FACTORS ASSOCIATED WITH GENERAL PSYCHOLOGICAL ADJUSTMENT AND POSTTRAUMATIC STRESS AMONG PARENTS OF CHILDREN WITH A BRAIN TUMOR

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Bachelor of Arts

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Albuquerque, New Mexico

1994

Submitted to the Faculty of the
Graduate College of the
Oklahoma State University
in partial fulfillment of
the requirements for
the Degree of
MASTER OF SCIENCE
December, 1998

FACTORS ASSOCIATED WITH GENERAL

PSYCHOLOGICAL ADJUSTMENT AND

POSTTRAUMATIC STRESS AMONG

PARENTS OF CHILDREN WITH

A BRAIN TUMOR

Thesis Approved:

Thesis Advisor

Dean of the Graduate College

ACKNOWLEDGMENTS

I wish to thank both my advisors Larry L. Mullins, Ph.D. and Brian P. Marx, Ph.D. for their encouragement and support when I needed it most. Their guidance, keen insight, and collaborative efforts were greatly appreciated and inspiring as I tackled a project which, when I started, I knew little about. I would also like to express my gratitude to John Chaney, Ph.D. for his helpful suggestions on the statistical portion of this project.

I wish to acknowledge Jim C. Scott, Ph.D. and Joan Parkhurst, M.D. for their consultation and assistance in helping see this project to fruition. My appreciation is also extended to all the parents from the Children's Hospital of Oklahoma who participated in this study. Their willingness to share their experiences will no doubt contribute to a broader understanding of family adjustment to cancer.

I wish to express my thanks to my parents, Leon and Marie, and my siblings, Renee, Joseph, and Matthew for their encouragement and support. Tambien, quisiera agradecerles a mis abuelos, Adelena y Prudencio, y a mis tios y tias por la contribucion que ellos me siguen dando en obtener mis objetivos.

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CHAPTER I

INTRODUCTION

Brain tumors are the second most common neoplasm next to leukemia among pediatric oncology populations (Cohen & Duffner, 1994). In the United States, it is estimated that there will be 1,200 to 1,500 new cases of brain tumors among children under the age of 15 diagnosed each year (Cohen & Duffner, 1994). In the past twenty years, advances in surgery, radiation, and chemotherapy have increased survival rates for many of these children (Duffner & Cohen, 1992). Although survival rates can vary depending upon the specific type of tumor, the average five year survival rate found among some cancer clinics is approximately 57% (Cohen & Duffner, 1994). With new medical technologies and increasing rates of survival, research and empirical data on psychosocial and psychological adjustment of these children and their families is warranted.

Much research has been directed at understanding the cognitive and neuropsychological sequelae of these children, and less has addressed behavioral and social adjustment. With regard to neuropsychological sequelae, research has demonstrated that the factors most likely to affect children with brain tumors may be related to the treatment itself. For example, studies have shown that children with brain tumors receiving cranial radiation therapy (CRT) show sharper declines in intelligence

quotient scores than those not receiving CRT (Ellenberg, McComb, Siegel, & Stowe, 1987; Kun, Mulhern, & Crisco, 1983; Packer et al., 1989). Likewise, pre- and post-treatment studies have demonstrated deficits in memory impairment (Cavazzuti, Winston, Baker, & Welch, 1980), and in visual-motor and visuospatial functioning (Duffner, Cohen, & Thomas, 1981). Certainly, it is difficult to differentiate the impact of the treatment from the impact of the illness with regard to cognitive decline, and more research is needed to help clarify these findings.

Studies examining behavioral adjustment have found that while children with brain tumors tend to show a higher incidence of behavioral maladjustment when compared to normative data, they do not tend to exhibit greater incidence of behavioral problems when compared to other cancer control groups (Carpentieri, Mulhern, Douglas, Hanna, & Fairclough, 1993; Mulhern, Carpentieri, Shema, Stone, & Fairclough, 1993). Again, the research is unclear as to the specific role that brain tumor illness has on behavioral adjustment. However, these same studies examining behavioral difficulties did find that children with brain tumors exhibit deficits in social functioning. Other studies have found that these children may have difficulties when it comes to relating to children their own age (e.g., Noll, Ris, Davies, Bukowski, & Koontz, 1992; Vannatta, Gartstein, Short, & Noll, 1998).

The emotional adjustment of children may also be affected by the brain tumor illness and subsequent treatment. In general, research has found that children with brain tumors rate themselves at or below normative levels of depression and anxiety on self-report measures (Radcliffe, Bennet, Kazak, Foley, & Phillips, 1996). However, studies have also found that children with non-brain tumor cancers who rate themselves low on

these measures tend to be high repressors or use repressive coping styles (Canning, Canning, & Boyce, 1992; Phipps & Srivastava, 1997). Thus, it is unclear whether the children's ratings on global measures of depression and anxiety are evidence of resiliency, denial of symptoms, or possibly inadequacies of self-report scales for cancer patients (Kazak, Segal-Andrew, & Johnson, 1995).

Being diagnosed with a life-threatening illness not only affects the patient but can also have an impact on the family, particularly the parents. Facing the possibility that the life of one's child is in danger, or at least that he or she may suffer from painful symptoms and treatment regimens, can be overwhelmingly stressful for parents. Unfortunately, there is a paucity of research investigating parental response to a child's being diagnosed with a brain tumor. The one study that has investigated parental adjustment among this population found that maternal levels of anxiety and depression were not significantly different than standardized norms (Radcliffe et al., 1996). However, these findings are not unique to parents of children with brain tumors. Research on parental adjustment to other childhood malignancies have also found that, as a group, a majority of parents do not display significant symptoms of anxiety and depression (Greenburg, Kazak, & Meadows, 1989; Kazak & Meadows, 1989; Kupst et al., 1995; Speechley & Noh, 1992). Although these studies seem to point to the resiliency of parents of children with cancer, the results need to be interpreted with caution. Studies have found that although some parents adjust well, a subset continue to have problems adjusting to their child's life threatening illness (e.g., Kazak, Christakis, Alderfer, & Coiro, 1994; Koocher & O'Malley, 1981). Methodological limitations, specifically reliance on global assessment of symptoms, may contribute to these findings. Researchers recognize that the psychological reaction to a

life-threatening illness is not captured by simply explaining the response in terms of depression and anxiety (Kazak, 1994; Kazak et al., 1997; Koocher & O'Malley, 1981; Pelcovitz et al., 1996; Stuber, Christakis, Houskamp, & Kazak, 1996). As a result, some researchers have begun to employ a model of psychological adaptation based upon a posttraumatic stress model (Kazak, Stuber, Barakat, & Meeske, 1996).

Posttraumatic stress disorder (PTSD) is characterized by the development of a multi-symptomatic response to an event, or events, which involves being witness to, experiencing, or being confronted with death, serious injury, or threat to the physical integrity of oneself or another (American Psychiatric Association, 1994). Symptoms of PTSD include reexperiencing symptoms (e.g., nightmares, intrusive thoughts), avoidance symptoms (e.g., estrangement, avoiding reminders of the event), and arousal symptoms (e.g., irritability, difficulty concentrating, or difficulty sleeping). Because of the very nature of the illness, children with brain tumors and their parents may be susceptible to PTSD symptoms. Although there have not been any studies to date investigating these symptoms among brain tumor patients and their parents, studies from the general pediatric cancer literature do suggest that the PTSD model is applicable to parents and children of cancer (Barakat, Kazak, Meadows, Casey, Meeske, & Stuber, 1997; Kazak et al., 1997; Pelcovitz et al., 1996; Stuber, Christakis, Houskamp, & Kazak, 1996).

Based on clinical observations, Nir (1985) reported that children with cancer, like other individuals who have experienced a traumatic event, may experience reoccurring emotionally painful thoughts and memories, such as those related to having to undergo medical procedures or having to deal with the side effects of treatment. Furthermore, these children may feel detached and estranged from others, as well as show signs of

hyperarousal. Recently, research has attempted to assess the incidence of PTSD symptomatology in pediatric cancer patients. These initial findings are mixed. Among children with leukemia, estimates of the incidence of PTSD range from 1.6% (Kazak et al., 1997) to 12.5% (Stuber et al., 1996). Higher rates were found among children who were undergoing treatment (21%; Butler, Rizzi, & Handwerger, 1995) and among adolescence who were assessed with a diagnostic interview (17%; Pelcovitz et al., 1998). Notably, this research is in its relative infancy, and the findings are tentative. The reported rates on the higher end fall slightly below the prevalence estimates among other trauma survivors. In a review of the literature, Green (1994) estimated that 25% of individuals exposed to a traumatic life event develop PTSD. The rates on the lower end may be the result of resiliency, inadequate PTSD measures for children, or denial of symptoms.

In contrast, the literature seems to suggest that the parents of cancer survivors may be at a high risk for developing PTSD symptoms. Prevalence estimates among parents range from 25% (Pelcovitz et al., 1996) to 39.7% (Stuber et al., 1996). Furthermore, the symptom pattern that seems to be characteristic of these parents is one predominated by avoidance symptoms and reexperiencing symptoms (Kazak et al., 1997; Pelcovitz et al., 1996). Research examining PTSD among parents of cancer survivors may be applicable to parents of children with brain tumors. Like parents of cancer patients, they may be witness to and have a great deal of uncertainty about their child's treatment procedures (e.g., radiation therapy, craniotomy, shunt placement, etc.). Parents may also notice a number of physical changes, such as enlargement of the head or abnormal growth. To date, however, there has been no research investigating posttraumatic stress in this population.

The purpose of the current study is to address this void in the literature and examine the applicability of the PTSD model to this subset of the pediatric cancer population. Further, this study examines underlying factors that may contribute to increased levels of distress. Studies within the general cancer literature have attempted to delineate those factors believed to be associated with the distress that parents of ill children experience. In general, these studies have found that lack of social support contributes to higher levels of overall distress (e.g., Morrow, Carpenter, & Hoagland, 1984; Speechley & Noh, 1992) and to is related to distress associated with PTSD symptoms among parents of children with leukemia (Kazak et al., 1997).

The use of specific coping strategies may also play a role in parents' adjustment to having a child with a life threatening illness. Lazarus and Folkman (1984) define coping as a cognitive and behavioral process or action that serves the adaptive function of controlling internal and/or external demands which are viewed as taxing. They delineate 8 types of coping: Confrontive-Coping, Distancing, Self-Controlling, Seeking Social Support, Accepting Responsibility, Escape-Avoidance, Planful Problem Solving, and Positive Reappraisal. Originally, Folkman & Lazarus (1980) distinguished two broad domains of coping; emotion-focused and problem-focused. Problem-focused strategies are thought to reflect and individuals effort aimed at changing the person-environment relation. Emotion focused strategies are thought to reflect and individuals effort aimed regulating and modifying one's emotional response. Researchers have aggregated these 8 discrete subscales into these two broad domains, with emotion focused coping consisting of Distancing, Self-Controlling, Accepting Responsibility, and Escape-Avoidance and problem focused coping consisting of Confrontive Coping, Seeking Social Support, and

Planful Problem Solving (Miller, Gordon, Danielle, & Diller, 1992). Utilizing these broad categories of coping preliminary research has found that, among parents of cancer patients, increased levels of distress is associated emotion-focused coping (Huszti et al., in preparation). Miller et al. (1992) found that the used of emotion focused coping strategies among mothers of disabled children contributed to higher levels of distress. Furthermore, the use of problem-focused type strategies has been associated with better PTSD adjustment among war veterans (Solomon, Mikulincer, & Arad, 1989).

Of particular interest in PTSD is Escape-Avoidance Coping, an emotion focused coping strategy. Folkman & Lazarus (1988) refer to Escape-Avoidance Coping as, "wishful thinking and behavioral efforts to escape or avoid the problem" (pp. 11). Polusny and Follette (1995) suggest that experiential avoidance among child sexual abuse survivors may function to maintain and possibly increase the risk of posttraumatic stress symptomatology. Other researchers have suggested that experiential avoiding one's distress has the contradictory effect of increasing it (Hayes, 1987).

Illness Uncertainty is another factor that may contribute to increased parental distress. Mishel, Hostetter, King, & Graham (1984) define uncertainty in illness as: ambiguity about the state of the illness, uncertainty about the treatment and the systems involved in care, lack of information about the diagnosis and seriousness of the illness, and the unpredictability of the course and prognosis of the illness. Patients' uncertainty about their illness, at least among non-cancer illness groups, appears to play a significant role in emotional adjustment (e.g., Mullins et al., 1995; Mullins, Chaney, Pace, & Hartman, 1997). Parent's of cancer survivors also report high levels of uncertainty (Van Dongen-Melman et al., 1995), however it's link with distress remains unknown. Parents of

children with a brain tumor are also likely to experience a great deal of uncertainty about their child's condition and this may contribute to their level of adjustment.

Another factor related to parental adjustment may be the invasiveness of the treatment protocol that parents are witness to, as well as disease-related stressors associated with having a child with a brain tumor. Overall, these factors have not been adequately examined in the pediatric brain tumor literature, however, being witness to medical procedures that children have to undergo can be extremely distressing for parents (e.g., Jay & Elliot 1990; Jay, Ozolins, Elliot, & Caldwell, 1983).

Other treatment-related factors that may play a role in a parents' level of distress and adjustment include the child's prognosis, length of remission and if relapse occurred. Furthermore, some researchers have begun to investigate the role that situational and demographic variables (e.g., having another ill family member, socioeconomic status, living in a single parent home, religious affiliation, age of child and parents at diagnosis, current age, and length of time since diagnosis) play in parental adjustment (Van Dongen-Melman, 1995).

In summary, studies have not yet examined the incidence of PTSD in parents of children with brain tumors, nor have they examined the predictive factors associated with increased levels maladjustment. Oftentimes, research examining adaptation to childhood cancer excludes this special subset of children with brain tumors because the disease and treatment are seen as unique and more troublesome for patients (Radcliffe et al., 1996). Given the overall lack of literature examining parental adjustment and predictive variables associated with increased symptomatology, there is a tremendous need to assess and examine these aspects among parents of children with brain tumors. The purpose of this

study is to address this void in the literature. Based upon the sparse literature available on parental adaptation to childhood brain tumors as well as the more considerable research on parental adaptation to other cancers the following hypotheses will be investigated:

Hypothesis 1: It was hypothesized that parents of children with a brain tumor would exhibit significant levels of general distress as compared to normative data, and PTSD prevalence would be similar to that found in other studies examining PTSD among parents of children with cancer (at least 25%).

Hypothesis 2: It was further hypothesized that social support, illness uncertainty, and coping strategies, would be significantly related to global levels of distress and posttraumatic symptom severity. It was believed that these variables would also predict global distress and posttraumatic symptom severity beyond demographic and illness variables in a hierarchical multiple regression analysis.

Specifically, it was expected that:

(1) A negative relationship would emerge between scores related to social network size and density and both posttraumatic symptom severity and global distress.

(2) Greater illness uncertainty would be related to higher levels of posttraumatic symptom severity and global distress.

(3) A positive relationship would emerge between emotion-focused coping and global distress and posttraumatic symptom severity. A similar positive relationship was expected for specific subscales which comprised emotion-focused coping (Distancing, Self-Controlling, Accepting Responsibility, Escape-Avoidance coping, and Positive Reappraisal) and measures of adjustment. On the other hand, a negative relationship was expected between problem-focused coping and global distress and PTSD severity.

Likewise, an inverse relationship was expected between the specific problem-focused coping subscales (i.e., Confrontive Coping, Planful Problem Solving, and Seeking Social Support) and the measures of adjustment.

From an exploratory standpoint, this study sought to examine the following additional research questions.

1) What is the relationship between parent's family, friendship, & professional social support networks and their self-reported level of adjustment?

2) What is the relationship between the parent's self-reported levels of adjustment and their perceptions of their child's health status, coping, and medical treatment adherence?

3) What role does escape-avoidance coping play in adjustment?

The following is a review of the literature regarding pediatric brain tumors. Research findings regarding the child's adjustment are reviewed, as well as research on parental adaptation. Because there is little research addressing the parents of childhood brain tumors, applicable research from the general pediatric cancer literature is also reviewed.

CHAPTER II

REVIEW OF THE LITERATURE

Description of the Disease

Childhood brain tumors are second to leukemia in incidence and cause of death among pediatric oncology populations. Overall, children with tumors constitute 20% of all cancer diagnoses (Stehbens, 1988). It is estimated that between 1,200 and 1,500 children under the age of 16 are diagnosed per year with some form of brain tumor (Mulhern, 1994). In general, the disease does do not distinguish between gender, with incidence being equally balanced between boys and girls (Mulhern, Crisco, & Kun, 1983).

A brain tumor is characterized by abnormal growth of tissue in the skull and can be classified as either malignant or benign. A malignant tumor containing cancer cells spreads to surrounding tissue and may also spread to other parts of the body causing a secondary growth. This is referred to as metastasis. In general, malignant tumors are a more life-threatening type of tumor. Benign tumors, on the other hand, do not metastasize or spread (Clayman, 1989). However, depending upon the location and the amount of space the mass occupies in the central nervous system, a benign tumor can be as dangerous as a malignant tumor (Bracken, 1986).

There are many different types of childhood brain tumors, and they are usually classified on the basis of location in the central nervous system. Tumors are either

classified as infratentorial (located in the lower part of the brain or below the tentorium) or supratentorial (located in the upper part of the brain or above the tentorium) (Mulhern et al., 1983), with infratentorial being the more prevalent type (Bloom & Walsh, 1975). The most common infratentorial tumors are medulloblastomas, cerebellar astrocytomas, and lesions of the brain stem. The more common supratentorial tumors are cerebral astrocytomas and supratentorial cerebral gliomas, supratentorial ependymoma, and craniopharyngioma (Bloom & Walsh, 1975). Supratentorial tumors are more common among children less than two years of age, however infratentorial tumors are more common among older children between 2 and 12 years of age (Cecalupo, 1995).

Children with infratentorial tumors tend to have initial symptoms that are more related to hydrocephalus (e.g., nausea, vomiting, headaches, irritability). Children with such tumors later may develop more pervasive problems such as lethargy, drowsiness, seizures, stupor, uncharacteristic aggressive behaviors and changes in temperament, which may initially resemble a behavioral disorder. Children with supratentorial tumors tend to exhibit more symptoms related to endocrine dysfunction and often report visual abnormalities (Mulhern et al., 1983).

In some cases, it is difficult to notice any obvious physical changes that result from a brain neoplasm, however physical sequelae can be observed with certain subtypes of tumors. For instance, children with glioma of the brain stem may display a facial weakness or wan of expression referred to as the "woebegone expression" (Jones & Campbell, 1976). Others may develop ataxia of gait, with neck stiffening and head tilting, as in medulloblastomas. Hydrocephalus can cause an enlargement of the head. Finally, children with tumors in the third ventricle can have loss of vision and develop diencephalic

syndrome (e.g., loss of weight and delayed skeletal growth) (Cohen & Duffner, 1994; Jones & Campbell, 1976).

Etiology

Theories have surfaced suggesting that the cause of brain tumors may be the result of errors in embryogenisis, genetic factors, or environmental toxins. For instance, genetic illnesses, such as neurofibromastosis, have been associated with the development of intercranial tumors (Goldgar, Green, Parry, & Mulvihill, 1989). Likewise, environmental factors, such as exposure to x-rays during prenatal development, have also been thought to be associated with childhood cancer (MacMahon, 1962). However, in general there is not a single cause for all brain tumors, and the etiology remains obscure (Cohen & Duffner, 1994; Black & Becker, 1990). Thus, the focus of treatment is not on prevention, but on control of growth and elimination of tumor cells.

Treatment

The treatment regimen for brain tumors usually involves some combination of surgery, radiation therapy, and/or chemotherapy (Granowetter, 1994). Often, the first course of treatment for any tumor involves a surgical procedure. The most hopeful goal of surgery is to remove the entire tumor. Full resection increases the probability of complete cure. However, curing the tumor in this way is not always possible. For instance, some tumors, such as brain stem tumors, can rarely be fully resected because of their inoperable location (Bracken, 1986). On the other hand, cerebellum tumors, such as cerebellar astrocytomas, have the highest likelihood of complete resection and cure (Bracken, 1986). In malignant tumors partial resection may be the best option, and

surgery in these cases can often stabilize or improve neurological signs and symptoms (Black & Becker, 1990).

Another goal of a surgical procedure may be to remove a sample so that a biopsy can be performed in order to identify the tumor. Also, surgical procedures may involve placing shunts, as tumors can cause blockage of fluid and increased cranial pressure. Shunts are thus designed to relieve cranial pressure by draining fluid from the brain to the bloodstream, where it can be absorbed safely (Bracken, 1986).

Surgery alone does not cure most brain tumors. In order to increase the likelihood of cure, radiation therapy is often prescribed (Kun, 1994). Radiation therapy involves focusing irradiation beams, usually x-rays or γ-rays, on the exact location of the tumor. This focused ionizing radiation, in high enough doses, causes a disruption in the intracellular particles of DNA cells, ultimately causing cellular decay of the tumor producing cells (Kun, 1994). The goal of this therapy is tumor cell death; however, the treatment can also slow the growth of the tumor cells. During the procedure, children must remain immobile and special devices have been fashioned in order to restrict movement. Younger children often must be sedated during the procedure in order to prevent movement (Kun, 1994). The immediate, common side effects of radiation therapy are nausea, vomiting, and hair loss. In addition, whole brain radiation has been associated with cognitive decline and neuropsychological deficits (e.g., Ellenberg et al., 1987; Packer, et al., 1989; Kun et al., 1983).

A final treatment that has also been prescribed for tumor management is chemotherapy. Chemotherapeutic agents help to prevent metastases from malignant tumors and can also aid in killing tumor cells. Currently, there are four basic types of

chemotherapeutic drugs: alkylating agents (e.g., carmustine, bisulfan, cyclophospamide, chlorambucil), antimetobolites (e.g., methotrexate, 6-mercaptopurine, 5-fluorouracil), antibiotics (e.g., actinomycin-D, bleomycin, mithramycin), and alkaloids (e.g., vincristine, vinblastine) (Glaze, Anderson, & Anderson, 1985). These drugs are often used in combination to treat different types of tumors. The utility of chemotherapeutic drugs for the treatment of brain tumors is potentially problematic and their effectiveness with some tumors is unknown (Braken, 1986). One problem with chemotherapeutic drugs is that their effectiveness may be limited because the drugs cannot cross the blood-brain barrier (Cohen & Duffner, 1994). Furthermore, the typical side effects of chemotherapy are numerous, including hair loss, nausea and vomiting, diarrhea, skin rash, mouth ulcers, anemia, and weakness (Glaze et al., 1985).

Prognosis and Survival Rates

In general, tumor identification techniques, such as the use of the CAT scan and MRI, as well as better surgical procedures have improved prognosis and ultimately length of survival (Braken, 1986). However, prognosis can be difficult to determine and can depend upon a number factors. For instance, the length of time between tumor detection and treatment, age of the child at diagnosis, operable location of the tumor, and likelihood of metastases are some of the factors that play a role in prognosis (Braken, 1986; Granowetter, 1994; Jones & Campbell, 1976). The different types of tumors can have different survival rates depending upon some of these factors. For example, glioblastoma multiforme tumors, a type of supratentorial hemispheric astrocytoma, are one of the most difficult tumors to identify and most malignant (Jones & Campbell, 1976). The presence of these factors reduce survival rates to a 4% chance of 5 year survival (Cohen & Duffner,

1994) and most of these children do not survive beyond one year (Jones & Campbell, 1976). Cerebellar astrocytomas, the second most common type of tumor, have the most favorable prognosis, because their location makes them amenable to surgery and they are slow growing (Cohen & Duffner, 1994; Braken, 1986). Other tumors, such as medulloblastomas, which tend to be partially operable, can have 10 year survival rates between 30 and 55% (Cohen & Duffner, 1994). In summary, prognosis and survival rates vary considerably and depend largely upon degree of malignancy, rate of growth, the location, and type of tumor.

Cognitive and Neuropsychological Sequelae

Children with brain tumors face the possibility of deteriorating cognitive function due to both the effects of the tumor itself and subsequent surgical, chemotherapy, or radiation therapy. However, it is unclear in the literature whether cognitive functioning is impaired more by the tumor or the treatment. Rowland et al. (1984) found that children with acute lymphoblastic leukemia (ALL) who received cranial radiation therapy (CRT) performed poorer on neuropsychological testing measuring intelligence and achievement than those children with ALL who did not receive CRT. Children who received CRT were also rated as having more difficulty attending and were more impulsive. Because none of the children in this study had primary brain tumors, the radiation therapy itself was thought to be a risk factor for cognitive dysfunction and deficits in attention.

A subsequent study conducted by Packer et al. (1989) provided further support for this hypothesis. When comparing intelligence quotient (IQ) scores of children who received CRT to children with similar brain tumor ailments who did not receive CRT, the authors found that children receiving CRT had a sharper decline in full scale intelligence

quotient (FSIQ) scores (IQ = 105 prior to CRT to IQ = 91 post-CRT) than those not receiving CRT (IQ = 105 at time 1 assessment to IQ = 106 at time 2 assessment). They also found that children receiving CRT prior to age 7 were especially susceptible to cognitive decline. Their study demonstrated a clear decline in IQ measured 2 years post whole brain radiation therapy, thereby suggesting that CRT can have drastic side effects. Overall, without regard to type of treatment used, pre- and post-treatment deficits documented among patients involve decrements in cognitive flexibility (LeBaron, Zeltzer, Zeltzer, Scott, & Marlin, 1988), memory impairment (Cavazzuti et al., 1980) and visual-motor and visuospatial functioning (Duffner et al., 1981). Certainly, additional research is needed to document the specific iatrogenic effects of the various interventions.

Behavioral, Social, and Emotional Adjustment

A landmark study conducted by Koocher and O'Malley (1981) demonstrated that while many survivors of childhood cancer can lead normal lives and adjust well, at least half can be expected to have psychological adjustment problems. Subsequent literature on adjustment has provided support for this initial finding (Kazak, 1994). Overall, the few studies of brain tumor survivors have found concordant results, with this subset of cancer patients showing similar types and prevalence of adjustment (e.g., Mulhern et al., 1993; Carpentieri et al., 1993; Radcliffe et al., 1996).

Children with brain tumors do not seem to have significantly greater behavior problems than children suffering from other types of cancer, however, they do tend to show behavioral adjustment difficulties when compared to normative data (Mulhern et al., 1993; Carpentieri et al., 1993). Given that studies show children with head injury exhibit a higher incidence of behavior problems (e.g., Asarnow, Satz, Light, Lewis, & Newmann,

1991), it would be reasonable to find similar problems among childhood brain tumor patients. However, studies have failed to demonstrate that these children are at a greater risk for behavioral problems above and beyond the non-brain tumor pediatric cancer populations. For example, Mulhern et al. (1993) found elevated scores on the behavioral adjustment subscale of the Child Behavior Checklist (CBCL; Achenbach & Edelbrock, 1983) for both a childhood brain tumor group and a pediatric cancer control group, however, CBCL scores were not different between the two groups. Notably, this study was designed to examine the acute and immediate response to brain tumor diagnosis (i.e., up to 3 months post-diagnosis), and thus did not evaluate longer term behavioral problems. However, another study by the same research group (Carpentieri et al., 1993) found similar results among long-term survivors of cancer and tumors. Similar studies have found elevated levels of behavioral problems among children with brain tumors (e.g., Carson-Green, Morris, & Krawiecki, 1995); however, without non-brain tumor cancer controls it is difficult to ascertain the specific role that brain tumors have with regard to behavioral adjustment.

A few of these studies have also attempted to delineate possible predictors of social and behavioral adjustment difficulties among brain tumor patients. For instance, Mulhern et al. (1993) found that low child IQ, residing in a single parent family, disfigurement, low socioeconomic status, tumor location, and functional impairment predicted decreased social competency. In this same study, predictors of behavioral problems were younger maternal age at childbirth, tumor location, and coming from a single parent family. Others studies have also identified family stress and stress related to

the parents' marriage as predictors of behavior difficulties among children with brain tumors (Carson-Green et al., 1995).

A relatively consistent finding specific to children with brain tumors are social competency deficits. In the two studies mentioned above, children with brain tumors were rated by primary caretakers as exhibiting lower levels of social competence on the CBCL (Mulhern et al., 1993; Carpentieri et al., 1993). In a unique investigation, Noll, Ris, Davies, Bukowski, & Koontz (1992) assessed the social reputation of three groups of hematology/oncology patients; a group of children with sickle cell (n=33); a group of children with cancer with non-primary brain tumors; and a group of children with primary brain tumor cancer. Every group of children were matched with classmates without a chronic illness who served as control groups. Social reputation was assessed using the Revised Class Play (RCP; Masten, Morison, & Pellegrini). With the RCP teachers are asked to "cast" their students in imaginary play. Three dimensions can be derived from the RCP, sociability-leadership, aggressive-disruptive, and sensitive-isolated. Compared to controls, children with brain tumors showed no difference on the sociability-leadership and aggressive-disruptive dimensions, however, they were rated significantly higher on the sensitive-isolated dimension. This was unique to the brain tumor sample. Children with non CNS cancer were rated similarly to controls on this dimension but scored significantly higher scores on sociability-leadership and significantly lower on the aggressive-disruptive dimension. Children with sickle cell did not differ from their matched control. The authors do warn readers to interpret these findings with caution because of the small sample size and heterogeneity of tumors and treatments; however, the findings do call for

further study investigating the social adaptation of children who manage to survive the iatrogenic effects of brain tumor cancer and treatment.

A recent study extended some of these findings. Using this same paradigm, Vannatta, Gartstein, Short, and Noll (1998) compared a group of 28 children (ages 8-18) to 28 non-chronically ill matched control group. All children were off treatment at the time of the study and were not receiving special education. Using the RCP, children who had been diagnosed with a brain tumor were less socially accepted by peers and were nominated by teachers and peers for socially-isolated roles. Like the above study this study seems to suggest that children with brain tumors may be at risk for social adjustment problems when they return to school after treatment ends.

In contrast, at least one study has found that teachers may not perceive children as having as many problems with social competence as mothers perceive (Radcliffe et. al., 1996). Thus, there may be a need to further clarify and confirm these findings. Using ratings from other family members, such as fathers, siblings, grandparents, and peers may be useful (Radcliffe et al., 1996), as well as using measures that are illness-specific.

The little data available regarding self-reported emotional adjustment among children with brain tumors tends to show that these children adjust well as a group, at least according to global, non-illness specific, measures of depression and anxiety. For instance, Radcliffe et al. (1996) found that children and adolescents with brain tumors rate themselves significantly below the normal range on measures of anxiety (i.e., Children's Manifest Anxiety Scale-Revised) and depression (i.e., Children's Depression Inventory). Although perplexing, these findings are consistent with those of other studies investigating depression and anxiety among children with non-brain tumor cancers (Canning et al.,

1992; Phipps & Srivastava, 1997; Greenburg et al., 1989). Greenburg et al. (1989) found that children with cancer do not rate themselves as being depressed or anxious as a group. Canning et al. (1992) and Phipps and Srivastava (1997) also found that children with cancer reported significantly lower levels of depression and anxiety. However, in the Canning et al. (1989) study, patients who reported lower levels of depression were also identified as repressors. In Phipps and Srivastava (1997), patients who rated themselves as less depressed and anxious also endorsed a more repressive coping style. Thus, it is unclear whether the children's ratings on global measures of depression and anxiety are evidence of resiliency, denial of symptoms, or possibly inadequacies of self-report scales for cancer patients (Kazak et al., 1995).

Impact of Childhood Brain Tumor Illness on Parent's Adjustment

Obviously, the experience of parenting a child with a brain tumor is no ordinary event. Facing the possibility that the life of one's child is in danger, or at least that he or she may suffer from painful symptoms and treatment regimens, can be overwhelmingly stressful for parents. As a function of the diagnosis of cancer, parent's responsibilities increase substantially, including bringing their child in for frequent examinations and hospitalizations, administering medication and treatment, taking care of other siblings and other family members, and maintaining occupational duties (Kalnins, Churchill, & Terry, 1980). Parents also may be overwhelmed by worry and fear related to the anticipation of the death of their child, as well as the fear related to the uncertainty associated with relapse (Koocher & O'Malley, 1981). It seems reasonable that a subset of parents adjusting to these new demands, as well as adjusting to the long-term effects of brain

tumor cancers may be at risk for developing depression, anxiety, and other stress-related symptoms.

However, there is a paucity of research investigating parental response to a child's being diagnosed with a brain tumor. Notably, there is only one study investigating parental adjustment among parents of children with a brain tumors. Radcliffe et al. (1996) found that maternal reports of anxiety and depression two to five years after their children had been diagnosed with a brain tumor were not significantly different than standardized norms. Such findings may seem contradictory to that expected. However, this study utilized a small sample size (38 mothers); global measures of depression and anxiety were utilized, which might not be sensitive to the specific nature of parental adjustment to their child's illness; appropriate control groups were not utilized; and fathers were not included in the study. Furthermore, this study only examined the two to five year post-diagnosis phase. How parents adjust immediately after diagnosis, and more long-term adjustment remains to be investigated. Given these limitations, however, the above findings are consistent with research on parental adjustment to childhood cancer in general. It remains an empirical question as to the extent to which research regarding parental adjustment to childhood cancer generalizes to the specific circumstance of parents coping with childhood brain tumors.

A review of the pediatric cancer literature regarding parental adjustment may provide some insight as to the effects of having a child with a potentially life threatening illness. The literature on childhood cancer suggests that different stages in the course of the child's illness can affect parental functioning and level of distress. The period shortly after learning of the diagnosis can be especially problematic and is often experienced as

being the most stressful (Koocher & O'Malley, 1981). Parents may respond to learning of the diagnosis similar to those mourning the loss of a loved one (Van Dongen-Melman & Sanders-Woudstra, 1986). They may also experience marital distress or symptoms of anxiety and depression. For instance, Dahlquist et al. (1993) demonstrated that at least 25% of mothers and 28% of fathers of newly diagnosed children (mean = 8 weeks post-diagnosis) experienced significant marital distress. Furthermore, they found that mothers and fathers reported state anxiety levels significantly greater than normative levels, and 13% of mothers and 8% of the fathers reported depressive symptomatology in clinical ranges on the Beck Depression Inventory (BDI; Beck, Ward, Mendelson, Mock, & Erbaugh, 1961).

With more effective treatment and better methods of earlier detection, childhood cancer patients have a better prognosis, and the probability of long-term survival is higher (Mulhern, 1994; Lansky, List, & Ritter-Sterr, 1986). This has important implications not only for the children who are surviving longer, but also for the parents of long-term survivors. Current research and practice has focused on investigating the psychological late-effects experienced by parents, in hope of developing better long-term care for children and their families. Although some studies have found that distressing symptoms can last a number of years (Hughes & Lieberman, 1990), a majority of recent studies have demonstrated the resiliency of parents of long-term survivors of cancer (Greenburg et al., 1989; Kazak & Meadows, 1989; Kupst et al., 1995; Speechley & Noh, 1992). For instance, Greenburg et al. (1989) found that mothers of children who were long-term survivors (8.8 years since diagnosis) had similar levels of personal stress as mothers in a non-illness control group. Kupst et al. (1995) found that mothers perceived themselves

and were perceived by hospital staff as coping well 10 years after their child's treatment for leukemia was terminated. Regarding depression and anxiety, Speechley & Noh (1992) found that both fathers and mothers of cancer survivors who had terminated treatment on average of 5.6 years earlier did not significantly differ from a control group of parents of healthy children in their reports of depressive and anxiety symptoms.

Although these studies are promising in that they point to the resiliency of parents who have children with a childhood brain tumor, the results should be interpreted with caution. First, it is important to note that although a majority of parents do not display significant symptoms of anxiety and depression, a subset continue to have problems adjusting to their child's life-threatening illness. For instance, Kazak et al. (1994) found that parents of child survivors of cancer did not significantly differ from normative samples on measure of psychological distress. However, 20% to 30% of their sample had scores consistent with individuals who seek help for psychological distress, and 10% had scores that fell within the psychologically "distressed" range. Second, there are a number of methodological problems that need to be considered. For one, the nature of many of these studies lend themselves to the underreporting of symptoms. The unsupervised nature of mail-in surveys may contribute to a higher likelihood of concealing and not admitting problems (Kazak et al., 1994). A second methodological problem concerns the selection of appropriate measures. Many of the measures utilized were not designed to detail the unique problems experienced by parents and cancer patients (Kazak et al., 1996), and furthermore they were not normed on such populations. In addition, little research has been conducted that attempts to measure specific traumatic symptoms such as reoccurring intrusive recollections or thoughts about one's child's condition, avoidance of reminders,

hyper-arousal, or negative symptoms (e.g., dissociation or numbing) that may characterize parent's response to the diagnostic stage, treatment stage, or recovery stage (Kazak et al., 1997).

Certainly, methodological problems in the pediatric oncology literature need to be addressed. Steps can and should be taken to minimize the above mentioned problems such as supervising the administration of surveys, collecting data from a variety of sources, or utilizing different methods of data collection. Regarding the problems associated with the use of global measures rather than specific measures, researchers have recently begun to utilize measures which assess more illness-specific symptoms related to chronic stress (e.g., Kazak et al., 1997; Pelcovitz et al., 1997).

As mentioned previously, parents may react to having a child with a life threatening illness with helplessness and fear. They may have disturbing vivid memories of their child's treatment or of other children in the cancer unit that had died (Kazak et al., 1997). However, global measures of depression and anxiety are limited and do not provide new information about the presence of such distressing trauma-related symptoms. What is needed are studies which are designed to assess this set of symptomatology. A few research studies have begun to examine such symptoms, and pediatric oncology research has refined the focus to include symptoms and experiences related to posttraumatic stress.

Posttraumatic Stress in Children and Parents

Posttraumatic stress disorder (PTSD) as defined in the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV; 4th ed.; American Psychiatric Association, 1994) is characterized by the development of a multi-symptomatic response to an event, or events,

which involves being witness to, experiencing, or being confronted with death, serious injury, or threat to the physical integrity of oneself or another. Further, a person's response to these events or event involves one of horror, helplessness, or fear. Symptoms of PTSD are clustered into three categories: reexperiencing, avoidance and numbing, and arousal. Reexperiencing symptoms can include such symptoms as having intrusive thoughts, nightmares, or becoming psychologically distressed when exposed to cues or reminders of the event. Avoidance and numbing symptoms include attempts to avoid any reminders of the event or becoming detached or estranged from others. Other symptoms may be related to arousal, such as irritability, difficulty concentrating, or difficulty sleeping.

Research regarding the etiology and nature of PTSD is still in its relative infancy. Most clinicians and researchers recognize that it is not the exposure to an event that is in and of itself what leads to PTSD, but rather the person's reaction and vulnerabilities to the event (Calhoun & Resick, 1993). Furthermore, a person may experience symptoms of PTSD in response to an overwhelming traumatic event without meeting full diagnostic criteria. Thus, traumatologists have also begun to look at possible subtypes of PTSD. For instance, Terr (1991) proposed that childhood traumas and the subsequent reaction can be divided into two types (type I and type II), both with somewhat different symptom presentations. Type I traumas are single and sudden shocks, whereas type II traumas are chronic, multiple incident occurrences. The response to type I trauma is associated with reexperiencing symptoms, whereas the response to type II traumas produces more dissociative symptoms, numbing, unremitting sadness, rage, and avoidance. Crossovers can occur when a sudden unexpected event leads to a number of subsequent stressful

events. The response in these crossover situations is similar to that of a type II response, however type I symptoms may appear. Although speculative, the crossover response or the type II response may best describe how parents and their children with brain tumors or other malignancies respond to the initial shock of diagnosis, the helplessness felt in the treatment phase, and the uncertainty in the survival stage (Steward, O'Connor, Acredolo, & Steward, 1996).

For the most part, the posttraumatic stress model has not been associated with the distress that children and their families encounter when dealing with a brain tumor or general cancer diagnosis, treatment, and remission. However, researchers have also recognized that the psychological reaction to a life-threatening illness is not captured by simply explaining the response in terms of depression and anxiety (Kazak, 1994; Kazak et al., 1997; Koocher & O'Malley, 1981; Pelcovitz,1996; Stuber et al., 1996). Koocher and O'Malley (1981) described the families' reaction to childhood cancer survival as the "Damocles Syndrome." This syndrome is characterized, not only by the measurable prevalence of depression and anxiety in some parents and children, but by the overall level of distress and omnipresent fear related to the uncertainty, uncontrollability, and unpredictable nature of the course of cancer. Some traumatologists have considered unpredictability and uncontrollability to be key predicting factors of PTSD following a traumatic event (Foa, Zinbarg, & Rothbaum, 1992). Currently, researchers and clinicians have begun to apply the posttraumatic stress model to parents and child survivors of cancer in order to enhance the understanding of psychological adjustment in this group.

Based on clinical observations, Nir (1985) reported that children with cancer, like other individuals who have experienced a traumatic event, may experience reoccurring

emotionally painful thoughts and memories, such as those related to having to undergo medical procedures or having to deal with the side effects of treatment. He also observed that children with cancer may feel detached and estranged from others, as well as show signs of hyperarousal (i.e., irritability and insomnia). Stuber, Nader, Yasuda, Pynoos, & Cohen (1991) further observed that children having to undergo a bone marrow transplant denied and avoided reminders of the treatment and showed a deficit in expression of positive emotion. This constriction of positive affect is thought to be a cardinal symptom of PTSD among survivors of war-related trauma (Litz, 1992).

Recently, research using empirically based measures has addressed the incidence of PTSD symptomatology in pediatric cancer patients. For instance, Stuber et al. (1996), utilizing the Child PTSD Reaction Index (Frederick, Pynoos, & Nader, 1992), found that 12.5% (8 of 64) of leukemia survivors surveyed reported PTSD symptoms in the severe range. Butler et al. (1995), using the PTSD Symptom Scale (PSS; Foa, Riggs, Dancu, & Rathobaum, 1993), found higher prevalence rates of PTSD among patients undergoing treatment (21%); however, lower rates were observed among patients who had completed treatment (7%). Notably, Kazak et al. (1997), using the Child PTSD Reaction Index, the Trauma Symptom Checklist (TSC; Briere, 1989), and the Impact of Events Scale (IES; Horowitz, Wilner, & Alvarez, 1979), did not find a significant difference in rates of PTSD symptomatology when comparing a pediatric leukemia survivor group to a non-chronic illness control. Prevalence rates among patients in this study were quite low; only 1.6% reported PTSD symptoms in the severe range. A recent study, however, comparing 23 adolescent survivors of cancer to physically abused adolescents found higher rates of PTSD among cancer survivors (17% vs. 11%; Pelcovitz, et al., 1998).

Thus, research in this area is in its relative infancy and the findings are tentative. One of the difficulties of assessing PTSD in this population is that there are few PTSD assessment measures for children in general, and little work has been done on developing assessment measures for pediatric oncology patients (Kazak et al., 1997). Another difficulty is that, like other studies assessing psychiatric symptomatology in this population, there is the possibility of denying, repressing, or avoiding the reporting of distressing symptoms (Canning et al., 1992; Phipps & Srivastava, 1997). This avoidance may actually be related to the posttraumatic condition of these children (Stuber et al., 1991; Kazak et al., 1997).

As mentioned above, parents of children with cancer or a brain tumor may also experience an overwhelming feeling of distress. The response that a parent has to their child's condition can also be conceptualized using a posttraumatic stress model. Heiney, Neuberg, Myers, and Bergman (1994) suggest that parents of children who undergo bone marrow transplant (BMT) because of a malignancy may be at high risk for developing PTSD. Parents of BMT patients, like parents of childhood brain tumors and other cancers, have to deal with a number of stressors, such as the fear that their child might die, being exposed to stressful events for a long period of time, the possibility that their child's condition may relapse, and exposure to their child's pain and suffering resulting from symptoms, the disease, or from treatment.

Recently, researchers have found empirical support for the hypothesis that parents of cancer survivors experience high levels of posttraumatic stress symptomatology. Stuber et al. (1996) found high prevalence rates of posttraumatic stress symptoms among parents of pediatric cancer survivors; 39.7% for mothers and 33.3% for fathers. Studies

that have used structured diagnostic interviews have found somewhat lower rates. For example, utilizing the Structured Clinical Interview for the DSM-IIIR (SCID; Williams et al., 1992), Pelcovitz et al. (1996) found current rates of PTSD to be equal to 25% among mothers of pediatric cancer survivors. Importantly, parents of children with cancer show significantly higher rates of PTSD and symptom severity in comparison to control groups (Kazak et al., 1997; Pelcovitz et al., 1996). Furthermore, the symptom pattern that seems to be characteristic of these parents is one predominated by avoidance symptoms and reexperiencing symptoms (Kazak et al., 1997; Pelcovitz et al., 1996). It is also noteworthy that both Kazak et al. (1997) and Stuber et al. (1996) found higher rates of PTSD symptoms among parents than among the child survivors of cancer, suggesting that pediatric cancer may be more psychologically distressing for the parents than for the child. However, as mentioned above, inadequate PTSD assessment for children may also be an explanation for this finding. More research is needed in order to clarify these findings.

In summary, the research examining posttraumatic stress symptoms among parents of cancer survivors may be applicable to parents of children with brain tumors. Parents of children with brain tumors often are faced with many of the same situations as parents of children with other cancers. Invariably, they experience shock and helplessness when learning of the diagnosis. Like parents of cancer patients, they may be witness to and have uncertainty about the treatment procedures, such as radiation therapy or a craniotomy. Furthermore, parents of children with brain tumors may notice physical changes (enlarged head, abnormal growth) which may be experienced as distressing for the parent. In general, parents of children with brain tumors may have reoccurring thoughts about their child's illness, hospital visitations, or their child's ever present symptoms.

To date, however, there has been no research investigating posttraumatic stress in this population. Similarly, there is no research documenting those specific factors potentially associated with posttraumatic symptoms. For instance, do factors related to lack social support and escape-avoidance coping strategies increase symptoms of distress? Is illness uncertainty associated with higher levels of parental distress? What role does the invasiveness of treatment play in parental adjustment? How do illness related variables, demographics, and prior stressful life events impact adjustment? Research is needed not only to identify the applicability of the posttraumatic stress model to this population of parents with children with brain tumors, but also to identify factors that are associated with the general level of distress, as well as the distressing symptoms of posttraumatic stress. In the next section, factors associated with parental stress will be reviewed with attention paid to variables potentially contributing to posttraumatic symptomatology.

Factors Associated With Parental Stress

Thompson et al. (1985) and Wallander et al. (1989) point out that psychological and psychosocial factors may be the most salient predictors of parental adjustment to a child's chronic illness across a number of illness populations. Yet, there has been a paucity of research on understanding similar psychosocial and psychological factors related to the adjustment of parents of children with brain tumors (Radcliffe et al., 1996). However, there are a number of studies that have delineated factors associated with parental distress within the general cancer literature and chronic illness literature. For example, studies on parental adjustment to childhood cancer have focused on lack of social support and maladaptive coping strategies as factors associated with poor adjustment (e.g., Chesler and Barbarin, 1987; Morrow et al., 1984; Speechley & Noh,

1992). Investigators have begun to examined other factors, such as uncertainty about one's child's illness, invasiveness of treatment, and situational variables and demographic variables (Van Dongen-Melman et al., 1995). Furthermore, prognosis, relapse, and prior stressful life events may also contribute to parental adjustment. These areas of research will be fully reviewed below.

Social Support. Social support is thought to play a large role in mediating the impact that the child's illness has on the parent. Parents of children with cancer in Koocher and O'Malley's (1981) study mentioned that the support of family members, their spouse, and friends made it possible for them to cope with the experience of having a child with cancer. Morrow et al. (1984) assessed adjustment difficulties in 107 parents of children with cancer and found that parent's perceived quality of support from their spouse, friends, relatives, and the physician was related to positive adjustment. In a more recent study, Speechley and Noh (1992) found that parents of children with cancer who were also experiencing low levels of social support showed higher levels of distress compared to normative samples. Parents in the control group (parents of healthy children), who also lacked social support, did not show levels of distress outside normative ranges. This suggests that having a child with cancer *and* having low levels of social support may put parents at an increased risk of experiencing distress. With regard to posttraumatic stress symptomatology, Kazak et al. (1997) found that higher levels of perceived social support were associated with fewer symptoms of PTSD. Notably, research in other areas of trauma have also found that social support can facilitate adjustment to traumatic stress (e.g., Golding, Siegel, Sorenson, Burnam, & Stein, 1989). In summary, social support may buffer the impact that the stressful and traumatic nature of

childhood cancer has on the parents. Additional research is needed assessing the generalizability of these findings to parents of children with brain tumors.

Coping Strategies. Other research has examined the relationship of specific coping strategies and the effectiveness of such strategies on how parents adjust to a child's chronic illness. Lazarus and Folkman (1984), as well as a number of other theorists (e.g., Endler & Parker, 1990; Roth & Cohen, 1986), have argued that it is useful to evaluate the ways in which people respond to stressful or life-threatening situations. Lazarus and Folkman (1984) conceptualize coping as a state dependent mediating variable between the person and the environment. In essence, Lazarus and Folkman (1984) define coping as a cognitive and behavioral process or action that serves the adaptive function of controlling internal and/or external demands which are perceived to be stressful. In this conceptualization, coping strategies are not thought of as preexisting traits or dispositions (i.e., something that someone *usually* does) but rather as a behavioral response to situational stressors (i.e., something that a person *actually* does) (Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986). Furthermore, coping is contextual, in the sense that it is descriptive of behavior occurring in a person-situation interaction (Folkman et al., 1986).

Originally, Folkman & Lazarus (1980) distinguished two broad domains of coping; emotion-focused and problem-focused. Problem-focused strategies are thought to reflect and individuals effort aimed at changing the person-environment relation. Emotion focused strategies are thought to reflect and individuals effort aimed at regulating one's emotional response and include strategies such as denial, avoidance, minimization, or positive reappraisal. The new Ways of Coping Checklist (WOC) Folkman and Lazarus

(1988) delineate 8 types of coping: Confrontive-Coping, Distancing, Self-Controlling, Seeking Social Support, Accepting Responsibility, Escape-Avoidance, Planful Problem Solving, and Positive Reappraisal. Researchers have aggregated these 8 discrete subscales into these two broad domains, with emotion focused coping consisting of Distancing, Self-Controlling, Accepting Responsibility, and Escape-Avoidance and problem focused coping consisting of Confrontive Coping, Seeking Social Support, and Planful Problem Solving (Miller et al., 1992).

Previous research utilizing the broad category distinction between emotion-focused and problem-focused coping has found that emotion focused coping may be problematic for individuals. For example, Miller et al. (1992) found increased levels of distress among mothers of disabled children who utilized emotion-focused strategies and lower levels of distress related to the use of problem-focused strategies. Huszti et al. (in preparation) have also found increased levels of distressing symptoms associated with emotion-focused strategies among mothers of children with cancer. Interestingly, problem-focused coping strategies may serve to inoculate against the development of PTSD symptoms. Solomon et al. (1989) found that among war veterans, those who use monitoring strategies (i.e., seeking out and attending to informational cues) report lower levels of PTSD symptomatology than veterans who use blunting strategies (i.e., avoiding informational cues about threat and attending to distracting stimuli). Furthermore, veterans who were classified as high monitors (used more monitoring strategies and less blunting) also reported using more problem-focused coping strategies in response to stressful events. Thus, the active problem solving strategies used by monitors may contribute to better post-traumatic adjustment. To date, there have been no studies which

have examined the potential relationship between coping strategies and psychological adjustments as it relates to either general levels of distress and/or PTSD symptomatology among parents of children with brain tumors.

Research is needed that helps to illuminate the particular situations in which the various types of coping strategies serve adaptive or maladaptive functions (Kupst, 1994). Perhaps some of the emotion-focused strategies, such as Escape-Avoidance coping, are adaptive in the initial contact with particularly stressful situations (e.g., observing one's child receive a spinal tap) because they allow parents short-term relief from experiencing emotional discomfort. However, these strategies could become over-utilized and generalize to other situations in the parent's life and lead to more distressing outcomes. Increased levels of global distress and the development of PTSD are examples of such outcomes. Other researchers have suggested that experiential avoidance of anxiety can have the contradictory effect of increasing it (e.g., Hayes, 1987; Hayes & Gifford, 1997). Likewise, Polusney & Follette (1995) suggest that emotional avoidance among sexual abuse survivors may increase the level of distress survivors experience as well as the number of related problems (e.g., revictimization, sexual dysfunction, and remaining in physically abusive relationships). In general, the emotion-focused coping strategies as measured by the WOC are consistent with this experiential/emotional avoidance perspective (Hayes, Wilson, Gifford, Follette, & Strosahl, 1996).

In summary, more research is needed which can clarify the relationship between particular coping strategies and psychological adjustment among parents of children with cancer and especially among parents of children with a brain tumor.

Uncertainty. Another factor that has received minimal attention within the literature, yet bears relevance to the study of parental and patient adjustment to cancer, is the illness uncertainty. In general, uncertainty refers to an individual's inability to assign definite value to an event or object and/or to make predictions about outcome (Mishel & Braden, 1988). With regard to disease, uncertainty is related to; the ambiguity about the current state of one's illness; the uncertainty about the treatment; lack of adequate information about the diagnosis and seriousness of the illness; and the unpredictable nature of the course of one's illness (Mishel, Hostetter, King, & Graham, 1984).

Patient's uncertainty about their illness, at least among non-cancer illness groups, appears to play a significant role in emotional adjustment (e.g., Mullins et al., 1995; Mullins et al., 1997). This same effect may be observed among caregivers of children with cancer. Van Dongen-Melman et al. (1994) interviewed 133 parents of children who survived cancer and found that uncertainty about their child's current condition, their future, prognosis, and parenting strategies were the most frequently reported problems.

Similarly, parents of children with a brain tumor may also have a great deal of uncertainty about their child's condition. The prognosis and neuropsychological outcome for these children can vary depending upon disease related factors, treatment and complications associated with treatment, patient factors, social factors, and family factors (Ris & Noll, 1994). This level of variability can be confusing for parents, making it difficult for them to predict the outcome of their child's illness, and thus adding to their level of uncertainty. Furthermore, not only do these parents face the same level of uncertainty that parents of children with other malignancies face, but they also may be confronted with other risk factors related to the damage to cerebral integrity and the

subsequent results (e.g., suboptimal behavioral, emotional, and cognitive outcomes; LeBaron et al., 1988; Noll et al., 1992). Uncertainty about factors such as the child's brain tumor diagnosis, his or her treatment protocol, or the child's future may play a significant role in how parents of children with brain tumors emotionally and psychologically adapt. To date, there are no studies examining the relationship of parental uncertainty to parental adaptation to childhood brain tumors.

Invasiveness of Treatment. Another factor related to parental adjustment may be the invasiveness of the treatment protocol that parents witness. In the study mentioned above investigating PTSD among parents of leukemia survivors, Stuber et al. (1996) found that medical procedures such as bone marrow aspirates or spinal taps were often reported as being traumatic events for these parents. Likewise, being witness to invasive medical procedures that children have to undergo can be extremely distressing for parents (e.g., Jay & Elliot 1990; Jay et al., 1983). Boyer and Barakat (1996) comment that waiting for test results and observing painful procedures may be experienced as a crisis for some parents of children with cancer. This distress experienced in anticipation of aversive medical procedures can be so extreme that the child as well as the parents may exhibit symptoms such as nausea, vomiting, insomnia, nightmares, and skin rashes prior to the procedures (Katz & Jay, 1984).

Although these factors may be initially stressful for parents during the acute phase of treatment, the long-term effects remain unknown. In a preliminary investigation, Van Dongen-Melman et al. (1995) did not find that intensity of chemotherapy or the use of radiation therapy was related to the parents' late psychosocial adjustment. However, they did find that the parents of children who underwent surgery reported more negative

feelings (i.e., a combination of increased anxiety, disease-related fears, sleep disturbances, loneliness, depression, and psychological distress). The children who underwent surgery were more likely to have medical side effects, which was further associated with perceived loss of control and negative feelings among parents. Overall, the invasiveness of the treatment protocol and its immediate and long term effects on parents' psychological adjustment has not been adequately examined in the pediatric oncology literature. Likewise, no investigations to date have included the effects of these factors among parents adjusting to their child's brain tumor illness. It remains to be seen what effect these factors have on the parents' level of adjustment.

Prognosis and Relapse. Consideration of the impact of treatment cannot be interpreted without understanding what role disease related factors play. Certainly the type of tumor and the rate of growth will determine the aggressiveness of treatment. The prognosis and whether or not relapse occurs may also contribute to a parent's level of distress. Relapse can be associated with poorer prognosis, and some parents of children with cancer perceive the relapse as even more distressing than the initial diagnosis (Koocher & O'Malley, 1981).

Situational and Demographic Variables. Situational and demographic variables may also contribute to parental adjustment. Low socioeconomic status (SES) has been associated with greater levels of depression and anxiety symptoms among parents of children with cancer (Speechley & Noh, 1992). Similarly, Van Dongen-Melman et al. (1995) found that a combination of situational and demographic variables (low SES, no religious affiliation, and chronic disease in another family member) increased the risk for poorer psychological adjustment among parents. They conjectured that parents who have

these multiple stressors may have more difficulties coping with their child's cancer. Other variables, such as age of child and mother at diagnosis, length of time since diagnosis, and current age of the child may also contribute to parental adjustment. Further, the developmental stage at which a child becomes ill and the length of time since diagnosis can play a role in the child's psychological adaptation. Koocher, O'Malley, Gogan, & Foster (1980) found that the younger a child was at time of diagnosis and the greater the number of years since diagnosis, the less likely the child was to have adjustment problems later in life. How this impacts the parent of a child with a brain tumor is unknown.

Stressful Life Events. Finally, prior and current experience with stressful life events may play a role in determining posttraumatic symptom severity. Among war veterans, King et al. (1996) found that previous trauma history directly predicted PTSD. McFarlane (1988) found that among bushfire victims, individuals with chronic PTSD had more adverse life events prior to the trauma. Thus, concurrent and prior history with stressful life events may also play a role in parental adjustment to their child's life-threatening illness. No studies have examined this variable in the pediatric brain tumor population, and the link between these variables needs to be explored in this population.

In summary, research has not addressed the variables mentioned above, i.e. social support, emotion-focused and problem focused coping strategies, uncertainty, illness severity, invasiveness of treatment, prognosis and relapse, situational and demographic variables, and prior stressful life events among parents of children with a brain tumor. Adequate research is needed investigating what role these variables have on the parents general level of distress, as well as posttraumatic stress.

CHAPTER III

STATEMENT OF PURPOSE

A number of studies from the general pediatric cancer literature, as well as from the pediatric brain tumor literature, point to the need to further examine the role that a child's illness plays in parental adjustment. Although some parents of children with a life threatening illness may adjust well to their child's condition, a significant portion of parents may experience distressing symptomatology (e.g., Kazak et al., 1994). The extant literature indicates that these parents show signs of depression and anxiety, yet researchers also recognize that these symptoms may not fully characterize the specific nature of parental adaptation. Further, the measures used to assess adaptation have traditionally been global assessment measures that focus only on symptoms of depression and anxiety.

Since the early 1980's, researchers have begun to conceptualize parental adaptation to cancer as a stress-related phenomena characterized by fear and uncertainty (e.g., Koocher & O'Malley, 1981). Recently, researchers have begun to focus on possible posttraumatic stress symptoms that parents may display in response to having a child diagnosed and treated for cancer (Barakat et al., 1998; Kazak et al., 1997; Pelcovitz et al., 1996; Stuber et al., 1996). Unfortunately, parents of children with a brain tumor have not been included in many of these studies examining adjustment. Oftentimes, research examining parental adaptation to childhood cancer excludes this special subset of children

with brain tumors because the disease and treatment are seen as unique and more troublesome (Radcliffe et al., 1996). The parents of these children may experience many of the same types of stressors that parents of other cancer patients face. Further, they may encounter additional and unique stressors, such as those related to the aggressive treatment, physical side effects, and manifestations of the disease and its life threatening nature. Only one study (Radcliffe et al., 1996), utilizing standardized measures of assessment, has attempted to examine psychological adjustment among the mothers of these children. However, this investigation did not take into account stress-related symptoms, such as those related to PTSD. In addition there have been no studies examining father's level of adjustment in the childhood brain tumor population.

Further, studies have failed to examine the predictors associated with increased levels of both general and posttraumatic types of distress. These factors may include demographic variables (income and age of parent), illness variables, level of social support, coping strategies, and illness uncertainty. Given the overall lack of literature examining parental adjustment and predictor variables associated with increased symptomatology, there is a tremendous need to assess and examine these aspects among parents of children with brain tumors. Thus, the purpose of this study was designed to investigate both global distress and PTSD status among parents of children with brain tumors, as well as investigate some of the predictors of poor adjustment. Based upon the sparse literature available on parental adaptation to childhood brain tumors, as well as the more considerable research on parental adaptation to other cancers, the following hypotheses were investigated.

Hypothesis 1: It was hypothesized that parents of children with a brain tumor would exhibit significant levels of general distress as compared to normative data, and PTSD prevalence would be similar to that found in other studies examining PTSD among parents of children with cancer.

Specifically, it was expected that parent's reports of general levels of distress, as measured by the Brief Symptom Inventory (BSI), would be at least one standard deviation above the standardization sample mean established for this measure. With regard to posttraumatic stress, it was expected that a subset of parents of children with brain tumors, approximately 25%, would meet symptom criteria for PTSD (i.e., one or more Criterion B symptoms, three or more Criterion C symptoms, and two or more Criterion D symptoms). Incidence estimates investigating current PTSD as defined by the DSM-III-R have been as high as 25% among parents of children with non-CNS cancers (Pelcovitz et al., 1996).

Hypothesis 2: It was further hypothesized that social support, illness uncertainty, and coping strategies, would be significantly related to global levels of distress and posttraumatic symptom severity. It was believed that these variables would also predict global distress and posttraumatic symptom severity beyond demographic and illness variables in a hierarchical multiple regression analysis.

Specifically, it was expected that:

(1) A negative relationship would emerge between scores related to social network size and density (measured by Social Network Reciprocity and Dimensionality Assessment Tool; SNRDAT) and both posttraumatic symptom severity (measured by the

Posttraumatic Diagnostic Scale; PDS) and global distress (measured by the Global Severity Index of the Brief Symptom Inventory; BSI-GSI).

(2) Greater illness uncertainty (measured by the Mishel Uncertainty in Illness Scale; MUIS) would be related to higher levels of posttraumatic symptom severity (measured by the PDS severity subscale) and global distress (measured by the Global Severity index on the BSI).

(3) A positive relationship would emerge between emotion-focused coping and global distress and posttraumatic symptom severity. A similar positive relationship was expected for specific subscales which comprised emotion-focused coping (Distancing, Self-Controlling, Accepting Responsibility, Escape-Avoidance coping, and Positive Reappraisal) and measures of adjustment. On the other hand, a negative relationship was expected between problem-focused coping and global distress and PTSD severity. Likewise, an inverse relationship was expected between the specific problem-focused coping subscales (i.e., Confrontive Coping, Planful Problem Solving, and Seeking Social Support) and the measures of adjustment. This combination of the discrete subscales to make up the broad emotion-focused and problem-focused dimensions has been employed in previous literature examining parental adjustment to child disability (Miller, Gordon, Daniele, and Diller, 1992).

Two hierarchical multiple regression analyses were employed to examine the contribution of each of these predictor variables on PTSD severity and on the BSI Global Severity Index. Entry of variables was based upon Thompson's (1985) transactional stress and coping model.

Exploratory Analyses

From an exploratory standpoint, this study sought to examine the following additional research questions.

1) What is the relationship between parent's family, friendship, & professional social support networks and their self-reported level of adjustment?

2) What is the relationship between the parent's self-reported levels of adjustment and their perceptions of their child's health status, coping, and medical treatment adherence?

3) What role does escape-avoidance coping play in adjustment? It was reasoned that parent's efforts aimed at avoiding the stressful situation of their child's illness may be associated with an increase in distress. This is consistent with theories that suggest that experiential avoidance of anxiety has the contradictory effect of increasing it (e.g., Hayes, 1987). Further, researcher have suspected that avoidance and denying psychological distress may be a common strategy for parents and families adjusting to pediatric cancer (Kazak et al., 1997, Radcliffe, 1996). Thus, two hierarchical multiple regression analyses were employed to examine the contribution of social support, illness uncertainty, and Escape-Avoidance coping on PTSD severity and on the BSI Global Severity Index. Entry of variables was based upon Thompson's (1985) transactional stress and coping model.

CHAPTER IV

METHOD

Participants

A total of 27 parents of 18 pediatric brain tumor patients from the Children's Hospital of Oklahoma agreed to participate in the study. This included 17 mothers and 10 fathers. Nine packets returned were from parental dyads, and 9 were returned by only one parent. All participants were custodial parents.

A majority of the parents were Caucasian (85%), 7.4% were African American, and 7.4% were Native American. The average age of parents was 42.5 (SD = 6.7) with a range from 31 years to 57 years. The median annual income fell within the $20,000 to and 29,999 range. Educational level averaged 13 years (SD = 2.73). Twenty-three parents were married, and 4 were single.

At the time of diagnosis, children were between 3 months and 17 months (M = 6.9 months) of age. At the time of the study all children were living, and the mean length of survival from time of diagnosis was 7 years, 2 months. Diagnoses included Astroblastoma (n = 1), Astrocytoma (n = 4), Ependymoma (n = 1), Medulloblastoma (n = 6), Optic Pathway Tumor Chaismatic/Hypothalamic Glioma (n = 1), Primitive Neuroectodermal Tumor (n = 3), and two unspecified brain tumors.

Measures

Demographic and Illness Variables.

Parents were asked to respond to a number of questions assessing demographic variables (Appendix A). Within this demographic questionnaire included inquiries about the parent's age, education, and income as. Other variables, such as age of child and parents at diagnosis, and religious affiliation were also assessed in the demographics questionnaire.

A chart review provided the specific diagnosis and date of diagnosis. The duration of survival in months was used as the main illness parameter.

Primary Independent Variables

The Social Network Reciprocity and Dimensionality Assessment Tool (SNRDAT; Kazak 1987; Kazak et al., 1997) is a self-administered social network assessment questionnaire. The SNRDAT asks parents to create a list of persons that they would describe as helpful. This refers to the parents' social network. The SNRDAT also asks parents to describe the extent to which network members know and interact with each other, referred to as density. Studies have shown that psychological adjustment may be affected by both network size and density (Kazak et al., 1997; Kazak, Reber, & Carter, 1988; Trute & Hauch, 1988).

The Ways of Coping-Revised (WOC-R; Folkman & Lazarus, 1988) is a 66 item self-report questionnaire developed to assess the coping strategies that individuals engage in when faced with a specific stressful situation. In the original instrument, respondents indicated the frequency in which they engage in various coping strategies in response to a self-determined stressful event. For the purpose of this study, parents were asked to

indicate the frequency with which they engaged in the various coping strategies in response to the specific stressor of their child's illness. This was done to insure that parents are responding to the same defined event.

Factor analysis of the items on the WOC-R results in eight groups of strategies (Folkman & Lazarus, 1988). The eight scales as described by Folkman and Lazarus, 1988 include the following: Confrontive Coping (efforts made to alter a stressful situation and suggests some degree of hostility or risk taking), Self-Controlling (efforts made to regulate one's feelings and actions), Seeking Social Support (efforts directed toward seeking informational, tangible, or emotional support), Accepting Responsibility (acknowledging one's role in the problem), Escape-Avoidance (behavioral efforts made to escape or avoid the problem and wishful thinking), Planful Problem Solving (efforts made to alter the situation, coupled with an analytic approach to solving the problem), and Positive Reappraisal (efforts to create positive meaning by focusing on personal growth). The reliability for the eight coping scales ranges from .61 to .79. For this study, the discrete subscales were combined into two broad scales: problem-focused and emotion-focused. In general, problem focused coping strategies reflect efforts directed toward managing the person-environment relationship that is the source of the stress, whereas emotion focused coping reflect an individuals efforts to manage their own emotions (Folkman & Lazarus, 1988). Problem-focused coping included confrontive coping, planful problem solving, and seeking social support. Emotion focused coping included distancing, self-controlling, self-blame, escape-avoidance, and positive reappraisal. This combination of the discrete subscales to make up the broad emotion-focused and problem-

focused dimensions has been employed in previous literature examining parental adjustment to child disability (Miller, Gordon, Daniele, and Diller, 1992).

Relative scores, rather than raw scores, were used in order to more accurately reflect individual coping differences (Vitaliano, Maiuro, Russo, & Becker, 1987). Relative scores reflect a percentage score of coping efforts accounted for by each strategy. Higher scores indicate that a person utilized these coping behaviors more often than other coping behaviors. Relative scores are obtained by the following: 1) calculating a mean response for each subscale (i.e., dividing the raw score by the number of items in the scale); 2) summing the mean responses across all subscales; 3) dividing the mean response for each subscale score by the sum of averages for all eight subscale scores (Folkman & Lazarus, 1988).

The Mishel Uncertainty in Illness Scale - Community Form (MUIS-C; Mishel 1981) is a 23-item self-report scale that asks respondents to rate on a 5-point scale the degree to which they agree or disagree with a variety of illness uncertainty statements. The statements depict four components of illness uncertainty: ambiguity, uncertainty, lack of information, and unpredictability. The MUIS-C yields a single composite score, with higher scores reflecting greater illness uncertainty. Previous studies have shown the MUIS-C to be a reliable and valid measure of illness uncertainty across a number of chronic disease states (e.g., Mishel & Braden, 1988; Mullins et al., 1995; Mullins et al., in press).

Dependent Variables

The Posttraumatic Stress Diagnostic Scale (PDS; Foa, 1996) was used to assess PTSD symptom severity. The PDS is a self-report inventory comprised of 49 items

designed to aid in the detection of and diagnosis PTSD. In addition, the PDS also classifies severity of PTSD and level of impairment in functioning. The item content for the PDS assessment closely resemble the diagnostic criteria for PTSD as outlined in the Diagnostic Statistical Manual fourth edition (DSM-IV; American Psychiatric Association, 1994). The PDS has been shown to have high test-retest reliability (.83 for symptom severity index) and internal consistency (Cronbach alpha = .92). Validity has also been shown to be high. In a study comparing the symptom severity score with the Structured Clinical Interview (SCID; Williams et al., 1992) the author found a kappa of .59 between the PDS and the SCID, with 79.4% agreement between the two measures. Sensitivity (82%) and Specificity (76%) were also high, indicating that the PDS is a valid tool for assessing PTSD (Foa, 1996). All parents were asked to fill out the PDS as it relates to their child's condition in order to assess PTSD symptom severity.

The Brief Symptom Inventory (Derogatis 1993; Derogatis & Spencer, 1982) is a short version of the Symptom Checklist-90-Revised (SCL-90-R; Derogatis, 1983) containing 53 items instead of 90. The BSI yields measures of nine clinical dimensions of psychological distress with *T* scores ranging from 30 to 80. The BSI has been shown to be highly correlated with the SCL-90-R, as well as having high internal consistency (.71-.85) and test-retest reliability (.68-.91) (Derogatis, 1993).

Respondents are asked to indicate the frequency to which they experience various psychological or physical symptoms within the past seven days. The Global Severity Index (GSI) score from the BSI was used to assess overall parental distress. The use of the GSI for both the SCL-90-R and the BSI is constant with previous research assessing parental adjustment to childhood chronic illness (Kronenberger & Thompson, 1992;

Miller, Gordon, Daniele, & Diller, 1992; Mullins et al., 1991). In addition, the BSI provides *T* scores that can be examined in terms of caseness. An individual is said to meet caseness if GSI *T* score is greater than or equal to 63 or if on any other two subscale scores *T* is greater than or equal to 63. Although research regarding caseness on sensitivity and specificity is not as extensive as it is with the SCL-90-R, the BSI caseness criteria is considered to provide a good indicator of a positive case (Derogatis, 1993). The caseness criterion for maladaption, at least with the SCL-90-R, has been utilized by a number of researchers investigating adaptation to chronic illness (e.g., Mullins et al., 1997; Thompson, 1985; Thompson, Gustafson, Hamlett, & Spock, 1992).

Procedure

Attempts were made to contact 53 families of children who had been diagnosed with some form of brain tumor. These families had received (or were currently receiving) treatment since 1979 to the current time from the Children's Hospital of Oklahoma Jimmy Everest Center for Cancer and Blood Disorders in Children. Although 62 children had been diagnosed with some form of brain tumor since 1979, current addresses were available for only 53 families. Letters were sent to these families inviting them to participate in the study. Twenty-three agreed to participate and were mailed packets. Thirteen families were approached and invited to participate upon their scheduled appointment to the Comprehensive Brain Tumor Clinic held monthly and were given the protocol to take home and return when completed. Three families refused to participate, stating that it was too emotionally difficult to think about and report on their child's illness. Of the 23 who had been mailed packets and the 13 given packets during the CBT Clinic, a total of 27 families returned the packets.

For the mail solicitation, a list of parent's names and addresses were provided by the child's primary physician. Letters inviting parents to participate were sent along with post-cards. Parents were asked to return the post-card if they were interested in participating. If parents indicated they were interested, they were sent a packet of questionnaires and a self-addressed stamped envelope. Follow-up calls were made on a two-week basis to find out if they had any questions or concerns about the material.

Parents were also recruited through the CBTC. Prior to the child's regularly scheduled appointment a letter was sent to all parents describing the purpose and nature of the study. During their scheduled visit to the clinic parents were again informed about the study, and, if interested, they were given a packet of questionnaires and a self-addressed stamped envelop to take home and fill out at their convenience. Follow-up calls were made on a two-week basis.

All packets included a description of how to complete the questionnaires, phone numbers to call if they had questions, and written consent forms (Appendix B). The questionnaire packet was the same for fathers as for mothers and included a demographics questionnaire, the Social Network Reciprocity and Dimensionality Assessment Tool (SNRDAT; Kazak, 1987), the Ways of Coping Scale-Revised (WOC-R; Folkman & Lazarus, 1988), the Mishel Uncertainty in Illness Scale-Community Form (MUIS-C; Mishel 1981), the Posttraumatic Diagnostic Scale (PDS; Foa, 1996), and the Brief Symptom Inventory (BSI; Derogatis 1993). Parents were asked to independently complete the questionnaires in order to insure anonymity, as well as to promote disclosure.

Upon completion, parents were sent a thank you letter. For every family who participated, a five-dollar donation was made by the researcher to the Make-A-Wish Foundation. Prior to taking the packets home, parents at the brain tumor clinic were offered the choice of a toy from a grab bag of toys to give to their child. Because toys would have been too expensive to send through the mail, parents recruited through the mail were mailed a gift certificate of equivalent value ($5.00).

CHAPTER V

RESULTS

Preliminary Analyses

Preliminary analyses were first conducted in order to examine the effect of parent's gender and the source of recruitment (i.e., parents recruited from the childhood brain tumor clinic or from patients diagnosed at the Jimmy Everest Center but not seen in the childhood brain tumor clinic) on primary measures. A 2 X 2 (gender X recruitment source) multivariate analysis of variance revealed no main effect or interactions for the BSI GSI, the PDS Severity Index, the SNRDAT Network Size dimension, the MUIS, or the WOC-R. A one-way multivariate analysis of variance was conducted for the SNRDAT Network Density dimension because missing data on this dimension prevented entering it in the above MANOVA. Likewise, no main effect for gender or recruitment source was found.

Hypothesis 1:

It was hypothesized that parents would exhibit significant levels of general distress as compared to normative data, and PTSD prevalence would be similar to that found in other studies examining PTSD among parents of children with cancer.

Means and standard deviations for the primary scales for the variables of interest are shown in Table I. As can be seen, the mean T score for the parents' score on the BSI

GSI scale was 61.27 (SD = 14.62), which is over one standard deviation above the mean for the normative group mean of 50. Notably, elevations above one standard deviation were also observed on the obsessive-compulsive, depression, anxiety, and the psychoticism subscales. Using Derogatis' (1993) criteria for caseness, 15 of the 26 (58%) parents evidenced significant levels of distress according to this criteria. Mothers scores were more elevated than fathers (M = 63.69, M = 57.4 respectively), however, this was not a significant difference. These data support the hypothesis that parents would exhibit significant levels of overall distress compared to normative data, suggesting that parents of children with CNS-malignancies may be at risk for emotional distress.

Of the 27 parents in the study 12 (44.4%) met DSM-IV criteria for PTSD(i.e., one or more reexperiencing symptoms, three or more avoidance symptoms, and two or more arousal symptoms). According to the severity rating scale for the PDS (Foa, 1995), the PTSD severity score for those who met criteria for PTSD fell within the "Moderate to Severe" range (M = 25.25). Also, for parents with PTSD, their Level of Impairment in Functioning Scores placed them within the "Severe" range (M = 7). These parents reported that posttraumatic stress symptoms affected and interfered with fun and leisure activities, relationships with family, general satisfaction with life, and overall level of functioning in all areas. Proportionately, slightly more mothers (8 of the 17; 47%) than fathers (4 of the 10; 40%) met criteria for PTSD. PTSD severity for all parents, regardless of diagnostic status, fell within the "moderate" range (M = 14.12). Similarly, their Level of Impairment in Functioning score placed them in the "Moderate" range. Thus, these data do support the expectation that prevalence rates of PTSD in this sample would equal or surpass 25%.

Table 1

Means and Standard Deviations for the BSI and PDS.

	All Parents (n=26)		Parents with PTSD (n=12)		Parents without PTSD (n=14)	
Measures	Mean	SD	Mean	SD	Mean	SD
Brief Symptoms Inventory						
Global Index Score	61.27	14.62	71.50	7.37	52.50	13.64
Depression	60.27	11.81	69.25	4.71	52.57	10.54
Anxiety	61.15	13.26	68.33	5.91	55.00	14.83
Obsessive-Compulsive	62.27	13.23	72.00	8.14	53.93	10.87
Psychotisism	63.54	11.60	71.08	8.27	57.07	10.16
PDS – Severity*	14.3	13.64	25.25	13.08	5.33	5.23

Note. *Means and standard deviations are from 27 participants, 12 with PTSD and 15 without PTSD. PDS = The Posttraumatic Stress Diagnostic Scale – Severity subscale (PDS; Foa, 1996)

For illustrative purposes, Table 2 shows the number of parents reporting each type of PTSD symptom within the last month. For all parents, regardless of PTSD status, more than two-thirds reported experiencing intrusive and upsetting thoughts or images about their child's illness and treatment, and feeling emotionally upset when reminded of their child's illness and treatment. Few parents, less than one-fourth, had difficulty recalling aspects of their child's illness and treatment and did not report being "overly alert".

Table 2.

Rates of PTSD Symptoms Reported By Parents.

DSM-IV Symptoms	Number of Parents Reporting Symptoms	
	Parents with PTSD (n=12)	All Parents (n=27)
B. Reexperiencing Symptoms		
B1. Intrusive recollections	10 (83%)	18 (67%)
B2. Recurrent distressing dreams	11 (92%)	15 (56%)
B3. Acting/feeling as if the event was recurring	10 (83%)	11 (44%)
B4. Psychological distress at exposure to cues	12 (100%)	22 (81%)
B5. Physiological reactivity on exposure to cues	9 (75%)	13 (48%)
C. Avoidance Symptoms		
C1. Avoiding thoughts, feelings, or conversations about event	11 (92%)	16 (59%)
C2. Avoiding activities, places, or people that arouse recollections	9 (75%)	10 (37%)
C3. Inability to recall important aspects of the trauma	6 (50%)	6 (22%)
C4. Diminished interest in activities	11 (92%)	13 (48%)
C5. Feelings of detachment or estrangement	12 (100%)	14 (52%)
C6. Restricted range of affect	8 (67%)	11 (41%)
C7. Sense of foreshortened future	10 (83%)	14 (52%)
D. Arousal Symptoms		
D1. Difficulty sleeping	12 (100%)	17 (63%)
D2. Irritability	11 (92%)	13 (48%)
D3. Difficulty concentrating	10 (83%)	14 (52%)
D4. Hypervigilance	5 (42%)	6 (22%)
D5. Exaggerated startle	8 (67%)	10 (37%)

Hypothesis 2: It was hypothesized that social support, illness uncertainty, and coping strategies, would be significantly related to global levels of distress and PTSD severity. It was believed that these variables would also predict global distress and PTSD

severity beyond demographic and illness variables in a hierarchical multiple regression analysis.

Inter-correlations

First, 1-tailed zero-order correlations were performed to determine the interrelationship among the primary measures (see Table 3). As can be seen, the results support the hypothesis that social network size would be related inversely to both posttraumatic symptom severity ($r = -.37$, $p \leq .05$) global distress ($r = -.44$, $p \leq .05$). Larger total social network size was associated with lower scores on the adjustment measures. However, network density was not related to posttraumatic stress symptom severity nor to global distress.

Also, as expected higher levels of illness uncertainty was related to greater posttraumatic symptom severity ($r = .39$, $p \leq .05$) and global distress ($r = .56$, $p \leq .01$).

With regard to coping strategies, it was expected that a positive relationship would emerge between emotion-focused coping and global distress and posttraumatic stress symptom severity. A positive relationship between the specific emotion focused subscales (i.e., Distancing, Self-Controlling, Accepting Responsibility, Escape-Avoidance, and Positive Reappraisal) and adjustment was also expected. On the other hand, a negative relationship was expected between problem-focused coping strategies and global distress and PTSD severity and a similar relationship was expected for the specific subscales (i.e., Confrontive Coping, Planful Problem Solving, and Seeking Social Support). In this sample, proportionately more parents utilized emotion-focused coping behaviors than problem-focused (60% vs. 40%).

As expected emotion-focused coping was related in a positive direction to posttraumatic stress severity ($r = .39$, $p \leq .05$) and global distress ($r = .53$, $p \leq .01$). Thus, greater reliance on efforts to manage one's emotional response to stressful situations was associated with higher scores on the measures of adjustment. Examination of the specific emotion-focused coping subscales revealed that Escape-Avoidance, Accepting Responsibility, and Self-Controlling were related in a positive direction to posttraumatic stress severity ($r = .49$, $p \leq .01$; $r = .49$, $p \leq .01$; and $r = .39$, $p \leq .05$ respectively) and global distress ($r = .61$, $p \leq .01$ and $r = .57$, $p \leq .01$; $r = .32$, $p \leq .05$). Thus, greater reliance on these strategies was associated with higher scores on the adjustment measures. Distancing was not significantly related to the adjustment measures. Interestingly, Positive Reappraisal was inversely related to both measures of adjustment (PTSD severity $r = -.47$, $p \leq .01$ and BSI GSI $r = -.43$, $p \leq .05$). Thus, greater reliance on Positive Reappraisal was associated with lower scores on the adjustment measures.

As hypothesized, problem-focused coping was inversely related to posttraumatic stress and global distress. Thus, greater use of efforts to managing the person-environment relationship was associated with lower scores on the adjustment measures. The specific subscale that was inversely related to posttraumatic symptom severity and global distress was Seeking Social Support ($r = -.37$, $p \leq .05$ and $r = -.48$, $p \leq .01$ respectively). Thus, greater efforts made toward seeking social support was related to lower scores on the adjustment measures. Planful Problem Solving was significantly, negatively correlated with global distress ($r = -.40$, $p \leq .05$), but not posttraumatic symptom severity. Thus, greater utilization of this strategy was related lower scores on

the BSI GSI, but not to posttraumatic symptom severity scores. Confrontive coping was not significantly related with the adjustment measures.

Parents age and time since diagnosis was found to be inversely related to posttraumatic symptom severity ($\underline{r} = -.43$, $\underline{p} \leq .05$ and $\underline{r} = -.35$, $\underline{p} \leq .05$ respectively). Thus, older parents and a longer duration of time since diagnosis was associated with lower scores on the posttraumatic stress severity measure. Global distress was unrelated to parents age, but lower levels of global distress was related to a longer duration of time since diagnosis ($\underline{r} = -.33$, $\underline{p} \leq .05$). Although not significant, there was less temporal distance between the time of the study and their child's diagnosis for parents who met criteria for PTSD than those who did not (6 years 2 months vs. 7 years 10 months).

Table 3

Zero – Order Correlations Among Primary Variables.

Variable	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18
1. Age																		
2. Education	-.01																	
3. Time Since Diagnosis	.49**	-.09																
4. Network Size	.13	-.22	.37*															
5. Network Density	-.00	-.21	.37*	-.68**														
6. MUIS	.21	-.34*	.07	-.38*	.43*													
7. Confrontive Coping	.13	-.08	.45**	.31	-.31	.22												
8. Distancing	.25	-.27	-.04	-.13	.22	.28	-.30											
9. Self Controlling	.09	-.11	.16	-.49**	.30	.42*	-.09	.48**										
10. Seeking Social Support	-.08	.07	.03	.47**	-.26	-.38*	.10	-.66**	-.58**									
11. Accepting Responsibility	-.16	-.01	.06	-.35*	.12	.41*	.14	-.08	.17	-.47**								
12. Escape-Avoidance	-.13	.01	-.21	-.41*	.25	.32	-.36	.36*	.42*	-.46**	.21							
13. Planful Problem Solving	-.08	.07	-.08	.12	-.16	-.34*	.28	-.32	-.36*	.26	-.19	-.56**						
14. Positive Reapraisal	.01	.21	-.13	.35*	-.18	-.54**	-.21	-.37*	-.66**	.46**	-.44*	-.48**	.05					
15. EMC	.05	-.05	-.11	-.45**	.31	.34*	-.49**	.67**	.57**	-.81**	.35*	.66**	-.71**	-.27				
16. PFC	-.05	.05	.11	.45**	-.31	-.34*	.49**	-.67**	-.57**	.81**	-.35*	-.66**	.71**	.27	-1.00**			
17. PTSD Severity	-.43*	-.08	-.35*	-.37*	.05	.39*	-.14	.07	.39*	-.37*	.49**	.49**	-.23	-.47**	.39*	-.39*		
18. BSI GSI	-.05	-.07	-.33*	-.44*	.16	.56**	-.10	.17	.32*	-.48**	.57**	.61**	-.40*	-.43*	.53**	-.53**	.71**	

Note: EMC = emotion-focused coping; PFC = problem focused coping *$p < .05$, **$p < .01$,

Regression Analyses

The second part of hypothesis 2 stated that psychosocial variables (social support, illness uncertainty, and emotion-focused coping) would predict global distress and posttraumatic symptom severity beyond demographic and illness variables in a hierarchical multiple regression analysis. Two hierarchical multiple regression analyses were conducted to examine the contribution of each of the predictor variables on PDS severity and on the BSI-GSI. Entry of variables was based upon Thompson's (1985) transactional stress and coping model. On step 1, age of parent was entered and on step 2 the illness variable (number of months child has survived beyond diagnosis) was entered. On step 3, social support (network size), illness uncertainty (MUIS), and emotion-focused coping variables were entered. To examine the possible moderating effects of illness uncertainty and emotion-focused coping on adjustment an interaction variable (MUIS x emotion-focused coping) was entered on step 4. This interaction, as opposed to other possible interactions, was chosen in order to specifically examine the effects of behavioral coping efforts aimed at modifying emotion which occur under conditions of the cognitive appraisal of uncertainty have on adjustment. Thus, the regression analyses were hierarchical between steps and stepwise within steps (Cohen & Cohen, 1983). This model was chosen based upon the assumption that social support, illness uncertainty and coping strategies would explain additional variance in posttraumatic symptom severity and the BSI GSI beyond the relevant demographic and illness variables.

Results of the regression analysis predicting PTSD severity can be seen in Table 4. PTSD severity was significantly associated with the first step (age of parents; R^2 change = .18, $p < .05$) but not the second. After controlling for demographics and illness variables

on steps 1 and 2, there was a significant effect associated for the third step (social support, illness uncertainty, and emotion-focused coping; R^2 change = .29, $p < .05$) with 12% of unique variance explained by illness uncertainty ($\beta = .40$, $p < .05$). There was no significant effect associated with the illness uncertainty - emotion-focused interaction. The set of variables accounted for a total of 50% of the variance in PTSD severity ($p < .05$).

Table 4.

Hierarchical Multiple Regression Analysis Predicting PTSD severity

Step	Predictor Variable	β	t for Within Step Predictors	R^2 Change	F Change for Step	Part Corr. (r_{sp})
1	Age	-.43	-2.37*	.184	5.63*	-.402
2	Time Since Diagnosis	-.19	-.914	.027	.836	-.107
3	Social Network Size	-.01	-.073	.289	4.25*	.011
	MUIS	.40	2.27*			.349
	Emotion-focused Coping	.27	1.51			.233
4	MUIS x emotion focused	.37	.244	.001	.059	.039

Note: *$p < .05$

The results of the regression analysis predicting BSI global distress can be seen in Table 5. BSI GSI was not associated with the first block (age of parents; R^2 change = .002, p = NS) or the second (time since diagnosis; R^2 change = .118, p = NS). There was a significant effect associated for the third step (social support, illness uncertainty, and Escape-Avoidance coping; R^2 change = .47, $p < .01$) with 17% of unique variance explained by illness uncertainty ($\beta = .44$, $p < .05$). There was no significant effect associated with the illness uncertainty - emotion-focused interaction. The set of variables accounted for a total of 55% of the variance in global distress ($p < .05$).

Table 5.

Hierarchical Multiple Regression Analysis Predicting BSI Global Severity Index

Step	Predictor Variable	β	t for Within Step Predictors	R^2 change	F Change for Step	Part Corr. (r_{sp})
1	Age	-.05	-.245	.002	.809	-.015
2	Time Since Diagnosis	-.39	-1.76	.118	.092	-.259
3	Social Network Size	.01	.051	.421	.001	.008
	Illness Uncertainty (MUIS)	.48	2.61*			.411
	Emotion-Focused Coping	.33	1.91			.289
4	MUIS x emotion focused	.94	.65	.010	.416	.099

Note: *$p < .05$

Exploratory Analyses

Research Question #1:

What is the relationship between parent's family, friendship, and professional social support networks and their self-reported level of adjustment?

One-tailed zero-order correlations were performed to determine any significant relationship among the above noted variables (see Table 6). Size of family network was significantly negatively correlated with posttraumatic symptom severity, global distress, and illness uncertainty. Family density was significantly negatively correlated with posttraumatic symptom severity and global distress. Size of friends network was significantly negatively correlated with the global distress. The perceived degree of helpfulness of parent's professional networks was significantly negatively associated with illness uncertainty, posttraumatic symptom severity, and global distress. The perceived helpfulness of parent's friendship networks was significantly negatively associated with global distress. These finding suggest that size of social networks is important, but equally

important is the quality of social networks. Parent' who perceived their family, friends, and professionals to be helpful reported less uncertainty and better adjustment.

Research Question #2:

What is the relationship between the parent's self-reported levels of adjustment and their perceptions of their child's health status, coping, and medical treatment adherence?

Parents were asked to report on how well they thought their child was coping with their illness, how well they adhered to the medical treatment, and their perceptions of their child's current health status compared to the previous year. Examination of table 6 revealed that positive parent perceptions of health status and adherence were related to less general distress. Positive parent perceptions of how well their child was coping was related to less illness uncertainty.

Table 6

Zero – Order Correlations Among Primary Variables

Variables	Illcope	Health Status	Adherence	Family Network Size	Family Helpfulness	Family Density	Friends Network Size	Friend Helpfulness	Professional Network Size	Professional Helpfulness
MUIS	-.408*	-.480**	-.444*	-.417*	-.252	.104	-.297	-.029	-.182	-.380*
PTSD Severity	-.046	-.301	-.153	-.457**	-.002	-.607**	-.282	-.118	-.156	-.434*
BSI GSI	-.146	-.408*	-.447*	-.399*	-.330	-.363*	-.453*	-.376*	-.126	-.434*

Illcope = Parent's rating of how well they think their child copes with their illness

Health Status = Parent's rating of current overall health status compared to the previous year.

*$p < .05$, **$p < .01$.

Research Question #3:

What role does the specific coping strategy, escape-avoidance coping, play in adjustment?

Two hierarchical multiple regression analyses were conducted to examine the contribution of each of the predictor variables on PTSD severity and on the BSI Global Severity Index. Entry of variables was based upon Thompson's (1985) transactional stress and coping model, and was similar to regression analyses above except escape-coping was entered instead of emotion-focused coping. On step 1 age of parent was entered and on step 2 the illness variable (number of months child has survived beyond diagnosis) were entered. On step 3, psychosocial variables were entered and included, social support (network size), illness uncertainty (MUIS), and Escape-Avoidance Coping. On step 4, an interaction variable comprised of illness uncertainty and escape avoidance was entered to examine the moderating effects of illness uncertainty and escape-avoidance coping on adjustment. The regression analyses were hierarchical between steps and stepwise within steps (Cohen & Cohen, 1983).

Results of the regression analysis predicting PTSD severity can be seen in Table 7. No changes were made to the first two steps and thus, the results for these steps replicated those in regression analysis under hypothesis 2. After controlling for demographics and illness variables in step 1 and 2, there was a significant effect associated with the third step (social support, illness uncertainty, and escape-avoidance coping; R^2 change = .30, $p < .05$) with 11% of unique variance explained only by illness uncertainty ($\beta = .38$, $p < .05$). PTSD severity was not associated with the interaction variable. The set of variables accounted for a total of 51% of the variance in PTSD severity ($p < .05$).

Table 7.

Hierarchical Multiple Regression Analysis Predicting PTSD Severity With Escape-Avoidance Coping

Step	Predictor Variable	β	t for Within Step Predictors	R^2 Change	F Change for Step	Part Corr. (r_{sp})
1	Age	-.43*	-2.37	.184	5.63*	-.429
2	Time Since Diagnosis	-.19	-.914	.027	.836	-.166
3	Social Network Size	-.01	-.073	.298	4.25*	.011
	MUIS	.38*	2.15*			.328
	Escape-Avoidance Coping (ESC-AVOID)	.28	1.64			.251
4.	MUIS x ESC-AVOID	-.39	-.271	.002	.074	-.042

Note: *$p < .05$

Results of the regression analysis predicting global distress can be seen in Table 8. Again, steps 1 and 2 replicate those in hypothesis 2 examining global distress. There was a significant effect associated with the third step (social support, illness uncertainty, and escape-avoidance coping; R^2 change = .47, $p < .01$) with 26% of unique variance explained by both illness uncertainty ($\beta = .44$, $p < .05$) and Escape-Avoidance Coping ($\beta = .41$, $p < .05$). Alone, these variables each accounted for 13% of unique variance. Further, there was an additive effect associated with the interaction variable (illness uncertainty x Escape-Avoidance; R^2 change = .14, $p < .01$). The set of variables accounted for a total of 73% of the variance in global distress ($p < .05$).

Table 8.

Hierarchical Multiple Regression Analysis Predicting BSI Global Severity Index With Escape-Avoidance Coping

Step	Predictor Variable	β	t for Within Step Predictors	R^2 change	F Change for Step	Part Corr. (r_{sp})
1	Age	-.05	-.245	.002	.809	-.05
2	Time Since Diagnosis	-.39	-1.76	.118	.092	-.34
3	Social Network Size	-.01	-.043	.471	.001	-.01
	Illness Uncertainty (MUIS)	.44*	2.61*			.37
	Escape-Avoidance Coping (ESC-AVOID)	.41*	2.57*			.37
4.	MUIS x ESC-AVOID	-3.4**	-3.09**	.137	.006	-.37

Note: *$p < .05$

Figure 1, based on median splits of illness uncertainty (MUIS $\geq$ 72) and Escape Avoidance coping (ESC-AVOID $\geq$ .12), illustrates that although global distress related to increased illness uncertainty for all parents, a higher level of distress was present among parents who utilized higher levels of escape-avoidance coping strategies than for those who utilized lower levels ($t = 3.977$, $p < .001$). Further, it appears from the figure, that a sharper increase in distress was present among parents reporting low escape-avoidance coping under conditions of high uncertainty.

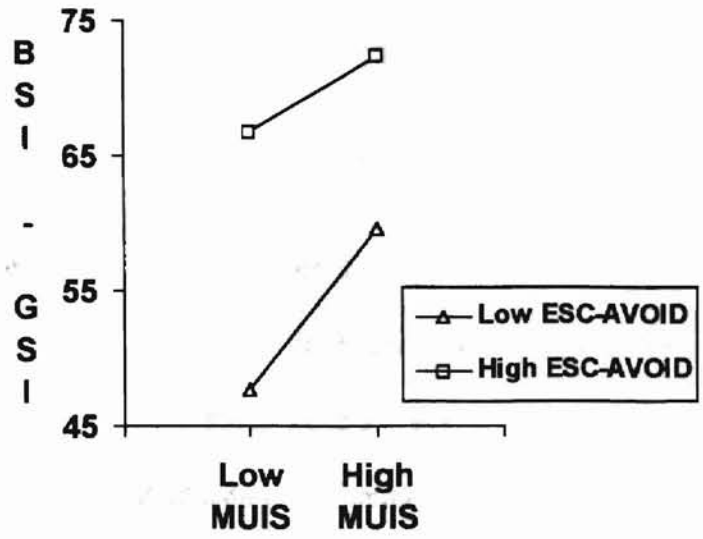

Figure 1. The interaction between escape-avoidance coping and illness uncertainty.

CHAPTER VI

DISCUSSION

The purpose of this study was twofold: 1) to investigate and assess both global distress and PTSD status among parents of children with a brain tumor; and 2) to examine possible predictors of increased posttraumatic stress symptom severity and global distress. The psychosocial predictors of adjustment examined in this study included social support, illness uncertainty, and coping strategies described by Folkman & Lazarus (1988). Overall the results showed that parents of children with a CNS malignancy are at risk for both elevated global distress and posttraumatic stress symptomatology. Further, higher levels of parent's perceived uncertainty about their child's illness is an important predictor in adjustment outcome.

The findings of this study support the hypothesis that parents of children with a brain tumor would exhibit significant levels of global distress compared to normative data. Scores on the BSI GSI were one standard deviation above the normative group mean and 58% of the parents met caseness criteria. Given that the normative data for the BSI suggest that only 10% of the population should meet caseness criterion (Derogatis & Spencer, 1982), the results suggest that these parents are indeed at risk for poor adjustment. Examination of the specific subscales of the BSI indicate that parents may be experiencing high levels of depression, anxiety, obsessive compulsive type symptoms and

psychotic symptoms. Most likely, elevations in the psychotic subscale reflect parents' responses to items that describe feelings of estrangement and detachment from others rather than a thought disorder. Parents of children with a brain tumor may find it difficult to relate to other parents who have healthy children because their experience of parenthood may be uniquely, qualitatively different.

The data also indicated that a large subset of parents of brain tumor patients (44%) meet diagnostic criteria for PTSD. High levels of posttraumatic stress symptomatology have also been reported by parents of children treated for leukemia (39.7% for mothers and 33.3% for fathers; Stuber et al., 1997), and by parents of children with a range of non-CNS cancers (25%; Pelcovitz, 1996). The percentage rate of PTSD in this study is higher than those found among violent crime survivors and rape survivors (7.5% and 16% respectively; Kirkpatric et al., 1987). It is also higher than what researchers would estimate to be the prevalence rate among individuals exposed to a traumatic life event. For example, based on a literature review, Green (1994) estimated that 25% of individuals exposed to a traumatic event would develop PTSD. Certainly, the differing methods by which PTSD has been assessed in previous studies make it difficult to compare rates found in the current study to others. Controlled studies comparing parents of children with CNS malignancies to those with non-CNS malignancies not to mention other groups of trauma victims are needed in order to determine if these parents are at greater risk for developing PTSD.

Posttraumatic stress symptoms that were more frequently reported by parents were intrusive recollections and psychological distress at exposure to cues. Few parents reported symptoms related to memory disturbances or hypervigilance. There may be a

predominating symptom pattern among parents of children with cancer. Indeed, other researchers have found that parents of pediatric cancer survivors infrequently report symptoms related to memory disturbances or exaggerated startle, whereas avoidance symptoms and reexperiencing symptoms (e.g., psychological distress related to cues) are more common (e.g., Pelcovitz et al., 1996 Stuber et al., 1996). This pattern seems to suggest that interventions aimed at promoting positive outcome may need to focus on reducing parent's reactivity to, and avoidance of, cues related to their child's cancer. For instance, parents with PTSD may overreact, perceiving non-related cancer symptoms to be an indication of relapse and thus may over-utilize medical services. Further, parents with PTSD may avoid following-up with medical treatments (e.g., administering shots) or following through with recommendations (e.g., making appointments to see specialists). Reducing these symptoms can greatly impact the child's well being as well as the cost of health care.

Correlational analyses indicated that social support, illness uncertainty, emotion-focused coping, and problem-focused coping were related to psychological adjustment in the expected direction. Parents who had larger social support networks reported less global distress and posttraumatic symptom severity. Such findings are consistent with that of other research findings examining the relationship between social support and adjustment among parents of cancer survivors (Barakat et al., 1997; Kazak et al., 1997; Speechley & Noh, 1992). The exploratory analyses also demonstrated that parents who perceived friends and professionals to be helpful reported better adjustment. Together, these findings suggest that size, as well as perceived quality of social support networks,

may be important in helping parents adjust to the demands of raising a child surviving a brain tumor.

A strong link between illness uncertainty and adjustment was also found. Greater levels of uncertainty was related to both higher levels of posttraumatic symptom severity and global distress. A number of researchers have pointed out that the experience of uncertainty is common among parents of pediatric cancer survivors (Koocher & O'Malley, Van Dongen-Melman et al., 1994); however, there are no studies that have quantitatively examined the relationship between perceived uncertainty and adjustment in this population. Parents in this sample reported relatively high levels of uncertainty compared to adult cancer survivors (Mishel & Braden, 1988) and individuals with post-polio (Mullins et al., 1995). The nature of caring for a child with a brain tumor may foster uncertainty among parents. The disease is difficult to understand, the etiology is often unknown, the treatment protocols are complicated and intense, there are large care providing systems involved in their child's rehabilitation that are difficult to navigate, and the course is unpredictable with the possibility of relapse or death. Overtime, the repeated experience of perceived uncertainty associated with their child's illness may foster a sense of hopelessness and maladaptive coping strategies. This may in turn contribute to increased levels of general distress and more intense levels of posttraumatic stress symptoms. In fact, results of the regression analysis also suggest that illness uncertainty seems to be a robust predictor of both posttraumatic stress symptomatology and global distress, even after accounting for demographic and illness variables. These findings are quite consistent with previous research (e.g., Mullins et al., 1995; Mullins et al., 1997). This finding has important practical utility, suggesting that parental adjustment may be

improved if those who intervene with families help parents become knowledgeable about their child's illness, treatment, and the systems (psychologists, neuropsychologists, social workers, oncologists, neurosurgeons, endocrinologists, etc.) involved in treating their child. Improving parental adjustment by reducing uncertainty may also ultimately impact their child's care and adjustment. Parents who are actively engaged in their child's care may be more likely to encourage their children to adhere and cooperate with medical regimens. From a social learning perspective, they may also serve as models for adaptive adjustment for their children (Bandura, 1962; 1969).

The data also support the hypothesis that higher levels of reliance on emotion-focused coping (i.e., the combination of Distancing, Self-Controlling, Accepting Responsibility, Escape-Avoidance, and Positive Reappraisal) would be related to both greater levels of global distress and posttraumatic symptom severity. A similar relationship has been found among mothers of children with non-CNS malignancies (Baskin, Forehand, & Saylor, 1985). Reviews of the literature on adjustment to pediatric chronic illness have concluded that, in general, emotion-focused coping tends to be associated with greater adjustment difficulties (Kliewer, 1997). Analyses indicated that the specific types of coping strategies related to poorer adjustment were Self-Controlling (e.g., "tried to keep my feelings to myself"), Accepting Responsibility (e.g., "criticized or lectured myself"), and Escape-Avoidance (e.g., "tried to make myself feel better by eating, drinking, smoking, using drugs or medication, etc."). Thus, these types of emotion-focused coping strategies may describe parents efforts at attempting to control their feelings, blaming themselves for their child's condition, and escaping from thinking about their child's condition. Although it remains to be investigated, utilization of some of these

types of coping strategies during different phases of the child's treatment may be helpful for parents and children. For instance, a parent who uses Self-Controlling coping strategies when their child is undergoing a painful medical procedure may help the child and the parent get through the procedure. However, reliance on these types of coping strategies may be detrimental to parents, interfering with their ability to meet the many demands that their child's treatment and rehabilitation requires, and potentially increasing parents' levels of distress. On the other hand, parents who use more problem-focused coping may experience a greater sense of competence and less adjustment problems. Parents in this study who utilized problem-focused coping reported less global distress and posttraumatic stress. Notably, the specific problem-focused coping strategy that was inversely related to both global distress and posttraumatic stress symptomatology was Seeking Social Support. This scale includes such items as "talking to someone to find out more about the situation", "I asked a relative or friend I respected for advice", and "talked to someone about how I was feeling". Seeking out people who can provide information and emotional support may be a very important aspect related to successful adjustment.

An interesting finding with regard to coping strategies was the relationship between Positive Reappraisal and levels of adjustment. Results showed that greater utilization of Positive Reappraisal coping strategies was related to better adjustment. Folkman and Lazarus (1988) describe positive reappraisal as "efforts to create positive meaning by focusing on personal growth" (p. 11). Elements of hope or being able to create a context focused on personal growth may play an important role in parents well-being as they learn to adjust and cope with having a child who is surviving cancer. This finding is similar to the findings of Grootenhuis and Last (1997) who found that parents of

children with cancer who had a more positive, hopeful, and optimistic outlook reported less negative emotions. Further research is needed clarifying this role between appraising adversity in a creative, optimistic manner, and adjustment.

A puzzling relationship was also found between parents age and adjustment. The older a parent was the fewer the posttraumatic symptoms they reported, however there was no significant relationship between age and global distress. Further, the regression analysis showed that with regard to posttraumatic symptom severity, parent's age and illness uncertainty predicted PDS severity scores. With regard to global distress, on the other hand, unique change in variance was explained only by illness uncertainty. An explanation for why parents age accounted for a significant proportion of the variance predicting posttraumatic symptom severity and not global distress is unclear. There was a relationship between parents age and the temporal distance from diagnosis, with older parents having greater temporal distance from diagnosis. Although speculative, posttraumatic stress symptoms among parents may be more affected by time that has lapsed since the traumatic "event" of the initial diagnosis and treatment. Global feelings of distress, on the other hand, may be less affected by the lapse of time and continue through the child's survival and rehabilitation.

Notably, the large number of correlations computed for this small sample size does increase the risk of type I error. The number of chance findings based upon the 153 correlations computed for the main analysis is seven to eight. Thus, the result of the above correlations should be interpreted tentatively and with caution.

In addition to addressing the above hypotheses, this study also sought to answer three research questions. The obtained results for these correlations should also be

considered tentative. Based on the fact that 30 correlations were computed it should be expected that one to two significant correlations may be due to chance. One relationship of interest was that parents in this study who perceived professionals in their network (physicians, oncologists, psychologists, etc.) to be more helpful reported less global distress and posttraumatic symptom severity. Thus, the quality and extent of medical care may be important as parents learn to cope with having a child with a life-threatening illness. Also, the data indicated that parents who rated their child as being more adherent to medical treatment, and who perceived their child as having improved health status compared to the previous year, reported less global distress. These findings should be interpreted with caution, however, as measures of health status and adherence were assessed via a single global rating provided by parents. There may be a link between a child's health status and medical adherence and parental adjustment, however, independent ratings such as those provided by physicians may be more helpful in determining this.

Further the role that Escape-Avoidance coping plays in parental adjustment was also assessed. Escape-Avoidance coping was substituted for emotion-focused coping in analyses as it was thought that attempts to avoid thinking about one's child's illness and treatment may have the contradictory effect of increasing distress. This finding would been consistent with theories that suggest that experiential avoidance of anxiety has the paradoxical effect of increasing it (Hayes, 1987). Further, researchers have suspected that avoidance may be a common strategy for parents and families adjusting to pediatric cancer (e.g., Kazak et al., 1997). With regard to posttraumatic symptom severity, the results showed that unique variance was explained by only parent age and illness uncertainty. However, with regard to global distress, the findings differed. In this regression analysis,

illness uncertainty, Escape-Avoidance, and the interaction variable (MUIS x Escape-Avoidance) all predicted BSI GSI scores. This set of variables accounted for 73% of the variance. Although this finding deserves further exploration, it does suggest that illness uncertainty may moderate an Escape-Avoidance - global distress relationship. That is, the combined influence of low Escape-Avoidance coping and greater illness uncertainty explained additional variance in global distress beyond the main effects of these variables. An examination of the median splits demonstrated that parents who reported using high levels of Escape-Avoidance coping as opposed to those who reported using low Escape-Avoidance reported greater distress. Further, the level of uncertainty seemed to play an important role in accentuating the degree to which Escape-Avoidance coping related to distress. Parents who reported using Escape-Avoidance coping under conditions of high uncertainty indicated the worst adjustment. Clearly, further studies are needed to verify these findings and the results need to be interpreted with caution. However, the findings do point to the need to develop models of parental adjustment which incorporate these relationship between Escape-Avoidance coping and illness uncertainty. It may be the case that parents who express ambiguity about their child's treatment and perceive their child's illness to be unpredictable, use higher levels of avoidance coping as a method of controlling their feelings of distress, which, in the end, has the contradictory effect of increasing their levels of distress.

Certainly, there are a number of limitations in this study. On account of the number of analyses performed, there is a risk of type I error and, thus, the findings are tentative. Also, with such a small sample size it is difficult to know if this data is generalizable to the larger population of parents with children with CNS-malignancies. A small sample also

limits the ability to examine within group differences. Examination of within group differences are necessary for researchers to be able to identify risk and resiliency factors related to parents adjustment. Three factors contributed to the low sample size. The first was that the available sample was relatively small. At this site only 62 children had been diagnosed with brain tumors in the last 20 years reflecting the overall low incidence of this disease. A second factor contributing to the low sample size was that many of the parents were difficult to contact with current addresses available for only 53 families. Third, some parents declined to participate indicating that thinking about their child's illness would be too stressful. In future studies, multi-site collaborations and strong attention to recruitment and retention efforts are needed.

A second limitation was the lack of an adequate comparison sample. To date, there have been no studies examining parental adjustment associated with having a child surviving a CNS-malignancy that have employed a comparison sample. Without adequate comparisons, it is difficult to ascertain whether the levels of posttraumatic stress symptomatology and global distress distinguish these parents from parents of healthy children, parents of children with non-CNS malignancies, or parents of children with a chronic illness.

Another important limitation was the use of self-report measures obtained via a mail out format. Two potential problems can arise with this type of data collection method. First, the complete reliance on self-report instruments can increase problems associated with curvilinearity (Cohen & Cohen, 1983). That is, some of these instruments may have a high inter-item correlation. Using multiple independent measurement modalities, such as structured interviews, may decrease the likelihood of finding a linear

relationship between variables that is merely an artifact of the instruments used. A second problem that can arise with the reliance on self-report data is the possibility that parents may not be filling out the questionnaires in an accurate and valid manner. With unsupervised administration of the questionnaires, there is always the chance that parents may not understand the instructions or fill out the questionnaire incorrectly. Supervised administration of the questionnaires may be helpful at reducing such methodological problems. Another methodological problem is the global nature associated with the instruments of measurement. All of the instruments were not necessarily designed with a cancer population in mind. For instance, the posttraumatic stress measure, although it was adapted to inquire about parent's reactions to their child's illness, may not assess some of the trauma-specific phenomena (e.g., intrusive recollections related to medical procedures or avoidance of illness specific cues).

This study is a first step at addressing the lack of the literature on parental adjustment to pediatric brain tumors. This population has been long neglected in the literature, and with increasing rates of survival of these children, further examination of the psychosocial adjustment of these families is warranted. Overall, the findings of this study suggest that parents of children surviving a brain tumor may be risk for numerous adjustment problems. Although it may not be not be useful to "pathologize" these parents understanding parental adjustment to having a child with a CNS malignancy using a posttraumatic stress model may be helpful in developing intervention strategies. This model can help guide and inform the development of intervention programs. Clearly, intervention programs for these parents need to incorporate not only treatment for depression and anxiety, but treatment for trauma-related symptoms as well. Further, there

is a need to continue to examine the relationship between illness uncertainty, escape-avoidance coping and adjustment. In this study, illness uncertainty seemed to play a relevant role in predicting adjustment. Intervention programs would most likely benefit from components which targeted reducing uncertainty.

Future studies are needed addressing the traumatic aspects of cancer survival and the impact that this has on the family. The use of structured interviews is warranted and may illuminate factors that contribute to the development of PTSD and global distress. Longitudinal studies may help to clarify when parents are most at risk for the development of PTSD and when these symptoms are likely to dissipate are also needed. Also studies that examine a wider range of predictor variables are needed. For instance, this study did not adequately assess social economic status or social position. Other factors that were not assessed include relapse, level of physical and cognitive impairment of the child, the type of brain tumor, the frequency and duration of medical procedures, and the number of hospitalizations. Certainly all of these factors may have potential adverse affects on parental adjustment. Studies that verify these findings are also needed, and hopefully by identifying the types of adjustment problems that parents of children with brain tumors may face as well as the predictors of poor adjustment, intervention strategies can be developed.

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APPENDIX A

BACKGROUND INFORMATION

Please provide us with some background information on yourself, your spouse, and your child.

Subject No. _____

Today's Date _____

Child's Name: _____
Mother's Name: _____
Father's Name: _____

Subject No._____

1. Who currently lives in the household with you and your child? Please note their relationship to the child and age (e.g., son - 15months)

Name	Relation to Child	Age

2. What is your Age? _____

3. What is your spouses age? _____

4. What is your child's age? _____

5. What was *your age* when your child was diagnosed? _____

6. What was *your spouse's age* when your child was diagnosed? _____

7. What was your *child's age* when he/she was diagnosed? _____

PARENT INFORMATION

8. What is your highest level of education completed? (circle year):

1	2	3	3	5	6	7	8	9	(Grade School)
9	10	11	12						(High School)
13	14	15	16						(College)
17 and over									(Graduate or Professional School)

9. What is your occupation? _____

10. What is your marital status? (Circle one):

Married	Single Parent	Remarried	Never Married	Other
1	2	3	4	5

11. Please indicate your total family income: ***(This information will be held strictly confidential)***

_____ 0 - 4,999	_____ 30,000 - 39,999
_____ 5,000 - 9,999	_____ 40,000 - 49,000
_____ 10,000 - 14,999	_____ 50,000 - 59,000
_____ 15,000 - 19,999	_____ 60,000 or greater
_____ 20,000 - 29,999	

12. What is your race?

Caucasian	African American	Hispanic	Native American	Asian	Other
1	2	3	4	5	6

13. Do you belong to a church or religion? ____ yes _____ no:
If yes, please specify you religious affiliation

_____

CHILD INFORMATION

14. Is your Child's Race different from your own? ____ yes ____ no:
If yes, please specify: _____

15. What is your child's grade? _____

16. Are special education services being provided? ____yes ____ no:
If yes, please specify

_____

Health Information

17. How long has your child had their current illness? (please indicated years and/or months since diagnosis) _____ years; _____months

Please provide us with some information on your child's treatment.

18. What medical intervention(s) is your child currently receiving or has your child received in the past for his/her illness? Check all that apply	**19. How many times has your child has undergone this intervention.**	**20. How stressful has this been for you as a parent?**				
		Not at all	**A bit**	**Some-what**	**Very**	**Extr em-ely**
Surgery _____	_____	1	2	3	4	5
Biopsy _____	_____	1	2	3	4	5
Shunts _____	_____	1	2	3	4	5
Craniospinal Radiation _____	_____	1	2	3	4	5
Local Radiation Only _____	_____	1	2	3	4	5
Chemotherapy _____	_____	1	2	3	4	5
Other (describe)_____ _____	_____	1	2	3	4	5
Other (describe)_____ _____		1	2	3	4	5

21. Has anyone else in your family (besides your child receiving care at OUHSC) or someone close to you been sick or in need of medical care? _____ yes _____ no:
If yes, please specify_____

22. Please rate how well you think your child copes with his/her disease.

1	2	3	4	5	6	7
Doesn't cope well at all			*Copes moderately well*			*Copes Extremely well*

23. Please rate your child's overall health status in the course of this past year compared to his/her health status the year before.

1	2	3	4	5	6	7
Extremely poor health			*Average health*			*Extremely good health*

24. Please rate your child's overall adherence with the medical regimen prescribed by your doctor (for example, taking his/her medication, following his/her diet).

1	2	3	4	5	6	7
Not at all adherent			*Adherent about half (50%) of the time*			*Adherent all (100%) of the time*

17. Please list the medications your child is currently prescribed.

_____ _____

_____ _____

_____ _____

APPENDIX B

CONSENT FORM

IRB # _____

University of Oklahoma Health Science Center
Comprehensive Pediatric Brain Tumor Clinic
Department of Hematology-Oncology

I, _____, voluntarily consent to participate in this study entitled "Parental Adjustment to Pediatric Tumors," and authorize Larry L. Mullins, Ph.D., Clinical Associate Professor; Brian Marx, Ph.D., Clinical Assistant Professor; Jim Scott, Ph.D., Clinical Assistant Professor; and Bernard Fuemmeler, B.A., Graduate Research Assistant, as principle investigators and/or such assistants of their choosing to perform the procedure described herein.

You understand:

Purpose: We know that some parents of children with a brain tumor or a chronic illness may cope well with illness in the family, whereas other parents seem to experience difficulties adjusting. However, we know little about how it is that some parents learn to cope well or the kind of life problems that lead to parents having difficulty adjusting. This study will look at how parents of children with a brain tumor cope and adjust, as well as those factors that seem to help parents adjust and those that do not.

Description of the Study: As a parent you will be asked to complete 8 separate questionnaires. Approximate time for completion is one hour. The research assistant will clarify any questions you have, or you may contact Dr. Larry L. Mullins, Dr. Brian Marx, or Bernard Fuemmeler at (405) 744-6027.

At a later time a research assistant will review your child's medical chart and/or neurological records. This assistant will be investigating information related to the course of your child's illness, symptoms, treatment, and side effects that date back to when your child was diagnosed with their current condition and up to information that was entered prior to the start of this study.

A research assistant will also contact your child's physician and request a five year rating of survival and a rating of the invasiveness of treatment.

Costs: There will be **no** cost to you or your insurance company for participation in this study.

Risks: Some people find that talking about stressful events and symptoms can be somewhat temporarily uncomfortable or fatiguing, however, typically participants in similar studies find that this discomfort is short-term. There are no other risks to participants involved in this study. You may choose to withdraw from this study at any time.

Benefits: For your participation in this study a $5.00 donation will be made by the researcher to the Make a Wish Foundation and you will be able to choose a toy from a grab-bag of toys for your child.

Alternative to Participation: The alternative is not to participate in this study.

By signing this consent form, I acknowledge that my participation in this study is voluntary. I also acknowledge that I have not waived any of my legal rights or released this institution from liability for negligence.

I may revoke my consent form and withdraw from the study at any time without penalty or loss of benefits. My treatment by, and relations with, the physicians and staff at the University of Oklahoma Health Science Center now and in the future will not be affected in any way if I refuse to participate.

Records of this study will be kept confidential with respect to any written or verbal reports making it impossible to identify me individually. The OUHSC Institutional Review Board may review my records for audit purpose only. Code numbers will be assigned to each parent's questionnaire packets and to data collected from your child's chart. Once the data are collected, all names will be removed from the materials and only code numbers will be utilized. At no point in time will subjects be individually identified in a public format or in any printed material.

If I have any questions or need to report an effect about research procedures, I will contact Dr. Larry L. Mullins, Dr. Brian Marx, Bernard Fuemmeler at (405) 744-6027 or Dr. Jim Scott at (405) 271-5251. If I have questions about my rights as a research subject, I may take them to the Director of Research Administration, University of Oklahoma Health Science Center, Room 121 Library Building, or by calling (405) 271-2090.

Signatures: I have read this informed consent document. I understand its contents, and I freely consent to participate in this study under the conditions described in this document. I understand that I will receive a copy of this signed consent form.

Participant's Signature	Date
Witness Signature	Date
Investigator Signature	Date

APPENDIX C

OKLHAHOMA STATE UNIVERSITY
IRB APPROVAL LETTER

OKLAHOMA STATE UNIVERSITY
INSTITUTIONAL REVIEW BOARD
HUMAN SUBJECTS REVIEW

Date: March 3, 1998 **IRB #: AS-98-049**

Proposal Title: PARENTAL ADJUSTMENT OF PEDIATRIC TUMORS

Principal Investigator(s): Larry L. Mullins, Brian P. Marx, Bernard F. Fuemmeler

Reviewed and Processed as: Expedited

Approval Status Recommended by Reviewer(s): Approved

ALL APPROVALS MAY BE SUBJECT TO REVIEW BY FULL INSTITUTIONAL REVIEW BOARD AT NEXT MEETING, AS WELL AS ARE SUBJECT TO MONITORING AT ANY TIME DURING THE APPROVAL PERIOD.
APPROVAL STATUS PERIOD VALID FOR DATA COLLECTION FOR A ONE CALENDAR YEAR PERIOD AFTER WHICH A CONTINUATION OR RENEWAL REQUEST IS REQUIRED TO BE SUBMITTED FOR BOARD APPROVAL.
ANY MODIFICATIONS TO APPROVED PROJECT MUST ALSO BE SUBMITTED FOR APPROVAL.

Comments, Modifications/Conditions for Approval or Disapproval are as follows:
REVIEWER #1:
1) Concerns in original proposal have been addressed.
2) The critique of content was noted by this reviewer but not the reason a change was requested. The project is important and the concerns for family well being were addressed in the addendum. The FES was replaced in the 80's and 90's by better Family Level Assessments (FACES, FAD and others) that are much shorter. That was offered as constructive input from an interested colleague.

REVIEWER #2:
1) Approved with revisions.

Signature: _____ Date: March 5, 1998
Chair of Institutional Review Board
cc: Bernard F. Fuemmeler

APPENDIX D

UNIVERSITY OF OKLAHOMA HEALTH SCIENCE CENTER IRB APPROVAL LETTER

The University of Oklahoma
Health Sciences Center

OFFICE OF RESEARCH ADMINISTRATION

IRB NUMBER: 07683
MEETING DATE: 02/09/98
APPROVAL DATE: 02/28/98

Final approval

Dr. Larry Mullins
Unassigned
OSU

SUBJ: Parental Adjustment to Pediatric Tumors.

Dear Dr. Mullins:

The University of Oklahoma Health Sciences Center's Institutional Review Board reviewed the above-referenced protocol at its regularly scheduled meeting. The informed consent document and the protocol are hereby approved. You may begin subject enrollment. It is the Board's judgment that the rights and welfare of the individual who may be asked to participate in this study will be respected; that the proposed research, including the process of obtaining informed consent, will be conducted in a manner consistent with the requirements of 45 CFR 46, as amended; and that the potential benefits to subjects and to others warrant the risks subjects may choose to incur.

As principal investigator of this protocol, it is your responsibility to insure that this study is conducted as approved by the Board. Any modifications to the protocol or consent form, initiated by you or by the sponsor, will require prior approval, which you may request in an amendment letter or memorandum to me. All study records, including copies of signed consent forms, must be retained for three (3) years after termination of the study.

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

The approval granted here is effective for one year. Should you wish to maintain this protocol in an active status beyond that date, you will need to provide the Board with a progress report summarizing study results to date. IRB staff in the Office of Research Administration will request that progress report from you approximately ten weeks before the anniversary date of your current approval.

If you have questions about these procedures, or need any additional assistance from the Board, please contact IRB staff. Finally, please review your professional liability insurance to make sure your coverage includes the activities in this study.

Sincerely yours,

Joan L. Walker, M.D.
Chair, Institutional Review Board

JLW/EHC/cc

Post Office Box 26901 • 1000 S.L. Young Blvd., Room 121
Oklahoma City, Oklahoma 73190 • (405) 271-2090 FAX (405) 271-8651

VITA

Bernard F. Fuemmeler

Candidate for the Degree of

Master of Science

Thesis: FACTORS ASSOCIATED WITH GENERAL PSYCHOLOGICAL ADJUSTMENT AND POSTTRAUMATIC STRESS AMONG PARENTS OF CHILDREN WITH A BRAIN TUMOR

Major Field: Psychology

Biographical:

Education: Graduated from Valley High School, Albuquerque, New Mexico in May 1989; received a Bachelors of Arts degree in Psychology and Philosophy from the University of New Mexico, Albuquerque, New Mexico in May of 1994. Completed the requirements for the Masters of Science degree with a major in Clinical Psychology at Oklahoma State University in December, 1998.

Experience: Worked as a direct care facilitator and educational assistant for two years at the University of New Mexico Children's Psychiatric Hospital in Albuquerque, New Mexico; psychological associate at the Psychological Services Center, Department of Psychology, Oklahoma State University, 1996 to present; employed by Oklahoma State University, Department of Psychology as a graduate assistant in Stillwater, Oklahoma, 1996 to present.

Professional Memberships: Association for the Advancement of Behavior Therapy, Student Member; American Psychological Association, Graduate Member ; Southwestern Psychological Association, Member; Oklahoma Psychological Association, Member.