QUALITY OF LIFE, SELF CONCEPT,
PAIN AND BEHAVIORAL RATINGS
OF ADOLESCENT CANCER SURVIVORS

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PREFACE

This study was conducted to provide new knowledge related to the behavioral and psychosocial functioning of adolescent cancer survivors. Results indicated that adolescents with cancer report their self concept and behavior to be similar in nature to those who have no history of cancer. There is limited evidence to support that females display some behavioral concerns when compared to males. However, parents of young people with cancer report that their children engage in externalizing behavior difficulties. Finally, adolescent reports of pain coping type is only marginally correlated with parental views of their quality of life.

ACKNOWLEDGEMENTS

The work for this dissertation is dedicated to the loving memory of my father, Michael F. Cruce, who was born on February 8, 1947 and passed away on September 8, 2001, due to complications of a more than decade-long battle with Chronic Lymphocytic Leukemia. My father was a graduate of Forest Park High School, attended Middle Georgia College, and was a veteran who served in Saigon, Vietnam between 1967 and 1968. Dad worked hard, spoke from his heart, and always gave to family, neighbors and strangers. Whereas many fathers today give up, do not care, or provide poor modeling, I am proud to say that my dad was part of a last great generation of fathers who worked hard, was socially responsible, and typified quiet resolve and integrity. For this I am forever grateful, and hope that I can impart some of his wisdom, sacrifice, and self-discipline to children in the future.

Thank you to my mother, Kay Cruce, for her continued faith in me and support. She has told me a million times that she would love to help me with my work if she only knew how. The truth is that she always knew how and she provided me with everything that I needed to work each day and be successful. Any positive traits that I display today are a direct reflection of her love, personal sacrifice and guidance. She has worked hard to provide for her children all of her adult life (for many years going directly from a day job to a night job) and without her, I would not have made it this far. I love her and will always be there for her, just as she has always been there for me.

My brother Ty Cruce is owed a thank you many times over for his encouragement and corroboration. He has endured reading many drafts and provided helpful comments and corrections, all while only managing to laugh at my writing minimally. It is a wonderful feeling to have a younger brother who (is it *whom* or *who*, Ty?) I respect, admire and strive to be like each day. I truly hope that we continue to have a close bond throughout the years, and that we are able to keep our eye on the prize, while changing our little corners of the world so that tomorrow's children may benefit.

I wish to express gratitude to my dissertation chair and advisor, Dr. Terry Stinnett, for serving as a mentor, colleague and friend over the course of my doctoral studies. Terry provided exactly what I needed to get through the program; a mix of wit, intelligence, restraint, and brutal honesty that only true southerners can appreciate and respect. He is the only man I know who can say "*no*" to you and you like him all the more for it. More than anything, Terry has taught me to be a professional psychologist like himself, which is the type of psychologist that I want to be; one who has priorities, picks his battles, and wins time and time again. I thank him for the enthusiasm and elbowroom that he provided in letting me branch out and take a chance on a dissertation that might yield as much disappointment as it does answers about how to best help kids with cancer.

I would also like to thank my training director, Dr. Judy Oehler-Stinnett for always surprising me, and for never coming back and saying "*I told you so*" the so many times that she could have. Judy has gone to bat for me more times that I can count, and I would not have made it through this program without her care, concern, time, and kind words of encouragement. She is more than a psychologist or training director, she is a mother to every student in the OSU program and she has been there to share joys and empathize during the hard times. She is the first person in a long time whom I worked hard not to disappoint, and that probably speaks more to her character than any words that I can write.

Special thanks are extended to my two additional dissertation committee members Dr. Steve Harrist and Dr. Katie Perry. Steve has always displayed sincerity, optimism and has repeatedly given me practical advice and helped make sense out of chaos. More than this he has been willing to share his experiences with me which has resulted in this being a better dissertation and in me gaining new insight into what is really important in life. Katie reminds me why I wanted to become a psychologist in the first place. Her love of life, genuine abilities and interest in others are traits that we should all be so lucky to have. I admire and respect the authenticity that that she brings to those who work with her.

I want to thank my grandparents, Henry and Allene Cruce, and Billy and Mary Purser. Without their love (and occasional well deserved acts of setting me straight) I would not have the sense of purpose to complete such tasks as a dissertation or a Ph.D. degree. They have shown me that the recipe of caring is equal parts love, modeling, and discipline. I love them and thank them for supporting me over the years and reminding me that they are always there.

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CHAPTER I

INTRODUCTION

> "Cancer is a group of diseases characterized by uncontrolled growth and spread of abnormal cells. If the spread is not controlled, it can result in death. Cancer is caused by both external (chemicals, radiation, and viruses) and internal (hormones, immune conditions, and inherited mutations) factors. Causal factors may act together or in sequence to initiate or promote carcinogenesis. Ten or more years often pass between exposures or mutations and detectable cancer. Cancer is treated by surgery, radiation, chemotherapy, hormones and immunotherapy." (American Cancer Society, 2000, p. 1).

Due to recent medical advances, children diagnosed with cancer are living longer, with a quality of life that had previously not existed. As a result, childhood cancer has gone through a reconceptualization from an inevitably fatal illness to that of a potentially life-threatening chronic difficulty (Varni, Katz, Colegrove, & Dolgin, 1994). This new conceptualization of cancer in young people has prompted psychological researchers to examine the specific types of difficulties that young people with cancer experience, as well as develop empirically validated treatment options based on these concerns.

Unfortunately, psychological science is not at a point where research on empirical treatments for cancer related psychosocial difficulties can be a major focus of attention, as psychologists do not, as of yet, have a firm understanding of the social/emotional difficulties and behaviors that are associated with cancer diagnosis, treatment, prognosis and remission. Only when psychologists have a full conceptualization of the types of behavioral difficulties that are experienced by young people with cancer, may research on treatment options begin.

Behavioral research related to cancer is a new and important venture for psychologists, as practitioners are increasingly likely to be presented with a young cancer survivor in their practice. Psychologists should seek out research related to treating young people with cancer, as current estimates show that children with cancer are living an average of five years longer than in past decades (Bleyer, 1990; Sposto & Hammond, 1985), and the cure rate for childhood cancer has risen to greater than 60% in the past three decades (American Cancer Society, 1996). Trends over time have suggested that cancer rates in children increased from the 1970's, when data on childhood cancer prevalence began being recorded, until the start of the 1990's, when they leveled off and declined until 1996. Since the mid 1990's there have been slight increases in several of the classes of cancer in children. These increases have been attributed to newer diagnostic techniques that enable doctors to identify and treat cancer at younger ages than were previously allowed by medical science (American Cancer Society, 2000).

Approximately 12,400 children were diagnosed with cancer in the year 2000, making it the third leading cause of death in children, behind unintentional injuries and homicides (American Cancer Society, 2000). Survival rates paint a somewhat brighter picture for children with cancer, with the five-year survival rate of children at 74.9% and the ten-year survival rate approaching 70% (American Cancer Society, 2000). Demographic data suggest that the incidence of cancer is higher in boys than in girls. Cancer is most common in Caucasians, followed by Hispanics, Asian/Pacific Islanders, African-Americans, with rates lowest in American Indian/Alaska Native populations (American Cancer Society, 2000).

The overall increase in survival rates has affected various areas of professional practice in psychology. As a result, cancer survivor's appearances will become more common in outpatient settings. Young people with cancer may be presenting with psycho-social difficulties that are similar in nature regardless of their gender or other demographic characteristics, however, it is unknown at this time if this is the case. School psychologists are likely to encounter young people with cancer in the schools as the educational system has been presented with the challenge of teaching children who previously would not have returned to school after diagnosis and treatment. Children and adolescents with cancer are now attending classes, and there is little empirical research examining the types of behavioral difficulties these young people may be experiencing at home and at school.

Interestingly enough, both clinical psychology and school psychology have chosen to focus almost exclusively on the cognitive functioning of young people with cancer. This research focus occurred after the discovery that prophylactic central nervous system chemotherapy was associated with declines in cognitive and academic functioning, specifically related to in arithmetic abilities, visual motor integration, and verbal fluency (Espy et al., 2001). As a result, social/emotional and behavioral difficulties have been largely overlooked by psychologists, with neuropsychological training and research becoming increasingly popular by scientists in attempting to legitimize psychology as a biological versus behavioral science.

Statement of the Problem

Current behavioral research has not focused on how cancer or related difficulties (i.e. cancer related pain and quality of life experiences) may affect the social/emotional and behavioral functioning of young people with cancer. Despite the need and call for psycho-social cancer research (American Cancer Society, 2000), cancer is being largely disregarded for more popular or controversial research topics such as Attention-Deficit/Hyperactivity Disorder or Bipolar Disorder in children. A literature review in the five major school psychology journals (School Psychology Review, School Psychology Quarterly, The Journal of School Psychology, Psychology in the Schools and The Journal of Psychoeducational Assessment) for the past five years using such keywords as "Cancer" and "Pain" yields only two journal articles related to "cancer" in children, with neither being an empirical study related to the psychosocial effects of living with cancer. One article consisted of a neuropsychological literature review of childhood cancer (Armstrong, Blumberg & Tolendano, 1999), and the other presented various school reintegration programs for children with cancer (Prevatt, Heffer & Lowe, 2000). The keyword "pain" resulted in no articles in the past five years in any of these journals. However, difficulties that have lower prevalence rates than cancer, and significantly lower prevalence rates than childhood pain, such as Selective Mutism and Fragile X Syndrome, each yielded 3 articles in these same journals. Additionally, keywords such as "WISC" yielded 17 articles and "ADHD" yielded 27 articles in these same periodicals. Certainly, these are topics that receive more attention in the school psychology literature, but there could be some question as to the needed value of empirical research related to cancer and pain in children when considering prevalence estimates, decreasing mortality rates, and known neuropsychological effects of cancer on children.

One specific area that school psychology has neglected concerning cancer in children relates to the scope and range of behavioral difficulties that the child may exhibit at home. Although substantial research has sought to examine the academic and neuropsychological functioning of pediatric oncology patients (Brown et al., 1998; Manne & Miller, 1998; Sanger, Copeland & Davidson, 1991; Vannatta, Zeller, Noll & Koontz, 1998), there is little documented research that examines the behavioral concerns of parents of children with cancer. This would serve as an important area of study as behavioral functioning at home has long been assumed to affect school behavior. Additionally, cooperation between the child's parents, the school and the cancer treatment facility has been recommended as the most helpful course of action for children with cancer by a variety of authors (Chekryn, Deegan & Reed, 1986; McCormick, 1986; Waskerwitz, 1987). The need for behavioral research to provide empirically validated treatment for students with cancer is becoming an concern due to a lack of necessary specialized services. Services and intervention training cannot take place until behavioral researchers have a firm understanding of the specific types of cancer difficulties that are displayed by adolescents. For instance, it is not currently known if: 1) children with cancer display similar behavioral "profiles" as other children with cancer; 2) if they engage in more or less internalizing or externalizing behaviors than children who do not have a cancer diagnosis; 3) if there are specific DSM-IV diagnoses that are more likely to occur in young people who have cancer; and 4) if there are gender differences related to potential DSM-IV diagnoses or behavioral profiles.

Another research question for psychological science relates to how cancer associated pain affects the behavioral functioning of pediatric oncology patients. However, for cancer and treatment pain to be examined in children it must first be operationalized. Although a variety of conceptualizations of pain exist in the literature (Walker, Garber, & Greene, 1993; Walker, Garber, & Greene, 1994), the prevailing model emphasizes four basic elements of a pain episode: 1) nociception; 2) pain; 3) suffering; and 4) pain behavior (Fordyce, 1988). "*Nociception* is the activity produced in the nervous system by potentially tissue-damaging stimuli. This process cannot be directly observed, but is thought to occur when a tissue damaging stimulus impinges on a pain-sensitive structure" (American Cancer Society, 2000, p. 4). "*Pain* is the unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage" (American Cancer Society, 2000, p.4). "*Suffering* is the perception of distress engendered by all the adverse factors that together undermine quality of life" (American Cancer Society, 2000, p. 4). Pain may contribute profoundly to suffering, but numerous other factors, such as the experience of other symptoms, progressive physical impairment, or psychological stressors, may be equally or more important. The *pain behavior* includes all of the observable behaviors by the individual who is in pain that are in response to the pain.

The extent of how pain affects behavioral functioning in children with chronic medical conditions has yet to be thoroughly examined in youth with a variety of conditions where pain is known to be present, including HIV infection, Sickle Cell Disease, and Multiple Sclerosis. The primary reason research has not systematically examined pediatric pain is the mistaken notion for many years that children have a lower sensitivity to pain than adults (Elliott & Jay, 1987). This may be due to the difficulties children have verbalizing their pain experiences, and researchers interpreting this silence as a lack of pain perception. Other researchers hypothesized that children do not experience pain perception due to undeveloped neural pathways in combination with high levels of resilience (Ross & Ross, 1984). This prior conceptualization of children not feeling pain often resulted in an under treatment of pain in pediatric populations, and a lack of necessary psychological services provided to children in pain (Gaffney & Dunne, 1986, Thompson & Varni, 1986). Recently, pain has been acknowledged as a real experience as it relates to pediatric patients, and research is beginning to reflect this.

Assessment of pain in children typically consists of examining the characteristics of pain and identifying the physical signs of the underlying disease or treatment that is causing the pain (Roxane Pain Institute, 1999). Although the treating clinician may have numerous concerns and questions about the pain experience, most often, the psychologist is interested initially with pain intensity, pain quality, pain distribution and temporal relationships. These characteristics yield data that the psychologist will ultimately draw on to provide treatments that emphasizes pain relief.

Utilizing comprehensive pain assessment instruments and emphasizing a multidimensional and systematic approach to treatment provides the psychologist with an accurate conceptualization of the pain experience in the child, and can improve methods and results of pain management (Hester & Foster, 1992). However, there are few measures that focus on the pain experience of young people. Patient self-reports have been considered to be the major determinant in assessment of pain intensity. The use of questionnaires, self reports and pain inventories could assist in facilitating communication between the child and the psychologist (Agency for Health Care Policy and Research, 1994; McCaffery & Ferrell, 1992).

The psychological literature has supported the conclusion that strong, positive family ties are one of the best predictors of positive cancer-pain coping skills in children (Manne & Miller, 1998; Quittner, Glueckauf, & Jackson, 1990; Wamboldt & Wamboldt, 2000), but that the intrusiveness of the disease itself mediates in the psychosocial impact of the family (Devins, Beanlands, Mandin, & Paul, 1997). Pain-related coping skills in children have been identified as an area of needed research. Coping skills may be a potential predictor of behavioral functioning in children with cancer (Manne & Miller, 1998). For instance, it has been suggested that children with chronic health conditions may use avoidant procedures and refuse to acknowledge their difficulties as their main cognitive coping strategies (Phipps & Srivastava, 1997).

Children may choose to cope with their cancer diagnosis and related pain utilizing a variety of strategies. One recently accepted conceptualization of pain coping was developed by Walker, Smith, Garber, & Van Slyke (1997). Their model posits three broad coping factors: 1) *Active Coping*, which consists of such skills as problem solving, seeking out support from others and using distraction techniques; 2) *Passive Coping*, which uses strategies related to isolation, catastrophizing, and behavioral disengagement; and 3) *Accommodative Coping*, which include strategies such as acceptance, self-encouragement, minimizing or ignoring the pain.

Research should also be concerned with the role of self concept and how self concept contributes to the behavior of adolescents diagnosed with cancer. Self Concept has only recently been explored as a potential factor involved in the behavioral functioning of patients with cancer. For instance, Nordin et al. (2001) found that adult cancer patient's self concept was predictive of behavioral adjustment and life satisfaction in a study of 85 newly diagnosed gastrointestinal cancer patients. Their results indicated that those with a positive self concept were more likely to display fewer symptoms that were associated with common internalizing difficulties such as depression and anxiety. Ultimately, it is difficult to gain a comprehensive understanding of how cancer impacts one's behavior without also examining a factor such as self concept, which has been shown to be involved in behavioral functioning.

Finally, there is some question as to how parental views of quality of life, pain experiences, and the behavioral functioning of young people with cancer are related. There is evidence to support the notion that as a child's prognosis worsens, family views of quality of life satisfaction decrease (Hunfeld et al., 2001). They concluded that as cancer-related difficulties increase, family members report more restrictions placed upon them, particularly related to the family members social lives, and with more adolescent reported stress. As social stress is considered an important factor in behavioral functioning, a more thorough examination of how parental views of quality of life affects behavioral functioning would serve as a valuable area of psychosocial research related to childhood cancer.

The American Cancer Society (2000, p. 9), sites two challenges for pediatric oncology in this century: 1) "to continue progress in effectively destroying the cancer", and 2) "minimizing the impact of treatments on the child' long-term *quality of life*". One might erroneously conclude that a child will return to normal functioning simply due to an absence of disease at the end of therapy, and this false belief has been substantiated through research (Mulhern et al., 1989). Although substantial research has been dedicated to medical cancer treatments, research has only recently begun to examine the *quality of life* of young people who have been diagnosed and living with cancer (Phipps & Srivastava, 1997; Varni, Katz, Colegrove, & Dolgin, 1994). This is an important area of research in that it has been suggested that young people diagnosed with chronic medical conditions may be at an increased risk for behavioral, psychological and social adjustment problems (Wallander et al., 1988), and there is some evidence to support that early diagnosis is the best predictor to overall self reports of quality of life (Slavin, O'Malley, Koocher, & Foster, 1982).

Purpose of the Study

This study sought to further the understanding of behavioral difficulties that are exhibited by adolescents with cancer, examine potential profiles of behavioral symptoms by gender, and further the understanding of the role of quality of life, self concept and pain-coping strategies and additional factors in the diagnosis of behavioral difficulties in young people with cancer. Such potential factors were measured by self report measures of coping with pain, child self-report measures of self concept, as well as demographic information relating to the child, the child's illness and the child's family. It was ultimately hypothesized that reports of pain coping would assist in the understanding of adaptive behavior and behavioral maladjustment of adolescents diagnosed with cancer. This information could be utilized to further the understanding of which factors, or groups of factors most accurately contribute to predicting behavioral difficulties and adaptive behavior in children with cancer. Data on behavioral and emotional functioning were collected from child self-report and parent report. This assisted in determining what relationship exists between the cancer diagnosis in children, pain coping beliefs, self concept, behavioral difficulties, gender and quality of life in children diagnosed with cancer.

The purpose of this study is to: a) identify the types of behavioral difficulties that are exhibited by adolescents with cancer by their gender; b) assess whether adolescents utilize active, passive or accommodative strategies in their pain coping; c) assess if adolescents with cancer have a reported self concept that is lower than those without cancer; and d) identify if parents of children with cancer report similar characteristics related to quality of life.

In essence, this study will examine the impact of pain, quality of life, self concept, and demographic variables on the behavioral functioning of male and female adolescents diagnosed with cancer. The hypotheses of this study were examined through the use of: a) various sources of behavioral and emotional functioning taken from self-reports and parent reports, the *Behavior Assessment System for Children- Self Report of Personality* and *Parent Rating Scale* (BASC-SRP and PRS); b) from self-report measures of pain response coping, the *Pain Response Inventory* (PRI); c) from a parent report of quality of life, the *Pediatric Oncology Quality of Life Scale* (POQOLS); and d) from a self-report measure of self concept, the *Multidimensional Self Concept Scale* (MSCS). This assisted in determining what relationship exists between the cancer diagnosis in children, associated behavior, pain intensity, pain coping beliefs, self concept and quality of life for children living with cancer.

Significance of the Study

Childhood Cancer has been reported to be one of the most significant health related problems of youth in the next century (American Cancer Society, 2000). It has been estimated that 8,600 new cases of childhood cancer occurred in children aged 0-14 in the year 2000, and that 1,600 deaths occurred in children of this age group during that same year (American Cancer Society, 2000). The necessity for research and intervention with this population is important because as medical advances give children the opportunity to live longer, more pediatric oncology patients will be attending school regularly. The American Cancer Society (2000) reports that although cancer mortality rates have decreased by 50% since 1973, cancer is still the chief cause of death in children under the age of 14, and is the third leading cause of death in adolescents. Since adolescents spend the vast majority of their time either at home or school, it is logical that any behavioral difficulties that they display will be observed in these settings. Additionally, difficulties that result from internalizing and externalizing behaviors, from cancer, and from cancer treatments have the potential to decrease social and academic functioning and impact school attendance and performance.

Prevalence rates of childhood cancer suggest that there is a need for school psychologists to focus on cancer in children. It is estimated that there were 12,400 new cases of childhood and adolescent cancer diagnosed nationwide in the year 2000, resulting in 2,300 deaths (American Cancer, Society, 2000). In Oklahoma, the rate of childhood cancer is more difficult to predict, but, a conservative estimate of 1,135 current cases of adolescent cancer could be predicted based on national childhood prevalence estimates and the state total estimate of new cancer diagnoses of 16,100 in all ages (American Cancer Society, 2000). This means that close to 1,200 adolescents are attending Oklahoma public schools, whom, 30 years ago, would not have returned to school after their cancer diagnosis and treatments. There is currently no data that provides evidence or empirical support for the types of social/emotional and behavioral difficulties that these adolescents may be experiencing. For instance, many of these young people may be hiding their diagnosis at school in hopes of maintaining a normal social life. Research is needed to examine the types of difficulties that young people with cancer report, and to assist them by building strong psychosocial and behavioral treatment programs that are empirically supported. This study is to serve as an opening examination seeking to further the understanding of the types of difficulties that are displayed by adolescents with cancer.

Substantive Questions

The following Substantive Questions have been chosen for examination in this study.

1. Do the children with cancer in this study display differences in self concept from those in the normal population, and are there gender differences in self concept of children who have cancer?

2. Are there differences in selected Behavior Assessment System for Children scores on the Parent Rating Scale (PRS) and the Self Report of Personality (SRP) in children who are cancer survivors, and are there differences between gender on the PRS and SRP in this sample?

3. Is there a relationship between adolescent pain coping type and parental measures of quality of life?

Hypotheses

1. The children with cancer in this study will report self concept's similar to those in the normal population, and there are no gender differences in self concept of children who have cancer.
2. There are no differences in selected Behavior Assessment System for Children scores on the Parent Rating Scale (PRS) and the Self Report of Personality (SRP) in children who are cancer survivors, and there are no differences between gender on the PRS and SRP in this sample.
3. There is no relationship between adolescent pain coping type (PRI) and parental measures of quality of life (POQOLS).

Assumptions Underlying the Study

1. It is assumed that the participants and their families will take adequate time and exercise caution in filling out the rating forms correctly.
2. Those who choose to participate in this study will look demographically similar to those who choose not to participate.

Limitations

The following limitations may influence the results of this study:

1. Sample sizes for behavioral research for children with cancer are typically small. Studies often report sample sizes containing no more that 20 children. This is due to a variety of reasons including: 1) the child's illness preventing participation; 2) the families reluctance to have their child participate in behavioral research as they do not see benefits for their child; and 3) parents of children with cancer are often asked to participate in numerous studies that interfere their already overly burdened schedules. As a result, it is difficult to gain large sample sizes for psychological research related the cancer experience in young people.
2. The factors used to predict behavioral difficulties in children were gathered after a careful review of the literature. However, there may be other variables that would provide additional information, but would prove difficult to gather. These factors may be better accounted for by the information gathered in this study (e.g. measures of likeability from the child's classmates would be useful information, but would be ethically difficult to gather due to such potential conflicts such as respecting the confidentiality and privacy of the young person with cancer).
3. Teacher ratings of behavior would provide useful and complementary data to what is collected by parent and self-reports. However, teacher data are difficult to consistently gather, as many adolescents wish to keep their cancer diagnosis confidential, and would not want their teachers completing ratings scales. Additionally, adolescents frequently have as many as six different teachers in a high school setting, and there is some question as to who should be used as a rater, or if all of the teachers should complete behavioral ratings. Such an examination is impractical for this particular study, due to the nature of

confidentiality of the participants, but should be considered for future research by psychologists in oncology settings.

Organization of the Study

This study will be organized in the following manner:

1. Chapter One will focus on the reasoning why a study of factors that contribute to behavioral outcomes for children with cancer is necessary.
2. Chapter Two will focus on a review of the current literature on pediatric oncology, self concept, quality of life, behavioral functioning and pain management in children with cancer.
3. Chapter Three will discuss the methodology of this study, the participants, the instrumentation used, and the data analysis to be utilized.
4. Chapter Four will focus on the results of the study.
5. Chapter Five will discuss what the results of this study mean for school psychologists, the implications on direct practice and future research, as well as the generalizability and the limitations of the study.

CHAPTER II

REVIEW OF THE LITERATURE

Over the past twenty years, cancer in children has been reconceptualized from an inevitably fatal illness to a life-threatening chronic difficulty (Varni, Katz, Colegrove, & Dolgin, 1994). This new conceptualization has been at least partially due to medical advances that have greatly increased longevity and quality of life in both children and adolescents. The emergence of survivorship of cancer in children and adolescents has prompted psychological researchers to examine the specific types of psycho-social difficulties that young people with cancer experience, as well as develop empirically-validated treatment options based on these concerns. Unfortunately, psychological science is not yet at a point where research on empirical treatments for cancer-related psychosocial difficulties can be a major focus of attention, as psychologists do not, as of yet, have a firm understanding of the social/emotional difficulties and behaviors that are associated with cancer diagnosis, treatment, prognosis and remission. Only when psychologists have a full conceptualization of the types of behavioral difficulties that are experienced by young people who have experienced cancer, may research on treatment options begin.

Behavioral research related to cancer is a new and important venture for psychologists, as practitioners are increasingly likely in their practice to be presented with a young cancer survivor. Psychologists should seek out research related to treating young people with cancer as, current estimates show that children with cancer are living an average of five years longer than in past decades (Bleyer, 1990; Sposto & Hammond, 1985), and that the cure rate for childhood cancer has risen to greater than 60% in the past three decades (American Cancer Society, 1996). Trends over time have suggested that cancer rates in children increased from the 1970's, as data on childhood cancer prevalence was not kept before this time, until the start of the 1990's where they have leveled off and since declined until 1996. There have been slight increases in several of the classes of cancer in children since the mid 1990's, but these increases have been attributed to newer diagnostic techniques that enable doctors to identify and treat cancer at younger ages than were previously detected by medical science (American Cancer Society, 2000).

Prevalence estimates of childhood cancer suggest that approximately 12,400 children were diagnosed with cancer in the year 2000, and that it was the third leading cause of death in children that year, behind unintentional injuries and homicides (American Cancer Society, 2000). Survival rates paint a brighter picture for young people with cancer, with the five-year survival rate of children at 74.9% and the ten-year survival rate approaching 70% (American Cancer Society, 2000). Other demographic data suggest that the incidence rates of cancer are higher in boys than in girls, and that incidence rates are highest in Caucasians, followed by Hispanics, Asian/Pacific Islanders, African-Americans, and are lowest in American Indians/Alaska Natives (American Cancer Society, 2000).

The overall increase in survivor rates has affected various areas of professional practice in psychology, and, as a result, cancer survivors will appear more frequently in outpatient settings. These young people may present with similar psycho-social difficulties, however, it is unknown at this time if this is the case. School psychologists are likely to encounter young people with cancer in the schools as the educational system has been presented with the daunting task of teaching children who previously would not have returned to school after diagnosis and treatment attempts. Children and adolescents who would have not previously returned to school are now attending classes, and there is little empirical research that has sought to examine the types of behavioral difficulties that these young people may be experiencing both at home and at school.

Despite the lower incidence rates of childhood cancer over time, the financial costs of cancer remain staggering. For instance, in 1996, roughly 18% of all Americans were reported to have no funding for health coverage, and this has been reported to significantly contribute to delays in childhood cancer treatments and in creating additional family stressors (American Cancer Society, 2000). Cancer is thought to currently cost over $107 billion dollars each year when considering medical costs, loss of life, loss of productivity due to chronic illness, and research dollars dedicated to prevention and cancer treatments (American Cancer Society, 2000).

Recent effective treatments for children with cancer have resulted in the new paradigm of cancer as a life-long chronic illness. Modern medical regimens for cancer in children typically consist of chemotherapy, surgery, radiation therapy, or a combination of these treatments. These scientific advances have provided the opportunity for an array of psychological research concerning the previously unexamined difficulties that children have as a result of living with a chronic illness. Research supports that communication of the child's diagnosis and prognosis early yields the most positive psycho-social adjustment in the child (Slavin, O'Malley, Koocher & Foster, 1982). For the most part, however, psychological research has not chosen to focus on the psychosocial aspects of childhood cancer, but rather, focus has been related exclusively to any potential neuropsychological deficits of students who have cancer (Andrews et al., 2001; Brown et al., 1998). This is unfortunate when considering that youth have reported that addressing psychosocial difficulties are their top priority after diagnosis and treatment (Chekryn, Deegan, & Reed, 1986). Thus, behavioral difficulties and psycho-social factors such as adaptive behavior characteristics, quality of life issues, and self concept have not been a priority for examination in the young person who is living with cancer.

Childhood Cancer Sub-types

Although in adults, cancer is typically categorized by its location within the body, e.g. breast cancer or lung cancer; in children, cancers are classified into 12 major categories under the International Classification of Childhood Cancers (ICCC). These categories provide a more accurate conceptualization of cancer that is useful in both research and treatment. Although this classification system now exists, the largest percentage of adolescents with cancer have one of a small handful of diagnoses, with the largest percentage of young people being diagnosed with either Leukemia, Central Nervous System Tumors or Lymphoma. Additionally, cancer is categorized or "staged" based on the extent of spread from the site or origin. Cancer is studied by the extent of the primary tumor (T), whether there is lymph node involvement (N), and whether the cancer has metastasized (M). Each of the "TNM" categories are then given a stage of I, II, III or IV, with I considered early and IV considered as an advanced stage (American Cancer Society, 2000). This staging procedure assists oncologists in determining the most appropriate treatment protocol. Children who are in cancer remission do not display any symptoms associated with cancer, but may, in the future display more symptomology and be assigned a TNM. There are many available books and resources provided by the American Psychological Association, the American Cancer Society and the National Cancer Institute that outline the specific diagnostic criteria, general descriptions of the diseases, as well as their prognosis and treatment options. As this information is readily available and commonly known to professionals only a brief overview of the major cancers of young people who were in the study are provided below.

The most prevalent type of cancer found in children is *Leukemia*, which accounts for about one-third of all oncology cases in children under 15, and currently affects approximately 2,600 children in the United States each year (American Cancer Society 2000; Bleyer, 1990,). Prior to the early 1970's, Leukemia was considered to be a fatal diagnosis, but with the advent of central nervous system prophylaxis such as cranial radiation therapy (CRT), the survival rate quickly approached 70% (Waber & Mullenix, 2000). Leukemia is known to be a malignant disorder of the blood-forming tissues, specifically the bone marrow, lymph nodes and spleen. The blood-forming tissues flood the bloodstream and lymph system with abnormal and immature white blood cells and these immature cells cannot carry out the normal cells' function of fighting infections in the body. They also reduce production of normal red blood cells (which prevents anemia), as well as tiny discs called platelets (which regulate coagulation and bleeding). If left uncontrolled, Leukemia will cause a) infections due to the lack of normal infection-fighting white blood cells, b) severe anemia, due to the lack of oxygen-carrying red blood cells, and c) bruising and hemorrhaging, due to the lack of platelets. Leukemia is labeled into two broad categories: *acute* and *chronic*. *Acute Leukemia* affects immature white blood cells. It progresses rapidly and is the type most often seen in children. *Chronic*

Leukemia occurs most frequently in adults and progresses slowly, often over a period of many years (Leukemia Society of America, 2000). Additionally, Leukemia can be either *lymphocytic/lymphoblastic*, which involves cells that are formed in the lymph nodes and spleen, or *myelocytic/myelogenous*, which affects cells directly in the bone marrow (Leukemia Society of America, 2000).

Another common type of cancer that occurs in children consists of *Central Nervous System tumors*, which make up approximately 20% of the cases of childhood cancer. The term Central Nervous System or (CNS), primarily refers to the brain and the spinal column. CNS Tumors and associated neoplasms are the second largest category of cancer in children, and the most common category of solid tumors in children. More than half of the central nervous system tumors are a specific subtype called *Astrocytomas*. Incidence rates are typically highest in children from birth to age seven, and survival rates appear to be better the later the onset of the disease. It has been established that five year survival rates have increased over the past few decades to 65%" (American Cancer Society, 2000).

Lymphomas make up approximately 10-15% of the cases of childhood cancer. They are the third most common form of childhood cancer, and directly affect the lymphatic system, the part of the body that fights disease and infections (National Cancer Institute, 1992). Lymphatic vessels carry *Lymph*, a colorless, watery fluid containing infection-fighting cells known as *lymphocytes* to areas known as *lymphnodes* (American Cancer Society, 2000). Lymphomas in children are classified as *Hodgkins Disease* or *Non-Hodgkins Lymphomas*.

Hodgkin's Disease is a specific lymphoma sub-type that contains an abnormal cell known as the *Reed-Sternberg Cell*, which is not found in other lymphomas. In Hodgkin's Disease, lymphoma cells spread from their original site to affect other sites as well as other organs through the bloodstream. The incidence rates of Hodgkins Disease have steadily declined between 1975 and 1995, and the five-year survival rate for Hodgkin's patients has increased to 91% (American Cancer Society, 2000). Overall, Hodgkin's Disease accounts for just slightly more cases than does non-Hodgkin's Lymphomas (American Cancer Society, 2000).

Non-Hodgkins Lymphomas, by contrast, consist of abnormal cells in the lymphatic system that can occur in any part of the body, and they may occur in a single part of the body or many parts simultaneously. Non-Hodgkin's Lymphoma rates typically increase throughout childhood. Non-Hodgkin's Lymphoma incidence rates have remained stable in recent years, and the five-year survival rate has been 73% among those diagnosed from 1989 to 1995 (American Cancer Society, 2000).

Additionally, there are a variety of diverse and more unique cancer diagnoses that may be seen in children and adolescents, but these subtypes occur infrequently in young people, and are certainly considerably more rare than the previously mentioned diagnoses of cancers. These additional cancers include: 1) Osteosarcomas, a bone cancer consisting of 2.4% of all childhood cancers, 2) Ewing's Sarcoma, another cancer of the bone, making up 1.7% of the cases, 3), Neuroblastomas, occurring in the abdomen in 7.5% of cancer cases, 4) Rhabdomyosarcomas, a soft-tissue sarcoma typically occurring in the head or neck in 3.4% of the cases, 5) Retinoblastomas, which make up 3.1% of the cases and consists of an often curable cancer of the eye, and 6)Wilm's Tumor, a kidney cancer that makes up approximately 6% of childhood cancers (American Cancer Society, 2000).

Self Concept of the Child with Cancer

Researchers have also been concerned with the role of self concept and how self concept contributes to the behavior of adolescents diagnosed with cancer. Self concept in this study is defined as "a multidimensional and context-dependent learned behavioral pattern that reflects an individual's evaluation of past behaviors and experiences, influences an individual's future behaviors, and predicts an individual's future behaviors" (Bracken, 1992). Self concept has only recently been explored as a potential factor involved in the behavioral functioning in patients with cancer. For instance, Nordin et al. (2001) found adult cancer patient's self concept to be a factor that predicted behavioral adjustment and life satisfaction in a study of 85 newly diagnosed gastrointestinal cancer patients. Their results indicated that those with a positive self concept were more likely to display fewer symptoms that were associated with common internalizing difficulties such as depression and anxiety. Ultimately, it is difficult to gain a comprehensive understanding of how cancer impacts one's behavior without also examining a factor such as self concept, which has been shown to be involved in behavioral functioning.

Research supports that children with cancer are likely to turn to family and friends for social support (Manne & Miller, 1998), and that it is necessary that this support be provided for the child to maintain a positive self concept. This support may be difficult for the child to seek out at school as social ostracism may occur. As social relationships between children are considered to be very important and a significant part of the child's life, school may prove to be an uncomfortable environment for the child without behavioral interventions in place (Prevatt, Heffer & Lowe, 2000). In a study by Vannatta, Zeller, Noll and Koontz, (1998) it was found that children with cancer were rated by their classmates as being more socially withdrawn, and were less likely to be thought of as a best friend by their classmates. There are questions amongst psychologists as to whether this is due to decreased social functioning on the part of the child with cancer, or a lack of empathy and understanding on the part of their classmates (Manne & Miller, 1998). The school psychologist is a viable professional to monitor the social functioning of the child with cancer, and to provide necessary psychosocial interventions. Monitoring and intervention by the behavioral specialist at the school is deemed important as there is a positive correlation between child uncertainty and psychological distress (Neville, 1998).

Research has supported the claim that the child's perceived social support from classmates to be the best predictor of positive self concept in the child with cancer (Varni, Katz, Colegrove, & Dolgin, 1994). Due to the stresses that accompany cancer, adolescents are especially likely to seek out emotional support from their friends and family members (Manne & Miller, 1998). Ironically, research indicates that the average size of the social network of the child with cancer is smaller than the social network of their healthy adolescent counterparts (Nichols, 1995). This may be, in part, explained by the adolescent displaying low self-confidence due to a perceived lack of social support coupled with noticeable signs of a health impairment, e.g. visible hair loss (Novakovic et al., 1996).

Research by Manne and Miller (1998) found lower self concept and higher rates of conflict with both mothers and fathers to be present when comparing the lives of children with cancer versus children with no chronic health impairments. Their results are attributed to the teen's desire for some degree of autonomy while facing the reality of needing increased assistance from parents. They also noted that conflict with the maternal figure in the adolescent's life is highly associated with psychological distress, and these authors suggest that mother-adolescent conflict should be a focus for psychosocial intervention. The higher rates of conflict between mothers and children could be conceptualized by behavioral psychologists to be due to the mother traditionally serving as the primary family caregiver and having more parent-child interactions.

Internalizing/Externalizing Behavior Difficulties of Young People with Cancer

One specific area that school psychology has neglected concerning cancer survivorship in children and adolescents relates to the scope and range of behavioral difficulties that the child with cancer may exhibit at home. Although substantial research has sought to examine the academic and neuropsychological functioning of pediatric oncology patients (Brown et al., 1998; Manne & Miller, 1998; Sanger, Copeland & Davidson, 1991; Vannatta, Zeller, Noll & Koontz, 1998), there is little documented research that examines the behavioral concerns of parents of children with cancer. This would serve as an important area of study as behavioral functioning at home has long been a factor in predicting school behavior (Christopherson & Mortweet, 2001). Additionally, cooperation between the child's parents, the school and the cancer treatment facility has been recommended as the most helpful course of action for children with cancer by a variety of authors (McCormick, 1986; Chekryn, Deegan & Reed, 1986; Waskerwitz, 1987). The need for behavioral research and providing empirically validated treatment for students with cancer is rapidly becoming an issue of necessity due to a lack of necessary specialized services for childhood cancer survivors. Of significance is that services and intervention training cannot take place until behavioral researchers have a firm understanding of the specific types of cancer difficulties that are displayed by adolescents. For instance, it is not currently known if 1) young people with cancer display similar behavioral "profiles" as other children with cancer, 2) if they engage in more or less internalizing or externalizing behaviors versus those who do not have a cancer diagnosis, and 3) if there are specific DSM-IV diagnoses that are more likely to occur in young people who have cancer than those who do not have cancer-related diseases.

Ultimately, children diagnosed with cancer may display a variety of behavioral difficulties, although there is little empirical evidence that has supported that young people with cancer have higher rates of psychopathology than their healthy counterparts. There are also few studies that have sought to examine if adolescents with cancer have a propensity to engage in similar behavioral difficulties as other young people with cancer. So there is some question as to how the prevalence rates of children with cancer compare with the rates of children who have not been diagnosed with a chronic medical condition. For example, a variety of studies have reported that the prevalence rates for children with cancer who display levels of depression are comparable to the rates of the population of children who have no chronic medical difficulties, and it has been hypothesized that this similarity is due to the lack of acknowledgment of difficulties that are associated with the cancer illness (Kaplan, Busner, Weinhold & Lenon, 1987; Phipps, Faircloth & Mulhern, 1995; Phipps & Srivastava, 1997). However, a low rate of depression has been noted, and it has been hypothesized that children with chronic illness are utilizing positive coping strategies rather than displaying poor behavioral adaptation (Phipps, Faircloth & Mulhern, 1995). Phipps et al. (1995) suggest that children, in the response to the overwhelming stresses of cancer, can call upon additional coping behaviors that increase their levels of avoidance, while other forms of coping may remain stable.

However, there is also evidence to support that young people with cancer may display more behavioral difficulties than their healthy counterparts (Kaplan, Busner, Weinhold, & Lenon, 1987; Kazak et al., 1997; Mesman & Koot, 2000). It is been noted that it is difficult to examine internalizing behaviors (e.g. depression, somatization and anxiety) in children due to parents and teachers reportedly seeking out assistance for difficulties that are externalizing in nature (e.g attention problems, hyperactivity and conduct problems) due to the overt nature of externalizing problems (Mesman & Koot, 2000). There are related theories, including that there is a high overlap or “comorbidity” of internalizing and externalizing difficulties (Gjone & Stevenson, 1997), or that externalizing symptoms may simply be “signals” of more important internalizing difficulties (Verhulst & Vander Ende, 1993). Adolescents with cancer may display symptoms that are associated with a variety of behavioral difficulties, including depression, somatization, anxiety, social stress, attention problems, and conduct problems. The current research related to these behavioral difficulties is briefly outlined below.

Internalizing Disorders

One factor contributing to the difficulty in diagnosing internalizing disorders in children with cancer is that parental awareness of anxiety and fear in children are not easily observable by parents, teachers or physicians (Messman & Koot, 2000). There is poor agreement among most studies of internalizing disorders in children with cancer, and there is frequently also poor inter-rater reliability between child self-reports and parent reports of internalizing difficulties. As a result, the use of multiple sources of data has been emphasized as best practice for screening of internalizing disorders in all children (BASC Manual, 1998).

The majority of studies that have examined prevalence rates of depression in children have indicated that the rate is significantly higher than the often reported 6% found in the general population (Locke & Regier, 1985). Perhaps the most widely cited study to date was completed by Kaplan, Busner, Weinhold, and Lenon, (1987) who reported that prevalence rates for depression in children with cancer occur less frequently than the depression rates in healthy children. Unfortunately, this study decelerated behavioral research in children with cancer, which is even more regrettable when considering that the study used deficient measures to examine depressive symptoms and over-generalized its findings in a study based only on 21 children. Additionally, the study contradicts a thorough research history on depression in adults with cancer. The prevalence of depression in adults with cancer has been estimated to be as low as 4.5% but frequently as high as 50%, depending on the type of cancer, the prognosis, and additional demographic data (Craig & Abeloff, 1974). Research by Ciaramella and Poli (2001) noted that 29% of the one hundred adult cancer patients in their sample displayed behaviors that were consistent with a diagnosis of major depression. In another study by Wellisch, Kaleita, Freeman, Cloughesy, and Goldman (2002) it was determined that major depression was an appropriate diagnosis in 28% of their sample of adult brain tumor patients when simply using the DSM-IV criteria for depression as a diagnostic tool. Additionally, it is becoming widely believed that cancer patients are not routinely screened for depression as only 5% to 6% of all cancer patients are also currently prescribed any type of antidepressant medication (Stiefel, Kornblith & Holland, 1990).

Although it is conceivable that actual prevalence rates may be higher than any single study suggests, many factors have not been considered that may limit the behavioral perception of depression, such as childhood resiliency and age-related understanding of the meaning of the cancer diagnosis, as well as parental expectations that the child not engage in whining or noncompliant behavior. Perhaps the most notable obstacle to obtaining reliable prevalence rates of depression in children with cancer is that the symptoms and side effects of treatments for cancer, e.g. sleep disturbances, weight loss, lack of energy, and loss of interest in previous activities, are the same vegetative symptoms and criteria used for diagnosis of major depression. For example, fatigue and insomnia have been shown to occur in at least 40% to 50% of adult cancer patients and may be higher in younger patients (Ginsburg, Quirt, Binsburg & MacKillop, 1995; Walsh, Donnelly & Rybicki, 2000). Engstrom et al. (1999) found chronic sleep problems in 44% of a sample of one hundred fifty cancer participants. To further complicate these matters, symptoms of depression are often seen as a developmentally appropriate response to having been diagnosed with a chronic medical condition and physicians may, as a result pay little attention to the depressive symptoms of cancer patients (Kathol, Noyes, Williams, Mutgi, Carroll, & Perry, 1990).

Ultimately, studies examining depression levels in children with cancer have 1) not been thorough in their operational definition of childhood depression, 2) utilized assessment instruments that are not fine-tuned enough to support their conclusions and have obvious face validity (i.e. Children's Depression Inventory) and 3) conceptualized the causes and effects of childhood cancer in psychoanalytic or other non-verifiable theories which has muddled results. For example, studies have proposed hypotheses that cannot even be investigated scientifically (i.e. unconscious thought processes in depression), then use psychometric measures that are poorly constructed, have obvious face validity and are not sensitive so subtle changes in behavior, such as the *Beck Depression Inventory*, as well as not provide a thorough operational definition of the symptoms involved in childhood depression. Studies examining depression in children with cancer should take a multidimensional approach, collecting information from multiple sources, e.g. parents, medical staff, teachers, as well as self report information from the child to make such a determination (BASC Manual, 1998).

Research has supported that those who are active participants in the life of the child (i.e. parents and teachers) are able to play a significant role in relieving the associated stress of depression (Cleave & Charlton, 1997). It has been shown that basic behavioral parent-training for families and teachers could assist children with chronic illnesses to behave more confidently, thereby reducing the risk of further emotional and behavioral problems (Cleave & Charlton, 1997). Antidepressant medications have been used extensively with patients of other chronic diseases and there is evidence to suggest that their use may be beneficial in treating depression in young cancer patients (Stoudemire, Moran, & Fogel, 1990). The school psychologist might assume the responsibility of in-service training and consultation with parents and teachers on the topics of listening skills, identifying behavioral difficulties, educating staff members, and intervention planning at home and at school.

An area that has been examined extensively consists of identifying the prevalence rates of depression in parents of children with cancer, although there is some question as to why researchers would want to examine depression in parents of children with cancer before logically determining if depression is a factor that is related to children with cancer. Research results indicate that as many as 25% to 33% of parents will eventually develop some level of psychological difficulty as a result of their child's diagnosis (Kupst et al., 1995). Perhaps having a child diagnosed with a serious medical condition could provoke a variety of stressors in parents including, watching the child's condition deteriorate, helping the child deal with painful medical treatments and side-effects in the hospital, and battling with health care bills. The parent is infrequently screened for psychological stresses by treatment facilities (nor the child in most cases), even though there is a potential for familial contributions and a genetic basis for depression. Hoekstra-Weebers, Jaspers and Kamps (1999) sought to examine predictors of psychological maladjustment in parents of children with cancer. Their results indicated that previous anxiety was the strongest predictor of future psychopathological distress in their sample of parents. Additional predictors include the previous coping abilities of fathers, i.e. satisfaction with familial support, and for mothers the number of pleasant events experienced prior to diagnosis.

Finally, demographic variables have also been suggested as possible predictors of depression in children with cancer. These hypothesized factors include having young inexperienced parents, parents with low education, low socioeconomic status, those with no religious affiliation, and those who have multiple stressors in their lives (Barbarin & Chesler, 1986; Kupst & Schulman, 1988). Depression has also been linked to catastrophizing, especially in those who have chronic pain, which may prove to actually mediate the symptomology of depression. Sullivan and D'Eon (1990) found a relationship between catastrophizing, depression and chronic pain, and believe that catastrophizing cognitions are related to reports of increased pain and depression. Ultimately, depression in children with cancer has not received thorough examination in the school psychology literature, and more research should be undertaken to examine depressive symptoms along with anxiety and somatization.

Children diagnosed with cancer may display symptoms associated with a variety of Anxiety Disorders. The child diagnosed with cancer has the potential to experience fear and avoidance of the topic of cancer as young people are often not developmentally able to understand the meaning of the diagnosis or its ramifications upon their life. These children must also deal with a course of treatment that they may consider unusual, and at times, painful. This may be bewildering to the child or adolescent, and may be especially unnerving if they sense dread on the part of their parents. It is difficult to calculate the prevalence of anxiety disorders in pediatric cancer patients, and there are no reliable estimates of the percentage of children who experience serious anxiety symptoms. Due to a lack of research on actual population estimates, it is difficult to gage the actual number of children who experience anxiety difficulties and psychologists could be of value in providing empirically-validated treatments to assist with anxiety difficulties.

One potential anxiety-related difficulty that may be found in children with cancer is Acute Stress Disorder (ASD). ASD was introduced in the Diagnostic and Statistical

Manual of Mental Disorders- Fourth Edition (DSM-IV) as a new diagnosis regarding anxiety symptoms for up to 28 days after a traumatic event. Research has supported the use of this diagnosis in children who are hospitalized for pediatric injury (Davis, Racusin, Fleischer, Mooney, Ford, & McHugo, 2000) and this diagnosis has been useful in conceptualizing the child's fears and autonomic arousal that results from hospitalization, and avoidance of procedures that are associated with their difficulties.

Another potential diagnosis to be examined in children who experience anxiety from the cancer diagnosis is Posttraumatic Stress Disorder (PTSD). Diagnostic criteria for a diagnosis of PTSD include a) a traumatic event that is re-experienced, b) avoidance of stimuli associated with the trauma, c) the event should be outside the range of usual human experience, and d) symptoms of increased arousal as a result of the trauma (Diagnostic and Statistical Manual of Mental Disorders, 1994). Interestingly enough, PTSD is being reconceptualized to accommodate very young children diagnosed with chronic diseases, including cancer. Research by Roy and Russell (2000) has attempted to utilize developmentally appropriate diagnostic criteria for diagnosis of PTSD in very young children who have received painful treatments for cancer. Their updated criteria include a) distress at exposure to previous traumatic stimuli, b) numbing of responsiveness, c) symptoms of increased arousal, and d) new symptoms that were not seen prior to the traumatic event. Roy and Russell suggest examining young children utilizing their developmental criteria when making treatment related decisions over the DSM-IV diagnostic criteria, which may be more appropriate for adults.

Kazak et al. (1997) examined anxiety and posttraumatic stress sequelae in 130 former childhood leukemia patients and their families. Their results indicated that there were significantly more posttraumatic stress symptoms in both mothers and fathers of childhood leukemia survivors and few reports of PTSD symptoms in the children. The clinical implications of this study indicate that PTSD may not actually be a relevant diagnosis in those who are in remission with cancer, however, there is still some question as to if those who are currently in treatment with cancer may be experiencing traumatic stress. Also interesting is that this study found no long-term anxiety or avoidance behaviors in cancer survivors. This may suggest that anxiety symptoms are situation specific or disease related and may be transient versus continuous.

Additionally, Mesman and Koots (2000) found a significant disparity between teacher and child self-reports of anxiety symptoms, and only a marginal correlation between self-reports and parent reports of anxiety in a sample of 420 children with no prior psychosocial difficulties. This may serve as further evidence that anxiety symptoms may not be readily noticed by parents and teachers. This is unfortunate, and furthers the hypothesis that all children with cancer should receive routine internalizing screenings as young people with cancer may experience anxiety difficulties upon initial diagnosis, later fears of pain, treatment procedures, and dread of the unknown.

Research has supported that somatic complaints in children are very often exacerbated by negative life events that maintain symptoms (Walker, Garber & Greene, 1994). Walker et al. found that negative thought patterns concerning illness often lead to more somatic complaints, less social activity, and higher rates of depression and anxiety. Children who cope with pain and disease in a more direct, active manner i.e. using techniques such as distraction, are more likely to be socially active as a result and engage in fewer episodes of somatization (Gil, Wilson & Edens, 1997).

Research further supports that utilizing effective coping strategies on painful days results in less contacts with health care professionals, thereby making somatization a focus for prevention by health care providers (Gil, Carson, Sedway, Porter, Schaeffer & Orringer, 2000). Various studies have linked more frequent health care visits as a result of negative life events (Beautrais, Ferguson & Shannon, 1982; Boyce et al., 1977). This is important when considering the course of chronic-health conditions and the many medical procedures and hospitalizations that children with cancer face. Cancer, in and of itself, is a negative life event, and the diagnosis, social consequences and implications have the potential to exacerbate somatic complaints in children.

It is a reasonable expectation that children with cancer might engage in higher rates of somatization than their healthy counterparts, especially, in children who were diagnosed with cancer at a very young age due to the influences of early learning history. Logically, learning history dictates parental and familial interactions, and if a child believes that “sick” behaviors (laying in bed, making pained noises, crying) results in reinforcement (i.e. more parental attention, toys, avoidance of undesirable activities) then the child will be more likely to continue to engage in somatic behaviors, even in the absence of pain or disease. This could also theoretically work against the parents as well. As care-givers, they may become conditioned to attend to their children when the child displays pain behaviors, even if the child is physically doing well. Essentially, it is important to identify the processes that maintain illness somatization as they are likely to result in treatment innovations for children and families (Walker, Garber & Green, 1994).

Externalizing Disorders

Substantially less is known about the effects of externalizing difficulties than internalizing difficulties in children with cancer. To date, there has been no comprehensive research study that has sought to examine if young people with cancer engage in externalizing behavioral difficulties at a higher rate than their same-age healthy peers. Externalized behavioral difficulties have the potential to adversely affect the social life, family dynamics and academic work of the child. Academic skills have been shown as a significantly influenced area of functioning that is affected due to externalizing difficulties in children (Brown et al., 1998; Sanger, Copeland & Davidson, 1991). For example, it has been shown that pediatric oncology patient's score significantly lower on standardized academic tests than those without cancer due to a variety of factors such as off-task behavior, school-refusal and work refusal (Brown et al., 1998; Sanger, Copeland & Davidson, 1991). The causes for these difficulties may be attributed to 1) numerous absences, 2) decreased cognitive abilities due to illness, or 3) decreased motivation due to acceptance of their limitations (Sanger, Copeland & Davidson, 1991). The school psychologist should be aware of any changes in the child's total school functioning, and should be prepared to make necessary accommodations or interventions.

Psychologists should also recognize the possibility that the treatments for cancer are having adverse cognitive and externalizing behavioral effects on the child. Research has only recently begun to examine the long-term behavioral and cognitive effects of various cancer treatments, and few long-term studies exist. However, current research has supported the notion that there may be modest negative effects in cognitive functioning following central nervous system (CNS) prophylactic chemotherapy in children (Brown et al., 1998). There is also support that other diseases of the blood, (i.e. Sickle Cell Disease), may negatively affect cognitive functioning, suggesting that hematological diseases in general may yield similar results (Brown, Buchanan, Doepke, & Eckman, 1993). In light of psychology and medicine not having come to a full understanding of the long term cognitive effects of many cancer treatments, psychologists may consider monitoring the cognitive and behavioral performance of children who are going through cancer treatment protocols.

Perhaps the externalizing difficulty that shows the most need for psychosocial cancer research is attention problems in children and adolescents. Attention is a key component of academic learning, and a lack of attentional skills has been considered to be an antecedent to a variety of special education classifications, including learning disabilities and other health impairments. Additionally, teacher ratings have been scarcely utilized as measures of behavioral and academic performance in children with cancer. Research does support that teachers typically report the child with cancer to display lower levels of attentional abilities, concentration and academic progress than their healthy peers (Charlton, Pearson, & Morris-Jones, 1986). Thus, collecting data from both current and previous teachers and utilizing record reviews could be effective means in determining the difference between the pre-diagnosis and post-diagnosis attentional behavior and schoolwork of the child.

There is also evidence supporting the notion that boys diagnosed with cancer engage in a greater frequency of externalizing difficulties than girls who have a similar diagnosis, although no precise estimates of gender differences exist at this time (Sanger, Copeland, & Davidson, 1991). It has also been shown that mothers of boys with chronic illnesses see their boys as sicker than mothers of girls with chronic illness (Hill & Zimmerman, 1995), and it is feasible that boys may engage in more acting out behavior as a result of differential parent treatment. Additionally, same age peers of both boys and girls diagnosed with cancer report that these youth engage in few disruptive-aggressive behaviors (Noll, Ris, Davies, & Bukowski, 1992), but precise estimates of the types of externalizing difficulties that young people with cancer display have not been considered by any large scale study at this time. Multidimensional assessment will provide psychological researchers with more precise answers, as well as a more comprehensive understanding of the scope of externalizing difficulties in pediatric cancer patients.

Quality of Life in Adolescents Diagnosed with Cancer

The American Cancer Society (2000), sites two challenges for pediatric oncology in this century 1) "to continue progress in effectively destroying the cancer", and 2) "minimizing the impact of treatments on the child's long-term *quality of life*". One might erroneously conclude that a child will return to normal functioning simply due to an absence of disease at the end of therapy, and this false belief has been denounced through research (Mulhern et al., 1989). Although research has been dedicated to medical cancer treatments, studies have only recently begun to examine the *quality of life* of young people who have been diagnosed and living with cancer (Phipps & Srivastava, 1997; Varni, Katz, Colegrove, & Dolgin, 1994). This is an important area of research as it has been suggested that young people diagnosed with chronic medical conditions may be at an increased risk for behavioral, psychological and social adjustment problems (Wallander et al., 1988), and there is some evidence to support that early diagnosis is the best predictor to overall self reports of quality of life (Slavin, O'Malley, Koocher, & Foster, 1982).

There is some question as to how parental views of quality of life and the behavioral functioning of young people who have survived cancer are related. For instance, there is evidence to support the notion that as a child's prognosis worsens, family views of quality of life satisfaction decrease (Hunfeld et al., 2001), but Hunfeld also concluded that as cancer-related difficulties increase family members report more restrictions placed upon them, particularly related to the family members social lives, and with more adolescent reported stress. As social stress is considered an important factor in behavioral functioning, a more thorough examination of how parental views of quality of life affect behavioral functioning would serve as a valuable area of psychosocial research related to childhood cancer.

A variety of factors have been studied as contributors to quality of life in the young person with cancer, and topics such as coping abilities, attributions, and various intervention programs have received minimal examination thus far (Blount, Powers, Cotter, Swan & Free, 1994; Cleave & Charlton, 1997; Schoenherr, Brown, Baldwin, & Kaslow, 1992). Ultimately, there are many events that may contribute to positive versus negative views of quality of life including the child's prognosis, associated painful side effects, and social and interpersonal difficulties such as limb or hair loss after cancer treatments (National Cancer Institute, 2000). Children may also have continued medical conditions that are directly related to the cancer or treatments even years after their cancer has been in remission. For example, there is research to support that children who have had cancer are at an increased risk for heart difficulties when they become adults (National Cancer Institute, 2000).

Psychosocial research has attempted to focus on the self-reports of quality of life in young cancer survivors. In a study by Zebrack and Chesler (2002), the authors examined statements of 176 childhood cancer survivors aged 16-28 through the use of an examiner made self report measure. The survivors indicated that long-term side effects such as fatigue, aches, and pain negatively impacted their quality of life, and that sensing a purpose to life, the perception of positive changes since having cancer and a low occurrence of physical symptoms to be associated with a positive quality of life.

Additionally, Montgomery, Pocock, Titley, and Lloyd (2002) examined the quality of life statements of 51 adult patients with leukemia or lymphoma through the use of various rating scales. These researchers found a negatively correlated relationship between quality of life, depression and anxiety as measured by another examiner-made rating scale. Their results indicated a distinct relationship between quality of life measures and resulting behavioral internalizing difficulties that warrants further investigation.

Research has not focused on parental views of quality of life in children, and there is some value in using parental reports of quality of life versus using child self reports. For instance, young children frequently yield self reports that are poor and unreliable (LaGreca, 1983), children often under report symptoms relative to the general population (Worchel et al., 1988), and many children and adolescents receive medications or are physically ill to the point that they may not directly participate in self report measures.

One suggested method of conceptualizing the quality of life of children with cancer is to examine their varied behavioral coping styles (Phipps, Fairclough, & Mulhern, 1995). It has been suggested that those with chronic health impairments may use avoidant procedures and cognitive thought stopping of difficulties as their main mechanisms of coping with illness (Phipps & Srivastava, 1997). However, multiple sources of data gathering appear to be neglected in research related to quality of life in young people with cancer. Thus, an examination of the child's quality of life, as reported by their parents, would be of value in a more thorough understanding of behavioral functioning. The ability of the child to adapt to the cancer diagnosis and to thrive despite continued stresses and difficulties has not been thoroughly examined, and there is little data regarding what parents report as to their views of their child's quality of life.

Several studies have attempted to examine parental views of quality of life, but have been primarily parent-focused, resulting in little data on the actual children with cancer. Hoekstra-Weebers, Jaspers, Kamps and Klip (2001) sought to investigate levels of support and the concurrent and prospective effects of support for parents of children who were cancer survivors. Their results indicated that parents received the most support for themselves from others, including their child, at the initial diagnosis. They also found that perceived social support decreased over time, but that parents generally indicated that they were equally satisfied with their level of support from others.

Research has also found some evidence that pain may have an effect upon the quality of life of young people. Hunfeld et al. (2001) examined the pain diaries and quality of life self reports of one hundred twenty-eight young people aged 12-18 years who reported headache, limb, abdominal or back pain. Their results indicated that frequency and duration of pain responses to be highest when the children were in direct contact with significant caregivers, and that chronic pain had a negative impact upon quality of life within the family. The importance of this study is that the adolescents believed their families lives to be most disrupted by repeated pain episodes, and that these experiences resulted in a poorer standard of family quality of life.

One specific sub-area related to parental views of quality of life consists of research on how adolescents with cancer attribute the causes of their health-related impairments. Although doctors frequently tell parents and children that the cause of the cancer is unknown, research has supported that both parents and children very often make attributions as to the cause of the disease (Bearison, Sadow, Granowetter, & Winkel, 1993). As would be expected, patients and parents who make external types of attributions about the cancer diagnosis and related difficulties display a significantly better quality of life than those who hold internal types of attributions as to the cause of their difficulties (Bearison, Sadow, Granowetter, & Winkel, 1993). Research by Schoenherr, Brown, Baldwin, and Kaslow (1992) focused on the attributions and internalizing and externalizing psychopathology in a group of children with various chronic medical conditions. Their results indicated that attributions of cancer cause (internal or external) to be an efficient predictor of self-reports of depressive symptoms. Of interest to the school psychologist is that teachers rated several of the children as exhibiting more internalizing behaviors than other students in the class, thus leading to a hypothesis that young people with cancer may experience psychosocial difficulties based on how they view the cause of their disease and how much control that they have over it.

Finally, Aaronson (1988) has suggested three areas to encompass quality of life in young people who also have chronic diseases. These areas are 1) physical function and role restriction, 2) emotional stress, and 3) reaction to any current medical treatments. Unfortunately, research has not sought to examine these three quality of life constructs, as well as parental beliefs concerning the behavioral functioning of the adolescent with cancer. This information would provide multiple sources of data that could assist in predicting positive and negative aspects of behavioral functioning in young people with cancer.

Pain

The concept of pain has not been adequately explained as a factor involved in the behavioral difficulties in adolescents. The role of pain in adjustment and psychosocial functioning has not been closely examined, specifically with regard to the severity and duration of painful experiences, and how pain experiences contribute to the overall behavioral functioning of the child. The studies that have examined pain's relationship to behavior in adolescents have typically used constructs rooted in psychodynamic or counseling rhetoric, such as guilt, shame and feelings of self-worth that are poorly operationally defined and loosely tied to eventual behavioral difficulties and functioning (Ferguson, Stegge, Miller, & Olsen, 1999; Walker, Garber & Greene, 1994). Thus, research has not comprehensively examined the role of pain in *behavioral* adjustment, with the exception that pain serves the role of an indirect contributor to overall psychological functioning.

Although a variety of conceptualizations of pain exist in the literature (Walker, Garber, & Greene, 1993; Walker, Garber, & Greene, 1994), the prevailing model emphasizes four basic elements of a pain episode: *nociception, pain, suffering* and *pain behavior* (Fordyce, 1988). "*Nociception* is the activity produced in the nervous system by potentially tissue-damaging stimuli. This process cannot be directly observed, but is thought to occur when a tissue damaging stimulus impinges on a pain-sensitive structure" (American Cancer Society, 2000). "*Pain* is the unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage" (American Cancer Society, 2000). "*Suffering* is the perception of distress engendered by all the adverse factors that together undermine quality of life" (American Cancer Society, 2000). Pain may contribute profoundly to suffering, but numerous other factors, such as the experience of other symptoms, progressive physical impairment, or behavioral difficulties, may be equally or more important. The *pain behavior* includes all of the observable behaviors by the individual who is in pain that are in direct response to the pain.

Theoretical Reasoning for Studying Pain

Theory and research are only recently merging to the point where outcomes regarding pain associated with cancer may be examined. Due to the mistaken notion for many years that children have a lower sensitivity to pain than adults, pain was not considered a real construct for children (Elliott & Jay, 1987). Prior to this time, science interpreted children not verbalizing their pain experiences as a lack of pain perception stemming from undeveloped neural pathways in combination with high levels of resilience (Ross & Ross, 1984). As a result of this conceptualization, children with cancer-associated pain were under-medicated and not provided with necessary behavioral-health services (Gaffney & Dunne, 1986, Thompson & Varni, 1986). Recently, pain in pediatric patients has been acknowledged as a real and serious construct, and research is beginning to reflect this change in practice. For example, Rudolph, Dennig, & Weisz, (1995) suggest that outcomes related to pain should be examined through a multidisciplinary framework, through clearly defined goals, and by replacing overly simplified conceptualizations with goodness-of-fit models.

Pain Coping and Assessment

A popular conceptualization of pain coping consists of primary and secondary control coping (Weiz, McCabe & Dennig, 1994). In this model, *primary control coping* consists of one's attempt to alter the environment or the conditions in the environment that are inflicting the pain, whereas, *secondary control coping* consists of ones attempts to adjust oneself to the conditions that are inflicting pain. The remaining alternative is one of *relinquished control,* where the person makes no attempt to cope with the pain. Research has supported that the most adaptive form of coping is to focus on adjusting oneself to the events surrounding the difficulty (Weisz, McCabe & Dennig, 1994). Further research has contended that these coping constructs are closely tied to attribution theory and control-related beliefs and behaviors (Altshuler & Ruble, 1989; Bearison, Sadow, Granowetter, & Winkel, 1993; Compas, Malcarne, & Fondacaro, 1988; Weisz, 1990).

Children may choose to cope with their pain using a variety of strategies. One recently accepted conceptualization of pain coping was developed by Walker, Smith, Garber and Van Slyke (1997). Their model posits three broad coping factors 1) *Active*

Coping, which consists of such skills as problem solving, seeking out support from others and using distraction techniques, 2) *Passive Coping*, which uses strategies related to isolation, catastrophizing, and behavioral disengagement, and 3) *Accommodative Coping*, which include strategies such as acceptance, self-encouragement, minimizing or ignoring the pain. This particular model shows great promise in working with children in pain as cognitive coping strategies that are already utilized by young people in pain may be included as a component of behavioral intervention.

Perhaps one of the most widely misunderstood factors concerning pain management in children is the degree to which painful experiences affect social interaction and psychological distress (Cleeland, 1984; Ventafridda, De Conno, & Ripamonti, 1990). This is at least in part due to pain only recently being recognized as a multifaceted phenomenon that includes sensory, affective, behavioral and cognitive components (Fordyce, 1988). It has also been found that there are differences in caregiver response to children who are in pain, based on the child's gender. For instance, mothers of son's with chronic disease have been shown to view their son's as sicker and to limit their activities more than mothers of chronically ill daughters (Hill & Zimmerman, 1995).

Assessment of pain in children consists of examining the characteristics of pain and identifying the physical signs of the underlying disease or treatment that is causing the pain (Roxane Pain Institute, 1999). Although the treating physician may have numerous concerns and questions about the pain experience, the physician is usually interested initially with pain intensity, pain quality, pain distribution and temporal relationships. These characteristics yield data that the physician or psychologist will ultimately draw on to provide treatment that emphasizes pain relief. Utilizing comprehensive instruments and emphasizing a multidimensional and systematic approach will provide the primary care giver with an accurate conceptualization of the pain experience in the child, and can improve methods and results of pain management (Hester & Foster, 1992). Patient self reports have been considered as the gold standard in assessment of pain intensity, and the use of questionnaires, self reports and pain inventories can assist in facilitating communication between the child and the physician (Agency for Health Care Policy and Research, 1994; McCaffery & Ferrell, 1992).

The past 25 years have seen an assurgency in assessment instruments designed to examine the various aspects of pain management in adults and children (Mikail, Dubreuil, & D'Eon, 1993). However, it would still appear that there is little consensus on precisely which pain measures should be utilized, and for which patients. Assessment instruments have emphasized such broad areas as pain response, pain beliefs, and the impact of pain on daily life events. Typically, these assessment instruments consist of a self-report of behavior and cognition, with a few having supplemental assessment sections for other caretakers, i.e., parents, teachers and nurses.

Current Treatment Options for Children in Pain

There are a variety of treatment options available for pediatric pain. Treatments prescribed by physicians for children who are in pain typically consist of local anesthetics, general anesthetics, sedative hypnotics, and opioids. This review will, however, focus on the behavioral treatment options available as adjuncts to pain medications. Among the most widely used therapeutic techniques by psychologists for pain control are medical crisis intervention, stress inoculation/education, and cognitive-behavioral coping strategies (Jay & Elliot, 1990; Keefe, Dunsmore & Burnett, 1992; Schultz & Masek, 1996). Other techniques are available and are widely publicized, e.g. hypnosis, but are used less frequently as there is some question as to the efficacy of the outcome when compared to treatments that emphasize a behavioral component (Smith, Barabasz, & Barabasz, 1996).

Medical crisis counseling is a time-limited, clinical intervention that may be utilized with children diagnosed with cancer who are in chronic pain (Pollin, 1992). The goals for this mode of therapy are to improve the child's ability to cope with chronic illness as well as to increase the child's level of physical activity. Medical crisis-counseling originated in the early 1990's as a treatment intervention that would emphasize the specific concerns of adults who were faced with serious medical conditions. The model was later adopted for use with a variety of pediatric populations, and has been successfully utilized not only with cancer populations, but also with those who have cystic fibrosis, diabetes and multiple other chronic health conditions (Pollin, 1994). Medical crisis counseling is currently seen as an approach that has shown efficacy through its use of the biopsychosocial model, and it appears to gaining popularity in hospital and other in-patient settings (Schulz & Masek, 1996).

Another treatment option for cancer-associated pain is stress inoculation and education. Stress inoculation procedures emphasize reducing the amount of anxiety experienced by the child that will, in turn, decrease the perceived levels of pain (Jay & Elliot, 1990). By adding an educational component, the child is often able to feel more secure and in control of their cancer related experiences (McGrath, 1990). Stress inoculation typically starts with a preparation phase in which the child is included in the discussion about pain and medical procedures. Very often the child is also given a tour of the treatment room, is allowed to handle the equipment, and may be encouraged to talk to others who have undergone treatment. Parental involvement is highly encouraged in both stress inoculation and education as research supports that parental involvement may reduce pain-associated stressors (Jay & Elliot, 1990).

In recent years, Cognitive-Behavioral treatments (i.e. coping strategies) have become one of the most popular treatment modalities for children who are in chronic pain (Keefe, Dunsmore, & Burnett, 1992). This popularity is, in part, due to the empirical validity of cognitive-behavioral treatments, and is further evidenced by surveys that indicate that many practicing clinicians consider themselves to have a cognitive-behavioral orientation (Craighead, 1990). This increase in cognitive-behavioral treatments has resulted in a more thorough understanding of the social context of pain, the cognitive variables that affect pain and the link between pain and psychopathology (Keefe, Dunsmore, & Burnett, 1992).

Cognitive-behavioral interventions for children in pain have shown efficacy in the treatment of recurrent abdominal pain (Sanders, Shepard, Cleghorn, & Woolford, 1994), nonspecific abdominal pain (Sanders, Rebgetz, Morrison, Bor, Gordon, Dadds, & Shepard, 1989), and for stress reduction during painful venipuncture (Manne, Redd, Jacobsen, Gorfinkle, Schorr, & Rapkin, 1990). These treatment successes have emphasized such techniques as the simultaneous practice of ignoring pain and replacing negative thoughts with positive coping self-statements (Jensen & Karoly, 1991). It should be noted that although coping strategies may be taught in children, not all improvements are maintained after a period of three months without receiving a booster session or verbal prompts for the continued use of learned skills (Gil et al., 1996). Longitudinal studies have, however, suggested that strategies for coping with pain are stable over time if an intervention does not continue (Gil, Wilson & Edens, 1997).

Pain and Children With Cancer

Perhaps one area of study that has not received thorough attention is understanding problems surrounding pain management in children with cancer. Surveys indicate that pain is experienced in roughly one third of all cancer patients who are in active therapy, and pain is experienced by more than two thirds of those who are in advanced stages of cancer (Coyle, Adelhardt, Foley & Portenoy, 1990; Johanson, 1991; Twycross & Fairfield, 1982). It is of value to examine pain management factors in pediatric oncology as the scientific literature cites that patients in pain frequently maintain symptom complaints at higher levels and for longer periods than would normally be expected on the basis of the presenting medical condition (Casey, Ludwig, & McCormick, 1986). For example, a survey of 1,177 oncologists found that only 51% reported that their patients received adequate pain relief (Von Roenn, Cleeland, & Gonin, 1993). This supports previous research that has indicated that as many as 40% to 50% of patients fail to receive adequate pain relief (Cleeland, 1984, Portenoy, Miransky & Thaler, 1992).

A comprehensive understanding of pain associated with cancer is necessary as pain is often one of the presenting symptoms when one is initially diagnosed with cancer. Sources of pain related to childhood cancer vary. Pain connected with childhood cancer is categorized into three broad classes: 1) Disease-related pain, 2) Procedure-related pain, and 3) Treatment-related pain. Disease-related pain occurs prior to diagnosis and usually disappears upon initial treatment efforts. Disease-related pain occurs as a result of cells having been invaded by cancer material. This may result in headache, joint and bone pain, and neuropathic pain. Procedure-related pains usually result from the diagnostic procedures that accompany cancer treatment. Such invasive procedures include lumbar punctures, veni-punctures, and bone marrow aspirations. Finally, treatment-related pain is associated with the multiple cancer treatments. Such procedures as radiation therapy and chemotherapy can result in nausea, infections, and abdominal pains in the child. A study by McGrath, Hsu and Cappelli (1990) reported that 75% of cancer pain in children stemmed from bone marrow aspirations, 50% reported pain stemming from other procedures and 25% reported pain that was a by product of the disease itself.

Cancer Pain as an Indicator of Behavioral Difficulties

The concept of pain has not been adequately explained as a factor involved in the behavioral difficulties in young people with cancer. The role of pain in adjustment and psychosocial functioning have not been examined, specifically with regard to the severity and duration of painful experiences, and how pain experiences contribute to the overall behavioral functioning of the child. The studies that have examined pain's relationship to behavior in adolescents have typically tied constructs such as self esteem to eventual behavioral disturbances in functioning. Unfortunately, these constructs do not account for a significant proportion of the variance, in addition to being theoretically weak and driven by jargon (Ferguson, Stegge, Miller, & Olsen, 1999; Walker, Garber & Greene, 1994). Psychological and behavioral research has not comprehensively examined the role of pain in behavioral adjustment, with the exception that pain serves the role of an indirect contributor to overall psychological functioning.

Summary

There are a variety of factors that may contribute to positive and negative behavioral outcomes for adolescents with cancer, e.g. pain, self concept, and quality of life. An understanding of these factors and how they contribute to the behavioral functioning of a child could potentially provide psychologists and other researchers with a broader understanding of the functioning of children and adolescents with cancer. School psychologists are challenged to provide empirically validated treatment options for the difficulties experienced by children with cancer. Empirically validated treatments are the result of theories that are based upon the conceptualization of hypotheses after a careful gathering of data. Although behavioral treatments have shown effectiveness across race, class, gender, and even species there is still resistance for using behavioral strategies by many practitioners who favor pop treatment modalities or who cling to theories with no empirical basis and poor outcomes (e.g psychoanalysis). Behavioral science has not yet adequately conceptualized the many potential factors that contribute to behavioral problems and adaptive behavior in children with cancer. The most efficacious psychosocial treatments for children with cancer will be based on a grounding in behavioral science and a full conceptualization of common strengths and needs in this special population. As previously mentioned, there are a variety of factors that are thought to be involved in the behavioral functioning of children with cancer, including the presence and intensity of pain, the self concept of the child with cancer, parent reports of quality of life, and the manner in which the child copes with the cancer diagnosis and pain. These factors have been examined by a multitude of professionals, including oncologists, hematologists, social workers, pediatric nurses, and, only recently, counseling, clinical and school psychologists. At this time, however, there has been no comprehensive examination into the known and commonly researched factors that are believed to contribute to positive and negative behavioral outcomes in children. Simply, yet ironically, this is due to behavioral research not being performed by behaviorists. Previous research results have been muddled due to a lack of operational definitions related to behavioral functioning, atheoretical doublespeak, weak research designs, and instrumentation with poor psychometric properties. Objective scientists are needed to research pain, quality of life, and self concept as well as the behavioral functioning of the young person with cancer in order to plan appropriate, data-based interventions for this population.

Purpose of the Study

This study will seek to further the understanding of behavioral difficulties that are exhibited by young cancer survivors, examine potential profiles of behavioral symptoms, and further the understanding of the role of quality of life, self concept and pain coping strategies and additional factors with diagnosis of behavioral difficulties in young people with cancer. Such potential factors are measured by self report measures of coping with pain, child self report measures of self concept, as well as demographic information relating to the child, the child's illness and the child's family. It is ultimately hypothesized that reports of pain coping may assist in the prediction of adaptive behavior and behavioral maladjustment of adolescents diagnosed with cancer. This information could be utilized to further the understanding of which factors, or groups of factors most accurately contribute to predicting behavioral difficulties and adaptive behavior in children with cancer. Data on behavioral and emotional functioning will be collected from child self-report and parent report. This will assist in determining relationships between the cancer diagnosis in children, pain coping beliefs, self concept and quality of life in children diagnosed with cancer, as well as in examining the behavioral difficulties of young people with cancer.

The purpose of this study is to a) identify the types of behavioral difficulties that are exhibited by adolescents with cancer, b) assess whether adolescents utilize active, passive or accomodative strategies in their pain coping, c) assess if adolescents with cancer have a reported self concept that is lower than those without cancer, and d) identify if parents of children with cancer report similar characteristics related to quality of life.

This study will examine the impact of pain, quality of life, self concept, and demographic variables on the behavioral functioning of adolescents diagnosed with cancer. The hypotheses of this study will be examined through the use of a) various sources of behavioral and emotional functioning taken from self-reports and parent reports, the *Behavior Assessment System for Children- Self Report of Personality* and *Parent Rating Scale* (BASC-SRP and PRS), b) from self-report measures of pain response coping, the *Pain Response Inventory* (PRI), c) from a parent report of quality of life, the *Pediatric Oncology Quality of Life Scale* (POQOLS), and d) from a self-report measure of self concept, the *Multidimensional Self Concept Scale* (MSCS). This will assist in determining what relationship exists between the cancer diagnosis in children, associated behavior, pain coping beliefs, self concept and quality of life for children living with cancer.

CHAPTER III

METHOD

The purpose of this study was to examine the impact of pain coping, quality of life, self concept and the behavioral functioning of children and adolescents who are cancer survivors. The hypotheses of this study were examined through the use of various sources of behavioral functioning taken from self-report and parent report (BASC), from self-report measures of pain response coping (PRI), from parent reports of quality of life (POQOLS), and from self-report measures of self concept (MSCS). These assessment instruments assisted in determining the potential difficulties experienced by the young person with cancer, including, their associated behavior, pain intensity, pain coping beliefs, self concept and quality of life. The procedures in this study are described in terms of selection of subjects, instrumentation, research procedure and statistical analyses.

Selection of Subjects

The participants for this study were drawn from a national sample of pediatric oncology patients. Parent consent and child assent were sought by the examiner prior to data collection. An example of the parent consent form and child assent form are located in Appendix A. Due to the nature of the measures utilized for this study, participants were drawn from a sample aged 12 through 18 years old. The measures for this study have been standardized with children and adolescents. Constructs such as subjective pain experience may be difficult for children under the age of 12 to describe and measure due to limited understanding of the concept of pain, so pain measures have been used primarily with adolescents aged 12-0 to 17-11 years old. However, the majority of the measures for this study have been standardized with both children and adolescent years, thus, the instrumentation used in this study may be generalizable to the population of young people with cancer.

Potential participants were of both genders, with as much attention as possible being given to having approximately equal numbers of both genders represented in this study. Children who had a variety of cancer diagnoses were accepted, as it was hypothesized that behavioral difficulties may vary little regardless of actual diagnosis (i.e. Leukemia, Lymphoma, Central Nervous System Tumor) and that disease prognosis may be a better indicator of behavioral adjustment. Regardless, cancer-associated pain is often similar across diagnoses, e.g., nausea, fatigue, vomiting and mouth sores. The parents were asked the type of diagnosis their child has, along with the time since the diagnosis, prognosis and additional demographic data that were collected through the use of a parent information sheet.

Prior to determining the sample size, the examiner weighed numerous factors to determine the adequacy of what would constitute an adequate sample size for this particular study. When considering the potential number of variables to be examined (e.g. the many types of cancer diagnoses, the various types and ratings of pain, and the differences in behavioral difficulties that are manifested by males versus females) a large sample size in the hundreds would be the most advantageous sample size for this study. However, the pediatric oncology population is considered to be very small, and its generalizability should be considered through both statistical means as well as allowing consideration of what constitutes generalizability in such a small population.

Despite the need for such large sample sizes in a variety of studies that have been published, most researchers have found difficulties in securing robust sample sizes due to a variety of factors. For example, a study examining the cognitive effects of various treatments for Leukemia was only able to secure 47 subjects, despite the authors' affiliations with 6 major medical schools (Brown et al., 1998). Another study examining behavioral interventions for children with cancer and their parents was only able to find 23 children for their study (Mann et al., 1990). A longitudinal study by Kaplan, Busner, Weinhold and Lenon (1987) that examined depressive symptoms in adolescents with cancer used 21 childhood oncology patients. Blount, Powers, Cotter, Swan and Free (1994) were only able to locate 3 children for a study on training children with cancer to cope with painful medical procedures, and surprisingly, Carmella and Russell (2000) examined PTSD in very young children with cancer with only a single participant in their study.

There are many identifiable reasons as to why it is difficult to establish sufficient sample sizes in research on childhood cancer and pain. Most notably, childhood cancer occurs in a considerably small proportion of the general population. Also, parents of these children are often overwhelmed by frequent doctors appointments, the stress of having a child with a chronic medical condition, and difficulties in adjustment that living with cancer causes on everyday life. It is conceivable that this would result in parents wishing not to participate if they believe research is too academic or is not something that will have positive long-term effects for their child. Finally, the child's illness itself may prevent participation in research studies. Side effects of cancer are often painful, making research participation an additional burden on the child and the family.

After examining past research, it is entirely conceivable that a sample size ranging from twenty to twenty-five subjects would appear to be the norm for research with this specific of a population. The total sample (*N* = 14) consisted of ten males and four females with a mean age of 15.71 years, as well as 14 adults identified as a parent or primary family caregiver. Table 1 displays the age ranges of the participants by their gender.

Table 1

Ages of Participating Adolescents by Gender

Age	Male	Female
13 years old	1	--
14 years old	--	2
15 years old	1	--
16 years old	4	1
17 years old	4	1

Parents reported their children to have varied diagnoses, including ten (71.4%) of the adolescents diagnosed with Leukemia, two (14.3%) with CNS tumors, and two (14.3%) with lymphoma. Results of the diagnosis by gender are found in Table 2.

Table 2

Diagnoses of Participants by Gender

Diagnosis	Male	Female
Leukemia	7	3
Lymphoma	2	0
CNS Tumors	1	1

Many parents reported their child's initial diagnosis to have occurred recently, including two (14.3%) of the children being diagnosed within the last six months, two (14.3%) diagnosed within the last year, two (14.3%) received the diagnosis within the last two years, three (21.4%) were diagnosed within the last five years, and five (35.7%) received their initial cancer diagnosis over five years prior to the start of this study. Ten (71.4%) members of the sample have been identified to currently be in cancer remission. Additionally, twelve (85.7%) of the sample report that they have spent at least one night in the hospital as a result of their illness.

Only two (14.3%) of the sample are identified to have an Individualized Education Plan (IEP) that is related to their cancer diagnosis, although all fourteen subjects reported that their schools are aware of their cancer diagnosis. All fourteen children reported that they were treated differently by their peers after their cancer diagnosis with nine (64.3%) reporting that their peers were less supportive and five (35.7%) stating peers to be more supportive of them. Nine (64.3%) of the subjects reported that their school provided some assistance to them due to their cancer diagnosis, and nine (64.3%) of the students are reported to have missed 30 days or more of school as a direct result of their illness.

Instrumentation

The instruments were chosen after careful examination of their technical properties as well as their general usefulness as measures related to this particular study. The specific measures are discussed in detail below with special attention given to examining their goals, utility, and technical properties. The measures utilized in this study may be found in Appendix B.

Parental Information Sheet

The *Parent Information Sheet* is an examiner-made data collection page designed to gather basic demographic information concerning the child and the family. Questions on the parent information sheet include such demographic information such as race, gender, and age of the child, as well as questions about cancer diagnosis, such as the type of diagnosis, the time since diagnosis, and if the child is currently in remission with cancer. The purpose of the parent information sheet is to allow the examiner to study the various factors that may have an effect on responses to the ratings scales of parents, teachers and the child, as well as to provide diagnostic data participant characteristics. The *Parental Information Sheet* took approximately five minutes to complete by an adult.

Adolescent Information Sheet

The *Adolescent Information Sheet* is an examiner-made data collection page that is designed to gather basic demographic information concerning the child. Questions on the adolescent information sheet include basic demographic information related to the child's views of the disease, interactions with health-care professionals, the child's school and peers. The purpose of the adolescent information sheet is to allow the examiner to study the various factors that may have an effect on responses to the child rating scales The *Adolescent Information Sheet* took approximately five minutes to complete.

Behavioral Assessment System for Children (BASC)

The BASC is a multi-method, multi-dimensional approach to evaluating the behavior and self perceptions of children aged 4-18 years. The BASC is multi-method in that it has five components, which may be used individually or in any combination: a self-report of scale (SRP) on which the child can describe his or her emotions and self-perceptions; two rating scales: one for teachers (TRS) and one for parents (PRS), which gather descriptions of the child's observable behavior; a structured developmental history; and a form for recording and classifying directly observed classroom behavior (BASC Manual, 1992).

The BASC was normed at 116 test sites across the United States that were selected to provide for diversity of socioeconomic status, as well as diversity of region. The standardization sample consisted of 2,401 teachers for the TRS, 3,483 parents for the PRS, and 9,861 children for the SRP. The BASC authors utilized a stratified random sample, a process whereby the sample was selected to closely resemble the United States population according to the 1988 census (BASC Manual, 1992). The BASC reports scores as T-scores, with a mean of 50 and a standard deviation of 10. The BASC components utilized for this study consist of the Self-Report of Personality and the Parent Rating Scales. Each of these rating scales yields a series of Clinical Scales, Composite Scales and Adaptive Scales.

The BASC was normed for use in school systems, in private practices, at research institutions, and it is one of the most versatile instruments available to examine child and adolescent behavior (BASC Manual, 1992). It provides an abundance of data due to its multidimensional approach that examines child behavior in multiple settings with multiple raters. The BASC was utilized in this study to provide data on the behavioral functioning of the child with cancer in a variety of settings, i.e. home and community. The BASC also provided information on the adolescent's self-perceptions of behavioral functioning, which were compared with the family observations of functioning. Additional technical information may be found in the BASC Manual (Reynolds & Kamphaus, 1998).

BASC-Self Report of Personality (SRP), ages 12-18

The Self Report of Personality (SRP) consists of 186 statements that may be responded to as *true* or *false* and takes about 30 minutes to complete. It is an omnibus personality inventory that consists of composite scores for School Maladjustment, Clinical Maladjustment, and Personal Maladjustment, as well as an overall composite score that is referred to as the Emotional Symptoms Index. The SRP child and adolescent versions used in this study also consist of subscales that make up the composites. There are also several validity indexes included in the SRP including an F index, an L index that detects "faking good" and a V index that that detects invalid responses due to a variety of reasons, such as poor reading skills or poor contact with reality (BASC Manual, 1992).

BASC-Parent Rating Scales (PRS), ages 12-18

The Parent Rating Scales (PRS) assesses a variety of composite indexes including the Externalizing Problems Index, the Internalizing Problems Index, Adaptive Skills, and a Behavioral Symptoms Index. The PRS consists of 126 questions that are answered based on a 4-point scale and takes around 20 minutes to complete. The PRS consists of 10 subscales, which make up the composite scales. The PRS also utilizes an F index for validity purposes, as well as provides a series of "critical items" that may be followed up on independently (BASC Manual, 1992). The composite, adaptive and clinical scales of the BASC SRP and PRS can be found in Table 3.

Table 3

BASC-SRP and PRS Composite and Clinical Scales

Scales	Self Report of Personality	Parent Rating Scales
Composite Scales	School Maladjustment	Externalizing Problems
	Clinical Maladjustment	Internalizing Problems
	Personal Adjustment	Behavior Symptoms Index
	Emotional Symptoms Index	Adaptive Skills
Clinical Scales	Attitude to School	Hyperactivity
	Attitude to Teachers	Aggression
	Sensation Seeking	Conduct Problems
	Anxiety	Anxiety
	Depression	Depression
	Somatization	Somatization
	Atypicality	Atypicality
	Social Stress	Withdrawal
	Locus of Control	
	Sense of Inadequacy	
Adaptive Scales	Relations with Parents	Social Skills
	Interpersonal Relations	Leadership
	Self Esteem	
	Self-Reliance	

Pain Response Inventory (PRI)

The PRI is a multidimensional instrument designed to assess children's coping responses to recurrent pain. The PRI assesses 3 broad coping factors-*Active Coping, Passive Coping*, and *Accommodative Coping*, each with subscales representing specific strategies for coping with pain. The final version of the PRI contains 60 questions that are answered based on a 5-point likert type scale. The PRI provided information relating to the coping strategies utilized by the adolescents in this study, whether they utilized active coping skills, passive coping skills, or accommodative coping skills. The three second-order factors of the PRI are listed in Table 4 with their corresponding subscales.

Table 4

Factor structure of the Pain Response Inventory

Active Coping Composite	Passive Coping Composite	Accommodative Coping
Problem Solving	Behavioral Disengagement	Acceptance
Seeking Emotional/Social Support	Self Isolation	Self Encouragement
Seeking Instrumental Support	Catastrophizing	Minimizing the Pain
Using Distraction		Ignoring the Pain

The PRI was initially standardized on 3 groups; 688 children recruited through various public schools, 158 current pain patients, and 175 former pain patients. The school-based sample consisted of children aged 9 to 16 years with a mean age of (M = 11.79, SD = 1.70), and was 59% female and 41% male. The racial demographics of the standardization sample consisted of Caucasian (64%), African American (23%) and other or unknown ethnicity (13%) (Walker, Smith, Garber, & Van Slyke, 1997). Covariance structure analysis was utilized to validate the factor structure of the PRI. Confirmatory factor analysis provided support for the factor structure of the PRI, with this factor structure remaining similar in samples ranging in age from middle childhood to young adulthood. The scales were found to be internally consistent, stable, and relatively independent of each other. Means, Standard Deviations, and Reliabilities of the Pain Response Inventory are found in Table 5.

Table 5

Means, Standard Deviations, and Reliabilities of Pain Response Inventory

Composite	*M*	*SD*	Reliability
Active Coping	1.93	.70	.76
Passive Coping	1.13	.68	.64
Accomodative Coping	1.49	.80	.80

Pediatric Oncology Quality of Life Scale (POQOLS)

The POQOLS is a 21-item parent report measure for assessing the quality of life of children with cancer. Aaronson (1988) has suggested three areas to encompass quality of life in young people who have chronic diseases. These areas are 1) physical function and role restriction, 2) emotional stress, and 3) reaction to any current medical treatments. Unfortunately, research has not sought to examine these three quality of life constructs, as well as parental beliefs concerning the behavioral functioning of the young person with cancer. The questions in the POQOLS are answered based on a 7-point weighted scale that ranges from *Never* to *Very Frequently*. The instrument provides a *Total Quality of Life* Score as well as three factor scores that assess *Physical Function and Role Restriction, Emotional Stress,* and *Reaction to Current Medical Treatment.*

The POQOLS was developed during a four-phase trial consisting of an item generation phase, an item selection phase, a first-generation measure and a second-generation measure. The second-generation measure was standardized on 107 parents of children with cancer at the oncology departments and inpatient medical units of two large research hospitals. The final version of the POQOLS was factor analyzed to reveal a three-factor scale with good internal consistency reliability, consisting of Physical Functioning/Role Restriction (.87), Emotional Stress (.79), and Reaction to Current Medical Treatment (.68). The inter-rater reliability values between mothers and fathers for the three factors were .91, .87, and .75 respectively.

Validity was determined by comparing the POQOLS factors with various other instruments that might yield similar results. These instruments included the Child Behavior Checklist (CBLC), the Reynolds Adolescent Depression Scale (RADS), and the Play Performance Scale for Children (PPSC). The POQOLS factors show moderate correlations to these behavioral measures.

The authors report the POQOLS to be a strong and valid indicator of parental attitude toward child quality of life (Goodwin, Boggs, & Graham-Pole, 1994). The POQOLS will provide data on parental assessments of quality of life for their child with cancer, specifically, data on the child's physical functioning, the child's emotional stress, and the child's reaction to current medical treatments.

Multidimensional Self Concept Scale

The Multidimensional Self Concept Scale is a comprehensive assessment instrument intended to assist in the clinical evaluation of youth that are aged 9-19. The MSCS is based on a 4-point Likert type scale consisting of the responses strongly agree, agree, disagree, and strongly disagree. It may be used to examine the overall self concept of an individual, or to gain further understanding of the six primary dimensions of self concept identified by the MSCS. The MSCS is based upon a hierarchical model of self concept that presumes that the many dimensions that constitute self concept are moderately correlated, and that there is an overall self concept dimension that is generalized. The MSCS was standardized on a sample of 2,501 children enrolled in grades 5-12 at 17 sites across the United States.

The six domains of the MSCS were theoretically derived based upon research that supports that children spend time engaged in social activities (Social Scale), that they spend time in school (Academic Scale), that they spend time with family (Family Scale), and that children are aware of their physical environment (Physical Scale), that they are aware of their effectiveness in differing environments (Competence Scale) and that they display emotions in various environments (Affect Scale). It is hypothesized that all of these environments and factors contribute significantly to the overall self concept of the child. For the purposes of this study, the MSCS will provide a thorough understanding of self concept as displayed in a variety of settings by children with cancer.

Procedure

The primary investigator of this research project, a doctoral student, began an online community for parents who have adolescents with cancer. The purpose of this community was for parents and adolescents to participate in this study. The participants located this site by looking through cancer related information and message boards on the MSN network. The online community was set in place after IRB approval was gained. The website contains a message board, a list of useful psychological and cancer-related links, and pictures of the primary investigators presenting previous conference research. Upon IRB approval, the parents who logged onto the online community were provided with the principal investigator's email address and telephone number. Parents did not have to join the community to take part in the study. No identifying information of any participant was displayed on the online community relating to this study unless the parents wished to post information. If parents and their adolescents wished to participate, they called or sent a private email to the examiner. The examiner then contacted participants by phone or email to explain the study, and then mailed the informed consent letter, and informed consent was explained to the family in detail. Parental consent, as well as adolescent assent was obtained. The family then completed the rating scales. The packets were pre-organized for the convenience of the families. The families were requested to mail the forms to the examiner, in the provided self-addressed, stamped envelope as soon as possible. The script explaining the study to the parents and child is contained Appendix A. The estimated time to complete the study by the parent and child is contained in Appendix A.

Additionally, the examiner participated in his pre-doctoral internship at the University of Nebraska Medical Center (UNMC) during the 2002-2003 school year. UNMC is considered to be a major training hospital in the Mid-western United States, and medical professionals are taught in conjunction with several other medical training facilities including Children's Hospital and Clinics in Omaha and Creighton University Medical Center, each having oncology departments. Research flyers relating to this study were made available to patients seen during clinic rotations and based on patient referral. The data collection procedure remained the same regardless if subjects logged onto the website for chose to participate in person. The examiner made contacts either by email or telephone with those who logged onto the website, and in person with those who wished to participate through clinics. All data collection procedures remained the same if they logged onto the message board site. A sample flyer is located in Appendix A.

Data Analysis

A three-stage analysis procedure was constructed for the data. First, data gathered through the *Parent Information Sheet* and *Adolescent Information Sheet* was coded and loaded into the SPSS database. Second, Behavioral Assessment System for Children (*BASC)* and Multidimensional Self Concept Scale (*MSCS)* protocols were scored so that standard scores could be loaded in the SPSS database and analyses could take place on with these instruments. Third, the *Pediatric Quality of Life Scale (POQOLS)* and *Pain Response Inventory* (PRI) items were loaded into the database and transformations were made as many items required recoding to be in the same direction for the analyses that followed.

Stage I

Data gathered through the *Parent Information Sheet* and *Adolescent Information Sheet* were coded and loaded into the SPSS database for the purposes of examining demographic information for the subjects' section of the methodology chapter. Demographic variables were compiled and descriptive statistics were derived and reported to provide a more accurate conceptualization of the participants and families who chose to participate in this study.

Stage II

BASC and *MSCS* protocols were scored so standard scores could be used in the SPSS database. Mean scores and standard deviations were derived for all composite, clinical, adaptive behavior and subscales of both instruments. Scores were examined and reported based on the criteria established by the standardization sample (one standard deviation above the mean for at risk and two standard deviations from the mean for clinical significance on the BASC and one standard deviation below the mean for at risk and two standard deviations below the mean for the MSCS). Data were also examined by gender to detect differences in reported self concept for both males and females. Significant mean scores are discussed in detail. Additionally, Mann-Whitney U tests were conducted to examine mean differences between three scales on the BASC-PRS and SRP (Depression, Anxiety, and Atypicality) to determine if parents and children held similar beliefs regard the adolescents possible difficulties.

Stage III

The *Pediatric Quality of Life Scale* and *Pain Response Inventory* items were loaded into the database and transformed as items required recoding to be in the same direction for further analysis. Items were then grouped into the determined factor structures of each instrument subscale and mean scores were calculated for further analysis. Correlations were then utilized to examine overlap between quality of life ratings of the parents (POQOLS) and pain coping strategies as reported by adolescents on the PRI.

CHAPTER IV

RESULTS

The purpose of this chapter is to report the findings of the data analysis. Prior to formal data analysis, all instruments were scored and the total scores on each of the measures was summed and computed. Data was then loaded into the SPSS-11 statistical package. Screening of the data included replacing missing values on the scale items with the means or a linear estimation with nearby points. The results of this study are organized in three sections to address the hypothesized questions. In the first section the results of the Multidimensional Self Concept Scale are presented. In the second section analyses from the Behavior Assessment System for Children are presented and in the third section analyses are presented for the Pediatric Oncology Quality of Life Scale, and its relationship to the Pain Response Inventory for young people with cancer.

Hypothesis #1

The children with cancer in this study will report self concept's similar to those in the normal population, and there are no gender differences in self concept of children who have cancer.

The Multidimensional Self Concept Scale was scored for each adolescent and loaded in the SPSS database. Means and standard deviations for the sample are provided in Table 6. All means of the scales on the MSCS are observed to be in the average range and cluster around the anticipated mean of 100. Results of the Multidimensional Self Concept Scale for adolescents with cancer yield results in the average range when compared to the normative sample gathered during standardization.

Table 6

Results of Multidimensional Self Concept Scale for Adolescent with Cancer

Scale	M	SD
Social	101	04.77
Competence	99	13.61
Affect	99	12.11
Academic	95	05.46
Family	93	23.21
Physical	94	09.68
Total Score	97	13.21

The MSCS scores were each subjected to a Chi Square to answer the question of whether the sample is significantly different from the anticipated mean of 100 for each scale. Results indicated all MSCS scales to be within the anticipated range, and all subscales as well as the composite score were non-significant.

The data were then re-grouped based on gender, which yielded several scores for the female group and were observed to be significantly lower (one to two standard deviations) than their male counterparts. These areas were noted to be Competence, Family, Affect, Physical and the Total Self Concept score. These data are displayed in Table 7 and Figure 1. It should be noted that there were only four female participants in this study and the generalizability should be called into question considering this low participant size and large standard deviations for female participant scores. For instance, the Family subscale for female participants yielded a mean score of 71.25 and a standard deviation of 30.31, and the MSCS Total Score mean for females was observed to be 84.50 with a standard deviation of 17.91.

Table 7

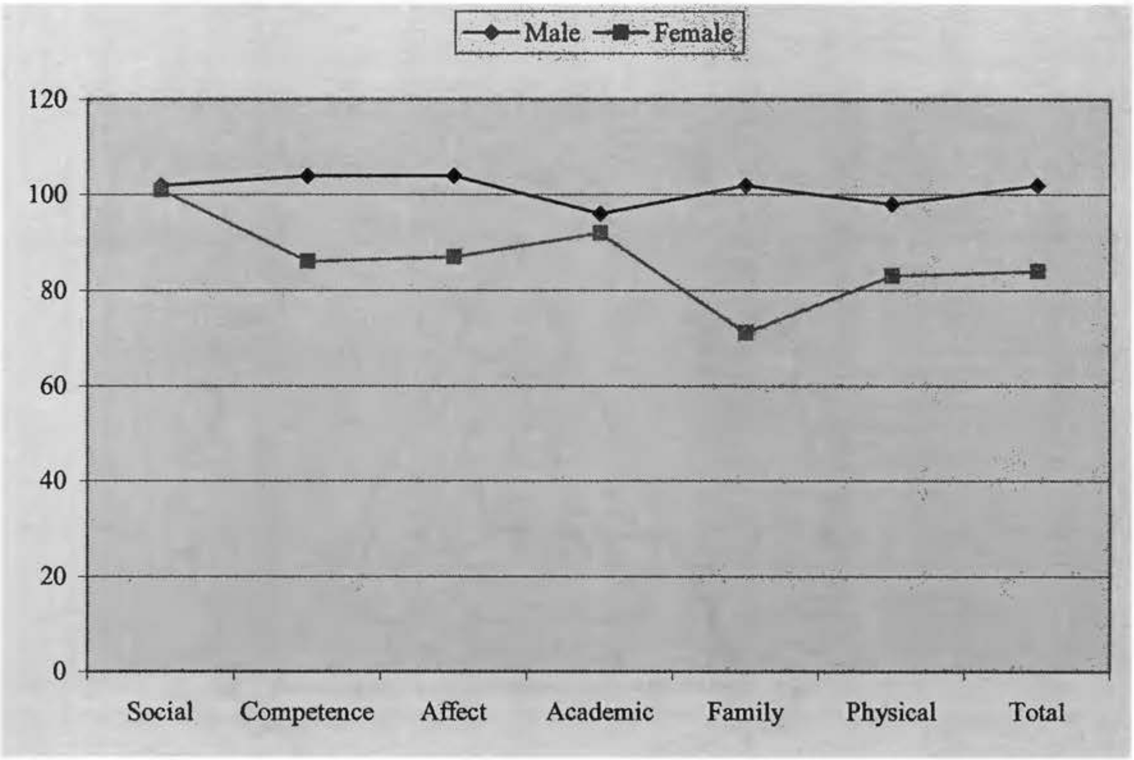
Multidimensional Self Concept Scale re-grouped by Gender

Scale	Male M	Female M	Point Difference
Social	102	101	01
Competence	104	86	18*
Affect	104	87	17*
Academic	96	92	04
Family	102	71	31*
Physical	98	83	15*
Total Self Concept	102	84	18*

Note: * indicates an observed standard deviation difference between mean scores.

Figure 1

Multidimensional Self Concept Scale re-grouped by Gender



A non-parametric test, the Mann-Whitney U test, was chosen to examine mean differences for this sample due to the small sample size. A nonparametric test was deemed appropriate as it does not make specific assumptions concerning the population distribution as there is a violation of assumptions. Thus, the Mann-Whitney U test was selected as it is the nonparametric alternative to an independent samples t-test. The Mann-Whitney U was performed on all subscales and the composite scores to detect mean differences between male and female participants in this sample. Results indicated significance for the Physical Scale, [$z = -2.63$, $p = .009$, $U = 1.5$]. Participants who were male ($M = 98.10$, $SD = 2.96$) reported higher self concept in their physical appearance than female participants ($M = 82.50$, $SD = 12.15$). Statistical significance was also observed for the Affect Scale [z = -2.35, *p* = .02 *U* = 3.5], with male participants (*M* = 104.30, *SD* = 8.49) reporting fewer affective difficulties than female participants (*M* = 87.0, *SD* = 11.58). Finally, there was a statistically significant effect on the Competence scale [z = -2.27, *p* = .02, *U* = 4.00]. Male participants (*M* = 104.86, *SD* = 12.11) reported themselves to have a higher competence self concept than female participants (*M* = 86.25, *SD* = 7.23). No significance was found for the Family, Academic, Social subscales or for the Total Self Concept Scale.

Hypothesis #2

There are no differences in selected Behavior Assessment System for Children scores on the Parent Rating Scale (PRS) and the Self Report of Personality (SRP) in children who are cancer survivors, and there are no differences between gender on the PRS and SRP in this sample.

The Behavior Assessment System for Children was scored for each adolescent and parent and loaded in the SPSS database. Means and standard deviations for the sample of parents (PRS) are provided in Table 8. Several scales on the BASC-PRS are observed to be in the at-risk range, including Aggression (T = 63) and Attention Problems (T = 61), and in the clinically significant range, Conduct Problems (T = 76). These significant scores result in an at-risk score on the Externalizing Problems Composite (T = 67).

Table 8

Results of BASC-PRS

Scale	M	SD
Externalizing Problems	67*	23.00
Internalizing Composite	53	16.34
Behavior Symptoms Index	56	20.94
Adaptive Skills	48	8.81
Hyperactivity	55	17.48
Aggression	63*	20.86
Conduct Problems	76**	32.29
Anxiety	47	11.20
Depression	53	25.36
Somatization	52	6.78
Atypicality	52	24.31
Withdrawal	46	7.83
Social Skills	49	11.67
Leadership	50	4.75
Attention	61*	22.47

Note: * At-risk, ** Clinically Significant Score

The BASC-PRS scores were each subjected to a series of Chi Squares to answer the question of whether the sample is significantly different from the anticipated mean for each scale. Results indicated a significant difference for the PRS Externalizing Composite (t (14) = 2.90; $p < .05$), with parents rating their children to display more externalizing symptoms in this study (M = 67.27, SD = 23.00) than would be expected from the Externalizing Composite (M = 50, SD = 10). There was also a significant effect for the Aggression subscale (t (14) = 2.38; $p < .05$). Parents rated their children (M = 62.87, SD = 20.86) as displaying more difficulties with aggressive behavior than the anticipated mean (M = 50, SD = 10). Finally, there was a significant effect for the Conduct Problems subscale (t (14) = 3.15; $p < .05$), with parents rating their adolescents (M = 76.27, SD = 32.29) to have more difficulties with conduct than would be expected from the BASC-PRS mean score (M = 50, SD = 10). No additional significance was found for the BASC-PRS. The data was then re-grouped based on gender, which yielded several scores for the female group that were substantially higher than their male counterparts. This data is shown in Table 9 and Figure 2.

Table 9

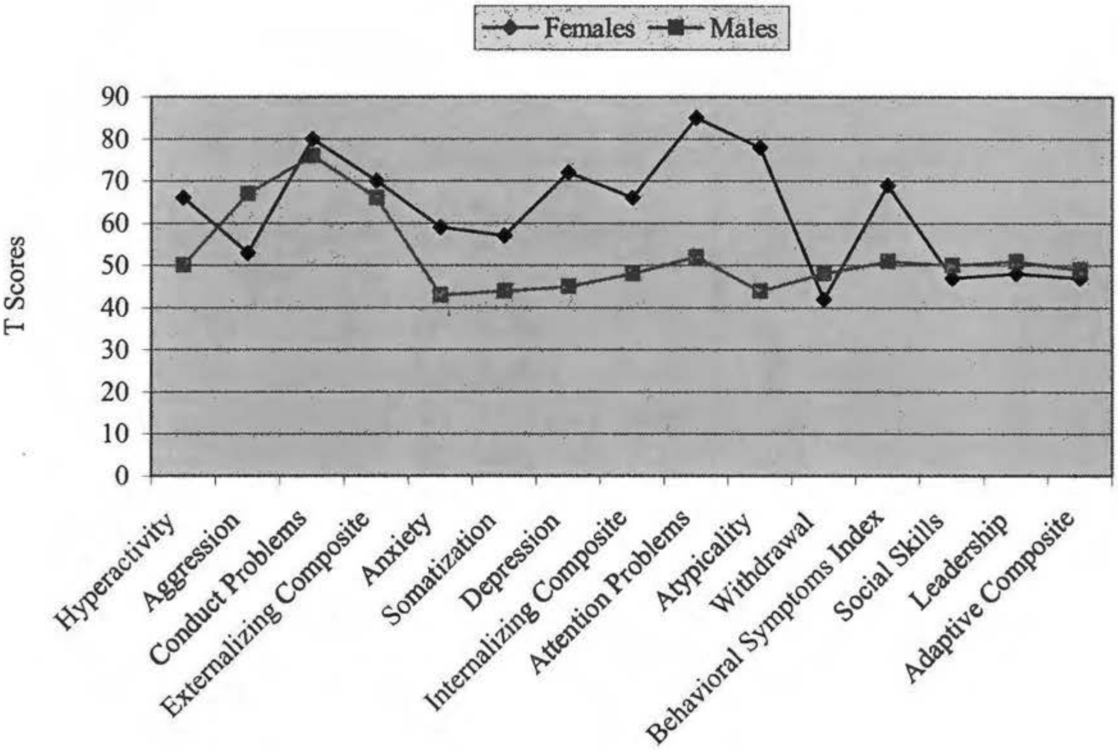
BASC-PRS by Gender

Scale	Male M	Female M
Externalizing Problems	66*	70**
Internalizing Composite	48	66*
Behavior Symptoms Index	51	69*
Adaptive Skills	49	47
Hyperactivity	50	66*
Aggression	67*	53
Conduct Problems	76**	80**
Anxiety	43	59
Depression	45	72**
Somatization	49	57
Atypicality	44	78**
Withdrawal	48	42
Social Skills	50	47
Leadership	51	48
Attention	52	85**

Note: * = At-risk range, ** = Clinically Significant range

Figure 2

BASC-PRS by Gender



Each subtest was submitted to further statistical analysis through the use of the Mann-Whitney U statistic. There was a statistically significant effect for gender on the Attention scale [z = -1.92, *p* = .05, U = 6.5], with females (*M* = 84.75, *SD* = 31.46) displaying more symptoms consistent with attention difficulties than their male counterparts (*M* = 52.10, *SD* = 7.82). The Somatization scale also displayed a significant main effect with regard to gender [z = --2.46, *p* = .05, U = 3.0]. Male participants (*M* = 49.10, *SD* = 7.00) displayed fewer symptoms of somatization difficulties than female participants (*M* = 57.00, *SD* = 1.15), although both the male and female scores are within the average range on the BASC. Finally, the Internalizing Composite yielded significance [z = -2.27, *p* = .02, U = 4.0]. Female participants (*M* = 66.25, *SD* = 21.65) are reported by their parents to display more Internalizing Problems than their male counterparts (*M* = 47.80, *SD* = 11.00) No significance was observed between males and female participants on any other BASC-PRS scales.

Next, BASC-SRP mean scores were calculated. The BASC-SRP yielded no scores in the at-risk or clinically significant range. Results of the BASC-SRP for adolescents with cancer yielded results that cluster around the expected mean (T = 50). Results of the BASC-SRP are found in Table 10.

Table 10

Results of BASC- Self Report of Personality

Scale	M	SD
School Maladjustment	49	11.81
Clinical Maladjustment	48	13.34
Personal Maladjustment	52	09.41
Emotional Symptoms Index	46	07.09
Attitude to School	50	09.81
Sensation Seeking	52	15.15
Atypicality	45	16.23
Locus of Control	47	11.17
Social Stress	43	07.10
Anxiety	51	07.03
Depression	50	08.32
Sense of Inadequacy	48	09.21
Relations with Parents	50	13.48
Interpersonal Relations	56	02.03
Self Esteem	54	07.15
Self Reliance	55	04.44

The BASC-SRP scores were then each subjected to a series of chi-squares to answer the question of whether the sample is significantly different from the anticipated mean for each scale. Results indicated all BASC-PRS scales to be within the anticipated range, and all subscales as well as the composite scores are non-significant. The data was then re-grouped based on gender, which yielded several scores for the female group that were in the at-risk range. These data are displayed in Table 11 and Figure 3.

Table 11

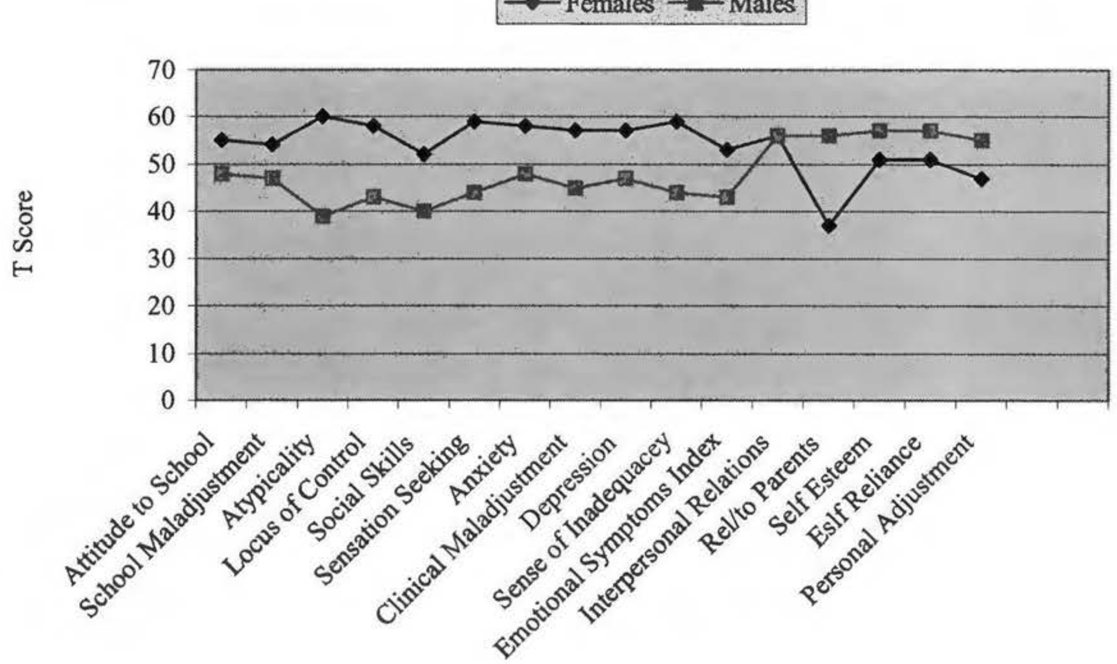
BASC-SRP by Gender

Scale	Male M	Female M
School Maladjustment	47	54
Clinical Maladjustment	45	57
Personal Maladjustment	55	47
Emotional Symptoms Index	43	53
Attitude to School	48	55
Sensation Seeking	50	58
Atypicality	39	60*
Locus of Control	43	58
Social Stress	40	52
Anxiety	48	58
Depression	47	57
Sense of Inadequacy	44	59
Relations with Parents	56	37*
Interpersonal Relations	56	56
Self Esteem	57	49
Self Reliance	57	51

Note: * = At-risk range, ** = Clinically Significant range

Figure 3

BASC-SRP by Gender



Composite scores were initially selected for further analysis. The Mann-Whitney U test was selected to examine mean differences for this sample due to the sample size and results indicated no significance for any of the composite scores. The Mann-Whitney U was performed on several additional subtests that were chosen for further statistical analysis. There was statistical significance on the Relationship with Parents scale with regard to gender [z = -1.99, p = .04, U = 6.0). Participants who were male (*M* = 55.90, *SD* = 2.42) reported fewer difficulties with their parents than female participants (*M* = 36.75, *SD* = 20.50). No significance was observed between males and female participants on any of the other BASC-SRP scales.

Finally, Several BASC-PRS and SRP scales are reported to examine similar constructs across instruments (Depression, Atypicality, and Anxiety). Each of these scales was subjected to further analyses to determine if there are differences between raters (self report vs. parent report). Table 12 displays the cell means and standard deviations of the selected BASC-PRS and SRP scores.

Table 12

Selected BASC PRS and SRP Scales for Cross Comparison

BASC Scale	PRS	SRP
Anxiety	47 (11.20)	51 (7.03)
Depression	53 (25.36)	50 (8.32)
Atypicality	52 (24.31)	45 (16.23)

Note: Scores are reported as means over standard deviation.

A correlation matrix was examined using a Pearson correlation coefficient as data points are measurement in nature versus ordinal or nominal. The selected scales resulted in moderate to high correlations, and most of the scales appeared to highly cross-load on other BASC scales. Results indicate moderate to very strong correlations between BASC-SRP results and BASC-PRS results. Results of the correlation between the BASC-PRS and SRP selected scales are found in Table 13.

Table 13

Correlation Matrix of Selected BASC-PRS and SRP scales

	PRS-Atypicality	PRS-Depression	PRS-Anxiety
SRP-Atypicality	.98	.96	.95
SRP Depression	.93	.83	.75
SRP-Anxiety	.98	.89	.92

<u>Hypothesis #3</u>

There is no relationship between adolescent pain coping type (PRI) and parental measures of quality of life (POQOLS).

The Pain Response Inventory (PRI) and Pediatric Oncology Quality of Life Scale (POQOLS) were subjected to reliability analyses. Additionally, a correlational analysis was computed for both of these instruments.

Upon completion of data collection, items from the Pain Response Inventory (PRI) were number coded for entry into an SPSS-11 database, which was the statistical computer package utilized for further analysis of the PRI. Scores on the PRI scale were coded from 0 = Never to 4 = Always. Reverse coded items were determined *a priori* and used throughout the analyses of the scores. Because of the low incidence of questions not answered, missing values within the data set were replaced with the mean of that variable. Summary statistics and internal consistency reliability estimates were calculated for the overall PRI scale. The three components are identified by the PRI authors to be <u>Active Coping</u> (Factor 1 = 25 items), <u>Passive Coping</u> (Factor 2 = 15 items), and Accommodative Coping (Factor 3 = 16 items). Five questions from the PRI scale (2, 12, 22, 40, and 50) are not suggested by the authors to be utilized in the analysis as they are purported to measure Stoicism, a construct that loads on all three components of the scale. The Active Coping Scale total mean score was 41.36 with a standard deviation of 14.73. The Passive Coping Scale total mean score was 19.86 with a standard deviation of 9.57. The Accommodative Coping Scale total mean score was 23.64 with a standard deviation of 7.60.

Reliability analyses were then undertaken for the PRI. The Pain Response Inventory for this sample yielded low internal consistency as measured by a standardized Cronback Alpha ($\alpha = .57$). Despite low overall reliability for the PRI with this sample due to few participants, the original proposed three-factor solution (Active, Passive, and Accommodative Coping) was again utilized for further analysis, as it was the expected and anticipated solution for the hypothesis of this study, and the PRI is reported to have strong reliability indices based on the standardization sample. Data were then transformed into a correlation matrix to examine potential overlap between the three proposed factors. Results of the component correlations are in Table 14.

Table 14

Component Correlation Matrix for Pain Response Inventory

Component	1	2	3
1	1.00	-.11	.22
2		1.00	.31
3		.	1.00

Note: Component 1 = Active Coping; Component 2 = Passive Coping; Component 3 = Accommodative Coping.

Results indicate low correlations between the three hypothesized constructs of the PRI indicated different constructs being measured by each factor. Items included in the resulting factors were analyzed with respect to each item's ability to discriminate between respondents and the item's correlation with the total of all other items within its factor.

The Pediatric Oncology Quality of Life Scale (POQOLS) was then number coded for entry into the SPSS-11 database for specific analysis. Scores on the POQOLS scale were coded from 1 = Never to 7 = Very Frequently. Reverse coded items were determined *a priori* and used throughout the analyses of the scores. Because of the low incidence of questions not answered, missing values within the data set were again replaced with the mean of that variable. Summary statistics and internal consistency reliability estimates were calculated for the overall POQOLS scale. The three components are identified by the POQOLS authors to be <u>Physical Functioning</u> (Factor 1 = 9 items), <u>Emotional Distress</u> (Factor 2 = 6 items), and <u>Reaction to Medical Treatment</u>

(Factor 3 = 5 items). The Physical Functioning Scale total mean score was 35.36 with a standard deviation of 6.09. The Emotional Distress Scale total mean score was 18.14 with a standard deviation of 9.64. The Reaction to Medical Treatment Scale total mean score was 17.78 with a standard deviation of 9.01.

Reliability analyses were then undertaken for the POQOLS. The Pediatric Oncology Quality of Life Scale for this sample yielded moderate internal consistency as measured by a standardized Cronback alpha ($\alpha = .71$). Data were then transformed into a correlation matrix to examine potential overlap between the three proposed factors. Results of the component correlations are in Table 15.

Table 15

Component Correlation Matrix for Pediatric Oncology Quality of Life Scale

Component	1	2	3
1	1.00	.01	.28
2		1.00	.93
3			1.00

Note: Component 1 = Physical Functioning; Component 2 = Emotional Distress; Component 3 = Reaction to Medical Treatment.

Results indicate low correlations between the hypothesized constructs of the POQOLS with the exception of component 2 (Emotional Distress) and component 3 (Reaction to Medical Treatment) which yielded a strong correlation at .93.

In a similar fashion to the PRI, the POQOLS displayed low overall reliability with this sample due to the study having few participants. The original proposed three-factor solution (Physical Restriction, Emotional Distress, Reaction to Medical Treatment) was utilized in further analysis, as it was the expected solution for the hypothesis of this study, and the POQOLS is reported to have strong reliability indices in the standardization sample as well as strong construct validity when measured against other commonly used behavior rating scales.

Next, the Pain Response Inventory (PRI) and Pediatric Oncology Quality of Life Scale (POQOLS) were subjected to a Pearson correlation to examine if the parent views of quality of life and adolescent views of pain coping were related. Results indicated a moderate inverse correlation between Passive Coping and Physical Functioning (-.67). indicating that parental views of positive physical functioning to be correlated with low adolescent use of passive coping strategies. There was also a moderate inverse correlation between parental reports of high adolescent emotional distress and low use by adolescents of active coping strategies (-.54). Results of the PRS and POQOLS correlations are provided in Table 16.

Table 16

Correlations between PRI and POQOLS Scores

	Physical Functioning	Emotional Distress	React to Medical Treatment
Active Coping	.21	-.54*	-.34
Passive Coping	-.67*	.45	.23
Accommodative Coping	-.09	-.19	-.21

Note: * indicates moderate correlations at $p < .03$.

CHAPTER V

DISCUSSION

This chapter presents a general summary including the purpose, overview with subjects, procedures, and findings of the study. The chapter then discusses the implications of the findings, limitations of the study and makes recommendations for future research.

Summary

The American Cancer Society (2000, p. 4), sites two challenges for pediatric oncology in this century 1) “to continue progress in effectively destroying the cancer”, and 2) “minimizing the impact of treatments on the child’ long-term *quality of life*”. One might erroneously conclude that a child will return to normal functioning simply due to an absence of disease at the end of therapy, and this false belief has been de-emphasized through research (Mulhern et al., 1989). Cancer in children continues to be a serious behavioral and psychosocial issue despite medical advances that are saving children’s lives now more than ever before. The quality of life and social functioning of these children has only recently begun to gain the national attention of school psychologists as professionals are encountering children with cancer in the educational system. At this time there are few studies and little empirical evidence for behavioral treatments available for this special population. Cancer is now being seen more as a serious, potentially life-threatening condition that children are living with, rather than the fate-sealing disease that it was thirty years ago. Little is known concerning what the lives of young cancer survivors are like. No one is certain of the strengths and unique challenges of the young person with cancer. Behavioral research is needed to focus on the exceptional needs that these young people present. The life of the child must go on.

The purpose of this study was to further the understanding of behavioral difficulties that are exhibited by adolescents with cancer, examine potential profiles of behavioral symptoms, and further the understanding of the role of quality of life, self concept, and pain coping strategies in young people with cancer. Such potential factors were assessed by self-report measures of coping with pain, child self-report measures of self concept, as well as demographic information relating to the child, the child's illness and the child's family. It was ultimately hypothesized that reports of pain coping would assist in furthering the understanding of adaptive behavior and behavioral maladjustment of adolescents diagnosed with cancer. This information could be utilized to further the understanding of which factors, or groups of factors most accurately contribute to predicting behavioral difficulties and adaptive behavior in children with cancer. Data on behavioral and emotional functioning was collected from child self-report and parent report. This assisted in determining the specific behavioral difficulties exhibited by young people with cancer. Additionally, pain coping beliefs, self concept and quality of life in children diagnosed with cancer, as well as gender effects were used to understand behavioral outcomes.

The purpose of this study was to: a) identify the types of behavioral difficulties that are exhibited by adolescents with cancer; b) assess whether adolescents utilize active, passive or accomodative strategies in their pain coping; c) assess if adolescents with cancer have a reported self concept that is lower than those without cancer; and d) identify if parents of children with cancer report similar characteristics related to quality of life.

In essence, this study examined the impact of pain coping, quality of life, self concept, and demographic variables along with the behavioral functioning of adolescents diagnosed with cancer. The hypotheses of this study were examined through the use of: a) various sources of behavioral and emotional functioning taken from self-reports and parent reports, the *Behavior Assessment System for Children- Self Report of Personality* and *Parent Rating Scale* (BASC-SRP and PRS); b) from self-report measures of pain response coping, the *Pain Response Inventory* (PRI); c) from a parent report of quality of life, the *Pediatric Oncology Quality of Life Scale* (POQOLS); and d) from a self-report measure of self concept, the *Multidimensional Self Concept Scale* (MSCS). This assisted in determining what relationship exists between the cancer diagnosis in children, associated behavior, pain coping beliefs, self concept and quality of life for children living with cancer.

Overview of the Study

The primary investigator of this research project, a graduate student, began an online community for parents who have children and adolescents with cancer. The purpose of this community was to recruit parents and adolescents to participate in this study. The participants located this site by looking through cancer related information and message boards on the MSN network. The website contains a message board, a list of useful psychological and cancer-related links, and pictures of the primary investigators presenting previous conference research. If parents and their adolescents wished to participate, they called or sent a private email to the examiner. Parental consent, as well as adolescent assent was obtained. The family then completed the rating scales. The packets were pre-organized for the convenience of the families. The families were requested to mail the forms to the examiner, in the provided self-addressed, stamped envelope as soon as possible. Additionally, research flyers relating to this study were made available on message boards at various community organizations. The data collection procedure remained the same if parents picked up a flyer and wished to participate, with the parents contacting the examiner by email or by telephone.

The participants for this study were drawn from a national sample of pediatric oncology patients. Parent consent and child assent were sought out by the examiner prior to data collection. Due to the nature of the measures utilized for this study, participants were drawn from a sample aged 13 through 18. Potential participants were of both genders, with as much attention as possible given to having approximately equal sizes of both genders represented in this study. Children who had a history of a variety of cancer diagnoses were accepted. It was hypothesized that behavioral difficulties may vary little regardless of actual diagnosis (i.e. Leukemia, Lymphoma, CNS tumors) and that disease prognosis may be a better indicator of behavioral adjustment. The parents were asked what type of diagnosis their child has, along with the time since the diagnosis, prognosis and other demographic data that was collected through the use of a parent information sheet. After examining past research it was noted that sample sizes ranging from one to twenty subjects appeared to be the norm for research with this specific of a population. The researcher of the current study made every effort possible to obtain a sample size that would adequately reflect the hypotheses of this study and affect the generalizability of this study in an advantageous manner.

The total sample (*N* = 14) consisted of ten males and four females with a mean age of 15.71 years and 14 adults identified as a parent or primary family caregiver. Parents reported their children to have several diagnoses, including ten (71.4%) of the adolescents with Leukemia, two (14.3%) with CNS Tumors, and two (14.3%) with lymphoma. Children were identified as having a varied times since initial diagnosis including two (14.3%) of the children being diagnosed within the last six months, two (14.3%) diagnosed within the last year, two (14.3%) received the diagnosis within the last two years, three (21.4%) were diagnosed within the last five years, and five (35.7%) received the initial cancer diagnosis over five years prior to the start of this study.

Summary of Findings

The ensuing considerations are appropriate in light of current research findings. The results of the statistical analyses are summarized as follows:

Hypothesis #1

The children with cancer in this study will report self concept's similar to those in the normal population, and there are no gender differences in self concept of children who have cancer.

Substantive Question #1

Do the children with cancer in this study display differences in self concept from those in the normal population, and are there gender differences in self concept of children who have cancer?

The Null Hypothesis is rejected. There were no overall significant scores on the MSCS for young people with cancer. However, it was observed that females participating in this study appeared to have significantly lower self concept scores upon regrouping by gender. Additionally, there were significant effects for several scores on the MSCS based on gender. Upon further examination of these scores, however, it is observed that several of the female participants appear to have active cancer or active cancer recently, which would account for lower scores related to self concept and may better explain their lower scores even in light of the statistically significant gender differences. Additionally, there were fewer female participants than male subjects and females who had outlying scores could push the group mean into the significant range. This is especially true when examining the large standard deviations from the female participants scores.

Hypothesis #2

There are no differences in selected Behavior Assessment System for Children scores on the Parent Rating Scale (PRS) and the Self Report of Personality (SRP) in children who are cancer survivors, and there are no differences between gender on the PRS and SRP in this sample.

Substantive Question #2

Are there differences in selected Behavior Assessment System for Children scores on the Parent Rating Scale (PRS) and the Self Report of Personality (SRP) in children who are cancer survivors, and are there differences between genders on the PRS and SRP in this sample?

The Null Hypothesis is rejected. On the BASC-PRS several scores were observed to be in the at-risk or clinically significant range (Conduct Problems, Attention Problems, Aggression) that contribute to a significant score on the Externalizing Composite. The bulk of previous research to date has focused primarily on internalizing disorders in young people with cancer and externalizing problems have been largely ignored. Given this research history it is surprising that parents identified numerous externalizing problems with their children and, yet, they identified no internalizing difficulties. When the PRS was regrouped by gender there are only a few overlapping difficulties between males and females (Conduct Problems and the Externalizing Composite), but there are numerous additional difficulties identified for females (Hyperactivity, Depression, Atypicality, and Attention Problems) which result in several significant composite scores (Internalizing Composite and the Behavioral Symptoms Index). Further analyses resulted in several significant effects for gender differences across the PRS (Aggression and Conduct Problems). However because of the sample limitations the findings can not be generalized to the population of young people with cancer.

The BASC-SRP yielded no overall at-risk or significant scores. However, when the SRP was re-grouped based on gender, at-risk scores are observed for Atypicality and

Relationship to Parents in the female participants. Further analyses yielded differences for the Relationship to Parents subscale. Again, as nonparametric analyses were used, these results may not be reflective of actual gender differences in the population.

Finally, several constructs (Depression, Atypicality, and Anxiety) are purportedly measured by both the BASC-PRS and SRP. These scales were subjected to correlations which indicate a great deal of overlap between identified constructs between instruments. Additionally, each of these internalizing scales was observed to correlate with similar internalizing constructs as expected.

Hypothesis #3

There will be no relationship between adolescent pain coping type (PRI) and parental measures of quality of life (POQOLS).

Substantive Question #3

Is there a relationship between adolescent pain coping type and parental measures of quality of life?

The Null Hypothesis is rejected. However, the factor structures for Pain Response Inventory and the Pediatric Oncology Quality of Life Scale did not hold true for this sample. Additionally, reliability for the three-factor solution of each instrument, as determined by Cronbach's alpha was observed to be modest to poor. Each instrument is purported to yield a three factor solution, yet reliability analyses resulted in an alpha in the moderate range, suggesting the scale for this sample is only marginally internally consistent. The hypothesized three-factor solution was utilized in further analysis and both the POQOLS and the PRI are reported to have strong reliability and validity indices and the lack of goodness-of-fit for this sample is believed to be a result of small subject size.

Finally, the Pain Response Inventory (PRI) and Pediatric Oncology Quality of Life Scale (POQOLS) were subjected to a Pearson correlation to examine if the parent views of quality of life and adolescent views of pain coping are related. Results indicated a moderate inverse correlation between Passive Coping on the PRI and Physical Functioning on the POQOLS indicating that parental views of positive physical functioning are correlated with low adolescent use of passive coping strategies. There was also a moderate inverse correlation between parent reports of high adolescent emotional distress on the POQOLS and low use by adolescents of active coping strategies on the PRI. However, no overall relationship was observed between the PRI and the POQOLS indicating that adolescent coping strategies are not substantially correlated with their parents views of their quality of life.

Implications of the Study

Perhaps the most notable implication for this research study and for studies such as this are related to the child's return to school after diagnosis and treatment. The return to school may present much apprehension and dread on the part of the child with cancer. The student may withdraw socially, academic functioning may decrease, and they may have emotional and behavioral difficulties that could negatively affect their medical condition, further social relationships and future academic work. This was the case for the fourteen participants of this study who reported that they were treated differently by their peers after their cancer diagnosis, with nine (64.3%) reporting that their peers were less supportive and five (35.7%) stating peers to be more supportive of them. Additionally, only two (14.3%) of the sample are identified to have an Individualized Education Plan (IEP) that is related to their cancer diagnosis, even though all fourteen subjects reported that their schools are aware of their cancer diagnosis. However, nine (64.3%) of the subjects in this study reported that their school provided some assistance to them due to their cancer diagnosis and treatment.

The role of the school in preparing for the child's return after the student has missed many school days has received little focus in the scientific literature. This is unfortunate when considering that children have cited that the most difficult part of their cancer experience is the return to school (Chekryn, Deegan, & Reid, 1986). Although research in school psychology has provided little focus on the child's return to school, ironically, much of the pediatric oncology research to date has focused on the nurse's role in preparing the child to return to school and to pre-morbid social functioning (Chekryn et al., 1986; McCormick, 1986). When considering the background and training of doctoral level school psychologists, they appear to be a natural liaison between the hospital and the school in assisting the child in re-entering the school.

Often the child with cancer will have to take extended or frequent absences due to medical appointments or hospitalizations for treatment. Nine (64.3%) of the students participating in this study are reported to have missed 30 days or more of school as a direct result of their illness

Depending on the duration and frequency of absence, a process of normalizing may be necessary for the child's return to school. Although the child's environment and life circumstances may have changed drastically over the course of cancer treatment, life at the school has probably changed little during this time, resulting in an environment that may not suite the particular needs of the child with cancer. The child may face a host of difficulties upon returning from even a relatively short absence from school. Academic, social and peer functioning may be seriously affected in a variety of forms.

As school is the environment where children practice socialization, children with newly diagnosed cancer are encouraged to return to school and their pre-morbid social experiences as soon as possible. Research, however, has shown that lower-perceived social support from classmates may increase the risk for psychopathology in the child with cancer and may result in avoidance behavior on the part of the child (Varni et al., 1994). Varni and colleagues, (1993) have suggested that children newly diagnosed with cancer should receive training in social skills such as problem solving, assertiveness training, and how to handle situations where they may be teased. They found that children who receive social-skills training report higher perceived classmate and social support.

Educating students and school personnel on information related to cancer has increasingly been seen to be of value in recent years (McCormick, 1986; Sachs, 1980). Perhaps one reason for educating school faculty is the increased understanding of social acceptance as a developmental factor in both young children and adolescents. McCormick (1986) suggests a three part program for the re-entry of the child to the school that consists of preparing both the child and school personnel for the child's return, a classroom presentation, and a program follow-up. The preparation of the faculty sets the tone for how the children will accept the child with cancer. It has been shown that the teacher's knowledge of childhood cancer and comfort in discussion influences the outcome of the child in the classroom either positively or negatively (McCormick, 1986).

School psychology has focused little on the range of behavioral difficulties exhibited by children with cancer. Behavioral research is an important venue of study as psychosocial functioning at home has long been assumed to affect school behavior. Furthermore, cooperation between the child's parents, the school, the cancer treatment facility and additional services may be the most helpful course of action for young people with cancer. The need for continued behavioral research and empirical treatment for students with cancer is becoming a necessity due to a lack of needed specialized services. Data from this study suggests that adolescents may engage in externalizing disorders more frequently than internalizing disorders. Behavior intervention cannot happen until researchers have a firm understanding of the specific types of psychosocial difficulties that are displayed by adolescents with cancer.

Research should also be concerned with the role of self concept and how self concept contributes to the behavior of adolescents diagnosed with cancer. Self Concept has only recently been explored as a potential predictor of behavioral functioning in patients with cancer. Self concept has been previously found to be a factor that predicted behavioral adjustment and life satisfaction in adult cancer patients. Previous results have also indicated that those with a positive self concept are more likely to display less symptoms that are associated with common internalizing difficulties such as depression and anxiety. It is difficult to gain a comprehensive understanding of how cancer impacts one's behavior without also examining a factor such as self concept, which has been shown to affect behavioral functioning. Results of this study indicate that reported self concept by adolescents appears to be in the expected average range when comparing these young people to those who participated in the standardization sample. However, when examining self concept by gender, females in this sample are observed to have significantly lower scores in several self concept areas including competence, physical, and family, which contributes to scores that are one standard deviation below the expected mean. If this is the case, females with cancer should be targeted for assessment an interventions related to their self concept and self perceptions, especially, as cancer may have adverse effects upon family relationships, beliefs about one's physical functioning, and overall competence.

This study also sought to examine if young people with cancer display similar behavioral "profiles" as other children with cancer, if they engage in more or less internalizing or externalizing behaviors versus those who do not have a cancer diagnosis, and if there are specific DSM-IV diagnoses that are more likely to occur in young people who have cancer. The results of the behavioral ratings taken in this study indicate that parents report their adolescents to display difficulties related to externalizing problems rather than internalizing problems. Specifically they rated their children to have troubles with aggression, conduct problems and attentional difficulties. Additionally, when parent ratings of child behaviors are divided by the gender of the adolescent, more problems were evident for female participants (externalizing and internalizing problems, including hyperactivity, conduct problems, depression, atypicality and attention difficulties) than for male participants (externalizing problems such as aggression and conduct problems). Conversely, adolescents did not report many difficulties with externalizing or internalizing problems in their behavior rating scales, even when scores were controlled for gender.

The extent that pain affects psychosocial functioning in children with cancer has yet to be thoroughly examined by behavioral researchers, but was initially addressed in this study. The primary reason science has not systematically examined pediatric pain is due to the mistaken notion for many years that children have a lower sensitivity to pain than adults. This study examined if cancer associated pain coping type and the quality of life of pediatric oncology patients were related. Pain-related coping skills in children have been identified as an area of needed research. Coping skills may also be a potential predictor of behavioral functioning in children with cancer. Pain coping was operationalized through the prevailing model that emphasizes three basic strategies. This conceptualization of pain coping was developed by Walker, Smith, Garber, and Van Slyke (1997). Their model posits three broad coping factors 1) *Active Coping*, which consists of such skills as problem solving, seeking out support from others and using distraction techniques, 2) *Passive Coping*, which uses strategies related to isolation, catastrophizing, and behavioral disengagement, and 3) *Accommodative Coping*, which include strategies such as acceptance, self-encouragement, minimizing or ignoring the pain. Behavioral research has questioned if quality of life is related to cancer-pain coping skills in children. It would appear that the intrusiveness of the disease itself would mediate in the psychosocial abilities of the family members. For instance, it has been suggested that young people with chronic health conditions may use avoidant procedures as their main cognitive coping strategies, and this study appears to support that conclusion. There is evidence to support the notion that the use of active coping strategies are related to reduced emotional stress. It could be extrapolated that as cancer-related difficulties increase, family members report more restrictions placed upon them, particularly related to the family members social lives, and with more adolescent reported behavioral, psychosocial and coping difficulties.

Finally, the school psychologist is best suited to provide direct service for these children. The extensive practice and research base of the school psychologist enables a multi-factored assessment and treatment approach for these children that they will receive at no other treatment facility, either public or private. Although the school psychologist may not have specialized training in treating children with serious medical conditions, they have a working knowledge of behavioral interventions. The school psychologist works in a collaborative nature with other professionals, and is the logical choice to be the person providing interventions for these children. The interests of the child with cancer would undoubtedly be fulfilled best by the skills of the school psychologist.

Limitations of the Study

Certain characteristics of design and procedures use in this study limit extrapolation and interpretation of results.

1. Sample sizes for behavioral research for children with cancer are typically small. Studies often report sample sizes containing no more that 20 children. This is due to a variety of reasons including 1) the child's illness preventing participation, 2) the families reluctance to have their child participate in behavioral research as they do not see benefits for their child, and 3) parents of children with cancer are often asked to participate in numerous studies that

interfere their already overly burdened schedules. As a result, it is difficult to gain large sample sizes for psychological research related the cancer experience in adolescents. This study was conducted with a modest 14 participants that greatly reduces the generalizability of the findings. For instance, the factor structures of several instruments used in this study may hold true to the standardization samples if more participants were in this study. Future behavioral researchers may wish to consider seeking out grant funding for larger recruitment of participants nationally.

2. The factors used to predict behavioral difficulties in children were gathered after a careful review of the literature. However, there may be other variables that would provide additional information, but would prove difficult to gather (differences in behavior based on prognosis, differences in behavior based on specific types of cancer). Additionally, family variables such as SES, family emotional support, and social support of the community may also predict positive and negative outcomes for these young people. However, factors for this study were chosen based on empirical research and the data gathered from this study may be of use for future researchers who are interested in providing empirical treatments for children with special needs.
3. Teacher ratings of behavior would provide useful and complementary data to what is collected by parent and self-reports. However, teacher data is difficult to consistently gather, as literature supports that many adolescents wish to keep their cancer diagnosis confidential, and would not want their teachers completing ratings scales. Additionally, adolescents frequently have as many

as six different teachers in a high school setting, and there is some question as to who would be the best rater of a child, or if all of the teachers should complete behavioral rating scales. Such an examination is impractical for this particular study, but should be considered for future research by school psychologists.

4. The generalizibility of many of the findings of this study should be called into question due to the under-representation of female participants compared to male participants. Additionally, as nonparametric statistics were utilized it is difficult to generalize the findings of this study to the normal population of young people with cancer. It is not known at this time if gender differences in self concept and behavior are as significant or obvious as this study purports due to the use of non-parametric statistics and the small sample size.
5. Finally, no pain intensity measure was used in this study. Although previous research supports that pain coping type is not highly correlated with pain intensity it would have been useful information to know the intensity and type (procedural, treatment or disease-related pain) of the participants.

Recommendations for Future Research

Based upon the results and conclusions of this study, the following recommendations for future research and practice are provided.

1. A longitudinal study examining a particular type of cancer (e.g. Leukemia) in children tracking behavioral changes based on factors that may mitigate differences for potential changes. The BASC could be used after initial diagnosis,

after treatment, and after remission and in follow-up appointments to determine long-term detrimental effects as well as adaptive behavior for the young person with cancer.

2. As pain is believed to be a factor in psychosocial functioning, future research should focus on utilizing the specific pain coping strategies used by young people with cancer (i.e. active, passive or accommodative coping). Assessment of coping strategy may yield valuable information in potential treatment planning for young people with cancer who report pain.
3. Quality of life is an identified area of future psychosocial cancer research as young people are living longer due to new and enhanced treatments. Research focusing on child behaviors based on parental treatment and views of their quality of life may be of value. Parental treatment of young people is considered important in the maintenance of both adaptive and maladaptive behaviors of young people.
4. As social stress is considered an important factor in predicting parenting skills, a more thorough examination of how parenting stress affects the behavioral functioning of a young person with cancer would serve as a valuable area of psychosocial research.

Glossary of Terms

Cancer. "Cancer is a group of diseases characterized by uncontrolled growth and spread of abnormal cells. If the spread is not controlled, it can result in death. Cancer is caused by both external (chemicals, radiation, and viruses) and internal (hormones, immune conditions, and inherited mutations) factors. Causal factors may act together or in sequence to initiate or promote carcinogenesis. Ten or more years often pass between exposures or mutations and detectable cancer. Cancer is treated by surgery, radiation, chemotherapy, hormones, and immunotherapy." (American Cancer Society, Cancer Facts and Figures, 2000).

Pediatric Oncology. Pediatric oncology is a medical specialty area that is concerned with studying and treating cancer that occurs during childhood and adolescence.

Pain. The International Association for the Study of Pain (1980) has defined pain as "an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage". Pain is the perception of nociception, and like other perceptions, it is determined by an interaction between activity in sensori-neural pathways and a variety of behavioral and psychological factors. Although psychological processes can strongly influence the expression and impact of pain, organic factors that produce activity in the sensori-neural pathways appear to predominate in the cancer population (Gonzales, Elliot, Portenoy, & Foley, 1991). (Information taken from the Roxane Pain Institute, 1999).

Prognosis. "The probable outcome of a disease: the prospect of recovery" (National Cancer Institute, 1992).

Quality of Life. Quality of life in this study will be defined by the parameters of the Pediatric Oncology Quality of Life scale. When quality of life is mentioned it will most often be discussed in terms of the parental view of the child's functioning and socialization into society. Specifically, quality of life in this study should be considered as the culmination of three specific factors; physical functioning, emotional stress, and reaction to any current medical treatments.

Self Concept. "Self Concept is a multidimensional and context-dependent learned behavioral pattern that reflects an individual's evaluation of past behaviors and experiences, influences an individual's future behaviors, and predicts an individual's future behaviors. Essentially, self concept, both domain specific and general, is an interactive environmental-behavioral construct that is organized according to behavioral principles. In this construct, "self" is a pattern of behavior that is sufficiently unique to an individual to be identified with that individual. Although domain-specific self concepts are acquired in each context within which an individual operates, these context-dependent self concepts are moderately intercorrelated. Collectively, the overlapping domain-specific self concepts represent global self concept. Thus, in this organizational conceptualization of self concept, the construct represents individuals' learned evaluations of themselves based upon their successes and failures, reinforcement histories, and the ways others react to them and interact with them" (Bracken, 1992). Self concept will be examined using the Multidimensional Self Concept Scale (MSCS), which is comprehensive assessment device utilized to facilitate the clinical appraisal of youth and examines the overall self concept of an individual or to gain further understanding of the six primary dimensions of self concept; social, competence, affect, academic, family and physical self concept.

Side Effects. "Problems that occur when treatment affects healthy cells. Common side effects of cancer treatment are fatigue, nausea, vomiting, decreased blood cell counts, hair loss, and mouth sores" (National Cancer Institute, 1992).

Suffering. "Suffering is the perception of distress engendered by all the adverse factors that together undermine quality of life. Pain may contribute profoundly to suffering, but numerous other factors, such as the experience of other symptoms, progressive physical impairment, or psychological disturbances, may be equally or more important" (Ventafridda, De Conno, & Ripamonti, 1990). "Suffering and pain are therefore best regarded as related but discrete experiences, which have distinct clinical implications. Analgesia alone may not lessen suffering, and consequently, pain therapy is not the sole objective in the supportive care of the cancer patient. Rather, pain therapy must be a critical component of a more comprehensive therapeutic plan designed to address the diverse factors that impair quality of life" (The Roxanne Pain Institute, 1999).

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APPENDIX A—Consent Form

CONSENT FORM

Dissertation Study: *PAIN, QUALITY OF LIFE, AND SELF CONCEPT AS PREDICTORS OF BEHAVIORAL RATINGS OF ADOLESCENTS DIAGNOSED WITH CANCER*

I,____________________________, hereby authorize or direct Michael K. Cruce, a graduate student at Oklahoma State University, or associates or assistants of his choosing, to perform the following treatment or procedure.

Present to me a packet containing several surveys for me and my adolescent to complete.

I will complete a:
<u>Parent Information Sheet</u>: Which contains demographic questions about my adolescent.
<u>Parent Rating Scale</u>: Which contains information about my adolescent's behavior.
<u>Pediatric Oncology Quality of Life Scale:</u> Which asks questions about my view of my adolescent's quality of life.

My adolescent will complete a:
<u>Adolescent Information Sheet</u>: Containing questions about his/her cancer diagnosis
<u>A Self Report of Personality</u>: Containing questions about routine behavioral functioning.
<u>The Pain Response Inventory</u>: Containing questions about how they cope with pain.
<u>The Multidimensional Self Concept Scale</u>: Which contains questions about self esteem.

The purpose of this study is to further the understanding of specific factors that contribute to behavioral difficulties in adolescents with cancer. I understand that this study may benefit psychologists, educators and other professionals who work with adolescents understand factors related to the cancer diagnosis, related pain and behavioral functioning. I further understand that I will be asked questions about my child's health and behavioral functioning, and my child will be asked questions about his/her perceptions of pain, coping, and related behaviors.

I understand that participation is voluntary and that I will not be penalized in anyway if I choose not to participate. I also understand that I am free to withdraw my consent and end my participation in this project at any time without penalty. The information contained in this packet is confidential, and only and the principal investigator will have access to any individual assessment results of my adolescent. I will be contacted with referral information if results indicate that my adolescent is in need of further assistance of a psychologist. There may be minimal discomfort to me and my adolescent for participating, as questions relate to my adolescent's behavior, and I may look through the sections of the research packet now to determine if I will be comfortable in participating.

I may contact Michael K. Cruce, a graduate student, the principal investigator for this dissertation at 744-6960, or Dr. Terry Stinnett, the chair for this dissertation at 744-9456. I may also contact Sharon Bacher, IRB Executive Secretary, Oklahoma State University, 203 Whitehurst, Stillwater, OK 74078.
Phone: 405-744-5700.
I have read and fully understand the consent form. I sign it freely and voluntarily. A copy will be given to me.

Date: ____________________

Time: ____________________

Signed: ____

I certify that I have personally explained all of the elements of this form to the participant before requesting him or her to sign it.

Signed: ____Project Director or Authorized Representative

APPENDIX B-Assent Form

ID Number ____________________

PAIN, QUALITY OF LIFE, AND SELF CONCEPT AS PREDICTORS OF BEHAVIORAL RATINGS OF ADOLESCENTS DIAGNOSED WITH CANCER

Adolescent Assent

I, ____, agree to take part in a study of how
(please print your name here)

I feel about my behavior, and about how I deal with pain. I know that my parents have given permission for me to take part in this study. However, I understand that I do not have to take part in this study if I don't want to. I also know that the results of this study may help doctors and psychologists better understand how to help adolescents who have cancer and that by taking part, I may be helping other kids with cancer in the future. I know that my identity will be kept confidential. This means that nobody but the researchers will know who I am when they read my answers. I also know that Mr. Cruce or members of the Oklahoma State University research team will talk to my parents if my answers show I am upset and might need someone to talk to about any problems that I may have.

I agree to do my best when answering the questions about how I feel. I will answer honestly and carefully.

____ ________________________
Please sign your name Date

APPENDIX-C

Script for Talking to Parents on the Phone and Administering Measures

"Hi. My name is Mike Cruce and I am a graduate student at Oklahoma State University. I am here today to ask for your help with a very important research project. The purpose of this study is to gather information about adolescents diagnosed with cancer. Information like amount of pain, self-concept, and quality of life. To obtain the necessary information, I will ask you to complete some questions which reflect your son's / daughter's behavior. All in all this should take you about 45 minutes to complete. I will also need your permission to administer surveys to your adolescent which will allow us to determine how they feel and how they deal with pain.

This is a very important study and has implications for developing intervention programs to ease the transition and adjustment period back into the school system for adolescents diagnosed with cancer. An individual summary report will be generated and will be available to you at the end of the study. This report may include recommendations for referral for those interested in receiving further services. Your help would be greatly appreciated. There is no requirement for you to participate and this is no way associated with your child's treatment or prognosis. You won't be penalized if you choose not to participate. You and your adolescent will not write your name on any of the forms except the consent form. This way you are assured confidentiality. Are you interested in participating? Do you have any questions so far?"

If they have questions, the questions will be answered. They respond "Yes":

"If you would please read and sign the release giving consent for your participation and your child's participation. Then I will need you to complete the Parent Information Sheet and the multiple-choice type surveys. Please feel free to ask if you have any questions about the consent form or while you are completing the surveys. Be sure you answer all of the questions. When you and your adolescent complete the surveys please place them in the self-addressed, stamped envelope provided, and drop them in the mail to me. I thank you for your participation. May speak to your adolescent for a moment to have them sign the assent form? "

Go over the Adolescent Assent form with the adolescent.

APPENDIX-D

Script for Administering Measures to Adolescents

"Hi. My name is Mike Cruce and I am a graduate student at Oklahoma State University. Today I am asking you to help me with a very important research project focusing on how you feel. Many adolescents like you will be answering the same questions. It is important for you to know that there are no right or wrong answers, and that everyone will answer differently because everyone has different feelings. Please answer honestly when you complete the surveys. These surveys will be kept confidential and only myself and my other research team members will see your responses. If you are unsure about a question, please ask me or your parents, and we will explain it to you. Do you have any questions before you begin? (Have child now read and sign child assent form.) You may begin filling out the forms."

APPENDIX-E

Research Participants Needed

Dissertation Project:

PAIN, QUALITY OF LIFE, AND SELF CONCEPT AS PREDICTORS OF BEHAVIORAL RATINGS OF ADOLESCENTS DIAGNOSED WITH CANCER

We are seeking adolescents aged 2 to 18 who are diagnosed with cancer and their parents to complete several short surveys related to behavior.

Please Contact:

Michael Cruce

402-614-5307

michaelcruce@hotmail.com

Oklahoma State University
School Psychology Program

Science-Based Child Success

APPENDIX-F

Estimated Time to Complete Study

Parent Forms	Time	Adolescent Forms	Time
Parent Info Sheet	3-5 min	Adolescent Info	3-5 min
		PRI	5-10 min
BASC-PRS	20-30 min	BASC-SRP	15-20 min
POQOLS	3-5 min	MSCS	15-20 min
Parent Total Time	30-45 min	Adolescent Total Time	45-60 min

APPENDIX-G

Parental Information Sheet

What is the age of your child?__________

What is the gender of your child?
_____Male
_____Female

What grade is your child in currently?_____________

What is the primary race of your child?
_____African-American
_____Asian/Pacific Islander
_____Hispanic/Latin Origin
_____Native-American
_____White
_____Other, please specify____

With what type of cancer has your child been diagnosed?

____

What type of treatment is currently being utilized with your child?

____

Is your child currently being assisted by someone in a mental health field?

_____No
_____Yes. If yes, what is their training? (psychologist, psychiatrist, social worker, professional counselor, ect...)____

How long has it been since your child's cancer diagnosis? Check the *one* that applies.
_____Less than six months
_____Less than one year
_____Less than two years
_____Less than five years
_____More than five years

Is your child currently in remission with cancer?

_____Yes
_____No

Did you talk to your child's school and make them aware of your child's diagnosis?

_____Yes
_____No

Does your child have and Individualized Education Plan (IEP) at school as a result of the diagnosis of cancer?

_____Yes
_____No

Is there anyone whom you have gone to from your child's school who has provided assistance for your child as a result of the cancer diagnosis?

_____Yes. If yes, what is their position_______________________________
_____No

Is there anyone whom you have gone to from your child's cancer treatment facility who has provided additional assistance for your child as a result of the cancer diagnosis?

_____Yes. If yes, what is their position_______________________________
_____No

How many schools days has your child missed as a result of their cancer?

_____1-5 days
_____6-10 days
_____11-15 days
_____16-20 days
_____20-25 days
_____25-30 days
_____30 or more days

APPENDIX-H

Adolescent Information Sheet

Rank order the following items that apply to you from "most difficult for you = 1" to "least difficult for you = 6". If they do not apply to you then leave them blank.

_____ Initial diagnosis
_____ Treatments (chemotherapy, radiation therapy, ect...)
_____ Return to school after diagnosis or treatment
_____ Medical procedures (needle sticks, blood tests)
_____ Side effects of treatments (Please list)_______________________________
_____ Pain as a result of the disease

Have you spent multiple nights in the hospital due to treatments?

_____Yes
_____No

Were you given information about your cancer?

_____Yes
_____No

If yes, how would you rate the quality of the information?

_____ excellent _____good _____fair _____poor

Were you treated differently by your peers after being diagnosed with cancer and returning to school?

_____Yes
_____No

If yes, how would you rate the peer interaction after returning to school (check one):
_____ less supportive
_____ more supportive

APPENDIX-I

Multidimensional Self Concept Scale

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APPENDIX- J

Pain Response Inventory-Child Report

When you are in pain, how often do you:

	Never	**Once in a while**	**Sometimes**	**Often**	**Always**
1. try hard to do something about it?	0	1	2	3	4
2. keep your feelings to yourself?	0	1	2	3	4
3. tell yourself that you can't deal with it and quit trying?	0	1	2	3	4
4. try to get used to it?	0	1	2	3	4
5. get as far away from other people as you can?	0	1	2	3	4
6. lie down to try to feel better?	0	1	2	3	4
7. eat something?	0	1	2	3	4
8. try to do something to make it go away?	0	1	2	3	4
9. tell yourself that it doesn't matter that much to you?	0	1	2	3	4
10. do something you enjoy so you won't think about it?	0	1	2	3	4
11. think to yourself that it's never going to stop?	0	1	2	3	4

When you are in pain, how often do you:

	Never	Once in a while	Sometimes	Often	Always
12. not let other people see what you're going through?	0	1	2	3	4
13. give up trying to feel better?	0	1	2	3	4
14. try to accept it?	0	1	2	3	4
15. go off by yourself?	0	1	2	3	4
16. try not to move around too much?	0	1	2	3	4
17. drink something?	0	1	2	3	4
18. feel like you can't stand it anymore?	0	1	2	3	4
19. try to think of a way that you could make it better?	0	1	2	3	4
20. tell yourself that it isn't that big a deal?	0	1	2	3	4
21. rub your stomach to try to make it better?	0	1	2	3	4
22. not tell anyone how you're feeling?	0	1	2	3	4
23. think to yourself that there's nothing you can do, so you don't even try?	0	1	2	3	4

24. try to learn to live with it?	0	1	2	3	4

When you are in pain, how often do you:

	Never	**Once in a while**	**Sometimes**	**Often**	**Always**
25. stay away from people?	0	1	2	3	4
26. try to rest?	0	1	2	3	4
27. try to go to the bathroom?	0	1	2	3	4
28. talk to someone to find out what to do?	0	1	2	3	4
29. bend over or curl up to try to feel better?	0	1	2	3	4
30. think to yourself that it's going to get worse?	0	1	2	3	4
31. tell yourself you can get over the pain?	0	1	2	3	4
32. try to figure out what to do about it?	0	1	2	3	4
33. tell yourself that it's not that bad?	0	1	2	3	4
34. try to think of something pleasant to take your mind off the pain?	0	1	2	3	4
35. be careful about what you eat?	0	1	2	3	4
36. give up since nothing helps?	0	1	2	3	4
37. tell yourself that's just the way it goes?	0	1	2	3	4

38. try to be alone?	0	1	2	3	4

When you are in pain, how often do you:

	Never	**Once in a while**	**Sometimes**	**Often**	**Always**
39. try to keep still?	0	1	2	3	4
40. keep others from knowing how much it hurts?	0	1	2	3	4
41. hold your stomach to try to make it better?	0	1	2	3	4
42. think to yourself that you might be really sick?	0	1	2	3	4
43. tell yourself to keep going even though it hurts?	0	1	2	3	4
44. try not to think about it?	0	1	2	3	4
45. ask someone for help?	0	1	2	3	4
46. talk to someone who will understand how you feel?	0	1	2	3	4
47. think hard about what to do?	0	1	2	3	4
48. think of things to keep your mind off the pain?	0	1	2	3	4
49. stay close to someone who cares about you?	0	1	2	3	4
50. keep quiet about it?	0	1	2	3	4

51. ask someone for ideas about what you can do?	0	1	2	3	4

When you are in pain, how often do you:

	Never	Once in a while	Sometimes	Often	Always
52. not even try to do anything about it because it won't help?	0	1	2	3	4
53. tell yourself, "That's life."?	0	1	2	3	4
54. try to get away from everyone?	0	1	2	3	4
55. stop what you're doing to see if it will help?	0	1	2	3	4
56. take some medicine?	0	1	2	3	4
57. think to yourself that something might be really wrong with you?	0	1	2	3	4
58. talk to someone so that you'll feel better?	0	1	2	3	4
59. tell yourself you can deal with the pain?	0	1	2	3	4
60. try to forget about it?	0	1	2	3	4

APPENDIXES

APPENDIX-K

Pediatric Oncology Quality of Life Scale (POQOLS)

Never Very Frequently
1 2 3 4 5 6 7

1. My child has anger outbursts.

   1 2 3 4 5 6 7

2. My child has expressed fear about the disease and its treatment.

   1 2 3 4 5 6 7

3. My child has been sad.

   1 2 3 4 5 6 7

4. My child has been able to participate in recreational activities (sports, games, etc.)

   1 2 3 4 5 6 7

5. My child has had less energy and has been early tired out.

   1 2 3 4 5 6 7

6. My child has required active medical treatment.

   1 2 3 4 5 6 7

7. My child has been able to interact/play with friends completely normally.

   1 2 3 4 5 6 7

8. My child has complained of pain from medical procedures.

   1 2 3 4 5 6 7

9. My child has been embarrassed about physical changes (hair loss, weight change, etc.) 1 2 3 4 5 6 7

10. My child has been physically capable of performing as usual.

    1 2 3 4 5 6 7

11. My child has had trouble sleeping.

1 2 3 4 5 6 7

12. My child has complained about physical pain from his/her differently.

1 2 3 4 5 6 7

13. My child has bee bothered by other people treating him/her differently

1 2 3 4 5 6 7

14. My child has been satisfied with his/her recent physical activity.

1 2 3 4 5 6 7

15. My child has played/visited with friends.

1 2 3 4 5 6 7

16. My child has been able to attend school.

1 2 3 4 5 6 7

17. My child has demanded more help with daily tasks than he/she needs.

1 2 3 4 5 6 7

18. My child has been hostile.

1 2 3 4 5 6 7

19. My child has spent time during the day resting.

1 2 3 4 5 6 7

20. My child has had nausea or vomiting due to treatment.

1 2 3 4 5 6 7

21. My child has needed extra help with daily living skills.

1 2 3 4 5 6 7

APPENDIX-L

Behavior Assessment System for Children

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APPENDIX-M

OKLAHOMA STATE UNIVERSITY
INSTITUTIONAL REVIEW BOARD
FOR HUMAN SUBJECTS

Date: 3/31/02 IRB#: ED0290

Proposal title: QUALITY OF LIFE, SELF CONCEPT, PAIN AND BEHAVIORAL RATINGS OF CHILD AND ADOLESCENT CANCER SURVIVORS

Principle Investigator: Michael K. Cruce, Terry A. Stinnett (Chair)

Reviewed and Processed as: Approved

Approval Status Recommended by Reviewers: Approved

APPROVAL STATUS PERIOD VALID FOR ONE CALENDAR YEAR AFTER WHICH A CONTINUATION OR RENEWAL REQUEST IS REQUIRED TO BE SUBMITTED FOR BOARD APPROVAL.

Comments, Modifications/Conditions for Approval or Reasons for deferral or Disapproval are as follows:

Signature: ________________________________ Date:
Chair of Institutional Review Board

VITA ②

Michael K. Cruce

Candidate for the Degree of

Doctor of Philosophy

Dissertation: QUALITY OF LIFE, SELF CONCEPT, PAIN AND BEHAVIORAL RATINGS OF CHILD AND ADOLESCENT CANCER SURVIVORS

Major Field: Educational Psychology (Option- School Psychology)

Biographical:

Personal Data: Born in Forest Park, Georgia, on January 13, 1973, the son of Michael and Kay Cruce.

Education: Graduated from Forest Park High School, Forest Park, Georgia in June of 1991; received Associates of Arts degree in Education and Associates of Science degree in Psychology from Middle Georgia College, Cochran, Georgia in June 1993; received Bachelor of Science degree in Psychology from The State University of West Georgia, Carrollton, Georgia in June 1995; received Master of Science degree in Psychology from Georgia College and State University, Milledgeville, Georgia in June 1997. Completed the requirements for the Doctor of Philosophy degree with a major in School Psychology at Oklahoma State University in December, 2003.

Experience: APA accredited Pre-doctoral Internship, Munroe-Meyer Institute of Genetics and Rehabilitation, University of Nebraska Medical Center, Nebraska Consortium in Professional Psychology; Practicum Student-Oklahoma State University School Psychological Services Clinic; Practicum Student,-Union Public Schools, Tulsa, Oklahoma; Team Coordinator-Brawner Psychiatric Hospital, Atlanta Georgia; Intern-Macon Regional Youth Development Campus, Macon, Georgia; Governor's Intern, Georgia; Intern-Developmental Disabilities Division, Central State Hospital, Milledgeville, Georgia.

Professional Memberships: American Psychological Association, National Association of School Psychologists, American Pain Society, Oklahoma School Psychological Association.