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Surviving Childhood Cancer: The Psychosocial Impact On Parents

Kathy Nixon Speechley

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SURVIVING CHILDHOOD CANCER:
THE PSYCHOSOCIAL IMPACT ON PARENTS

by

Kathy Nixon Speechley

Department of Epidemiology
and Biostatistics

Submitted in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy

Faculty of Graduate Studies
The University of Western Ontario
London, Ontario

December, 1986

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ABSTRACT

Childhood cancer is no longer viewed as inevitably fatal but rather as a chronic life-threatening illness. Child cancer patients and their families are now faced with longer phases of treatment and an inability to predict the future. Beyond a general recognition of the potential hardships they must endure, we know very little about the psychosocial consequences for the families of children who are surviving cancer.

The present study was designed to assess whether the presence of chronic strain, as experienced by families of child cancer survivors, is associated with a) increased psychological distress, as measured by levels of depression and anxiety in the parents or b) lower family adaptation, as measured by levels of functioning in the family and by marital adjustment. The ability of certain personal and social resources to moderate the association of chronic strain with psychological distress and family adaptation was also assessed.

Outcomes for survivors' families were assessed by using a matched comparison sample of parents whose children have never experienced a chronic life-threatening illness and who lived in the neighbourhoods of the survivors' families. A total of 143 parents (80 mothers and 63 fathers) of 80 cancer survivors and 151 parents (79 mothers and 72 fathers) of 80 healthy children completed self-administered questionnaires.

Overall, the families of cancer survivors were not found to be at higher risk for psychological distress or family

dysfunction than families with healthy children. The relationship of chronic strain with psychological distress was observed under the condition of low levels of experienced social support, however. Social support appeared to buffer the effect that chronic strain had on depression in fathers and on anxiety in mothers and fathers. Parents of child cancer survivors may represent appropriate targets for intervention, if the assumed direction of the relationships found here can be confirmed through longitudinal research.

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participation rates through his communication with families about the study and his financial support. Mrs. Marie Shier gave willingly of her time to help me wade through patients' medical files and track down addresses of families. The Health Care Research Unit housed the study and offered clerical as well as some financial support. I would like to thank Mrs. Edna Dell for her administrative assistance and the many favours she has done for me. My appreciation also goes out to Julie Dinon, Scott Hebert, and Shari Campbell for their able assistance in data collection and especially for coding the data. I am also indebted to all of the families who gave of themselves to make this project possible.

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London, Ontario
January, 1987

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CHAPTER ONE

INTRODUCTION

1.0 Overview

The past thirty years have resulted in substantial improvements in the prognosis of child cancer patients. It is no longer the case that the diagnosis of cancer in a child is synonymous with a death sentence. Both patients and their families are now faced with longer phases of treatment, an inability to predict the future and consequently, with a set of new and complex problems of both an emotional and a practical nature (Johnson et al., 1979; Kagen-Goodheart, 1977).

Beyond this general recognition of the potential hardships they must endure, we know very little about the psychosocial consequences for the families of children who are surviving cancer. The increasing number of pediatric cancer patients who survive disease-free for substantial periods of time requires that health professionals and researchers take a serious look at the psychosocial consequences that the chronic nature of such illnesses have for families of children surviving cancer and at the factors that may affect the well-being of these families.

The success of intervention efforts to improve the quality of life for such families will be determined to a large extent by the oncology team's understanding of the processes by which the experience of childhood cancer may lead to various negative effects on the family and the factors that may intervene in the process. Limited personnel and financial resources could be more efficiently allocated by directing attention to these families

identified as high risks for maladaptation.

The research described here studied the parents of children surviving cancer to assess whether they are currently experiencing psychological distress in the form of elevated rates of depression and anxiety or problems with family adaptation as measured by levels of family functioning and marital adjustment. Outcomes for survivors' families were assessed by using a control sample of families who had not experienced a chronic life-threatening illness in a child. The ability of certain personal and social resources to mediate between stress and distress or maladaptation was examined as well.

This thesis is organized in the following manner. It begins with background information outlining the changes that have occurred in the medical prognosis for various types of childhood cancer and the medical and psychosocial sequelae for survivors. The research problem is then presented along with more complete objectives of the study. Chapter Two provides a review of the literature on the psychosocial issues of childhood cancer and an overview of two theoretical models, the stress process and family stress theory. In Chapter Three the research questions to be addressed are presented. Chapter Four describes the method used in the study including the samples chosen, selection criteria, and participation rates. Details concerning measurement are outlined in Chapter Five. In Chapter Six the results of the study are presented and Chapter Seven offers a discussion of these results and their implications.

1.1 Background

1.1.1 Improvements in Prognosis.

Childhood cancer is no longer considered inevitably fatal but is viewed as a chronic life-threatening illness. Although cancer still represents the second most prevalent cause of death in children after the neonatal period (the first being accidents) (Siegel, 1980), recent successes in the treatment of childhood cancer have produced substantial improvements in the prognosis for such children. It has been estimated that, of the approximately 144,000 white children in the United States diagnosed with cancer at ages 0 to 14 years from 1953 to 1979, 31 percent were alive in 1984 (Mandelson and Li, 1986).

In a study of cancer mortality among children in the United States using death certificate diagnoses, Miller and McKay (1984) reported a dramatic decrease in rates from 1950 to 1979, especially in the latter half of the interval. According to their results, "the numbers of deaths of persons younger than fifteen years, 1965 through 1979, as compared to the number expected at 1950 rates, fell 50 percent for leukemia, 32 percent for Non-Hodgkin's lymphoma, 80 percent for Hodgkin's disease, 50 percent for bone sarcoma, 68 percent for kidney cancer, and 31 percent for all other cancer" (Miller and McKay, 1984:1567).

Thirty years ago many types of childhood cancer such as lymphoblastic leukemia were classified as acute terminal illnesses with a median survival of three to six months (Fernbach, 1973). Recently, however, sixty percent of such patients survive for as long as five years after diagnosis and

increasing proportions survive, free from disease, for ten to twenty years after diagnosis (Hammond, 1978).

Similarly, advancements have also been made in the treatment of some of the malignant solid tumours such as Wilm's tumour, Hodgkin's disease, rhabdomyosarcoma and osteogenic sarcoma. Fifty percent of Wilm's tumour patients now have a ten-year survival rate, sixty percent of those with Hodgkin's disease have a five-year survival rate, fifty percent of rhabdomyosarcoma patients have a four-year survival rate and fifty percent of osteogenic sarcoma patients have a five-year survival rate (Kung, 1981).

1.1.2 Medical and Psychosocial Sequelae.

The dramatic increase in the potential for prolonged survival is associated with the prospect of years of treatment and the anticipation that a normal life span may be possible for the child--an anticipation tempered, that is, by a great deal of uncertainty (Johnson et al., 1979). Parents are faced with the fact that the experience of childhood cancer may result in some rather serious complications including physical and psychological impairments. In the twenty years after diagnosis and treatment, cancer victims have potentially lower age-controlled survival rates (80%) than those in the general population (97%) (Jaffe et al., 1981).

In a study of the late effects of childhood cancer among 142 former cases who were eighteen years of age or older at the time of the study, Li and Stone (1976) found that 52 percent had major

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defects in treated organs and 12% had developed second primary neoplasms. Holmes and Holmes (1975), in a study of 124 children treated for cancer who had survived at least ten years after diagnosis, concluded that recurrences and the development of second primary cancer represent small but real risks for the survivors of childhood cancer. It has also been documented that many long-term survivors have suffered medical complications such as major abnormalities in skeletal growth or development and reproductive abnormalities due to the delayed effects of radiation (Jaffe et al., 1981). Another consequence of radiation in long-term survivors of childhood cancer can be dental and maxillofacial abnormalities. Jaffe et al. (1984) detected such abnormalities in 82 percent of the 45 radiated patients evaluated. As well, it is anticipated that increased use of certain powerful chemotherapeutic agents will lead to long-range complications such as heart failure and diffuse lung disease (Minow et al., 1975; Samuels et al., 1976).

Grace Holmes and her associates (1986) followed up a sample of 100 cancer patients aged 21 and over who had been diagnosed and treated by age nineteen and had survived more than five years, and a matched control sample of same-sex siblings. They found that the childhood cancer survivors had much more difficulty obtaining both life and health insurance than did the matched controls. Similarly, Koocher and O'Malley (1981) reported that two-thirds of their sample of sixty recovered childhood cancer patients indicated that they had suffered discrimination in their attempts to secure employment, health insurance or life

insurance.

The survivors of childhood cancer, have also been found to be at significantly greater risk for psychological maladjustment than are the survivors of chronic childhood illnesses that are not life-threatening (Koocher, 1984). Links and Stockwell (1985) reviewed the small number of studies that have reported on the psychosocial outcomes of survivors and those that focused on the neuropsychological status of survivors of acute lymphocytic leukemia (ALL) treated with cranial radiation. They concluded from their review that some childhood cancer survivors have major psychological, social, or neuropsychological problems in adjustment.

For example; Koocher and O'Malley (1981) reported that approximately 23 percent of the 117 survivors of childhood cancer they interviewed could be considered to have moderate to severe impairment of functioning due to psychological maladjustment, based on global adjustment ratings completed independently by a psychiatrist and a psychologist. Also, two of the studies reviewed found that both I.Q. and perceptual motor skills seemed to have been adversely affected by cranial radiation treatment. These studies also showed that children who were younger at the time of treatment demonstrated greater disability than those who were older (Meadows et al., 1981; Moss et al., 1981).

1.2 Statement of the Problem

The dilemma experienced by parents is perhaps best summarized by Obetz and his colleagues when describing the reactions of a group of parents whose leukemic children had been in remission four years or more:

The parents continue to be more aware and troubled than their children by the potential terminal nature of the illness. They believe that death is likely or inevitable yet with the lengthening of remission they become increasingly hopeful that a cure may occur. The haunting possibility of relapse is still felt and several spoke of feeling as if a sword were hanging over their heads (Obetz et al., 1980:200).

Clearly, the families of child cancer survivors have experienced one of the most stressful life events that a family will ever encounter--the diagnosis of cancer in a child (Futterman and Hoffman, 1973). Such an event is obviously both highly undesirable and uncontrollable. These families continue to live in a situation characterized by ongoing problems and concerns that develop out of and linger long after the diagnosis is made. The nature of such strain has been aptly described as living one's life under the "sword of Damocles" (a metaphor for a strongly coveted good obtained at the cost of continuing danger) (Rocher and O'Malley, 1981). The chronic strain experienced by families of child cancer survivors stems not only from concerns about the child's uncertain future, but also from the reality of changes in family patterns of interaction and role performance that inevitably occur in the aftermath of such an event.

At present, we know very little about the psychosocial consequences associated with the experiences of families of

child cancer patients. Some attempts have been made to provide descriptions of the problems that accompany childhood cancer for both the patient and the family but the value of these research efforts is limited by two factors.

First, the majority of available studies have been based on the now outdated assumption that childhood cancer is necessarily an acute and invariably fatal disease. As a result, these research efforts tended to focus on three specific stages of the illness: the period immediately following initial diagnosis, the final, terminal stage and the period following the child's death. Clearly this literature cannot be directly applied to the families of children surviving cancer who are really a different population than those upon whom previous studies have focused. As noted by Links and Stockwell (1985) the needs felt by the acutely ill child are not those felt by the survivor. By logical extension, the same is also likely to be true of the child's family. These research findings may be useful, however, to the extent that they may provide a starting point for the examination of the plight of survivors' families. Given the seriousness and enduring nature of the problems faced by families subsequent to the diagnosis of cancer in a child, it is reasonable to hypothesize that these problems may still be relevant to the families of survivors. This literature will be reviewed in section 2.1.

The second limitation of most previous work is that the observations are fragmented and do not stem from any conceptual

framework. Consequently, there has been little or no systematic testing of theoretical models. Some observations in the literature, however, suggest that both the stress process model and family stress theory may provide useful bases for investigating the complex impact that childhood cancer may have on the families of survivors. Both of these theoretical models are discussed in relation to the present study in section 2.2.

1.3 Objectives

This research project was designed to study the parents of child cancer survivors to examine the psychosocial consequences of experiencing such a stressful life circumstance and the factors that may either mediate or exacerbate the stress process. The study addresses the question of whether the presence of chronic strain, as experienced by the families of child cancer survivors, is associated with a) variations in psychological distress, as measured by depression and anxiety levels in the parents and b) variations in family adaptation as measured by levels of functioning in the family and marital adjustment. Outcomes for the parents of cancer survivors were assessed by comparing their scores on these measures with those of a control sample of parents who have not experienced a chronic life-threatening illness in a child.

It is crucial that health professionals charged with the care of the child cancer patient and his family understand the nature and extent of the impact on the family and the nature of possible mediating factors. Because one of the primary goals of medical

teams should be to improve the quality of life within the families they are servicing, the efficacy of intervention efforts depends on the level of knowledge regarding the process by which the experience of childhood cancer comes to have negative effects on the psychological well-being of the family. This study is an attempt to contribute toward a better understanding of the stress process that is initiated by the diagnosis of cancer in a child.

CHAPTER TWO

REVIEW OF THE LITERATURE

2.0 Introduction

In this section, two separate bodies of literature will be presented. To begin, research dealing with the psychosocial aspects of childhood cancer is reviewed followed by an overview of the two theoretical models chosen to structure the current investigation.

2.1 The Psychosocial Aspects of Childhood Cancer

Previous research on the psychosocial consequences of childhood cancer is of significance to the current study of survivors' families for two reasons. First, although these studies have not considered the stage in which families may realistically consider the long-term survival of the child, it is important to remember that survivors' families have lived through each of the previous stages that have been described in the literature, from initial diagnosis through the cessation of treatment. Despite increased probability of long-term survival, the majority of people still tend to associate a diagnosis of cancer with death. Consequently initial reactions to cancer in a child are still characterized by the shock and grief outlined in previous research (Johnson et al., 1979). As well, the nature of many of the problems experienced in the early stages of the illness make it reasonable to speculate that many will remain unresolved for some time. Second, many of the findings in the psychosocial literature suggest that both the stress process

model and family stress theory offer appropriate frameworks for conceptualizing the present study. These findings include instructive observations concerning separate components of the stress inducing event of childhood cancer.

This literature can be broken down into two major categories, one dealing with the implications of childhood cancer for the afflicted child and the other reporting the effects of the child's illness on individual family members or the family as a unit. The present work will be limited to the latter category--the consequences of childhood cancer for the child's family and the factors affecting the impact that childhood cancer has on the family.

2.1.1 Effects of Childhood Cancer on the Family.

It has been well documented that each stage of the illness process including initial diagnosis, the treatment phase, the cessation of treatment, and the terminal stage has associated with it a variety of negative effects on the family as a whole and also on specific family members. Following initial diagnosis of the illness, parents typically experience feelings of doubt, denial, despair, and detachment and tendencies to overprotect the child (Friedman et al., 1963; Kubler-Ross, 1969). As well, a large proportion of parents experience increased levels of anxiety and depression and other signs of emotional maladjustment during the first year of oncologic treatment (Powazek et al., 1980). Many complain of various somatic problems including fatigue, insomnia, and lack of appetite (Lascari and Stehbens, 1973). Evidence has also been presented suggesting that parents

suffer from an erosion of self-esteem as the role of principal caretaker is transferred to medical professionals (Chodoff et al., 1964; Putterman and Hoffman, 1973; Schulman, 1976).

Following the preliminary stage of shock, a period of anticipatory grief is common where the parents begin to prepare themselves for the possibility of death (Binger et al., 1969). If the child lives beyond this stage, Green and Solnit (1964) have stated that a "vulnerable child syndrome" may develop out of unresolved anticipatory grief where the life-threatening experience of the past continues to persist as a dominant factor governing ongoing behaviour.

Undergoing treatment for pediatric cancer is a very stressful experience for the family as well as the patient due to the radical and invasive procedures used and the potential physical costs to the patient. Parents must provide informed consent for complex treatment protocols after receiving detailed information about every possible side effect of each drug (Johnson et al., 1979). There are also several reports of financial strain on the families of children in treatment. Outpatient treatment for the child is not only physically demanding for the parents but the distance to the treatment centre may involve the expense of overnight accommodations and necessitate arrangements for supervision of other children left at home (Evans, 1975; Kagen-Goodheart, 1977; Johnson et al., 1979).

Another very stressful time for these families is "coming

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off treatment", that is, the elective cessation of treatment after an extended period of control over the disease. It is often difficult for the patient and his family to believe that the child will continue in health without active treatment (Kagen-Goodheart, 1977; Johnson et al., 1979). Based on their exploratory study of twenty parents whose children had completed chemotherapy treatment for leukemia, Lewis and LaBarbera (1983) reported that 80% of these parents had strong feelings of anxiety at the time chemotherapy was terminated. Parents said that the reasons underlying their responses were fears of possible relapse, uncertainty about the correct period of time during which the child should receive medication, and negative responses to the thought of severing contact with hospital staff and other parents with whom they had shared some stressful experiences.

Re-entry of the cancer patient into the home may also be problematic. Although the family is reunited it cannot fully resume its pre-crisis routines because the child will still require special attention including frequent trips to the hospital for check-ups. As parents continue to focus much of their time and energy on the chronically ill child, jealousy is often a problem among the siblings (Kagen-Goodheart, 1977; Cairns et al., 1979b; Johnson et al., 1979). In a study of school-aged patients and their healthy siblings from seventy-one families, Cairns et al. (1979b) noted that the siblings experienced even more distress than the patients when tested on the dimensions of perceived social isolation, perception of their parents as over-indulgent and over-protective of the sick child, fear of

confronting family members with negative feelings and concern with failure. They found patients and siblings to be similar on other outcome variables such as anxiety and vulnerability to illness and injury.

Having a child with cancer has rarely been shown to result in the disintegration of a previously sound marital relationship but it has been linked to the acceleration and culmination of family problems already present. In a study comparing 38 parents of children with cancer, 23 parents of hemophiliac children, 71 parents of healthy children, and 115 parents receiving marriage counselling, the results indicated that parents of children with cancer scored higher on marital distress than the parents of hemophiliacs. Both parental groups with chronically ill children scored higher on marital distress than the couples with healthy children but their scores were lower than the group of parents receiving marital counselling (Lansky et al., 1978).

In recognition of the need for pediatric oncology teams to shift their focus from strategies to deal with dying and death to maintaining quality of life for child cancer patients and their families, Kupst et al. (1982) began a prospective study of coping among 64 families of children diagnosed with leukemia. Family coping was rated at one year post-diagnosis by physicians, nurses, psychosocial staff and the parents themselves. One year after diagnosis, 81 percent of the children were in first remission and doing well medically. The authors concluded that most families (71.7%) seemed to be coping well at follow-up based

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on total family ratings compiled by physicians, nurses, and the psychosocial staff. On the basis of these evaluations, however, 23.4% of the families were found to be coping poorly. The authors recognize that limitations have been imposed on their results, though, due to a problem with missing data. Ratings were not provided by physicians and nurses whenever they felt inadequately prepared to rate a family, nor by the psychosocial staff when they were unable to schedule home visits with a family. Because of this, the follow-up ratings were only completed by physicians for 62.5 percent of families, by nurses for 37.5 percent of families, and by the psychosocial staff for 39.1 percent of families.

One major study (Koocher and O'Malley, 1981) has investigated the psychosocial consequences for child survivors of cancer. The project, initiated by Norman Jaffe and John O'Malley, was designed to locate a group of former child cancer patients using a computerized registry of child cancer survivors from the Sidney Farber Cancer Institute in Boston. Their goal was to study the social and psychological consequences of childhood cancer both for the former patients and for their families. Results were based on interviews with 117 former patients, 190 parents, and 101 siblings. Attempts were made to locate and interview a control group of persons who had been successfully treated for a chronic childhood illness five or more years prior to the study. Due to severe problems in locating the controls selected, data were collected from a control group of only 22.

The interviews with parents gathered retrospective information by asking parents to recall various aspects of the illness period and their feelings about them. Parents were also asked to comment on ways in which their current behaviour was a result of the cancer experience. All assessments of parents' current levels of functioning were based entirely on the parents' self-reports. Unfortunately there was no attempt to formally assess levels of psychological well-being using standardized instruments.

It was learned from the parent interviews, however, that parents still harbored concerns about the former patient. Among their concerns were the long-term effects of treatment, the possibility of cancer recurring, the child's reproductive ability and general physical health. Many parents reported that their fears of recurrence remained, regardless of how many years had passed uneventfully. Some parents did feel, however, that five years after diagnosis the "magic cure time" had been reached.

2.1.2 Factors Affecting the Impact of Childhood Cancer.

Some attempts have also been made to describe the factors that may be important in determining the impact that childhood cancer has on a family. The importance of the availability of an emotional support network has been investigated by the examination of parents' relationships with one another, with the grandparents of the child, with friends, with other parents of chronically ill children, and with medical team members (Binger et al., 1969; Bozeman et al., 1955; Friedman et al., 1963; Hebron

et al., 1973; Kaplan et al., 1973; Lascari and Stehbens, 1973; Morrow et al., 1981). Morrow et al. (1981) studied 107 parents attending a national mutual-help organization convention for parents of children with cancer; 37 whose child had died, 48 whose child was currently receiving chemotherapy, and 22 whose child had finished treatment. For parents with children currently on treatment, there were significant positive correlations between perceived support from spouse, relatives, primary physician and other parents of ill children as well as average amount of support and psychosocial adjustment to the child's illness. For parents whose child was off treatment, only support from relatives was correlated with adjustment. No associations between any source of support and adjustment were found for parents whose child had died.

Strength of religious beliefs and adjustment have been shown to be conditionally related (Bozeman et al., 1955; Friedman et al., 1963). The relationship appears to depend on the parents' religious orientation before the child's illness is diagnosed. If parents have found comfort in their religious beliefs in the past, they are likely to find emotional support in these beliefs during the crisis, and the denunciation of strongly held religious beliefs due to a child's fatal illness is rare (Bozeman et al., 1955; Friedman et al., 1963).

Length of time since the child's diagnosis has been shown to be related to ratings of marital quality by the parents (Barbarin et al., 1985). Thirty parents whose child had been diagnosed within the previous three years rated the quality of their

marriages significantly higher than did 34 parents who were between three and five years beyond their child's diagnosis.

Finally, several personal characteristics of the parents have been shown to have significant effects on adjustment. Psychosocial adjustment was shown to vary by parents' age by Morrow et al. (1981). Parents under age thirty had significantly more impaired adjustment across several dimensions. Although gender of parent did not affect ratings of adjustment in the study by Morrow et al. (1981), Obetz et al. (1980) reported that their evaluation of eighteen sets of parents with children who had had remissions of at least four years indicated that fathers' reactions to the illness differed from mothers' reactions. Unfortunately, no information was given about the nature of these differences. Among parents with seriously ill children, selected by hospital staff as being good copers, Schulman (1976) identified several common characteristics including a good self concept, openness and honesty, a generally optimistic attitude, and the affirmation of life rather than the denial of illness.

2.1.3 Overview and Implications.

This literature provides some indication of the experiences faced by families of child cancer patients. These research efforts remain largely on the descriptive level, however. There have been a wealth of in-depth, anecdotal accounts that express families' views of the experience of childhood cancer yet there has been relatively little rigorous quantitative research. Small sample size and lack of control groups tend to characterize these

studies. As previously mentioned, the literature reports little or no systematic testing of theoretical models and hence cannot offer much in terms of explanations for the variations observed in the adaptation of these families.

A review of the literature on the correlates of childhood cancer makes clear the need for further research that is theoretically based, empirically sound, and that attempts to understand the interconnections of the various components that might be involved in the stress process. Such efforts seem crucial for understanding the impact of childhood cancer on families across every stage of the illness but especially for those families about whom we know the least--those who have entered the stage where they must prepare themselves for the child's normal development while coping with long-term uncertainty.

2.2 Theoretical Models

Two models, the stress process model and family stress theory, were used to guide the present investigation. The first model is particularly useful in conceptualizing the process whereby stressful experiences can result in varying levels of distress for an individual. The second model lends itself to the explanation of variations in adaptation at the family level. Sections 2.2.1 and 2.2.2 provide brief descriptions of these models, identify the components of each model that were included in the study, and present hypotheses generated from each model that were tested in the present study.

It should be noted that these two models are separate but closely related. They share some common constructs while other constructs are probably related. Given the nature of these models it may seem wise to simply combine them. This was not done, however, because they were derived from two distinct theoretical backgrounds each with its own proponents. It is believed that the results would contribute more to each of the two schools of thought if presented as tests of hypotheses unique to each separate model.

2.2.1 The Stress Process.

It has been widely accepted and well documented that there is a relationship between stressful life events and psychological distress or well-being. Although there is a long history of attention focused on the role and significance of life stress, only recently has interest centered on the task of explaining how various components of stress are linked to form a process. (Billings and Moos, 1982; Kaplan, 1983; Pearlin et al., 1981).

The stress process, as conceived by Pearlin and his associates, involves a complexity of relationships among life events, chronic life strains, mediating resources and the stress outcome. According to these investigators, "stress can be seen as arising out of two broad circumstances: the occurrence of discrete events and the presence of relatively continuous problems" (Pearlin et al., 1981:338). They believe that "events may induce adverse changes in the more persistent circumstances of people's lives; these adverse changes then act to intensify the level of stress that people experience" (Pearlin et al.,

1981:343).

The focus of most research efforts has tended to be on the significance of discrete events (Myers et al., 1975; Paykel, 1978; Tausig, 1982; Thoits, 1983) rather than on the more continuing problems, referred to as chronic strains by Pearlin et al. (1981). It is not the case that such a focus was determined by the relative importance of these two sources of stress. On the contrary, it makes intuitive sense that events with more enduring consequences should be more important in determining distress than those events that are of limited duration. The problem lies in ascertaining the extent to which distress can be attributed to discrete events or to enduring strains. The fact that the effects of events and strains are confounded makes it difficult to assess the theoretical significance of chronic strains for psychological distress (Turner and Wood, 1984).

The parents of children who have been treated for cancer and are currently in long-term remission present a rather unique research opportunity. This population offers a circumstance for the study of a particular chronic strain, associated with the uncertainty of a child's future, which is relatively unconfounded with recent life events.

The importance of considering factors that may buffer the impact of stress has been voiced by those studying the stress process (Kaplan, 1983; Pearlin et al., 1981). Certain social and personal resources have been identified as relevant factors. Social support has been shown to moderate or buffer the

relationship between life stress and psychological distress (Pearlin and Schooler, 1978; Pearlin et al., 1981; Kaplan, 1983). There is also strong evidence to suggest that social support has a direct effect on psychological health among diverse populations (Turner, 1983; Turner et al., 1983). Mastery (the extent to which one views life as being within one's personal control as opposed to being fatalistically controlled) has been shown to be inversely associated with psychological distress for those experiencing chronic strain (Pearlin and Schooler, 1978; Pearlin et al., 1981; Turner and Noh, 1983). Recent reviews have suggested that coping is also an important intervening variable in the relationship between life stress and psychological distress (Burish and Bradley, 1983; Killilea, 1982; Menaghan, 1983a).

The present study examines the stress process as it applies to the stressful circumstance of childhood cancer. It assesses the association between chronic strain, as experienced by the parents of children surviving cancer, and psychological distress assessed in terms of levels of depression and anxiety. Specifically, it tests three hypotheses derived from the stress process model:

- 1) individuals experiencing chronic strain will have significantly higher levels of psychological distress than those not experiencing such strain;
- 2) the impact that chronic strain has on psychological distress will be greater in the presence of recent life events;
- 3) the relationship between chronic strain and psychological distress will be moderated by both personal and social resources.

2.2.2 Family Stress Theory.

The groundwork for the study of family stress was laid in 1949 by Reuben Hill's ABCX model of family response to stress. This model, briefly stated, is as follows: "A (the event)--interacting with B (the family's crisis-meeting resources)--interacting with C (the definition the family makes of the event)--produces X (the crisis)" (Hill, 1958:141). More recently the issue for researchers has not been whether an event causes a crisis but instead what factors, in combination with the stressor event, act to increase or mitigate its effect on the family (McCubbin and Patterson, 1982).

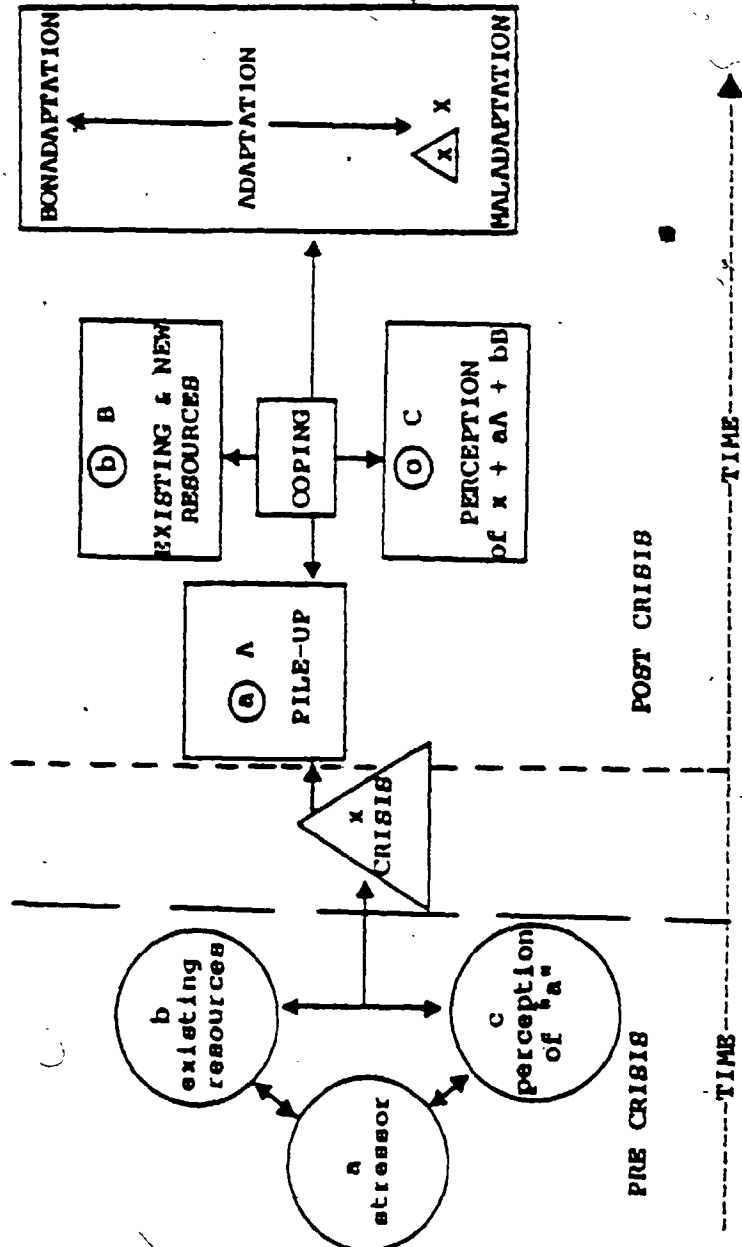
Hill's original theory has been extended by McCubbin and Patterson (1982) to include post-crisis variables in an effort to understand why certain families are better able to adapt to crises than others. Because the extended model examines the relationships among the same variables in the post-crisis period as in the pre-crisis period, McCubbin and Patterson have labelled it the Double ABCX Model. It was formulated inductively through the study of families subjected to war-induced separations. They concluded that the concept of "family adaptation" is useful in describing the outcome of family post-crisis adjustment. Adaptation, as defined in the context of their model, "involves the processes of stimulus regulation, environmental control, and balancing to achieve a level of functioning, which preserves family unity and enhances the family system and member growth and development" (McCubbin and Patterson, 1982:45).

The post-crisis factors that are considered to be relevant to adaptation and thus comprise the Double ABCX Model are stressors, resources and perceptions. This model is presented in Figure 2.1.

McCubbin and Patterson (1982) distinguish three types of stressors: the initial stressor event with its associated hardships, normative family life changes and events that occur independent of the initial stressor, and the consequences of the family's efforts to cope with the ensuing burdens. In their view, families attempting to manage a crisis situation tend to be faced with many stressors and strains occurring simultaneously producing a "pile-up" (Patterson and McCubbin, 1983). A pile-up of unresolved stressors and strains has been shown to contribute to undesirable characteristics in family environments such as more conflict (Nevin et al., 1981). In this study the experience of multiple life events occurring in clusters is assessed by recording the number of normative and non-normative life events and changes experienced by the families in the past six months.

Resources include those psychological, social and interpersonal characteristics of family members and of the community that a family can utilize in their efforts to meet the demands placed on them. There are two types of family resources: those that were already available to the family to minimize the effect of the initial stressor and those coping resources developed in response to the crisis. McCubbin et al. (1981), in a study of families who had a cerebral palsy child, found less

FIGURE 2.1: The Double ABCX Model.



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conflict in families who had the resources of self-esteem, mutual support and assistance, a sense of mastery over experienced events, and an optimistic definition of the situation. The present study considers the mitigating effects of the following resources: self-esteem, sense of personal control, and social support. Due to the cross-sectional nature of this study it was not possible to distinguish between the two types of resources. It was possible, however, to assess the nature of the resources available to the family at the time of interview.

Finally, there are two forms of family perception: the family's perception of the initial stressor and its perception of the total situation including associated hardships and other stressors. According to Patterson and McCubbin (1989), family coping, and eventually adaptation, are facilitated by family attempts to redefine the situation as a challenge, or as an opportunity for growth, or by attempts to endow the situation with meaning. McCubbin, Hunter and Metres (1974) found in a longitudinal study of families faced with war-induced separation that religion and/or religious beliefs assisted these families in ascribing an acceptable meaning to their situation. In this study, religiosity is assessed in an attempt to determine whether it is related to level of adaptation achieved.

It is difficult to distinguish between the concepts of family "resources" and the family's "perception" of the situation as used in the family stress theory. McCubbin and Patterson (1981) recognize this point and contend that a reasonable way of dealing with the problem is to study both variables

simultaneously under the label of "coping strategies". Whether these concepts are dealt with in terms of Hill's (1958) original terminology, grouped together as McCubbin and Patterson (1981) suggest, or classified as personal and social resources as in the stress process model, the important point is that these constructs represent personal and social characteristics that may affect adaptation. For present purposes, we will refer to sense of personal control, self-esteem, and religiosity as personal resources and to social support as a social resource.

The extension of Hill's model to the Double ABCX Model appears to be a promising prediction model for the study of the impact that childhood cancer has on the survivors' families. The experience of childhood cancer clearly falls within Hill's definition of a crisis as "any sharp or decisive change for which old patterns are inadequate" (Hill, 1949:51). According to the Double ABCX Model, survivors' families are in a post-crisis situation characterized by multiple stressors and strains occurring simultaneously. The present study examines family adaptation in the context of the family stress theory. Consideration is given to 1) the association between stressors associated with a post-crisis period and family adaptation as measured by level of family functioning and by level of marital adjustment and 2) the factors posited to be associated with post-crisis adaptation--social and personal resources. Specifically, the study tests three propositions generated from the family stress theory:

- 1) families in a post-crisis situation tend to experience a pile-up of stressors;
- 2) families in a post-crisis situation will have significantly lower levels of adaptation than families who have not experienced such a crisis;
- 3) the relationship between the fact of a crisis experience and associated post-crisis stressors and level of adaptation will be moderated by both personal and social resources.

Proposition 2 may seem to over-simplify the concepts depicted in Figure 2.1 where many variables are shown as intervening between Crisis and Adaptation. McCubbin and Patterson (1982) do not explicitly discuss a direct relationship between Crisis and Adaptation. The development of a theory to study families' response to stress suggests, however, that families experiencing a crisis differ from those who have not experienced a crisis. Given that families without crises would be expected to vary in degree of adaptation, the Family Stress Theory implies that families in a post-crisis situation vary as well but with a lower average level of adaptation. Proposition 2 allows us to test for this basic relationship between Crisis and Adaptation.

2.2.3 Relationships Between the Two Models.

It is very likely that components from the two models outlined above interact in complex ways. For example, family adaptation and psychological well-being are likely to be closely related. While marital discord may lead to anxiety or depression, psychological distress resulting from chronic strain

could presumably affect marital adjustment. Because associations among various components of the two models could provide valuable insight into the dynamics involved, these relationships are examined as well.

CHAPTER THREE

RESEARCH QUESTIONS

3.0 Introduction

The hypotheses generated from the stress process model as well as the propositions generated from family stress theory can be explicated in terms of specific questions. Each of the theoretical constructs comprising the models, including psychological distress, family adaptation, stressful life events, and personal and social resources, was operationally defined by selecting variables thought to be appropriate based on a review of both theoretical descriptions of the construct and empirical findings related to the psychosocial aspects of childhood cancer. The result of these considerations was the following operational definitions for each of the theoretical constructs: depression and anxiety for psychological distress; family functioning and marital adjustment for family adaptation; mastery, self-esteem, and religiosity for personal resources; and social support for social resources. A more detailed account of these variables is provided in Chapter Five, where measurement is discussed.

3.1 Questions Generated from the Stress Process Model

Section 2.2.1 presented three hypotheses derived from the stress process model. The first hypothesis was that individuals experiencing chronic strain will have significantly higher levels of psychological distress than those not experiencing such strain. This was addressed by asking the following questions:

- 1 Do parents experiencing the chronic strain of having a child surviving cancer have a higher mean score on a) depression or b) anxiety than parents not experiencing such strain?
- 2 Is there a larger proportion of parents experiencing the chronic strain of having a child surviving cancer at high risk for clinically significant depression than of parents not experiencing such strain?

The second hypothesis from the stress process model was that the impact of chronic strain on psychological distress will be greater with the occurrence of recent life events. In other words, recent life events will interact with the presence of chronic strain in their effect upon psychological distress. This hypothesis was tested by asking:

- 3 Does the occurrence of recent life events increase the impact that chronic strain related to the uncertain future for a child surviving cancer has on parents' levels of a) depression and b) anxiety?

The final hypothesis derived from the stress process model was that the relationship between chronic strain and psychological distress will be moderated by both personal and social resources. In other words, the experience of chronic strain will interact with certain personal and social resources in their effect upon psychological distress. This hypothesis was addressed by asking:

- 4 Do the personal resources of mastery or self-esteem buffer the effect of chronic strain on a) depression or b) anxiety?
- 5 Does the social resource of social support buffer the effect of chronic strain on a) depression or b) anxiety?

3.2 Questions Generated from the Family Stress Theory

Three propositions were derived from the family stress theory. The first was that families in a post-crisis situation tend to experience a pile-up of stressors. Although it is possible that "pile-up" may occur at a particular point in the natural history of the process, this cannot be assessed here because the study sample varied in the length of time since the cessation of treatment and were not followed over time. This study was able, however, to test the more general hypothesis that the presence of chronic strain is associated with an increased risk for eventful stressors. This was tested by asking:

- 6 Do parents experiencing the chronic strain of having a child surviving cancer report more life events in the previous six months than parents not experiencing such strain?

The second was that families in a post crisis-situation will have significantly lower levels of adaptation than families who have not experienced such a crisis. This was addressed by asking the following questions:

- 7 Do parents experiencing the chronic strain of having a child surviving cancer have a lower mean score on a) family functioning or b) marital adjustment than parents not experiencing such strain?
- 8 Is there a larger proportion of parents living with the chronic strain of having a child surviving cancer experiencing a disturbance in family functioning than of parents not living with such strain?

The third hypothesis from family stress theory was that the relationship between the fact of a crisis experience and associated post-crisis stressors and level of adaptation will be moderated by both social and personal resources. This was tested

by asking:

- 9 Do the personal resources of self-esteem, mastery, or religiosity buffer the effect of stressors on a) family functioning or b) marital adjustment?
- 10 Does the social resource of social support buffer the effect of stressors on a) family functioning or b) marital adjustment?

CHAPTER FOUR

METHOD

4.0 Introduction

This chapter begins by providing a brief overview of the method used. The two samples of parents are then described focusing on such issues as selection criteria, data collection strategies and participation rates.

Before proceeding, a comment about the terms chosen to label the two samples of parents seems appropriate. The parents of child cancer survivors will be identified as "cases" and the parents of healthy children will be referred to as "controls". It is recognized that these labels represent somewhat of a misnomer. The study to be described here is not a case-control study, which begins by identifying persons with a particular disease and a comparison group of persons without the disease, starts after the onset of the disease and studies postulated causes of the disease, retrospectively (Last, 1983). The decision to use these terms, cases and controls, even though they are technically not appropriate, was made in the interests of simplicity.

4.1 Overview

The design of the study was cross-sectional and included two matched samples. The case sample was composed of parents of child cancer patients who had been treated for cancer at Children's Hospital of Western Ontario in London. This hospital serves the geographic area that extends as far north as the tip

of the Bruce Peninsula, as far east as Kitchener and as far west as Windsor. Because pediatric oncology cases are also treated in both Kitchener and Windsor, the hospital in London tends not to treat patients that live within approximately twenty miles of these two centres. Children's Hospital of Western Ontario treats an estimated ninety to ninety-five percent of all oncology patients sixteen years of age and younger who reside within its catchment area. The remaining proportion are treated at other centres within the province or outside of the country.

The control sample was composed of parents whose children have not experienced a chronic illness and who lived in the neighbourhoods of the families with children surviving cancer. Parents chosen for both samples were located and answered self-administered questionnaires that took approximately one hour to complete. Both the mother and the father participated where possible. Data were gathered from both samples regarding their current circumstances including demographic characteristics, stressful life events, personal and social resources, psychological well-being, and family adaptation.

In the following sections of this chapter, the two samples will be described in terms of the selection criteria used to select potential respondents, the data collection procedures adopted, and participation rates.

4.2 Sample of Parents of Child Cancer Survivors

4.2.1 Selection Criteria.

All parents whose children met the criteria that follow were considered potential respondents. Parents were asked to participate in the study if their child met these sampling criteria:

- 1) s/he began treatment for a childhood malignancy* before December 1, 1984
- 2) s/he had not received any treatment for cancer for at least six months before the time of the parents' participation in the study
- 3) his/her cancer was in remission at the time of the parents' participation in the study

*Cases of histiocytosis were also included because, although the pathology is different than cancer, it has several similarities to cancer. It is life-threatening, progresses like cancer and is treated using the same agents that are used for cancer.

An initial review of the files on all pediatric oncology cases indicated that 101 patients met these criteria.

4.2.2 Data Collection Procedures.

All potential respondents, for whom mailing addresses could be obtained, were sent an introductory letter from the pediatric oncologist responsible for managing the child's illness. The letter (Appendix A) described the study, asked for their participation, and explained that they would be receiving a telephone call to arrange for the completion of questionnaires (Appendix B). The letter requested the participation of both parents, where possible, but indicated that the participation of even one of them would be appreciated. Approximately one week after the letters were sent, the potential respondents were

called and arrangements were made to mail out questionnaires and consent forms to those who agreed to participate. At this time it was stressed that spouses were to complete the questionnaires independently without discussing the questions and they were told to feel free to call about any questions that might arise during the completion of the questionnaires.

Respondents living within the City of London or within a short driving distance of the city (32% of families) were told that they would receive a call in approximately ten days to set up a time to have the questionnaire(s) and consent form(s) picked up at their homes. In cases where the distance to respondents' homes made the pick-up method impractical (68% of families), respondents were told that they would be provided with self-addressed, stamped envelopes in the questionnaire packages mailed to them. They were asked to return the questionnaires as soon as they were completed. Separate envelopes were provided for the return of the questionnaires and the consent forms so that confidentiality could be maintained by making sure no identifying information had to be included with the completed questionnaires. More reminder calls were used with the mail-back method in an attempt to improve upon the rates of return usually associated with mailed questionnaires.

Some data about the child cancer survivors were abstracted from the records of their pediatric oncologists at the Children's Hospital of Western Ontario. Permission to access these records, as well as formal consent to participate in the study, was given

in the consent forms signed by every parent participating in the study (Appendix A). The following pieces of information were abstracted from the files: sex, date of birth, diagnosis, and the dates of diagnosis, the beginning of treatment, and the cessation of treatment.

4.2.3 Participation Rates.

Parents of 99 of the 101 child cancer survivors meeting the sample criteria were located and contacted using the introductory letter. Although the majority of families were still living in southwestern Ontario, some families had moved to more distant areas of the province, two to western Canada, and two to the United States. Of course those families who had not been in contact with Children's Hospital for several years were the most challenging to locate.

A child cancer survivor in one of these families died after the study began, leaving 98 families still eligible to participate. Of these families, both parents refused to participate in eighteen (18.4%) of the families. At least one parent participated in eighty (81.6%) of families eligible to participate and, of these, 63 families were represented by both spouses. These participation rates are shown in Table 4.1.

Because both spouses were asked to participate independently, it is also important to examine the response rates using parents, rather than families, as the unit of analysis. The number of parents considered eligible for participation was 185—87 fathers and 98 mothers. The discrepancy in the numbers of eligible fathers and mothers resulted from that portion of the families

TABLE 4.1: Participation Rates for Families of Child Cancer Survivors

Child Cancer Survivors Meeting Sample Criteria	101
Families Lost to Follow-Up	2 (2.0%)
Families Contacted for Participation	99 (98.0%)
<hr/>	
Family Where Child Died After Study Began	1
<hr/>	
Families Still Eligible for Participation	98
Families Where Both Parents Refused to Participate	18 (18.4%)
Families Where At Least One Parent Participated	80 (81.6%)

TABLE 4.2: Participation Rates for Parents of Child Cancer Survivors.

Total Number of Parents Eligible for Participation (87 Fathers & 98 Mothers)	185
Parents who Refused to Participate {24(27.6%)Fathers and 18(18.4%)Mothers}	42 (22.7%)
Parents who Participated {63(72.4%)Fathers and 80(81.6%)Mothers}	143 (77.3%)

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where the parents were found to be separated/divorced or one parent was deceased and where, as a consequence, only one of the parents had maintained contact with the child surviving cancer. In cases where the parents were separated or divorced but both parents had contact with the child cancer survivor, both were asked to participate. Such was the case for six fathers. In situations where one parent had no contact with the child, it was decided that attempts would not be made to include this parent in the study. The rationale behind this decision was that it does not seem relevant to examine the current levels of psychological distress or family adaptation for a parent who has, for one reason or another, severed all ties with the child cancer survivor.

Of those eligible, 42 parents (22.7%) refused to participate. Of these, 24 were fathers (27.6% of those eligible) and eighteen were mothers (18.4% of those eligible). In total, 143 parents (77.3% of those eligible) participated in the study. This sample was comprised of 63 fathers (72.4% of those eligible) and 80 mothers (81.6 % of those eligible). The participation rates using parents as the unit of analysis are illustrated in Table 4.2.

4.2.4 Analysis of Lost Cases.

Only two families were lost to follow-up. A variety of tracking methods, used to locate the rest of the sample, proved unsuccessful in locating these parents. One of the sets of parents was known to be separated but both parents were

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apparently living in the London area. The other family had moved from the catchment area served by Children's Hospital several years ago and no follow-up information could be obtained.

As mentioned above, eighteen mothers and 24 fathers refused to participate. Families who were lost to the study—those who could not be located or who refused to participate--were compared, using all data available, with families who participated. Comparisons were made between these two groups in terms of some characteristics of the child cancer survivors (sex, age, diagnosis, and years off treatment) and in terms of some characteristics of the parents (age, marital status, and the number of children living at home). There were no statistically significant differences between these two groups. These comparisons are presented in Appendix D.

All parents who refused to participate were asked to provide a reason for their decision not to participate. The reasons given are displayed in Table 4.3. It can be seen that the largest proportion of parents classified as refusals originally agreed to participate but did not return the questionnaires. The precise reason for refusal is not known for these cases since each of them maintained throughout the entire call-back period that s/he was still planning to respond. The second most common reason given for refusal was that the information requested was too personal to reveal.

TABLE 4.3: Reasons Given by Parents for Refusing to Participate

Reason for Refusal	MOTHERS		FATHERS	
	N	%	N	%
Information Too Personal	5	27.8	6	25.0
Emotional Cost Too High	3	16.7	3	12.5
Too Busy To Participate	2	11.1	3	12.5
Other (Unrelated to Cancer)	3	16.7	4	16.7
Agreed to Participate but Did Not Send Questionnaire Back	5	27.8	8	33.3
TOTAL	18	100.0	24	100.0

4.3 The Control Sample

4.3.1 Justification of Choice of Sample.

It is not immediately obvious what group of individuals constitutes the most appropriate control group for a study of the psychological adaptation achieved by the parents of children who have been treated for a chronic life-threatening disease. A control group is usually composed of persons who are demographic counterparts of the study sample but who differ regarding the main independent variable; in this case being the parent of a child cancer survivor. To examine the impact that this status can have on a parent, one could compare these parents to their demographic counterparts found among parents of children: 1) who have another chronic life-threatening illness; 2) who have a chronic non life-threatening illness; 3) who have not had any chronic or serious illnesses; or 4) who are currently in one of the other stages of childhood cancer (at time of initial diagnosis or undergoing treatment). Another alternative would be to include two or more of the possible control groups listed above.

It is possible to think of how each of these potential control groups could be used to add to our understanding of the impact that childhood cancer has on the families of survivors. For the present study, however, a control sample of parents whose children have not experienced any chronic or other serious illness was considered to be the most appropriate for two reasons.

First, such a control group enhances the study of the stress

process, by allowing an examination of the extent to which the presence of chronic strain, as experienced by the parents of children surviving cancer, is associated with psychological distress and with family adaptation. This can be accomplished by comparing a group experiencing chronic strain with a group who are not experiencing such strain.

Second, the comparison between families of child cancer patients and families of healthy children has implications for intervention. The issue being considered here is whether the families of children who have suffered from chronic illnesses that lead to chronic strain should be considered as potential targets for intervention. Have they successfully adapted in the face of the uncertainties associated with the illness? Are they experiencing problems that distinguish them from the families of healthy children to the extent that formal intervention may be advised? If it were found, for example, that the parents of cancer patients had significantly higher levels of anxiety or depression than the parents of healthy children or that their families functioned at significantly lower levels, then serious consideration should be given to extending psychosocial follow-up to families with children in long-term remission. Using this rationale, it was decided to select a control sample that was similar to the study sample in terms of family composition and socioeconomic status but that consisted of families where none of the children had experienced a serious chronic or life-threatening illness. The strategy employed was one of frequency

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matching, as opposed to pair-wise matching. It is designed to result in two samples with similar frequency distributions on sociodemographic variables and in this way control for the effects of these variables in the design stage.

4.3.2 Selection Procedures and Criteria.

Given that the goal was to select an unbiased sample of families with healthy children that was roughly equivalent to the study sample in terms of socioeconomic status and that neighbourhoods tend to be homogeneous in this regard, it was decided that this goal could be accomplished by selecting control families from within the case families' neighbourhoods. A control family was to be obtained for every family of a child cancer patient where at least one parent agreed to participate in the study.

The procedures followed were guided by the methods previously used by Dr. Aileen Clarke of the Ontario Cancer Treatment and Research Foundation and Dr. Stephen Walter of the Department of Clinical Epidemiology and Biostatistics at McMaster University. The method takes advantage of the public records and maps kept by regional assessment offices. The first step was to determine the county in which each of the index families lived and the location of the assessment offices where records for each of those counties are kept. With this information in hand, trips were made to each of the relevant regional assessment offices. Forty-three percent of the relevant records were to be found in the regional assessment office located in London while the remainder were spread over an additional six offices.

The process of identifying residents in the neighbourhood of each case family from the assessment records involved the following procedures. For those families residing in a city or a town with designated street addresses, the Street Indexes were consulted. They are arranged alphabetically by street and numerically by street numbers of each residence and provide the principal occupant's name as well as that of the registered owner, if different than the occupant. The address of the case family was found in the appropriate street index and the names and addresses associated with approximately ten residences around the case family were recorded. This number was arbitrarily chosen, based on both the knowledge that some listings would not reflect current occupancy status and the ultimate goal of obtaining two families from each neighbourhood that would be suitable for selection as controls. At times it was not possible to record as many as ten surrounding neighbours because they did not exist. Examples of this would be a family living in a apartment over a business on the main street of a small town and a family living on a small dead-end street right at the edge of a town.

Thirteen case families (16.3 %) had rural addresses. The street indexes could not be used at this stage to locate the neighbours of these families since the indexes are arranged by physical addresses only, which in the case of rural property is not the same as the mailing address. In this situation, the name of the case family was located on the alphabetical listing of

residents and the roll number assigned to their property was then used to locate the property of the case family on the maps drafted by the assessment offices to illustrate the physical boundaries of every property within their jurisdictions. Once this property was found, the roll numbers of approximately twenty properties surrounding the case family's property were recorded. An attempt was made to identify a larger sample of neighbouring properties for the case families in rural areas than those in urban areas because often the rural roll numbers selected were found to be assigned to property with no one living on it, such as agricultural land or businesses. Equipped with the roll numbers, the Assessment Rolls that are arranged according to county and roll number were used to look up the occupant's name and mailing address.

In the next stage of the process for selecting a control sample, telephone numbers were sought for as many of the neighbours of each case family as possible using telephone directories, directory assistance, and the Vernon's Directories. Each household was then called to screen the occupants for eligibility as participants. The goals at this stage were as follows: to identify the residences that met the criteria of at least one parent (with children either at home or elsewhere) living there and none of the children having experienced a serious chronic illness or life threatening disease; and to ascertain the ages of each member of the family. Families where all of the children were living elsewhere were also considered potential controls because there were case families where such

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was the case. The screening method used was as follows:

1. The person answering the telephone was told that the caller was from the Health Care Research Unit, at the University of Western Ontario where preparations were being made to conduct a survey of families in the area. If a child answered the telephone, s/he was asked to forward the call to an adult in the home.
2. The person was asked if s/he could spare a few moments to answer some brief questions and told that the answers would be held in strictest confidence.
3. If the person agreed to answer the questions, s/he was asked to list the age of everyone that lived in the household, including him/herself, and tell how each was related to him/her. The person was then asked if s/he had any children/siblings not living at home at the present time and if so, to give their ages.
4. At this point, if the household contacted did not have at least one parent (with children living there or elsewhere), the call was terminated. If there was an adult with children, the person was asked if any of his/her children/siblings (including the one(s) not living at home) had ever had a serious chronic illness or life-threatening disease. If the answer was yes, s/he was asked to describe the type of illness and it was recorded.
5. The address on record was then verified. The conversation was ended by saying that the family may be receiving a letter from us if their household was selected for the study.

If, at any point in the conversation, a question about the nature of the study was asked, it was answered by saying that a study of families with children surviving cancer was being conducted and that it was crucial for this research that these families, with children who have been chronically ill, be compared to families with children who have not been chronically ill.

4.3.3 Results of Screening by Telephone.

Telephone numbers were found for a total of 488 households identified as surrounding the case families, meaning that on average, six households thought to be neighbours of each case family were telephoned. 380 (77.9%) of these telephone numbers resulted in contact with the residents sought, while for 78 (16.0%) of the numbers no answer was received after at least three call backs at different times of the day and 30 (6.1%) of the numbers resulted in contacts with the wrong address. On average, five neighbours of each case family were successfully contacted. Of the 380 contacts where the correct residents were found, eight people (2.2%) had insufficient English language skills to answer the questions, 53 people (13.9%) refused to answer the questions over the telephone, and the remaining 319 people (83.9%) agreed to be screened. The screening of these 319 people resulted in the following reports: 46 (14.4%) lived in households that were not composed of at least one parent (with children living there or elsewhere), 13 (4.1%) said that a child in the household had experienced a serious chronic illness or life-threatening disease, and the remaining 260 (81.5%) indicated by their answers that they fit the screening criteria.

The 260 households successfully screened and meeting the screening criteria were ranked according to their comparability to the case family for which they were chosen as a control. A family's comparability to a case family was assessed in terms of the ages of children, both the child closest in age to the index case (the cancer survivor) and any siblings, and the ages of the

parents. On this basis, the families that ranked first and second were considered to be potential participants for the control sample.

4.3.4 Data Collection Procedures.

The two families considered to be the first and second best matches were both mailed introductory letters from the principal investigator (Appendix C). Two control families were contacted for each case family in anticipation of high refusal rates for this sample. By sending both letters at the same time and then following up with the mailing of questionnaires to both families, if they agreed, time was to be saved by having already processed the second choice family in the event that the first choice family refused initially or failed to return the questionnaires. The letter described the study, asked for the participation of both parents where possible and offered them a small token payment. As well, it explained that they would receive a telephone call to arrange for the completion of the questionnaires. These questionnaires were identical to those completed by case parents (Appendix B) with the exception that the final section of the questionnaire containing open-ended questions dealing specifically with perceived effects of cancer was excluded.

The remainder of the procedures followed were the same as those used for the case sample including the call back to ask for participation, the mailing of questionnaires and the retrieval method of pick-up or mail back depending on distance. The only

exception in procedures was the implementation of a token payment to participants in the control sample. When both parents completed questionnaires they were offered \$10.00 and if only one parent agreed s/he was offered \$5.00. At the outset of the study there was a concern that parents whose lives had not been touched by childhood cancer would be less motivated to participate than parents of childhood cancer survivors. A payment of the size given could certainly not be thought of as a substantial monetary incentive but it was reasoned that perhaps for some parents even such a small payment might give them sufficient motivation to participate. As with the case sample, members of the control sample were each asked to sign a consent form indicating their formal agreement to participate in the study (Appendix C).

4.3.5 Results of Matching Procedures.

Matched control families were needed for the eighty case families that agreed to participate in the study. For 62 (77.5%) of the case families, the control families that were rated as the best match participated. For the remaining eighteen (22.5%) families, the family rated as the best match for them could not be used for one of three reasons. For eleven (13.7%) case families, the families rated as the best match either refused to participate (three families) or agreed to participate but failed to return the questionnaires (eight families); for three (3.8%), the best matches had to be excluded due to illness in a child that was revealed through further screening during the telephone call to ask for participation; and for four (5.0%), the method of neighbourhood matching was not feasible due to the distance of

the appropriate regional assessment office from London.

For ten of these eighteen case families without matched control families, the control families that were rated as the second best match participated. For the remaining eight (10%) case families without matched control families (four where both control families chosen refused and four living in distant locations), the most appropriate control families that could be found among the remaining sample of control families, not already selected as matches, were chosen. These selections were made on the basis of family income and age composition of the family. Family income was used to match on the socioeconomic status of the families to compensate for the fact that these controls could not be chosen from the case families' neighbourhoods.

It will be recalled that, as with the case sample, both parents were asked to participate independently. Of the 80 families comprising the final control sample, 71 families were represented by both spouses.

CHAPTER FIVE

MEASUREMENT

5.0 Introduction

In this chapter, the measurement strategies used for the major variables will be discussed. For each variable assessed using a multi-item instrument, a description of the instrument chosen is provided along with information concerning the scale's psychometric properties.

5.1 Psychological Distress

Two indices of psychological distress were employed in the present study--anxiety and depression. Both are accepted as indices of psychological distress and the psychosocial literature available reports that elevated rates of both anxiety and depression have been documented in the parents of children undergoing the first year of oncologic treatment (Powazek et al., 1980).

5.1.1 Anxiety.

Anxiety was measured using the State-Trait Inventory (STAI) (Spielberger et al., 1970). The STAI was deemed appropriate for the present study since it was originally developed to be administered in research investigating anxiety in "normal" (non-psychiatrically ill) adults. It was also appealing by virtue of its relatively concise nature.

The STAI is composed of two separate 20-item self-report scales each measuring a distinct anxiety concept. The first, A-State scale, is an index of a transitory emotional state or

condition composed of subjective, consciously perceived feelings of tension and apprehension, and elevated activity of the autonomic nervous system. State anxiety may vary over time in terms of intensity so respondents are asked to indicate how they feel at a particular moment in time. The A-State scale was included in the survey instrument to estimate the level of anxiety at the particular time when respondents were completing the questionnaires to be able to compare the two samples' levels on this emotional state. The second scale, A-Trait, is a measure of relatively stable individual differences in anxiety across people. A-Trait represents the more central concept of anxiety for the study in that interest lies in examining the level of this more stable emotional state as an outcome for parents.

Both STAI scales have been found to be quite reliable when tested on normative samples of college and high school students. The internal consistencies, measured using Cronbach's alpha (1951), ranged from .83 to .92 for A-State and from .86 to .92 for A-Trait (Spielberger et al., 1970). In the present study, the alpha coefficient was .91 for A-Trait and .81 for A-State. Spielberger and his associates (1970) have also reported evidence of the concurrent validity of the A-Trait scale using its correlations with other anxiety scales such as the IPAI Anxiety Scale (Cattell and Scheier, 1963) and the Taylor (1953) Manifest Anxiety Scale (TMAS). These correlations ranged from .73 to .85.

5.1.2 Depression.

Depression was measured by the Centre for Epidemiological Studies Depression Scale (CES-D). The CES-D offers the advantage

that it was designed to be used in research on the epidemiology of depressive symptomatology in the general population. This distinguishes it from other depression scales, which have been used primarily for diagnosis or evaluating the severity of symptoms during the treatment process (Radloff, 1977).

The CES-D includes twenty items designed to measure an individual's current level of depressive symptoms, with an emphasis on depressed mood. On a four-point scale ranging from "rarely or none of the time" to "most or all of the time" respondents are asked to indicate how often they experienced each of the symptoms in the last week. Scores may range from 0 to 60 with higher scores indicating greater depression.

The CES-D appears to be highly reliable. Radloff (1977) reported that Cronbach's alpha ranged from 0.84 to 0.90 in field tests of the CES-D. The present study resulted in an alpha coefficient of .89. The scale has been found to have criterion validity in that it discriminated well between a psychiatric inpatient sample and a general population sample and also among levels of severity within patient groups with moderate efficiency. Also, it correlates well with other self-report measures of depression (Radloff, 1977). Results of follow-up studies have indicated that the CES-D identifies both acute and chronic mood disturbances, even though it is oriented to present condition (Radloff, 1977).

The CES-D was also designed to give a probable case rating for depression. A score of 16 is the most commonly used cut-off

score (Radloff, 1977). Scores at least this high are thought to indicate a clinically significant level of depressive symptoms. The cut point is intended to be used as a way of identifying high risk groups, however, rather than for the clinical evaluation of individual cases.

5.2 Family Adaptation

In the present study, two indices of family adaptation were included—family functioning and marital adjustment.

5.2.1 Family Functioning.

Family functioning was measured using the Family Assessment Measure (FAM) (Skinner et al., 1983). FAM is a self-report instrument designed to provide quantitative indices of family strengths and weaknesses. It seemed suitable for the current purposes on the grounds that it is of a reasonable length, offers the opportunity to evaluate families' level of functioning relative to samples of normal families, and includes two response style subscales assessing social desirability and defensiveness.

The concepts assessed by the FAM are: task accomplishment, role performance, communication, affective expression, affective involvement, control, values and norms. FAM rates the family from three perspectives:

- (1) a General Scale that provides an overall rating of family functioning, seven subscales measuring the concepts listed above, and two response style subscales tapping Social Desirability and Defensiveness;
- (2) a Dyadic Relationship Scale composed of seven subscales focusing on relationships between specific pairs in the family; and

- (3) a Self-Rating Scale with seven subscales providing information on the individual respondent's perception of his/her functioning in the family.

For the present study only the 50-item General Scale was administered because this allowed for the assessment of families' overall level of functioning and reduced the time required to respond to the scale.

As mentioned above, the FAM can be used to identify persons reporting high degrees of problems in family functioning, in comparison to typical families. FAM profile scores are normalized such that each subscale has a mean of fifty and a standard deviation of ten. The majority of nonclinical families should have scores between 40 and 60. Scores below 40 are likely indicative of very healthy functioning while those above 60 would indicate considerable disturbance, relative to a sample of normal families (Skinner et al., 1984).

This scale was found to be internally consistent (alpha coefficient of .93) in a heterogeneous sample of 475 families (N=933 adults) tested at various health and social service settings in the Toronto area (Skinner et al., 1983). The Cronbach's alpha in the study reported here was .82. Skinner and his associates also report preliminary evidence of concurrent validity in that the FAM-General Scale significantly differentiates between problem and non-problem families. In the study, "problem families" were defined as those where at least one family member was receiving professional help for a variety of problems including psychiatric/emotional, alcohol or other

drugs, school-related and major legal.

5.2.2 Marital Adjustment.

Although there are several marital adjustment scales available that appear to be psychometrically sound, such as the Waring Intimacy Questionnaire (Waring, 1979) and the Dyadic Adjustment Scale (Spanier, 1976), it was difficult to find an instrument that was brief enough to be included in a questionnaire that was already relatively lengthy. Largely due to this consideration, the marital questionnaire developed at the Western Psychiatric Institute and Clinic, University of Pittsburgh was chosen to assess marital adjustment. It incorporates items from several existing instruments including the Locke-Wallace Marital Adjustment Test (Locke and Wallace, 1959). Six subscales were developed on the basis of a factor analysis. Two of these, Overall Satisfaction and Marital Conflict, were used in the present study. The former subscale is composed of six items and the latter of five items.

In the third wave of the Three Mile Island Study (N=1158) conducted by the Western Psychiatric Institute and Clinic, the investigators report acceptable levels of internal consistency for both of these subscales resulting in Cronbach's alphas of 0.79 for Overall Satisfaction and 0.75 for Marital Conflict. Although formal tests of this scale's validity were unavailable, the Locke-Wallace Marital Adjustment Test, from which it was adapted, has been demonstrated by Locke and Wallace (1959) to have concurrent validity in that scores for well-adjusted couples were found to differ significantly from those of maladjusted

couples. In the present study, both subscales appeared reliable with an alpha of 0.81 for Overall Satisfaction and 0.70 for Marital Conflict.

5.3 Chronic Strain

As mentioned previously, the chronic strain of interest here is that experienced by the parents of children surviving cancer, resulting from a combination of the uncertainty associated with the child's future and the enduring effects that such an event has on a family's patterns of interaction and role performance. The presence of chronic strain was measured as a dichotomous variable where the case sample represented a group experiencing the enduring or chronic strain of being a parent of a child surviving a life-threatening illness and the control sample represented a group that was not experiencing such a strain.

Because there was so much variation in the sample of cancer survivors in terms of diagnosis and length of time off treatment and, as a consequence of these two variables, prognosis, it was believed that the degree of chronic strain felt by parents was also likely to vary. In recognition of these potential variations, an attempt was made, in one series of analyses, to quantify the degree of strain experienced by case parents.

5.4 Life Events

Although the focus of the present study is on the consequences that a particular enduring or chronic strain may have for parents, it is essential that consideration is given to the role played by discrete life events. As outlined in the

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overview of the stress process, it has been posited by both Brown and Harris (1978) and Pearlin et al. (1981) that stress can arise out of two circumstances: the occurrence of discrete events and the experience of ongoing problems or chronic strains. It has been suggested that these two sources unite to produce stress. It may be that recent life events aggravate or intensify existing strains or that the presence of enduring strains amplifies the impact of discrete events. It is not possible to discriminate between these two explanations but this is not important in that it is sufficient to hypothesize that chronic strain will be more relevant to distress in the face of recent life events.

In the present study, life events were assessed using a list of 30 events drawn from other life events scales (Henderson et al., 1981; Sarason et al., 1978), which have been patterned after the scale developed by Holmes and Rahe (1967). Respondents were asked to indicate which of these events they had personally experienced. For twenty of these events, respondents were also asked if their spouse had experienced such an event and for ten of the events, they were asked if this event had occurred to their children, relatives or close friends. Only events that occurred within the past six months were recorded. This was done to produce a count of recent life events that was relatively unconfounded with the major events resulting from childhood cancer itself such as the diagnosis, beginning treatment, and the cessation of treatment.

Respondents were asked to identify the particular month in which each event occurred, rate the event on a scale from very

bad to very good, and indicate how long the event affected them afterwards. Finally, respondents were asked to speculate on whether each of the events that occurred was related to their child's health condition. The number of events listed was limited to 30 because of the extra time involved in answering the probes about each event.

To address the research questions asked here, only counts of the number of events occurring to the respondent personally and the total number of events experienced by the respondent and those close to him/her were used. There were two reasons for this decision. First, given that stressful events was only one of several intervening variables to be considered within the theoretical models, a simple count served to keep the analyses within manageable bounds. Second, given the limited sample sizes, analyses by the various dimensions was deemed inappropriate.

5.5 Personal Resources

Three indices of personal resources, sense of personal control, self-esteem, and religiosity that, as outlined in earlier sections, have been hypothesized to have the ability to mediate the impact that stressors may have on psychological distress or adaptation, and have been demonstrated to be particularly relevant to parents faced with the experience of childhood cancer were included in the present study.

5.5.1 Mastery.

Mastery or sense of personal control was measured using a seven item mastery scale constructed by Pearlin and Schooler (1978). Mastery can be defined as the extent to which one believes one's life is under one's control in contrast to being controlled by external forces. Another way of describing mastery is as "an intrapsychic resource that influences one's ability to competently manage life's challenges" (Turner and Wood, 1984). This scale has been demonstrated to have a satisfactory level of reliability in studies conducted at The Health Care Research Unit, University of Western Ontario, with an alpha coefficient of approximately 0.74. In the present study, a Cronbach's alpha of 0.81 was produced. There is also some evidence of its construct validity in that it tends to be more highly correlated with achieved statuses such as education and income than with ascribed statuses such as age and sex, as one would expect of a measure of self-attitude (Pearlin and Schooler, 1978).

5.5.2 Self-Esteem.

Self-esteem was assessed using the short version of the Self-Esteem Scale developed by Rosenberg (1979). This version includes six items. Respondents are asked to record their degree of agreement with each statement on a four-point Likert scale ranging from strongly disagree to strongly agree. The scale's internal reliability is suggested by Rosenberg's (1979) report that the scale has a Coefficient of Reproducibility of .92. In this study, the Self-Esteem Scale had a Cronbach's alpha of .85. Rosenberg's self-esteem scale also appears to possess construct

validity. Consistent with theoretical expectation, it has been shown to be strongly related to depressive affect, anxiety and peer-group reputation (Rosenberg, 1979).

5.5.3 Religiosity.

Religiosity was assessed using a 13-item inventory of religious activities and attitudes developed by Kenney et al. (1977). The inventory measures three dimensions of religiosity: religious activity and attitudes in one's personal and family life, responsiveness to non-group modes of institutionalized religion (that is, media forms), and activity within institutionalized religious groups. The higher the score, the higher the degree of religiosity. A multidimensional measure of religiosity offers the advantage of sensitivity to religious behaviours that lie outside of mainstream institutional patterns. This broader definition of religiosity seemed to be appropriate in the present context since one would not expect religiosity, as a personal resource, to be limited to only institutional aspects.

The authors of this scale do not provide any information regarding its psychometric properties. It does, however, appear to have face validity and content validity. In the present study, the inventory proved to be reliable, producing a Cronbach's alpha of .93.

5.5.4 Coping.

Coping was not included as a measure in the present study. The concept of coping, broadly defined as "behavior that protects people from being psychologically harmed by problematic social

experience" (Pearlin and Schooler, 1978:2), is clearly central to efforts to understand adaptation and has attracted a great deal of attention in the stress literature. There are two viewpoints regarding how this important concept should be handled in research, however. Some have argued, including Dohrenwend (1984), that coping is a general concept best revealed in considering variations in outcome. In other words, that it is possible to infer that those individuals who score high on life stress but low on psychological distress are coping effectively while those who score high on both life stress and psychological distress are coping less effectively.

Others have attempted to describe and assess coping directly. The focus of such research has been divided among three sets of coping variables: coping resources (generalized attitudes and skills thought to be advantageous), coping styles (ways of approaching problems), and coping efforts (specific actions taken in specific situations in an attempt to reduce certain problems or stress) (Menaghan, 1983b). As well, attempts to empirically assess the effectiveness of coping have involved the use of a variety of outcome criteria (Menaghan, 1983b). It is clear that the complex nature of this construct has posed difficulties in definition, measurement and interpretation. For these reasons, in the present study the position of Dohrenwend was taken.

5.6 Social Resources

Social resources were assessed by focusing on the concept of social support. This concept has been addressed using a wide variety of definitions but underlying all of these definitions is the notion of the significance of human relationships (Turner, et al., 1983). Based on reviews of the theoretical and empirical literature, House (1981) and Turner (1983) both concluded that experienced or perceived social support is the critical element and dominant theme found in this literature. From this perspective, social support "refers to the clarity or certainty with which the individual experiences being loved, valued, and able to count on others should the need arise" (Turner et al., 1983:75). There is also evidence to suggest that it is perceived social support that is most consistently related to psychological well-being (Turner, 1983; Turner et al., 1983).

Given these findings, it was decided, for the purposes of the present study, to focus on the perceptual aspect of support. Within the area of perceived support, it is not entirely clear which dimensions are most relevant to psychological well-being. Because of this, three instruments were selected to assess the following: emotional social support received from family and friends; emotional support, with attention to the negative as well as the positive aspects of support; and instrumental or material assistance from family and friends.

Due to the fact that the sample of parents of cancer survivors were all past the period of their children's illnesses where they would be especially likely to need to rely on others

for instrumental or material assistance in dealing with the many disruptions to family life that surround the earlier stages of childhood cancer, it was suspected at the outset of the study that case and control parents would not vary on the importance of instrumental support. It was thought, however, that the perception of emotional support may be more important to case parents than to controls because of their lingering concerns about their children surviving cancer.

The first measure of perceived level of social support, the Provisions of Social Relations (PSR) Scale was developed at the Health Care Research Unit, the University of Western Ontario. It is a 15-item scale (Question 39, Appendix B) whose development was influenced by Weiss' (1974) conceptualization of the provisions of social relationships and was an attempt to test the respondents' perceptions in relation to five of the "provisions" identified by Weiss. These provisions are attachment, social integration, reassurance of worth, reliable alliance, and guidance.

Aside from its obvious face validity and content validity, there is also evidence of its concurrent validity in studies conducted at the Health Care Research Unit where the PSR was found to be correlated with two other measures of the perception of social support, the Revised Kaplan Scale ($r=.62$) and Reflected Self-Esteem and Reflected Love ($r=.37$ to $.61$) developed at the Health Care Research Unit (Turner et al., 1983). These authors also reported that the PSR produced satisfactory levels of

internal reliability with alpha coefficients ranging from 0.74 to 0.87. In the present study, the alpha coefficient was .84.

Although this perceptual measure may appear to be operationally confounded with symptoms of depression, evidence has been presented (Turner, 1981; Turner et al., 1983) to indicate that this index of social support has underlying determinants that are distinct from those of several scales measuring psychiatric symptomatology, including the measure of depression used in the present study (the CES-D).

The positive and negative aspects of emotional support from family and friends were indexed using items adapted by investigators at the Health Care Research Unit from an instrument developed by Kessler and currently being tested at the Institute of Social Research (ISR) at the University of Michigan, Ann Arbor. Evidence of this scale's psychometric properties are not yet available from ISR or the Health Care Research Unit, but in the current study it appeared quite reliable with a Cronbach's alpha of .76 for family support and .89 for support from friends.

And finally, the perceived availability of instrumental or material social support from family and friends was measured using a scale adapted at the Health Care Research Unit from one of the dimensions of the Inventory of Socially Supportive Behaviors (Barrera et al., 1981). Tests of this scale are now in process so information regarding its psychometric properties is not yet available. In the present study, the adapted instrument did appear to be internally consistent, however, producing an alpha coefficient of 0.81.

5.7 Family Characteristics

Information concerning the demographic characteristics of the families studied was also collected. A series of items were included to provide data on household composition (members by age, sex, and relationship to respondent), parent's age, level of education, marital status, employment status, occupation, family income and perceived financial difficulty. Occupational level was rated using the classification of Pineo et al. (1977).

As well, an attempt was made to gather some qualitative information from the case parents using several open-ended questions. They were asked to describe in their own words how they and their family are affected now by the fact that their child has had cancer, about their present concerns related to the child's illness, how they cope with such concerns, and whether they perceive the need for any social services not currently offered to families such as their own.

CHAPTER SIX

RESULTS

6.0 Introduction

The findings will be presented in four parts. To begin, a description of the child cancer survivors is provided followed by a sociodemographic profile of the case and control families. The chapter then proceeds by presenting the results of case/control comparisons for the major outcome variables. Next, each of the social psychological factors hypothesized to be relevant to psychological distress and family adaptation, is considered separately as well as in combination with the other key components in the conceptual frameworks that guided the present study. Finally, a brief account of case parents' responses to questions regarding how they are affected now by their children's illness is provided.

The results pertaining to parents are reported on a gender specific basis. The reason for this is that the psychosocial literature offers some suggestion that gender differences may exist in parents' adjustment (Obetz et al., 1980) and it has been previously reported that women have a higher prevalence of psychological disorders, including depression and anxiety than men (Dohrenwend and Dohrenwend, 1969; Warheit et al., 1975).

6.1 Description of the Child Cancer Survivors

As outlined by the selection criteria, families of interest to the study were those with a child who had been treated for a childhood malignancy and had completed all treatment at least six months before the time of the parents' participation in the

study. Just under one third of the sample of cancer survivors had been diagnosed as having leukemia, 15 percent had Wilm's tumour, 14 percent had histiocytosis and 11 percent had Hodgkin's disease, while the remaining 30 percent were spread across a variety of other diagnoses as shown in Table 6.1.

The amount of time that had lapsed since the diagnosis was made ranged from two to nineteen years with a mean of nine years (S.D.=3.6). Associated with this variation in the time that had passed since diagnosis, was a great deal of variation in the lengths of time since the child's last treatment for cancer. They ranged in time off treatment from less than one year to nineteen years with a mean of 6.1 years (S.D.=3.6). Sixteen percent of the sample had completed treatment within two years of the time of the study, 35 percent were more than two years but not more than five years from last treatment, 36 percent were more than five years but not more than ten years from last treatment, and the remaining 13 percent were more than ten years from the time of their last treatment for cancer.

The sample was almost equally divided by gender, with 52 percent (N=42) of the sample being males and 48 percent (n=38) being females. They ranged in age from three to thirty years with a mean age of fourteen and S.D. of 5.8.

6.2 Sociodemographic Characteristics of Case and Control Families

The design of the study involved the selection of comparison families from the neighbourhoods of case families in an attempt to produce a control sample of families with healthy children.

TABLE 6.1: Diagnoses of Child Cancer Survivors

DIAGNOSIS	N	%
Acute Lymphoblastic Leukemia	25	31.3
Wilm's Tumour	17	15.0
Histiocytosis	11	13.8
Hodgkin's Disease	9	11.3
Neuroblastoma	6	7.5
Rhabdomyosarcoma	5	6.3
Non-Hodgkin's Lymphoma	2	2.5
Hypothalamic Glioma	2	2.5
Osteosarcoma	2	2.5
Ewing's Sarcoma	2	2.5
Retinoblastoma	1	1.2
Medulloblastoma	1	1.2
Clear Cell Sarcoma	1	1.2
Leiomyosarcoma	1	1.2
TOTAL	80	100.0

that was roughly equivalent to the case sample in terms of family composition and socioeconomic status. Before embarking upon the case/control comparisons of central importance to the study, it was necessary to investigate the outcome of these matching procedures; to assess the level of comparability between the case and control samples. The two samples of mothers and the two samples of fathers were compared on a series of sociodemographic variables including age, number of children living at home, age of the index child, marital status, employment status, education, occupational level and family income.

As can be seen from Table 6.2, the distributions of parents' age, age of index child, and number of children living at home were very similar for both the two samples of mothers and the two samples of fathers. Case/control comparisons did reveal, however, that for both mothers and fathers, there were statistically significant differences in marital status. These results are illustrated in Table 6.3. The status of divorced or separated was reported by 12.5 percent of the case mothers compared to only 3.8 percent of the control mothers. Of the case fathers, 9.5 percent were divorced or separated while all of the control fathers were married.

According to the 1981 Census, 10.98 percent of families in the province of Ontario were lone parent families. Given this estimate, it appears that lone parent families may have been slightly underrepresented in the control sample while the rates of lone parent families for the case sample was quite comparable to official estimates for the geographic area from which the

Table 6.2: Means of Parents' Age, Index Childs' Age and Number of Children at Home by Parent and Sample

	MOTHERS		FATHERS		
	CASE	CONTROL	CASE	CONTROL	
PARENTS' AGE	\bar{X}	41	40	43	41
	S.D.	7.37	10.16	8.27	9.87
	RANGE	26-64	22-66	27-67	25-63
	N	80	79	63	72
INDEX CHILD'S AGE	\bar{X}	14	14	14	13
	S.D.	5.78	6.19	5.78	5.97
	RANGE	3-30	2-25	3-30	2-24
	N	80	79	63	72
NUMBER OF CHILDREN AT HOME	\bar{X}	2.3	2.0	2.3	2.0
	S.D.	1.3	1.0	1.4	1.0
	RANGE	0-8	0-4	0-8	0-4
	N	80	79	63	72

TABLE 6.3: Frequencies and Percentage Distributions of Marital Status, Employment Status, and Education by Parent and Sample

Marital Status	MOTHERS				FATHERS			
	Case		Control		Case		Control	
	N	%	N	%	N	%	N	%
Married	67	83.7	74	93.7	57	90.5	72	100.0
Separated/Divorced	10	12.5	3	3.8	6	9.5		
Widowed	2	2.5	2	2.5				
Single	1	1.3						
TOTAL	80	100.0	79	100.0	63	100.0	72	100.0
	(x ² =4.01, df=1, p<.05)				(x ² =7.18, df=1, p<.01)			

Employment Status	MOTHERS		FATHERS		MOTHERS		FATHERS	
	Case		Control		Case		Control	
	N	%	N	%	N	%	N	%
Employed full or Part-time	49	62.8	45	57.0	56	88.9	68	95.8
Homemaker	24	30.8	28	35.4				
Unemployed	5	6.4	4	5.1	2	3.2	1	1.4
Retired			2	2.5	2	3.2	1	1.4
Student							1	1.4
Disabled					3	4.7		
TOTAL	78	100.0	79	100.0	63	100.0	71	100.0
	(x ² =.561, df=1, p>.05)				(x ² =2.29, df=1, p>.05)			

(Note: These x² values were calculated using 2X2 tables where each sample was divided into employed and all other.)

Level of Education	MOTHERS		FATHERS		MOTHERS		FATHERS	
	Case		Control		Case		Control	
	N	%	N	%	N	%	N	%
Some Public School	4	5.2	1	1.3	5	8.0	2	2.8
Public School	4	5.2	5	6.3	7	11.3	7	9.7
Some High School	22	28.5	26	32.9	13	21.0	19	26.4
High School	28	36.4	31	39.3	11	17.7	20	27.7
1-2 Yrs. University /College	10	13.0	8	10.1	13	21.0	12	16.7
3 or More Years University/College	9	11.7	8	10.1	13	21.0	12	16.7
TOTAL	77	100.0	79	100.0	62	100.0	72	100.0
	(x ² =2.54, df=5, p>.05)				(x ² =4.70, df=5, p>.05)			

samples were drawn.

It should be noted that, of the case mothers, five had remarried from the time of their child's diagnosis to the time of the study, while of the case fathers, two had remarried during this period. Unfortunately, it is not known how many of the matched control mothers and fathers had experienced a similar change in marital status during this period of time.

The distributions of employment status and level of education, as shown in Table 6.3, were both quite similar across the two samples of mothers and the two samples of fathers. Occupational level was rated using the classification of Pineo et al. (1977) that provides sixteen categories of occupation. All mothers who were employed outside the home were rated on occupational level. For both cases and controls the mean score on occupational level for mothers fell within the ninth category. This category represents skilled clerical, sales and service occupations. For case fathers, the mean score fell within the seventh category representing supervisory positions while control fathers produced a mean that was one category below the case fathers, that of foremen positions. Using parents' occupational levels as one indicator of socioeconomic status, it appears that the two samples were almost identical in this regard.

The same was true when family income was assessed as a second indicator of social class using a nine-point interval scale. Through extrapolation from the levels of family income reported, the mean was estimated to be \$24,500 for case mothers'

families and \$27,500 for control mothers' families. Among fathers, the cases were estimated to have a mean family income of \$28,000 while the controls were estimated to have a mean of \$30,000. From these comparisons of occupational level and family income, it seems that the case and control families live in very similar socioeconomic circumstances.

On the basis of the preceding case/control comparisons, it is reasonable to conclude that the matching procedures were effective in the provision of a control sample composed of parents who could be considered sociodemographic counterparts of the case parents. The only variable on which the two samples differed was marital status. The implications of this difference will be dealt with later within the context of specific analyses involving case/control comparisons.

6.3 Levels of Psychological Distress and Family Adaptation

One of the central goals of the study was to determine whether the chronic strain of having a child threatened by cancer is associated with elevated levels of either psychological distress in the parents or maladaptation at the family level. Restated, the aim was to ascertain whether the parents of child cancer survivors differ from parents not experiencing such strain in terms of adjustment on two levels--psychological distress for the individual parent and adaptation at the family level.

In Chapter Three the research questions regarding levels of adjustment were directional in nature, implying that one-tailed tests of significance would be appropriate. For the analyses to

follow, however, two-tailed tests were used. The reason for this decision was that, although the relevant practical issue is whether families of cancer survivors are at elevated risk for psychological distress or family dysfunction, the lack of previous research on this population precludes arguing with confidence that the predicted relationships could not be in the opposite direction.

Given the use of multiple significance tests throughout the analysis of the data, caution must be advised in the interpretation of any isolated significant findings. Although the conventional alpha level of .05 was adopted, there is actually a much greater risk of drawing a false positive conclusion from these analyses, as a function of performing many significance tests.

It will be recalled that the present study assessed two dimensions of psychological distress—depression and anxiety—as well as two dimensions of family adaptation—family functioning and marital adjustment. The findings related to each of these aspects of adjustment are outlined below.

Depression. As stated earlier, depression was measured using the Center for Epidemiological Studies Depression Scale (CES-D). It can be seen from Table 6.4 that the mean levels of depression for cases and controls were almost identical for both mothers and fathers. CES-D scores for case mothers produced a mean of 9.09 while the mean score for control mothers was 9.52. Case fathers had a mean CES-D score of 7.75 while the control fathers' mean score was 7.32. Although it is obviously not statistically

Table 6.4: Mean Levels of Depression Scores (CES-D) by Parent and Sample

		CASE	CONTROL	T-Test Case/Control
Mothers	\bar{X}	9.09	9.52	t=-.28
	S.D.	9.21	9.70	df=153
	N	80	75	p=.78
Fathers	\bar{X}	7.75	7.32	t=.31
	S.D.	8.79	6.28	df=102.4
	N	59	71	p=.76
T-Test Mothers/Fathers		t=-.87, df=137, p=.39	t=-1.63, df=127.6, p=.11	

Table 6.5: Percentage of Depression Scores (CES-D) ≥ 16 by Parent and Sample

		CASE	CONTROL	Chi-Square Case/Control
Mothers	%	25.0	21.3	$\chi^2=.292$
	N	80	75	df=1
Fathers	%	11.9	8.5	$\chi^2=.417$
	N	59	71	df=1
Chi-Square Mothers/Fathers		$\chi^2=3.74, df=1, p=.05$	$\chi^2=4.73, df=1, p=.03$	

significant, the difference in average depression scores between the two samples of mothers was not in the predicted direction either. A closer examination of the distributions revealed that this was attributable to a very high depression score for one control mother.

Perhaps more substantively relevant than the mean scores on depression is the extent to which these scores are associated with the psychiatric diagnosis of depression. This issue can be examined because normative data on the CES-D scale are available and the scores' relationship to clinical status has been studied. A score of 16 or higher is thought to roughly identify those in the community with clinically significant depression or at high risk for such depression (Radloff, 1977; Myers et al., 1979).

Table 6.5 illustrates that the difference between the proportions of the case sample and the control sample with scores above the cut-off was in the predicted direction, for both mothers and fathers, (with a larger proportion of cases over the cut-point than controls), but not statistically significant. Compared to data from a study done by Comstock and Helsing (1976) on two community samples, where approximately 21 percent of the women and about fourteen percent of the men scored sixteen or higher on the CES-D, a slightly larger proportion of case mothers (25.0%) exceeded the cut-point and for both samples of fathers, the proportions at high risk for depression (cases: 11.9%; controls: 8.5%) were below the proportion reported by Comstock and Helsing.

Although the majority of parents studied were married, it will be recalled that significantly more of the control parents were married at the time of the study than the case parents. With this fact in mind the analyses for depression described above were repeated, confining the samples to only those parents who were married to assess the impact of holding marital status constant. For both the mean levels of depression scores and the percentage of depression scores indicating high risk, the results were very similar to those for the full samples (See Appendix E, Tables E1 and E2).

A larger proportion of mothers than fathers was found to be at risk for depression in both samples. This finding is consistent with other research results (Aneshensel et al., 1981; Comstock and Helsing, 1976).

Anxiety. As outlined in the measurement chapter, anxiety was assessed using the State-Trait Anxiety Inventory (STAI), which is comprised of two separate scales; one measuring a transitory emotional state (A-STATE), and one measuring relatively stable individual differences in anxiety across people (A-TRAIT). In Table 6.6 the mean levels of A-STATE and A-TRAIT for both mothers and fathers in the two samples are shown. Neither of the anxiety scores produced differences in mean scores between the two samples of mothers or fathers that were statistically significant; these case/control comparisons revealed mean scores that were almost identical.

As with the analyses for depression, the test for a difference of means between cases and controls was repeated for

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MICROCOPY RESOLUTION TEST CHART
NBS 1010a
ANSI and ISO TEST CHART No. 2

1.0	1.5	2.8	2.5
1.1	2.0	3.2	2.2
1.25	2.5	3.6	2.0
	3.15	4.0	1.8
	3.6	4.5	1.6
	4.0	5.0	1.4
	4.5	5.6	1.25
	5.0	6.3	1.1
	5.6	7.1	1.0
	6.3	8.0	0.9
	7.1	9.0	0.8
	8.0	10.0	0.7
	9.0	11.2	0.63
	10.0	12.5	0.56
	11.2	14.0	0.5
	12.5	16.0	0.45
	14.0	18.0	0.4
	16.0	20.0	0.36
	18.0	22.5	0.32
	20.0	25.0	0.28
	22.5	28.0	0.25
	25.0	31.5	0.22
	28.0	36.0	0.2
	31.5	40.0	0.18
	36.0	45.0	0.16
	40.0	50.0	0.15
	45.0	56.0	0.14
	50.0	63.0	0.13
	56.0	71.0	0.125
	63.0	80.0	0.12
	71.0	90.0	0.11
	80.0	100.0	0.1

Table 6.6: Mean Levels of Anxiety Scores (A-State and A-Trait) by Parent and Sample

		CASE	CONTROL	T-Test Case/Control
A-STATE				
Mothers	\bar{X}	32.87	32.77	t=.06
	S.D.	10.27	10.70	df=148
	N	76	74	p=.95
Fathers	\bar{X}	31.28	31.43	t=-.09
	S.D.	9.74	8.66	df=119
	N	54	67	p=.93

T-Test Mothers/Fathers t=-.89, df=128, p=.38 t=-.81, df=139, p=.42

A-TRAIT

Mothers	\bar{X}	36.84	36.14	t=.44
	S.D.	10.41	9.43	df=148
	N	76	74	p=.66
Fathers	\bar{X}	33.07	32.77	t=.20
	S.D.	9.21	7.85	df=125
	N	56	71	p=.85

T-Test Mothers/Fathers t=-2.16, df=130, p=.03 t=-.33, df=143, p=.02

anxiety including only those parents who were married at the time as a way of controlling for the case/control difference in marital status. The mean scores that resulted were very similar to those produced by the full sample, leaving the results described above unaffected (See Appendix E, Table E3).

Family Functioning. As indicated in Chapter Five, family functioning was assessed using the general scale of the Family Assessment Measure (FAM). The scale was designed to provide quantitative indices of family health/pathology (Skinner, 1983). This instrument provides an overall rating as well as ratings on seven subscales. For each of the ratings of functioning, higher raw scores correspond to more family problems being reported in that particular area of functioning.

To offer a better understanding of FAM scores, the authors provide normative data to act as reference points. To facilitate such a comparison, scores on the FAM were translated into standard scores using the normative data from normal families such that each subscale has a mean of fifty and a standard deviation of ten. Relative to the sample of normal families used to convert scores then, scores that are more than one standard deviation from the mean are interpreted as indicative of either a disturbance in family functioning (above sixty) or very healthy functioning (below forty).

Table 6.7 provides case/control comparisons of means for standardized scores on total family dysfunction, and for each of the subscales, for mothers and fathers. The only statistically

Table 6.7: Standardized Mean Levels of Family Dysfunction (FAM-General Scale Score) by Parent and Sample

		MOTHERS		FATHERS	
		CASE	CONTROL	CASE	CONTROL
TOTAL SCORE	\bar{X}	50.02	50.63	50.29	50.14
	S.D.	8.50	9.81	7.74	6.30
	N	77	74	59	69
TASK ACCOMPLISHMENT	\bar{X}	48.51	50.19	47.52	50.89*
	S.D.	10.44	11.36	8.77	9.03
	N	80	78	61	71
ROLE PERFORMANCE	\bar{X}	52.43	51.60	50.20	48.27
	S.D.	11.00	11.85	10.99	7.21
	N	79	78	61	70
COMMUNICATION	\bar{X}	50.94	51.64	50.90	50.91
	S.D.	8.75	10.74	8.85	7.70
	N	80	78	60	70
AFFECTIVE EXPRESSION	\bar{X}	51.38	51.55	51.98	51.97
	S.D.	10.49	11.27	10.09	8.42
	N	79	78	61	71
AFFECTIVE INVOLVEMENT	\bar{X}	49.79	49.78	50.95	49.32
	S.D.	10.61	10.45	9.15	8.16
	N	80	78	62	71
CONTROL	\bar{X}	49.68	50.85	51.67	51.00
	S.D.	11.35	11.44	10.94	7.32
	N	79	79	61	70
VALUES & NORMS	\bar{X}	50.35	50.06	50.31	49.36
	S.D.	11.31	11.66	8.13	8.49
	N	79	79	61	69

*t=-2.16, d.f.=130, p=.033

significant difference in mean scores between the case and control samples was in the comparison of task accomplishment for case and control fathers with the cases producing a lower mean score. This difference in means, as well as a few of those for the other subscales, was not in the predicted direction; the control sample produced a slightly higher mean score than the case sample, indicating more family problems on average.

Table 6.8 indicates that although the case sample had a larger proportion of parents with scores above sixty, signifying dysfunction, than did the control sample for both mothers and fathers, and that a larger percentage of mothers in both the case and control samples scored above sixty than in the two samples of fathers, none of these differences in proportions was statistically significant. The cutpoint score of sixty was also used to compare the cases and controls on each of the seven subscales. None of these differences in proportions was statistically significant either.

When the analyses on the FAM scores were repeated for only those parents who were married, to control for the case/control difference on marital status, both the mean scores and the proportions of the samples with scores indicative of problems in family functioning were similar to those produced by the full samples (See Appendix E, Tables E4 and E5).

As noted in the measurement chapter, two response style subscales (social desirability and defensiveness) are included in the FAM. The authors suggest that social desirability and defensiveness scores above sixty are indicators that scores on

**Table 6.8: Percentage of Overall FAM Ratings >60
by Parent and Sample**

		CASE	CONTROL	Chi-Square Case/Control
Mothers	%	13.0	10.7	$\chi^2 = .196$
	N	77	75	d.f.=1 $p = .658$
Fathers	%	8.5	2.9	$\chi^2 = 1.91$
	N	59	69	d.f.=1 $p = .167$

Chi-Square $\chi^2 = .693, d.f. = 1, p = .405$ $\chi^2 = 3.36, d.f. = 1, p = .067$
Mothers/Fathers

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the other scales may not be valid. They believe that elevated scores on these response style subscales may distort the FAM profile by either an artificial suppression of otherwise elevated scores or an alteration in the shape of the profile.

To ensure that such potential distortions were not affecting the distributions of scores in the present study, those parents who had elevated scores on either social desirability or defensiveness were excluded and the proportions of parents above the cut-point were recalculated. Of the mothers, 17 percent of the cases and 23 percent of the controls were excluded on this basis, while for fathers, 29 percent of the cases and 19 percent of the controls had to be excluded. It appears that the responses of case mothers were least likely to be affected by a tendency to respond in a socially acceptable manner or to be defensive, while the responses of case fathers were most likely to be affected. The exclusion of these parents resulted in slight increases in the proportions of parents with FAM scores above sixty but did not change the overall pattern of scores or produce any statistically significant differences between samples.

Marital Adjustment. All parents who were married at the time of the study were asked to complete the Overall Satisfaction and the Marital Conflict subscales from the Marital Questionnaire developed at the Western Psychiatric Institute and Clinic, University of Pittsburgh. These two subscales were summed to derive a total score on marital adjustment. For this purpose,

the scores on marital conflict were recoded so that high scores resulted in lower adjustment scores. The results of the comparisons between cases and controls, provided in Table 6.9, demonstrate that the scores on marital adjustment were virtually identical across all four samples.

Summary. The families of child cancer survivors were not found to be at higher risk for maladjustment than families with healthy children whether personal adjustment or adaptation at the family level was considered. The two samples did not vary significantly in terms of levels of depression, anxiety, family functioning or marital adjustment. The results described in this section offer no statistically significant evidence in support of the hypothesis that parents experiencing the chronic strain associated with having a child who is surviving cancer are at elevated risk for psychological distress (Research Questions One and Two) or the hypothesis that these families have lower levels of adaptation (Questions Seven and Eight).

Despite the lack of variation between the samples on the four major outcome variables studied, it would have been premature to conclude, at this point, that parents of cancer survivors are indistinguishable from parents of healthy children. Instead, a series of analyses were considered appropriate. A more detailed look at the results presented thus far may be instructive. Also, an examination of the social psychological factors central to the stress process model and the family stress theory may reveal differences between the samples that are relevant to psychological distress and family adaptation but that

Table 6.9: Mean Levels of Marital Adjustment by Parent and Sample

		CASE	CONTROL	T-Test Case/Control
Mothers	\bar{X}	46.04	45.53	t=.49
	S.D.	6.01	6.14	df=137
	N	66	73	p=.63
Fathers	\bar{X}	45.79	45.69	t=.09
	S.D.	6.66	5.54	df=125
	N	56	71	p=.93
T-Test Mothers/Fathers		t=-.21, df=120, p=.83	t=.16, df=142, p=.87	

are undetectable at the bivariate level.

6.3.1 An Examination of Psychological Distress and Family Adaptation by Degree of Chronic Strain.

As noted in Section 6.1, the child cancer survivors who formed the basis of the study varied widely in terms of diagnosis and the length of time since last treatment for cancer. Prognosis is related to both diagnosis and the amount of time off treatment. Further, the significance of time off treatment is related to diagnosis. Although oncologists tend to be cautious in the amount of confidence they are willing to place on the prognostic significance of length of remission after treatment has been completed, there are rough benchmarks associated with specific types of cancer that are used to signal the approximate point where a low probability of relapse has been reached.

Even though these benchmarks are by no means firmly established, there is some evidence that cancer patients and their families do attach significance to them (Koocher and O'Malley, 1981). It seems reasonable to speculate then, that the degree of chronic strain experienced by parents would, to some extent, depend on whether their child had passed the benchmark associated with his/her illness. Based on this speculation, the case sample was sub-divided into those parents whose children had not yet reached this point and those who had.

This dichotomy was constructed using years off treatment and diagnosis. In consultation with a pediatric oncologist, it was decided that those parents whose children had acute lymphoblastic leukemia, Hodgkin's disease, histiocytosis, hypothalamic glioma or

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medulloblastoma would be rated as being under higher strain if their child completed treatment within the previous five years and as being under lower strain if treatment ended more than five years earlier. Parents whose children had any of the other diagnoses (Wilm's tumour, non-hodgkin's lymphoma, neuroblastoma, rhabdomyosarcoma, retinoblastoma, osteosarcoma, clear cell sarcoma, ewings sarcoma or leiomyosarcoma) were rated as being under higher strain if their child completed treatment within the previous two years and as being under lower strain if treatment ended more than two years earlier. The scores of these two subsamples on depression, anxiety, family functioning and marital adjustment were then examined to see whether there was any evidence that those thought to be experiencing a higher level of chronic strain were at higher risk for distress or maladaptation than those under lower strain.

Although the interpretation of these analyses is limited by the cross-sectional nature of the data and by the statistical power associated with the relatively small sample sizes, these analyses do offer some insight into the variation among survivors' families in current levels of adjustment. Examination of the mean levels of depression and anxiety (See Table 6.10) indicates that the degree of chronic strain does not appear relevant for mothers. Similarly, there were no differences in levels of anxiety by degree of strain for fathers but the average level of depressive symptoms reported by fathers was four points higher for those experiencing higher strain.

Table 6.10: Mean Levels of Depression, Anxiety, Family Dysfunction and Marital Adjustment by Degree of Chronic Strain for Case Parents

		LOWER STRAIN	HIGHER STRAIN	T-Test High/Low Strain
DEPRESSION	Mothers	\bar{X} 9.48	8.43	$t=.49$
		S.D. 8.27	10.72	$df=78$
		N 50	30	$p=.63$
DEPRESSION	Fathers	\bar{X} 6.54	10.50	$t=-1.35$
		S.D. 10.50	11.51	$df=22.92$
		N 41	18	$p=.19$
T-Test Mothers/Fathers		$t=-1.80, df=89, p=.08$	$t=.63, df=46, p=.53$	
ANXIETY	Mothers	\bar{X} 36.96	36.64	$t=.13$
		S.D. 10.15	11.03	$df=74$
		N 48	28	$p=.90$
ANXIETY	Fathers	\bar{X} 32.24	34.83	$t=-.98$
		S.D. 8.37	10.83	$df=54$
		N 38	18	$p=.33$
T-Test Mothers/Fathers		$t=-2.31, df=84, p=.02$	$t=-.55, df=44, p=.59$	
FAMILY DYSFUNCTION	Mothers	\bar{X} 4.87	5.18	$t=-.71$
		S.D. 1.78	1.93	$df=75$
		N 47	30	$p=.48$
FAMILY DYSFUNCTION	Fathers	\bar{X} 5.19	4.76	$t=.92$
		S.D. 1.59	1.84	$df=57$
		N 40	19	$p=.36$
T-Test Mothers/Fathers		$t=.87, df=85, p=.39$	$t=-.75, df=47, p=.46$	
MARITAL ADJUSTMENT	Mothers	\bar{X} 45.51	46.43	$t=-.59$
		S.D. 6.02	6.04	$df=62$
		N 41	23	$p=.56$
MARITAL ADJUSTMENT	Fathers	\bar{X} 46.65	44.50	$t=1.13$
		S.D. 5.69	8.21	$df=53$
		N 37	18	$p=.26$
T-Test Mothers/Fathers		$t=.85, df=76, p=.40$	$t=-.87, df=39, p=.39$	

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These subsamples are not large enough, however, to reliably detect a difference of this size. Also of note is the fact that those fathers in the higher strain group had a higher mean score on depression than either of the subgroups of mothers.

As one would expect, given the average scores, the proportions of mothers above the cut-point for clinically relevant depression varied little by degree of strain (See Table 6.11) but for fathers, the subgroup experiencing higher strain had 1.7 times the proportion over the cut-point as the subgroup under lower strain. As with the mean scores, the limited size of the subsamples does not provide adequate power to detect a difference of this magnitude. This difference in proportions is consistent, however, with the hypothesis that the fathers of child cancer survivors who have not reached the benchmark for their illness may be at higher risk for depression than fathers of children who have passed the benchmark. No evidence was found that the risk of depression in mothers varies by degree of chronic strain.

When this analysis was repeated, excluding those fathers not currently married, the fathers experiencing higher strain had 1.5 times the proportion over the cut-point signifying depression as those under lower strain. This decrease in the difference of proportions of fathers over the cut-point between the fathers in the two levels of strain may indicate that the higher risk for depression in fathers whose children have not reached the

TABLE 6.11: Percentages of Depression and Family Dysfunction Scores Above the Criterion by Degree of Chronic Strain for Case Parents

		LOWER STRAIN	HIGHER STRAIN	Chi-Square Low/High Strain
DEPRESSION				
Mothers	%	26.0	23.3	$x^2=.071$ d.f.=1
	N	50	30	p=.790
Fathers	%	9.8	16.7	$x^2=.571$ d.f.=1
	N	41	18	p=.450
Chi-Square Mothers/Fathers		$x^2=3.91, d.f.=1, p=.048$	$x^2=.303, d.f.=1, p=.581$	
FAMILY DYSFUNCTION				
Mothers	%	8.5	20.0	$x^2=2.14$ d.f.=1
	N	47	30	p=.144
Fathers	%	10.0	5.3	$x^2=.373$ d.f.=1
	N	40	19	p=.452
Chi-Square Mothers/Fathers		$x^2=.057, d.f.=1, p=.811$	$x^2=2.06, d.f.=1, p=.151$	

benchmark is partially attributable to those fathers who were divorced or separated.

Turning to family adaptation, the mean levels of overall family dysfunction as well as marital adjustment were almost the same for each subgroup (See Table 6.10). The proportions of parents with scores indicative of disturbances in family functioning (Table 6.11) did vary rather substantially by degree of chronic strain, however. The interesting thing here is that the pattern for mothers was opposite to the one observed for fathers. The proportion of mothers in the higher strain group reporting family dysfunction was more than double the proportion for the lower strain group. Alternately, for fathers the proportion of the lower strain group experiencing family dysfunction was almost double that of the higher strain fathers. Again a caveat must be issued that the subsample sizes are insufficient to provide the necessary power to detect a difference of this size. Having said this, however, mothers appear more likely to perceive disturbances in family functioning when under conditions of higher strain while fathers are more likely to perceive such disturbances under the circumstance of lower strain.

It will be recalled that the case samples of mothers and fathers were not based on quite the same set of families due to instances where only the mother participated and not the father. To ensure that the apparent differences in dysfunction by degree of strain for mothers and fathers were not due to this circumstance, the crosstabular analysis was repeated confining

the sample to families in which both parents had participated. This analysis also indicated that the relevance degree of chronic strain has for the perception of family dysfunction may be dependent on the parents' gender. For fathers, the difference in the proportions experiencing disturbances in family functioning decreased slightly with 8.6 percent of those in the lower strain group and 5.6 percent of those in the higher strain group falling above the cut-point. For mothers, on the other hand, the difference in proportions was greatly increased. Only 2.8 percent of mothers experiencing lower strain had scores indicative of family dysfunction while 21.1 percent of those under higher strain scored above the cut-point.

Taken together, these analyses offer some evidence that the risk for both clinically relevant depression in fathers of children surviving cancer and family dysfunction, especially as perceived by mothers, is associated with the degree of chronic strain, when crudely categorized using a dichotomy of "pre- and post-benchmark". Fathers in the higher strain category appeared to be at slightly higher risk for depression. The results related to family functioning suggested not only that parents experiencing certain degrees of chronic strain may be at elevated risk for disturbances in family functioning, but also that the direction of this relationship was different for mothers and fathers.

It may be argued that this categorization is really too simplistic and that one would not expect degree of chronic strain

felt by parents to drop abruptly at the point when their child reaches the point of low probability of relapse but rather decrease more gradually as time passes. If this is the case, perhaps there is a linear relationship between the phase of the child's illness, relative to the benchmark associated with his/her particular diagnosis, and the level of adjustment achieved by parents. To test for the presence of such a relationship, a variable was computed to estimate how many years each child was from the benchmark associated with his/her illness. The scores ranged from -5 to 17 years, meaning that some survivors will not reach their benchmark for five more years while others were as many as seventeen years past their benchmark. Pearson product moment correlations of this measure with depression, anxiety, family functioning, and marital adjustment revealed no significant correlations for mothers or for fathers. Contrary to expectation, these data do not offer any evidence that parents' levels of psychological distress or levels of family adaptation are linearly related to the phase of the child's illness in relation to the benchmark associated with his/her illness.

6.4 The Assessment of Potentially Relevant Factors

In the study of the psychosocial consequences that the stressful life circumstance of having a child threatened by cancer may have on families, it is also important to examine the social context surrounding these parents as well as the personal and social resources possessed by parents that may be effective

in altering the impact of chronic strain. Although cases and controls were not found to vary in terms of levels of psychological distress or family adaptation, there remains the possibility that the consideration of certain social psychological factors may offer insight into these findings by revealing case/control differences in these factors or by identifying mediating roles played by these factors in the chronic strain-distress/adaptation relationship. In the current investigation, the following social psychological factors were evaluated: the number of stressful life events that had occurred to parents within the past six months, levels of the personal resources of self-esteem, mastery and religiosity, and the social resource of social support.

In the subsections that follow a variety of analytic strategies were employed in attempts to understand the nature of the roles played by the social psychological factors described above. First, to determine if there were any significant differences in the number of life events experienced or the personal and social resources possessed by cases and controls, the mean scores on these variables were calculated. Next, to detect any differences across the samples in the bivariate relationships between these factors and each of the outcome variables, zero-order correlations were done. The next logical step was to determine which of the social psychological factors were related to the various outcome variables, independent of the other variables in the model and to compare the relative strengths of these relationships. And, finally, the role of each

of these factors was examined within the full models of the stress process and family stress theories to determine if they acted as exacerbators or moderators in the relationship of chronic strain with psychological distress and family adaptation.

6.4.1 Levels of Social Psychological Factors.

The mean scores on life events, self-esteem, mastery, social support and religiosity are presented in Table 6.12. The case/control comparisons revealed that the distributions on most of these variables were very similar for the two samples of mothers and the two groups of fathers.

No evidence was found to support the hypothesis, expressed in Research Question Six, that the presence of chronic strain is associated with an increased risk for eventful stressors. For both events experienced by parents personally and by those close to the parents, there were no meaningful differences between cases and controls. For mothers, the difference of means on social support from friends was significant with case mothers reporting more support from friends. As well, the difference of means on religiosity was on the verge of statistical significance for mothers, with the controls scoring higher on religiosity. None of the differences for fathers was significant.

Comparisons were also made between mothers and fathers in each of the samples. In the case sample, mothers and fathers differed significantly on mean levels of religiosity with fathers having a higher average score. Mothers and fathers in both

Table 6.12: Mean Levels of Social Psychological Variables
By Sample and Parent

		CASE	CONTROL	T-Test Case/Control	
PERSONAL EVENTS	Mothers	\bar{X}	1.64	1.33	t=1.13
		S.D.	1.83	1.54	df=151
		N	75	78	p=.26
	Fathers	\bar{X}	1.30	1.26	t=.13
		S.D.	1.72	1.37	df=130
		N	60	72	p=.89
T-Test Mothers/Fathers		t=-1.10, df=133, p=.27	t=-.29, df=148, p=.77		
ALL EVENTS	Mothers	\bar{X}	2.88	2.73	t=.36
		S.D.	2.55	2.64	df=151
		N	75	78	p=.72
	Fathers	\bar{X}	2.20	2.10	t=.29
		S.D.	2.00	2.01	df=131
		N	61	72	p=.78
T-Test Mothers/Fathers		t=-1.75, df=133.8, p=.08	t=-1.66, df=143, p=.10		

Table 6.12: Mean Levels of Social Psychological Variables
(Continued) By Sample and Parent

		CASE	CONTROL	T-Test Case/Control	
SELF ESTEEM	Mothers	\bar{X}	25.67	25.40	t=.38
		S.D.	4.67	4.06	df=154
		N	78	78	p=.70
	Fathers	\bar{X}	26.16	26.38	t=-.33
		S.D.	3.55	3.84	df=132
		N	62	72	p=.74
T-Test Mothers/Fathers		t=.71,df=137.76,p=.48	t=1.51,df=148,p=.13		
MASTERY	Mothers	\bar{X}	26.59	26.69	t=-.11
		S.D.	6.11	5.99	df=154
		N	78	78	p=.92
	Fathers	\bar{X}	27.89	29.23	t=-1.51
		S.D.	5.26	4.95	df=131
		N	63	70	p=.13
T-Test Mothers/Fathers		t=1.34,df=139,p=.18	t=2.79,df=146,p=.01		
RELIGIOSITY	Mothers	\bar{X}	39.63	43.29	t=-1.86
		S.D.	11.43	12.54	df=146
		N	78	70	p=.07
	Fathers	\bar{X}	44.73	46.22	t=-.71
		S.D.	11.73	11.81	df=125
		N	62	65	p=.48
T-Test Mothers/Fathers		t=2.59,df=138,p=.01	t=-1.27,df=138,p=.21		

Table 6.12: Mean Levels of Social Psychological Variables
(Continued) By Sample and Parent

		CASE	CONTROL	T-Test Case/Control
PERCEIVED SUPPORT	Mothers	\bar{X} 62.13	62.63	t=-.38
		S.D. 8.35	7.60	df=148
		N 75	75	p=.71
	Fathers	\bar{X} 62.12	60.94	t=.12
		S.D. 8.83	8.37	df=128
		N 60	70	p=.91
T-Test Mothers/Fathers		t=-.69,df=133,p=.49	t=-1.27,df=143,p=.21	
FAMILY SUPPORT	Mothers	\bar{X} 25.36	25.32	t=.06
		S.D. 4.39	3.78	df=157
		N 80	79	p=.95
	Fathers	\bar{X} 25.13	24.81	t=.46
		S.D. 4.42	3.76	df=133
		N 63	72	p=.65
T-Test Mothers/Fathers		t=-.31,df=141,p=.76	t=-.84,df=149,p=.40	
FRIEND SUPPORT	Mothers	\bar{X} 27.95	26.77	t=1.99
		S.D. 3.53	3.90	df=155
		N 79	78	p=.05
	Fathers	\bar{X} 26.33	25.24	t=1.65
		S.D. 3.91	3.66	df=129
		N 60	71	p=.10
T-Test Mothers/Fathers		t=-2.56,df=137,p=.01	t=-2.46,df=147,p=.02	
INSTRUMENTAL SUPPORT	Mothers	\bar{X} 27.72	27.71	t=.03
		S.D. 2.82	3.06	df=156
		N 79	79	p=.98
	Fathers	\bar{X} 28.56	28.35	t=.50
		S.D. 2.53	2.49	df=132
		N 62	72	p=.62
T-Test Mothers/Fathers		t=1.84,df=139,p=.07	t=1.40,df=149,p=.16	

samples differed on mean scores for the social support from friends with mothers in both samples scoring higher. In the control sample, the average level of mastery for fathers was significantly higher than for mothers.

6.4.2 Relationships Among the Social Psychological Factors and the Dependent Variables.

The next step in the investigation was to look at the bivariate relationships of the social psychological factors examined in the previous sections with the two dimensions of psychological distress and of family adaptation. This was done to establish which of these relationships posited in the literature do in fact describe the samples studied here and to identify any case/control variations in the nature of these associations. The Pearson product-moment correlation matrices for the major variables in the two theoretical models are presented separately for mothers and fathers in each sample. Discussion of these analyses will be organized by directing attention first to the relationships central to the stress process and then to correlations among the major elements of the family stress theory. Before moving into the description of the bivariate analyses, a comment about the data set used in analyses to follow must be made.

The Data Set to be Used in Subsequent Analyses. Examination of the subsamples of mothers and fathers revealed that, for some of the central variables in the theoretical models, as much as ten percent of the data were missing. Missing data are particularly relevant to the remaining analyses that assess relationships

between sets of two variables as well as among groups of several variables, where only cases with complete data for all of the variables involved in an analysis can be included. Because most variables that had missing data were the result of the omission of only one or two items of a scale, a decision was made to prorate the scores of respondents for whom at least 75 percent of the items for a particular scale had been completed. The data set that resulted by including these estimations produced distributions on all of the variables that were very similar to those generated by the sample with complete data.

The Stress Process. It will be recalled from Chapter Two that the stress process has been posited to involve a complexity of relationships among chronic strain, life events, mediating resources and psychological distress. The correlation matrices (See Tables 6.13 and 6.14) indicate that personal life events, self-esteem, mastery and some of the dimensions of support were related to depression and to anxiety for both samples of mothers and both samples of fathers.

An examination of the correlations with CES-D and A-Trait scores revealed that mastery was the social psychological factor most highly related to depression and anxiety for mothers and fathers in both samples. It was interesting to note that for mothers, social support from family showed quite a strong relationship to depression and anxiety for cases but for controls the relationship between family support and depression was not significant and there was only a modest relationship between

TABLE 6.13: Pearson Correlations Among the Social Psychological Factors and the Dependent Variables for Mothers

CASES	(2)	(3)	(4)	(5)	(6)	(7)	(8)	(9)	(10)	(11)	(12)
(1) Life Events	-.19	-.11*	-.01*	-.23	-.03*	-.05*	.18*	.40	.34	.18*	-.10*
(2) Self-Esteem		.32	.31	.27	.37	.12*	-.22	-.40	-.52	-.20	.28
(3) Mastery			.39	.35	.27	.22	.05*	-.67	-.65	-.51	.41
(4) PSR				.57	.51	.36	.04*	-.44	-.60	-.30	.41
(5) Family Support					.49	.41	-.08*	-.42	-.49	-.46	.63
(6) Friend Support						.18	-.10*	-.33	-.33	-.24	.10*
(7) Instrumental Support							-.00*	-.26	-.27	-.16*	.27
(8) Religiosity								.04*	.08*	.23	-.25
(9) CES-D									.80	.50	-.50
(10) A-Trait										.51	-.49
(11) Family Dysfunction											-.55
(12) Marital Adjustment											
CONTROLS	(2)	(3)	(4)	(5)	(6)	(7)	(8)	(9)	(10)	(11)	(12)
(1) Life Events	-.17*	-.19	-.02*	-.03*	-.09*	-.33	.20	.21	.20	.17*	-.22
(2) Self-Esteem		.31	.17*	.07*	.11*	.18*	-.12*	-.34	-.33	-.18	.24
(3) Mastery			.50	.22*	.31	.39	-.03*	-.63	-.68*	-.47	.49
(4) PSR				.42	.61	.47	-.01*	-.36	-.38	-.51	.23
(5) Family Support					.38	.25	-.05*	-.14*	-.21	-.25	.02*
(6) Friend Support						.46	-.05*	-.25	-.26	-.37	.20*
(7) Instrumental Support							-.11*	-.34	-.32	-.34*	.32
(8) Religiosity								.19	.15*	.20	-.17*
(9) CES-D									.82	.32	-.36
(10) A-Trait										.45	-.42
(11) Family Dysfunction											-.57
(12) Marital Adjustment											

* Not Significant (P<.05)

TABLE 6.14: Pearson Correlations Among the Social Psychological Factors and the Dependent Variables for Fathers

CASRS	(2)	(3)	(4)	(5)	(6)	(7)	(8)	(9)	(10)	(11)	(12)
(1) Life Events	-.23	-.03*	-.12*	-.17*	.05*	.03*	.19*	.41	.41	.14*	-.39
(2) Self-Esteem		.50	.21	.18*	.05*	.04*	.06*	-.47	-.59	-.30	.26
(3) Mastery			.29	.25	.24	.18*	.16*	-.52	-.58	-.42	.35
(4) PSR				.46	.47	.43	.00*	-.47	-.43	-.60	.41
(5) Family Support					.58	.57	-.12*	-.31	-.34	-.59	.45
(6) Friend Support						.29	.06*	-.18*	-.28	-.37	.22
(7) Instrumental Support							.02	-.24	-.18*	-.31*	.36
(8) Religiosity								.08*	.07*	.12*	-.09*
(9) CES-D									.78	.46	-.39
(10) A-Trait										.59	-.59
(11) Family Dysfunction											-.66
(12) Marital Adjustment											
CONCORDS	(2)	(3)	(4)	(5)	(6)	(7)	(8)	(9)	(10)	(11)	(12)
(1) Life Events	-.12*	-.12*	-.16*	-.05*	-.17*	-.03*	.05*	.33	.32	.03*	-.18*
(2) Self-Esteem		.34	.35	.17*	.05*	.12*	-.04*	-.25	-.34	-.34	.24
(3) Mastery			.29	.05*	.07*	.36	-.13*	-.37	-.62	-.41	.09*
(4) PSR				.43	.40	.41	-.21	-.15*	-.17*	-.42	.12*
(5) Family Support					.45	.33	-.01*	-.22	-.25	-.26	.35
(6) Friend Support						.35	-.12*	-.16*	-.28	-.33	.16*
(7) Instrumental Support							.06*	-.14*	-.21	-.31	.16*
(8) Religiosity								-.04*	-.02*	.10*	-.14*
(9) CES-D									.58	.32	-.34
(10) A-Trait										.48	-.31
(11) Family Dysfunction											-.41
(12) Marital Adjustment											

* Not Significant (P<.05)

family support and anxiety.

Family Stress Theory. As outlined in Chapter Two, family stress theory outlines the inter-relationships among stressors, resources of family members, the family's perception of the situation, and family adaptation. From Tables 6.13 and 6.14 it can be seen that, of the social psychological variables, perceived social support (PSR) was found to produce the highest correlation with family dysfunction across each of the subsamples except case mothers. For this group, mastery was most highly correlated with functioning. For fathers and especially mothers social support from family was more highly correlated with family functioning for cases than for controls.

Social support from family had the highest correlation with marital adjustment for three of the four subsamples. The exception was control mothers where family support was not significantly related to marital adjustment and mastery was the variable most strongly related to this outcome.

Correlations Among the Dependent Variables. Because there are four dependent variables examined within the study, it is instructive to look at the correlations among these variables as well as at the relationships between each of them and the various independent variables outlined above. Tables 6.13 and 6.14 indicate that all of the relationships between dependent variables were statistically significant. As one would expect, some of these dimensions of adjustment are quite closely related. With the possible exception of depression and anxiety for mothers and the case fathers, however, it seems that each of the

dependent variables is tapping a separate dimension of adjustment.

6.4.3 Consideration of the Social Psychological Factors Within the Full Models.

From the bivariate analyses two observations were made. First, the majority of social psychological variables were shown to be quite highly correlated with psychological distress and family adaptation, as postulated by the two theoretical models guiding this investigation. Second, comparisons of the correlation matrices for cases and controls suggested that the relationships of certain social psychological factors with psychological distress and family adaptation may be different for parents of child cancer survivors than they are for parents whose children have never been seriously ill.

Out of these observations two further questions emerge. The first is whether the social psychological factors found to be relevant for psychological distress and family adaptation by the correlational analyses are also relevant independent of the effects of other variables in the models. To test for the independent effects of the social psychological variables on each of the four dependent variables, they were entered into multiple regression equations simultaneously. Due to the cross-sectional nature of the data, it was not possible to establish the time order of events and thus causal relationships but it was possible to assess associations among variables comprising the full models. References to main effects, therefore, are not intended to imply causation, but rather associations with the dependent

variables, independent of all other variables in the equation.

The second question is whether the relationship that chronic strain has with psychological distress and family adaptation is moderated by such social psychological factors as self-esteem, mastery, religiosity, and social support or exacerbated by such factors as recent life events. In other words, is the impact that chronic strain has on psychological distress and family adaptation dependent on the level of any of these social psychological factors?

To determine if any of these social psychological factors did alter the relationships of chronic strain with psychological distress and family adaptation, multiple regression analyses were conducted for mothers and fathers where multiplicative interaction terms were formed using chronic strain and each of the factors relevant to the stress process model (life events, self-esteem, mastery, social support) and to family stress theory (each of the variables listed above plus religiosity). As outlined in the measurement chapter, chronic strain was treated as a dichotomous variable with the parents of cancer survivors representing a strained population and the control sample representing a group not experiencing that particular chronic strain.

Whenever a significant interaction was found, the exact nature of the interaction effect was examined by using the methods of Cohen and Cohen (1975) to graphically present each conditional effect. By assigning high and low values to the

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independent variables, the regression lines can be defined and may be graphically depicted to demonstrate that the relationships of chronic strain with psychological distress and family adaptation are conditional on the level of the social psychological factor in question.

Because any such interaction terms would be exact nonlinear functions of the two variables used to construct them, the product-moment correlations of the interaction terms with both of the original variables are likely to be high. In such a situation, a problem of multicollinearity results that in turn limits the amount of confidence that can be placed on the estimates of the coefficients of these independent variables (Blalock, 1972). In recognition of this circumstance, emphasis will be placed on the extent to which these interaction terms add significantly to the variance explained rather than on the evaluation of the relative effects of individual interaction terms.

For the majority of these analyses, where marital status was variable, it was entered in the first step of the regression as a control variable. Controlling for the effect of marital status was deemed necessary given that case and control parents were found to vary significantly on this characteristic.

The analyses testing for independent effects of each of the social psychological factors, followed by the analyses testing for statistical interactions will be presented using the elements central to the stress process model first and then using those relevant to the family stress theory. Before outlining these

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results, a brief comment must be made about the measurement of social support in the analyses to follow.

It will be recalled that several dimensions of social support were assessed in the present study and the results of these assessments were described in the sections on the bivariate analyses. Due to limitations placed on the number of variables that could be handled in the multiple regression equations by the restricted subsample sizes, however, only one measure of social support could be accommodated. Based on the conceptual argument outlined in the measurement chapter and the examination of the relative strengths of correlations between the various dimensions of social support and the dependent variables, perceived social support measured by the Provisions of Social Relations scale was chosen to assess social support in the multivariate analyses.

The Stress Process. To begin, results using depression as the dependent variable will be presented followed by those where anxiety was the dependent variable. It should be noted at this point that the measure of depression used in these analyses was the total score on the CES-D scale and not the dichotomy formed using the cut-off criterion specified earlier. The variable referred to as anxiety is the A-Trait measure and not the A-State measure.

From Table 6.15 it can be seen that, for case mothers and fathers, life events, mastery and social support all had independent main effects on depression, while for controls only

mastery had a significant effect for mothers and life events and mastery were significant for fathers. A substantial amount of the variation in level of depression was accounted for by this combination of variables for both groups of mothers and fathers, but especially mothers. The equation seemed to be a much better predictor of depression for cases (Mothers' $R^2=.572$, Fathers' $R^2=.542$), however, than for controls (Mothers' $R^2=.407$, Fathers' $R^2=.232$). For mothers, this equation explained 16.5 percent more of the variance in depression for cases than for controls, while for fathers the equation explained 31 percent more of the variance for cases than for controls.

To establish if any of the social psychological factors assessed significantly altered the relationship between chronic strain and depression, the multiplicative interaction terms described earlier were entered in the third step of a multiple regression analysis, after the control variable of marital status in Step One, and all main effects in Step Two. The final regression equation, as shown by the column labelled Regression 3 in Table 6.16, indicates that, for mothers, none of the interactions with chronic strain was significant. The non-relevance of the interaction terms for mothers is evident in the increase in the variance explained of only two percent when the interactions were entered into the equation. For fathers, however, as shown by Regression 3 in Table 6.17, the chronic strain--social support interaction was significant. The addition of the interaction terms resulted in an increment of .07 in the

TABLE 6.15: Independent Main Effects of Social Psychological Variables on Depression by Sample and Parent

PREDICTOR VARIABLE	SAMPLE			
	CASE MOTHERS		CONTROL MOTHERS	
	<u>N=71</u>		<u>N=73</u>	
	b	B	b	B
Marital Status	-.19	-.01	-3.33	-.10
Life Events	1.50	.31***	.28	.05
Self-Esteem	-.19	-.10	-.35	-.17
Mastery	-.78	-.50***	-.69	-.48***
Social Support	-.24	-.22***	-.13	-.11
R ²		.572***		.407***

PREDICTOR VARIABLE	SAMPLE			
	CASE FATHERS		CONTROL FATHERS	
	<u>N=57</u>		<u>N=70</u>	
	b	B	b	B
Marital Status	-2.36	-.07		
Life Events	1.71	.32**	1.35	.30**
Self-Esteem	-.31	-.12	-.26	-.16
Mastery	-.68	-.39***	-.30	-.25*
Social Support	-.30	-.29**	.02	.03
R ²		.542***		.232**

* p<.05

** p<.01

*** p<.001

b = Unstandardized Regression Coefficient

B = Standardized Regression Coefficient

TABLE 6.16: Regression of Depression (CES-D) on Selected Variables for Mothers

SAMPLE: MOTHERS (N=144)

PREDICTOR VARIABLES	REGRESSION 1		REGRESSION 2		REGRESSION 3	
	b	B	b	B	b	B
Marital Status	-3.74	-.14	-1.52	-.06	-1.26	-.05
Chronic Strain			-.47	-.03	4.15	.24
Life Events			.95**	.19	.37	.07
Self-Esteem			-.28*	-.14	-.34	-.17
Mastery			-.71***	-.48	-.68***	-.46
Social Support			-.19**	-.17	-.13	-.12
Strain X Events					1.05	.19
Strain X Esteem					.14	.21
Strain X Mastery					-.08	-.13
Strain X Support					-.12	-.44
R ²	.021		.478***		.493***	

* p<.05
 ** p<.01
 *** p<.001

b = Unstandardized Regression Coefficient
 B = Standardized Regression Coefficient

TABLE 6.17: Regression of Depression. (CES-D) on Selected Variables for Fathers

SAMPLE: FATHERS (N=127)

PREDICTOR VARIABLES	REGRESSION 1		REGRESSION 2		REGRESSION 3	
	b	B	b	B	b	B
Marital Status	-5.11	-.13	-2.15	-.05	-2.35	-.06
Chronic Strain			.19	.01	31.35**	2.01
Life Events			1.53***	.31	1.35**	.27
Self-Esteem			-.26	-.12	-.26	-.12
Mastery			-.48***	-.33	-.30*	-.21
Social Support			-.14*	-.16	.02	.02
Strain X Events					.36	.06
Strain X Esteem					-.05	-.08
Strain X Mastery					-.38	-.69
Strain X Support					-.32*	-1.29
R ²	.128		.368***		.435***	

* p<.05

** p<.01

*** p<.001

b = Unstandardized Regression Coefficient

B = Standardized Regression Coefficient

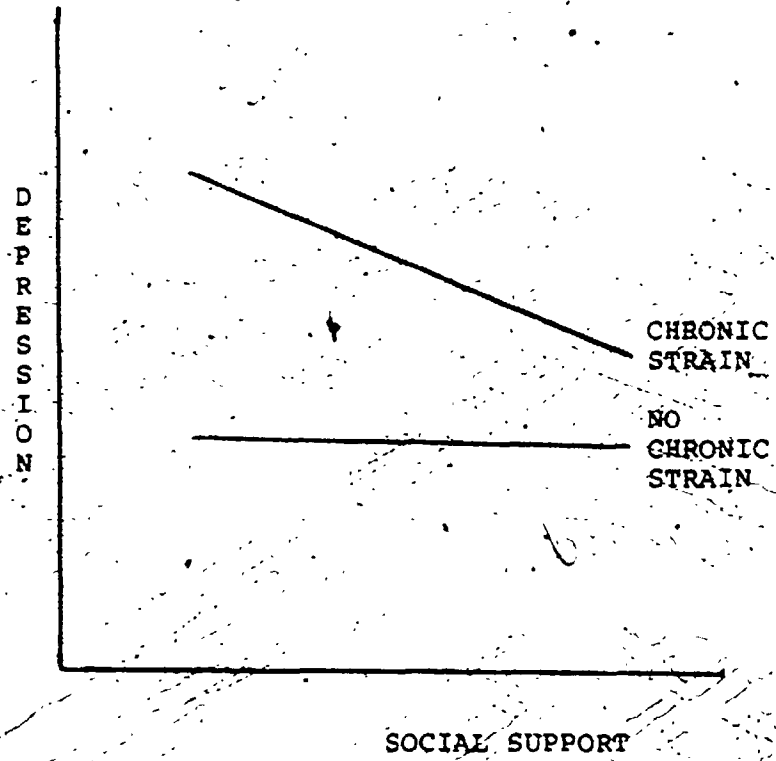
R^2 for fathers, with three percent of this variance being explained by the chronic strain—social support interaction after controlling for the effects of all other variables in the equation.

Within the context of the full stress process model, only mastery had a significant main effect on depression for mothers while for fathers the main effects of chronic strain, life events and mastery, as well as the interaction between chronic strain and social support were significant. This significant interaction term demonstrates that the relationship between chronic strain and depression for fathers was moderated under the condition of high social support.

Figure 6.4.1 presents, graphically, the interaction between chronic strain and social support for fathers. Level of social support was clearly not as important to depression for those not experiencing chronic strain as it was to those who were experiencing strain.

A significant main effect of chronic strain on depression for fathers together with a significant interaction is not necessarily evidence of a main effect (Cohen and Wills, 1985). A statistical main effect often occurs as an artifact of a significant interaction (Dawes, 1969; Reis, 1984). This is consistent with the fact that the effect of chronic strain was not significant when only the main effects were entered into the equation (Regression 2, Table 6.17) without the interaction terms. Thus, the important point to be considered in the final

FIGURE 6.4.1: Interaction of Chronic Strain and Social Support for Depression in Fathers



regression equation presented in Table 6.17 is not the significant effect of chronic strain but rather the significant interaction between chronic strain and social support.

Turning to these same analyses for anxiety, Table 6.18 indicates that for case mothers and fathers all four social psychological variables had independent effects on anxiety. For the control samples, only mastery was significant for mothers while life events and mastery were significant for fathers. For each of the subsamples, a substantial proportion of the variance in anxiety was explained by this combination of independent variables but, for both mothers and fathers, much more variance was explained for the case sample than for the controls (case mothers' $R^2=.653$, control mothers' $R^2=.491$, case fathers' $R^2=.614$, control fathers' $R^2=.479$).

Tables 6.19 and 6.20 show the regression equations that resulted for mothers and fathers, respectively, when the interaction terms were added to the equation for anxiety, in the third step (Regression 3), after marital status (Regression 1) and the main effects of the social psychological factors (Regression 2). Tables 6.19 and 6.20 point out that a substantial amount of the variation in anxiety was accounted for by the full model for both mothers and fathers and that the amount of explained variance was very similar for mothers ($R^2=.581$) and fathers ($R^2=.562$). The main effects of chronic strain and mastery as well as the interaction between chronic strain and social support all had significant effects for both mothers and fathers and life events were also significant for fathers only.

TABLE 6:18: Independent Main Effects of Social Psychological Variables on Anxiety by Sample and Parent

PREDICTOR VARIABLE	SAMPLE			
	CASE MOTHERS		CONTROL MOTHERS	
	N=71		N=73	
	b	B	b	B
Marital Status	-1.79	-.07	-5.73	-.16
Life Events	1.24	.22**	.14	.02
Self-Esteem	-.52	-.24**	-.30	-.13
Mastery	-.67	-.38***	-.89	-.58***
Social Support	-.49	-.39***	-.09	-.08
R ²		.653***		.491***

PREDICTOR VARIABLE	SAMPLE			
	CASE FATHERS		CONTROL FATHERS	
	N=56		N=70	
	b	B	b	B
Marital Status	-5.83	-.16		
Life Events	1.41	.24*	1.52	.27**
Self-Esteem	-.76	-.26*	-.39	-.19
Mastery	-.75	-.38***	-.80	-.53***
Social Support	-.28	-.25**	.09	.09
R ²		.614***		.479***

* p < .05
 ** p < .01
 *** p < .001

b = Unstandardized Regression Coefficient
 B = Standardized Regression Coefficient

TABLE 6.19: Regression of Anxiety (A-TRAIT) on Selected Variables for Mothers

SAMPLE: **MOTHERS** (N=144)

PREDICTOR VARIABLES	REGRESSION 1		REGRESSION 2		REGRESSION 3	
	b	B	b	B	b	B
Marital Status	-4.39	-.15	-2.64	-.09	-3.13	-.11
Chronic Strain			.18	.01	23.91*	1.25
Life Events			.79*	.14	.25	.05
Self-Esteem			-.47***	.21	-.29	-.13
Mastery			-.72***	.43	-.89***	-.53
Social Support			-.33***	-.27	-.10	-.08
Strain X Events					.88	.14
Strain X Esteem					-.25	-.34
Strain X Mastery					.24	.35
Strain X Support					-.40*	-1.33
R ²	.023		.548***		.581***	

* p<.05
 ** p<.01
 *** p<.001

b = Unstandardized Regression Coefficient
 B = Standardized Regression Coefficient

TABLE 6.20: Regression of Anxiety (A-TRAIT) on Selected Variables for Fathers

SAMPLE: FATHERS (N=126)

PREDICTOR VARIABLES	REGRESSION 1		REGRESSION 2		REGRESSION 3	
	b	B	b	B	b	B
Marital Status	-9.13*	-.20	-5.94	-.13	-5.83	-.13
Chronic Strain			.08	.01	30.93**	1.70
Life Events			1.51***	.26	1.52**	.26
Self-Esteem			-.48**	-.20	-.39	-.16
Mastery			-.81***	-.46	-.80***	-.46
Social Support			-.09	-.09	.09	.08
Strain X Events					-.11	-.02
Strain X Esteem					-.37	-.54
Strain X Mastery					.05	.08
Strain X Support					-.37**	-1.26
R ²	.039		.522***		.562***	

* p<.05
 ** p<.01
 *** p<.001

b = Unstandardized Regression Coefficient
 B = Standardized Regression Coefficient

Social support did not affect anxiety directly, but it did act as a buffer in the relationship between chronic strain and anxiety for both mothers and fathers. This interaction for mothers is depicted in Figure 6.4.2 and for fathers in Figure 6.4.3. For case parents, experiencing chronic strain, the negative relationship between social support and anxiety was stronger than for control parents, not experiencing chronic strain. Phrased differently, for mothers and fathers with high levels of social support, chronic strain was not associated with anxiety but when level of social support was low, chronic strain and anxiety were positively related.

Again, as in the analysis of depression in fathers, the presence of a main effect of chronic strain in combination with a significant chronic strain--social support interaction for fathers should not be interpreted as support for the existence of a main effect of chronic strain. This significant effect was likely an artifact of the significant interaction since chronic strain was not significant in the second step of the regression (See Regression 2) before the interaction terms were entered.

The presence of a significant chronic strain--social support interaction effect on depression for fathers and on anxiety for both mothers and fathers supports the hypothesis addressed in Research Question Five. The social resource of social support was found to buffer the effect of chronic strain on depression for fathers and on anxiety for both mothers and fathers.

FIGURE 6.4.2: Interaction of Chronic Strain and Social Support for Anxiety in Mothers

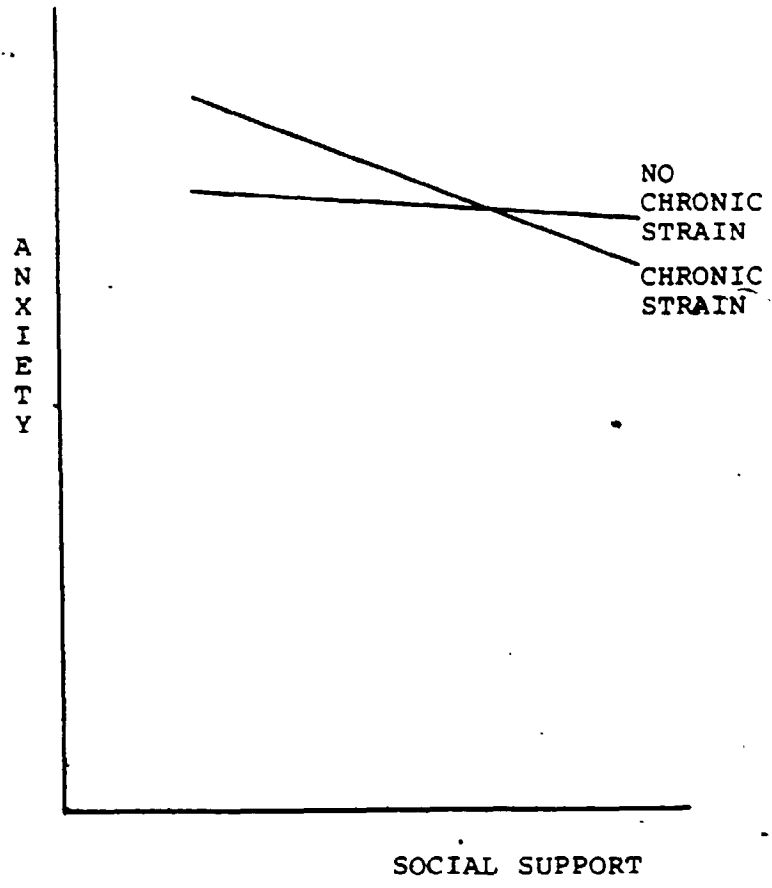
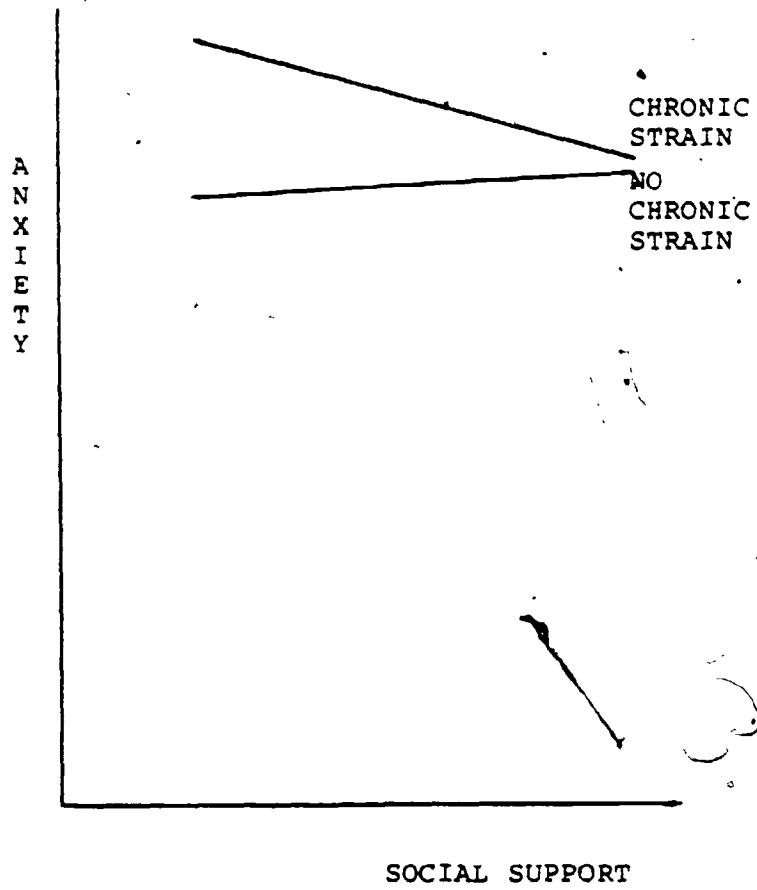


FIGURE 6.4.3: Interaction of Chronic Strain and Social Support for Anxiety in Fathers



Family Stress Theory:

The analyses using the two indicators of family adaptation-- family functioning and marital adjustment--as the dependent variables will be presented beginning with the former. As with depression, the measure of family functioning used in the following analyses was the total scores of the FAM overall rating of family dysfunction and not the dichotomy using the cut-off score designed to indicate disturbances in functioning. It should also be kept in mind that high scores on FAM are indicative of disturbances in family functioning or dysfunction.

Table 6.2f presents the results when all of the social psychological variables relevant to family stress theory were regressed simultaneously on family dysfunction in Step Two, after entering the control variable of marital status in the first step. It will be noted that marital status was not entered for control fathers because it was a constant in this subsample.

From this table it is apparent that, for both case and control mothers, mastery, religiosity and perceived social support all had significant effects on family dysfunction when the effects of all other variables in the equation were controlled. For both groups of mothers, this collection of variables explained approximately 41 percent of the variation in family dysfunction. For fathers, social support had a significant effect on family dysfunction for both cases and controls and was in fact the only significant variable for cases. For control fathers, mastery also had an effect on dysfunction. The explained variation in family dysfunction for fathers was

TABLE 6.21: Independent Main Effects of Social Psychological Variables on Family Dysfunction by Sample and Parent

PREDICTOR VARIABLE	SAMPLE			
	CASE MOTHERS		CONTROL MOTHERS	
	N=71		N=72	
	b	B	b	B
Marital Status	-1.01	-3.61	.23	.00
Life Events	.08	.08	.11	.08
Self-Esteem	.02	.06	.00	.01
Mastery	-.13	-.39***	-.12	-.35**
Religiosity	.04	.25*		.21*
Social Support	-.05	-.23*	-.01	-.33**
R ²		.406***		.415***

PREDICTOR VARIABLE	SAMPLE			
	CASE FATHERS		CONTROL FATHERS	
	N=55		N=68	
	b	B	b	B
Marital Status	-.25	-.04		
Life Events	-.03	-.03	-.06	-.06
Self-Esteem	-.04	-.08	-.08	-.23
Mastery	-.06	-.18	-.07	-.25*
Religiosity	.02	.17	.01	.05
Social Support	-.10	-.55***	-.05	-.28*
R ²		.455***		.303***

* p<.05
 ** p<.01
 *** p<.001

b = Unstandardized Regression Coefficient
 B = Standardized Regression Coefficient

quite a bit larger for cases ($R^2=.455$) than for controls ($R^2=.303$), however.

Interaction terms were then entered into the equations for mothers and fathers to determine if any of these social psychological factors affected the relationship between chronic strain and family dysfunction. These results are shown in Table 6.22 for mothers and in Table 6.23 for fathers. Collectively, the full equation explained 40.7 percent of the variation in dysfunction for mothers and 38.9 percent for fathers.

As would be expected, given the similarity of the equations for the main effects on family dysfunction for the two samples of mothers, Table 6.22 shows that there were no significant interactions with chronic strain for mothers, but the main effects of mastery, religiosity and social support did remain significant. For fathers, however, Table 6.23 indicates that the interaction between chronic strain and social support was significant along with the main effects of mastery and social support. Thus, although there was no main effect of chronic strain on dysfunction, it did have a conditional effect for fathers.

The exact nature of this interaction was not similar to those discussed previously, however. As Figure 6.4.4 demonstrates, at high levels of social support, chronic strain and family dysfunction demonstrated a negative relationship that was more pronounced than the same relationship for those fathers experiencing low levels of social support. In other words, the two samples of fathers differed very little in levels of family

TABLE 6.22: Regression of Family Dysfunction on Selected Variables for Mothers

SAMPLE: MOTHERS (N=143)

PREDICTOR VARIABLES	REGRESSION 1		REGRESSION 2		REGRESSION 3	
	b	B	b	B	b	B
Marital Status	-1.15	-.19	-.73	-.12	-.66	-.11
Chronic Strain			-.28	-.07	-4.10	-1.02
Life Events			.09	.08	.08	.07
Self-Esteem			.02	.04	.00	.00
Mastery			-.13	-.39	-.13***	-.37
Religiosity			.04	.24	.04*	.22
Social Support			.07***	-.26	-.09**	-.37
Strain X Events					.02	.02
Strain X Esteem					.03	.19
Strain X Mastery					-.00	-.01
Strain X Relig.					.01	.06
Strain X Support					.05	.72
R ²	.036		.398***		.407***	

* p<.05
 ** p<.01
 *** p<.001

b = Unstandardized Regression Coefficient
 B = Standardized Regression Coefficient

TABLE 6.23: Regression of Family Dysfunction on Selected Variables for Fathers

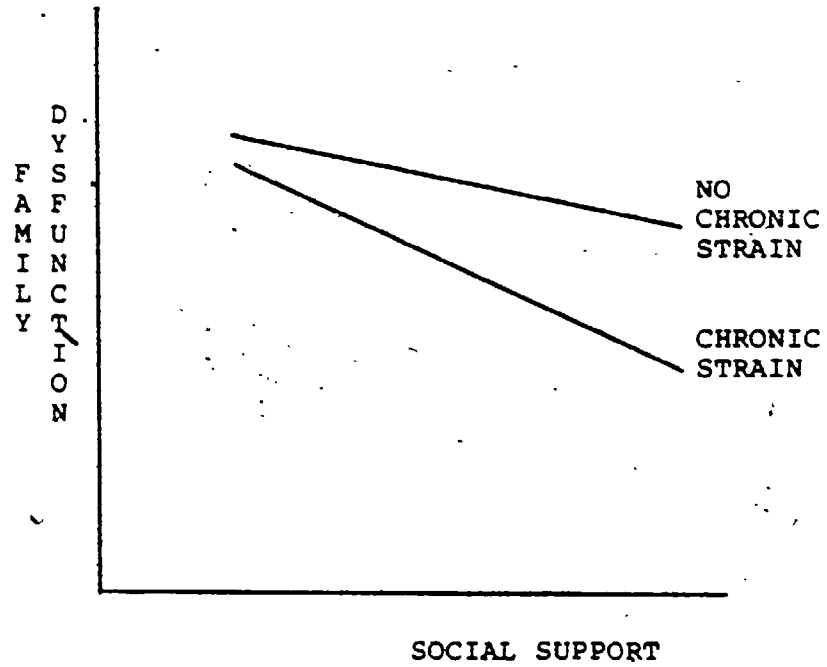
SAMPLE: FATHERS (N=123)

PREDICTOR VARIABLES	REGRESSION 1		REGRESSION 2		REGRESSION 3	
	b	B	b	B	b	B
Marital Status	-.27	-.04	-.28	-.04	-.25	-.03
Chronic Strain			.06	.02	1.43	.48
Life Events			-.04	-.04	-.06	-.06
Self-Esteem			-.06	-.14	-.08	-.19
Mastery			-.07**	-.22	-.07*	-.22
Religiosity			.01	.09	.01	.05
Social Support			-.07***	-.41	-.05*	-.26
Strain X Events					.03	.03
Strain X Esteem					.04	.38
Strain X Mastery					.01	.06
Strain X Relig.					.02	.28
Strain X Support					-.06*	-1.19
R ²	.001		.357***		.389***	

* p<.05
 ** p<.01
 *** p<.001

b = Unstandardized Regression Coefficient
 B = Standardized Regression Coefficient

FIGURE 6.4.4: Interaction of Chronic Strain and Social Support for Family Dysfunction Reported by Fathers



dysfunction at low levels of social support, but at high levels of social support, fathers experiencing chronic strain had lower family dysfunction scores than did those not experiencing chronic strain.

The finding of a chronic strain--social support interaction effect on family functioning offers support for the hypothesis assessed using Research Question Ten in that the relationship between social support and family functioning was stronger for those experiencing chronic strain than for those not experiencing strain. The finding that the combination of a high level of social support and chronic strain was associated with fathers' perceptions of healthy family functioning was unexpected.

Attention will now be shifted to analyses with marital adjustment as the dependent variable. Since marital status was a constant for all those whose marital adjustment was evaluated, it was not entered as a control variable. As shown in Table 6.24, when the relevant social psychological variables were regressed simultaneously on marital adjustment for mothers, mastery, religiosity, and social support all had significant effects on marital adjustment for cases while only mastery was significant for controls. The variance explained for case mothers ($R^2=.363$) was slightly higher than the corresponding amount for control mothers ($R^2=.323$). For case fathers, life events and social support had significant effects on marital adjustment and the entire equation accounted for 37.7% of the variance. None of the variables in the equation for control fathers was significant.

Inclusion of the interaction terms of chronic strain with

TABLE 6.24: Independent Main Effects of Social Psychological Variables on Marital Adjustment by Sample and Parent

PREDICTOR VARIABLE	SAMPLE			
	CASE MOTHERS		CONTROL MOTHERS	
	N=57		N=67	
	b	B	b	B
Life Events	-.15	-.04	-.66	-.14
Self-Esteem	-.01	-.01	.14	.09
Mastery	.27	.27*	.51	.47***
Religiosity	-.19	-.38**	-.09	-.17
Social Support	.28	.37**	.01	.02
R ²		.363***		.323***

PREDICTOR VARIABLE	SAMPLE			
	CASE FATHERS		CONTROL FATHERS	
	N=51		N=69	
	b	B	b	B
Life Events	-1.43	-.33**	-.53	-.13
Self-Esteem	.24	.12	.27	.19
Mastery	.22	.17	.05	.04
Religiosity	-.01	-.17	-.06	-.12
Social Support	.21	.31*	-.00	-.00
R ²		.377***		.085

* p<.05
 ** p<.01
 *** p<.001

b = Unstandardized Regression Coefficient
 B = Standardized Regression Coefficient

each of the social psychological variables did not result in any statistically significant interactions for mothers (See Table 6.25) or for fathers (See Table 6.26) but the chronic strain-social support interaction was of borderline significance for mothers ($p=.066$). The full equation did account for 34.2% of the variation in marital adjustment for mothers but only 22.6% for fathers.

Summary. Multiplicative interaction terms were formed using chronic strain and each of the social psychological factors relevant to the two theoretical models to address the research questions that asked whether the impact that chronic strain had on psychological distress and family adaptation was dependent on the levels of any of these social psychological factors. Question Three asked whether the occurrence of recent life events increased the impact that chronic strain, related to the uncertain future for a child surviving cancer, had on parents' level of depression or anxiety. The results of the current study offer no evidence that the occurrence of recent events does exacerbate the effects of chronic strain on depression or anxiety.

Question Four asked whether the personal resources of mastery or self-esteem affected the relationship of chronic strain with depression and anxiety and Question Nine asked whether either of these two resources or religiosity affected the relationship of chronic strain with family functioning and marital adjustment. No evidence was found to suggest that any of

TABLE 6.25: Regression of Marital Adjustment on Selected Variables for Mothers

SAMPLE: MOTHERS (N=124)

PREDICTOR VARIABLES	REGRESSION 1		REGRESSION 2	
	b	B	b	B
Chronic Strain	.30	.02	-2.29	-.19
Life Events	-.48	+.11	-.66	-.15
Self-Esteem	.07	.05	.14	.10
Mastery	.39***	.37	.51***	.48
Religiosity	-.12**	-.25	-.09	-.17
Social Support	.14*	.17	.01	.02
Strain X Events			.51	.10
Strain X Esteem			-.15	-.33
Strain X Mastery			-.24	-.55
Strain X Relig.			-.11	-.36
Strain X Support			.27	1.36
R ²	.304***		.342***	

* p<.05

** p<.01

*** p<.001

b = Unstandardized Regression Coefficient

B = Standardized Regression Coefficient

TABLE 6.26: Regression of Marital Adjustment on Selected Variables for Fathers

SAMPLE: FATHERS (N=120)

PREDICTOR VARIABLES	REGRESSION 1		REGRESSION 2	
	b	B	b	B
Chronic Strain	.19	.02	-14.11	-1.19
Life Events	-.90*	-.22	-.53	-.13
Self-Esteem	.22	.14	.27	.17
Mastery	.12	.10	.05	.04
Religiosity	-.06	-.12	-.06	-.11
Social Support	.11	.16	-.00	-.00
Strain X Events			-.90	-.17
Strain X Esteem			-.04	-.08
Strain X Mastery			.18	.42
Strain X Relig.			-.04	-.14
Strain X Support			.21	1.11
R ²	.173***		.228***	

* p<.05

** p<.01

*** p<.001

b = Unstandardized Regression Coefficient

B = Standardized Regression Coefficient

these personal resources acted as mediators in the chronic strain-distress/adaptation relationships.

Evidence was found to support the hypotheses that the social resource of social support affects the relationships that chronic strain has with depression and anxiety (as presented in Question Five) and with family functioning (as expressed in Question Ten). The relationship between chronic strain and depression was moderated under the condition of high social support for fathers. For both mothers and fathers, social support buffered the relationship between chronic strain and anxiety. Finally, for fathers only, chronic strain had a conditional effect on family functioning, but the exact nature of this effect did not conform to expectation.

6.5 Case Parents' Perceptions of the Current Effects of Childhood Cancer

It will be recalled that case parents were asked, in the final section of the questionnaire, to respond to open-ended questions regarding both the presence and nature of present concerns that they had about their children surviving cancer. Of the case parents who participated in the study, 95 percent of the mothers and 81 percent of the fathers responded to the open-ended questions. For the purposes of the thesis, the analysis of these qualitative data is limited to a basic description.

To the question asking parents if they had any concerns about the cancer survivor's health, now that the child's cancer was in remission and he/she was off treatment, 81 percent

responded that they did. Of these parents, 68 percent were concerned about the possibility of relapse and 26 percent about illnesses or health problems related to cancer such as side effects resulting from treatment (See Table 6.27).

When asked if they had any current concerns about the survivor, not related to health, 61 percent of the parents said yes. Of these parents, 29 percent were concerned about their child's emotional well-being or personality problems and 24 percent had concerns about problems related to learning or educational difficulties experienced by the child (See Table 6.28).

Parents were also asked about the current effects on both their family and personal lives. The majority of parents (70 percent) said their family life was still affected; 50 percent of these parents thought the effect was positive, 24 percent thought it was negative, and 10 percent said their families were affected both positively and negatively. The majority of parents (80 percent) also felt that their personal lives were currently affected; 57 percent thought the effects were positive, 29 percent thought they were negative, and 11 percent thought the personal effects were both positive and negative.

It is the author's impression, based on a subjective evaluation of all comments written by parents, that there was a great deal of variation in the degree to which these parents and their families were affected by childhood cancer at the time the data were collected. For some parents it seemed that they had been able to put the experience of childhood cancer behind them

TABLE 6.27: Types of Concerns Parents Have About the Cancer Survivor's Health

	N	%
Relapse	62	68.1
Illnesses or Health Problems Related to Cancer	24	26.4
Illnesses or Health Problems <u>Not</u> Related to Cancer	14	15.4
Reproductive Problems	6	6.6

NOTE: A total of 91 parents answered that they had concerns about their cancer survivor's health. The total represented here exceeds this number because some parents reported more than one concern.

TABLE 6.28: Types of Concerns Parents Have About the Cancer Survivors, Not Related to Health

	N	%
Emotional Well-Being/ Personality Problems	18	28.6
Learning Problems/ Educational Concerns	15	23.8
Typical Parental Concerns	12	19.0
General Concerns About Child's Future	9	14.3
Employment Potential	8	12.7
Behavioural Problems	6	9.5
Society's Reactions	3	4.8

NOTE: A total of 63 parents answered that they had concerns about their cancer survivor, not related to health. The total represented here exceeds this number because some parents reported more than one concern.

while for others it appeared that their lives were still very
much influenced by the event.

CHAPTER SEVEN

DISCUSSION AND IMPLICATIONS

7.0 Introduction

In this chapter, attempts will be made to offer some interpretations for the observations reported in the previous chapter. A comment will be made about the present study's relation to the existing literature on the psychosocial aspects of childhood cancer. As well, the findings will be considered within the context of several methodological issues. The limitations inherent in the present study will also be outlined along with some suggestions for future research and a comment on the implications of this study.

7.1 The Relationship of Chronic Strain with Psychological Distress and Family Adaptation

Parents of child cancer survivors were not found to be at higher risk for maladjustment, overall, than parents with healthy children whether personal adjustment of parents or adaptation at the family level was evaluated. Likewise, the cases were not found to experience more life events, on average, than controls.

Although the analyses demonstrated convincingly that case and control parents did not differ in terms of average levels of psychological distress or family adaptation, it is important to note that the relationship of chronic strain with distress and adaptation was observed under certain conditions. In other words, the data failed to support the major hypotheses that predicted higher levels of psychological distress and lower levels of family adaptation among cases than controls but this

conclusion cannot be applied to all subgroups.

Chronic strain was found to be positively associated with depression and anxiety for fathers and with anxiety for mothers, when the level of experienced social support was low. At high levels of social support, chronic strain and family dysfunction demonstrated a negative relationship for fathers that was more pronounced than the same relationship for those fathers experiencing low levels of social support. This finding was somewhat unexpected but was consistent with the results for case fathers when they were divided into lower and higher chronic strain. More of the fathers under lower strain than those under higher strain had scores indicative of family dysfunction.

Chronic strain was not found to be related to marital adjustment nor was there an interactive effect of chronic strain with any of the social psychological factors on marital adjustment. Further discussion of the findings related to marital adjustment will be reserved for the section dealing with the quality of measurement.

In light of the conditional relationships found, it appears that overall differences between the two samples in depression and anxiety for fathers and in anxiety for mothers were not detected at the bivariate level because most of the parents of the cancer survivors were receiving sufficient support. Chronic strain does appear to represent a risk for depression and anxiety for those parents experiencing a low level of social support.

That chronic strain was found to interact with social

support in its effect on depression and anxiety for fathers but only with anxiety for mothers is worthy of consideration. The consistency of a chronic strain-social support interaction for fathers across the two indices of psychological distress may indicate a generalized risk for maladaptation in fathers of child cancer survivors experiencing low social support that does not exist for mothers.

The relevance of the strain-support interaction for depression in fathers is increased when viewed within the context of the findings for depression among survivors' fathers by degree of chronic strain. The finding suggesting that more fathers under higher strain were at risk for depression than those under lower strain may mean that the magnitude of the interaction of chronic strain with social support, observed without any attempts to quantify degree of chronic strain, was actually an under-estimation of the true effect.

One explanation for the fact that chronic strain was not found to be related to depression or family functioning in mothers, even under the condition of low social support may be differential coping capacities related to parental roles. Generally mothers of child cancer survivors tend to be more actively involved than fathers in the care of the child during the stages of diagnosis and treatment. It has been argued that stressful encounters do not necessarily lead to personal deterioration but that stress can, in fact, benefit people in the sense that, after the stress has passed, they feel they have proven themselves and are better or wiser as a result of the

experience (Haan, 1982).

It may be that mothers, as a function of their tendency to accept primary responsibility for the child's care and be in close, regular contact with the oncology team, are more likely than fathers to feel that they have learned from the stressful experience and are better equipped to deal with the subsequent strain. Perhaps as a consequence, it is unlikely that chronic strain will be translated into depression or the perception of family dysfunction in mothers, even in the circumstance of low social support.

Fathers, on the other hand, having been more isolated from these experiences, may be vulnerable to the impact of chronic strain. If, given their limited amount of time and energy to devote to the child's illness, fathers experienced a sort of "stress limit", this may explain why expressions of family dysfunction were more typical of fathers under lower strain than of those under higher strain. Perhaps those experiencing higher strain are too preoccupied with their own distress to perceive problems at the family level.

The question that remains unanswered using this rationale, however, is why there was a significant relationship between chronic strain and anxiety for mothers experiencing low social support. Perhaps a mother's survival of the extremely stressful initial stages of childhood cancer cannot protect her against anxiety because its source, unlike depression and family dysfunction, lies in concerns that were not typical of the

initial stages but instead that are particular to the period of survival after the cessation of treatment. An example of such concerns might be whether the survivor will suffer the failure of treated organs as a result of treatment. Without prospective data to assess relative changes in depression, anxiety, and family functioning for mothers and fathers across the various stages of childhood cancer, these hypotheses remain purely speculative.

It was hypothesized that the personal resources of mastery, self-esteem, and religiosity would act to buffer the effects of chronic strain on psychological distress and family adaptation. The findings were consistent across all outcomes for both mothers and fathers, however, that none of these personal resources interacted with chronic strain.

In the case of mastery, its effects on depression, anxiety, and family functioning were uniformly very strong for both cases and controls rather than specific to only those parents experiencing the chronic strain of having a child surviving cancer. Of all the social psychological factors assessed, a sense of mastery stood out as being the best predictor by far of the outcomes studied. A sense of control over one's life appears to be strongly related to psychological well-being regardless of the presence or absence of chronic strain.

The same cannot be said of self-esteem or religiosity. Neither of these resources tended to exert main effects on the outcomes studied, within the context of the full models, with the exception of the effect of religiosity on family dysfunction for

mothers. It may be that these two personal resources, as mediators in the relationship of chronic strain with psychological distress, are more likely to play a role when chronic strain is operationalized in a more general way such that it encompasses the experience of a wide range of strains and not just one particular type of strain as was studied here.

Finally, the results did not support the prediction that the occurrence of discrete life events would exacerbate the effects of chronic strain on psychological distress and family adaptation. One explanation for this finding may be the use of a simple count of the number of life events experienced by parents.

It is possible that further specification of the events experienced to include the perceived desirability or undesirability of each event when it occurred and the duration of the effects following each event may be necessary to demonstrate the interactive effects of the particular type of chronic strain of interest here and discrete events. Although the two groups of parents did not differ in the number of events experienced or the effect of the number of events on the various outcomes, it may be that certain events have differential meanings for the two groups. Perhaps attention to the experience of events that were viewed as particularly undesirable or as affecting parents for a long period of time may have revealed evidence that the relationship of chronic strain with psychological distress and family adaptation is in fact conditioned by the experience of discrete life events. The data necessary for such refinements to

the measurement of life events were collected but there was insufficient variation in the number of events experienced to allow for such analyses because the time period was limited to the previous six months.

7.2 The Present Study Within the Context of the Literature

Despite the methodological shortcomings that characterize the literature on the psychosocial aspects of childhood cancer, and the fact that the majority of findings from the available literature cannot be directly applied to survivors and their families, it was reported in Chapter One that this literature did provide a starting point for the present investigation. Having said this, however, it seems futile to embark upon a comparison of the results of the current study with the existing literature, even though this is usually done in a discussion chapter. There are two reasons why such comparisons are not considered useful.

First, due to the focus of most research on the psychosocial aspects of childhood cancer, the majority of the comparisons would be based on two different populations--parents whose children were experiencing the early stages of childhood cancer and those who were dealing with their children's survival. Second, the one major study that studied the social and psychological consequences for survivors and their families. (Koocher and O'Malley, 1981) did not use standardized instruments to assess parents or include a control group. They relied, instead, on parents' comments about how their current behaviour was a result of the cancer experience and whether they still had

concerns about the former patient. As a result, it is impossible to interpret their results in terms of whether these parents were experiencing psychological distress or problems in family adaptation.

7.3 Methodological Considerations

The process of interpreting the results must involve the consideration of a number of methodological issues such as response bias, the generalizability of the results, the adequacy of measurement, and statistical power. Each of these issues will be dealt with separately.

7.3.1 Response Bias.

One issue in the interpretation of the finding of no overall differences between cases and controls is whether these results can be generalized to the population of parents with children surviving cancer from which the sample was drawn or whether a response bias could have obscured a real difference in distress or adaptation between the two samples. These results could be attributed to non-response bias if those case parents with the poorest adjustment were the most likely to either be lost to follow-up or refuse to participate.

It should be kept in mind that attempts to follow up the parents of the entire population of child cancer survivors treated at Children's Hospital of Western Ontario were very successful in that only two families out of 101 could not be located. Also, response rates were quite acceptable with 81.6 percent of the case mothers and 72.4 percent of the case fathers

contacted agreeing to participate and with 77.5 percent of the control families rated as the best match for a case family participating. Comparisons of the respondents with non-respondents revealed no significant differences between the two groups on the variables available for comparison. These response rates, in combination with the similarity of non-respondents to respondents, lessen the likelihood that bias due to non-response is a viable explanation for the findings. This suggests that the results may be generalized to the entire population of parents whose children were treated for childhood cancer at Children's Hospital of Western Ontario and are surviving.

7.3.2 Generalizability.

Another issue is whether these results may be further generalized to parents whose child cancer survivors were treated at other centres within the province. Unfortunately, it is not possible to comment at this time on the appropriateness of generalizing from the present sample to other parent populations due to insufficient information about other centres' treatment procedures and patient populations.

A final point with regard to generalizability needs to be made. Due to the design of the present study, where the chronic strain of interest was that associated with being the parent of a child cancer survivor and where the control group chosen was parents with healthy children, the interpretation of the results remains specific to the comparison of these two particular groups. The findings from this study cannot be generalized to other forms of chronic strain such as that which may be generated

by the presence of a child with another chronic life-threatening illness or a chronic non life-threatening illness.

7.3.3 Adequacy of Measurement.

The majority of variables were measured using multi-item indices that have been widely used and have been demonstrated to have satisfactory psychometric properties, as described in Chapter Five. The measurement of chronic strain and marital adjustment represent exceptions to this statement, however.

Chronic Strain. It will be recalled that what distinguished case parents from controls was the chronic strain associated with being the parent of a cancer survivor. It is possible that any relationship this particular chronic strain has with psychological distress and family adaptation was attenuated by the way chronic strain was operationally defined. Grouping the sample of parents of cancer survivors altogether as the "strained sample" may have diluted the relationships of chronic strain with psychological distress and family adaptation. The inability to categorize parents in the case sample by degree of chronic strain may also have washed out any interactive effects of chronic strain and certain social psychological factors on distress or adaptation.

Based on the assumption that degree of chronic strain experienced by parents is at least partially determined by the combination of the length of time the child has been off treatment and the type of cancer, a rather crude attempt was made in this study to assess variations by degree of chronic strain by

dividing the parents into lower and higher strain groups. This line of inquiry was limited by the size of the resulting subsamples but it did offer at least tentative evidence that the inability to categorize parents by their degree of chronic strain may have affected the results.

Marital Adjustment. There may be reason to question the validity of the instrument used to assess marital adjustment. Not only were the average scores high and virtually identical for cases and controls, but there was also very little variation in the scores reported. Scores were free to vary from eleven to fifty-five, but none of the parents in any of the subsamples scored below twenty-nine.

Self-reports of marital adjustment have been criticized as being susceptible to the forces of social desirability (Spanier, 1973). It is possible that the scores reported by both case and control parents were artificially inflated by this effect.

Further, it has been suggested that parents of chronically ill children are particularly susceptible to the tendency to respond in a socially desirable manner and thus, that studies using self-assessment may have difficulty detecting differences in marital distress (Sabbeth and Leventhal, 1984). If such is the case, the findings indicating a lack of a case/control difference in marital adjustment and no interactive effects of chronic strain with any of the social psychological variables on marital adjustment may be artifacts resulting from attempts among parents of cancer survivors to appear "normal". Unfortunately, given these reservations about the validity of the measurement of

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marital adjustment, little confidence can be attached to the findings related to this variable.

Statistical Power. One of the alternate explanations that comes to mind for the failure to find significant overall differences between the two samples on the major outcomes is the possibility that the size of the samples was too small to provide sufficient statistical power for the bivariate analyses to detect substantively relevant differences, should they have existed. In the proposal for this study it was determined, however, that the present study would in fact have sufficient power to detect any meaningful case/control differences on each of the four outcome variables of interest. The power calculations done at the proposal stage are provided in Appendix D. It is true that the study did not have sufficient power associated with it to detect differences as small as the one found between case and control mothers on mean depression scores (0.43), but this point is moot given that such a slight difference in average scores would not be considered clinically relevant.

7.4 Limitations of the Study and Directions for Future Research

Although the present study represents a contribution to the current body of knowledge about the psychosocial aspects of childhood cancer by virtue of its design and the methods used, it has associated with it a number of limitations or weaknesses. These limiting characteristics will be discussed below along with suggestions concerning the direction that further research efforts should take.

The design of the study was cross-sectional. As a result, the causal ordering of events could not be determined. For instance, in the author's interpretation of the interactive relationships observed, it has been assumed that the associations among chronic strain, social support and distress/adaptation are such that a large portion of the effect moves from the social psychological factors to distress/adaptation. The current data, however, are incapable of refuting the conjecture that these relationships actually operate in the opposite direction or determining the extent to which the relationships tend to be reciprocal in nature. Confirmation of the direction of these relationships requires longitudinal data. Further research on the psychosocial consequences of childhood cancer for families, in the form of prospective studies could make a valuable contribution to our current level of understanding.

By following child cancer patients and their families from the point of diagnosis, through the treatment phase and continuing into the survival phase, a great deal more could be learned about the process by which the experience of childhood cancer can result in negative psychosocial consequences for the family. Further specification of the model would also provide suggestions about both the nature and the best timing of potentially effective interventions.

It will be recalled that attempts were made to recruit the entire population of parents with children surviving cancer and treated at the Children's Hospital of Western Ontario and that the participation rates tended to be high. As a function of the

size of the population, however, the sample assessed in the present study was relatively small. Although the size of the sample resulted in sufficient statistical power to test the primary research questions posed, the capacity to address secondary questions, emerging out of the first set and requiring subsample analyses, was restricted by the size of the sample. This was unfortunate given that the index cases were found to vary rather substantially in terms of type of cancer and length of time off treatment.

A large enough sample to allow analyses on subsamples based on the classification of cancer survivors by these two characteristics would have strengthened the study. The logical successor to the present study is a multi-centre investigation whose study population would include all parents of child cancer survivors treated in the province of Ontario. Such a design would also offer the opportunity to evaluate the psychosocial effects associated with the various strategies employed by oncology teams of each treatment centre.

As outlined in the section on the adequacy of measurement, another limitation, related to the size of the available sample, was imposed by the manner in which chronic strain was assessed. For the majority of the analyses, degree of strain experienced by parents of child cancer survivors was not considered. For one set of analyses, an attempt was made to classify parents by degree of chronic strain, based on the assumption that such strain is at least partially determined by

the type of cancer and the length of time that has passed since the cessation of treatment. These analyses were characterized by insufficient statistical power, but they did suggest that the combination of these two factors may be relevant to psychological distress and family dysfunction.

Although none of the open-ended questions regarding the presence and nature of case parents' present concerns about their children surviving cancer directly assessed their perceived degree of chronic strain, two impressions were drawn from a subjective evaluation of the responses. First, the majority of parents reported that they did have concerns about their children surviving cancer; the most common concern being the possibility of relapse, followed by concerns regarding other illnesses or problems related to cancer. Second, there appeared to be substantial variation in the extent of parents' concerns.

Based on the experience of the present investigation, it seems important to attempt to assess chronic strain more directly, even though there are problems inherent in attempting to conceptually define chronic strain. Such efforts should involve an attempt to quantify parents' subjective perceptions of their chronic strain in terms of both the nature of specific concerns they have and the degree or intensity of these concerns. As well, a method for rating chronic strain more objectively or directly by incorporating various aspects of the illness itself, such as the type of cancer, the specific nature of the treatment regimen and the length of time since treatment ended that has passed uneventfully, should be developed and refined. Having

done this, it will be possible to determine the extent to which parents' perceptions of chronic strain are associated with particular aspects of the course of the illness.

Finally, restricting the study to only the parents of cancer survivors and not the survivors themselves or their siblings represents a weakness of the study. Clearly parents' adjustment cannot be fully understood independent of the levels of adjustment that characterize the other members of the family. It may be, for example, that a parent's psychological adjustment is associated with such factors as the level of the cancer survivor's own adjustment, treatment protocol, or the severity of medical complications or long-term treatment side effects experienced by the child. The claim seems justified that the use of theoretical models to guide this study represents an important contribution to current knowledge as one of the first systematic attempts to understand the interconnections of the various components involved in the stress process as it applies to families of child cancer survivors. These models are not the only possibilities, however, and others may better represent the relevant underlying process.

7.5 Implications

The findings of this investigation related to the psychosocial consequences associated with surviving childhood cancer are testimony to the resilient nature of parents, and families in general. Overall, the parents of child cancer survivors did not differ from a matched sample of parents with

children who have never experienced a serious chronic illness or a life threatening disease in terms of levels of psychological distress and family adaptation.

Keeping in mind that the chronic strain of interest was that associated with a particular stressful life event--cancer in a child--the results of the current study should not be taken to suggest that the models used to guide the investigation need to be altered. The study was not designed as a test of either the stress process model or the family stress theory or their degree of comparability but rather as an evaluation of the psychosocial consequences associated with being the parent of a child cancer survivor. As a result, any implications to be drawn from the study pertain to parents with children surviving cancer and not to the relative merits of these two parallel theoretical models.

We know that an increasing number of pediatric cancer patients now survive, disease free, for substantial periods of time and the present study suggests that their families do not necessarily experience higher levels of psychological distress or lower levels of family adaptation than families with healthy children. The findings discussed here do suggest, however, that those parents who experience a low level of social support may be at elevated risk for psychological distress; that social support may be a key factor in determining whether the chronic strain associated with being a parent of a child surviving cancer is translated into psychological distress.

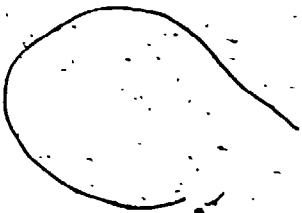
If the assumed direction of these relationships can be

verified through longitudinal research, then parents experiencing low levels of social support could be considered appropriate targets for intervention. Currently, child cancer survivors and their families have very little or no contact with the oncology team once the treatment phase is completed. Of course the specific nature of programs that would be effective in increasing levels of social support remains to be determined through intervention studies.

It may be that the implementation of regular group sessions for parents of survivors, which offer the opportunity to voice concerns and have questions answered, would be beneficial in communicating to parents that they are in fact cared for, valued and able to count on others should the need arise. It seems that parents' associations that exist now are predominantly composed of parents with children undergoing treatment and are not appropriate sources of support for survivors' families. It has been suggested to the author that some survivors' parents actually find participation in such groups stressful in that it forces them to relive the extremely difficult period, which they want to put behind them but that characterizes the present circumstance of the majority of the other members. Survivors' parents are likely to be reluctant to raise their own concerns related to survival within a group where many parents are faced with a high probability of losing their child to cancer.

The current investigation also offers at least tentative evidence that fathers and mothers may be likely to perceive problems in family functioning at different times; that more

mothers tend to perceive family problems when experiencing a higher level of chronic strain while more fathers perceive such problems when under a lower level of strain. This may mean that counselling for couples or entire families is indicated in that it might provide the opportunity for family members to become aware of any discrepancies between their own perceptions of their family environment and those of the other members of the family. Again, before seriously considering such interventions, further research of the types outlined earlier must be conducted to offer a more complete context within which to consider observations made here.



CHAPTER EIGHT

SUMMARY AND CONCLUSIONS

As a function of substantial improvements in the prognosis of child cancer patients, both patients and their families face longer phases of treatment and an inability to predict the future. In general, we know very little about the psychosocial consequences associated with the experience of childhood cancer. Although some attempts have been made to provide descriptions of the problems faced by both the patient and the family, the value of this research tends to be limited by the fact that most studies have been based on the now outdated assumption that childhood cancer is invariably fatal and by the lack of rigorous quantitative research.

The present study addressed the question of whether the presence of chronic strain, as experienced by the families of child cancer survivors, is associated with psychological distress, in the form of depression or anxiety in the parents or problems with family adaptation, in the form of family dysfunction or marital maladjustment. The roles played by personal and social resources in mediating or exacerbating the effect of chronic strain on psychological distress and family adaptation were also examined.

Outcomes for parents of cancer survivors were assessed by comparing their scores to those of a matched sample of parents, chosen from the case families' neighbourhoods and whose children had never had a serious chronic illness or life threatening

disease. Both mothers and fathers in the two samples were asked to respond to self-administered questionnaires.

Overall, parents of child cancer survivors were not found to be at higher risk for psychological distress or problems with family adaptation. It is important to note, however, that although the two groups of parents did not differ in terms of average levels of psychological distress or family adaptation, the relationship of chronic strain with distress and adaptation was observed under the condition of low levels of experienced social support. Chronic strain appears to represent a risk for depression in fathers and for anxiety in mothers and fathers who are experiencing low levels of social support.

These findings offer encouraging evidence of the resilient nature of parents and families in general. It appears that families of the increasing number of surviving pediatric cancer patients, who have experienced the extremely stressful event of cancer in a child, do not inevitably experience higher levels of psychological distress or lower levels of family adaptation. It does seem, however, that the level of social support experienced may be an important factor in determining the extent to which chronic strain is associated with psychological distress.

If the assumed direction of the relationship of chronic strain with psychological distress and family adaptation can be confirmed in longitudinal research, serious consideration should be given to the development and evaluation of intervention strategies aimed at parents of child cancer survivors

experiencing low levels of social support.

APPENDIX A

INTRODUCTORY LETTER AND CONSENT FORM
FOR CASE PARENTS

TELEPHONE 432-8341 - LOCAL 884

L. L. DE VEEER, M.D., F.R.C.P.(C)
WAR MEMORIAL CHILDREN'S HOSPITAL
382 SOUTH STREET
LONDON, CANADA N6B 1B8

Pediatric Oncology Services at War Memorial Children's Hospital is working with Kathy Speechley from the Department of Epidemiology and Biostatistics at The University of Western Ontario on a study of families with children surviving cancer. The purpose of this letter is to request your participation in this study. The procedures are described below.

Your participation will involve the completion of a questionnaire that will be mailed out to you. We would like both parents to answer the questionnaire separately where possible because fathers and mothers tend to react differently to various aspects of their lives. Several areas are covered in the questionnaire, including how you and your family are doing these days and the way you feel about your life and other people around you.

You will be able to complete the questionnaire at your convenience. It will take about one hour of your time. Any questions that might arise as you complete the questionnaire will be answered by Kathy Speechley, the Project Director. She may be contacted at the Health Care Research Unit (519)679-6760. If you live outside the City of London, please call collect.

You will be asked to sign a form granting permission for a member of the project staff to examine your child's medical file at War Memorial Children's Hospital to record only your child's date of birth, diagnosis, and dates of diagnosis and treatment.

All information obtained will be kept in the strictest confidence. Questionnaires will be identified by means of a unique number and no personal information that could lead to the identity of any individual respondent will remain on the questionnaire. The list of names and identification numbers will be kept locked up, with access limited to the project director. In this way, anonymity will be assured.

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You are free to refuse to participate in this study or you may refuse to answer specific questions in the questionnaire. Should you decide to do so, this will not affect your child's future medical care in any way.

Although this study may be of no direct benefit to you or your child, the results may help us to determine the problems faced by families whose children have severe chronic illnesses so we may be able to prevent such problems in the future. Please feel free to give me a call at 432-5241 Ext. 656 if you have any questions about the study. Kathy Speechley, the Project Director, will be calling you soon to make arrangements to mail the questionnaire to you.

Sincerely,



L.L. deVeber M.D., F.R.C.P.(C)
Professor of Paediatrics
University of Western Ontario
Director of Hematology-Oncology
War Memorial Children's Hospital
(519) 432-5241 Ext. 656

CONSENT FORM

I.D. NUMBER _____

The nature of the study of parents with children surviving cancer has been explained to me and I hereby agree to participate in this project. I understand that my participation involves the completion of a questionnaire and the granting of permission for the project staff to have access to my child's files at War Memorial Children's Hospital in London to obtain diagnosis and dates of diagnosis and treatment.

Signature: _____

FOR OFFICE USE ONLY:

NAME: _____

ADDRESS: _____

TELEPHONE NO: _____

DATE RETURNED: _____

APPENDIX B
QUESTIONNAIRE FOR CASE PARENTS

I.D. NUMBER _____

STUDY OF PARENTS WITH CHILDREN SURVIVING CANCER
AND PARENTS WITH HEALTHY CHILDREN

Please find attached a questionnaire concerning important information about how families with children function.

It is important that you complete this questionnaire by yourself, to give your own personal opinions. ~~We ask that you do not discuss your answers with anyone, including your spouse.~~ If you have any questions as you complete this questionnaire, please call the Project Director, Kathy Speechley at (519)679-6760 during office hours or at (519)434-0081 in the evening.

Please remember that all responses will be held in strict confidence. No information will appear on any questionnaire that will permit identification of individual participants.

L.D. NUMBER _____

PLEASE CIRCLE ONE ANSWER FOR EACH QUESTION WHERE NUMBERED CHOICES ARE GIVEN.

1. Are you:
- 1. male?
 - 2. female?

2. When were you born?

____	____	____
DAY	MONTH	YEAR

3. What is your current marital status?

- 1. single (never married)
- 2. married (including common-law relationship)
APPROXIMATE DATE OF MARRIAGE _____
- 3. separated APPROXIMATE DATE OF SEPARATION _____
- 4. divorced APPROXIMATE DATE OF DIVORCE _____
- 5. widowed APPROXIMATE DATE OF SPOUSE'S DEATH _____

4. a) What was the highest grade you ever completed at primary and secondary school?

- 0 - none
- 1 2 3 4 5 6 7 8 9 10 11 12 13

b) How many years of schooling have you had since secondary school?

- 0. none
- 1. university/community college: number of years attended: _____
degree/diploma received: _____
- 2. other (SPECIFY) _____
number of years attended: _____
degree/diploma received: _____

Now we would like to ask you some questions about religious matters.

10. Using the expressions—VERY OFTEN, OFTEN, SOMETIMES, ALMOST NEVER, and NEVER, please describe ways in which you are involved in religion. (CIRCLE NUMBER)

	VERY OFTEN	OFTEN	SOMETIMES	ALMOST NEVER	NEVER
a) I attend religious crusades, revival meetings or missions.	1	2	3	4	5
b) I attend religious services.	1	2	3	4	5
c) I listen to religious services on the radio or T.V.	1	2	3	4	5
d) I pray, either privately or with family.	1	2	3	4	5
e) I listen to religious music.	1	2	3	4	5
f) I use ideas I have learned from religion to help me understand my own life.	1	2	3	4	5
g) I contribute money to my church.	1	2	3	4	5
h) I regularly take part in various activities in my religious organization.	1	2	3	4	5
i) I try to see that my children learn something about our religion.	1	2	3	4	5
j) I encourage my children to participate in activities sponsored by religious groups.	1	2	3	4	5
k) The religious beliefs I learned when I was young still help me.	1	2	3	4	5
l) I feel that the church or religion helps me in my marriage.	1	2	3	4	5
m) I feel that the church or religion helps me in getting ahead in life.	1	2	3	4	5

It is important for this study that we know something about your family's financial circumstances. We realize these are extremely personal matters and we wish to assure you again that your responses will be kept strictly confidential.

11. Please circle the number of the category that gives the best estimate of your total yearly family income before taxes.

- 1. under \$5,000
- 2. \$5,000 to \$9,999
- 3. \$10,000 to \$14,999
- 4. \$15,000 to \$19,999
- 5. \$20,000 to \$24,999
- 6. \$25,000 to \$29,999
- 7. \$30,000 to \$39,999
- 8. \$40,000 to \$49,999
- 9. \$50,000 or over

12. When you think of your financial situation overall, how difficult is it for you to meet the following commitments?

	VERY DIFFICULT	SOMEWHAT DIFFICULT	NOT AT ALL DIFFICULT
a) housing	1	2	3
b) food	1	2	3
c) personal expenses (e.g. clothing, recreation, entertainment)	1	2	3
d) transportation	1	2	3
e) medical expenses	1	2	3
f) Are there any other commitments that are difficult to meet? (PLEASE SPECIFY) _____	1	2	3

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13. In this next section you will find 50 statements about your family as a whole. Please read each statement carefully and decide how well the statement describes your family.

Please circle the number that best describes the extent of your agreement with each of the statements.

Circle only one number (response) for each statement. Answer every statement, even if you are not completely sure of the answer.

	STRONGLY AGREE	AGREE	DISAGREE	STRONGLY DISAGREE
1 We spend too much time arguing about what our problems are.	1	2	3	4
2 Family duties are fairly shared.	1	2	3	4
3 When I ask someone to explain what they mean, I get a straight answer.	1	2	3	4
4 When someone is upset, we don't know if they are angry, sad, scared or what.	1	2	3	4
5 We are as well adjusted as any family can possibly be.	1	2	3	4
6 You don't get a chance to be an individual.	1	2	3	4
7 When I ask why we have certain rules, I don't get a good answer.	1	2	3	4
8 We have the same views on what is right and wrong.	1	2	3	4
9 I don't see how any family could get along better than ours.	1	2	3	4
10 Some days we are more easily annoyed than on others.	1	2	3	4
11 When problems come up, we try different ways of solving them.	1	2	3	4
12 I am expected to do more than my share.	1	2	3	4
13 We argue about who said what.	1	2	3	4
14 We tell each other about things that bother us.	1	2	3	4
15 We could be happier than we are.	1	2	3	4

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	STRONGLY AGREE	AGREE	DISAGREE	STRONGLY DISAGREE
16 We feel loved.	1	2	3	4
17 When you do something wrong, you don't know what to expect.	1	2	3	4
18 It's hard to tell what the rules are.	1	2	3	4
19 I don't think any family could possibly be happier than mine.	1	2	3	4
20 Sometimes we are unfair to each other.	1	2	3	4
21 We never let things pile up until they are more than we can handle.	1	2	3	4
22 We agree about who should do what.	1	2	3	4
23 I never know what's going on.	1	2	3	4
24 I can let my family know what's bothering me.	1	2	3	4
25 We never get angry.	1	2	3	4
26 My family tries to run my life.	1	2	3	4
27 If we do something wrong, we don't get a chance to explain.	1	2	3	4
28 We argue about how much freedom we should have to make our own decisions.	1	2	3	4
29 My family and I understand each other completely.	1	2	3	4
30 We sometimes hurt each others' feelings.	1	2	3	4
31 When things aren't going well it takes too long to work them out.	1	2	3	4
32 We can't rely on family members to do their part.	1	2	3	4
33 We take the time to listen to each other.	1	2	3	4
34 When someone is upset, we don't find out until much later.	1	2	3	4
35 Sometimes we avoid each other.	1	2	3	4
36 We feel close to each other.	1	2	3	4

	STRONGLY AGREE	AGREE	DISAGREE	STRONGLY DISAGREE
37 Punishments are fair.	1	2	3	4
38 The rules don't make sense.	1	2	3	4
39 Some things about my family don't entirely please me.	1	2	3	4
40 We never get upset with each other.	1	2	3	4
41 We deal with our problems even when they're serious.	1	2	3	4
42 One family member always tries to be the centre of attention.	1	2	3	4
43 My family lets me have my say, even if they disagree.	1	2	3	4
44 When we get upset, we take too long to get over it.	1	2	3	4
45 We always admit our mistakes without trying to hide anything.	1	2	3	4
46 We don't really trust each other.	1	2	3	4
47 We hardly ever do what is expected of us without being told.	1	2	3	4
48 We are free to say what we think.	1	2	3	4
49 My family is not a perfect success.	1	2	3	4
50 We have never let down another family member in any way.	1	2	3	4

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14. The following section asks some questions about married life and is to be answered by those who are currently married (or in a commonlaw relationship). If you are not currently married, please go to QUESTION 16.

Every marriage has its strengths and its problems. We are interested in learning about the kinds of things that have affected your marriage. For the following questions, please circle the number which you believe best describes what is true in your marriage.

a) How often does your spouse show affection to you?

1 2 3 4 5
NOT AT ALL SOMETIMES OFTEN

b) How often do you show affection to your spouse?

1 2 3 4 5
NOT AT ALL SOMETIMES OFTEN

c) In general, how often do you think that things between you and your spouse are going well?

1 2 3 4 5
NOT AT ALL SOMETIMES OFTEN

d) How often do you and your spouse laugh together?

1 2 3 4 5
NOT AT ALL SOMETIMES OFTEN

e) How often do you find yourself thinking over marital problems?

1 2 3 4 5
NOT AT ALL SOMETIMES OFTEN

f) How satisfied are you with the amount of time you and your spouse spend together?

1 2 3 4 5
NOT AT ALL SOMEWHAT EXTREMELY

g) How often have you asked the advice of relatives, friends, or neighbours about getting along in marriage?

1 2 3 4 5
NEVER SEVERAL OCCASIONS OFTEN

h) How often do you discuss or have you considered divorce, separation, or ending your relationship?

1 2 3 4 5
NOT AT ALL SOMETIMES OFTEN

i) Do you and your spouse do things outside the home together?

1 2 3 4 5
 NOT AT ALL SOMETIMES OFTEN

j) Have you or your spouse left the house because of a fight?

1 2 3 4 5
 NEVER SOMETIMES ALMOST ALWAYS

k) How often have you gone to a doctor, counsellor, or other professional person for marriage advice?

1 2 3 4 5
 NEVER SEVERAL OCCASIONS OFTEN

l) Please circle the letter on the scale below that best describes the degree of happiness, all things considered, of your relationship.

A B C D E F G
 EXTREMELY FAIRLY A LITTLE NEITHER SOMEWHAT VERY EXTREMELY
 UNHAPPY UNHAPPY UNHAPPY HAPPY HAPPY HAPPY HAPPY
 NOR
 UNHAPPY

15. Most couples have disagreements in their relationships. Please indicate below how often you and your spouse disagree on each item. (Circle the appropriate number.)

	NEVER	RARELY	SOMETIMES	OFTEN
a) Handling the children	1	2	3	4
b) Recreation or leisure activities	1	2	3	4
c) Religion	1	2	3	4
d) Aims, goals, and things believed important	1	2	3	4
e) Physical affection	1	2	3	4
f) Handling money	1	2	3	4
g) Friends	1	2	3	4
h) Ways of dealing with in-laws or parents	1	2	3	4
i) Sex	1	2	3	4
j) Making major decisions	1	2	3	4
k) Household tasks	1	2	3	4

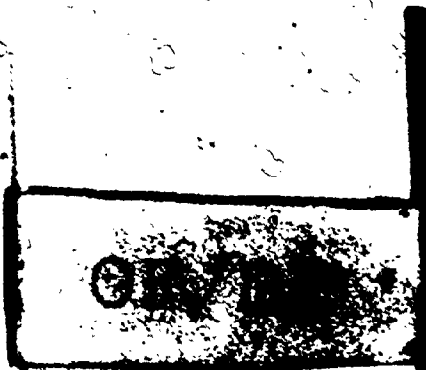
Now we would like to ask you about experiences that people sometimes have. Some of these things happen to most people at one time or another, while some happen to only a few people. We would like to know about things that have happened over the past six months.

16. First, we would like you to tell us about some things that happened to you, or to anyone close to you (that is your spouse, children, family, relatives or close friends).

Please indicate which experiences happened to you or someone close to you in the past 6 months and then answer each of the other 4 questions about that experience. Choose the number of the answer for each question that best applies to your experience and write that number in the space provided. If the same experience happened to more than one of the people listed, treat each separately by dividing up the space provided, writing in the number representing each person and answering the other questions about each of the experiences. It is very important that you answer each question about every experience that has happened.

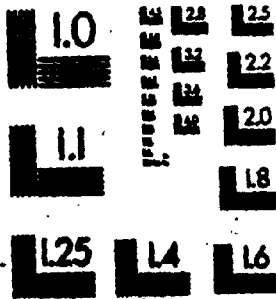
	1. YES 2. NO	TO WHOM DID THE EVENT OCCUR? 1. self 2. spouse 3. children 4. relatives 5. friends	IN WHAT MONTH DID IT OCCUR? 1. June 1985 2. May 1985 3. Apr. 1985 4. Mar. 1985 5. Feb. 1985 6. Jan. 1985 7. Dec. 1984	AT THE TIME IT OCCURRED DID YOU SEE IT AS: 1. very bad 2. fairly bad 3. neither good nor bad 4. fairly good 5. very good	HOW LONG DID IT AFFECT YOU AFTERWARDS? 1. less than 2 weeks. 2. 2 weeks to 1 month 3. more than 1 month.
Have you, your spouse, children, relatives or close friends had:					
a) a serious accident or injury?					
b) a serious illness?					
c) a marital separation or divorce?					
d) continuous financial worries?					
e) a major financial crisis?					
f) trouble with the law?					
g) a pregnancy?					
h) an abortion, miscarriage, or still birth?					
i) a child die?					
j) a spouse die?					

3



3

MICROCOPY RESOLUTION TEST CHART
NBS 1010a
(ANSI and ISO TEST CHART No. 2)



17. Now we would like you to think about you and your spouse (if applicable). Please tell us which of the following occurred to you or to your spouse in the past 6 months. Follow the same pattern as you did on the last page but record only those experiences that happened to you or to your spouse.

	1. YES	TO WHOM DID THE EVENT OCCUR?	IN WHAT MONTH DID IT OCCUR?	AT THE TIME IT OCCURRED DID YOU SEE IT AS:	HOW LONG DID IT AFFECT YOU AFTERWARDS?
Have you or your spouse:	2. NO	1. self 2. spouse	1. June 1985 2. May 1985 3. Apr. 1985 4. Mar. 1985 5. Feb. 1985 6. Jan. 1985 7. Dec. 1984	1. very bad 2. fairly bad 3. neither good nor bad 4. fairly good 5. very good	1. less than 2 weeks. 2. 2 weeks to 1 month 3. more than 1 month.
a) experienced a continuous threat of lay off from work?					
b) been down-graded or demoted at work?					
c) begun a completely different type of work?					
d) been fired or laid off from work?					
e) had a business that failed?					
f) experienced a big change in the people or responsibilities at work?					
g) had troubles or arguments or other difficulties with people at work?					
b) retired or resigned from work?					
i) had a close family member die?					
j) had a close friend die?					

18. Now we would like to ask about some things that happened to you personally. Please tell us which of the following experiences you have had in the past 6 months. Follow the same pattern as you did on the last two pages but record only those experiences that happened to you personally.

	IN WHAT MONTH DID IT OCCUR?	AT THE TIME IT OCCURRED DID YOU SEE IT AS:	HOW LONG DID IT AFFECT YOU AFTERSWARDS?
1. YES	1. June 1985 2. May 1985 3. Apr. 1985	1. very bad 2. fairly bad 3. neither good nor bad	1. less than 2 weeks.
2. NO	4. Mar. 1985 5. Feb. 1985 6. Jan. 1985 7. Dec. 1984	4. fairly good 5. very good	2. 2 weeks to 1 month 3. more than 1 month.
Have you:			
a) got together again after a marital separation?			
b) had increasingly serious arguments with a friend, relative or neighbour not living in your home?			
c) had other serious problems in your relationship with a close friend, relative or neighbour not living in your home?			
d) had a problem with the behaviour of one of your parents?			
e) had a problem with the behaviour of your spouse?			
f) had a problem with the behaviour of one of your children?			
g) ended an engagement?			
h) been separated from some one else close to you?			
i) moved to a new neighbourhood or to a new town?			
j) gone on welfare?			

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19. For each of the following statements please circle the number that describes how strongly you agree or disagree with each statement. Please answer every statement even if you are not completely sure of your answer.

1. strongly agree
2. mildly agree
3. neither agree nor disagree
4. mildly disagree
5. strongly disagree

- a) I have little control over the things that happen to me. 1 2 3 4 5
- b) There is really no way I can solve some of the problems I have. 1 2 3 4 5
- c) There is little I can do to change many of the important things in my life. 1 2 3 4 5
- d) I often feel helpless in dealing with problems of life. 1 2 3 4 5
- e) Sometimes I feel that I am being pushed around in life. 1 2 3 4 5
- f) What happens to me in the future mostly depends on me. 1 2 3 4 5
- g) I can do just about anything I really set my mind to. 1 2 3 4 5

20. The following statements describe the ways people feel about themselves. Please circle the number to the right of each sentence that indicates how strongly you agree or disagree.

1. strongly agree
2. mildly agree
3. neither agree nor disagree
4. mildly disagree
5. strongly disagree

- | | | | | | |
|--|---|---|---|---|---|
| a) I feel that I have a number of good qualities. | 1 | 2 | 3 | 4 | 5 |
| b) I feel that I'm a person of worth at least equal to others. | 1 | 2 | 3 | 4 | 5 |
| c) I am able to do things as well as most other people. | 1 | 2 | 3 | 4 | 5 |
| d) I take a positive attitude toward myself. | 1 | 2 | 3 | 4 | 5 |
| e) On the whole I am satisfied with myself. | 1 | 2 | 3 | 4 | 5 |
| f) All in all, I'm inclined to feel that I'm a failure. | 1 | 2 | 3 | 4 | 5 |

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21. The sentences below say something about how people sometimes feel. Please read each sentence and circle the number that best tells how often you have felt this way in the past 7 days.

Have you felt this way:

0. Rarely or none of the time (less than one day)
1. Some or a little of the time (1 to 2 days)
2. Occasionally or a moderate amount of time (3 to 4 days)
3. Most or all of the time (5 to 7 days)

During the past seven days:

- | | | | | |
|--|---|---|---|---|
| a) I was bothered by things that usually don't bother me. | 0 | 1 | 2 | 3 |
| b) I did not feel like eating; my appetite was poor. | 0 | 1 | 2 | 3 |
| c) I felt that I could not shake off the blues even with help from my family or friends. | 0 | 1 | 2 | 3 |
| d) I felt that I was just as good as other people. | 0 | 1 | 2 | 3 |
| e) I had trouble keeping my mind on what I was doing. | 0 | 1 | 2 | 3 |
| f) I felt depressed. | 0 | 1 | 2 | 3 |
| g) I felt that everything I did was an effort. | 0 | 1 | 2 | 3 |
| h) I felt hopeful about the future. | 0 | 1 | 2 | 3 |
| i) I thought my life had been a failure. | 0 | 1 | 2 | 3 |
| j) I felt fearful. | 0 | 1 | 2 | 3 |
| k) My sleep was restless. | 0 | 1 | 2 | 3 |
| l) I was happy. | 0 | 1 | 2 | 3 |
| m) I talked less than usual. | 0 | 1 | 2 | 3 |
| n) I felt lonely. | 0 | 1 | 2 | 3 |
| o) People were unfriendly. | 0 | 1 | 2 | 3 |
| p) I enjoyed life. | 0 | 1 | 2 | 3 |
| q) I had crying spells. | 0 | 1 | 2 | 3 |
| r) I felt sad. | 0 | 1 | 2 | 3 |
| s) I felt that people disliked me. | 0 | 1 | 2 | 3 |
| t) I could not get "going". | 0 | 1 | 2 | 3 |

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PLEASE NOTE: The next two pages look very similar but the directions are different so please read each set of directions very carefully before answering.

22. A number of statements which people have used to describe themselves are given below. Read each statement and then circle the appropriate number to the right of the statement to indicate how you feel right now, that is, at this moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feelings best.

		1.	2.	3.	4.
		not at all			
		somewhat			
		moderately so			
		very much so			
a)	I feel calm	1	2	3	4
b)	I feel secure	1	2	3	4
c)	I am tense	1	2	3	4
d)	I am regretful	1	2	3	4
e)	I feel at ease	1	2	3	4
f)	I feel upset	1	2	3	4
g)	I am presently worrying over possible misfortunes	1	2	3	4
h)	I feel rested	1	2	3	4
i)	I feel anxious	1	2	3	4
j)	I feel comfortable	1	2	3	4
k)	I feel self-confident	1	2	3	4
l)	I feel nervous	1	2	3	4
m)	I am jittery	1	2	3	4
n)	I feel "high strung"	1	2	3	4
o)	I am relaxed	1	2	3	4
p)	I feel content	1	2	3	4
q)	I am worried	1	2	3	4
r)	I feel over-excited and "rattled"	1	2	3	4
s)	I feel joyful	1	2	3	4
t)	I feel pleasant	1	2	3	4

23. A number of statements which people have used to describe themselves are given below. Read each statement and then circle the appropriate number to the right of the statement to indicate how you generally feel. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe how you generally feel.

- 1. almost never
- 2. sometimes
- 3. often
- 4. almost always

a) I feel pleasant	1	2	3	4
b) I tire quickly	1	2	3	4
c) I feel like crying	1	2	3	4
d) I wish I could be as happy as others seem to be	1	2	3	4
e) I am losing out on things because I can't make up my mind soon enough	1	2	3	4
f) I feel rested	1	2	3	4
g) I am "calm, cool, and collected"	1	2	3	4
h) I feel that difficulties are piling up so that I cannot overcome them	1	2	3	4
i) I worry too much over something that really doesn't matter	1	2	3	4
j) I am happy	1	2	3	4
k) I am inclined to take things hard	1	2	3	4
l) I lack self-confidence	1	2	3	4
m) I feel secure	1	2	3	4
n) I try to avoid facing a crisis or difficulty	1	2	3	4
o) I feel blue	1	2	3	4
p) I am content	1	2	3	4
q) Some unimportant thought runs through my mind and bothers me	1	2	3	4
r) I take disappointments so keenly that I can't put them out of my mind	1	2	3	4
s) I am a steady person	1	2	3	4
t) I get in a state of tension or turmoil as I think over my recent concerns and interests	1	2	3	4

Now, we would like you to answer some questions about your family and relatives who do not live with you.

24. Not counting family members or relatives with whom you live, about how many live nearby, say within an hour's drive?

PLEASE RECORD NUMBER

IF NONE GO TO QUESTION 28

25. On average, how often do you either see them or talk to them on the phone?

- 1. daily
- 2. once or twice a week
- 3. once or twice a month
- 4. once or twice a year
- 5. I hardly ever see them or talk to them

26. How many of them could come to your home at any time and no one would be embarrassed if the house were untidy or you were in the middle of a meal?

PLEASE RECORD NUMBER

27. How many family members or relatives could you visit without waiting for an invitation? You could arrive without being expected and still be sure that you would be welcome?

PLEASE RECORD NUMBER

- 20 -

Now, we would like you to answer some questions about your friends. Try to keep in mind those people whom you feel close to rather than those people who are just acquaintances.

28. About how many friends live nearby, say within an hour's drive?

IF NONE, GO TO QUESTION 32

PLEASE RECORD NUMBER

29. On average, how often do you either see them or talk to them on the phone?

1. daily
2. once or twice a week
3. once or twice a month
4. once or twice a year
5. I hardly ever see them or talk to them

30. How many friends could come to your home at any time and no one would be embarrassed if the house were untidy or you were in the middle of a meal?

PLEASE RECORD NUMBER

31. How many friends could you visit without waiting for an invitation? You could arrive without being expected and still be sure that you would be welcome?

PLEASE RECORD NUMBER

32. Spending time with family and relatives including those with whom you live, is often pleasant and rewarding, but there are also times when negative things can happen. Please circle the number of the category that best describes how often your family and relatives do the following things:

- 1. never or almost never
- 2. seldom
- 3. sometimes
- 4. often

- a) listen to you when you need to talk about any problems you might have? 1 2 3 4
- b) get on your nerves? 1 2 3 4
- c) make too many demands on you? 1 2 3 4
- d) express interest in your well-being? 1 2 3 4
- e) create tensions or arguments while you are around them? 1 2 3 4
- f) comfort you when you need it? 1 2 3 4
- g) make you feel that they care about you? 1 2 3 4
- h) make you feel like they are taking advantage of you? 1 2 3 4

33. The same kinds of positive and negative things can happen with your friends. Please circle the number of the category that best describes how often your friends do the following things:

- 1. never or almost never
- 2. seldom
- 3. sometimes
- 4. often

- a) listen to you when you need to talk about any problems you might have? 1 2 3 4
- b) get on your nerves? 1 2 3 4
- c) make too many demands on you? 1 2 3 4
- d) express interest in your well-being? 1 2 3 4
- e) create tensions or arguments while you are around them? 1 2 3 4
- f) comfort you when you need it? 1 2 3 4
- g) make you feel that they care about you? 1 2 3 4
- h) make you feel like they are taking advantage of you? 1 2 3 4

- 23 -

34. Among all your family and friends, is there someone in whom you can confide and with whom you can share your most private thoughts?

1. no GO TO QUESTION 37
2. yes - What is this person's relationship to you? _____
Is the person male/female? _____

35. If that particular person wasn't available for some reason, is there someone else who you could confide in?

1. no
2. yes - What is this person's relationship to you? _____
Is the person male/female? _____

36. How much can you really open up to (him/her/these people) without having to hold back on your feelings? Would you say:

1. a great deal
2. quite a bit
3. some
4. a little
5. very little if at all

37. Most of us need various kinds of assistance from time to time. Thinking about family members or friends who do not live with you, please circle the number of the category that describes how likely it is that they would give you the following kinds of assistance:

- 1. very likely
- 2. likely
- 3. not sure
- 4. unlikely
- 5. very unlikely

- a) Look after your home/apartment (pets, plants etc.) while you are away? 1 2 3 4 5
- b) Lend you over \$100.00? 1 2 3 4 5
- c) Help you to do things such as house or car repairs, painting, moving? 1 2 3 4 5
- d) Lend you things such as tools, equipment, household items, car etc.? 1 2 3 4 5
- e) Provide you with a place to stay if you needed one? 1 2 3 4 5
- f) Drive you somewhere if you needed a ride? 1 2 3 4 5

38. Sometimes people feel uncomfortable asking for these kinds of help even though they believe that they would receive it. Please circle the number of the category that best describes how difficult it would be for you to ask for these kinds of help.

- 1. impossible
- 2. very difficult
- 3. somewhat difficult
- 4. a little difficult
- 5. not at all difficult

39. Now we would like to know something about your relationships with other people. For each of the following statements please circle the number of the category that best describes you.

- 1. very much like me
- 2. much like me
- 3. somewhat like me
- 4. not very much like me
- 5. not at all like me

- a) When I'm with my friends I feel completely able to relax and be myself. 1 2 3 4 5
- b) I share the same approach to life that most of my family and friends do. 1 2 3 4 5
- c) People who know me trust me and respect me. 1 2 3 4 5
- d) No matter what happens, I know that my family will always be there for me should I need them. 1 2 3 4 5
- e) When I want to go out to do things I know that many of my friends would enjoy doing these things with me. 1 2 3 4 5
- f) I have at least one person that I could tell anything to. 1 2 3 4 5
- g) Sometimes I'm not sure if I can completely rely on my family and friends. 1 2 3 4 5
- h) People close to me let me know they think I'm a worthwhile person. 1 2 3 4 5
- i) I feel very close to some of my friends. 1 2 3 4 5
- j) People in my family have confidence in me. 1 2 3 4 5
- k) There are some problems that I can't share with anyone. 1 2 3 4 5
- l) People close to me provide help in finding solutions to my problems. 1 2 3 4 5
- m) My friends would take the time to talk over my problems, should I ever want to. 1 2 3 4 5
- n) I know my family will always stand by me. 1 2 3 4 5
- o) Even when I am with my friends I feel alone. 1 2 3 4 5

This is the last section of the questionnaire. We would appreciate it if you could answer the following questions using your own words. If necessary, continue your answers on the back of the page. Please feel free to add any additional comments you would like to make. In this section the phrases "your child" and "this child" refer to your child that has had cancer.

40. a) Now that your child is in remission and off treatment do you have concerns about his/her health?

- 1. No - GO TO QUESTION 41
- 2. Yes - Please list these concerns and explain a bit about them. _____

b) When you are concerned about your child's health, what do you do to try to cope with your concern? Please describe:

41. a) All parents have concerns about their children from time to time. Do you have any particular concerns about your child, other than his/her health?

- 1. No - GO TO QUESTION 42
- 2. Yes - Please list these concerns and explain a bit about them. _____

b) When you are concerned about these things, other than your child's health, what do you do to try to cope with your concern? Please describe:

42. a) Please try to tell us, in your own words, how your family life is affected now by the fact that your child had cancer.

b) Please try to tell us how your own personal life is affected now by the fact that your child had cancer.

43. All families have problems from time-to-time. Thinking back over the past six months, please list the three biggest problems that your family has had.

44. Do you feel that families like your own, with a child who is in remission and off treatment, could benefit from any social services (e.g. counselling, self-help groups, lecture series, etc) that are not available to you now?

1. No

2. Yes - Please describe the type(s) of service(s) that would be helpful:

- 28 -

Additional Comments:

Thank you very much for taking the time to complete this questionnaire.

One of our project staff will be calling you to arrange a time to pick up your questionnaire.

APPENDIX C
INTRODUCTORY LETTER AND CONSENT FORM
FOR CONTROL PARENTS



The University of Western Ontario

Health Care Research Unit
First Floor, C.F.C. Building
London, Ontario
N6A 5B8

The Health Care Research Unit, in cooperation with Pediatric Oncology Services at War Memorial Children's Hospital, is conducting a study of families with children surviving cancer. It is crucial for our research that we compare these families to families with children who have not been chronically ill. Your household has been randomly selected from a list of households in your neighbourhood.

Your participation would involve the completion of a questionnaire. We would like both parents to answer the questionnaire separately where possible because fathers and mothers tend to react differently to various aspects of their lives. Several areas are covered in the questionnaire, including how you and your family are doing these days and the way you feel about your life and other people around you.

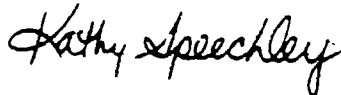
All information obtained will be kept in strictest confidence. To assure your privacy, questionnaires will be identified by means of a unique number and no personal information that could lead to the identity of any individual respondent will appear on the questionnaire. Not even our own office staff will know whose responses they are processing.

The questionnaire would be mailed to you so you could complete it at your convenience. Because it will take about 45 minutes of your time, we are offering a token payment of \$10.00 to each family in appreciation for your completion of the questionnaire. Of course you are free to refuse to participate in this study or you may refuse to answer specific questions in the questionnaire.

-2-

Although this study may be of no direct benefit to you or your child(ren), the results may help us to determine the problems faced by families whose children have severe chronic illnesses so we may be able to prevent such problems in the future. One of the project staff will call you soon to see if you would like to participate in this study. If you have any questions or would like more information about the study you may call Kathy Speechley at the Health Care Research Unit (519) 679-6760. If you live outside the City of London, please call collect.

Sincerely,



Kathy L. Speechley, M.A.
Project Director

KLS:kl

CONSENT

The nature of the study of parents with children surviving cancer has been explained to me and I hereby agree to participate in this project. I understand that my participation involves the completion of a questionnaire.

Signature: _____

FOR OFFICE USE ONLY:	
NAME:	_____
ADDRESS:	_____
TELEPHONE NUMBER:	_____
DATE RETURNED:	_____

APPENDIX D
ANALYSIS OF LOST CASES

A. CHARACTERISTICS OF CHILD CANCER SURVIVORS

1. Age

	Participants	Lost Cases
\bar{X}	14.4	13.6
S.D.	5.8	6.4
N	80	20

($t=.510$, d.f. = 98, $p > .05$)

2. Sex

	Participants		Lost Cases	
	N	%	N	%
Males	42	52.5	13	65.0
Females	38	47.5	7	35.0
TOTAL	80	100.0	20	100.0

($\chi^2=1.01$, d.f. = 1, $p > .05$)

A. CHARACTERISTICS OF CHILD CANCER SURVIVORS (Cont'd.)

3. Diagnosis

	Participants		Lost Cases	
	N	%	N	%
A.L.L.	25	31.2	4	20.0
Wilm's Tumour	12	15.0	4	20.0
Hodgkin's Disease	9	11.2	5	25.0
Histiocytosis	11	13.8	1	5.0
Neuroblastoma	6	7.5	3	15.0
Other	17	21.3	3	15.0
TOTAL	80	100.0	20	100.0

($\chi^2=5.44$, d.f.= 5, $p > .05$)

4. Years off Treatment

	Participants	Lost Cases
\bar{X}	6.3	6.0
S.D.	3.6	3.0
N	80	20

($t=.383$, d.f.= 98, $p > .05$)

B. CHARACTERISTICS OF PARENTS

1. Age

	Mothers		Fathers	
	Participants	Lost Cases	Participants	Lost Cases
\bar{X}	40	39	43	42
S.D.	7.4	7.9	8.3	8.2
N	80	15	63	22
	(t=.454, df=98, p > .05)		(t=.491, df=83, p > .05)	

2. Marital Status

	Mothers				Fathers			
	Participants		Lost		Participants		Lost	
	N	%	N	%	N	%	N	%
Currently Married	67	83.7	15	83.3	57	90.5	23	95.8
Not Currently Married	13	16.3	3	16.7	6	9.5	1	4.2
TOTAL	80	100.0	18	100.0	63	100.0	24	100.0
	(X ² =.002, df=1, p>.05)				(X ² =.674, df=1, p>.05)			

B. CHARACTERISTICS OF PARENTS (Cont'd.)

3. Number of Children at Home

	Mothers		Fathers	
	Participants	Lost Cases	Participants	Lost Cases
\bar{X}	2.3	2.6	2.3	2.7
S.D.	1.3	1.2	1.4	1.0
N	80	18	63	24

($t=.944$, $df=96$, $p > .05$)

($t=1.48$, $df=85$, $p > .05$)

APPENDIX E

LEVELS OF PSYCHOLOGICAL DISTRESS AND FAMILY ADAPTATION:
MARRIED PARENTS ONLY

Table E1: Mean Levels of Depression Scores (CES-D) by Parent and Sample for Married Parents Only

		CASE	CONTROL	T-Test Case/Control
Mothers	\bar{X}	8.55	9.55	t=-.64
	S.D.	8.74	9.61	df=136
	N	67	71	p=.53
Fathers	\bar{X}	7.30	7.32	t=-.02
	S.D.	8.10	6.28	df=97.2
	N	54	71	p=.98
T-Test Mothers/Fathers		t=-.81, df=119, p=.42	t=-1.63, df=120.6, p=.11	

Table E2: Percentage of Depression Scores (CES-D) >16 by Parent and Sample for Married Parents Only

		CASE	CONTROL	Chi-Square Case/Control
Mothers	%	20.9	21.1	$\chi^2=.001$
	N	67	71	df=1
Fathers	%	9.3	8.5	$\chi^2=.025$
	N	54	71	df=1
Chi-Square Mothers/Fathers		$\chi^2=3.06, df=1, p=.08$	$\chi^2=4.53, df=1, p=.03$	

**Table E3: Mean Levels of Anxiety Scores (A-Trait)
by Parent and Sample for Married Parents Only**

		CASE	CONTROL	T-Test Case/Control
A-TRAIT				
Mothers	\bar{X}	36.37	36.04	t=.19
	S.D.	10.01	9.35	df=131
	N	63	70	p=.85
Fathers	\bar{X}	32.33	32.77	t=-.30
	S.D.	8.36	7.85	df=121
	N	52	71	p=.76

T-Test t=-2.32,df=113,p=.02 t=-2.25,df=139,p=.03
Mothers/Fathers

Table E4: Standardized Mean Levels of Family Dysfunction (FAM-General Scale Score) by Parent and Sample for Married Parents Only

		MOTHERS		FATHERS	
		<u>CASE</u>	<u>CONTROL</u>	<u>CASE</u>	<u>CONTROL</u>
TOTAL SCORE	\bar{X}	48.97	50.61	50.15	50.14
	S.D.	8.02	9.44	7.35	6.30
	N	65	70	53	69
TASK ACCOMPLISHMENT	\bar{X}	47.42	50.00	47.56	50.89*
	S.D.	9.89	11.45	8.38	9.03
	N	67	73	55	71
ROLE PERFORMANCE	\bar{X}	51.55	51.87	49.82	48.27
	S.D.	10.94	11.44	9.97	7.21
	N	67	73	55	70
COMMUNICATION	\bar{X}	50.46	51.64	50.87	50.91
	S.D.	8.78	10.36	8.77	7.70
	N	67	73	54	70
AFFECTIVE EXPRESSION	\bar{X}	50.48	51.40	51.47	51.97
	S.D.	10.76	10.81	9.93	8.42
	N	66	73	55	71
AFFECTIVE INVOLVEMENT	\bar{X}	49.21	49.43	50.89	49.32
	S.D.	10.54	9.80	8.72	8.16
	N	67	74	56	71
CONTROL	\bar{X}	48.33	50.64	51.66	51.00
	S.D.	10.79	10.99	10.31	7.32
	N	67	74	55	70
VALUES & NORMS	\bar{X}	48.65	49.81	50.62	49.36
	S.D.	10.30	11.54	7.92	8.49
	N	66	74	55	69

*t=-2.11, d.f.=124, p=.037

**Table E5: Percentage of Overall FAM Ratings >60
by Parent and Sample for Married Parents Only.**

		CASE	CONTROL	Chi-Square Case/Control
Mothers	%	9.2	10.0	$\chi^2=.023$ d.f.=1 p=.880
	N	65	70	
Fathers	%	7.5	2.9	$\chi^2=1.39$ d.f.=1 p=.239
	N	53	69	

Chi-Square $\chi^2=.107, d.f.=1, p=.744$ $\chi^2=2.89, d.f.=1, p=.089$
Mothers/Fathers

APPENDIX F

POWER CALCULATIONS FROM PROPOSAL

APPENDIX A (from the proposal)

As outlined in Section 6.3 the estimated final sample size is 139 parents of 74 children for each of the two samples. Statistical power calculations will be based on the estimate of 74 independent cases. There are two reasons for this. The first is statistical -- the assumption of a normal and independent distribution of variables cannot be violated. The samples must consist of the 74 independent cases, where the data from only one parent of each child are included. The second is theoretical -- because we know there are gender differences in the prevalence of two of the outcome measures depression and anxiety, one would want to analyze the mothers and the fathers separately.

As indicated in the section on strategies for analyses, the major techniques to be used are t-tests, chi-square tests and multiple regression analyses. These techniques will be discussed in the context of statistical power to detect the effect that having a child surviving cancer has on parents' levels of depression and anxiety and level of family functioning given a specified sample size ($n=74$) and level of significance ($p=.05$). The procedures suggested by Cohen (1977) were followed.

T-Tests. By performing a t-test to determine mean differences between the parents of children surviving cancer and the parents of healthy children on the various outcome measures, the estimated sample sizes will allow the detection of an effect that falls just under what Cohen calls a "medium effect size" with a power of 0.80. This means that differences as small as 0.47 of a standard deviation can be detected. Within the context of normative data available for the

measures to be used in the proposed study, it seems that differences of this magnitude would be of substantive importance.

For instance, an effect of this magnitude is equivalent to the difference between the mean depression scores on the CES-D reported in a survey of physically disabled adults (Turner and Wood, 1984) and a survey of a representative community sample (Radloff, 1977). This difference, when translated into raw scores, is equal to approximately five points on the CES-D scale. There is reason to expect that the parents of children may deviate from the general population in rates of depression as much as those with physical disabilities. Many in the disabled sample suffered from disabilities as minor as lower back pain and all of the sample were able to function in a household as opposed to an institutional setting. This difference observed by Turner and Wood (1984) is considered to be of substantive importance. The rates of depression in the disabled sample, as estimated using the recommended cut-off score thought to indicate clinically significant depression, were about double those found in the general population (Comstock and Nelsing, 1976).

This detectable difference of 0.47 of a standard deviation also seems to be substantively relevant in the context of anxiety as an outcome. Although the normative samples available for the State-Trait Anxiety Inventory are not ideally suited for our comparison purposes, they do provide some evidence that the proposed study will have sufficient power to detect important differences.

When college students' trait anxiety scores were compared to those of general medical and surgical patients without psychiatric complications (Spielberger et al., 1970), the difference in anxiety scores between the two groups produces an effect size of 0.3. When

these college students' scores are compared to those of neuropsychiatric patients an effect size of 0.4 results. Thus our capacity to detect a difference of 0.47 falls between these two comparisons, being closer to the student-medical patient comparison.

Chi-Square Tests. By using chi-square contingency tests and predetermined cut-off scores to assess differences between the two samples ($N=139$) in risk for clinically significant depression and for disturbances in family functioning, again a "medium effect size" can be detected with a power of 0.94. In terms of relative risk, this means that the present study will have sufficient statistical power to detect a relative risk of clinically significant depression and of disturbance in family functioning as small as 1.5. The power of detecting such a difference still remains at an acceptable level of 0.81 when the sample is reduced to 90.

Multiple Regression. Using a multiple regression analysis with a maximum of seven prediction variables in the equation will permit the detection of a "medium-large effect size" (falling between the effects defined as medium and large). In terms of total variance explained in the dependent variable, the effect size that can be detected here is $R^2 = 0.175$. The only outcome variable for which normative data using multiple regression are available is the CES-D. In their study of physically disabled adults Turner and Wood (1984) found that the major elements of the stress process, to be examined in the present study, were able to explain well over 30 percent of the variance in depression scores.

A Final Note. It is true that given the limited sample size there may be differences between the groups to be studied that,

although substantively important, are undetectable in the proposed study. It is believed nonetheless that this study will be capable of making a valuable contribution to the current knowledge.

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