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THE EFFECTS OF PEDIATRIC ACUTE LYMPHOBLASTIC LEUKEMIA ON SOCIAL FUNCTIONING: AN INVESTIGATION INTO THE FIRST YEAR OF TREATMENT

by

Rachel L. Duchoslav

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

of

DOCTOR OF PHILOSOPHY

in

Psychology

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2012

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ABSTRACT

The Effects of Pediatric Acute Lymphoblastic Leukemia on Social Functioning:

An Investigation into the First Year of Treatment

by

Rachel L. Duchoslav, Doctor of Philosophy

Utah State University, 2012

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Department: Psychology

Cancer is currently the leading cause of death by disease in children under the age of 15 in the US. While the number of childhood cancer survivors continues to grow, psychological research on this population has lagged. Existing research on the psychosocial effects of childhood cancer is marked by inconsistent conclusions as well as methodological limitations. However, the effect of childhood cancer on social functioning is one area with relatively more consistency. Existing research suggests that childhood cancer can lead to deficits in prosocial skills as well as the emergence of social problems. The present study investigated individual change in social functioning for five children diagnosed with Acute Lymphoblastic Leukemia ALL) over the first year of treatment compared to healthy control peers. Children with cancer demonstrated a

decrease in social activity as well as an unexpected increase in social skills not demonstrated by healthy control children.

(129 pages)

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Cancer is currently the leading cause of death by disease in children under the age of 15 in the US. While the number of childhood cancer survivors continues to grow, psychological research on this population has lagged. Existing research on the psychosocial effects of childhood cancer is marked by inconsistent conclusions as well as methodological limitations. However, the effect of childhood cancer on social functioning is one area with relatively more consistency. Existing research suggests that childhood cancer can lead to deficits in prosocial skills as well as the emergence of social problems.

The present study investigated individual change in social functioning for five children diagnosed with Acute Lymphoblastic Leukemia (ALL) over the first year of treatment compared to healthy control peers. This investigation sought to answer the following research questions.

1. Following diagnosis and during the first year of treatment, do children with Acute Lymphoblastic Leukemia (ALL) display diminished levels of prosocial skills?

2. Following diagnosis and during the first year of treatment, do children with Acute Lymphoblastic Leukemia (ALL) display increased levels of social problems?

3. Do children with Acute Lymphoblastic Leukemia (ALL) display patterns of social functioning that are different relative to control children during their first year of treatment?

Children with cancer demonstrated a decrease in social activity as well as an unexpected moderate increase in social skills not demonstrated by healthy control children. If substantial future research supports these initial findings, encouraging data could be presented to families of children with cancer. The knowledge that a diagnosis of cancer is not equivalent to likely future social deficits may allay parent and child concerns, and may allow for more natural, less stressful, interactions throughout the cancer experience. This current research was unfunded.

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Thank you to my wonderful husband, Jon. You have helped me every step of the way down this very long road. I am so blessed to have you in my life. For the unwavering support of my loving family and excellent friends—thank you for everything.

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CHAPTER I

INTRODUCTION

In the US, cancer is currently the leading cause of death by disease for children under the age of 15. However, survival rates for this disease have increased significantly, approaching 80% at 5 years post diagnosis (Vannatta & Gerhardt, 2003). Psychological research in childhood cancer has lagged in comparison to current medical advances in treatment, growing survival rates, and understanding of the disease. There is a need to investigate the psychological effects of childhood cancer given the increasing population of childhood cancer survivors who experience a range of challenges, including social reintegration, school adjustment, and health transformation.

Existing research was somewhat inconsistent in its conclusions on the effects of childhood cancer. A comprehensive review of the literature revealed mixed findings. The literature did not consistently demonstrate that children with cancer display elevated levels of clinical psychological problems or maladaptive symptomatology compared to peers. Some research indicated no increases in diagnoses 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). However, other research indicated that children with cancer have significant difficulties with school adjustment, internalizing and externalizing problems, and quality of life challenges, suggesting that there are genuine psychological challenges for children coping with a cancer diagnosis and treatment. Mixed findings across studies warrant further investigation to advance the understanding of childhood cancer as well as its

psychological and social ramifications.

The social effects of childhood cancer have been more widely researched than other psychological domains. The available evidence suggests that children in treatment for cancer and those who have been successfully treated suffer significant social deficits (Vance & Eiser, 2002) such as decreased prosocial skills and increased social problems.

Conclusions from pediatric psycho-oncology research are fairly consistent regarding peer relationships, social functioning, and social competence. Considering the increasing size of this growing population of childhood cancer survivors, there is a relative dearth of longitudinal research in the area of childhood cancer and social functioning. The few longitudinal studies that exist have relied heavily on qualitative data. In addition to the scarcity of longitudinal data, studies have typically not incorporated healthy peers as a control group in order to better understand the magnitude of deficits compared to the typical population. Despite these limitations, the literature consistently reveals that children with cancer demonstrate significantly lower social competence (Olson, Boyle, Evans, & Zug, 1993; Van Dongen-Melman, 1995), less satisfaction with peer relationships (Vannatta, Gartstein, Short, & Noll, 1998), less popularity (Sloper, Larcombe, & Charlton, 1994), and more social isolation (Vannatta et al., 1998) when compared to population norms (or, less commonly, healthy control peers). These findings form a discouraging picture of the long-term social effects for survivors of childhood cancer.

There are important gaps in the literature of childhood cancer survivors that warrant increased empirical attention. It is not possible to predict which children will

develop cancer, and, therefore, not possible to collect data prior to diagnosis. While it is feasible to retrospectively collect data on prediagnostic social functioning at the point of diagnosis, this had not yet been done in the literature. Current research suggested that children with cancer are qualitatively different from healthy peers, but no precancer data exists confirming this tentative conclusion. It may be possible that prediagnostic baseline functioning is predictive of the course and severity of social competence deficits during treatment but again this has not been empirically discussed. Whatever the case, the diagnosis of cancer and its treatment may alter or diminish a child's social competence. However, without an estimate of prediagnostic social competence, the magnitude of its effect is unknown.

Additional longitudinal research is needed to understand individual patterns of functioning throughout the course of cancer diagnosis and treatment. Longitudinal data may provide the missing details centered on pre and post-diagnosis differences in functioning as well as patterns and points of risk during treatment and post treatment. Longitudinal data would contribute to increased understanding of the experience of childhood cancer that cross-sectional research cannot provide (Eiser, Hill, & Vance, 2000; Patenaude & Kupst, 2005a, 2005b).

The longitudinal research that is available has employed large numbers of participants and analyzed data in a group format. While useful, much of the individual experience of childhood cancer is missing. By investigating individual change in pro-social skills and social problems over time, a deeper understanding of the progression, severity, and patterns of social competence could be more clearly assessed. These

patterns, then, could be further incorporated into our understanding and more targeted treatment directions may be possible.

In sum, there is a growing amount of research that has been conducted in this important area of pediatric psycho-oncology. Longitudinal research to investigate individual pre and post-diagnosis differences, as well as individual trends over time is warranted. The evidence is clear that the population of pediatric cancer survivors is growing steadily due to medical advances. Further investigation on the effects of cancer on social functioning would continue to address the needs of this growing population.

This current research study first began as a smaller initial project and included a retrospective measure of childhood social functioning at the time of a cancer diagnosis as well as a second measure of social functioning three months into cancer treatment. The results yielded from the initial project demonstrated that while children with cancer exhibited a decrease in social activity after diagnosis and throughout the first 3 months of cancer treatment, they also exhibited an increase in social skills. The current project extended these findings by investigating progress across 12 months of treatment after a cancer diagnosis.

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

4. Following diagnosis and during the first year of treatment, do children with acute lymphoblastic leukemia (ALL) display diminished levels of prosocial skills?

5. Following diagnosis and during the first year of treatment, do children with ALL display increased levels of social problems?

6. Do children with ALL display patterns of social functioning that are different relative to control children during their first year of treatment?

CHAPTER II

REVIEW OF LITERATURE

Introduction to Childhood Cancer

Prevalence and Survival

Cancer is the leading cause of death by disease in children under the age of 15 in the US. Each year, approximately 10,000 children in the US receive a new cancer diagnosis, with an overall prevalence rate of .3%, or one out of every 330 children (Vannatta & Gerhardt, 2003). Although the prevalence rate for childhood cancer has remained stable in the past 10 years, the survival rate has increased from 55% to 79% when assessed at 5 years post diagnosis. Long-term remission can be expected for the majority of children with cancer due to significant advances in medical treatment (Patenaude & Kupst, 2005a, 2005b). This improvement in treatment, as well as life expectancy, has greatly increased the number of childhood cancer survivors in the US population, which, in turn, increased the need for pediatric psychologists to focus on research and psychological treatments (Vannatta & Gerhardt, 2003). As a field, pediatric psychology has begun to focus on the impact childhood cancer has on immediate and long-term emotional, behavioral, and psychological functioning (Eiser et al., 2000)

The term childhood cancer refers to a group of various malignancies and related diseases. ALL is the most common form of all childhood cancers and is associated with a higher than average survival rate 5 years post diagnosis (83%).

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 lowers overall immune system functioning, and decreases the available space for healthy white blood cells, platelets, and red blood cells (Pui, Campana, & Evans, 2001). Symptoms preceding diagnosis of ALL include fever, bruising, joint pain, weakness, loss of appetite, and the emergence of small painless lumps in the lymph nodes (Pui et al., 2001).

Treatment for ALL is consistent with the treatment of other serious and potentially life-threatening childhood cancers; it is extremely rigorous and may include three components: chemotherapy, radiation, and stem cell transplant (Pui et al., 2001). The average treatment period for ALL typically continues for 2-3 years (Pui et al., 2001) and includes intense chemotherapy treatments. When considering the rapid developmental changes a child experiences, this treatment period can have a considerable psychological impact including internalizing problems, externalizing problems, and social difficulties (Vannatta & Gerhardt, 2003). Common side effects of chemotherapy include hair loss, fatigue, nausea, vomiting, diarrhea, and mouth pain. Common side effects of radiation can include weakness, fatigue, and a decrease in immune system functioning.

The following review of literature review can be conceptualized in two main parts; (a) the general psychological effects of childhood cancer and (b) the impact of the illness and treatment on the social functioning of afflicted children. Initially, the effects

of childhood cancer on general psychological functioning including display of internalizing and externalizing problems, academic difficulties, negative cognitive effects, and quality of life will be reviewed. Subsequently, the impact of cancer and treatment are considered in relation to social functioning in a developmental context. As the effects of childhood cancer on social functioning is the focus of the current research study, this domain in the research literature will be reviewed in detail.

General Psychological Effects of Childhood Cancer

It has been well documented that children with cancer encounter a variety of complications such as hair loss, amputation, appetite reduction/weight loss, weakness, and other significant physical outcomes. While the negative physical complications due to treatment are apparent, there are concurrent negative psychological effects that may also occur.

Psychological Effects Throughout Treatment

Psychological complications of childhood cancer such as depression, anxiety, and posttraumatic stress have been investigated (Eiser et al., 1997; Phipps et al., 2006; Stuber & Shemesh, 2006; Van Dongen-Melmen, 1995). Interestingly, after a systematic review of the literature, Eiser and colleagues (2000) concluded that children with cancer are not significantly different than healthy controls across many psychological domains. However, there is also a substantial research indicating that children with cancer are more likely to encounter psychological problems than their healthy counterparts, warranting

continued investigation (Kullgren, Morris, Morris, & Krawiecki, 2003; Pao, Ballard, & Zito, 2009; Stuber & Shemesh, 2006)

Internalizing problems. Existing research indicated that the prevalence of prescription antidepressant medication use is significantly higher among children with cancer, as compared to healthy peers. Portteus, Ahmad, Tobey, and Leavey's (2006) review of medical records from a large medical center concluded that children with cancer were prescribed antidepressant medication at a ratio of 10:1 as compared to children without cancer. A more recent investigation (Pao et al., 2009) indicated that children and adolescents with cancer are prescribed antidepressants at a much higher rate than those without cancer. From these studies, the assumption can be made that children with cancer are prescribed antidepressants at higher rates due to higher levels of depressive symptoms.

Sawyer, Antoniou, Toogood, and Rice (1997) studied the psychological adjustment of young children for 2 years following a cancer diagnosis. In this study, children were assessed with the Child Behavior Checklist (CBCL) and General Health Questionnaire at three time periods: within 5 weeks of their cancer diagnosis, 1 year later, and 2 years post diagnosis. They concluded that children with cancer experienced significant emotional distress as compared to healthy peers during the period immediately following diagnosis. Across time, the level of emotional distress returned to levels comparable to children without cancer. Within 1 year of termination 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. It appears that

while there is an initial spike of distress for children with cancer, there is a return to typical levels of psychological functioning.

Post-traumatic stress disorder (PTSD) has been another area of focus within the childhood cancer research literature. In 1994, the American Psychological Association (APA) added life threatening illness to their list of traumatic stressors sufficient to precede a diagnosis of PTSD. An increase in the assessment and rates of diagnosis of PTSD among children with cancer subsequently followed APA's criteria expansion. Stuber and Shemesh (2006) concluded that symptoms of PTSD such as: disturbing dreams, fear of their cancer diagnosis, and feelings of isolation, are not unusual in children during the acute treatment phase. Eiser and colleagues (2000) conducted a meta-analysis of the literature, and found that 20% of children with cancer experience symptoms of posttraumatic stress. It is noted that the research that addresses "post-traumatic stress" for children with cancer often does not include diagnostic criteria for the disorder of PTSD; rather, this literature includes more liberal "post-traumatic stress." Further, the majority of studies did not utilize the comparison of children with cancer to any healthy normative group, a significant methodological limitation.

Despite inconclusive findings in this area, treatments have been developed to address the symptoms of post-traumatic stress in children with cancer. In a randomized controlled trial, researchers employed the Surviving Cancer Competently Intervention Program (SCCIP) to decrease symptoms of post-traumatic stress in children with cancer. They found that the SCCIP significantly decreased physiological arousal to hospital and medical cues in children with cancer and therefore increased functioning and adaptability

to stressful medical procedures and situations (Kazak et al., 2004). In this study, the researchers concluded that problematic post-traumatic stress symptoms in this population such as intrusive thoughts, avoidance, and arousal could effectively be treated. Phipps and colleagues (2006) investigated the correlation between levels of PTSD with specific adaptive styles in children with cancer. One specific adaptive coping style, characterized by high defensiveness and low anxiety was found to be common in children with cancer. Researchers concluded this defensive 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 specific coping style may contribute towards inconsistent research findings of maladaptive symptoms of PTSD, depression, and anxiety throughout the literature (Phipps et al., 2006). Findings in the domain of internalizing problems were inconsistent. However, research demonstrating there are significant symptoms in children with cancer (depression, PTSD) suggests that this phenomenon should be investigated further.

Externalizing problems. Research on the externalizing behavioral problems of children with cancer suggest that children with cancer display high levels of externalizing problems compared to peers. For example, Olson and colleagues (1993) found a significantly higher percentage of children with behavioral problems in the childhood cancer population compared to the general population. Further, children with cancer have a higher likelihood than healthy peers for having behavioral problems in the clinical range, as measured by the CBCL.

Researchers have concluded that higher rates of behavior problems during cancer

treatment are strong predictors of longer-term behavioral problems (Kullgren et al., 2003). Others (Newby, Brown, Pawletko, Gold, & Whitt, 2000) have noted that the amount of time away from cancer treatment was negatively correlated with the severity of externalizing behavior problems. Children are at high risk for behavioral difficulties both during and immediately after treatment for cancer as measured by parent report on the CBCL; this risk declines with time post treatment termination. While these studies provide reason for concern over the behaviors of children with cancer, a review of the literature concluded that maladaptive behaviors and general maladjustment in children with cancer is not the norm and thus is less of a concern than others might purport (Patenaude & Kupst, 2005a, 2005b).

What continues to remain unknown is the magnitude and longitudinal course of child behavioral problems during and following cancer treatment. Therefore, additional research is needed to explore this area before conclusive recommendations can be offered.

Functioning in the academic setting. Armstrong and Briery (2003) discussed the effects of chemotherapy on a child's functioning at school. Chemotherapy drug and steroid combinations can cause jaw pain, constipation, tingling in the feet and hands, slowed motor functioning, rapid weight gain, and volatile mood swings. The combination of medication, chemotherapy, and radiation treatment side-effects may impact a child's ability to perform efficiently and effectively in a classroom environment.

In a review of existing literature, Vance and Eiser (2002) concluded that children with cancer exhibit significantly more behavior problems in a classroom setting than

controls, as indicated by teacher report. The authors hypothesized that the peer relationships of children with cancer can be negatively affected by common behavioral problems at school such as hyperactivity, restlessness, irritability, and fatigue. While clearly not unique to this population, children recently diagnosed with cancer may display uncharacteristic behaviors due to the stressful nature of cancer treatment and the uncertainty of their prognosis.

Simms, Kazak, Golomb, Goldwein, and Bunin (2002) studied the effects of stem cell transplantation on cognitive outcomes. Parents rated children's academic abilities to be significantly lower both 1 and 2 years after stem cell transplant, compared to standardization norms on the Parent Rating Scale of Everyday Cognitive and Academic Abilities. This suggests that children who underwent stem cell transplant are significantly more likely to struggle with academics than their healthy peers.

Barrera, Shaw, Speechley, Maunsell, and Pgany (2005) used the CBCL to evaluate the effects of childhood cancer upon academic functioning. Based on parental report, child cancer survivors had significantly more academic problems than controls. Compared to healthy peers, children who successfully underwent treatment for cancer more often repeated a grade (21% vs. 9%), more often attended learning disability programs (19% vs. 7%), were more often involved with special education services (20% vs. 8%), and had more educational or other school problems (46% vs. 23%).

Cognitive late effects. One of the most consistently documented effects of childhood cancer treatment is an area called cognitive late effects. Daly and Brown (2009) outlined the cognitive late effects of childhood cancer that includes decreases in

academic achievement, executive functioning, attention/concentration, processing speed, memory, and visual-spatial/visual-motor skills. These effects can vary in time of when they appear (or if they appear at all), which can range from several months to up to years after the completion of treatment. Specific childhood cancer treatments carry higher risk for cognitive late effects. Leukemia and Lymphoma are considered to be high risk treatments, due to the likelihood of chemotherapy and/or radiation administered intrathecally to prevent the spread of cancer into the brain. Medical treatments that carry higher risks for cognitive late effects include surgery, cranial radiation therapy, bone marrow transplantation, and chemotherapy drug combinations (methotrexate, cytarbine, and corticosteroids; Daly & Brown, 2009).

Quality of life. The pediatric psychology literature has also focused on the effects of childhood cancer on quality of life. Shankar and colleagues (2005) investigated the self-reported 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 healthy control peers. Researchers concluded that the children currently in treatment experienced the lowest overall quality of life with specific deficits in the areas of physical functioning and future outlook on life.

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 after their child's diagnosis, and again at 1 and 2 years post diagnosis. Quality of life was evaluated based on the child's behavior in the contexts of friendships, school, understanding of their illness, and appearance. Researchers concluded that the

oldest group of participants with ALL (10-14 years old) had a lower overall quality of life compared to younger participants with ALL (0-4 years old, and 5-9 years old). This suggests that children and adolescents over the age of 10 may be more impacted than younger children.

Further empirical research specific to ALL has demonstrated the difficulty for families to maintain a level of "normality" during the 2-3 year treatment phase. Earle, Clarke, Eiser, and Sheppard (2006) concluded that maintaining a normal family life during treatment was extremely difficult to accomplish for mothers of children diagnosed with ALL. After longitudinal qualitative interviews, the researchers concluded that parents need concrete advice, guidelines, and information to maintain a sense of normality within their family during treatment. Mothers identified multiple barriers to a sense of normality including changes in eating habits, child's variable mood, missed school, painful procedures, weakness, clingy behaviors, multiple hospital visits, and personality changes (Earle et al., 2006).

However, in a systematic review of the literature, Patenaude and Kupst (2005a, 2005b) discussed evidence that is incongruent with these findings of lowered quality of life. The authors discussed research that failed to find any significant maladaptive effects of childhood cancer on psychological functioning, and also found strong positive outcomes in this population. They concluded that childhood cancer can, in some cases, create positive changes in perception of life focus, a reordering of priorities in life, increased resiliency, and a stronger appreciation for relationships and life itself. These factors could combine and contribute to an actual increase in quality of life.

Findings remains varied on whether childhood cancer is damaging to quality of life, depending on which aspects are measured. This area of positive psychology warrants further investigation with a childhood cancer population.

Long-Term Effects of Childhood Cancer Survivorship

The results from research on the long-term psychological effects of childhood cancer on survivors have been mixed. In a review of the literature, Eiser and colleagues (2000) found only one study where childhood cancer survivors demonstrated 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. As previously discussed, possible psychological effects include symptoms of posttraumatic stress, anxiety, and depression (Eiser et al., 2000). However, these symptoms have not been demonstrated to be consistent long-term outcomes of childhood cancer. However, cancer survivors with extreme or pronounced difficulties are typically excluded from research, which may skew the results to a more positive view of the cancer experience. This possible sampling bias limits the generalizability of results.

Concerns with their physical appearance are reported in over 66% of adult survivors of childhood cancer. 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 difficulty with school adjustment are also experiences common to long-term 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 negative view of adult survivorship of childhood cancer (Vannatta & Gerhardt, 2003).

Some researchers have suggested that the experience of childhood cancer, and its treatment, may actually have long term protective effects in the domains of future aggression, antisocial behavior, and substance abuse. Young adult survivors of childhood cancer reported significantly less illegal drug use and substance experimentation, years after the completion of their treatment, compared to healthy control peers (Verrill, Schafer, Vannatta, & Noll, 2000). With varied evidence, it is reasonable to state that a clear picture of the long-term psychological effects of childhood cancer are not, as of yet, established.

Social Functioning

It is difficult to draw clear conclusions of the experience of children with cancer. It is important, at a point when survival rates approach 80%, to begin to better understand the childhood cancer experience. Studies of the effects of childhood cancer on social functioning have yielded more conclusive findings than many other psychological domains. Consistently, children with cancer and survivors demonstrate social skills deficits relative to their healthy peers.

Social Competence from a Developmental Perspective

Within the developmental literature, social competence has been broadly defined as effectiveness in interaction and has been conceptualized differently over time. Traditionally, social competence has been conceptualized as a "trait model." 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, social competence has been conceptualized as a characteristic of social behavior rather than a stable individual trait. In this "social skills model," some behaviors (i.e., assertive communication, initiation of positive contact) reflect greater social competence than others (i.e., aggression, passive communication). The social skills model appeared to be better supported by empirical evidence than the trait model (Dirks, Treat, & Weersing, 2007).

There is divergence of opinion on whether social competence is a stable characteristic or a collection of changing social behaviors. There is also diversity in the operational definitions of social competence. Elliot and Gresham (1987) discussed social skills as positive social behaviors built into a child's repertoire, which can be defined by behaviors, peer acceptance, or social validity. According to this definition, children with social skills engage in behaviors in which rewards from peers are likely gained, and punishment (from peers) are avoided. Children are considered to possess social skills to the degree that they are accepted by their peers and maintain positive attitudes regarding specific social outcomes (i.e., peer acceptance, peer judgment, academic competence, and self-esteem). Elliot and Gresham additionally discussed social skills as a lack of inappropriate social behaviors.

Asher (1983) defined social competence to be comprised of three dimensions: relevance, responsiveness, and social knowledge. A child who can appropriately read social cues and situations from peers and adults would measure high on the relevance dimension of social competence. A child who can initiate and receive appropriate peer contact would measure high on the responsiveness dimension of social competence. Finally, a child who can comprehend that relationships take time to form as well as to repair will measure high on the social knowledge dimension of social competence. Further, social competence in children is negatively correlated with the following characteristics: anxious/withdrawn, submissive, sensitive, wary, and isolated/ lonely. Social competence has been positively correlated with popularity among peers (Asher, 1983; Rubin, Coplan, Nelson, & Lagace-Seguin, 1999).

Regardless of the variance in opinions on the stability and definition of social competence, there is general agreement that a child's social skills are very important. It has been accepted that childhood peer friendships can instill feelings of self-worth, promote the growth of interpersonal sensitivity, and create a foundation for adult intimate relationships (Rubin et al., 1999). Parker and Gottman (1989) concluded that social competence itself is determined by early childhood friendships. In early childhood, higher levels of social competence can maximize enjoyment in interpersonal play. In middle childhood, social competence evolves to include skills of self-presentation and impression management. In adolescence, social competence includes self-exploration, conflict resolution, and emotional regulation. Social skills are clearly an important element in childhood. Thus, the research that suggests that children with cancer

consistently exhibit deficits in social skills further underscores the need for better understanding in this area.

Social Competence from an Oncology Perspective

In the pediatric psycho-oncology literature, social competence has often been broadly and generally defined 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, emphasizing the importance and variability of social behaviors across different developmental stages and situations.

Measurement of Social Competence in Oncology Literature

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. Behavioral rating scales, commonly completed by parents and teachers, are effective in identifying patterns of child behavior that are both predictive and valid measures of social competence. According to the authors, the Social Skills Rating System (SSRS), the Child

Behavior Checklist (CBCL), the Matson Evaluation of Social Skills for Youngsters, and the Child Behavior Scale are the most commonly used behavior rating scales for social competence. These measures are thought of as effective ways in which to get a basic understanding of a child's social competence and are also the primary method of measuring social competence in the pediatric psycho-oncology literature.

While there is some consistency in the measurement of social competence in the pediatric psycho-oncology literature there is also some diversity in measurement techniques. Parents are the most common sources of information for social competence of children with cancer. In addition to parent report, social competence has also been measured by self-report and other-report sources (peer, teacher), albeit less frequently.

Self-report measures are typically avoided within the pediatric oncology research. While self-report may be conceptualized as too invasive or taxing for a child currently undergoing cancer treatment, it is more widely used with adolescents or adult cancer survivors. 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 can provide additional insight in the area of social competence. Multiple peer report measures were utilized by Vannatta and colleagues (1998) to assess peer relationships of children with cancer. In the "Three Best Friends" measure, the number of times a child is nominated as the best friend of a classmate is summed, as well as the percentage of reciprocated best friend nominations. In the Liking Rating Scale, every child in a classroom rates every other child on a "liking scale" of 1

(do not like) to 5 (like a lot). In the Revised Class Play 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.

Teacher-report measures of social competence are more common in pediatric oncology literature, and often include the Teacher Report Form (Olson et al., 1993; Vannatta et al., 1998). Often, teacher-report measures are combined with parent-report measures to gain multiple perspectives on a child's social functioning. Newby and colleagues (2000) utilized parent and teacher report measures, both the Social Skills Rating System (SSRS) and the CBCL/TRF, to assess the social skills and psychological adjustment of childhood cancer survivors. These researchers found significant variability between the ratings of teachers and parents, highlighting the potential need to gather data from multiple sources for an accurate assessment. This variability is seen across populations, and likely reflects that parents and teachers see children in different settings (Achenbach, McConaughy, & Howell, 1987).

To study children with cancer, researchers most often utilize parent report as the measure of social competence (Vance & Eiser, 2002). The CBCL is the most commonly utilized parent report measure for social competence within the literature, specifically the Social Competence Scale. Its widespread use, utility with children across a wide range of ages, and its consistent production of significant research findings makes the CBCL popular with researchers in the field of pediatric oncology. In a review of the literature concerning the school experience of children with cancer, Vance and Eiser reported that over half of all reviewed studies used the CBCL when reporting school issues for

children with cancer. This may also be due to the available Teacher Report Form version of the CBCL, which can be scored alongside Parent Report forms to get a fuller picture of the child's social competence. The CBCL has been used by a wide variety of researchers to study the psychosocial effects of childhood cancer (Bagner, Fernandez, & Eyberg, 2004; Carpentieri, Mulhern, Douglas, Hanna, & Fairclouh, 1993; Newby et al., 2000; Noll et al., 1997; Olson et al., 1993; Shelby, Nagle, Barnett-Queen, Quattlebaum, & Wuori, 1998).

Caution for the use of the CBCL with pediatric oncology population. Despite its widespread use, the CBCL has been criticized for its use with children with chronic illness. Perrin, Stein, and Drotar (1991) strongly emphasized the need for caution when using the CBCL in populations of chronically ill children. The authors argued that the CBCL has a limited ability to detect more mild adjustment difficulties likely to be seen in chronically ill children. The authors 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 is not surprising that cancer treatment 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 social competence during such a complex experience as childhood cancer. The CBCL social problems scale provides a more applicable social competence measure that involves a child's perceived overdependence on adults, internal

emotions (i.e., loneliness, jealousy, paranoia), and peer acceptance. Similar concerns were echoed by other childhood cancer researchers (Patenaude & Kupst, 2005a, 2005b).

Applicability of the SSRS with a pediatric oncology population. The Social Skills Rating System (SSRS) has also been used (although not frequently) within the childhood cancer population (Newby et al., 2000; Willard, Hardy, & Bonner, 2009). The SSRS was developed based on theory and has been demonstrated to be a valid measurement of social functioning (Elliot, Gresham, Frank, & Beddow, 2008). The subscales of the SSRS are cooperation, empathy, assertion, self-control, and responsibility. These domains do not appear to have the restrictive quality of the CBCL Social Competence Scale when used to assess a chronically ill population. Finally, the SSRS has convergent validity with other behavioral rating scales (Flanagan, Alfonso, Primavera, Povall, & Higgins, 1996).

Effects of Childhood Cancer on Social Functioning

The social effects of childhood cancer have been more commonly researched than other psychological domains, and have yielded relatively consistent results. The available evidence suggested that children in treatment and children who have survived cancer suffer significant social deficits. This can be described in terms of decreased prosocial skills (social competence) as well as increased social problems that have detrimental effects on peer relationships. An overview of findings on social competence in pediatric oncology literature will be outlined, followed by a review of pertinent research findings. For consistency with the current research study, this review of the social effects of

childhood cancer will be divided into two domains: prosocial skills and social problems.

The study of social functioning within the childhood cancer literature is primarily cross-sectional, while the only longitudinal studies rely heavily on qualitative data. Despite the scope of the issue and the increasing size of this population, there is much to explore concerning childhood cancer and social functioning. Additionally, studies often neglect the use of healthy peers as a control group.

In general, the literature supports the conclusion that survivors of childhood cancer struggle in the area of social functioning. While this literature is reviewed in detail in the following pages, Table 1 presents a brief summary of relevant past research to aid in the reader's understanding of the general conclusions in the literature.

Social Problems

For the current study, social problems were conceptualized as the presence of difficulties in social interactions and peer relationships, such as social isolation, peer rejection, interaction avoidance, withdrawal, and a negative view of one's social self. With this definition in mind, relevant literature was reviewed in detail concerning childhood cancer patients and survivors, with a focus on the presence of social problems.

A qualitative study conducted by Patterson and colleagues (2003) highlighted the social problems experienced by childhood cancer survivors. Researchers held a series of seven focus groups of 45 parents of 26 children at least 1 year posttreatment for various types of cancer. The group sessions were taped, and transcripts were recorded and later coded for relevant data. Struggles with feelings of self-consciousness in the presence of peers were reported by the majority of parents. There were also reports of negative

Table 1

Summary of Major Findings in Similar Childhood Cancer Research

Author, year	Sample size	Measures	Major findings
Patterson, Holm, & Gurney, 2003	*N* = 45 parents of children at least 1 year posttreatment for cancer	Qualitative focus groups	Children with cancer exhibited self-consciousness about perceptions of others and loss of normal life/normal social activities
Vannatta et al., 1998	*N* = 28 childhood brain cancer survivors between 8-18 yrs old; 28 matched peers	Three Best Friends Liking Rating Scale	Brain cancer survivors had more social problems than healthy peers and were perceived by peers as sick and fragile; BC survivors equally able to maintain close friendships ('best friends')
Barrera et al., 2005	*N* = 800 childhood cancer survivors under age 18; 923 matched peers	Ontario Health Survey CBCL	Cancer survivors had fewer close friends, less confidantes, more socially isolated
Earle & Eiser, 2007	*N* = 32 mothers of children with ALL 0-14 yrs old	Qualitative interviews	Older children with cancer (10-14) demonstrated lowest quality of life, most social withdrawal, and greatest concern about appearance
Olson et al., 1993	*N* = 20 children with cancer; 40 matched peers	Vineland CBCL	Children with cancer had lower social competence than matched peers
Shelby et al., 1998	*N* = 34 parents of children with ALL	CBCL BASC	Children with cancer had social competence in clinical range, and lower than national norms in social skills and leadership skills; Older children had more severe deficits
Kullgren et al., 2003	*N* = 40 children with brain cancer	CBCL	Social competence 3-4 years post diagnosis is predicted by social competence 1-2 years post diagnosis; Social competence lower than national norms
Gerhardt, Vannatta, Valerius, Correll, & Noll, 2007	*N* = 56 childhood cancer survivors; 60 matched peers	Self-perception profile CBCL	No concerns regarding social outcomes for childhood cancer survivors on average 7 months post-treatment
Reiter-Purtill, Vannatta, Gerhardt, Correll, & Noll, 2003	*N* = 69 childhood cancer survivors; 77 matched peers	Three Best Friends Liking Rating Scale	Survivors were perceived by peers as more sick/tired and had fewer "best friends;" Survivors also demonstrated higher levels of social skills and less aggression than matched peers

emotions related to missing social, academic, and extracurricular activities. Although these data were not compared to parent reports of healthy peers, 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 functioning (Patterson et al., 2003)

Peer relationships are often used as indicators of a child's social problems. 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, teacher, and self-reports 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-report, and teacher report. In addition, despite no longer receiving treatment for their illness, survivors were rated by peers to be 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. Also, they may continue to be perceived by peers as sick and fragile despite the remission of their cancer.

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) 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. This suggests that while the medical community may place greater emphasis on the children who receive more severe treatments, the psychological effects for varied treatment severities may be similar.

However, some researchers have noted significant differences in social effects of cancer depending on disease and treatment severity. For example, Carpentieri and colleagues (1993) compared the behavioral resiliency of child survivors of brain cancer to those who had 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 suggested that children with brain cancer exhibit greater 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. There is not a consensus on the issue of severity of social effects regarding radiation therapy versus nonradiation therapy treatments and brain cancers versus non-CNS cancers.

Barrera and colleagues (2005) studied the social effects of childhood cancer on survivors under the age of 18. In a retrospective cohort design, over 800 children who survived multiple types of childhood cancer were matched with 923 healthy control peers of the same gender and age. The researchers concluded that, according to parent report, the childhood cancer survivor group was more likely than control group to have no close friends (19% vs. 8%) and was significantly less likely than control group to use friends as confidants (58% vs. 67%). This evidence of social isolation and avoidance of peer intimacy may suggest reasons for the wider social problems evident in this population.

Self-image, as it relates to social functioning and overall social problems, was researched by Stern and colleagues (1993). Participants included 48 adolescents with cancer and 40 healthy control peers. Participants completed the Offer Self-Image Questionnaire and the Social Provision Scale, which measured self-image and perceived social support. 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. Adolescents with cancer reported significantly more negative views of their social and sexual selves, both of which may contribute to overall social functioning. While many adolescents with cancer reported social rejection from teachers and peers during their cancer treatment, results were not statistically different from control

participants (Stern et al., 1993)

In one of the few longitudinal studies in the literature, Earle and Eiser (2007) studied children with ALL 6-8 weeks postdiagnosis, and then again 1 and 2 years into their treatment. The researchers concluded, through qualitative interviews, that younger children (ages 0-4) adjusted with the least problems to the cancer diagnosis. Older children (ages 5-9) reported significantly more social problems and worried about their appearance more than the youngest group. The oldest group of children (ages 10-14) adjusted the least well. Mothers of children in this age group 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.

For the oldest participants (ages 10-14), parent report of social problems was present shortly after diagnosis and remained throughout treatment. However, all other age groups were reportedly more moody and clingy than developmentally expected at the second data collection point, 1 year postdiagnosis. For the children over 4 years old, significant problems at 1 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 were not further analyzed or evaluated, and the children with cancer were never compared to healthy control peers. The researchers concluded that the quality of life for the older children was the lowest, and that this group experienced the most social withdrawal and concern about appearance. These social problems appeared almost

immediately after diagnosis and remained stable throughout the study (Earle & Eiser, 2007).

In sum, children with cancer have been found to have more social problems than healthy children. This appears to be more likely with older children, and can take the form of lower self-confidence, fewer close friendships, and increased social isolation. However, these social problems may be affected by cancer type and severity of treatment.

Prosocial Skills

Prosocial skills have been conceptualized as healthy and appropriate skills for social interaction and peer relationships, commonly discussed in the literature as social skills and social competence. Relevant literature is reviewed concerning children with cancer and childhood cancer survivors, with a focus on any change (increase or decrease) in prosocial skills.

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. The CBCL and the Vineland Revised Scale of Social Maturity were used as parent and teacher report measures to evaluate overall prosocial skills. On the Vineland Revised Scale of Social Competence, childhood cancer survivors were rated significantly lower than the healthy controls by both teachers and parents. 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. The percentage of participants who fell below the normal range for social competence was significantly

higher in the childhood cancer survivor group (60%) compared to the healthy control group (15%). This suggested that a majority of children with cancer have clinically referable deficits in social competence (Olson et al., 1993)

Shelby and colleagues (1998) designed a study to evaluate the overall social competence of child survivors of ALL. Parents of 34 children who had completed treatment for ALL completed the CBCL and the Behavior Assessment System for Children (BASC). Scores on both tests were then compared to published norms for the measures. On the CBCL childhood cancer survivors demonstrated social competence that was significantly lower than the normative group across all dimensions of the scale. In addition, on the BASC, childhood cancer survivors scored significantly lower than the normative group in social skill display and leadership skills. Older children demonstrated more severe deficits. This study supported the conclusion that children with cancer exhibit significantly lower levels of prosocial skills than population norms, and that older children may be at greater risk (Shelby et al., 1998).

Kullgren and colleagues (2003) investigated the social competence of children 1-2 years following a cancer diagnosis and again 3-4 years following the diagnosis. The researchers concluded that the children demonstrated social competence (as measured by parent report on the CBCL) that was lower than the normative sample of the measure. Also, time 2 social competence was significantly predicted by social competence at time 1, suggesting that a child's deficits in prosocial skills 1 year post diagnosis are likely to continue, even many years later, without intervention (Kullgren et al., 2003).

However, not all research corroborates the conclusion that children with cancer go

on to suffer deficits in prosocial skills. Gerhardt and colleagues (2007) studied 56 survivors of childhood non-CNS cancers who were, on average, over 7 years post treatment and 60 comparison peers. According to self-report measures and parent report measures, concerns regarding social outcomes were not found. The researchers concluded that survivors of childhood cancer were well adjusted during the transition from adolescence to young adulthood, and that they displayed similar levels of social competence as their control peers. Childhood cancer survivors were similar to their comparison peers in the domains of social, self-concept, family and friend relationships, romantic relationships, and social competence (Gerhardt et al., 2007).

Reiter-Purtill and colleagues (2003) investigated the prosocial skills of children who recently completed cancer treatment. Peer, teacher, and self-report measures were given to evaluate the prosocial skills of 69 children who recently completed cancer treatment and 77 healthy control peers. The researchers concluded that children who received more intense cancer treatment were actually rated by peers to be more prosocial and less aggressive than healthy controls, although they were rated as having fewer ‘best friends’ than controls. Also, children who completed cancer treatment were more stable over time in their self-report of prosocial skills than healthy control peers. The researchers concluded that while cancer treatment may carry minor social effects for children, such as being perceived by peers as more sick and tired than peers, or the decrease in number of ‘best friends,’ these effects are in addition to the maintenance of, or perhaps even improvement in, prosocial skills (Reiter-Purtill et al., 2003). While findings like these may not be common, they have appeared in the literature more often in

recent years. The concept that children maintain appropriate levels of prosocial skills during and after cancer treatment is one which warrants further investigation and consideration.

Long-Term Social Effects

The existing literature on the effects of childhood cancer on adult survivors' social functioning is limited. Gray and colleagues (1992) performed a qualitative analysis of adult survivors of childhood cancer, evaluating 62 adult survivors and 51 healthy comparison peers. All participants were given various projective and self-report measures and participated in a semistructured interview. Significant differences emerged from the qualitative 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. The authors concluded that adult survivors of childhood cancer 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) studied 102 adults between the ages of 19-30, who survived childhood ALL (n = 67) or a Wilms Tumor (n = 35). Interpersonal relationships and social performance was assessed by the Adolescent to Adult Personality Functioning Assessment. 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 daily 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 non-brain cancer. These results, which suggest greater social deficits among the ALL survivors, warrant 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 needed.

The current study first began as a thesis project (Duchoslav, 2010), which included a retrospective measure of childhood social functioning at the time of a cancer diagnosis, and a second measure of social functioning three months into cancer treatment. The CBCL and SSRS were utilized, and CBCL Social Competence Score and SSRS Total Social Skills Score were examined for four children with ALL and four control peers. Results from the initial study revealed that while children with cancer exhibited a decrease in social activity after diagnosis and throughout the first 3 months of cancer treatment, they also exhibited an increase in social skills. Surprisingly, the children will ALL were more likely than healthy controls to demonstrate an increase in social skills over the three month period, despite their decrease in social activity. This encouraging study warranted additional investigation. Therefore, additional data were collected to more fully evaluate longer-term individual patterns in social functioning over time.

Summary and Conclusions

There is an increased need for research on the psychosocial effects of childhood cancer due to the growing population of survivors. The literature yields inconsistent

conclusions in many psychosocial domains such as depression, anxiety, post-traumatic stress, and quality of life. However, one moderately consistent conclusion is that children with cancer demonstrate significantly lower levels of social functioning than healthy controls.

Within the social functioning research in pediatric psycho-oncology is the conclusion that children with or surviving cancer exhibit lower levels of social functioning, both in prosocial skills and social problem domains, than healthy peers. However, despite the relative consistency of these conclusions, there are important gaps in the literature that need to be addressed. First, there have been no studies that estimate 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. 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. Also, the longitudinal research in this area is limited. Investigating trends of social functioning over time may yield conclusions that have yet to be discovered regarding the trends or patterns of social decline, if any, over time. Finally, the literature has yet to fully investigate individual data over time. A focus on individual rather than group data may yield a clearer picture of individual change over time.

Systematic reviews by Eiser and colleagues (2000) and Patenaude and Kupst

(2005a, 2005b) noted 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, longitudinal data that provides information regarding pre and postdiagnosis change, patterns, and points of risk during and after treatment is lacking. The longitudinal research that is available has used large numbers of participants, and has analyzed the data in a group format, and often qualitatively. By investigating individual change in social competence over time, a clear picture of progression, severity, and patterns of social competence could be assessed. Further, the literature contains studies with 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 needed.

CHAPTER IV

METHODOLOGY

Participants

Participants in this study were five children between the ages of 6-11 years old, diagnosed with ALL at a children's hospital in a large metropolitan area, and five typically developing peers who served as matched controls. Mothers of the ALL patients were initially contacted for research participation by a hospital pediatric psychologist. All participants were within 1-week of their cancer diagnosis. The typically developing participants were recruited through university-affiliated organizations in a metropolitan area and informative flyers posted at a large university. The control participants were matched with the child with cancer on the variables of age and gender.

Table 2 describes the participants across a variety of demographic variables. Participants labeled C1-C5 were the children diagnosed with cancer; participants labeled H1-H5 were the corresponding matched healthy control peers.

All participants were female and between the ages of 6 and 11. Most of the participants identified themselves as White and all participants spoke English. The majority of the participants lived in towns of between 10,000 and 50,000 people. The participants came from households with varied income levels; however, two participants did not answer that particular question on the demographic questionnaire.

The children in the current study were diagnosed with ALL and began the same medical treatment protocol. Consultation with healthcare providers suggested that it is

Table 2

Demographic Information of Participants

Participant	Gender	Age	Ethnicity	Community	Income
C1	F	8	White	Town less than10,000	High
C2	F	7	White/Hispanic	Suburbs over 50,000	Low
C3	F	6	Hispanic	Town 10-50,000	Average
C4	F	11	Hispanic	Town 10-50,000	Not reported
C5	F	8	White	Town 10-50,000	Average
H1	F	8	White	Farm	Low
H2	F	7	White	Town less than 10,000	Average
H3	F	6	White	Town 10-50,000	High
H4	F	11	White	Town less than10,000	Not reported
H5	F	8	White	Town 10-50,000	Low

Note. Household income: High = over $100,000; Average = $50,000 – 100,000; Low = Below $50,000.

difficult to discuss a "typical" course of treatment, due to the individual progress and needs of each child. However, a brief outline of a "typical" treatment may guide the reader's understanding of the participants' experience. A child with ALL will usually begin to lose their hair within the first 2 weeks of chemotherapy treatment. A child will likely lose all of his/her hair 1 month after beginning treatment. However, many parents choose to shave their child's hair before it begins to fall out. A bone marrow transplant is not typical for treatment of ALL, but may be medically necessary in some cases. Most children miss the majority of the first 6-8 months of school after diagnosis. After the first year of chemotherapy, typical children will enter the "maintenance phase" of treatment and receive fewer and less intense doses of chemotherapy treatments. In this phase, children may only miss 5-10 days of school per month, depending on their immune

system functioning. Typical maintenance therapy lasts two years for girls and three years for boys. It is again noted that the variability in course of treatment is high.

Measures

The CBCL (ages 4-18) is a parent report measure that provides ratings of three competence scales for children: activity, social, and school (Achenbach & Rescorla, 2001). In addition, the CBCL includes eight syndrome scale scores (anxious/depressed, withdrawn/depressed, somatic complaints, social problems, thought problems, attention problems, rule-breaking behavior, and aggressive behavior) and six DSM-Oriented scales (affective problems, anxiety problems, somatic problems, attention deficit/hyperactivity problems, oppositional defiant problems, and conduct problems). The CBCL has high internal reliability, with a range of reliability within subscales of .96 to .64. The scores of interest for the proposed research study are social competence and social problems. The social competence scale has a test-retest reliability of .93 and internal consistency reliability (alpha) of .68. The social problems scale has a test-retest reliability of .90 and internal consistency reliability (alpha) of .82. Affective problems and anxiety problems (two DSM-oriented scales) were also of interest in the discussion section. The affective problems scale has a test-retest reliability of .84 and internal consistency reliability (alpha) of .82. The anxiety problems scale has a test-retest reliability of .80 and internal consistency reliability (alpha) of .72. The measure does not utilize norms based on ethnicity (Furlong & Wood, 1998)

For normative comparisons raw scores on the CBCL are converted to *t* scores. On

the social competence scale, a *t* score equal to or lower than 31 is in the clinical range. A *t* score between 32 and 35 is in the borderline clinical range, and any *t* score above 35 is in the normal range. On the social problems, affective problems, and anxiety problems scales, a *t* score at or below 64 is considered to be in the normal range. The *t* score of 65-69 are in the borderline clinical range and *t* score at or above 70 are in the clinical range.

The SSRS (Gresham & Elliot, 1990) is a parent-report measure that provides ratings on four subscales: cooperation, assertion, responsibility, and self-control as well as a social skills total scale. There is a high level of internal consistency, with a range of .73 to .95 for all subscales. The scores of interest are the total social skills score and all subscale scores (cooperation, assertion, responsibility, and self-control). The measure does not utilize norms based on ethnicity (Benes, 1995).

The total social skills score on the SSRS is presented in standard scores. Based on the national norms of the SSRS, a standard score below 86 is in the “Less than average” range (indicating that the child being rated is below average in social skills). A standard score from 86-114 is considered to be in the average range. A standard score above 114 is considered to be in the “More than average” range (indicating that the child has above average social skills). The standard error measurement (SEM) for the total social skills score is $\pm$ 11. The subscales on the SSRS (cooperation, assertion, responsibility, self-control) are presented in summed scores (i.e., raw scores) and are not standardized or comparable across subscales. The standard error measurement for subscale scores is $\pm$ 3. However, national norms have also been developed for these summed scores and outcomes are presented and discussed in relation to these national norms as well.

Procedure

A total of four assessments of social functioning were given (T1 = time of diagnosis, with retrospective prediagnosis reporting, T2 = 3 months post diagnosis, T3 = 6 months post diagnosis, and T4 = 1 year post diagnosis). The methods of measurement were paper and pencil forms of the CBCL and the SSRS. The dependent variable was social functioning as measured by these questionnaires; specifically the CBCL's social competence score and social problems score, and the SSRS's total social skills score, as well as the SSRS's subscale scores for cooperation, empathy, assertion, self-control, and responsibility. The addition of these variables expanded the investigation of social functioning to include both prosocial skills as well as social problems in addition to investigating these variables longitudinally, throughout the first full year of treatment. Further, additional data (from the study completion survey, included in the appendix of this document) were obtained from the mothers regarding the nature of their child's first year of treatment, including the amount of time spent away from school, the amount of time spent as an inpatient in the hospital, any significant changes to the treatment protocol (e.g., bone marrow transplant), the approximate time of hair loss, any specific changes they noticed regarding their child's social and emotional functioning, and the concerns they had for their children.

It is important to note that while the enrollment of the five participants with cancer took over 12 months, the participants (both children with ALL and controls) were at different steps in their individual treatments. Therefore, year-long data collection for each individual was conducted on a rotating schedule until all data points were collected

for all five individuals. Institutional Review Board (IRB) approval was granted, by both the Utah State University (USU) IRB and the Intermountain Healthcare (IHC) IRB, before any data collection began, and applied to all 12 months of data collection for all participants.

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. The pediatric psychologist collected the contact information of those who were willing to participate. The researchers contacted the pediatric psychologist at least once per week to collect potential participant contact information. The mothers were contacted by phone by 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, arrangements were made for face to face meetings.

The first measure was given at the time of diagnosis (within 1 week), and was retrospectively completed according to child social functioning for the month previous to diagnosis. This information at diagnosis served to establish a premorbid baseline measure of the child's functioning. The second measure was given at 3 months post-diagnosis, and evaluated social functioning well into initial medical treatment. The third measure was given at 6 months post cancer diagnosis, and evaluated social functioning much later into medical treatment. Finally, the fourth measure was given 1 year after the diagnosis, and evaluated social functioning a full twelve months into medical treatment. These four measurements provided a more complete picture of a child's social functioning

throughout the first full year of treatment.

The data collected for the initial research study conducted by Duchoslav (2010) included T1 (retrospective prediagnosis measure of functioning) and T3 (3 months after diagnosis). The data collected for the current study included T3 (6 months after diagnosis), T4 (12 months after diagnosis), and the collection of qualitative information from the mothers of the participants with ALL (through interviews and additional mailings).

The CBCL and SSRS were completed by mothers at all four time periods. For T1 through T4, the researchers met the participants at the treatment hospital to complete initial measures. At this meeting (T1), researchers instructed the mothers to complete measures based on the past month, not including the days since diagnosis. Data collected at T2, T3, and T4 also occurred at the same location. Similar procedures were conducted with control participants, who were recruited with flyers posted around a university campus. However, their initial data collection was not contingent on a medical diagnosis and therefore measures were completed at participants' homes or other location during convenient times.

Analysis

Scores were graphed for both the CBCL and SSRS results. Data from both measures were graphically compared and analyzed across individuals for change in social functioning 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, and identifying any trends that emerged over time for the individuals.

CHAPTER V

RESULTS

All participants completed each time phase (T1, T2, T3, and T4) of the project with the exception of participant C4 who was unable to complete time phase 4 (T4). Participant C4's family moved out of state during the eighth month of her cancer treatment, and although contact with her and her family was attempted by researchers, these attempts were not successful. Therefore, there is only data for participant C4 for the duration of the first 6 months of her treatment (T1, T2, and T3).

Table 3 displays time phase T1 results for the children with ALL and their healthy control peers on the SSRS Total Social Skills Score. The five participants with ALL were in the average range according to their T1 (retrospective, prediagnostic) measure of social functioning on the SSRS. Four out of the five control children were in the average range on the SSRS Total Social Skills, while one was in the above-average range for Total Social Skills. Each of the five children with ALL was within 1.5 standard deviations of their matched healthy control peers on the SSRS Total Social Skills score.

Table 3

Social Functioning of Participants at T1

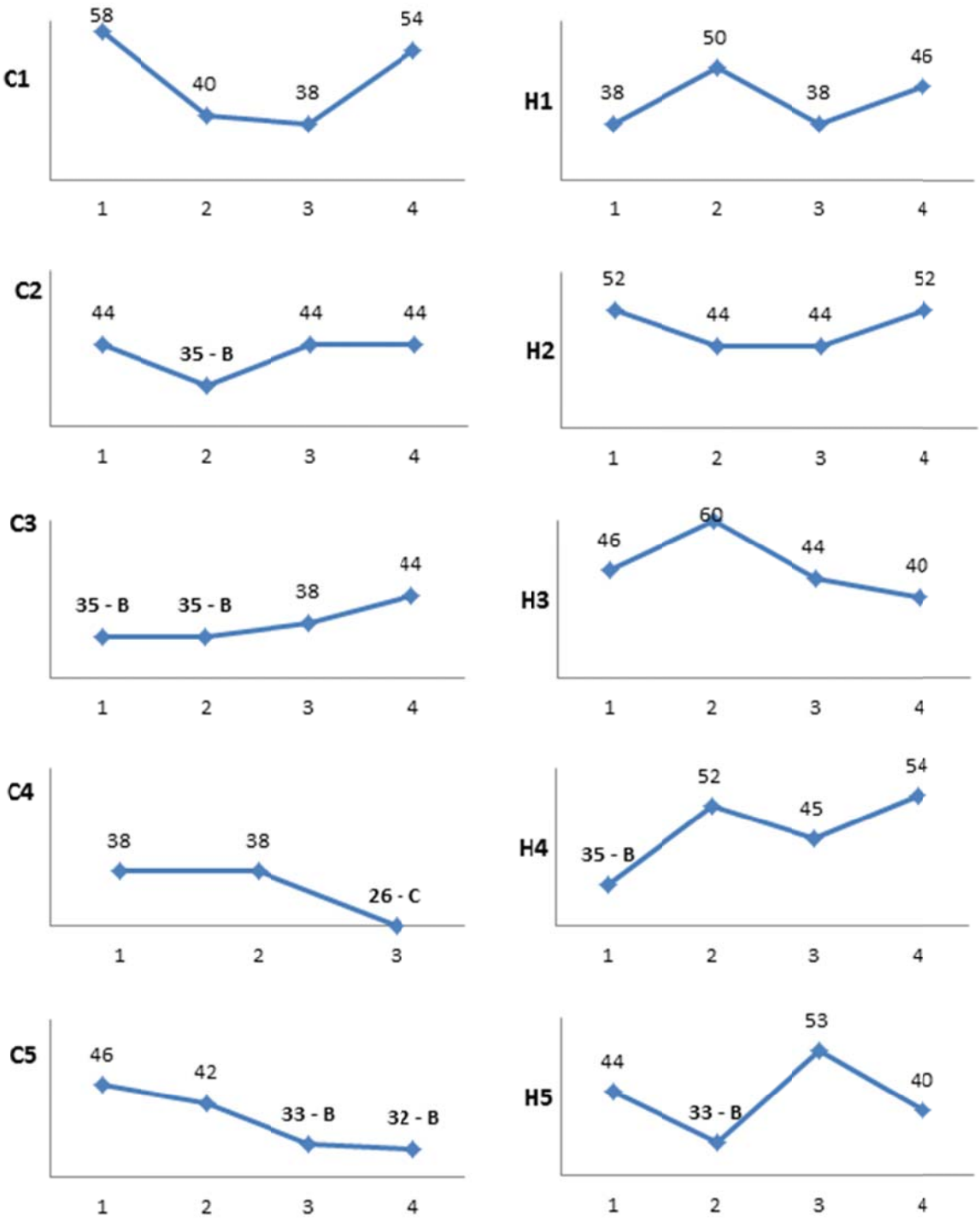
Participant	SSRS total social skills score	Participant	SSRS total social skills score
C1	98 (average range)	H1	95 (average range)
C2	108 (average range)	H2	108 (average range)
C3	110 (average range)	H3	122 (above-average range)
C4	104 (average range)	H4	101 (average range)
C5	93 (average range)	H5	106 (average range)

Empirical Question #1

Following diagnosis and during the first year of treatment, do children with ALL display diminished levels of prosocial skills?

A brief introduction about how individual change over time will be discussed in this section may be helpful to guide the reader's understanding. First it is important to recognize that the CBCL and SSRS both have impressive test-retest reliability (r = .80 to .94 for the CBCL and r = .77 to .87 for the SSRS). For *t* score on the CBCL, individual changes across time are discussed according to standard deviations. Any individual change that is greater than one standard deviation (>10 points) will be discussed as "significant," and as a change greater than chance fluctuation over time. For the SSRS total social skills scores, individual changes across time are discussed according to standard error measurement. Any individual change that is greater than one standard error measurement (>11 raw score points) will be discussed as "significant," and as a change greater than a chance fluctuation over time. For the SSRS subscale scores, individual changes across time are also discussed according to standard error measurement. Any individual change that is greater than one standard error measurement (>3 raw score points) will be discussed as "significant," and as a change greater than a chance fluctuation over time.

Figure 1 graphically displays CBCL social competence *t* score for each participant at T1 through T4. The children with ALL, visible on the left hand side of the figure, are compared to their healthy control peer on the right hand side of the figure.



Note. C = Clinical range ($t \leq 31$); B = Borderline clinical range ($31 < t < 36$).

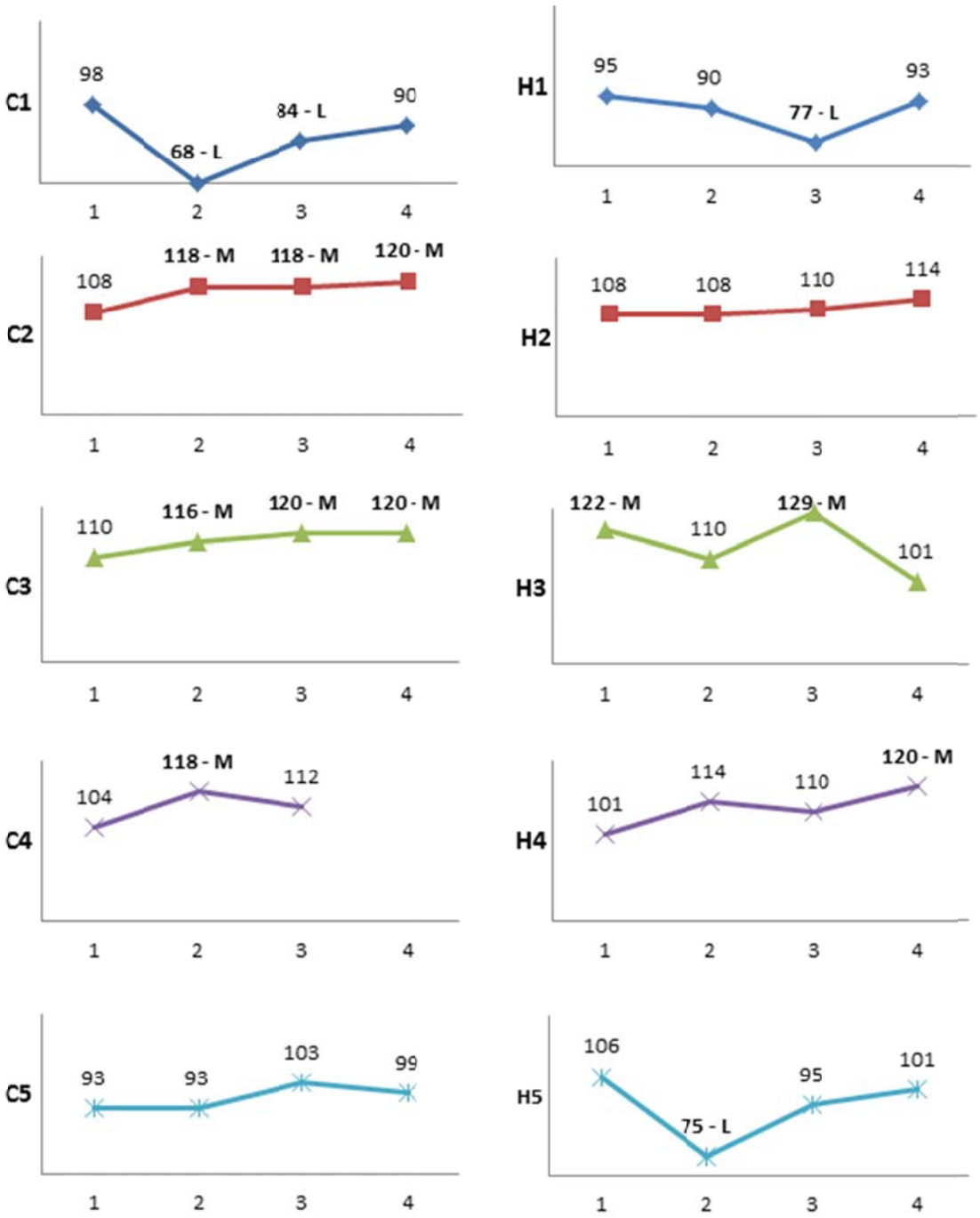
Figure 1. CBCL Social competence *t* scores for children with ALL and healthy control peers at T1-T4.

Scores for the CBCL are marked according to the national norms of the CBCL. In the figure, *t* score followed by a "B" next to the score indicate that the score is in the borderline clinical range, with a *t* score between 32-35. The *t* score with a "C" following the score indicate that the score is in the clinical range, with a *t* score at or below 31. All *t* scores above 35 are in the normal range and are not marked with a letter in the figure. All scores that are not in the normal range are also in bold text.

A wide variability in patterns of social competence over time is apparent from T1 (prediagnosis baseline), T2, T3, and T4 for children with ALL. Only one child in this group maintained a stable level of social competence throughout the year that she received treatment for cancer, and demonstrated variation less than one standard deviation between measurements. One child with ALL (C2) remained stable in her social competence across the year of data collection. C2 had a social competence *t* score of 44 (normal range) at T1 and at T4. One child with ALL (C3) appeared to increase her social competence from a *t* score of 35 (borderline range) at T1 to 44 (normal range) at T4. Three children with ALL (C1, C4, and C5) appeared to decrease in their overall social competence from T1 (prior to diagnosis) to their last data collection point. C1 had a social competence *t* score of 58 (normal range) at T1, and a social competence *t* score of 54 (normal range) at T4. C4 had a social competence *t* score of 38 (normal range) at T1 and a social competence *t* score of 26 (clinical range) at her last data collection point, T3. C5 had a social competence *t* score of 46 (normal range) at T1 and a social competence *t* score of 32 (borderline range) at T4. Overall, children with ALL demonstrated an initial drop in social competence.

Focusing on the healthy control children in Figure 1, wide variability in patterns of social competence over time is also apparent in this group from T1 through T4. Only one child in this group (H2) maintained a stable level of social competence throughout the year (demonstrating change less than one standard deviation between measurements). Two control children (H1 and H4) appeared to increase in their social competence between T1 and T4. H1 had a social competence *t* score of 38 (normal range) at T1 and a social competence *t* score of 46 (normal range) at T4. H4 had a social competence *t* score of 35 (borderline range) at T1 and a social competence *t* score of 54 (normal range) at T4. Two control children (H3 and H5) appeared to decrease in their overall social competence from T1 to T4. H3 had a social competence *t* score of 46 (normal range) at T1 and a social competence *t* score of 40 (normal range) at T4. H5 had a social competence *t* score of 44 (normal range) at T1 and a social competence *t* score of 40 (normal range) at T4. Instability in social competence across time was the norm for both children with ALL and their matched peers.

Figure 2 graphically displays SSRS total social skills standard scores for each participant at T1 through T4. The children with ALL, visible on the left hand side of the figure, are alongside their healthy control peer, who are visible on the right hand side of the figure. The scores in the figure are marked according to the national norms of the SSRS. In the figure, standard scores with an “L” following the score indicate “Less than average” total social skills, with a standard score below 86. Standard scores with an “M” following the score indicate “More than average” total social skills, with a standard score above 114. All standard scores between 86-114 are in the average range and are not



Note. M = "More social skills than average" (SS > 114); L = "Less social skills than average" (SS < 86).

Figure 2. SSRS Total social skills standard scores for children with ALL and healthy control peers at T1-T4.

marked with a letter in the figure.

One child with ALL significantly increased her total social skills score from T1 (prediagnosis) to her last data collection point. C2 increased from a standard score of 108 (average range) at T1 to a standard score of 120 (above average range) at T4. Three additional children with ALL demonstrated moderate increases in their total social skills scores; however, these increases were within the normal variance over time. C3 increased from a standard score of 110 (average range) at T1 to a standard score of 120 (above average range) at T4. C4 increased from a standard score of 104 (average range) at T1 to a standard score of 112 (average range) at T3. C5 increased from a standard score of 93 (average range) at T1 to a standard score of 99 (average range) at T4. One child in this group decreased (but not significantly so) in her total social skills score from T1 to T4. C1 decreased from a standard score of 98 (average range) at T1 to a standard score of 90 (average range) at T4. One of the children with ALL significantly increased in her total social skills score across the data collection period. No child with ALL demonstrated a significant decrease in total social skills.

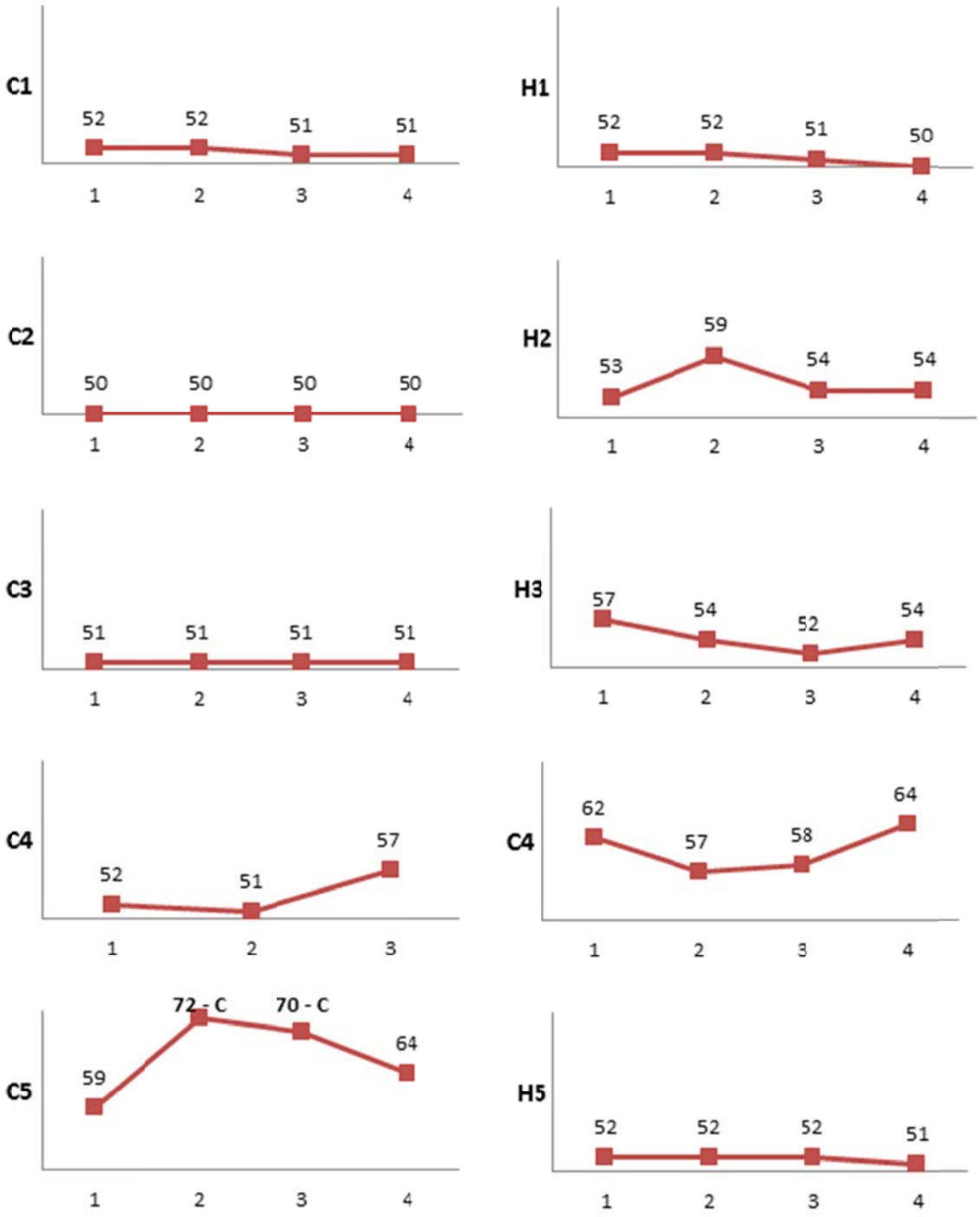
Focusing on the healthy control peers in Figure 2, one child in this group significantly increased in her total social skills score from T1 to T4. H4 increased from a standard score of 101 (average range) at T1 to a standard score of 120 (above average range) at T4. One additional child demonstrated moderate increases in her total social skills score; however, this increase was within the normal variance over time. H2 increased from a standard score of 108 (average range) at T1 to a standard score of 114 (average range) at T4. One child in this group significantly decreased in her total social

skills score from T1 to T4. H3 decreased from a standard score of 122 (above average range) at T1 to a standard score of 101 (average range) at T4. Two additional children demonstrated moderate decreases in their total social skills score; however, these decreases were within the normal variance over time. H1 decreased from a standard score of 95 (average range) at T1 to a standard score of 93 (average range) at T4. H5 decreased from a standard score of 106 (average range) at T1 to a standard score of 101 (average range) at T4. One control child demonstrated a significant increase in total social skills scores from T1 to T4. One control child demonstrated a significant decrease in total social skills.

Empirical Question #2

Following diagnosis and during the first year of treatment, do children with ALL display increased levels of social problems?

Figure 3 graphically displays CBCL social problems *t* scores for each participant at T1 through T4. Again, the children with ALL, visible on the left-hand side of the figure, are alongside their healthy control peers, who are visible on the right-hand side of the figure. The scores in the figure are marked according to the national norms of the CBCL. In the figure, *t* scores with a "B" following the score indicate that the score is in the Borderline Clinical Range, with a T-Score between 65-69. The *t* scores with a "C" following the score indicate that the score is in the clinical range, with a *t* score at or above 70. All *t* score below 65 are in the normal range and are not marked with a letter in the figure.



Note. C = Clinical range ($T \geq 70$); B = Borderline range ($70 > t > 64$).

Figure 3. CBCL social problems for children with ALL and healthy control peers at T1-T4.

Focusing on the children with ALL in Figure 3, variability in patterns of social problems over time is apparent. Some children in this group maintain their absence of social problems throughout the year, while others do not. Two children with ALL (C3 and C4) increased in their social problems between T1 (prediagnosis) and their last data collection point. C3 increased from a social problems T Score of 51 (normal range) at T1 to a *t* score of 57 (normal range) at T3. C5 increased from a social problems *t* score of 59 (normal range) to a *t* score of 64 (normal range) at T4. One child with ALL (C1) decreased slightly in her social problems, from a *t* score of 52 (normal range) at T1 (prediagnosis) to a *t* score of 51 (normal range) at T4. Two children with ALL (C2 and C3) remained stable in their social problems throughout their first year of treatment. C2 remained in the normal range with a social problems *t* score of 50 for each data collection point and C3 remained in the normal range with a social problems *t* score of 51 for each data collection point. While she began and ended the data collection period with social problems in the normal range, participant C5 had social problems in the clinical range at both T2 and T3. It is noted that although minimal variability of social problems *t* scores was present across time for children with ALL, only one child ever had a social problems score that was outside of the normal range. Focusing on the healthy control peers in Figure 3, some variability in patterns of social problems over time is again apparent. The children in this group maintain a relatively stable level of social problems throughout the year. Two control children (H2 and H4) increased in their social problems between T1 and T4. H2 increased in social problems, with a *t* score of 53 (normal range) at T1 to a *t* score of 54 (normal range) at T4. H4 increased from a social problems *t* score of 62

(normal range) at T1 to a *t* score of 64 (normal range) at T4. Three control children decreased in their social problems between T1 and T4. H1 decreased in social problems, with a *t* score of 52 (normal range) at T1 to a *t* score of 50 (normal range) at T4. H3 decreased in social problems, with a *t* score of 57 (normal range) at T1 to a *t* score of 54 (normal range) at T4. H5 decreased in social problems, with a *t* score of 52 (normal range) at T1 to a *t* score of 51 (normal range) at T4. It is noted that although minimal variability of social problems *t* scores was present across time for the healthy control children, all scores at each time point for all participants were in the normal range.

Empirical Question #3

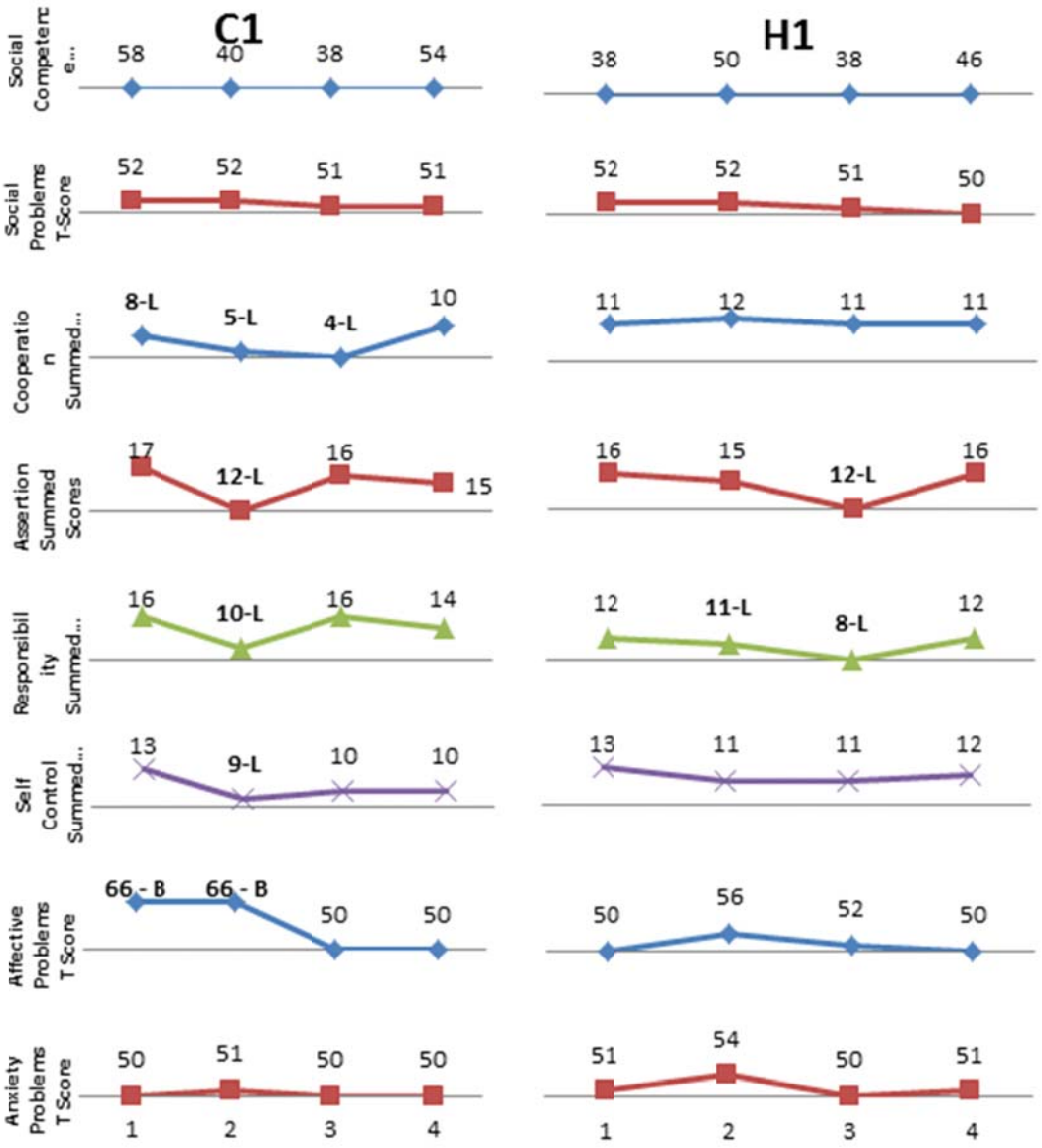
Do children with ALL display patterns of social interaction that are different relative to control children?

To analyze results related to this empirical question, individual trends for each child with ALL are displayed across all domains of social skills collected from both the CBCL and SSRS. The following figures are presented differently than the previous figures. In the following pages, each participant with cancer is compared alongside her healthy control peer for each research variable. The information is presented in one single figure for ease of comparison and discussion. For example, C1 and H1 are compared with each other, in one graph that includes all individual variables. Each participant with ALL was analyzed, and compared with their matched control peer, first on cbcl social competence and social problems, and second on the SSRS domains. Finally, each child with ALL was also compared to her matched control peer on the CBCL domains of

anxiety problems and affective problems. After a review of the data, three additional domains became of interest to the researchers due to a rise in clinically significant problems. The three domains were affective problems, anxiety problems, and somatic problems. While somatic problems (e.g., nausea, headaches, stomach aches, vomiting) are expected due to the rigorous medical treatment of ALL, anxiety problems and affective problems are of interest in the current study and were also analyzed. Findings across domains were visually analyzed with available qualitative data to further enrich understanding of the participants.

A brief introduction about how individual change over time will be discussed in this section may be helpful to guide the reader's understanding. First it is important to recognize that the CBCL and SSRS both have impressive test-retest reliability (r = .80 to .94 for the CBCL and r = .77 to .87 for the SSRS). For t scores on the CBCL, individual changes across time are discussed according to standard deviations. Any individual change that is greater than one standard deviation (>10 points) will be discussed as "significant," and as a change greater than chance fluctuation over time. For the SSRS subscale scores, individual changes across time are discussed according to standard error measurement. Any individual change that is greater than one standard error measurement (>3 raw score points) will be discussed as "significant," and as a change greater than a chance fluctuation over time. Any minimal change in scores that is within the expected, normal variation for the measures will be discussed as stable over time.

Participants C1 and H1. Participants C1 and H1 are presented in Figure 4, across multiple variables and time (social competence, social problems, cooperation,



Time	Notes
T1	Organizations – Church youth group; 4 or more close friends (3 or more times per week)
T2	Organizations – None; 4 or more close friends (less than 1 time per week) Does not attend school because she has cancer; Has lost all hair
T3	Organizations – None; 4 or more close friends (less than 1 time per week) Bone Marrow Transplant one month ago Does not attend school because she has been ill.
T4	Organizations – Church youth group; 4 or more close friends (1 or 2 times per week) Does not attend school, being tutored through school. Away from school over nine months – Bone Marrow Transplant between T2 and T3.

C = Clinical Range; B = Borderline Clinical Range; M = "More social skills than average"; L = "Less social skills than average."

Figure 4. CBCL and SSRS scores for C1 and H1 at T1-T4.

assertion, responsibility, self-control, affective problems, and anxiety problems). Specific data regarding the course of C1's cancer diagnosis and first year of treatment are briefly highlighted in Figure 4 as well. During the third month of C1's cancer treatment, at T2, she was removed from school, lost all of her hair due to chemotherapy, and had failed to respond well to her chemotherapy treatment. Regarding her concerns, C1's mother stated, "Cancer has caused her to miss school and other normal 8 year old activities…she is getting left out and left behind because of her illness." Between T2 and T3, C1 underwent a bone marrow transplant and was an inpatient with her mother at the hospital while recovering from this procedure. While this may not be reflected in her social skills scores, C1 lived away from home for the majority of the time between T2 and T3, and away from her father, siblings, and friends. Her mother reported that her daughter (C1) was unable to attend school from her third through 12th month of treatment.

Focusing first on social competence, Figure 4 demonstrates that C1's social competence score on the CBCL dropped significantly (over 1.5 standard deviations) between T1 (prior to diagnosis) and T2 (three months after diagnosis), and remained stable at T3 (6 months after diagnosis). However, by T4, 1 year post diagnosis, C1's social competence scores were very similar to her precancer baseline measurement. While displaying variability across time, C1's social competence scores remained in the average range throughout her first year of treatment. Figure 4 demonstrates that her matched peer, H1, also demonstrated significant changes in social competence scores on the CBCL throughout the measured year. However, H1 also remained in the average range for social competence at each data point.

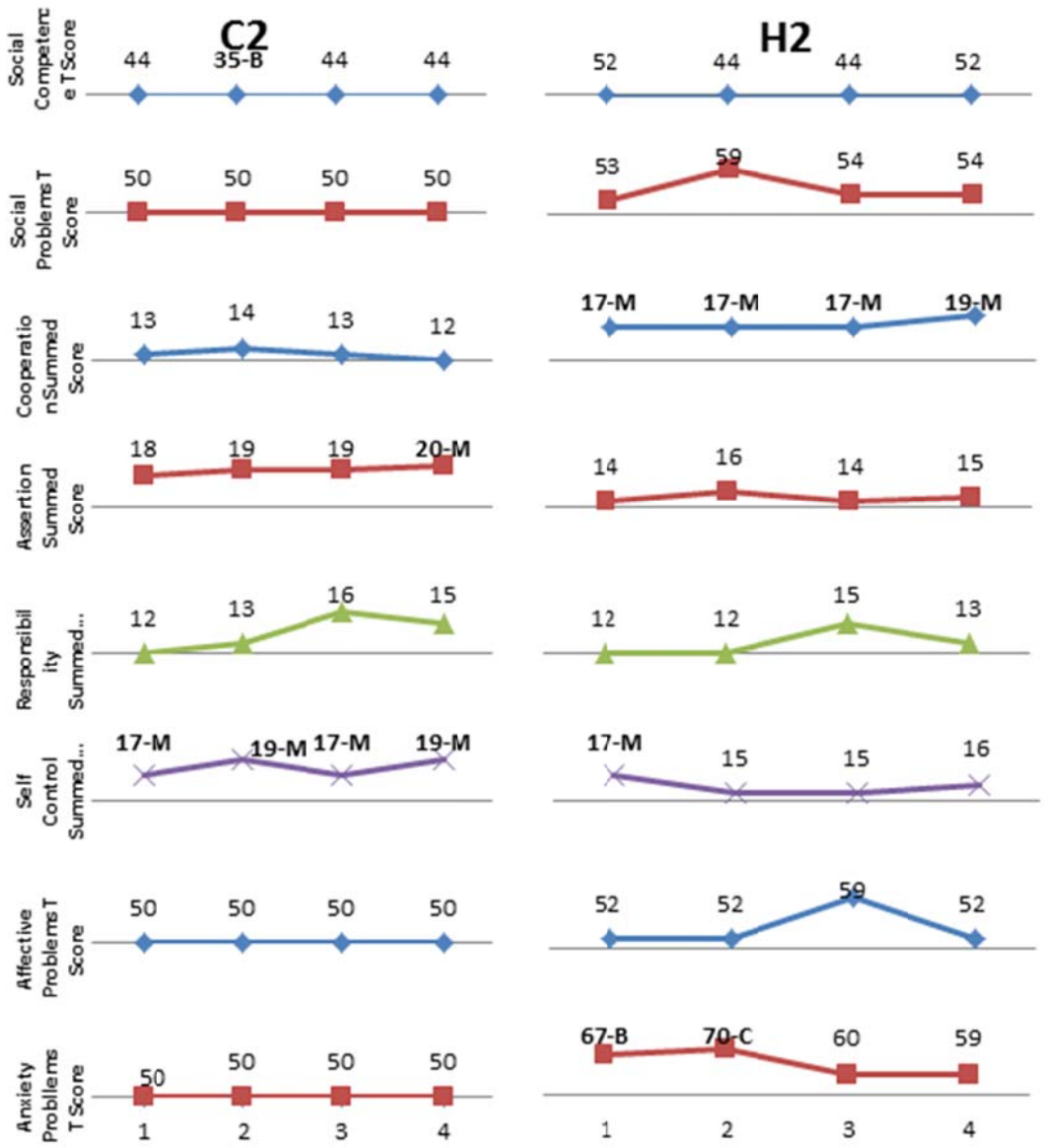
The stability of C1's social problems across her first year of treatment can be seen in Figure 4, with her social problems *t* score remaining within one point of prediagnosis baseline, and in the normal range, throughout the data collection period. Her matched peer, H1, also demonstrated stability in social problems across the year-long data collection with her social problems *t* score remaining near baseline, and in the normal range, throughout the data collection period.

Figure 4 also presents the summed scores for SSRS social skill domains for C1 and H1 (cooperation, assertion, responsibility, and self-control). C1's score in the domain of cooperation began at a prediagnosis level that was below average. This below average level of cooperation remained stable through her third and sixth month of treatment. However, at the conclusion of her first year of cancer treatment, C1's cooperation had risen significantly to its highest level and was in the normal range for the first time during the 12-month period. C1's measure of assertion was in the normal range prior to her cancer diagnosis, and significantly dropped into the below average range at T2. However, during her sixth month of treatment, her assertion scores significantly returned to the average range where they remained through the 12th month. C1's responsibility scores also varied during the course of her treatment. Her responsibility score significantly dipped below the average range during her third month of treatment. C1's self-control also remained relatively stable and in the average range, with the exception of the measurement taken during her third month of treatment (T2). For C1, all of her social skills domain scores (cooperation, assertion, responsibility, and self-control) were below average during her third month of treatment.

H1's summed scores in the SSRS social skills domain are also presented in Figure 4. H1's scores in the domain of cooperation remained relatively stable throughout the year and remained in the average range. Her assertion and responsibility scores were in the normal range for T1 and T2, and decreased into the below average range at T3. However, by T4, H1's assertion and responsibility scores increased into the average range. H1's self-control score remained average at all times. For H1, two of four social skills domain scores (assertion and responsibility) were below average at T2 and T3.

Focusing finally on Affective Problems and Anxiety Problems, C1 and H1 can again be compared using Figure 4. At her prediagnosis baseline, C1 had a borderline level of affective problems on the DSM-oriented scales on the CBCL. This borderline level of affective problems was maintained at T2, and significantly decreased into the normal range at T3 and remained in the average range at T4. C1's level of anxiety problems was in the normal range throughout the data collection period. H1's affective problems and anxiety problems remained in the normal range at all data collection points.

Participants C2 and H2. Participant C2 and H2 are presented in Figure 5, for multiple variables across time. Specific data regarding the course of C2's cancer treatment are briefly highlighted in Figure 5 as well. Participant C2 missed school for the first four entire months of her treatment. She began losing her hair during the first month of treatment, and had lost all of her hair by the sixth month of treatment (T3). Regarding her concerns throughout her child's cancer treatment, C2's mother stated, "No concerns other than health." She reported that she did not notice any changes in her daughter "other than the physical changes, such as hair loss. Her personality remained the same.



Time	Notes
T1	Organizations – None; 4 or more close friends (3 or more times per week)
T2	Organizations – None; 4 or more close friends (less than 1 time per week) 'Home school' – missed at least half of school for first four months of treatment Began losing hair in first month of treatment
T3	Organizations – None; 4 or more close friends (3 or more times per week) Lost all hair by 6th month
T4	Organizations – None; 4 or more close friends (3 or more times per week) Significant changes: Other than the physical changes (such as hair loss) none really. Her personality remained the same. She is always positive and happy. Total school missed: 4 months.

C = Clinical range; B = Borderline clinical range; M = "More social skills than average"; L = "Less social skills than average."

Figure 5. CBCL and SSRS scores for C2 and H2 at T1-T4.

She is always positive and happy." Her mother noted that C2 returned to seeing her close friends at least three times per week by her sixth month of treatment. C2 did not live away from home for any period of time during her first year of treatment. Figure 5 demonstrates that C2's social competence score on the CBCL decreased between T1 (prediagnosis baseline) and T2, decreasing from the normal range to the borderline range. However, by T3, six months after her cancer diagnosis, C2's social competence scores returned to her prediagnosis baseline; this effect was maintained at T4, 1 year after diagnosis. C2's matched peer, H2, remained in the average range with stability over time.

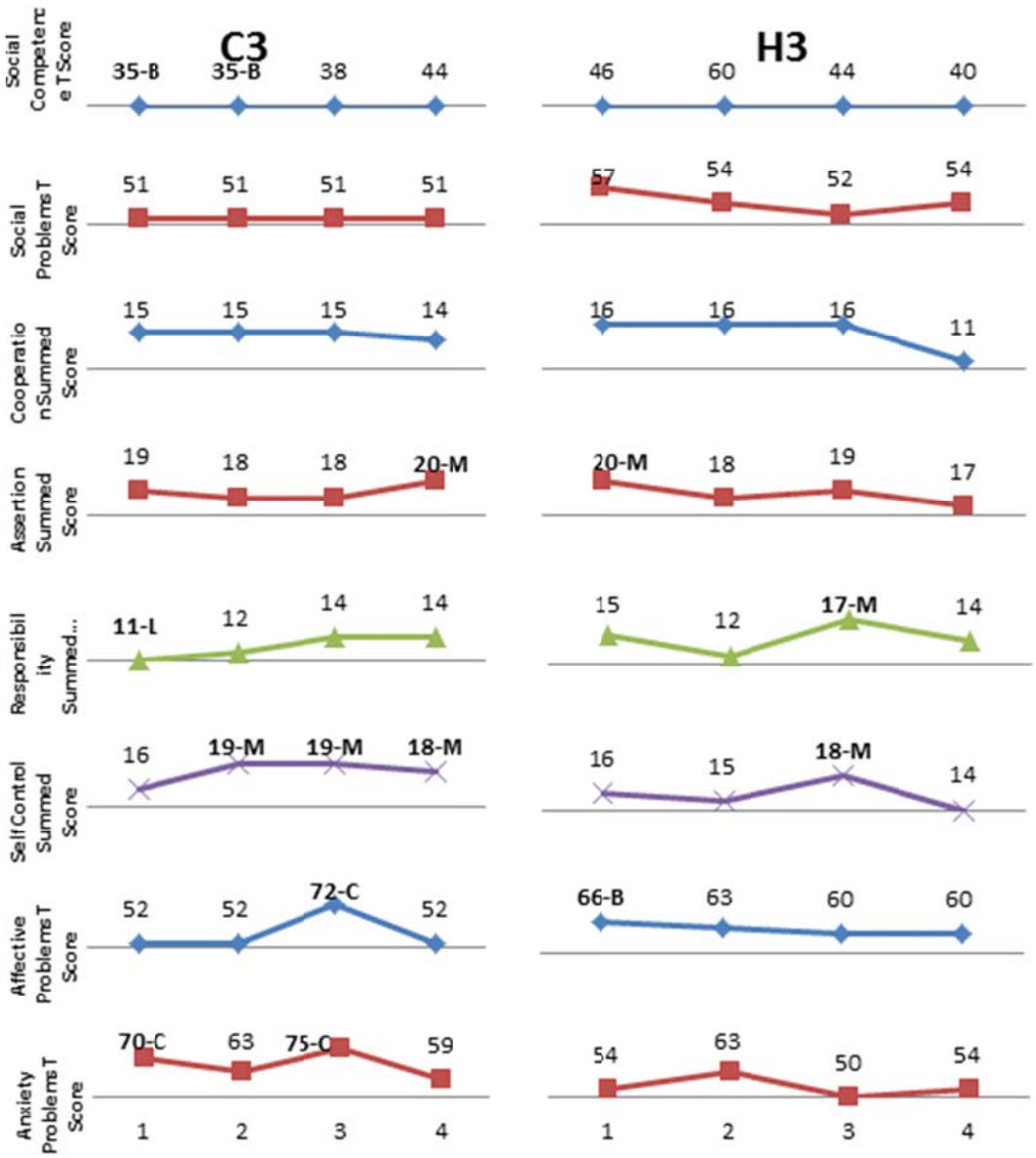
The stability of C2's social problems across her first year of treatment is displayed in Figure 5. Her social problems *t* score remaining at 50 (normal range) throughout the data collection period. H2's social problems score on the CBCL remained stable throughout the measured year and remained in the average range.

Figure 5 also presents the summed scores for SSRS social skill domains for C2 and H2 (cooperation, assertion, responsibility, and self-control). C2's score in the domain of self-control began at a prediagnosis level that was above average. Self-control remained in the above average range throughout the first year of treatment. C2's score in the domain of assertion was in the average range prior to diagnosis, remained stable throughout her first year of treatment, and was in the above average range by T4. C2's responsibility and cooperation scores remained relatively stable in the average range over the course of her treatment. No domain scores for C2 were in the below average range throughout the first year of her treatment.

H2's summed scores in the SSRS social skills domain are also presented in Figure 5. H2's scores in the domain of cooperation remained relatively stable throughout the year and remained in the above average range. Her self-control score began at T1 in the above average range, but decreased within normal variation into the average range at T2 and remained in the average range throughout the rest of the data collection period. H2's assertion and responsibility remained in the average range throughout the year.

Focusing finally on Affective Problems and Anxiety Problems, C2 and H2 can again be compared using Figure 5. C2 maintained a normal level of affective problems and anxiety problems throughout the data collection period. H2 exhibited normal levels of affective problems throughout the data collection period. H2 began with anxiety problems in the borderline range, which increased into the clinical range at T2. Her anxiety problem scores decreased into the normal range for T3 and T4.

Participants C3 and H3. Participants C3 and H3 are presented in Figure 6, for multiple variables across time (social competence, social problems, cooperation, assertion, responsibility, self-control, affective problems, and anxiety problems). Specific data regarding the course of C3's cancer diagnosis and first year of treatment are briefly highlighted in Figure 6 as well. Participant C3 became very seriously ill and was not responding to aggressive cancer treatments after T3 data was collected. During her ninth month of treatment (between T3 and T4), C3 was removed from school completely due to physical symptoms and limited response to treatment. By T2, C3 had lost all of her hair, and had gained a significant amount of weight due to steroid treatment. C3 lived as an inpatient in the hospital for over two months between T3 and T4, away from most of



Time	Notes
T1	Organizations – None; 2 or 3 close friends (1 or 2 times per week)
T2	Organizations – None; 2 or 3 close friends (1 or 2 times per week) Has lost all hair; significant weight gain
T3	Organizations – None; 2 or 3 close friends (1 or 2 times per week) Summer – not attending school
T4	Organizations – Hopekids, Dance; 2 or 3 close friends (less than 1 time per week) Missed all school from 9 – 12 month of treatment, living in–patient, parents rotating. Very physically ill. Passed away next month.

C = Clinical range; B = Borderline clinical range; M = "More social skills than average"; L = "Less social skills than average."

Figure 6. CBCL and SSRS scores for C3 and H3 at T1-T4.

her family, siblings, and friends. Her parents rotated to stay with her in the hospital. Sadly, while in the hospital, C3 passed away within weeks after T4 data collection.

Figure 6 demonstrates that C3's social competence score on the CBCL remained stable between T1 (prediagnosis baseline) and T2, at a *t* score of 35, in the borderline range, and increased with normal fluctuation over T3 and T4 to remain in the normal range in the last nine months of treatment. C3's matched peer, H3, demonstrated less stability in social competence, and had significant changes in social competence scores on the CBCL that were quite variable throughout the measured year; however, H3 remained in the average range for social competence at each data point.

The stability of C3's social problems across her first year of treatment can be seen in Figure 6, with her social problems *t* score remaining at 51, in the normal range, throughout the data collection period. H3's social problems also remained quite consistent; with her social problems *t* score remaining within 5 points of baseline, and in the normal range, throughout the data collection period.

Figure 6 also presents the summed scores for SSRS social skill domains for C3 and H3 (cooperation, assertion, responsibility, and self-control). C3's score in the domain of responsibility began at a prediagnosis level that was below average. This below average level of responsibility within normal fluctuation over her first year of treatment, and remained in the average range at all post diagnosis data points. C3's cooperation score remained in the average range across her first year of treatment. Both C3's assertion and self-control scores were in the average range prior to diagnosis, at T1. However, C3's self-control score increased at T2, during her third month of treatment,

into the above average range, where it remained at T3 and T4. C3's assertion score remained in the average range for the first three data collection points, but was measured to be in the above average range during her 12th month of treatment, at T4. C3 was never measured to have a below average domain score after her cancer diagnosis.

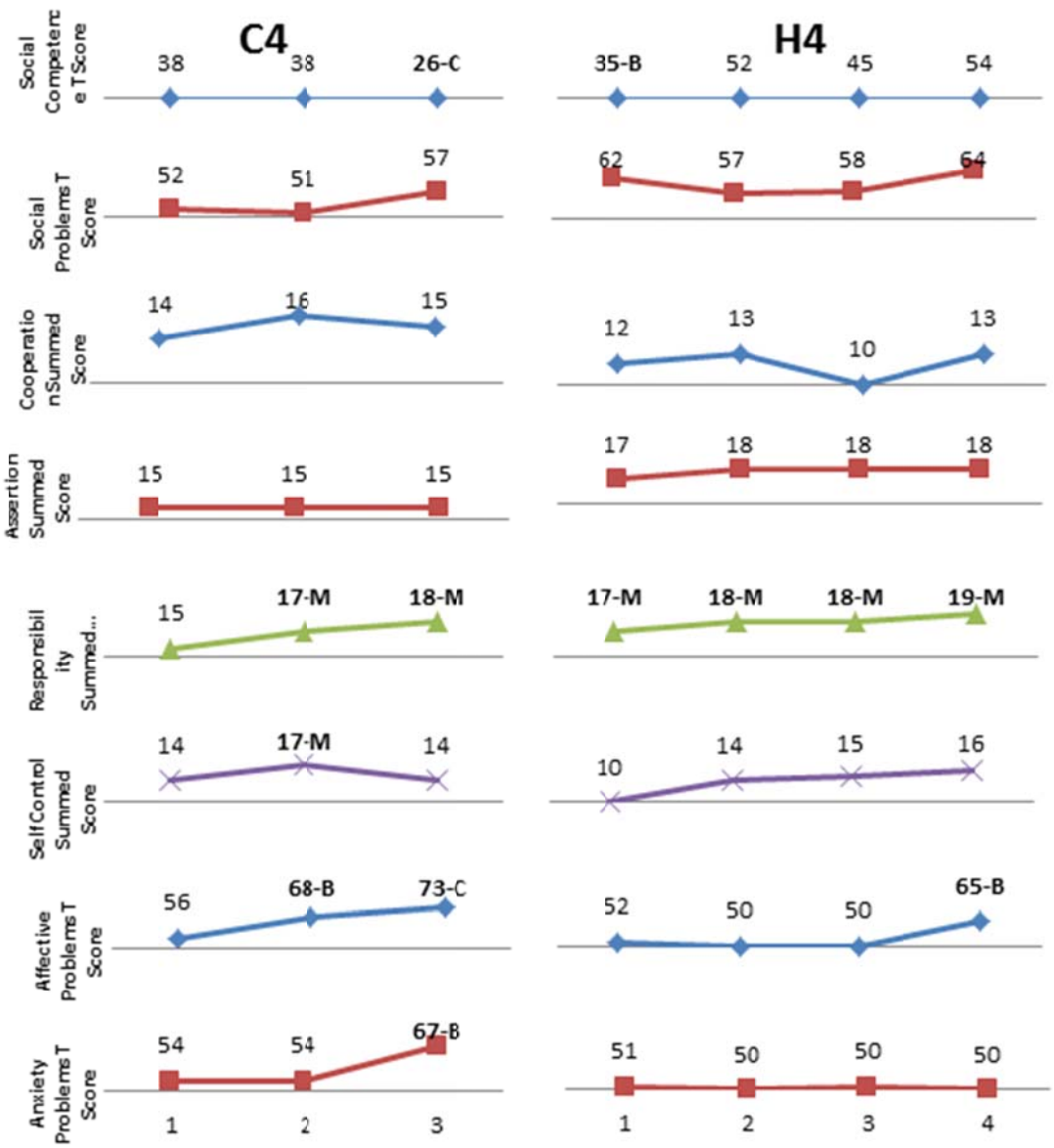
H3's summed scores in the SSRS social skill domain are presented in Figure 6. H3's assertion score at T1 was in the above average range, but later decreased to the average range for the remainder of data collection. H3's scores in the domain of cooperation remained in the average range throughout the year. H3's responsibility and self-control scores, which were in the average range at baseline, increased significantly to the above average range at T3, then decreased significantly again into the average range at T4. Although H3 demonstrated variability in scores within domains over time she did not demonstrate any score in the below average range throughout the year.

Focusing finally on affective problems and anxiety problems, C3 and H3 can again be compared using Figure 6. It is noted that at her prediagnosis baseline measurement, C3 had a clinical level of anxiety problems on the DSM-oriented scales on the CBCL. Also, while her level of affective problems on the DSM-oriented scales on the CBCL were within the normal range at baseline, they increased significantly into the clinical range by the end of her first year of treatment. C3 had a normal level of prediagnostic affective problems, which increased into the clinical range at T3, si6x months after her diagnosis. Her level of affective problems significantly decreased (two standard deviations) to baseline levels at T4. While C3's level of anxiety problems began at T1 in the clinical range, it decreased into the normal range at T2, then increased back

into the clinical range at T3, and significantly decreased to the normal range, and the lowest measured level of anxiety problems at T4. At baseline, H3 began with affective problems in the borderline range, which decreased into the normal range for the remained of the data collection period. While H3 demonstrated significant variance in her anxiety problems, they remained in the normal range throughout the data collection period.

Participants C4 and H4. Participants C4 and H4 are presented in Figure 7, for multiple variables across time (social competence, social problems, cooperation, assertion, responsibility, self-control, affective problems, and anxiety problems). Specific data regarding the course of C4's cancer diagnosis and first year of treatment are briefly highlighted as well. There is only data for the first 6 months of C4's cancer treatment. T4 data are not available for C4, as her family moved out of state and she began treatment at another hospital. Researchers were unable to contact C4's mother. However, at T3, C4's mother expressed concern for her daughter, "Just not having any energy in her body, having a hard time with everything…Not being able to walk in the stores, lots of things she cannot do. That sometimes she gets very sad and she says she feels she can't fight her cancer anymore, that she is too tired she feels she can't fight and she wants to give up." She had lost her hair completely by the second month of treatment. C4 missed almost all of school beginning at the time of diagnosis, as she and her family lived over 3 hours from the hospital and C4 did not feel well enough to attend school. Also, C4's mother reported that she had at least four close friends prior to her diagnosis but at 6 months after her diagnosis her mother reported that her daughter had only one close friend.

Figure 7 demonstrates that C4's social competence score on the CBCL decreased



Time	Notes
T1	Organizations – None; 4 or more close friends (less than 1 time per week) Not attending school (lives approx.. 6 hours from hosp)
T2	Organizations – None; 2 or 3 close friends (less than 1 time per week) Not attending school (she is not feeling well enough to attend school) Completely lost hair
T3	Organizations – None; 1 close friend (less than 1 time per week) Not attending school (because of the leukemia and low energy level) Moved to a hospital closer to home for treatment after T3; unreachable for T4 collection

C = Clinical range; B = Borderline clinical range; M = "More social skills than average"; L = "Less social skills than average."

Figure 7. CBCL and SSRS scores for C4 and H4 at T1-T4.

significantly from the normal range at T1 (prediagnosis baseline) and T2, into the clinical range, with a *t* score of 26, at T3. In contrast, Figure 7 demonstrates that H4's social competence scores on the CBCL were unstable throughout the measured year. H4's social competence score began in the borderline range at T1 and was in the normal range, with some significant fluctuation within that range, for the rest of data collection period.

While C4's social problems score increased at T3, her social problems remained in the average range at all three data collection points. Likewise, H4's social problems scores remained in the normal range at each time point.

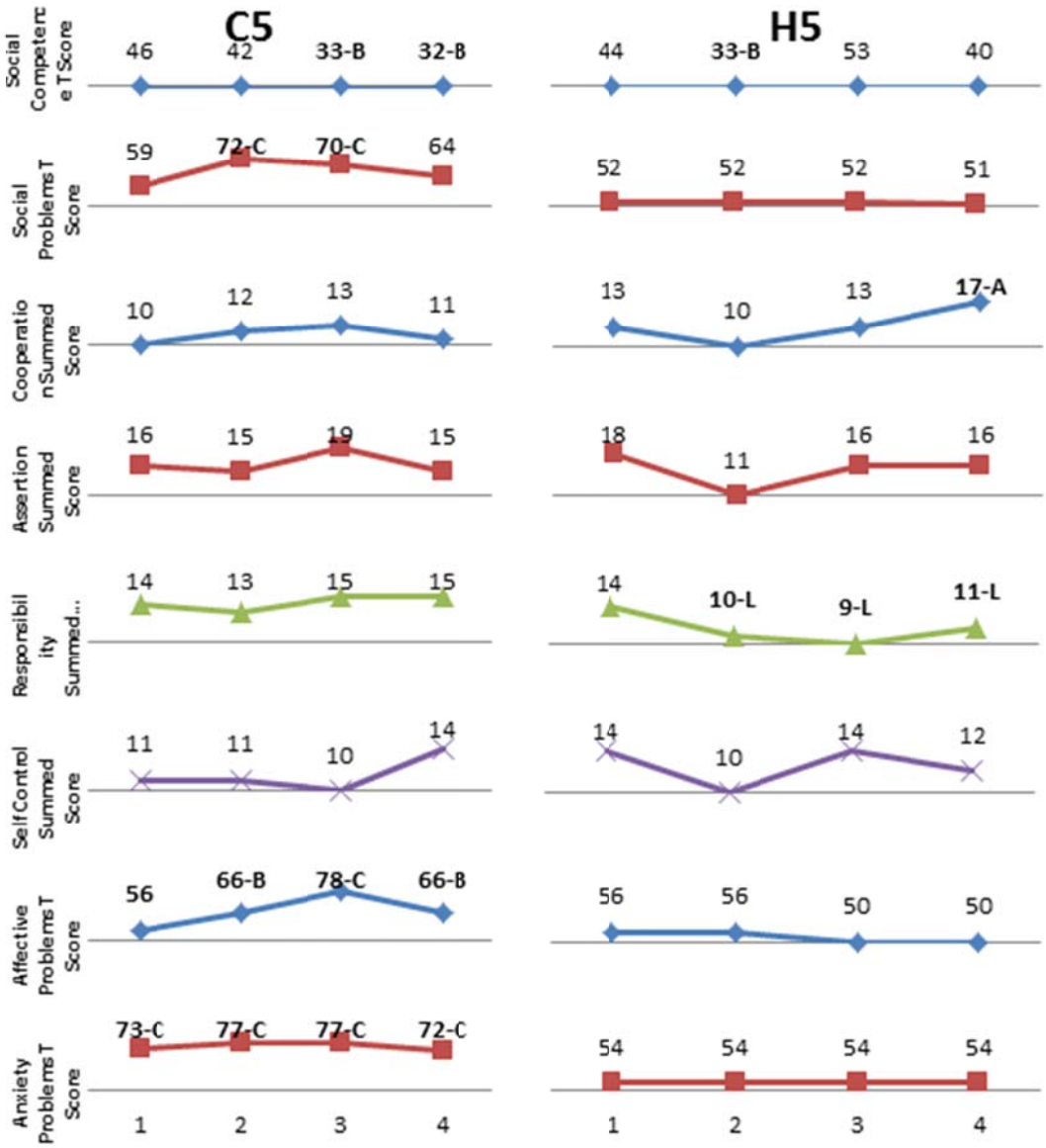
Figure 7 also presents summed scores for SSRS social skill domains for C4 and H4 (cooperation, assertion, responsibility, and self-control). C4's score in all domains (cooperation, assertion, responsibility, and self-control) were in the average range at T1, prior to her cancer diagnosis. At T2, both her responsibility and self-control scores increased to above average. At T3, C4's responsibility score remained above average while her other domain scores were in the average range. C4's cooperation and assertion scores remained relatively stable, and average, for the first 6 months of treatment.

H4's summed scores in the SSRS social skill domain are also presented in Figure 7. Although minor fluctuations across time were present, H4's scores in the domains of cooperation, assertion, and self-control were in the average range throughout the year. Her responsibility domain scores were in the above average range throughout the year.

When focusing on affective problems and anxiety problems, C4 and H4 can again be compared using Figure 7. It is noted that C4 began with a normal level of affective problems on the DSM-oriented scales on the CBCL prior to her diagnosis. However, her

level of affective problems rose significantly across time, and increased to borderline by her third month of treatment and into the clinical range by her sixth month of treatment. C4 began with a normal level of anxiety problems on the DSM-oriented scales on the CBCL. While her anxiety problems remained stable at T2, they significantly increased to borderline by her sixth month of treatment. C4's matched peer, H4 also had an increase in her affective problems score over time. Throughout most of the data collection period, H4 maintained normal levels of affective problems and anxiety problems, until her significant increase of affective problems at T4 into the borderline range.

Participants C5 and H5. Participants C5 and H5 are presented in Figure 8, for multiple variables across time (social competence, social problems, cooperation, assertion, responsibility, self-control, affective problems, and anxiety problems). Specific data regarding the course of C5's cancer diagnosis and first year of treatment are briefly highlighted in Figure 8 as well. Participant C5 missed the majority of school between her fourth and eleventh months of treatment (T2-T4). She stayed at the hospital as an inpatient during the first and ninth month of treatment. The number of close friends reported by her mother decreased from at least four close friends, prior to diagnosis, to only one close friend at T4. Additionally C5 lost all of her hair in the second month after diagnosis. C5's mother stated her concerns throughout her daughter's treatment as, "Increase in depression symptoms since ALL diagnosis…playing with friends helps, but is extremely limited due to poor health." Her mother also noted, "sleep problems—big increase in anxiety and fear of being alone…increase in anxiety since diagnosis—very fearful of being alone at night…very clingy to objects and people—starting to hoard



Time	Notes
T1	Organizations – Soccer Team; 2 or 3 close friends (1 or 2 times per week)
T2	Organizations – None ('too sick'); 4 or more close friends (less than 1 time per week) Not attending school – summer break and home school status until well enough to return Lost all hair
T3	Organizations – None; 2 or 3 close friends (less than 1 time per week) Not attending school – Immune suppression, home hospital
T4	Organizations – None; 1 close friend (1 or 2 times per week) Missed at 6 months of school between T2 and T4. Significant changes: Weight gain, low energy, fearful of being alone

C = Clinical range; B = Borderline clinical range; M = "More social skills than average"; L = "Less social skills than average."

Figure 8. CBCL and SSRS scores for C5 and H5 at T1-T4.

items, won't give or throw them away." Her mother also noted significant weight gain in her child and loss of energy.

Figure 8 demonstrates that C5's social competence score on the CBCL decreased significantly (almost 1.5 standard deviations) after her diagnosis and over the course of her first year of treatment. At T1 (prediagnosis baseline) and T2, C5's social competence score was in the normal range but decreased to the borderline range at T3 and T4. The social competence scores of her matched peer, H5, were quite unstable throughout the measured year. Her social competence score at T1 was in the normal range, but decreased into the borderline range at T2. At T3, her social competence score significantly increased, rising almost two standard deviations into the normal range, but decreased significantly again at T4, remaining in the normal range.

The increase in C5's social problems during her treatment is apparent. Her social problems score was in the normal range prior to her cancer diagnosis, and increased significantly to the clinical range at T2 and T3. By her twelfth month of treatment (T4), C5's social problems score returned to the normal range with a *t* score of 64. H5's social competence scores on the CBCL H5's social problems scores remained stable, and in the normal range, throughout the year.

Figure 8 also presents the summed scores for SSRS social skill domains for C5 and H5 (cooperation, assertion, responsibility, and self-control). C5's domain scores began prior to her diagnosis in the average range, and remained stable in the average range throughout her first year of treatment. C5's domain scores changes significantly in two domains; she increased significantly in her assertion scores from T2 to T3 and

increased significantly in her self-control scores from T3 to T4.

H5's summed scores across the SSRS social skills domains were quite variable across the year. Her assertion score, which began in the above average range decreased significantly at T2 into the average range, and increased significantly again at T3 and T4, returning to the above average range. Her score in the domain of responsibility began at T1 in the average range, but decreased significantly into the below average range for the duration of the year. H5's self-control scores significantly decreased at T2 and again significantly increased at T3 but remained in the average range throughout data collection. Her cooperation scores, which were in the average range from T1 through T3, significantly increased into the above average range at T4. H5's scores in all domains decreased at T2, and increased at T3.

Focusing on affective problems and anxiety problems, C5 and H5 can be compared looking at Figure 8. Prior to diagnosis, C5 had a clinical level of anxiety problems on the DSM-oriented scales on the CBCL. Affective problems increased from the normal range into the borderline range by her third month of treatment, and increased significantly into the clinical range by her sixth month of treatment. At the end of her first year of treatment, C5's level of affective problems significantly decreased into in the borderline range. While C5's level of anxiety problems began at T1 in the clinical range, they remained in the clinical range throughout her first year of treatment. H5 maintained a normal level of affective problems and anxiety problems throughout the data collection period.

CHAPTER VI

DISCUSSION

A general conclusion in the research literature has been that a diagnosis of and the treatment for cancer yields decreased social functioning in children over time. However, as mentioned previously, aspects of this current research are limited and conclusions regarding changes in social skills may have been prematurely determined. Researchers have speculated about diminished social skills without measuring precancer social functioning. Speculation regarding a child's social functioning prior to a cancer diagnosis is not sufficient to conclude that decline has occurred. Therefore, having only post-cancer data without precancer functioning data limits the conclusions that can be made concerning change in social functioning. The current research addressed this gap in the research by conducting a retrospective precancer assessment of social competence at the time of diagnosis. This additional precancer social functioning data provided a baseline of social functioning prior to diagnosis, rather than relying on speculation of precancer social functioning.

Within the research literature, the CBCL and its social competence score have been heavily utilized to make conclusions about children with cancer. However, given the well-documented criticisms of employing only the CBCL for evaluating chronically ill children, this current research included a more robust measure of child social competence through use of the SSRS. The SSRS is a dedicated and more thorough measure of social skills and was expected to yield a more robust understanding of child social functioning than the CBCL alone.

Utilizing a single-case experimental design allowed us to examine individual differences in social competence. A review of childhood cancer research suggested that this is the first time that a single-case design has been used to evaluate the social skills of this population. Assessing social competence at the individual level provided a detailed picture of change and individual differences across time, access to dynamic patterns of change at four time points, and yielded qualitative data that promoted contextual understanding of the factors that contribute to a child's functioning. Additionally, a comparison group was employed, a rarity in the current literature, which facilitated comparison against normative variation in social competence over a 12-month period. Further, the five children with ALL were followed for their first full year of treatment, providing additional longitudinal research with a childhood cancer population that is not common in the literature.

Prosocial Skills

When attempting to measure prosocial skills after a cancer diagnosis, special consideration of the measure used is important. According to the CBCL measure of social competence, there was wide variability across time for all participants. Two of the children in the current study with ALL demonstrated a significant decrease (over one standard deviation) in social competence from prediagnosis baseline to their final data point. This significant decrease between the first and last data points in levels of social competence, according to the CBCL, was not demonstrated by any healthy control peers.

As discussed previously, the CBCL measurement of social competence is highly

affected by the quantity of social activity level, as gauged by the child's number of activities, organizations, close friends, and visits with friends per week. It is not surprising that children with cancer will likely decrease in the quantity of their social and organizational activities.

Decreased immune system functioning, medical treatment, and temporary removal from school is likely to limit social activity level, thereby decreasing CBCL social competence scores. This does not suggest a decrease in the quality of social interaction, skills, or relationships for the child with cancer, but rather a decrease in the *quantity* of available, reasonable, and healthy social activities that a child experiences during cancer treatment.

It is thought that factors such as physical health, immune system functioning, medical treatment, and school removal rather than actual deficits in social skills are the primary mechanisms of decreased measures of social activity. However, such wide fluctuation of social competence over a 1 year period for healthy children is quite remarkable and may speak to the overall amount of variability in social activity even in children without significant challenges. This warrants careful interpretation of changes in social competence for children with cancer, as fluctuation over time may be typical rather than constituting a clinical concern.

Numerous studies have utilized the CBCL in justifying the conclusions that children with cancer have lower levels of social competence. Evaluating 800 childhood cancer survivors and matched peers, Barrerra and colleagues (2005) concluded that the cancer survivors had fewer close friends, less confidants, and were more socially isolated

than their matched peers. The CBCL measure of social competence was the basis for these conclusions. These results are consistent with the findings of the current research. Olson and colleagues (1993) and Shelby and colleagues (1998) also concluded that children with cancer exhibited lower levels of social competence as measured by the CBCL. Shelby and colleagues concluded that older children with ALL were more likely to exhibit clinical deficits in social competence than younger children with ALL. Consistent with this conclusion, the oldest child in the current study had the lowest social competence T-score compared to the younger children with ALL. Children in this older age group may have a higher need to feel similar to and accepted by their peers.

Kullgren and colleagues (2003) concluded that social competence 1 to 2 years post diagnosis predicted future social competence, and that children with cancer exhibited social competence below national norms. These findings are consistent with the current research, and as discussed previously, it is not surprising that children with cancer demonstrated lower social competence as measured by the CBCL.

The SSRS total social skills score provides additional information of the experience of childhood cancer. Data from the SSRS total social skills score indicated there was moderate variability across time for most participants. Comparing baseline (precancer) measurement of total social skills to the children's final data collection point, four of the five children with ALL increased in their total social skills by at least six standard score points but only one child with ALL increased in her total social skills score beyond normal variation for the total social skills score ($\pm$11). While this may appear counterintuitive, it is informative to look closely at some individual aspects of the

SSRS total social skills score. The SSRS is composed of the subscale 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 children with increased total social skills scores, elevations across multiple domains were demonstrated.

Although the child's quantity of social activity may have decreased following her cancer diagnosis, her social skills were likely to improve for a variety of possible reasons. After a cancer diagnosis and throughout treatment, a child may spend the bulk of their time around adults rather than other children. Thus, these children may be faced with a variety of mature concepts (i.e., illness, health, death). An increase in interactions with adults may promote dialogue beyond the child's typical developmental experiences fostering a level of maturity that is not typical. During cancer treatment, a child is also likely to be exposed to a variety of medical procedures; complying with medical care may increase a child's self-control, responsibility, and cooperation. Past research has suggested that children with cancer may be better at perspective-taking and possess greater capacity for expressing gratitude (Shankar et al., 2005). In addition, children matured over the course of this study and it may be reasonable to assume that they naturally increased in mastery of their social skills. These factors may explain their increased scores on cooperation, assertiveness, responsibility, and self-control.

Further, children with cancer may be exposed to more opportunities to develop 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 these domains. Children without significant health concerns may have less opportunity to display growth in these domains. Children with ALL are exposed to a variety of experiences that may increase their abilities in the areas measured by the SSRS total social skills score.

The current research did not find decreases in prosocial skills according to the SSRS. This is consistent with a systematic review of the literature (Patenaude & Kupst, 2005a, 2005b), which indicated that much of the research has failed to find significant maladaptive effects of childhood cancer on overall quality of life and psychological functioning. They concluded that childhood cancer can, in some cases, create positive changes in perception of life, a reordering of priorities in life, increased resiliency, and a stronger appreciation for relationships. Additionally, childhood cancer has been found to be protective in some domains. Young adult survivors of childhood cancer reported significantly less illegal drug use and substance experimentation, years after completion of treatment, compared to their healthy peers (Vannatta & Gerhardt, 2003). It is possible that the same factors that contribute to a moderate increase in prosocial skills positively impact other psychological domains as well.

Social Problems

The CBCL scale of social problems was utilized to evaluate level of social problems in children with ALL. There was very little variability across time for most participants. The majority of children with ALL displayed few social problems. It is of interest that the two children who demonstrated an increase in social problems also demonstrated clinical increases in affective problems. This increase in social problems could, in fact, be an interaction between illness and clinical levels of other internalizing problems.

An increase in social problems after a cancer diagnosis and treatment, while not expected, did occur for two of these children. Further, this increase in social problems may have been more likely if compounded by co-occurring increases in clinical levels of affective problems.

While children in the current study did not consistently exhibit social problems, this has not always been the case in the literature. Vannatta and colleagues (1998) concluded that children with cancer had more social problems than peers and were more likely to be perceived by peers as “sick and fragile.” Additionally, Patterson and colleagues (2003) also found social problems within the childhood cancer population. They concluded that children with cancer exhibited more self-consciousness about the perceptions of others, as well as a loss of “normal life” and “normal social activities” in qualitative focus group discussions.

In one of the only existing longitudinal studies on children with ALL, Earle and Eiser (2007) concluded that older children (10-14) exhibited significantly more social

problems than did younger children with cancer. These children had significant social problems, withdrew socially, and avoided school more often according to qualitative interviews with their mothers. Additionally, they were highly concerned about their appearance and lacked social interaction. It is possible that the current study did not identify social problems among the children with ALL for a variety of reasons. First, the children in the current study were between the ages of six and eleven (with the majority under the age of 8). Perhaps this group did not encounter social problems due to their age. Also, it is possible that the CBCL may lack specificity or sensitivity in identifying social problems in this population.

In sum, the majority of change across time was within the expected fluctuations for both prosocial skills and social problems, and general patterns did not emerge. Within the sample, the children with cancer were more likely to demonstrate moderate increases in total social skills over the course of their first year of treatment, compared to the healthy control children. However, this net increase in social skills was largely due to a significant increase in both responsibility and self-control.

Results of the CBCL and SSRS data on measures of social functioning (e.g., social competence, social problems, cooperation, assertion, responsibility, self-control, and total social skills), revealed normal variability over time in both healthy control children and children with ALL. No clear patterns in either group emerged as “typical” throughout the data collection period. It is important to note that the changes discussed above are predominantly within the standard error measure for the subscale domain scores. Thus, it may be that the variability observed across these domains is consistent

with typical variability expected over time. At a minimum, children with cancer did not demonstrate decreases in these domains over their first year of treatment.

Additional Findings

Affective Problems and Anxiety Problems

The group of children with ALL displayed an increase in their social skills and generally did not reveal significant increases in social problems. However, three of the five children with ALL demonstrated significant increases (>1 *SD*) in affective problems. For all three of these children, their levels of affective problems peaked, and were in the clinical range, at their sixth month of treatment. Of note is that no healthy control children demonstrated clinical levels of affective problems throughout the data collection period.

It is notable that two of the children with ALL who had clinical levels of affective problems also demonstrated clinical levels of anxiety problems during their treatment. Both of these children exhibited baseline levels of anxiety problems that fell in the clinically significant range, before developing clinical levels of affective problems. It may be possible that for children with ALL, risk of developing significant affective problems is heightened with premorbid anxiety.

It is concluded that the children with ALL were more likely to experience clinical levels of anxiety problems and affective problems within their first year of treatment compared to healthy children. However, not all of the children with ALL demonstrated clinical levels of affective problems or anxiety problems during their treatment. Attempts

to differentiate the children who demonstrated clinical problems from those who did not, have not been fruitful. One child who demonstrated clinical levels of affective problems and anxiety problems spent a significant period of time living away from home and in the hospital (over 2 months). She also became significantly ill during her treatment, and passed away weeks after T4 data was collected. However, another child who did not demonstrate clinical affective or anxiety problems also spent a significant portion of time away from school (over 9 months) and lived as an inpatient in the hospital (approximately two months) while receiving a bone marrow transplant. A third child with clinical levels of affective problems lived significantly farther from the hospital than most other participants. She and her mother traveled over three hours, one way, for each appointment at the hospital. However, this was also true for another child who lived approximately three hours away from the hospital as well. It is notable, however. The two children who demonstrated both affective problems and anxiety problems in the clinical range began with a baseline measurement of clinical levels of anxiety problems. Also common between these two children is their mother's reported concern regarding significant weight gain due to treatment. These results suggested that for these five children, a cancer diagnosis did not lead to an increase in affective problems unless the child had preexisting anxiety.

This current finding is consistent with the research that indicates increased internalizing problems for some children with cancer. As previously discussed, children with cancer are prescribed antidepressant medications at a rate of 10:1 compared to their healthy peers (Pao et al., 2009). Additional studies have shown that a large percentage of

children with cancer (20%) experience significant symptoms of post-traumatic stress (Eiser et al., 2000). The current research presents a possible link between the anxiety and depression experienced by some children with cancer. This potential link has yet to be evaluated in the literature.

Assessment of Social Competence

Although the CBCL is widely used in the literature with reported diminished levels of social competence in children with cancers, there are fundamental concerns regarding the appropriateness of this measure. The CBCL measure of social competence for children with cancer has been criticized as a potentially misleading measure of social competence. The CBCL is very sensitive to changes in quantity of social activities and contact with friends (Perrin et al., 1991). Measuring social competence through 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 may be misleading within the population of children with cancer.

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 may reflect a matter of medical necessity rather than a true decrease in social competence. It is 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. Therefore, the CBCL may be too limited in its scope to fully address social competence especially with children diagnosed with cancer.

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. Given the limitations of the CBCL, the SSRS may be a more accurate measure of social functioning and social competence in populations of chronically ill children. The SSRS total social skills score is composed of: 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 measures of social functioning for a child who is medically restricted from participating or being able to engage in activities with peer contact.

Given the concerns with the CBCL, it is important to fully explore the SSRS Total Social Skills score. The CBCL and SSRS presented conflicting pictures of social functioning of the children with ALL. These results suggested 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 12 months of medical treatment. These preliminary data are encouraging, and additional investigation in this area may undercut the widespread belief that childhood cancer leads to decreased social functioning.

In sum, the widespread use of the CBCL social competence score as evidence of low social competence for children with cancer may be misleading. Use of the CBCL to measure social functioning in children with chronic illness should 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 to reflect a more accurate measure label. However, the CBCL is still useful in determining the impact that cancer has had on the quantity of social contact, and can still be a useful tool in fully understanding the experience of childhood cancer. The use of the SSRS as a measure of social functioning for children with chronic illness is recommended as a more accurate measure for this population than the CBCL alone.

Limitations

A limitation to the current research is the lack of generalizability of the results. Any results in a sample of five children should be generalized with caution. It may be possible that children with more aggressive forms of cancer, more invasive types of treatment (i.e., surgery, amputation, etc.), or more time spent as a hospital inpatient, may exhibit a different pattern of social functioning than the current group of research participants. It is not assumed that all cancer experiences are void of social difficulties, isolation, or other social concerns. While the results are encouraging, it is important for further research to be conducted, with larger samples, for broader conclusions to be drawn.

The availability of only the first twelve months of treatment from which to gather data limits conclusions. The first 12 months of cancer treatment is only a portion of a much longer treatment process. While it was concluded that these children with ALL did not demonstrate decreases in social functioning, this can only be applied to the first year of their cancer experience, as compared to their precancer levels of functioning. It is

possible that with extended treatment, decreases in social functioning would emerge.

A final limitation is the method through which social functioning was measured. While there exists a clear precedent for the use of parent report measures in the current literature, there is significant potential for parental bias and therefore inaccuracies to be reported. Drawing conclusions based solely on parent report may not accurately capture child social functioning. Self-report measures may increase accuracy and broaden the scope of conclusions that can be made. Observational assessment would also increase the objectivity of data. However, sensitivity with a family experiencing a new diagnosis of childhood cancer is paramount in conducting research with this population. The potential intrusiveness of naturalistic observations is an important consideration.

Implications and Future Research

Implications for the current research are encouraging. This study was exploratory and novel, utilizing new measures, matched control peers, a longitudinal design, measurement of prediagnosis functioning, and qualitative information. These strategies, applied to a larger sample would further solidify the cautious conclusions discussed. Comparing the spectrum of cancer diagnoses may illustrate potential differences in trends in social functioning due to prognosis, severity of medical treatment, time spent in inpatient care, and the use of radiation as mediating factors upon social functioning. It would be useful for medical and psychological providers 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 negative effects.

In addition, longitudinal research conducted throughout the entirety of cancer treatment would provide more complete data on the course of social functioning. Collecting several additional measurements of social functioning for a longer period of time would allow researchers to follow children throughout their treatment, examining potential trends that arise in final stages of treatment. This would broaden the scope of conclusions that can be drawn in regard to the social functioning of children with cancer.

The current study also demonstrated a possible relationship between preexisting anxiety problems and the rise in clinical levels of affective problems after a cancer diagnosis. This relationship warrants further investigation.

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 a more consistent conclusion that cancer does not decrease 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 suffer.

Families facing a new childhood cancer diagnosis grapple with concerns

regarding the physical and emotional well-being of their child. If substantial future research supports these initial findings, encouraging data could be presented to families of children with cancer. 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.

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APPENDIX

Do you have a child between the ages of 6 – 11?

Are you interested in participating in a brief research study that investigates social functioning over time?

USU Combined Psychology PhD student is looking for parents who answered YES to both of these questions. All interested parents please contact Rachel Duchoslav at rachel.d@aggiemail.usu.edu.



CONSENT and AUTHORIZATION DOCUMENT
INTERMOUNTAIN INSTITUTIONAL REVIEW BOARD

TITLE: The Effects of Pediatric Cancer on Social Competence:
A Longitudinal Investigation

PRINCIPAL INVESTIGATOR: Rachel Duchoslav, B.S. (435) 797-5210

CO-INVESTIGATOR(S): Clint Field, Ph.D. (435) 760-4132
Paul Colte, Psy.D.

SPONSOR: Not applicable.

LOCATIONS: Primary Children's Medical Center
Utah State University

BACKGROUND:
Rachel Duchoslav and Professor Clint Field in the Department of Psychology at Utah State University (USU) are conducting a research study to find out more about the relationship between children's social competence and its development over the course of cancer treatment in children. You have been invited to participate as a result of your interest in the study and your fulfillment of the following study requirements:

1. You have a child between the ages of 6 and 11 years of age that has recently been diagnosed with cancer.

Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends, and relatives if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you volunteer to take part in this research study. We anticipate that approximately 12 families will be participating in this study. All participants will experience the following set of specific procedures, as outlined below.

STUDY PROCEDURE:
If you agree to be in this study, you will be asked to complete two measures today, and then complete the same two measures on three additional occasions after today. The measures you will complete are rating scales that allow you to indicate the presence or absence of typical child social skills. This will take approximately 30 minutes of your time.

The second phase of the project will occur approximately three months later and will involve the same exact procedure. You will again complete both questionnaires which will take approximately 30 minutes of your time. The third phase of the project will occur approximately three months after the second meeting and will again involve the exact same procedure. The fourth phase of the project will occur approximately six months after the third and will again involve the exact same procedure. You will again complete both questionnaires which will take approximately 30 minutes of your time. Thus, your participation in the project will ultimately involve a total of four meetings with a researcher over a 12 month period of time. All meetings will be arranged at your convenience, at the hospital, and will co-inside with times that you will already be at the hospital for your child's treatment.

It is important to understand that while the researchers seek to investigate the effects of childhood cancer on social functioning, this research study in no way will interfere with the medical treatment of your child. This study does not involve collaboration or manipulation of medical treatment in any way. All medical procedures and treatment are managed independently from the researchers by a completely separate pediatric oncology team of medical professionals.

At the end of the study, all participants will receive a small gift bag of approximately $5-$10 in value (e.g., including small toys and trinkets).

RISKS:

Participation in this study may involve risk or discomfort such as:

1. Despite our best efforts to protect your identity, there is still a very small chance that someone could discover your personal or family information.
2. Negative results are not anticipated from the completion of the questionnaires, however; such measures can provide undesirable information that may produce emotional discomfort for parents.

BENEFITS:

There is no guarantee that your participation will directly benefit you. However, by increasing the amount and quality of research done in the field of pediatric psycho-oncology, important information may be obtained could be used to better serve the needs of this population. As investigators, we hope to learn more about the experience of childhood cancer and it's impact on social functioning in children. Thus, at a general level, we hope that this study will produce results that are helpful to many professionals that work with childhood cancer patients and their families in the future. Also, you will receive a summary of the results of this study as well as recommendations that may be helpful to you and your family concerning the findings of the research.

ALTERNATIVE PROCEDURES:

You may choose at any time to not participate, or to discontinue participation in, this study.

PERSON TO CONTACT:

Please feel free to contact the principal investigator, Rachel L. Duchoslav at any time with questions or concerns regarding this study. She can be reached, or a message can

be left 24 hours a day, at (435) 797-5210. In the case of a left message, you will be contacted promptly.

INSTITUTIONAL REVIEW BOARD:
If you have questions regarding your rights as a research subject, or if problems arise which you do not feel you can discuss with the Investigator, please contact the **Intermountain Office of Research at 1-800-321-2107.**

INJURY NON-COMPENSATION STATEMENT:
"In the event you sustain injury resulting from your participation in the research project, Primary Children's Medical Center can provide to you, emergency and temporary medical treatment and will bill your insurance company. Since this is a research study, payment for any injury resulting from your participation in this research study may not be covered by some health insurance plans. If you believe that you have sustained an injury as a result of your participation in this research program, please contact the investigator as soon as possible. You may also contact the **Intermountain Office of Research at 1-800-321-2107.**

VOLUNTARY PARTICIPATION:
Participation in research is voluntary. You may refuse to participate or withdraw at any time without consequence or loss of benefits. This will not affect the relationship you have with the investigator or staff nor standard of care you receive.

UNFORESEEABLE RISKS:
Since this is an experimental study, there may be some unknown risks that could arise. However, such risks are considered minimal for this study and problems are not anticipated.

RIGHT OF INVESTIGATOR TO WITHDRAW:
You may withdraw from the study at any time without penalty. The principal investigator can withdraw you without your approval. Possible reasons for withdrawal include the inability to complete questionnaires provided.

COSTS TO SUBJECTS AND COMPENSATION:
There are no additional costs involved in this research.

NEW INFORMATION:
During the course of this study, you will be informed of any new significant findings (either good or bad), such as changes to the risks or benefits resulting from participation in this research, or new alternatives to participation that might cause you to change your mind about continuing in the study. If new information is obtained that is relevant or useful to you, or if the procedures and/or methods change at any time throughout this study, your consent to continue participating in this study will be obtained again.

NUMBER OF SUBJECTS:
We expect about 12 people from two sites will be in this study. This is part of a study conducted by a student researcher at Utah State University.

CONFIDENTIALITY/ AUTHORIZATION FOR USE OF YOUR PROTECTED HEALTH INFORMATION

Intermountain Healthcare has a commitment to protect your confidentiality. Federal regulations require that you understand how your protected health information (PHI) is used for this study.

This is the information we will use:

- Name
- Telephone number
- Child's Diagnosis
- Questionnaire data from two questionnaires (Child Behavior Checklist, Social Skills Rating System)

Research records will be kept confidential in a manner consistent with federal and state regulations. Circumstances under which your identity would be required by law to be divulged to a person outside of the research team include those in which threats of abuse (child/elderly) and/or harm (toward self/others) are discovered or reported. Only Dr. Field and his research assistants will have access to the data which will be kept in a locked file cabinet in a locked room. Additionally, your name and other identifying information will be kept separate from data to further protect your identity. Data will be kept for one year to provide time for analysis following completion of the project. Data retained in a computer database beyond that point will have all identifying information permanently removed and destroyed.

Others who will have access to your protected health information for this research project include Intermountain's Institutional Review Board (the committee that oversees research studying people) and authorized members of the Intermountain workforce who need the information to perform their duties (for example: provide treatment, to ensure integrity of the research, and for accounting or billing matters), the Food and Drug Administration, and others as required by law.

Signing this document means you allow us, the researchers in this study, and others working with us to use protected health information about your health for this research study. You can choose whether or not you will participate in this research study. However, in order to participate you have to sign this consent form.

You may change your mind later and ask us to stop using or disclosing your protected health information. **This must be done in writing.** You must either give this notice, called a revocation, in person to the Principal Investigator, the Principal Investigator's staff, or mail it to Rachel Duchoslav, 2810 Old Main Hill, Department of Psychology, Utah State University, Logan, Utah 84322. If you revoke this authorization, we will not be able to collect new information about you, and you will not be able to participate in the study. However, we can continue to use information we have already started to use in our research, as needed to maintain the integrity of the research.

Just so you know, if we send protected health information about you outside Intermountain, based on this or any other authorization you sign, we cannot guarantee

that the recipient will not redisclose your protected health information to a third party. The recipient of the information may not be required to abide by this Authorization or applicable federal and state law governing the use and disclosure of your protected health information.

This authorization lasts until this study is finished.

For more information about my rights to my protected health information, how to revoke this authorization, and how Intermountain uses my health information, I may ask to see or obtain a copy of the Intermountain Notice of Privacy Practices.

I hereby acknowledge that I have received or been offered a copy of Intermountain's Notice of Privacy Practices.

The Institutional Review Boards (IRB) for the protection of human participants at USU and IHC (Intermountain Healthcare) have approved this research study. If you have any questions or concerns about your rights you may contact the USU IRB at (435) 797-1821 or the IHC IRB at (801) 408-6781.

You have been given two copies of this Informed Consent. Please sign both copies and retain one copy for your files.

CONSENT:

I confirm that I have read and understand this consent and authorization document and have had the opportunity to ask questions. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

I agree to participate in this research study and authorize you to use and disclose health information about me for this study, as you have explained in this document.

_____
Participant's Name (Print) [this line must be included]

_____ _____
Participant's Signature Date

"I certify that the research study has been explained to the individual, by me or my research staff, and that the individual understands the nature and purpose, the possible risks and benefits associated with taking part in this research study. Any questions that have been raised have been answered."

_____
Name of Person Obtaining Authorization and Consent

_____ _____
Signature of Person Obtaining Authorization and Consent Date



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PRINCIPAL INVESTIGATOR: Rachel Duchoslav, B.S. (435) 797-5210

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Paul Colte, Psy.D.

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I agree to participate in this research study and authorize you to use and disclose health information about me for this study, as you have explained in this document.

_____

Participant's Name (Print) [this line must be included]

_____ _____

Participant's Signature Date

"I certify that the research study has been explained to the individual, by me or my research staff, and that the individual understands the nature and purpose, the possible risks and benefits associated with taking part in this research study. Any questions that have been raised have been answered."

_____

Name of Person Obtaining Authorization and Consent

_____

Signature of Person Obtaining Authorization and Consent

Date

Demographic Information Sheet

1. How long ago, if ever, did you first begin to notice physical symptoms of illness in your child?
___Less than 1 week ago
___1-2 weeks ago
___2-3 weeks ago
___Over 1 month ago

2. Ethnicity: Check the category you identify with:
___White (non-Latino)
___Black (non-Latino)
___Am Indian/Alaskan Native
___Hispanic
___Asian or Pacific Islander
___Other
___Prefer not to answer

3. Which area best describes the area in which you live?
___Farm
___Town under 10,000 & rural non-farm
___Towns and cities 10,000 to 50,000
___Suburbs of cities over 50,000
___Central cities over 50,000

4. How many children do you have?
___0
___1
___2
___3
___4
___5 or more

5. How many children live in your household?
___0
___1
___2
___3
___4
___5 or more

6. What is your marital status?
___Single
___Married
___Separated
___Divorced
___Widowed

7. What is your current household income?
___Under $10,000
___$10,000-$29,000
___$30,000-$49,000
___$50,000-$69,000
___$70,000-$99,000
___$100,000-$149,000
___Over $150,000
___Prefer not to answer

Study Completion Survey

1. Approximately what month did your daughter first lose her hair?

2. Approximately how much total school has your daughter missed over the past year?
   a. 1-2 months
   b. 3-4 months
   c. 5-6 months
   d. 7-8 months
   e. 9 months (approximately an entire school year)

3. Approximately when did your daughter miss the most school? (Please circle the months that she was away from school for more than half of the time. You can circle more than one.)

   January February March April May June

   July August September October November December

4. Did your daughter undergo a bone marrow transplant? _____
   If yes, when? _____

5. Has there been any period of time in the past year when your daughter had to live away from home?_____ If yes, how long did she live away from home?_____ Approximately when did this occur?_____

6. What, if any, significant changes have you noticed in your daughter over the past year?

**Thank you for your continued support in this important research!

CURRICULUM VITAE

RACHEL LYNN DUCHOSLAV

Education

Ph.D. 2012	Utah State University, Logan, UT Combined Clinical/Counseling/School Psychology Program (APA accredited) Dissertation: *The effects of acute lymphoblastic leukemia on social and behavioral functioning: An investigation into the first year of treatment* Chair: Clint Field, PhD
M.S. 2010	Utah State University, Logan, UT Counseling Psychology Thesis: *The effects of acute lymphoblastic leukemia on social competence: An investigation into the first three months of treatment* Chair: Clint Field, PhD
B.S. 2003	John Carroll University, University Heights, OH Psychology, Mental Health Services Track

Clinical Experience

08/11 – Present Clinical Psychology Intern: Wright Patterson Medical Center Wright Patterson Air Force Base, OH

Responsibilities: Provided individual psychotherapy and assessment in Clinical Health Psychology, Primary Care, and Outpatient Mental Health settings to active duty military members, retirees, and family members with a wide range of diagnoses (post-traumatic stress disorder, depression, anxiety, pain disorder, sleep problems, substance use disorders, and chronic illness). Led groups in the hospital setting for diabetes, weight management, and chronic pain. Managed multiple on-call duties (ER consultation, night on-call for mental health clinic, and domestic violence on-call services).
Supervisor: Anne C. Dobmeyer, Ph.D.

6/10 – 5/11 Student Therapist: Clinical Services, Center for Persons with Disabilities, Utah State University, Logan, UT
Clinical Assistantship

Responsibilities: Conducted diagnostic assessments, interpreted, and wrote reports for adults and children with a wide range of diagnoses (autism spectrum disorders, learning disabilities, brain injury, genetic disorders, hearing impairments, cerebral palsy, etc.). Gained extensive experience with diagnosis, assessment, and interpretation in a University Center for Excellence in Developmental Disabilities.
Supervisor: Martin Toohill, PhD

5/10 – 5/11 Student Therapist: Primary Children's Medical Center, Department of Hematology and Oncology; Budge Clinic Pediatrics, Salt Lake City, UT; Logan, UT
Advanced Clinical Practicum (Multi-site practicum)

Responsibilities:
Primary Children's Medical Center: Conducted assessments, interpreted, and wrote neuropsychological and psychoeducational reports for pediatric oncology patients in both an inpatient and outpatient setting. Participated in consultation and liaison with children, families, physicians, and a multidisciplinary medical staff. Participated in multidisciplinary Brain Tumor Clinic.

Budge Clinic Pediatrics: Formulated and implemented behavioral interventions with parents and children in a pediatric primary care setting. Participated in consultation with multidisciplinary medical staff.
Supervisor: Clint Field, PhD; Paul Colte, PsyD

8/09 – 5/10 Student Therapist: Utah Regional Leadership Education in Neurodevelopmental Disabilities (URLEND), Utah State University, Logan, UT
Clinical Assistantship

Responsibilities: Participated in diverse clinical experiences at interdisciplinary clinics that serve children with special healthcare needs. Assisted in intervention and consultation in multidisciplinary medical environments (e.g., pediatric brain tumor clinic, cranio-facial clinic, feeding disorder clinic). Served as co-investigator on a multidisciplinary research project. Attended didactic seminars with trainees and faculty from various disciplines in the child healthcare field.
Faculty Advisor: Gretchen Gimpel Peacock, PhD

7/09 – 5/10 Student Therapist: Student Health and Wellness Center, Utah State University, Logan, UT
Clinical Practicum

Responsibilities: Provided individual therapy and assessment for college students in a primary care setting. Conducted intake assessments, formulated and implemented both long- and short-term treatment plans for depression, anxiety, substance abuse, sleep problems, weight management, health problems, and smoking cessation. Consulted with medical staff regarding treatment.
Supervisor: Scott DeBerard, PhD

1/08 – 8/09 Student Therapist: Cache Valley Cancer Treatment Center, Logan, UT
Counseling Practicum

Responsibilities: Provided individual psychotherapy to adult oncology patients undergoing medical treatment in a primary care setting. Conducted, formulated and implemented treatment plans. Consulted regularly with physicians and staff. Presenting problems included depression, anxiety related to medical procedures, sleep problems, chronic pain and fatigue related to treatment, and end of life issues.
Supervisor: Scott DeBerard, PhD

7/08 – 7/09 Student Therapist: Up to 3 Early Intervention Program, Center for Persons with Disabilities, Utah State University, Logan, UT
Clinical Assistantship

Responsibilities: Formulated and implemented behavioral interventions with parents of children between the ages of birth to three with special healthcare needs and severe behavioral dysfunction. Conducted assessments and worked within a diverse multidisciplinary team consisting of nurses, physical therapists, occupational therapists,

speech pathologists, social workers, and parents. Led a pediatric feeding clinic focused on multidisciplinary treatment and behavioral management of a variety of feeding problems.
Supervisor: Gretchen Gimpel Peacock, PhD

8/07 – 5/08 Student Therapist: Psychology Community Clinic, Utah State University, Logan, UT
School/Child Psychology Practicum

Responsibilities: Conducted intakes, assessments, formulated treatment plans, and implemented psychotherapy with children, adolescents, and families in a community mental health setting. Conducted a limited amount of observation and consultation within the school environment.
Supervisor: Gretchen Gimpel Peacock

1/07 – 5/07 Student Therapist: Psychology Community Clinic, Utah State University, Logan, UT
Adult Counseling Practicum

Responsibilities: Conducted intakes, formulated treatment plans, and implemented individual adult psychotherapy for two clients in a community mental health setting.
Supervisor: Melanie Domenech Rodriguez, PhD

Research Experience

8/06 – 5/11 Student Researcher: Behavioral Pediatric Research Lab, Utah State University, Logan, UT

Involved with the design and investigation of multiple aspects of behavioral pediatric psychology, including pediatric psycho-oncology, ADHD, non-compliance, and behavioral parent training. Collaborated in a team environment and participated in team meetings and discussion/reading groups.
Supervisor: Clint Field, PhD

5/09 – 5/10 Research Consultant: Hole in the Wall Gang Camp Association, The Hero's Journey, Hole in the Wall Camp, Ashford, CT

Designed, implemented, and analyzed research aimed at evaluating program effectiveness of a therapeutic recreation program for adolescents with life threatening diseases. Designed methods, collected data, analyzed data for 5 hours per week.
Supervisor: Matthew Cook, MSW

7/09 – 7/10 Graduate Assistant: Psychology Community Clinic, Utah State University, Logan, UT

Assisted in the development and investigation of multidisciplinary research projects for 20 hours per week. Assisted in administrative duties including the creation and dissemination of a clinic policy and procedures manual. Assisted in the daily management of a community mental health facility.
Supervisor: Clint Field, PhD

5/02 – 8/02 Undergraduate Research Fellow: Department of Pediatric Neuropsychology, The Cleveland Clinic, Cleveland OH

Collected and analyzed data pertaining to pediatric neuropsychology patients (e.g., children and adolescents with autism, epilepsy, traumatic brain injury). Developed and conducted an independent research project.
Supervisor: Lisa Stanford, PhD

Teaching Experience

1/07 – 8/09 Graduate Instructor: Abnormal Psychology (PSY 3210)
Utah State University, Logan, UT
Graduate Assistantship
Designed on campus course and taught as sole instructor for 1 spring semester and 3 summer semesters for a total of 150 students.

8/07 – 5/08 Graduate Instructor: Psychology of Human Adjustment (PSY 1210)
Utah State University, Logan, UT
Graduate Assistantship

Designed on campus course and taught as sole instructor for 1 fall semester and 1 spring semester for a total of 100 students.

8/06 – 5/07 Teaching Assistant: Introduction to Psychology (PSY 1010)
Utah State University, Logan, UT
Graduate Assistantship

Assisted in teaching and grading of on campus course for 1 fall semester and 1 spring semester for a total of 250 students.

Other Professional Experience

3/10 – 6/10 Treatment Protocol Developer: ACT-Enhanced Behavioral Parent Training, Behavioral Pediatric Research Lab

Responsibilities: Assisted in the development of a treatment protocol for young children with behavioral problems, utilizing existing behavioral parent training techniques enhanced with mindfulness, acceptance, and behavioral flexibility techniques for parents. This treatment protocol was presented in workshop format at a national conference and is in the process of being empirically evaluated.

3/07 – 8/07 Program Developer: Hole in the Wall Gang Camp Association, The Hero's Journey, Hole in the Wall Gang Camp, Ashford, CT

Responsibilities: Developed a therapeutic recreation program focused on self-confidence, leadership, and identity for adolescents with life threatening diseases (e.g., cancer, HIV). This week-long program has taken place over two consecutive summers and has served over 60 adolescents.

2/05 – 11/05 Wilderness Program Leader: Hole in the Wall Gang Camp Association, Barretstown Camp, County Kildare, Ireland

Responsibilities: Led the wilderness program for Barretstown, a therapeutic recreation program that serves terminally ill children and adolescents, their families, and bereaved families from over 20 countries in the world. Designed and implemented therapeutic

activities in an outdoor setting focused on increasing self-efficacy, confidence, and quality of life.

5/03 – 2/05 Lead Wilderness Instructor: Hurricane Island Outward Bound School, Yulee, FL

Responsibilities: Led 30-day canoeing expeditions for adjudicated teenagers in the Florida Everglades and on various rivers. Program aimed at developing skills in leadership, conflict management, communication, and anger management. Supervised a team of two staff and 15 students per trip.

Community Outreach and Volunteer Experience

9/10 – Present Task Force Member: Veteran's Brain Injury Task Force
Utah State University, Logan, UT

Participated in a multidisciplinary team consisting of mental health, academic, medical, and administrative professionals focused on the development of a grant-funded treatment and academic plan for veterans with traumatic brain injury in the community. Developed educational training materials for community leaders and facilitated communication between professionals in various disciplines regarding service provision, available resources, and needs assessment for the veteran population.

9/10 – Present Committee Member: Veteran's Planning Committee
Utah State University Veteran's Resource Center, Logan, UT

Assisted in the planning and implementing of activities and events for veterans and their families on campus and in the community.

2/10 Presenter: Behavioral Basics: Children with Autism at the Dentist's Office
Dental Learning Collaborative, Salt Lake City, UT

Developed and presented to dentists and dental residents for a grant-funded full day training workshop regarding useful behavioral strategies for children with autism during dental exams and procedures.
Total participants: 50

2/09 Workshop Leader: Parenting Techniques for Children with Hearing Impairments
Edith Bowen Charter Elementary School, Sound Beginnings Program, Logan, UT

Developed and led a workshop for parents of young children with hearing impairments and behavioral concerns (e.g., tantrums, noncompliance, toileting problems, refusal to wear transmitter for cochlear implants).
Total participants: 24

11/08 Presenter: Behavioral Parenting Techniques
English Language Center, Logan, UT

Presented behavioral parenting techniques to Spanish speaking families of young children with developmental disabilities. Worked closely with a translator for presentation and discussion with families.
Total participants: 30

8/01 – 8/02 Pediatric Volunteer: Child Life Division
Rainbow Babies & Children's Hospital, Cleveland OH

Volunteered with children, adolescents, and families with cancer, sickle cell anemia, and HIV. Conducted patient visits, led play groups, and hosted a children's game show on a hospital television network.

Publications

Field, C. & **Duchoslav, R.** (2009). Family influence on adolescent treatment outcomes. In W. T. O'Donohue & L. W. Tolle (Ed.'s), *Behavioral Approaches to Disease in Adolescence* (pp. 47-54). New York: Springer.

Haut, J.S., Stanford, L.D., **Duchoslav, R.L**., Lineweaver, T.T., Wyllie, E., & Kotagal, P. (2003). Prose memory in older children (9 to 14) with epilepsy. *Journal of the International Neuropsychological Society*, 9 (2), 191. (In special issue of abstracts presented at International Conference)

Haut, J.S., Stanford, L.D., Lineweaver, T.T., **Duchoslav, R.L.**, Wyllie, E., & Kotagal, P. (2003). Verbal and visual learning in children and adolescents with epilepsy. *Journal of the International Neuropsychological Society*, 9 (2), 191. (In special issue of abstracts presented at International Conference)

Professional Presentations

Duchoslav, R. L. & Field, C. (November, 2009). *Parenting concerns about child cancer: Effects of acute lymphoblastic leukemia on children's social competence.* Poster presented at the annual conference, Association for Behavioral and Cognitive Therapies, New York, NY.

Duchoslav, R. L., & DeBerard, M. S. (November, 2009). *Finding peace and purpose at the end of life: A cognitive behavioral approach to an aging adult with advanced stage cancer.* Poster presented at the annual conference, Association for Behavioral and Cognitive Therapies, New York, NY.

Malmberg, J., Armstrong, A., Field. C., Scharton, R., Dahl, A., **Duchoslav, R.**, & Bolton, A. (November, 2007). *Preventative behavioral parent training: Immediate and long-term impact on observed parenting skills and maternal report of conduct problems.* Poster presented at the annual conference, Association for Behavioral and Cognitive Therapies, 2008.

Armstrong, A., King, J., Scheidel, G., Vlahos, M., **Duchoslav, R.**, & Rigby, J. (May, 2007). *Preventative behavioral parent training: Immediate impact on reported and observed rates of child problem behavior.* Poster presented at the annual conference, Association for Behavior Analysis, San Diego, CA.

Duchoslav, R. L., Stanford, L. (May, 2003). *The impact of right hemisphere dysfunction in children with epilepsy, Asperger's Syndrome, or nonverbal learning disabilities.* Poster presented at the annual Psi Chi Midwestern Regional Conference, Chicago, IL.

Professional Affiliations

1/2009 – Present Student Member: Association of Behavioral and Cognitive Therapies (ABCT)
1/2009 – Present Student Member: Parenting Special Interest Group, ABCT
5/2007 – Present Student Member: Association for Contextual Behavioral Sciences
1/2007 – 1/2008 Student Member: Association for Behavior Analysis International (ABAI)

Honors and Awards

08/10 – Present	Michael Bertoch Scholarship, Psychology Department, Utah State University
10/09	Research Travel Award, Psychology Department, Utah State University
5/03	Graduated Cum Laude, John Carroll University
5/03	Achievement Recognition Award, Psychology Department, John Carroll University
12/99 – 5/03	Dean's List, John Carroll University
8/99	President's Honors Scholarship, John Carroll University
8/99	American Values Scholarship, John Carroll University
8/99	The John Carroll Scholarship, John Carroll University

Additional Training

12/11	Deployment Psychology Presented by the Center for Deployment Psychology Navy National Medical Center, DC Total: 40 hours
12/11	Cognitive Processing Therapy for Post-Traumatic Stress Disorder Presented by Priscilla Schulz, LCSW Navy National Medical Center, DC Total: 16 hours
12/11	Interpersonal Psychotherapy for Depression Presented by Hsuehmei Price, PsyD Navy National Medical Center, DC Total: 8 hours
12/11	MMPI-2 RF Presented by Josef Ben-Porath, Ph.D Dayton VA Medical Center, OH Total: 16 hours
10/11	Cognitive Behavioral Therapy for Insomnia Presented by the Center for Deployment Psychology Wright Patterson AFB, OH Total: 16 hours
2/10	The Dynamics of Gottman Couples Therapy Presented by John Gottman, PhD Salt Lake City, UT Total: 8 hours
6/09	Ethics in Psychology: American Psychological Association Roundtable Seminar Presented by Stephen Behnke, JD, PhD Utah State University, Logan, UT Total: 16 hours
4/09	Acceptance and Commitment Therapy Training Presented by Steven Hayes, PhD Utah State University, Logan, UT Total: 30 hours

11/08	Treating Behavior Problems Associated with Neuro-cognitive Impairments Presented by Bear River Mental Health Staff Psychologists Bear River Mental Health Services, Logan, UT Total: 8 hours
11/08	Multicultural Training for Psychologists Presented by Melanie Domenech Rodriguez, PhD & Michael Twohig, PhD Utah State University, Logan UT Total: 8 hours