The majority of research in this area has sought to evaluate the effects of cancer on a child using measures of psychopathology such as depression, anxiety, and posttraumatic stress (Eiser et al., 1997; Phipps et al., 2006; Stuber & Shemesh, 2006; Van Dongen-Melmen, 1995). However, there are not consistent findings regarding the presence of traditional symptoms. Further research is needed in the investigation of positive measures of functioning (i.e., social competence, self-esteem), and is warranted due to the consistent lack of evidence that children with cancer possess clinical problems.

Childhood cancer stereotype. A significant and controversial area of research has focused on the existence of negative stereotypes for children with cancer. Data suggesting the presence of a childhood cancer stereotype has been inconsistent; recently Wiens and Gilbert (2000) replicated previous findings of the presence of a stereotype and concluded that a childhood cancer stereotype exists. They found that children labeled as currently undergoing treatment for cancer and children labeled as in remission from cancer for 6 years were rated as less social and less physically capable than children labeled as healthy. There were no significant differences between ratings of children undergoing current cancer treatment and children survivors of cancer. This suggested that a childhood cancer stereotype exists, is long lasting, and does not depend on the child's current health status after having survived cancer (Wiens & Gilbert, 2000). This finding has implications for children in treatment as well as long-term cancer survivors,

who are negatively viewed long after treatment for cancer terminates. The presence of a childhood cancer stereotype, which seems to be stronger among medical students, should be considered throughout a child's medical and psychosocial treatment.

Academic functioning. In a review of research addressing the school adjustment of children with cancer, Vance and Eiser (2002) concluded that according to teacher reports, children with cancer exhibit significantly more behavior problems than healthy controls. The authors theorized that behavioral problems occurring at school such as hyperactivity, restlessness, irritability, and fatigue can have a significant negative effect on the relationships of a child with cancer. However, these behavioral patterns within the school environment were not consistent across studies and in general, findings are mixed.

Armstrong and Briery (2003) discussed direct effects of chemotherapy suffered by children currently undergoing treatment. Because healthy cells can be harmed by chemotherapy, children can encounter great difficulty when attempting to perform normal academic tasks while undergoing treatment. Armstrong and Briery reported on the chemotherapy drug Vincristine and the steroid often used in combination with chemotherapy, Prednisone. Vincristine can cause jaw pain, constipation, tingling in feet and hands, as well as slowed motor functioning. Prednisone can cause rapid weight gain and volatile mood swings. The authors concluded that these medication side effects have great impact on a child's ability to perform efficiently and effectively in a classroom environment.

Internalizing problems. In 1994, the authors of the DSM-IV included the diagnosis of a life threatening illness to the list of traumatic stressors sufficient to cause

PTSD. This sparked an increase of measuring posttraumatic stress symptomology among children with cancer. In their meta-analysis of the literature, Eiser and colleagues (2000) found that only 20% of research concluded that children with cancer experience posttraumatic stress symptoms. The majority of studies did not utilize the comparison of children with cancer to any healthy normative group, a remarkable limitation of much of the pediatric psycho-oncology literature.

However, some researchers were able to conclude that PTSD was significantly higher in children with cancer than would normally be expected. Stuber and Shemesh (2006) concluded that symptoms of PTSD (i.e., bad dreams, feeling afraid when thinking about their disease, and feeling alone) are often seen in children during the acute treatment phase, and that higher levels of PTSD symptoms are associated with threat appraisal, trait anxiety, and lower levels of family and social support. Phipps and colleagues (2006) investigated the correlation between levels of PTSD with specific adaptive styles in children with cancer. A specific adaptive coping style found to be common in children with cancer was characterized by high defensiveness and low anxiety. The researchers concluded that this repressive adaptive coping style was linked with low self-report of negative life stressors, decreased overall well-being, and higher levels of PTSD symptoms. Due to its defensive nature, this particular coping style may contribute to inconsistent research findings of maladaptive symptoms of PTSD, depression, and anxiety throughout the literature (Phipps et al., 2006)

Sawyer, Antoniou, Toogood, and Rice (1997) studied the psychological adjustment of young children for 2 years following a cancer diagnosis. The children

were assessed within 5 weeks of diagnosis, 1 year later, and then again 2 years post diagnosis with the Child Behavior Checklist (CBCL) and General Health Questionnaire. They concluded that during the period immediately following diagnosis, children with cancer experienced significant emotional distress as compared to healthy peers. Across time, the level of emotional distress normalized, and after the first year of treatment children with cancer were similar to healthy peers in levels of emotional distress as measured by qualitative interviews and the CBCL internalizing scales.

Although findings are inconsistent in the domain of internalizing problems, research demonstrating that there are significant symptoms in children with cancer (anxiety, depression, PTSD), suggests that this phenomenon should be investigated further.

Externalizing problems. Behavioral conclusions concerning children with cancer have also not been consistent in the literature. However, some research suggests that children with cancer exhibit significantly higher levels of externalizing problems. For example, Newby, Brown, Pawletko, Gold, and Whitt (2000) concluded that there was a significant negative correlation between amount of time off treatment for cancer and severity of externalizing behavior problems. Both during and immediately after treatment for cancer, children are at high risk for displaying behavioral difficulties as measured by the CBCL. Olson and colleagues (1993) found significantly higher numbers of children with behavioral problems in the childhood cancer population as compared with healthy controls. Children with cancer are at a much higher risk than healthy peers for behavioral problems in a clinically referable range, as measured by the CBCL.

The literature does not reach a reliable conclusion that children with cancer are more likely to exhibit behavioral difficulties than healthy children. However, in light of research studies that demonstrate significant behavioral findings in children with cancer, more research is critical for further understanding.

Quality of life. Another effect of childhood cancer that has been evaluated in the pediatric psycho-oncology research is quality of life. Shankar and colleagues (2005) investigated the health-related quality of life of 8- to 12-year-old children currently in treatment for cancer, survivors in remission for at least 1 year, and same-aged healthy peers. Results indicated that children currently in treatment experienced lower overall quality of life, specifically in the areas of physical functioning and future outlook on life, as measured by a self report quality of life measure.

Another study that focused on quality of life was specific to children with ALL. Earle and Eiser (2007) conducted a longitudinal qualitative investigation of the quality of life of children with ALL. Mothers participated in a semistructured interview within 3-4 months of diagnosis, and again at 1 and 2 years postdiagnosis. The content of the interviews was then evaluated for data related to the child's behavior in the contexts of school, friendships, understanding of their illness, and appearance. These factors contributed to the researcher's overall understanding of the individuals' quality of life. They concluded that the oldest group of participants with ALL (10-14 years old) had a lower overall quality of life than either of the younger groups of participants with ALL (0-4 years old, and 5-9 years old).

Empirical research specific to ALL also demonstrated that it is extremely difficult

for families to maintain a level of “normality” during the 2-3 year treatment phase. Earle, Clarke, Eiser, and Sheppard (2006) concluded that although maintaining a normal family life during treatment was a common goal for mothers of children diagnosed with ALL, this was extremely difficult to accomplish. After longitudinal qualitative interviews, the researchers concluded that to reliably maintain a sense of normality within a family during treatment, parents need concrete advice, guidelines, and information. The mothers identified multiple barriers to the sense of normality, including; changes in eating habits, mood, missed school, painful procedures, weakness, clingy behaviors, multiple hospital visits, and personality changes (Earle et al., 2006).

Psychosocial Effects of Childhood Cancer on Long-Term Survivors

The results from research on the long-term psychosocial effects of childhood cancer on survivors have also been mixed. Eiser and colleagues (2000) conducted a systematic review of the literature in this area and found that only one study clearly concluded that childhood cancer survivors demonstrate more negative symptoms than control participants, five studies concluded that there was no difference in negative symptoms, and one study concluded that childhood cancer survivors actually exhibited fewer negative symptoms. It is reasonable to state that a clear picture of the long-term effects of childhood cancer are not, as of yet, established. Possible long-term psychosocial effects include symptoms of posttraumatic stress, anxiety, and depression (Eiser et al., 2000). However, these symptoms have not been demonstrated to be consistent or reliable experiences. In addition, childhood cancer patients and survivors

with extreme or pronounced difficulties are often excluded from research, which may skew the results to a more positive view of the cancer experience. This sampling bias severely limits the generalizability of results.

Eiser and colleagues (1997) reported that survivors of childhood cancer are likely to struggle significantly in areas of physical functioning, role performance, and general health. Grey and colleagues (1992) concluded that adult survivors of childhood cancer reported more concern about infertility issues than healthy peers. In a study by Madan-Swain and colleagues (1994), it was reported that survivors of childhood cancer report more difficulties with body image and school adjustment than healthy peers, as per self-report measures.

It has also been found that childhood cancer survivors experience impaired school performance (Olson et al., 1993; Sloper et al., 1994), more behavior problems (Carpentieri, Mulhern, Douglas, Hanna, & Fairclough, 1993; Olson et al., 1993), less concentration (Sloper et al., 1994), and more internalizing problems (Van Dongen-Melman, 1995) than healthy peers.

Vannatta and Gerhardt (2003) reported that childhood cancer survivors are at high risk (up to 12%) for recurrence of cancer or the development of a secondary cancer. Cosmetic problems are reported in over 66% of childhood cancer survivors. Physical limitations, including limited endurance and general weakness are experienced by up to 35% of survivors. Thyroid complications are also not uncommon, which can lead to low growth rates, weight gain, and reproductive difficulties in adulthood. Cosmetic problems, including a lack of healthy hair regrowth can lead to social and self-esteem

deficits. Repeating grades, missing school, and school adjustment difficulties are also experiences common to survivors. Unfortunately, adult survivors of childhood cancer are at higher risk for job discrimination, rejection from the military, and lower levels of career success. Together, these findings represent a currently incomplete, yet dismal view of adult survivorship of childhood cancer (Vannatta & Gerhardt, 2003).

Social Competence

It is difficult to draw clear conclusions of the experience of children with cancer. It has been inconsistently demonstrated that children with cancer may experience increased levels of internalizing symptoms (i.e., anxiety, depression, PTSD), externalizing symptoms (behavior problems), lowered quality of life, and academic difficulties. However, these findings have not been consistently replicated or adequately investigated. It is critical, at a point when survival rates approach 80%, to begin to better understand the childhood cancer experience. Not all areas of the pediatric psychoncology literature are plagued with the degree of inconsistency and inconclusive findings as has been discussed thus far. In fact, studies of the effects of childhood cancer on social functioning have yielded more conclusive findings. For example, it has been consistently demonstrated that children with cancer, as well as cancer survivors, demonstrate underdeveloped social skills relative to their healthy peers.

Social Competence from a Developmental Perspective

Within the developmental literature, social competence has been theoretically and

broadly defined as effectiveness in interaction. Dirks, Treat, and Weersing (2007) wrote a review of past and current research of social competence in children and reported that social competence has been theorized differently across time. Traditionally, social competence has been conceptualized in a “trait model” framework. Social competence, in this model, is defined as a personality or character trait that is life long and present across all social situations. More recently, however, social competence has been conceptualized less as a stable individual trait, and more as a characteristic of social behavior. For example, some behaviors (i.e., assertive communication, initiation of positive contact) reflect greater social competence than others (i.e., aggression, passive communication). This “social skills model” of social competence is better supported by empirical evidence than the trait model (Dirks et al., 2007).

There is diversity across operational definitions of social competence. Asher (1983) reported on the three dimensions of social competence: relevance, responsiveness, and social knowledge. Rubin, Coplan, Nelson, and Lagace-Seguin (1999) further simplified this definition as peer acceptance and social skillfulness. A child who measures high on the relevance dimension of social competence can appropriately read social situations and social cues from both peers and adults. A child who measures high on the responsiveness dimension of social competence will initiate positive contact with peers, as well as receive the positive initiation of contact by peers in an appropriate and welcoming way. Finally, a child who measures high on the social knowledge dimension of social competence will comprehend that relationships can take time to form and repair. It is also noted that social competence in children is negatively correlated with the

following characteristics; anxious/withdrawn, submissive, sensitive, wary, and isolated/lonely. Social competence is positively correlated with popularity among peers (Asher, 1983; Rubin et al., 1999).

It is accepted that children's peer and social relationships foster feelings of self-worth, promote the growth of interpersonal sensitivity, and provide a foundation for future adult intimate relationships (Rubin et al., 1999). Parker and Gottman (1989) concluded that childhood friendships are at the root of social competence. In early childhood, high levels of social competence facilitate the maximization of amusement and enjoyment in interpersonal play. In middle childhood, social competence includes the integration of skills necessary for self-presentation and impression management. Finally, in adolescence, social competence includes self-exploration, conflict resolution, and emotional regulation. Social competence plays a critical role in the successful social and emotional development of a child. These conclusions, in addition to the findings that children with cancer consistently exhibit lowered social competence than healthy peers, combined to create a compelling need to further study this phenomenon.

Social Competence from an Oncology Perspective

In the pediatric psycho-oncology literature, social competence has often been defined generally as a child's involvement in sports and outside activities, quality and quantity of friendships, and social behaviors with others. Treatment for cancer will obviously impact a child's level of involvement and satisfaction in these areas, particularly sports and activities. The literature also infrequently defines social

competence in terms of social problems, which include a child's perceived dependence on adults, internal emotions (i.e., loneliness, jealousy, paranoia) and peer acceptance. This definition of social competence often adopted in the pediatric psycho-oncology literature mirrors the "social skills model" discussed previously. This model emphasizes the importance of social behaviors and their variability across different developmental stages and situations.

Measurement of Social Competence

Dirks and colleagues (2007) reported on the variety of measures of social competence used in empirical studies. They reported that behavioral rating scales are the most commonly used measures of social competence in the developmental literature. While they may not be sensitive to individual behaviors of children, behavioral rating scales are effective in identifying patterns of child behavior that are both predictive and valid measures of social competence. According to the authors, the most commonly used behavioral rating scales of social competence used in the literature are the Social Skills Rating System (SSRS), the CBCL, the Matson Evaluation of Social Skills for Youngsters, and the Child Behavior Scale. These measures are thought of as effective ways in which to get a basic understanding of a child's social competence and the primary method of measuring social competence in the pediatric psycho-oncology literature.

There is consistency in the measurement of social competence in the pediatric oncology literature. Although different measures have been used, parents have been the most commonly employed informants regarding social competence of children with

cancer. Within the literature, social competence has been measured by self-report methods and other-report measures (parent, peer, teacher, etc.).

Self-report measures have not been consistently utilized within the pediatric oncology research, although they are occasionally utilized with adolescents or adult survivors. For example, self-report measures for social competence were used by Gray and colleagues (1992), Stern, Norman, and Zevon (1993), and Vannatta, Gartstein, Short, and Noll (1998).

Peer report measures, although also not often used in the field of pediatric oncology, provide a useful evaluation of social competence. Vannatta and colleagues (1998) used a peer report measure to assess peer relationships of children with cancer. They utilized the “Three Best Friends” technique, in which the number of times a child is nominated as the best friend of a classmate is summed, as well as the percentage of his reciprocated best friend nominations. Vannatta and colleagues utilized another interesting peer report measure called the ‘Liking Rating Scale’ within the same study. The Liking Rating Scale consists of every child in a classroom rating every other child on a “liking scale” of 1 (do not like) to 5 (like a lot). These measures, although deceptively simple, provide an interesting measure of social competence and are appropriate for even very young children. In the same study, the researchers utilized the Revised Class Play as a third evaluation of social competence. With this measure, children in a classroom assign roles in a mock play to their classmates according to common characteristics between the classmates and the imaginary roles. It is designed to measure multiple dimensions of peer reputation—sociability-leadership, aggressive-disruptive, and

sensitive-isolated.

Teacher-report measures of social competence are more common within the pediatric oncology literature, and often include the Teacher Report form of the CBCL (Olson et al., 1993; Vannatta et al., 1998). Parent report has been the most commonly used measure of social competence among children with cancer. Among parent report measures, the CBCL is by far the most commonly utilized measurement for social competence within the literature, specifically in terms of the Social Competence Scale. Its widespread use, as well as its consistent production of significant research findings, makes the CBCL popular with researchers in the field of pediatric oncology. Its ease of use with children of all ages makes it highly accessible. In a review of the literature concerning the school experience of children with cancer, Vance and Eiser (2002) reported that over half of all reviewed studies used the CBCL when reporting school issues for children with cancer. Regarding studies that specifically focus on the psychosocial effects of childhood cancer, as well as social competence, the CBCL has been used by Bagner, Fernandez, and Eyberg (2004), Carpentieri and colleagues (1993), Newby and colleagues (2000), Noll and colleagues (1997), Olson and colleagues, and Shelby, Nagle, Barnett-Queen, Quattlebaum, and Wuori (1998). Consistent use within the literature makes the CBCL a desirable measure for social competence of children with cancer.

Despite its widespread use, the CBCL has been criticized for its use in evaluating children with chronic illness. Perrin, Stein, and Drotar (1991) emphasized the need for caution when using the CBCL in populations of chronically ill children, due to the

possibility of a limited ability to detect more mild adjustment difficulties likely to be seen in chronically ill children. Perrin and colleagues also cautioned researchers against the CBCL as a potentially misleading measure of social competence. The CBCL contains a social competence and social problems scale. The social competence scale measures involvement in sports and outside activities, quality and quantity of friendships, and social behaviors with others. It may not be surprising that treatment for cancer may impact a child's level of involvement and satisfaction in these areas, particularly sports and activities. The authors reported concern that these items may be too constricted in their scope to adequately measure the social competence during such a complex experience as childhood cancer. The CBCL scale of social problems provides a more specific social competence measure that involves a child's perceived overdependence on adults, internal emotions (i.e., loneliness, jealousy, paranoia), and peer acceptance. The authors' concern over the misinterpretation of this general scale as true social competence is valid. According to the authors, if the names of the scales were actually reversed (social competence would be named social problems and vice versa) less misinterpretation would occur.

The Effects of Childhood Cancer on Social Functioning

The social effects of childhood cancer have been more widely researched than other psychosocial domains, although the research has been primarily cross-sectional. This research has yielded interesting and consistent results. The available evidence suggests that children in treatment and children who have survived cancer suffer

significant social deficits. This can be described in terms of decreased social competence as well as problems in social functioning that have detrimental effects on peer relationships. A general overview of the findings on social competence in the pediatric oncology literature will be outlined, followed by a detailed review of pertinent research findings.

General areas of study of social competence within the childhood cancer literature include peer relationships, social functioning, and social competence. This research is primarily cross-sectional, while the only longitudinal studies rely heavily on qualitative data. Considering the scope of the issue and the increasing size of this population, there is a surprising lack of research in the area of childhood cancer and social competence. Studies also often disregard the use of healthy peers as a control group. Despite these limitations of the literature, social competence is an area that yields consistent conclusions.

Research studies have indicated that childhood cancer survivors experience lower social competence (Olson et al., 1993; Van Dongen-Melman, 1995), less popularity (Sloper et al., 1994), more negative image of sexual and social selves (Stern et al., 1993), and less satisfaction with social relationships (Vannatta et al., 1998) than healthy peers. Eiser and colleagues (1997) reported that survivors of childhood cancer struggle in the area of social functioning. Gray and colleagues (1992) reported that adult survivors of childhood cancer are less satisfied with social relationships than a group of healthy peers, and that these relationships were more likely to be characterized by a heightened sensitivity and cautiousness. Vance and Eiser (2002) reported that the vast majority of

research studies focused on the social functioning of children with cancer, and childhood cancer survivors have more significant social deficits as compared with healthy peers, particularly in the areas of social isolation and emotional sensitivity. It has been found that children with cancer or surviving cancer are less popular with peers and are more socially isolated (Vannatta et al., 1998), struggle more with social adjustment as adults and are more sensitive and cautious in close relationships (Gray et al., 1992), are likely to struggle with feelings of self-consciousness (Patterson, Holm, & Gurney, 2003), and have significantly more social problems (Olson et al., 1993; Shelby et al., 1998) as well as more internalizing problems (Shelby et al., 1998). These findings combine to paint a broad image of diverse long-term social effects for survivors of childhood cancer.

Peer Relationships

Peer relationships are often used as indicators of a child's social competence. Vannatta and colleagues (1998) compared the peer relationships of 28 brain cancer survivors between the ages of 8 and 18 to same-aged, nonchronically ill peers from the same classroom. Peer relationships were measured by peer, teacher, and self-reports that focused on a child's tendencies to interact in either social, aggressive, or withdrawn patterns. A second social measure was taken by averaging the participants "liked" rating according to classroom peers. Finally, participants were asked to nominate their best friends from the classroom, and averages were taken of reciprocated "best friend" scores. The researchers reported that the childhood cancer survivors were significantly more socially isolated than healthy controls, according to all three sources of data—peer, self- and teacher report. In addition, despite no longer receiving treatment for their illness,

survivors were rated significantly higher than controls along characteristics involving illness or fatigue (i.e., someone who is often sick, misses school, and is often tired). Finally, child survivors were nominated as a best friend significantly less often than controls. However, there was no significant difference between groups on the number of reciprocated friendships. The researchers concluded that although children with cancer may experience significant social problems as compared to healthy peers, they are equally able to maintain close personal friendships, and are aware of these quality relationships.

This same study also compared children who received radiation therapy during their brain cancer treatment with those who did not receive radiation therapy for their brain cancer. Due to the intensity of whole brain radiation therapy (WBRT) used to treat brain cancer in children, Vannatta and colleagues (1998) hypothesized that greater social deficits would be seen in the children who received WBRT compared to children who did not receive WBRT. The researchers concluded that there were no significant differences among these groups of children, and that equal social deficits were seen in childhood brain cancer survivors who did and did not receive WBRT.

Social Functioning

A qualitative study conducted by Patterson and colleagues (2003) highlighted the difficulties in social competence experienced by childhood cancer survivors. A series of seven focus groups of 45 parents of 26 children at least 1 year posttreatment for various types of cancer were held. Transcripts of the group sessions were taped and later coded for relevant data regarding the effects of childhood cancer. The majority of the parents

reported that their children struggled with feelings of self-consciousness around others. There were also reports of negative emotions related to missing social, academic, and extracurricular activities. Although this data was not compared statistically to healthy peers and their parents, the authors concluded that four themes emerged from the data. Children with cancer exhibited: (a) strong emotions (fear, anxiety), (b) self-consciousness about the perceptions of others, (c) loss of a normal life and loss of social activities, and (d) financial worries about treatment and hospitalization. The first three themes can be directly related to a child's level of social competence and functioning as defined by the developmental research (Patterson et al., 2003)

Self-image, as it relates to social functioning and overall social competence was researched by Stern and colleagues (1993). Participants included 48 adolescents with cancer and 40 healthy adolescents. Participants completed the Offer Self-Image Questionnaire and the Social Provision Scale, that measured two main factors; self-image and perceived social support. Although not statistically different from control participants, many adolescents with cancer reported social rejection by teachers and peers during their cancer experience. In addition, adolescents with cancer reported more negative views of their social and sexual selves, both of which can be thought to contribute to overall social competence. For this study, social self-image was comprised of dimensions such as number of social relationships and sexual self-image was comprised of dimensions such as sexual attitudes (Stern et al., 1993)

Carpentieri and colleagues (1993) compared the behavioral resiliency of children survivors of brain cancer to those who had survived noncentral nervous system cancers.

The researchers concluded that children with brain cancer were significantly more socially impaired than children with noncentral nervous system cancers as measured by the CBCL. These data suggest that children with brain cancer may exhibit more significant social deficits than children with other types of cancer. Participant criteria for studies that have excluded children with brain cancer would not accurately portray the deficits of this population.

Earle and Eiser (2007) studied children with ALL 6-8 weeks postdiagnosis, and then again 1 and 2 years later. The researchers concluded, through interview data, that younger children (0-4) adjusted with the least problems to the cancer diagnosis. Older children (5-9) reported significantly more social problems and worried about their appearance more than the youngest group. The oldest group of children (10-14) adjusted least well. For this age group, mothers reported significant social problems as well as a lack of social interaction and school avoidance. Many in this group withdrew socially and were described as overly concerned with appearing and acting similarly to healthy peers.

Report of social difficulties were present shortly after diagnosis and throughout treatment for the oldest participants. However, by the second data collection interview, even the youngest group of children were reportedly more moody and clingy than developmentally expected. For the older groups of children, significant problems at one and 2 years postdiagnosis included difficulty accepting medical treatments, preoccupation with the illness, and problems in social interactions as measured by qualitative interviews with mothers. Due to the qualitative nature of this study, data was not further analyzed or

evaluated. The researchers concluded that the quality of life for the older children was the lowest. This group also experienced the most social withdrawal and concern about appearance, which remained stable throughout the study (Earle & Eiser, 2007).

Social Competence

Olson and colleagues (1993) studied the effects of childhood cancer on social competence in 20 rural children (aged 6 to 16 years) compared to 40 matched healthy peers. Multiple parent and teacher self-report measures were used to evaluate overall functioning, with the CBCL and the Vineland Revised Scale of Social Maturity specifically aimed at measuring social competence. On the Vineland Revised Scale of Social Competence, childhood cancer survivors scored significantly lower than the healthy controls by both teacher and parent reports. Their scores were also significantly lower than the published norms for social competence. According to the parent report form of the CBCL, children with cancer were more likely than healthy controls to exhibit social competence that is lower than normal limits. Over 60% of the childhood cancer survivors demonstrated social competence significantly lower than normal limits as compared to only 15% of the healthy peers that scored below the normal range. This suggested that a majority of children with cancer have clinically referable social difficulties (Olson et al., 1993)

Shelby and colleagues (1998) designed a study to evaluate the overall psychosocial adjustment and social competence of child survivors of ALL. Parents of 34 children who had completed treatment for ALL completed two parent report measures, the CBCL and the Behavior Assessment System for Children (BASC). Scores on both

tests were then compared to normative groups during data analysis. The researchers concluded that according to parent report on the CBCL, social competence of childhood cancer survivors was significantly lower than the normative group across all dimensions of the scale. In addition, according to the parent report on the BASC, childhood cancer survivors scored significantly lower than the normative group in social skill display and leadership skills. The researchers concluded that the deficits were more severe for older children, although age at diagnosis was not a mediating factor for social competence. This study supported the conclusion that children with cancer exhibit significantly lower levels of social competence than population norms (Shelby et al., 1998).

Long-Term Social Effects

Gray and colleagues (1992) performed a qualitative analysis of adult survivors of childhood cancer. They concluded that there were marked social differences between adult survivors and healthy comparison peers. Participants consisted of 62 cancer survivors and 51 healthy comparison peers. All participants were given various projective and self-report measures and participated in a semistructured interview. Although there were no significant between-group differences on either the self-report measure or the projective measure, significant differences emerged from the interview data. The researchers concluded that the adult survivors of childhood cancer, according to the interviews, were significantly less satisfied with their spouse or partner, children, and sex lives. It is difficult to interpret these results when considered alongside the data that demonstrated that survivors were more motivated than healthy control peers to spend time with others. Gray and colleagues concluded that although adult survivors of

childhood cancer hold healthy attitudes and possess motivation for interpersonal interaction, they are overall less satisfied with the most important relationships in their lives.

In a study that focused on the social functioning and psychiatric dysfunction of adult survivors of childhood ALL, Mackie, Hill, Kondryn, and McNally (2000) concluded that survivors had significantly higher difficulties than controls in the areas of love/sex relationships, friendships, nonspecific social contacts, and day-to-day coping. In this study, 102 adults between the ages of 19-30, who survived childhood ALL or a childhood Wilms' Tumor, were compared with 102 healthy controls. There were a total of 67 participants who had ALL and 35 participants who had a Wilms' Tumor.

Mackie and colleagues (2000) assessed the participants on a variety of measures. Psychiatric disorder was assessed by the Schedule for Affective Disorder and Schizophrenia Lifetime (SADS-L). Interpersonal relationships and social performance was assessed by the Adolescent to Adult Personality Functioning Assessment. This detailed interview included the domains of education or work, love/sex relationships, friendships, nonspecific social interactions, negotiations, and organization of daily coping skills. Both groups of cancer survivors were compared with healthy controls and were found to have significantly lower scores in love/sex relationships, friendships, nonspecific social contacts, and coping skills. The researchers also concluded that the differences between the adult cancer survivors and controls were much greater for the ALL participants compared with the Wilms' Tumor survivors. This is the only study to date that compares ALL specifically with another type of nonbrain cancer. Results that

suggest greater social deficits among the ALL survivors warrants further investigation into this conclusion. If ALL results in greater deficits than other cancers, and it is also among the most common and survivable cancers, need for further ALL-specific research is detrimental.

Summary and Conclusions

Due to the growing survival rate for childhood cancer, there is an increased need for research on the psychosocial effects of this disease. Research in the literature has yet to yield consistent conclusions in many psychosocial domains such as depression, anxiety, PTSD, and quality of life. However, a consistent conclusion is that children with cancer demonstrate significantly lower social competence than healthy controls.

Within the social competence research in pediatric psycho-oncology is the consistent conclusion that children with or surviving cancer exhibit lower social competence than healthy peers. However, despite the consistency of these conclusions, there are important gaps in the literature that need to be addressed. First, there have been no studies to date that measure prediagnostic functioning of children with cancer. Although it is impossible to predict which children will develop cancer, and therefore improbable to collect data prior to diagnosis, it is possible to retrospectively collect data on prediagnostic social functioning. For example, completing an interview or standardized measures at the time of diagnosis would allow parents and children to retrospectively report on prediagnostic functioning. Current research suggests that children with cancer are qualitatively different from healthy peers, but this difference

may exist prior to the cancer diagnosis. While improbable, this possibility has not yet been subjected to experimental scrutiny. It also may be possible that prediagnostic baseline functioning is predictive of the course and severity of social competence deficits during treatment. To conclude that cancer decreases a child's social competence, without a prediagnostic measure of social competence is illogical.

Systematic reviews by Eiser and colleagues (2000) and Patenaude and Kupst (2005) also note the lack of longitudinal research in the field. More longitudinal research is needed to focus on individual patterns of functioning during the cancer experience. Although cross-sectional research has demonstrated that children with cancer have lower social competence than healthy peers, there is a lack of longitudinal data that would provide information regarding pre- and postdiagnosis change, patterns, and points of risk during and after treatment. The longitudinal research that is available has used large numbers of participants, and has analyzed the data in a group format. By investigating individual change in social competence over time, a clear picture of progression, severity, and patterns of social competence could be assessed. Other limitations of the current research include; a heavy reliance on cross-sectional data, rare use of healthy control groups, sampling bias, and inconsistent results on clinical measures of psychopathology.

Longitudinal research that investigates individual pre- and postdiagnosis differences is desperately needed in the field. The population of pediatric cancer survivors is growing steadily, and with marked differences in social competence. It is critical to further investigate this phenomenon in depth to appropriately address the needs of this growing population.

CHAPTER III

PURPOSE AND OBJECTIVES

The literature has consistently suggested that children with cancer and survivors of childhood cancer exhibit diminished social competence relative to healthy peers. However, the process of decline is poorly understood. It is known that deficits in social functioning exist, but how and when these deficits developed is yet to be established.

Assessing a child's emotional, social, and behavioral functioning prior to diagnosis with a longitudinal research design would facilitate understanding of social changes among children during the cancer experience. This information would likely inform current treatments and promote a focus on the prevention of social deficits in children with cancer.

The aim of the current research was to utilize longitudinal methods in assessing social competence of children with cancer before and after diagnosis, throughout their first 3 months of treatment. A retrospective precancer assessment of social competence was taken for the first time in the current literature. This addressed a large gap in the research, and provided a comparative baseline of social functioning prior to diagnosis.

In addition, single case experimental methodology was utilized to examine individual pre- and postdiagnosis differences for the first time in the literature. Evaluating social competence over the first 3 months of treatment at the individual level provided a detailed picture of individual differences that emerged. The strength of this method was further established by the inclusion of a control group in examining change in social competence over time. This facilitated comparison against normative changes

in social competence over a 3-month period of time.

Given the well-documented criticisms of using the CBCL, the current research included an additional measure of child social competence, the SSRS. As previously mentioned in the discussion of the measurement of social competence in the developmental psychology literature, the CBCL and the SSRS are two of the most commonly utilized measures of social competence. However, they have not been used simultaneously within the same study. Combining the CBCL, which is widely used within the childhood cancer literature, with the SSRS, which may be a more sensitive and accurate measure for the childhood cancer population, led to a more comprehensive and thorough evaluation of social competence. This provided a needed addition to the literature as well as addressed the concerns over the possible misinterpretation of the CBCL.

To summarize, the current project was designed to answer the following specific questions.

- 1) Do children with ALL function similarly to healthy controls in the social domain, prior to diagnosis?
- 2) Following diagnosis and during treatment, do children with ALL display diminished levels of social competence?
- 3) Do children with ALL display patterns of social interaction that are different relative to control children?

CHAPTER IV

METHODOLOGY

Participants

Four children between the ages of 6-11 years, recently diagnosed with ALL at Primary Children's Medical Center (PCMC) in Salt Lake City, Utah, were recruited. Mothers of the patients were initially contacted by a hospital pediatric psychologist. All participants were within 1-week postdiagnosis at entry into the project. In addition, four typically developing children were recruited to serve as matched control participants. These participants were recruited through university-affiliated organizations in Cache Valley, Utah. The control participants were matched with the child with cancer on the variables of age, gender, and a global rating of social functioning as determined by the SSRS and CBCL. They were screened before participating in the study to ensure that they were not significantly different from their matched participant in the area of social functioning at the time of the first assessment. Method of screening consisted of a global rating of social skills obtained by the SSRS and CBCL. While this matching process was intended to be an additional step to protect the validity of the results, it was quite simple to accomplish; participants selected based on age and gender 'immediately' matched on global rating of social functioning on the SSRS and CBCL.

Procedure

Two assessments of social competence were given (T1 = time of diagnosis, with

retrospective prediagnosis reporting, and T2 = 3 months post diagnosis). The methods of measurement were paper and pencil forms of the CBCL and the SSRS. The dependent variable to be measured was social functioning as measured by these questionnaires; specifically the CBCL's Social Competence Score and the SSRS's Total Social Skills Score.

The first measure was given at time of diagnosis, and was retroactively completed according to child social competence during the previous month; this obtained a measure of prediagnostic functioning. The second measure was given at 3 months postdiagnosis, and evaluated child social competence 3 months into medical treatment. These two measures provided the researcher with a more complete picture of a child's social competence and how the pre- and postcancer social functioning differed. Two measures, the CBCL and SSRS, were given at both times of measurement to get as full a picture of social competence as possible. The mothers of the children completed the measures at both data collection points. T1 was a retrospective measurement of the child's precancer social competence as reported by their mothers on both the CBCL and the SSRS questionnaires. For the healthy control peers, T1 was taken upon giving consent to participate in the study, and T2 was taken 3 months later.

The mothers of children recently diagnosed with ALL were identified by a hospital pediatric psychologist who asked if they were willing to be contacted about a research opportunity. For those who were willing, the pediatric psychologist collected their contact information. The researchers were in contact with the pediatric psychologist at least once per week to collect potential participant contact information. Next, the

participants were contacted by phone by the researchers. Permission was obtained to discuss the research with the participants over the phone. When the participant noted that they were further interested in participating, a time and date was arranged to meet. All participants were contacted by researchers within one week of diagnosis to be included in the study. For T1 and T2, the participants were met at the hospital by the researchers to complete the measures. Upon meeting, the researcher instructed the participant to complete the measures based on the past month, not including the days since diagnosis. Data collected at T2 also occurred at the hospital, during a meeting with the participants. The same procedure applied to the group of healthy controls; however, their start in the study was not be contingent on any medical diagnosis, and measurements were completed at the participants' home or another convenient location, determined by the mother.

Measures

The CBCL (4-18) is a parent-report measure that provides ratings of three competence scales (activity, social, and school). These scales can be combined in a reported total competence scale. In addition, the CBCL generates eight subscales. These subscales can also be combined in the reported Internalizing Problem Scale, Externalizing Problem Scale, and Total Problem Scale. The CBCL also has high internal reliability, with a range of reliability within subscales of .96 to .64. However, there is concern about the Activity Competence Scale, with its internal reliability of only .42. This subscale was not a focus of the current research (Furlong & Wood, 1998).

The score of interest for the current research study was Social Competence. For the CBCL score of Social Competence, any *T* score above 35 is considered to be in the normal range, while any *T* score between 30 and 35 is considered in the borderline range. Any *T* score below 30 is considered to be in the clinical range for social competence. The measure takes less than 20 minutes to complete, and does not utilize different norms based on ethnicity (Furlong & Wood, 1998)

The SSRS is a parent-report measure that provides ratings on four subscales; cooperation, assertive, responsibility, and self-control as well as a social skills total scale. There are also two subscales of problem scores (internalizing problems and externalizing problems). There is a high level of internal consistency, with a range of .73 to .95 for all subscales. The score of interest for the current study was the total social skills score. For the SSRS total social skills score, a standard score of 100 is the mean, with a standard deviation of 10. A score below 86 is considered in the below-average range, a score between 86 and 114 is considered in the average range, and a score above 116 is considered in the above-average range for social skills. The measure takes from 15-20 minutes to complete, and does not utilize different norms based on ethnicity (Benes, 1995).

Analysis

After the measures were scored for each individual, the scores were graphed separately for both the CBCL and SSRS results. Data from both measures were graphically compared and analyzed across individuals for change in social competence

specific to the childhood cancer experience, not demonstrated by healthy controls. In addition, within subject graphical analysis was utilized, using prediagnostic social competence as a baseline for each individual.

CHAPTER V

RESULTS

Introduction

As indicated previously, four children with ALL and four healthy control peers were recruited to participate in the current study. Table 1 describes the participants across a variety of demographic variables.

All participants were female, between the ages of 6 and 11 years of age, although all but two fell between 6 and 8 years of age. Most of the participants identified themselves as White, and all children (and parents) were English speaking. The majority of the participants live in towns of between 10,000 and 50,000 people. The participants came either from households with a low or average income level, however, two participants preferred not to answer that particular question on the demographic questionnaire.

Table 1

Demographic Information of Participants

Group	Gender	Age	Ethnicity	Community	Income
C2	F	7	White/Hispanic	Suburbs 50+	Low
C3	F	6	Hispanic	Town 10-50	Average
C4	F	11	Hispanic	Town 10-50	Not reported
C5	F	8	White	Town 10-50	Average
H2	F	7	White	Town -10	Average
H3	F	6	White	Town 10-50	High
H4	F	11	White	Town -10	Not reported
H5	F	8	White	Town 10-59	Low

Empirical Questions

Do Children with ALL Function Similarly to Healthy Controls in the Social Domain, Prior to Diagnosis?

Table 2 displays T1 results for the children with ALL and their healthy control peers on the SSRS Total Social Skills Score and the CBCL Social Competence Score. Each of the four participants with ALL were in the average range according to their T1 (retrospective, prediagnostic) measure of social functioning on the SSRS, and three participants with ALL were in the normal range according to the CBCL Social Competence Score, while one was in the borderline range. Three out of the four healthy control children were in the average range on the SSRS Total Social Skills, while one was in the above-average range. Three out of the four healthy control children were in the normal range on the CBCL Social Competence score, while one was in the borderline range. All children with ALL were within 1.5 standard deviations of their healthy control peers on the CBCL Social Competence score as well as SSRS Total Social Skills score.

Table 2

Social Functioning of Participants at T1

Participant	SSRS total social skills score	CBCL social competence score
C2	108 (average range)	44 (normal range)
C3	110 (average range)	35 (borderline range)
C4	104 (average range)	38 (normal range)
C5	93 (average range)	46 (normal range)
H2	108 (average range)	52 (normal range)
H3	122 (above-average range)	46 (normal range)
H4	101 (average range)	35 (borderline range)
H5	106 (average range)	44 (normal range)

**Following Diagnosis and During Treatment,
Do Children with ALL Display Diminished
Levels of Social Competence?**

Figure 1 graphically displays CBCL social competence T scores for children with ALL, at T1 and T2. Two children in this group (C3 and C4) maintain a stable level of Social Competence ($T = 38$, in the normal range of functioning, and $T = 35$, in the borderline range of functioning), while two children decrease in their Social Competence score (from $T = 46$ to $T = 42$, remaining in the normal range of functioning, and from $T = 44$ to $T = 35$, decreasing from the normal range of functioning to the borderline range of functioning).

Figure 2 displays CBCL social competence T scores for healthy control children at T1 and T2. Two children in this group displayed increased social competence scores

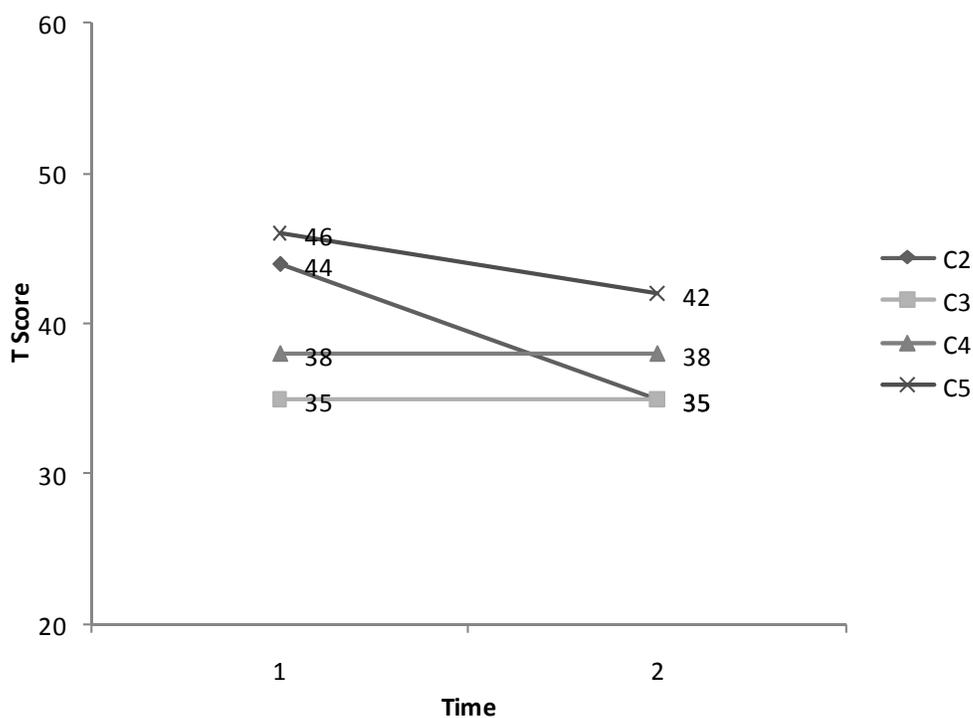


Figure 1. CBCL social competence T scores for children with ALL at T1 and T2.

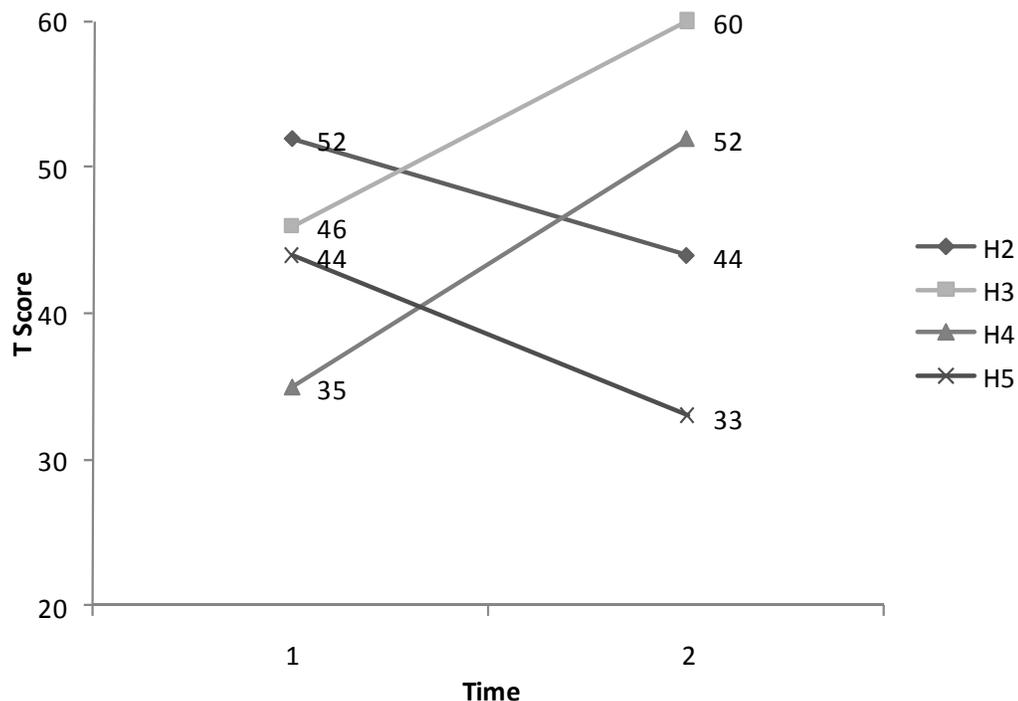


Figure 2. CBCL social competence T scores for healthy control children at T1 and T2.

(from $T = 46$ to $T = 60$; this remained in the normal range of functioning, and from $T = 35$ to $T = 52$; this increased from the borderline range to the normal range of functioning), while two children displayed decreased Social Competence scores (from $T = 52$ to $T = 44$; this remained in the normal range of functioning, and from $T = 44$ to $T = 33$; this decreased from the normal range of functioning to the borderline range of functioning).

Figure 3 shows results of the SSRS total social skills scores for children with ALL at T1 and T2. One child in this group maintained a stable level of total social skills (93, in the average range), while three children increased in their total social skills score (from 110 to 116, from 108 to 118, and from 104 to 118, all of which demonstrated an increase from the average range to the above-average range of social skills).

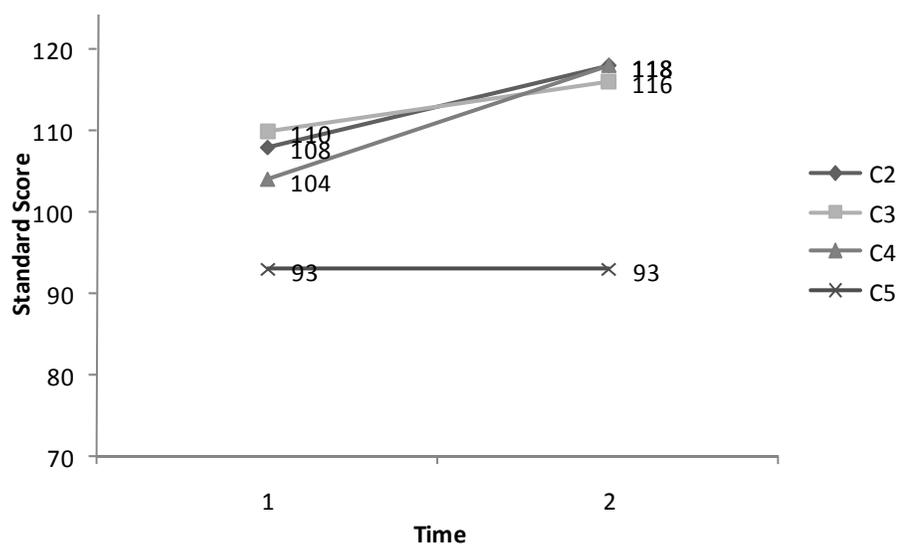


Figure 3. SSRS total social skills scores for children with ALL at T1 and T2.

Figure 4 displays the results of the SSRS total social skills scores for the healthy control children, at T1 and T2. One child in this group maintained a stable level of total social skills (108, in the average range), while one child increased in their total social skills score (from 101 to 114; this remained in the average range), and two children decreased in their total social skills score (from 122 to 110; this decreased from the above-average range to the average range, and from 106 to 75; this decreased from the average range to the below-average range).

Do Children with ALL Display Patterns of Social Interaction That Are Different Relative to Control Children?

Figure 5 and Figure 6 present the CBCL and SSRS data for a child with cancer as well as her matched comparison peer. Figure 5 demonstrates that participant C2 decreased in her social competence score on the CBCL after her cancer diagnosis and

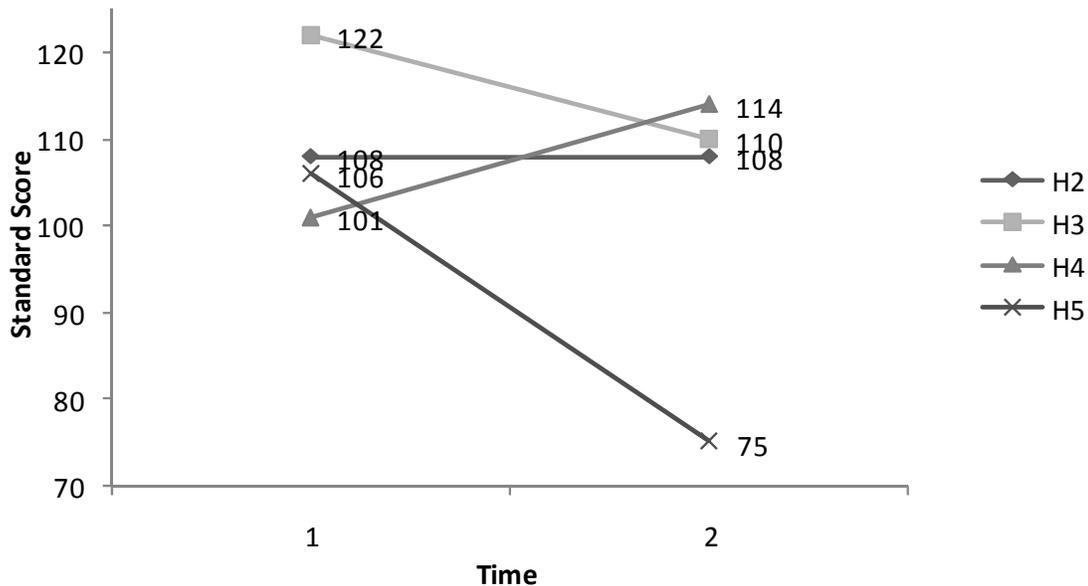


Figure 4. SSRS total social skills scores for healthy control children at T1 and T2.

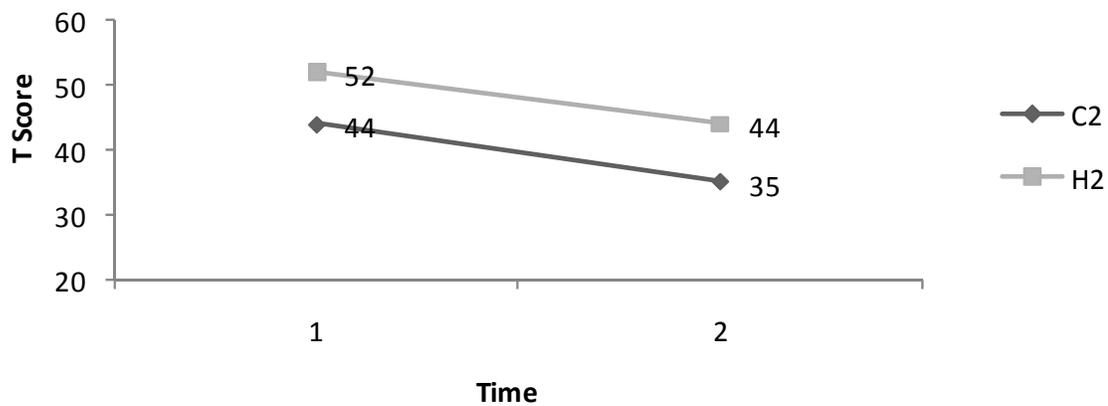


Figure 5. CBCL social competence data for C2 and H2 children at T1 and T2.

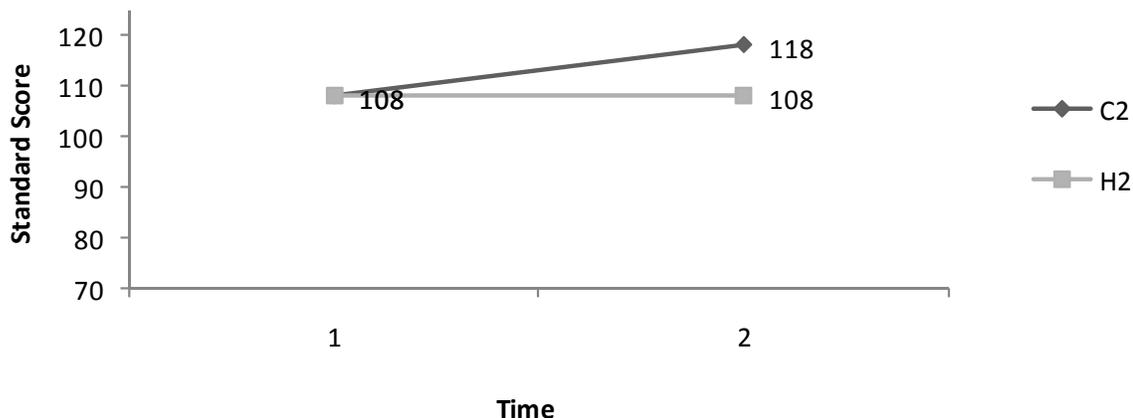


Figure 6. SSRS social skills data for C2 and H2 children at T1 and T2.

first 3 months of medical treatment (from $T = 44$ to $T = 35$). Her social competence score, which was in the normal range prior to her cancer diagnosis, fell into the borderline range of functioning according to the CBCL. However, Figure 5 demonstrates that the matched peer, H2, also decreased in her social competence score on the CBCL between T1 and T2 (from 52 to 44). Despite the decrease in social competence score, H2's score remained in the normal range at T2.

Figure 6 demonstrates that participant C2 increased in her total social skills score on the SSRS after her cancer diagnosis and first 3 months of medical treatment (from 108 to 118). C2's total social skills score rose from the average range before her cancer diagnosis to the above-average range at T2. There is a noted difference in the direction of change between Figure 5 and Figure 6 for participant C2. Figure 5 also demonstrates that the matched peer, H2, remained stable in her total social skills score on the SSRS between T1 and T2 (108), which was in the average range.

Figures 7 and 8 present the CBCL and SSRS data for a child with cancer as well as her matched comparison peer. Figure 7 demonstrates that participant C3 remained stable in her social competence score on the CBCL after her cancer diagnosis and first 3 months of medical treatment ($T = 35$), which was in the borderline range of functioning according to the CBCL. However, the figure also demonstrates that the matched peer, H3, increased in her social competence score on the CBCL between T1 and T2 (from 46 to 60). H3's social competence score remained in the normal range at both T1 and T2.

Figure 8 demonstrates that participant C3 increased in her total social skills score on the SSRS after her cancer diagnosis and first 3 months of medical treatment (from 110 to 116). C3's total social skills score rose from the average range before her cancer diagnosis to the above-average range at T2. There is a noted difference in the direction of change between Figures 7 and 8 for participant C3. Figure 7 demonstrates that the matched peer, H3, decreased in her total social skills score on the SSRS between T1 and

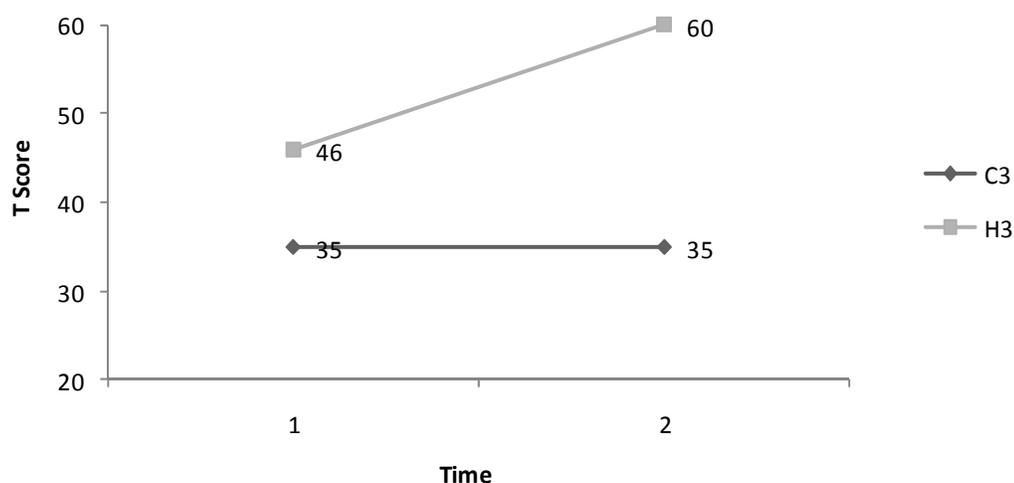


Figure 7. CBCL social competence data for C3 and H3 children at T1 and T2.

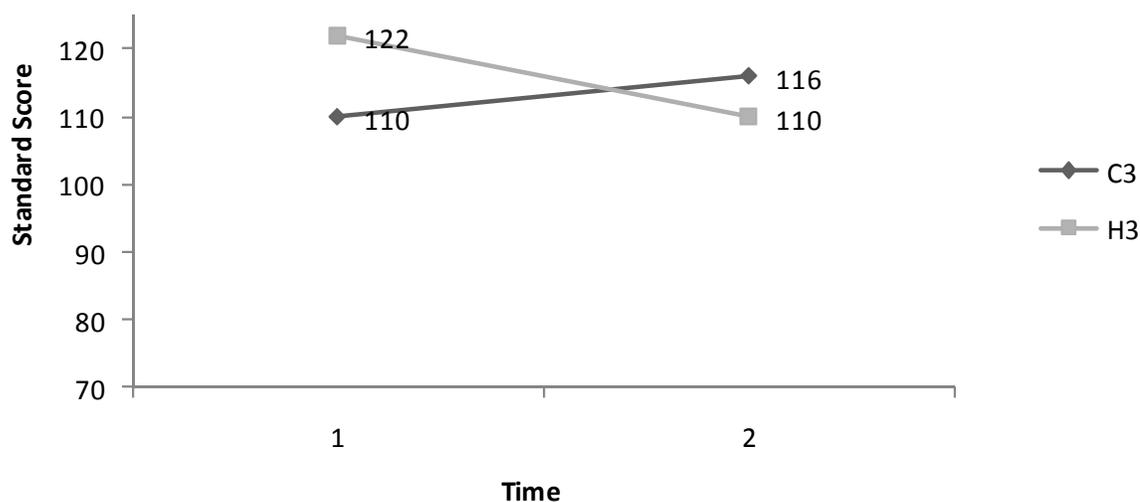


Figure 8. SSRS social skills data for C3 and H3 children at T1 and T2.

T2 (from 122 to 110). H3's total social skills score fell from the above-average range to the average range at T2.

Figures 9 and 10 present the CBCL and SSRS data for a child with cancer as well as her matched comparison peer. Figure 9 demonstrates that participant C4 remained stable in her social competence score on the CBCL after her cancer diagnosis and first 3 months of medical treatment ($T = 38$), which was in the normal range of functioning according to the CBCL. In addition, Figure 9 demonstrates that the matched peer, H4, increased in her social competence score on the CBCL between T1 and T2 (from $T = 35$ to $T = 52$). H4's social competence score rose from the borderline range at T1 to the normal range at T2.

Figure 10 demonstrates that participant C4 increased in her total social skills score on the SSRS after her cancer diagnosis and first 3 months of medical treatment (from 104 to 118). C4's total social skills score rose from the average range before her cancer

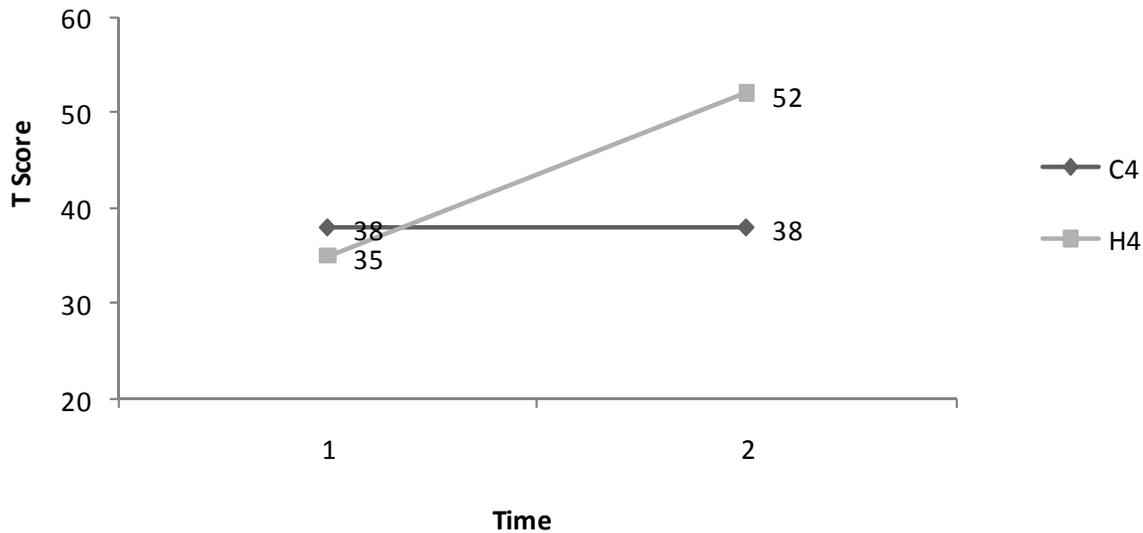


Figure 9. CBCL social competence data for C4 and H4 children at T1 and T2.

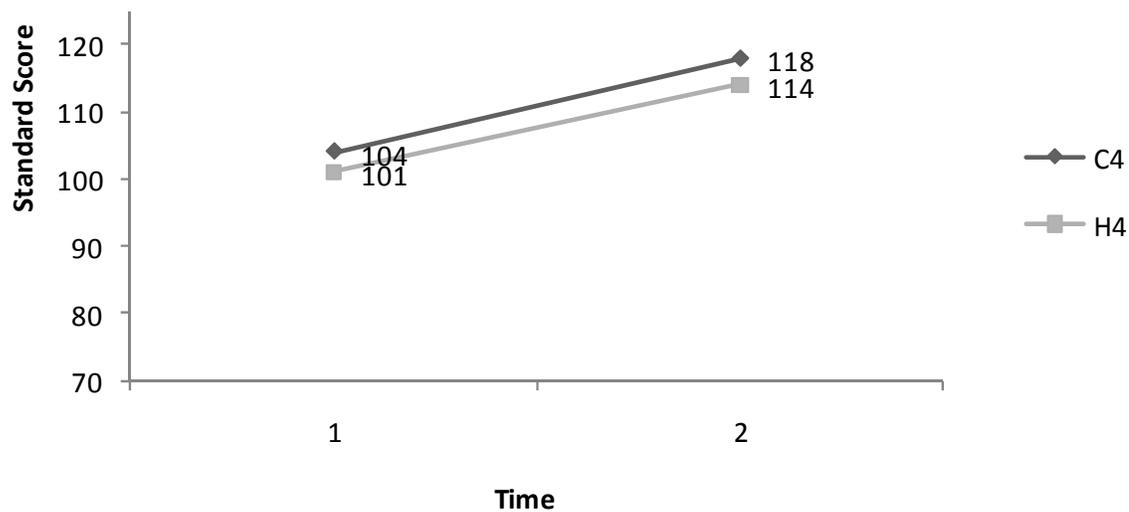


Figure 10. SSRS social skills data for C4 and H4 children at T1 and T2.

diagnosis to the above-average range at T2. There is a noted difference in the direction of change between Figures 9 and 10 for participant C4. Figure 10 demonstrates that the matched peer, H4, also increased in her total social skills score on the SSRS between T1 and T2 (from 101 to 114), but remained in the average range.

Figures 11 and 12 present the CBCL and SSRS data for a child with cancer as well as her matched comparison peer. Figure 11 demonstrates that participant C5 decreased slightly in her social competence score on the CBCL after her cancer diagnosis and first 3 months of medical treatment (from $T = 46$ to $T = 42$), but remained in the normal range of functioning according to the CBCL. Figure 11 also demonstrates that the matched peer, H5, decreased in her social competence score on the CBCL between T1 and T2 (from $T = 44$ to $T = 33$). H5's social competence score fell from the normal range at T1 to the borderline range at T2.

Figure 12 demonstrates that participant C5 remained stable in her total social skills score on the SSRS after her cancer diagnosis and first 3 months of medical

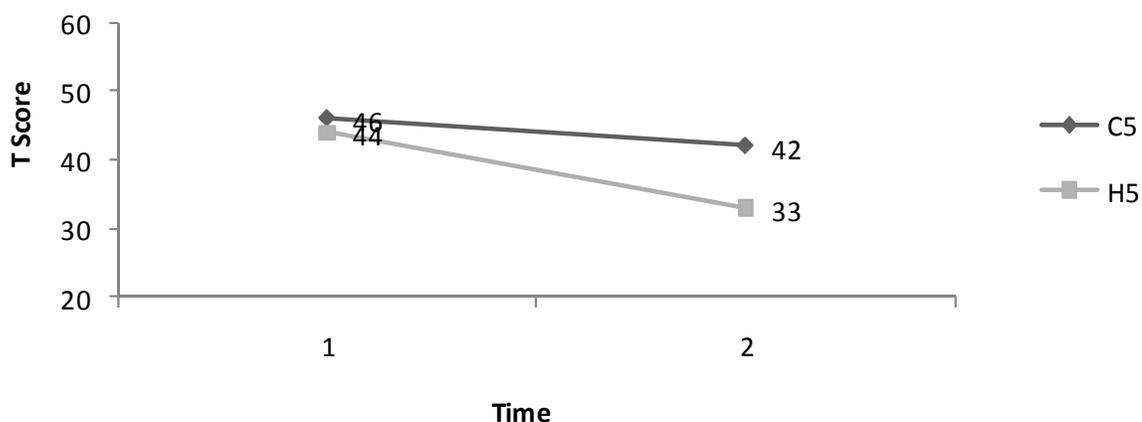


Figure 11. CBCL social competence data for C5 and H5 children at T1 and T2.

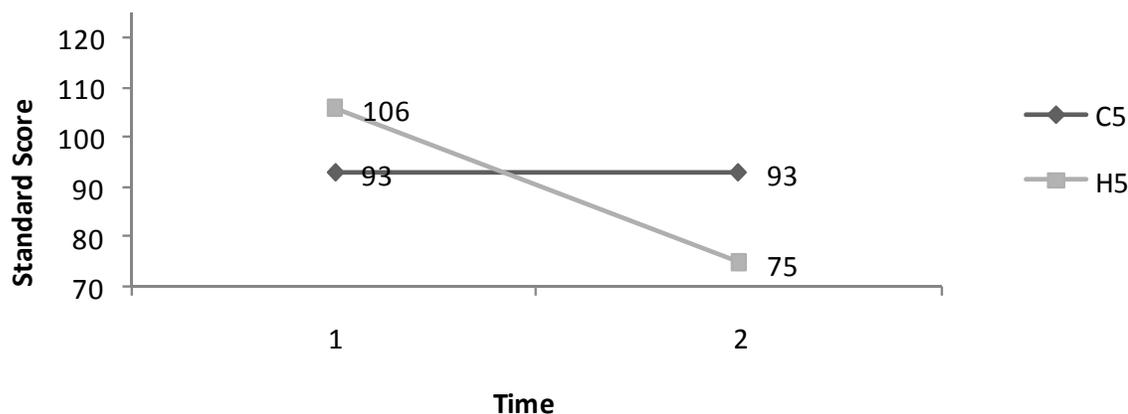


Figure 12. SSRS social skills data for C5 and H5 children at T1 and T2.

treatment (93). C5's total social skills score remained in the average range from before her cancer diagnosis to 3 months into her medical treatment. There is a noted difference in the direction of change between Figures 11 and 12 for participant C5. Figure 12 demonstrates that the matched peer, H5, decreased in her total social skills score on the SSRS between T1 and T2 (from 106 to 75). H5's total social skills score fell from the average range at T1 to the below-average range at T2.

Although the data are best understood in single-subject design methodology, Figures 13 and 14 represent condition averages across participants' scores. Figure 13 shows average CBCL social competence scores for children with cancer and healthy control peers at T1 and T2. There is little variation across time, with the children with ALL decreasing slightly (from $T = 41$ to $T = 38$) after their cancer diagnosis and first 2 months of medical treatment. Both scores remained in the normal range of the CBCL. Similarly, there is little variation across time for the healthy control peers, for which the average score increased slightly (from $T = 44$ to $T = 47$), but remained in the normal range of the CBCL.

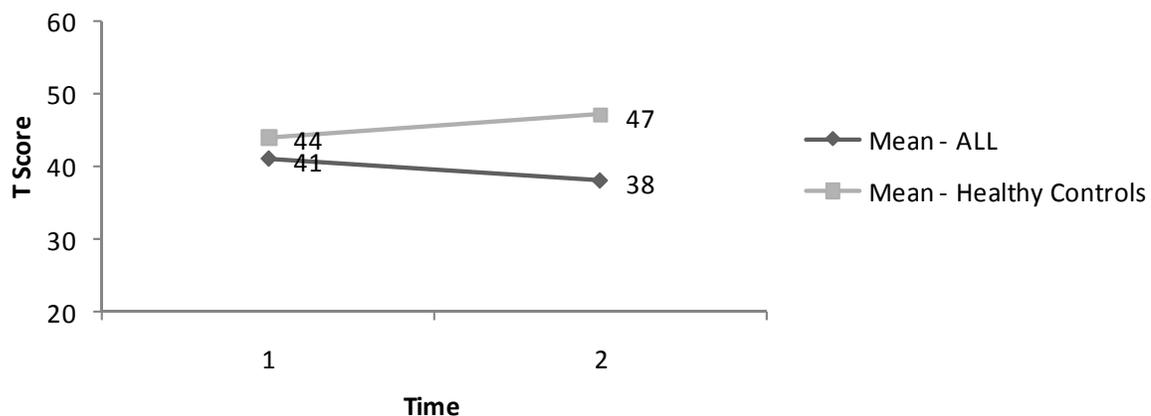


Figure 13. CBCL social competence averages across participant scores.

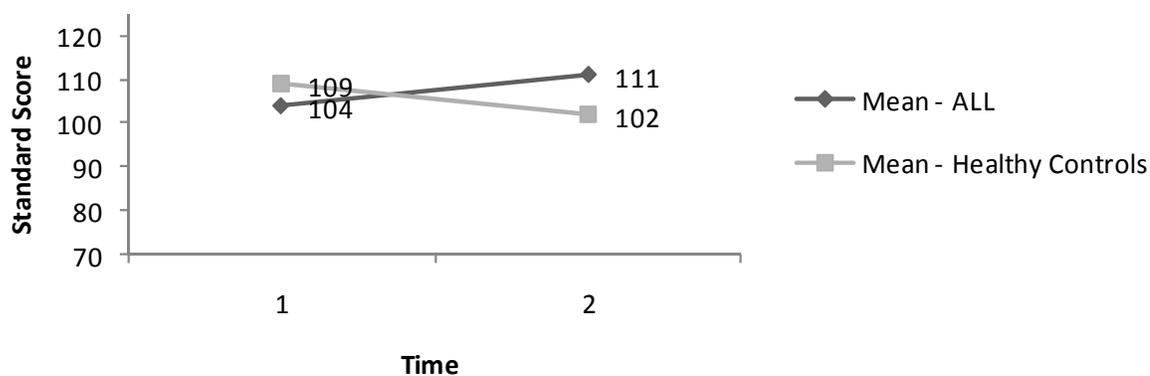


Figure 14. SSRS social skill averages across participant scores.

Figure 14 displays the average SSRS total social skills scores for children with cancer and the healthy control peers at T1 and T2. Here, there is variation across time, with the children with ALL demonstrating increased social skills (from 104 to 111) after their cancer diagnosis and first 3 months of medical treatment. Both scores remained in the average range of total social skills. There is also variation across time for the healthy control peers, for which the average score decreased (from 109 to 102), but also remained

in the average range of total social skills.

It can be observed in participants' individual graphs (Figures 5-12 shown previously) as well as in the summary graphs (Figures 13-14) that for all four of the children with ALL, the CBCL and SSRS reported change in different directions regarding social functioning over time.

CHAPTER VI

DISCUSSION

A consistent conclusion in the literature is that the experience of cancer decreases social functioning in children. However, the limitations to this conclusion are glaring for multiple reasons, many of which have been previously discussed. Primarily, researchers have speculated diminished social skills without measuring any precancer social functioning. Mere speculations regarding a child's social functioning before cancer are hardly enough to conclude that a decline has occurred. Looking only at postcancer data vastly limits the conclusions that can be made regarding any change in social functioning. The current research addressed this gap by conducting a retrospective precancer assessment of social competence at the time of diagnosis, for the very first time in the literature. This provided a comparative baseline of social functioning prior to diagnosis, rather than mere speculation or assumption.

In addition, in the literature, the CBCL social competence score has been heavily utilized to support the conclusion that children with cancer have diminished social competence. Given the well-documented criticisms of using the CBCL for chronically ill children, the current research included an additional, potentially more accurate, measure of child social competence, the SSRS. This provided a needed addition to the literature, and may decrease the likelihood of future misinterpretation of the CBCL.

Finally, single case experimental methodology was utilized to examine individual differences in social competence for the first time in the literature. Evaluating social competence at the individual level provided a detailed picture of change and individual

differences. The strength of this method was further established by the inclusion of a comparison group, a marked rarity in the current literature, which facilitated comparison against normative variation in social competence over a 3-month period.

Empirical Questions

Do Children with ALL Function Similarly to Healthy Controls in the Social Domain, Prior to Diagnosis?

The data collected suggested that children with ALL do function similarly to healthy controls in the social domain prior to diagnosis. According to their scores on both the SSRS and the CBCL, children with ALL were quite similar to the normative samples of these questionnaires. All four children with ALL were in the average range at T1 (retrospective precancer measurement) on the SSRS Total Social Skills Score. Three out of the four children with ALL were in the normal range on the CBCL Social Competence Score at T1, while one child with ALL was within the borderline range. Although one child was within the borderline range of CBCL Social Competence at T1, the borderline range does not suggest clinical significance. This also occurred within the sample of four healthy control children; one out of the four healthy children was in the borderline range of social competence on the CBCL at T1.

Not only were the children with ALL similar to the normative samples of the CBCL and SSRS questionnaires, but they were also quite similar to each other on both measures. As demonstrated in Table 2 of the Results section, all children with ALL were within 1.5 standard deviations from each other on both the CBCL and SSRS at T1.

Finally, in addition to the similarity of the children with ALL to the normative samples of the questionnaires, as well as to each other, they were also similar to their healthy control peers. Although it was a requirement that the children with ALL were matched on T1 social competence on both the CBCL and SSRS, this was not difficult to accomplish. Each child with ALL was within 1.5 standard deviations on the CBCL Social Competence Score and the SSRS total social skills score of their healthy control peer at T1.

Given these initial similarities, it is reasonably concluded that children with ALL function similarly to their healthy peers in the social domain prior to diagnosis. This has been a consistent assumption in the literature, but this is the first study to provide empirical support for this conclusion. In this study, any change in social skills can now be compared to a baseline measurement. A databased context to assess change has been created.

Following Diagnosis and During Treatment, Do Children with ALL Display Diminished Levels of Social Competence?

Regarding the issue of children with ALL displaying diminished levels of social competence after a cancer diagnosis, special consideration into the measure being used is warranted. According to the CBCL measure of social competence, two of the children with cancer maintained their level of social competence, while two of the children with cancer demonstrated a decrease in social competence. This would suggest that some children will exhibit lower levels of social functioning after a cancer diagnosis, while other will maintain their level of social functioning. As discussed previously, the CBCL

measurement of social competence is highly affected by the quantity of social activity level, as gauged by the number of activities the child is involved in, the number of organizations they participate in, the number of close friends the child has, and the number of visits per week the child has with friends. It is certainly not surprising that a child with cancer will likely decrease in the quantity of their social activities and organization participation. Decreased immune system functioning, medical treatment, and temporary removal from school is likely to strictly limit social activity level, thereby decreasing the CBCL social competence score. It is concluded that a child's social activity level is likely to decrease after a diagnosis of cancer and the beginning of medical treatment. This conclusion does not suggest a decrease in the quality of social interaction, skills, or relationships for the child with cancer, but merely a decrease in the quantity of available, reasonable, and healthy social activity that a child can have in the beginning 3 months of cancer treatment.

Results according to the SSRS total social skills score present additional information of the childhood cancer experience. According to the SSRS, three of the four children with ALL demonstrated improvements in their social skills after their cancer diagnosis, all rising from the average range to the above-average range of social skills; this increase is considered to be clinically significant. The fourth child with ALL did not demonstrate change in her social skills, and maintained her average level of functioning. This would suggest that children with ALL are likely to demonstrate an increase in social functioning after a cancer diagnosis and first 3 months of treatment, when compared to their level of social functioning before the cancer diagnosis. While this may appear

confusing or counterintuitive, it is informative to look closely at some individual aspects of the SSRS total social skills score. For the parent report questionnaire, social skills are composed of individual scores of cooperation (i.e., household chores, appropriate use of time with friends and family), assertiveness (i.e., ability to make friends, positive appraisal by others, self-confidence), responsibility (i.e., ability to ask for help when needed, appropriateness in interactions with others, ability to recognize own mistakes), and self-control (i.e., appropriate conflict management, avoidance of troublesome behaviors, ability to control temper and respectful tone). For the three children who improved in their total social skills score, increased scores in multiple domains were demonstrated. This suggests that although a child's quantity of social activity may decrease following a cancer diagnosis, their social skills are likely to improve. It is speculated that this may be true for a variety of reasons. After a cancer diagnosis and beginning of treatment, a child may be surrounded by adults rather than other children, and be faced with a variety of mature concepts (i.e., illness, health, death). This may promote dialogue beyond the child's typical developmental level, which promotes a maturity that is not the norm in healthy children. During cancer treatment, a child is also likely to be exposed to a variety of medical procedures that they would rather avoid. Complying with medical care could certainly increase a child's abilities in the domains of self-control, sense of responsibility, and cooperation. In addition, past research suggests that childhood cancer may promote better perspective-taking abilities, and actually increases a child's appreciation for what they do have (Shankar et al., 2005). In addition, the children with ALL had aged 3 months over the course of this study; it may be

possible that over time, they are developing richer and more advanced social skills.

These factors may combine to contribute to an increase in reported cooperation, assertiveness, responsibility, and self-control.

Do Children with ALL Display Patterns of Social Interaction That Are Different Relative to Control Children?

According to the results of the CBCL data, change in social competence over a 3-month period of time was different in the group of children with ALL compared to the healthy control children. Two children with ALL demonstrated decreases in their social competence, while two maintained their level of social competence. Contrastingly, in the healthy control group, two children decreased in their social competence while two children increased in their social competence. It appears, according to the results of the CBCL data, that improvement in social competence is more likely for healthy children than children with ALL. Conceptualizing this finding in the context of what the CBCL social competence score actually measures (social activity level), the results are logical. A child beginning cancer treatment has significantly less opportunity to increase the amount of social activity (i.e., quantity of activities, organizational participation, and quantity of visits with friends) over a 3-month period than a healthy child. It is concluded that following a cancer diagnosis, children with ALL are less likely than healthy control children to increase their social activity level. Again, it is conceptualized by the researchers that this is related to physical health, immune system functioning, medical treatment, and school removal rather than genuine social skills.

Likewise, according to the results of the SSRS data, change in social competence

over a 3-month period of time was different in the group of children with ALL compared to the healthy control children. In contrast to CBCL data, three children with ALL rose from average social skill functioning to above-average social skill functioning, while one child with ALL remained in the average range. This general direction of improvement in total social skills demonstrated by children with ALL was not demonstrated by the healthy control children. In the group of healthy controls, two children decreased in their total social skills (one fell from the above-average range to the average range, and one fell from the average range to the below-average range), one child maintained her average level of social skills, and one child increased in her social skills but remained in the average range. The mixed presence of improved and diminished social skills for the healthy controls is markedly different when compared to children with ALL. It is concluded that children with ALL are less likely than their healthy control peers to exhibit decreases in social skills, as measured by the SSRS, over a 3-month period of time. Said differently, children with ALL are more likely than healthy peers to demonstrate an increase in social skills. This result can potentially be explained in multiple ways. Referring to the previous discussion of the domains of the SSRS, children with cancer may be more exposed to opportunities to display growth in the areas of cooperation, assertiveness, responsibility, and self-control relative to healthy peers. In addition, the manner in which a child copes with their cancer diagnosis and treatment may be perceived as highly positive by their mothers, which, in turn could affect parent report in the same domains. Healthy control children may, in fact, have less opportunity to display growth and improvement than children coping with a new cancer diagnosis. In

addition, as mentioned before, children with ALL are exposed to a variety of experiences that may genuinely increase their abilities in the areas measured by the SSRS total social skills score.

In sum, it is concluded that children with cancer do display patterns of social interaction that are different relative to control children. Specifically, children with ALL are more likely to demonstrate a decrease in social activity level compared to their healthy peers, and children with ALL are more likely to demonstrate an increase in social skills compared to their healthy peers.

Additional Findings

Assessment of Social Competence

Although the CBCL is widely used in the literature to support the conclusion that children with cancer exhibit diminished levels of social competence, there are fundamental concerns regarding the appropriateness of this use. The use of the CBCL measure of social competence for children with cancer has been criticized by Perrin and colleagues (1991). The potentially misleading measure of social competence is highly sensitive to any changes in variables regarding quantity of social activities and contact with friends. Questions that contribute to social competence relate to the number of activities the child is involved in, the number of organizations the child belongs to, the number of close friends a child has, and the number of times per week a child visits with their friends. In the current research, while participants with cancer did not display a change in their number of close friends, they did demonstrate marked reduction in their

activity and group participation, as well as their number of visits with friends per week. Regarding children with a newly diagnosed chronic illness, particularly one that greatly affects their immune system, a decrease in contact with peers and group activities hardly represents a true decrease in social competence. It is certainly not surprising that a cancer diagnosis will impact a child's involvement in these areas, reflecting prominent face validity but utilizing an overly narrow definition of social competence. This scale in the CBCL is too limited in scope to fully address social competence during the cancer experience. In addition, this measure of social competence possesses bias in that children with higher quantity of contact with friends and group participation appear to be negatively impacted to a greater degree due to the necessary decrease in the activity level during medical treatment. In the current research, all four children with ALL were removed from school immediately after their cancer diagnosis, due to impaired immune system and a need for chemotherapy. These results suggest that the SSRS may be a more accurate measure for social functioning and social competence in the population of chronically ill children. The total social skills score is composed of domains such as cooperation, assertion, responsibility, empathy, and self-control. These are more consistent with accepted constructs of social competence (Dirks et al., 2007), and may be more appropriate markers of social functioning for a child who is medically restricted from previously enjoyed activities and peer contact.

Given the concerns with the CBCL, it is important to again look fully at the SSRS Total Social Skills score, and the results that were presented in the graphs. The CBCL and SSRS present highly divergent pictures of social functioning of children with ALL.

Two children with ALL demonstrated a decrease in CBCL social competence; one of these same children actually demonstrated an increase in SSRS total social skills, while the other child demonstrated stability in her SSRS total social skills. The other two children who demonstrated stability in CBCL social competence actually demonstrated an increase in their SSRS total social skills. This suggests that while activity level, organizational participation, and quantity of contact with friends may be restricted (and, therefore reflected by a decrease in CBCL social competence score), varied elements of social functioning (as measured by the SSRS total social skills score) either remain stable or increase after a cancer diagnosis and the first 3 months of medical treatment. This data calls into question the widespread belief in the current literature that childhood cancer leads to decreased social functioning, a belief fueled largely by the CBCL social competence score.

In sum, the widespread use of the CBCL social competence score as evidence of low social competence for children with cancer is unfortunate, and potentially inaccurate. It is the strong opinion of the researcher that if the CBCL is used to measure social functioning in children with chronic illness, the social competence score must be interpreted carefully, and in the specific context of quantity of social contact and activity level. Ideally, the social competence score would be referred to as “social activity level” rather than social competence. However, the use of the CBCL may still be helpful in determining the impact that cancer has had on the quantity of social contact, and can still be seen as a useful tool in fully understanding the experience of childhood cancer. With the appropriate interpretation and discussion of the CBCL social competence score for

children with cancer, conclusions can still be drawn. However, these conclusions should relate to activity level rather than social competence. It is the strong opinion of the researcher, then, that the SSRS is be a more appropriate measure of social functioning for children undergoing cancer treatment, and should be relied on more heavily than the CBCL to understand the genuine social skills of a child with chronic illness. The use of the SSRS as a measure of social functioning for children with any chronic illness is recommended as a more accurate measure for this population than the CBCL.

Fluidity of Social Skills in Healthy Controls

The lack of any consistency in social functioning (as measured by both the CBCL and SSRS) among the healthy comparison children over a 3-month period of time is noteworthy. Social functioning, which has generally been considered to be a somewhat stable and enduring characteristic (Dirks et al., 2007), appears in the current research to be a highly dynamic construct, sensitive to change even in healthy children when examined at the individual level. According to the CBCL, two healthy children increased in their social competence, while two healthy children decreased in their social competence. According to the SSRS, one healthy child increased in her social skills, one child maintained her social skills, and two children decreased in their social skills. It is a possibility that examining change in social function at multiple points over time and at the individual level yields different results than large group analyses have previously suggested. When examined individually, the current healthy controls exhibited significant variability in social functioning without any general consistency. However, if averaged together, it would appear that the group of healthy controls as a whole,

maintains average levels of social functioning, on both measures, across time. This is yet another example of how examining change at the individual level yields a full and accurate picture of the construct of interest.

The remarkable variability in change demonstrated over a 3-month period by healthy comparison peers suggests that changes in social functioning may be a normal and anticipated experience. This also suggests that any change found in children with cancer may not be due to the cancer experience itself, and may be due to a variety of daily factors experienced by the general population. Social functioning, previously thought of as stable and consistent throughout development, may actually be a dynamic and fluid construct that can vary greatly across time in the general, healthy population of children. It is possible that the current literature on social functioning is in need of single case design methodology to further examine the possibly dynamic nature of the construct, which can be lost in large group designs.

Finally, the variability demonstrated by the healthy controls in this study further highlights the necessity of a healthy comparison group for all research with chronically ill children. Having a matched comparison sample is crucial to concluding whether or not results found in the chronically ill sample are abnormal.

Limitations

One clear limitation to the current research is the limited generalizability of the results. Clearly, any results found (or not found) in a sample of four children should be generalized with caution. It is appropriate to generalize the conclusions of the current

research to girls with ALL between the ages of 6 and 11, with a similar course of treatment as the participants in the study (i.e., chemotherapy, without bone marrow transplant or radiation therapy). It may be possible that children with more aggressive forms of cancer, more invasive types of treatment (i.e., surgery, radiation treatment, amputation, etc.), or more time spent as an inpatient, may exhibit a different pattern of social functioning than the current group of participants. The researcher does not intend for these conclusions to be applied to children with all types of cancer. It is not assumed that all cancer experiences are void of social difficulties, isolation, or other social concerns. The conclusions of the current research must be generalized appropriately, and with caution.

Another limitation to the current research is the availability of only two data points from which to gather conclusions. Evaluating only the first 3 months of cancer treatment provides data for a relatively small portion of an enduring treatment process. While it was concluded that children with ALL do not demonstrate decreases in social functioning, this can only be applied to early phases of the cancer experience, as compared to their precancer levels of functioning. It is certainly a possibility that with prolonged treatment, decreases in social functioning may emerge.

A final limitation to the current research is the method through which social functioning was assessed. While there exists a clear precedent for the use of parent report measures in the current literature, there is significant potential for maternal bias to occur. Drawing conclusions based solely on parent report may not fully capture child social functioning. For example, attaining self-report measures from the children themselves

may broaden the scope of conclusions that can be drawn. Observational assessment would also increase the objectivity of the research conclusions. However, sensitivity regarding a family experiencing a new diagnosis of childhood cancer is paramount in conducting research with this population, and the invasiveness of research is an important consideration.

Implications and Future Research

Comparing separate cancer diagnoses with each other may illustrate potential differences in trends in social functioning based on severity of medical treatment, time spent in inpatient care, and the use of radiation. It would be useful for medical and psychological staff to better understand which cancers, and their treatments, are associated with a higher likelihood of diminished social outcomes. Perhaps the allocation of hospital resources (i.e., support groups, monitored online chat rooms, counseling services, etc.) to children at high risk for decreased social functioning throughout their cancer treatment could reduce the potential effects.

In addition, longitudinal research conducted throughout the first one to two years of cancer treatment would provide more substantial data on the course of social competence over time. Collecting several measurements of social competence for a longer period of time would allow researchers to follow children throughout their treatment, examining potential trends that arise in later stages of treatment. This would broaden the scope of conclusions that can be drawn, extending the conclusion throughout the entire cancer treatment process.

Finally, the use of the SSRS, or other measures of social competence, in future research may further highlight disparity from previous conclusions that, based on the CBCL, suggested that chronically ill children suffer significant decreases in social functioning. Parents of children with ALL may be encouraged by the conclusion that cancer does not decrease genuine social skills, despite a decrease in social activity level. This may allow parent attention to be directed at more appropriate areas of concern, regarding physical health and general family well-being. This may also encourage parents to continue to facilitate their child's social contact with peers when medically appropriate, without unnecessary concerns that relationships will diminish or social competence will plummet. Families facing a brand new childhood cancer diagnosis grapple with vast concerns regarding physical and emotional well being of their child. It would be invaluable for a physician to provide parents with the accurate, reliable, and well-documented conclusion that despite school removal and prolonged medical treatment, children with cancer do not face diminished social functioning. The knowledge that a diagnosis of cancer is not equivalent to likely future social incompetence may not only allay parent and child concerns, but may also allow for more natural, less stressful, interactions throughout the cancer experience.

Conclusions

In conclusion, while children with ALL exhibit a decrease in social activity after diagnosis and throughout the first 3 months of cancer treatment, they are likely to exhibit an increase in their genuine social skills. Prior conclusions regarding the decrease in

social competence in children with cancer need to be evaluated in light of the use of the CBCL Social Competence Score, the lack of matched healthy control peers, and the reliance on qualitative data.

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