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## Coping Strategies, Psychological Distress Experience, and Perceived Adjustment of Long-Term Survivors of Pediatric Leukemia

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LOYOLA UNIVERSITY OF CHICAGO

COPING STRATEGIES, PSYCHOLOGICAL DISTRESS  
EXPERIENCE, AND PERCEIVED ADJUSTMENT OF  
LONG-TERM SURVIVORS OF PEDIATRIC LEUKEMIA

A DISSERTATION SUBMITTED TO THE FACULTY OF THE GRADUATE  
SCHOOL OF LOYOLA UNIVERSITY OF CHICAGO IN PARTIAL  
FULLFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF  
DOCTOR OF PHILOSOPHY

DEPARTMENT OF PSYCHOLOGY

BY

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CHICAGO, ILLINOIS

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## DEDICATION

To my wife, Lisa, whose love, dedication, and support gave me the strength to bring this project to fruition.

## VITA

The author, Mario Brian Natta, is the son of Mario Joseph Natta and Eileen Ann Natta. He was born January 22, 1960 in Evanston, IL. His elementary education was obtained at Benjamin Franklin Elementary School, Park Ridge, IL, and secondary education at Maine Township High School East, where he graduated in 1978.

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## INTRODUCTION TO THE RESEARCH PROBLEM

This dissertation is an examination of the coping strategies and psychological distress styles of long-term survivors of Acute Lymphocytic Leukemia (ALL). The purpose is to examine the strategies that enable them to remain well functioning despite the experience of living with cancer in remission. The subjects for this study were drawn from a prospective, longitudinal study of individual and family coping with pediatric cancer. Subjects were assessed at diagnosis, early out-patient treatment, 1, 2, and 6 years post-diagnosis, and are currently 10-12 years post diagnosis. A more detailed review of this project is presented in following sections. The focus of this study is to examine the qualities and patterns of coping utilized by survivors of pediatric leukemia as related to psychological distress style and perceived adjustment.

### Surviving Leukemia

The most common form of childhood cancer is Acute Lymphocytic Leukemia (ALL). A disease of the blood forming tissues, it primarily affects children under 10 years of age (Madan-Swain & Brown, 1991) and is slightly more prevalent in males (Koocher & O'Malley, 1981). Prior to the 1960's, mortality rates for this disorder were nearly 100%. However,

since that time dramatic improvements have been made in its diagnosis and treatment. Advances in multi-modal cancer treatments during the past two decades have yielded lengthy remissions, transforming many such diseases from usually fatal to frequently curable. Such advances include improvements in diagnosis and categorization of diseases, development of multiple chemotherapeutic drugs and radiation treatment, improvements in bone marrow transplantation procedures, and advances in supportive care (Skelton & Pizzo, 1986). The present five year survival rate across all sites of cancer is greater than 50%, while for ALL the figure is approximately 70% (National Cancer Institute, 1988). As recurrence beyond this period is rare for ALL survivors, many refer to such individuals as "cured" (Hammond, 1986; van Eyes, 1987). However, others have offered that this "biological cure" does not take into account the importance of psychosocial aspects of living with leukemia in remission (Bull & Drotar, 1991; Madan-Swain & Brown, 1991; van Eyes, 1991).

The issue of psychosocial aspects is particularly salient for children who survive cancer, as they deal simultaneously with the stressors inherent in a chronic, life-threatening disease and with normal developmental issues. The idea of a truly cured child, one who is developmentally on par with others his or her age intellectually, physically, and emotionally, has become a

stated goal of pediatric oncology. However, it has become clear that while some individuals in this group are able to adapt exceedingly well, others are not. The presence of a severe, chronic, potentially fatal disease has a major impact on development. Yet, it remains unclear what separates those individuals who experience few residual emotional sequelae from those who experience many.

The stressful situation faced by these children involves multiple and repeated exposure to intrusive, invasive, and painful treatment, often in an apparently non-contingent form. Most often, the incidence of cancer, particularly ALL, is not related to any behavior of the patient. Both the diagnostic and treatment procedures can seem random and/or unnecessary as they are based upon cellular behavior rather than child behavior. When painful procedures such as chemotherapy, radiation, bone marrow transplants, lumbar punctures, or surgery are required, both immediate (e.g. pain, infection, multiple hospitalizations) and delayed (e.g. nausea, alopecia, learning problems) consequences can result (Armstrong, 1992). Of these consequences, concerns about the effects of various medical interventions on later cognitive functioning have generated the most research. Results have documented mild to moderate intellectual impairments, particularly in ALL survivors treated with central nervous system irradiation and/or intrathecal methotrexate. Such impairments have been associated with age at diagnosis, where

these treatments appear to have more deleterious effects on younger children (Michael & Copeland, 1987; Mulhern, Friedman, & Stone, 1989; Van Dongen-Melman & Sanders-Woudstra, 1986).

### Living with Leukemia

Attention to the long term psychosocial aspects of cancer diagnosis, treatment, and remission has lagged behind the progress in medical treatment. Early anecdotal research seemed to suggest that the diagnosis of childhood cancer inevitably led to serious psychological problems for patients, their parents, and their family members (Friedman, 1967). However, early survey studies (Fergusson, 1976; Holmes & Holmes, 1975; Li & Stone, 1976) indicated that long term survivors adjusted fairly well to school, marriage, and employment. Later studies using more standardized psychological measures noted similar findings (Nagler, 1978; Obetz, Swenson, McCarthy, Gilchrist, & Burgert, 1980). Others began noting developmental difficulties in this population. In a review of the impact of cancer diagnosis on psychosocial development in children, Katz (1980) identified several risk factors distinguishing cancer patients from their healthy peers. These included self-esteem, peer acceptance, gender, developmental level, and availability of appropriate school programs. Cancer patients, particularly during treatment, are constantly confronted with the realization that they are different.

They must make significant adjustments to account for the unique stressors inherent in a life-threatening disease. They must also cope with chronic uncertainty about their bodies, which, to some extent, have failed them.

The relative lack of comprehensive research on the psychological adjustment in childhood cancer survivors led to the work of Koocher & O'Malley (1981). The results of their research were summarized in a book entitled The Damocles Syndrome named for the story of Damocles, who was made to sit at a banquet in the court of Dionysus under a sword which was suspended by a single hair, representing the precariousness of his fortunes. The authors used this as illustrative of the dilemmas faced by all successfully treated cancer patients during their course of treatment, if not for the remainder of their lives. The book draws its conclusion from data involving 117 childhood cancer survivors with a comparison/control group of 22 children with various other chronic diseases. The cancer patients represented several different types of illness, including neuroblastoma, leukemia, osteosarcoma, non-Hodgkins lymphoma, or Hodgkins disease. The primary finding of the study indicated that 47% of the cancer group demonstrated some adjustment difficulties, a significantly greater percentage than that of a comparison group of children with other chronic maladies. However, no differences were found between both groups in verbal intelligence or social maturity

(Koocher & O'Malley, 1981). Nor did cancer patients show any greater death anxiety, manifest anxiety, or depression than their chronic illness counterparts. Likewise, self-esteem scores as measured by self report were not significantly different. Variables found to be predictive of positive adjustment were higher intelligence and socioeconomic status. In addition, the younger the child is at diagnosis, the more likely the absence of adjustment problems. Similarly, time since diagnosis was also predictive of positive adjustment, which improved as time increased.

#### Coping with the Disease

One of the longest running prospective studies regarding family coping with pediatric leukemia was begun in 1977 by Kupst and her colleagues with results published in several papers (Kupst, Schulman, Hoenig, Maurer, Morgan, & Fochtman, 1982; Kupst, Schulman, Hoenig, Maurer, Morgan, & Fochtman, 1983; Kupst, Schulman, Davis, & Richardson, 1983; Kupst, Schulman, Hoenig, Maurer, Morgan, & Fochtman, 1984; Kupst & Schulman, 1988). Family coping with ALL was followed from diagnosis, to six months, one, two, and six years post-diagnosis. Summarizing these results, while psychological distress was evident early in the experience, both parents and survivors were found to cope well despite the stresses of the disease and its treatment. Measures of coping included self ratings and ratings by psychosocial staff, hematologists/oncologists and nurses, and standardized

measures (Kupst et al., 1983; Kupst & Schulman, 1988). Coping scores remained relatively stable from diagnosis to two years, but were significantly higher at six years for both patients and their parents.

Among family members, the pattern of coping strategies used varied widely. During the early phase of treatment, factors related to good coping by survivors included outside and family support, better quality of the parent's marital relationship, fewer concurrent stressors, and more open family communication. Adequacy of children's coping was related to parent's coping. A brief psychological intervention was also found to be related to better coping in mothers at six months, however this was not found to be a correlate of coping in children or fathers (Kupst et al., 1983).

An interesting finding was that while survivor's coping was in the constructive adjustment range for all time frames (i.e. diagnosis, two, and six years post diagnosis) coping success was variable over time. In other words, early successful coping with the stresses of the disease and its treatment was not predictive of later coping success as evaluated by project staff.

Others have also begun to explore the psychological attributes of long-term survivors of pediatric cancer. Utilizing the Minnesota Multiphasic Personality Inventory and the Personality Inventory for Children, one study reported



several common characteristics among survivors including passivity, social withdrawal, and agitation (Chang, Nesbit, Youngren, & Robison, 1987). Despite the fact that the mean MMPI profile was within the normal range, one-third of the sample evidenced moderate to severe emotional maladjustment. A retrospective study of 52 pediatric cancer survivors (Fritz, Williams, & Amylon, 1988) indicated that while global adjustment was good for most survivors, there was significant variability in individuals' experience and response to their cancer. In addition, more than half of this sample reported doing worse in academic achievement since diagnosis. In another retrospective study, survivors of ALL (five years post-diagnosis) demonstrated a three to four fold higher incidence of deficiencies in social competence and behavioral problems as compared to healthy peers (Mulhern, Friedman, & Stone, 1988). Most frequent problems involved poor school performance and increased somatic complaints of unknown etiology.

#### Long-Term Coping

The focus of study in this area has shifted from an emphasis on dealing with death from cancer toward the need to address coping with the chronicity of the illness, with the consequences of treatment, and with coping as a long-term survivor. Limited research has focused on coping as a process in these individuals and on the relationship of coping to overall long-term functioning. Because of the

great strides in medical treatment, longer remissions and increasing cure rates inevitably impact the ways in which this disease is perceived. However, the "disease-free" former ALL patient is still at higher risk for other forms of cancer in later life than the general population (Cella, 1985). In this sense, cancer might be better defined as a chronic life-threatening illness than as a fatal disease. Therefore, today's "cured" patient faces some of the same stresses and tasks as those suffering from any serious chronic illness. Patients must adjust their emotional and social functioning. Consequently, coping strategies must accommodate the experience of living with a potentially life-threatening illness.

The National Cancer Institute (1984) has identified two general tasks which the cancer patient must confront: 1) coping with the illness and its complications, such as pain or paralysis and 2) coping with life as it is altered by the illness. The focus of research must shift from an emphasis on dysfunction to examining how these individuals cope with life stress in an effort to determine how coping skills may be enhanced and improved. This is particularly salient to the long term survival of these patients. After all, the primary reason for cancer treatment is to help them survive. To improve the quality of life beyond treatment is and should be a high priority. The National Cancer Institute requires an assessment of "quality of life" in pediatric cancer

treatment protocols. Unfortunately, despite the medical communities assurance of "cure", these survivors can face significant difficulties in finding employment and health insurance due to discrimination based on their medical history (Zevon, Neubauer, & Green, 1990).

Following an extensive review of the available literature, Koocher & O'Malley (1980) formulated a model of adaptation to cancer. They offered that the "stress" caused by the presence of cancer is most prevalent at diagnosis and initiation of treatment, slowly diminishing over time, and reaching baseline at approximately five years post-diagnosis. Recurrence, symptoms related to pain from either the disease or its treatment, or a death in the family could affect the settling process and cause increases in stress. One striking aspect of this hypothesis is that the return to baseline at five years coincides with the time frame most physicians associate with biological cure. Those patients who have been cancer-free for this same time period are considered "cured".

Though they can be extremely stressful and demanding events, many patients are able to adjust quite adequately to the illness and treatment. Indeed, as medical advances have improved at a dramatic pace, the focus of coping and adaptation has shifted from preparing for death to living with a potentially terminal illness and its treatment. Intervention strategies available for use with childhood cancer patients and their families are varied, ranging from

behaviorally-oriented techniques for pain management to supportive counselling and insight-oriented psychotherapy (Schulman & Kupst, 1980). These short term psychotherapeutic approaches may situationally reduce stress and improve the family perspective, including that of the patient (Adams-Greely, 1986). In their prospective study of ALL survivors, Kupst, et al (1986) found that maternal coping was predictive of patient coping, if mothers coped well so did the patients. However, these studies do not address the coping strategies and distress experience of the pediatric cancer patient over the long term. Studies of the effectiveness of such interventions have failed to follow patients beyond the termination of treatment. Consequently, little is known about how these cancer survivors learn to cope with the chronicity of their illness, and with the usual demands of growing up. It would appear that like any group, there are those who appear to cope better over time than others. By identifying the characteristics of distress experience and coping strategies of survivors of pediatric cancer, we can better identify patterns of successful adaptation to this illness.

### Models of Coping

One of the problems inherent in studying coping is that there is no standard definition of the concept. The confusion surrounding the definition of coping, and the confounding of the coping process and its outcome have been

highlighted by Lazarus and Folkman (1984). They have concluded that four major issues have evolved out of the myriad of existing theories from which operational measures of coping have been derived. The issues are: 1) coping as a structural trait or style; 2) coping as synonymous with automatized behavior; 3) a lack of differentiation between the process and outcome of coping; 4) the equating of coping with mastery.

The last issue was highlighted by Kaplan and his colleagues (1976) who equated adaptive coping with mastery over the socio-psychological difficulties associated with stressful events. In looking at family functioning, these authors supported their definition of adaptive coping by parents of children with leukemia in that "...parents understand that leukemia is a serious, ultimately fatal illness involving remissions and exacerbations but moving toward a terminal state. (p. 73)." Discrepant or inconsistent coping resulted from several problems in understanding and communicating about the disease, i.e., the parents' inability to agree on definitions of the illness, disagreement on what to tell others both in and outside the immediate family about it, and a discordant emotional state. The consequences of such a lack of synchrony across these attitudes and emotions were posited to adversely affect family functioning, thereby equating effective coping with problem solving and mastery. In this view, coping as related

to emotional management, maintenance of self esteem, or positive outlook was de-emphasized.

However, when the source of stress cannot be "mastered", as in the case of a life threatening or terminal illness, to view coping as mastery over the environment may not be realistic. In this case, effective coping strategies may be more involved with minimizing, ignoring, tolerating, or accepting the stressor. In a sense, this may suggest a shift toward mastering self experience rather than the situation. In order to understand the relationship between a coping behavior and its success in dealing with the stressor, Folkman (1984) suggested that we must explore the coping processes used to manage stressful demands, regardless of outcome in order to understand the mechanisms by which they are chosen and utilized.

### Stress and Coping Model

The model of stress and coping developed by Lazarus and Folkman (1984) has evolved from a long tradition of Western thought, psychology, and sociology (Lazarus & Folkman, 1984). Its underlying framework posits that it is the subjective meaning of experience which shapes emotional and behavioral responses. This cognitive-phenomenological model of stress and coping emphasized the concept of appraisal (Coyne, Aldwin, & Lazarus 1981). "Appraisal" refers to the individual's subjective experience and interpretation of that experience and is consequently used in coping to shape or

alter the course of events (Folkman & Lazarus, 1984). Both psychological and social processes are involved in the complex structure of one's repertoire of coping strategies and responses. As a person appraises the ongoing encounters with the environment within the context of an over-riding theme, such as the experience of a life-threatening illness, his/her coping strategies and the social context of adaptation must influence his/her emotional and social functioning. These authors have extended this model to include the ongoing stresses of daily living which are referred to as "hassles" (Folkman, Lazarus, Dunkel-Schetter, & DeLongis, 1986).

#### Primary and Secondary Appraisal

Lazarus and Folkman have broken the concept of appraisal into primary and secondary processes. Primary appraisal is concerned with the cognitive evaluation of what one has at stake, both immediately and in the future. This type of appraisal is further broken down into three discrete categories which have important implications for coping response: 1) irrelevant; 2) benign-positive; and, 3) stressful. Stressful appraisal contains those situations most likely to produce coping efforts, and can be further categorized in three ways: 1) damage already sustained, (e.g. loss, catastrophic illness) ; 2) threat , as in the anticipation of above damage; and, 3) challenge, which highlights the potential for improvement or growth, despite

the above damage. The latter two may provide an opportunity for anticipatory coping, in terms of preparing for a difficult experience. Threat is seen to evoke feelings such as anger, anxiety, and/or fear. Challenge is equated with feelings such as excitement, exhilaration, and vigor. It is these "positive" feelings which are felt to enhance and facilitate the overall level of functioning, enabling the individual to effectively utilize all his/her available resources (Lazarus & Folkman, 1984; Lazarus & Launier, 1978).

The availability and relative effectiveness of coping efforts and strategies fall under the rubric of secondary appraisal. This complex evaluative process involves the judgement of what the individual can or might do in response to the demands or limitations of the situation. Coping strategies are shaped by both the individual's analysis of his/her current resources, by his/her primary appraisal, and by his/her past experience with similar experiences (Lazarus & Folkman, 1984). These authors also suggest that appraisal of stressful encounters is affected by certain "person" and "environment" factors. Person factors, identified as commitments and beliefs, are concerned with what is valued and important to the individual, which can strongly affect the individual's perception of what is appraised as threatening or challenging. Beliefs regarding personal control, power, and resource availability affect appraisal. Environmental or situational factors such as the newness of



the experience, predictability, or uncertainty of outcome also influence appraisal. In terms of person factors, individual patterns of psychological distress experience may have a significant effect on coping styles (Blount, 1991; Harris, Canning, & Wong, 1991; Vitaliano, Russo, Carr, Maiuro, & Becker, 1985).

#### Repression/Sensitization

Several authors have examined coping in relation to distress experience along a continuum of repression/sensitization (Lazarus, 1981). One of the first people to study coping as an enduring trait was Byrne (1964), who utilized such a continuum. As a global dimension, his repressor/sensitizer model was purported to "...measure of the extent to which a person tries to escape anxiety through the use of avoidance or repressive strategies or tends to focus upon anxiety through the ruminative or sensitizing strategies" (Wilson, 1985, p. 268). As a measure of distress this construct is related to coping through its impact on an individual's assessment of the demands of a stressor and the resources available. However it is identified as a separate and distinct construct. A series of studies developed and reviewed by Goldstein (1973) utilized this paradigm to describe how individuals approach information when dealing with stressful experiences. He offered that in the case of anticipatory stress situations, the sensitizer actively seeks detailed information in preparation for the event while the

repressor tends to avoid information. Much of the data using this paradigm suggest that a sensitizing style is related to more positive outcomes. However, most of these studies have focused on response to coping with painful medical procedures (Blount, Davis, Powers, & Roberts, 1991). Others have argued that when dealing with the ongoing demands of a chronic and potentially fatal illness, a repressive style of distress management "...facilitates age appropriate integration and prevents them from becoming overwhelmed by the negative aspects of their condition." (Harris, et al, 1991, p. 9). Research with this construct in chronic illness populations is limited. It is possible that one type of distress style is more adaptive in various stages of exposure to a stressor. In the case of ALL, during early stages (e.g. diagnosis or early treatment), a repressive style might be ineffective, as patients are confronted with noxious treatment experiences which feel random and out of their control. As time progresses, treatments diminish, in which case a repressive style might be more adaptive, as it would enable the patient to "deny" the existence of his/her cancer status, thereby minimizing its effect as a stressor. In contrast, a sensitizing style early in treatment might enable the patient to accept the inevitable treatments, and adjust to them more easily (Blount, et al, 1991).

Whereas the repression/sensitization continuum is concerned with the emotional reaction to stress, coping is

concerned with the manner in which an individual deals with the stress. To date, there have been no studies attempting to examine these variables as they relate to each other and to overall adjustment to pediatric cancer, particularly long after the termination of medical treatment.

### The Process of Coping

In the cognitive-phenomenological model, coping is defined as "...constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (Lazarus & Folkman, 1984; p. 141). This view dismisses the notion of automatized behavioral responses and instead underscores the process of coping. The process approach reflects a mobilization and modification of effort in response to both internal and external variables. The characteristics of this process have been outlined as follows: 1) observations/assessments remain focused on what the person thinks and does, 2) these thoughts and actions are contextually based and 3) as the stressful encounter continues, these thoughts and actions may change (Lazarus & Folkman, 1984). When viewed as a process, coping is then characterized by dynamics and changes that result from continuous appraisals and reappraisals of the ever-changing person-environment relationship (Folkman, et al, 1986). Primary appraisal determines whether the situation is a threat. If so, secondary appraisal assesses possible coping

responses, and selects and engages them. For example, in the case of ALL, when an individual is first diagnosed with the disease, he/she is given a great deal of information. His/her initial coping response might be to attempt to avoid the stimulus, in this case the patient's treatments. However, as his/her parents continue to bring them to the hospital and treatment procedures progress, this response may be experienced as ineffective. The patient may then abandon this coping strategy in favor of another, such as seeking information or emotional support from others. As time goes on individuals adapt their coping response to changes in the stressor, as well as to changes in their understanding and experience with it. Consequently, the fluid nature of this process presupposes that all coping efforts and strategies are a part of the process. None are considered as necessarily "good" or "bad" strategies. This is an important aspect of this model, as an individual may use different strategies at different times to deal with the same problem, in this case a life-threatening illness. One may, however, attempt to judge the effectiveness of a given strategy at a given time, in an effort to determine more beneficial coping strategies. In turn, these may become established coping patterns that the individual uses in dealing with more generalized stress, and/or later problems unrelated to the cancer. Such patterns may be related to an individual's style of distress experience, where certain coping strategies

are more consistent and successful for certain distress styles.

#### Problem vs. Emotion-Focused Coping

In the "stress and coping" model coping activity involves internally directed behaviors, such as the management of emotional reactions, and externally directed behaviors, such as seeking support from others (Friedman, 1967; Kupst & Schulman, 1980; Lazarus, 1980). This approach identifies the function of coping as two-fold: 1) problem-focused coping, in which efforts are directed at the problem which is causing the distress; 2) emotion-focused coping, which involves the regulation of emotional responses to such stressors (Compas, Malcarne, & Fondecaro, 1988; Folkman & Lazarus, 1980; 1985).

Research to date has not identified any particular patterns of coping in survivors of pediatric leukemia, particularly in regards to stressors not directly related to their cancer. However, in a study of coping in children with a variety of chronic illnesses (cancer, diabetes, heart disease, and hemophilia) findings indicated gender differences in coping strategies employed. Females used more emotion-focused coping strategies than males (Spirito, Stark, & Knapp, 1992). Gender differences have also been identified by Folkman and Lazarus (1980), who found that adult women may use more emotion-focused coping than men. They suggested that women report more health-related

stressors, which are positively correlated with emotion-focused coping. When type of stress was controlled, gender differences disappeared.

In the case of chronic illness, such as ALL, the uncertain outcome of the illness is a striking feature. It does not represent a time-limited or normal situation. Instead it involves repeated exposures to aversive situations, including treatments, and the emotional strain of its potential to be life-threatening. However, as children grow older they must deal simultaneously with the demands of everyday stressors (e.g. school, dating, work, family problems) that healthy children encounter (Koocher & O'Malley, 1981). Developmental differences in the type of coping strategies children use have also been examined. Several authors have found that older healthy children use more cognitively oriented coping methods such as emotion-focused coping (Compass, Mulcarne, & Fondecaro, 1988; Wertlieb, Weigal, Feinstein, 1987). Band & Weiss (1988) found that young children preferred to perform some action to change the environment (problem-focused coping) rather than use cognitive abstraction to fit into existing stressful situations. Finally, Bull and Drotar (1991) examined age differences in coping in a sample of school age children and adolescents with cancer in remission. They found that adolescents used more emotion-management coping strategies than younger children, while younger children used more

problem-solving strategies than the adolescents.

As living with a chronic illness impacts on an individual's somatic experience, survivors must incorporate their cancer status into their self-image, both physically and emotionally. Consequently, the process and experience of coping with such physical demands is sure to impact on long-term, more generalized coping patterns. This combination of physical and emotional stressors is very likely to have a profound effect on the development of an individual's coping repertoire.

### Rationale for the Research Study

Based on the foregoing introduction and literature review, the following conclusions were presented as the rationale for the practical and theoretical need for the study:

1. Advances in the medical treatment of previously fatal diseases such as pediatric leukemia have enabled children to survive in ever increasing numbers. However, though now considered a chronic, rather than fatal disease, it may still place these children at increased risk for psychosocial adjustment problems.

2. Research in this area has demonstrated the general lack of significant psychopathology in this sub-population. However, there is a need for greater understanding of the ways in which the experience of having cancer affects long-term coping and adjustment. An alternative approach to the psychopathology model is the utilization of the "coping model" (Chang, 1991; Zeltzer, 1991), which emphasizes task, problem solving, and adjustment. The study of survivor patterns of coping, distress experience, and adjustment may assist in identifying possible ways of educating and intervening when assisting survivors in their psychosocial development.



### Hypotheses

This research sought to examine differences in coping strategies, distress experience, and perceived adjustment among long-term survivors of ALL. Based on previous research the following hypotheses were offered:

- 1) Survivors report adequate general adjustment as measured by the Current Adjustment Rating Scale (CARS).
- 2) Adjustment as measured by the CARS is positively related to age in this survivor sample.
- 3) Males and female survivors report equivalent levels of adjustment as measured by the CARS.
- 4) Survivors utilize more emotion-focused coping than problem-focused coping as measured by the Ways of Coping Questionnaire (WCQ).
- 5) Female survivors utilize more emotion-focused coping strategies than male survivors as measured by the WCQ.
- 6) The use of emotion-focused coping as measured by the WCQ increases with age.
- 7) Survivors exhibit a wide range of psychological distress styles as measured by the Positive Symptom Distress Index (PSDI) of the Brief Symptom Inventory.
- 8) Male and female survivors report similar patterns of psychological distress style as measured by the PSDI.
- 9) Survivors who report a repressive style of psychological distress experience utilize more emotion-focused coping strategies.

10) Survivors who report a sensitizing style of psychological distress experience as measured by the PSDI utilize more problem-focused coping strategies.

11) Repressors who favor emotion-focused coping strategies and sensitizers who favor problem-focused coping strategies report better adjustment than repressors who favor problem-focused coping strategies and sensitizers who favor emotion-focused coping strategies.

## CHAPTER 2

## RESEARCH DESIGN AND METHODOLOGY

This study was designed to assess the interrelationship of coping strategy, psychological distress experience, and perceived adjustment in long-term survivors of pediatric leukemia. Gender and age were also included as variables.

Subjects

Subjects were long-term survivors who were consecutively diagnosed with Acute Lymphocytic Leukemia at Children's Memorial Hospital of Chicago (CMH). They all participated in the Coping Project, a longitudinal study of coping with pediatric leukemia. Excluded were patients who had been diagnosed or treated prior to coming to CMH, who had multiple diagnoses, or where language translation was necessary (N=6). A total of 64 patients began the study. The mean age at diagnosis was 6.50 years (SD = 4.54 years). Of the original sample, 29 subjects are deceased from cancer related illnesses. Of the 35 remaining, we were able to locate 28 families and collect complete data from 22 of them. Six of the families did not return completed materials despite follow up from project staff. Of the 22 remaining, 12 were male and 10 were female. Descriptive characteristics of the sample are presented in Table 1.

Table 1Subject Age and Education by Gender

| Subject        | Age             | Education |
|----------------|-----------------|-----------|
| <b>Males</b>   |                 |           |
| 01             | 16.34           | H.S.      |
| 02             | 19.95           | COL       |
| 03             | 30.08           | COL       |
| 04             | 16.88           | H.S.      |
| 05             | 20.30           | COL       |
| 06             | 16.30           | H.S.      |
| 07             | 21.24           | H.S.      |
| 08             | 14.00           | H.S.      |
| 09             | 20.08           | COL       |
| 10             | 19.17           | COL       |
| 11             | 16.77           | H.S.      |
| 12             | 30.25           | COL       |
| Mean (SD)      | 19.77 (SD=4.79) |           |
| <b>Females</b> |                 |           |
| 13             | 14.32           | H.S.      |
| 14             | 16.20           | H.S.      |
| 15             | 17.95           | H.S.      |
| 16             | 16.11           | H.S.      |
| 17             | 27.35           | COL       |
| 18             | 16.24           | H.S.      |
| 19             | 15.51           | H.S.      |
| 20             | 25.24           | COL       |
| 21             | 15.89           | H.S.      |
| 22             | 18.28           | COL       |
| Mean (SD)      | 18.23 (SD=4.15) |           |

Mean age was 19.11 years (SD=4.51). Mean time since diagnosis was 13.26 years (SD=.98). Seven were in college, two had finished college, and two were married with children, all others are currently in high school. All subjects had received cranial irradiation and intrathecal methotrexate as CNS prophylaxis. No other significant health problems were noted at diagnosis or currently.

## Measures

### Coping

The Ways of Coping Questionnaire (WCQ) (Folkman & Lazarus, 1988; Appendix A) is a 66 item Likert-type scale designed to elicit information about the strategies an individual uses to cope with stressful situations. This scale was chosen for two primary reasons. It is based on a definition of coping compatible with the theoretical orientation of this study, namely that coping is the cognitive and behavioral effort to manage specific external and internal demands appraised as taxing or exceeding the resources of the individual. Secondly, it has been used extensively in studies of coping processes, including various cancer populations (Folkman & Lazarus, 1984; 1988).

The instrument takes about 15 minutes to complete. The measure was originally designed to discriminate between problem-focused and emotion-focused coping strategies. The revised edition has factored these broad categories into eight factors. Problem-focused factors include confrontive

coping and planful problem solving. Emotion-focused factors include distancing, self-controlling, seeking social support, accepting responsibility, escape-avoidance, and positive reappraisal (Folkman & Lazarus, 1984; 1988; Vitaliano, Russo, Carr, Maiuro, & Becker, 1985). In this study, these sub-categories of problem focused and emotion focused coping will be used to increase the power of our analyses by the expected higher reliabilities. This format coincides with that used by Compas, Worsham, & Ey (1992) in their conceptual formulation of children's coping strategies.

The instrument was standardized on a sample of 75 middle- and upper-middle class Caucasian married couples with at least one child living with them. Both spouses were interviewed separately once per month for five months, and asked to fill out the WCQ each time. The items on the WCQ were factor analyzed, using alpha and principal factoring with oblique rotation, yielding eight scales (above).

Reliability of the measure was established by examining the internal consistency of the coping measures, estimated with Cronbach's coefficient alpha. Alpha coefficients have been calculated for the eight subscales. Coefficients for the two categories used in this study were calculated via the mean alpha of the combined subscales, yielding a coefficient of .65 for prblem-focused coping and .71 for emotion-focused coping (Folkman & Lazarus, 1988).

The items of the WCQ evidence construct validity through

various studies, using both the original Ways of Coping Checklist and the WCQ, in which the results remained consistent with theoretical predictions (Folkman & Lazarus, 1980, 1985; Folkman, et al, 1986). Those predictions held that coping is a process that consists of both problem-focused and emotion-focused coping. Face validity of the measure is supported by the fact that the strategies described are those that subjects have reported using to cope with the demands of stressful experiences.

#### Psychological Distress Style

The subject's "style" of psychological distress experience was assessed with the Positive Symptom Distress Index (PSDI), a factor subscale of the Brief Symptom Inventory (BSI) (Derogatis, 1986; Appendix B). This subscale places respondents along a continuum of two categories of style, repressors, who tend to minimize their distress and sensitizers, who tend to maximize their distress. As a measure of intensity, the PSDI "corrects" for numbers of symptoms and yields information regarding the average level of distress experienced by the respondent. The PSDI is derived by taking the sum of all items, dividing this number by 53 (the total number of items), then again dividing this number by the total number of positive responses. The test can be used to measure psychological distress style along a continuum and provides non-patient adolescent norms. This self-report inventory has been used widely with a

variety of both psychiatric and medical populations, including cancer patients (Derogatis, 1992). With the clinical subscales (which were not used in this study), Derogatis (1992) reported a value to be used in a selection model to define a positive case, which was developed across a variety of populations (Kuhn, Bell, Seligson, Laufer, & Lindner, 1988; Zabora, Smith-Wilson, Fetting, & Enterline, 1990; Derogatis, 1992). Using the Global Severity index, he defined a positive case as having a T-score equal to or greater than 63. In this study, respondents were classified as sensitizers or repressors utilizing the same criterion value, i.e. by scoring at least 13 points from the mean for nonpatient adolescents, i.e. one standard deviation above is a sensitizer, one standard deviation below is a repressor. The author reports no other standard for breakdown into categories (Clinical Psychometric Research Inc., personal communication, 1994).

Psychological distress falls somewhere between trait-mediated characteristics and fluctuating state-manifestation type moods (Derogatis, 1992). Test-retest coefficients for the PSDI scale were conducted by Derogatis (1983) on a sample of 60 non-patient subjects tested across a two week interval. The PSDI demonstrated a stability coefficient of .87. The measure was also normed on a sample of 2408 non-patient adolescents from a wide variety of cultural and economic backgrounds. Reproducibility of the internal structure of



the BSI was examined through a principle components analysis using data from 1002 psychiatric outpatients. A varimax rotation of the principle components resulted in nine primary BSI dimensions, and global scales including the PSDI were subsequently derived.

This measure has been utilized by several investigators to explore the psychological distress status of cancer patients and their families. Studies include examining the general psychiatric status of oncology patients (Stefanik, Derogatis, & Shaw, 1987), contrasting long versus short term survivors of testicular cancer (Edwards, DeClemente, & Samuels, 1985), evaluating the psychological adjustment to breast reconstruction in cancer patients (Schain, et al, 1985), and evaluating the reactions of parents to the death of a child from cancer (Shanfield, Benjamin, and Swain, 1984).

### Adjustment

The Current Adjustment Rating Scale (CARS) (Appendix C), is a 12-item self-report Likert-type scale. It is a measure of perceived adjustment, and requires the respondent to evaluate his/her current functioning in several areas, which include personal, social, family, school, work, and leisure. It also yields a global adjustment score. The scale was originally developed as an indicator of self reported adjustment for psychotherapy patients by Traux (1967) and examined statistically by Berzins, Bednar, & Severy (1975).

When the Coping Project was initiated, this measure was chosen for several reasons. There were no other available self report questionnaires dealing with perceived adjustment per se. Most other measures were more focused on psychiatric symptomatology and pathology. The CARS is brief, non-intrusive and has been shown to correlate strongly to other measures of adjustment. In a sample of 79 psychotherapy patients and their therapists Berzins, et al (1975) found strong correlations between the CARS and the following measures: the Minnesota Multiphasic Personality Inventory, of which the subscales (K,D,Pt,Sc, and Es) were used as they have shown special sensitivity to patient adjustment (Garfield, Prager, and Bergin, 1971); the Psychiatric Status Schedule (Spitzer, Endicott, Fless, & Cohen, 1970), which is a method for evaluating psychopathology and impairment in social functioning; and the Q-Sort (Roger & Dymond, 1954), a measure of the patient's degree of self-acceptance was also found to correlate well.

A total of 15 different scores were intercorrelated resulting in 76% of the coefficients reaching or exceeding the .05 level of significance. Intersource agreement on the CARS between respondents (patients, their therapists) was also explored via canonical correlation, and revealed good intersource agreement (reliability) (pre-therapy,  $r=.36$ ,  $p=.001$ ; post-therapy,  $r=.37$ ,  $p=.001$ ).

### Procedure

All potential participants were sent a brief letter stating the purpose of the study, accompanied by a reply card indicating their willingness to participate. All patients we were able to reach agreed to be telephoned by an investigator who provided further explanation of the study and then made an appointment time to conduct the interview portion of the assessment. The interview data were not applicable to this study. Prior to any data collection, all parents and children were asked to read and sign the Informed Consent Form (Appendix D). After the interview was conducted, participants were given a packet containing the WCQ, the BSI, and the CARS. Subjects were instructed to follow the directions provided by each questionnaire, and asked to return them within one week via an included return envelope. In the case of individuals who had moved out of state, the self-report materials were mailed to them following their consent to participate. Subjects were told that a summary of results would be available upon request, and that staff were available for further consultation if needed.

## CHAPTER 3

## RESULTS

Evaluation of Hypotheses

Hypothesis 1 - Survivors report adequate general adjustment as measured by the Current Adjustment Rating Scale (CARS). This was evaluated by calculation of the mean CARS score for survivors, which was 7.42 (SD = .96). A score of 6 or greater indicates positive perceived adjustment, indicating that this group of survivors is reporting positive general adjustment which supported the hypothesis.

Hypothesis 2 - Adjustment as measured by the CARS is positively related to age. Pearson product-moment correlations yielded a positive significant relationship between age and adjustment, indicating that as survivors' age increases, perceived adjustment also improves,  $r(20)=.39$ ,  $p=.04$ . These findings supported the hypothesis.

Hypothesis 3 - Male and female survivors report equivalent levels of adjustment as measured by the CARS. This was evaluated via a t-test of adjustment score means. Results of this analysis indicated no significant difference between male and female adjustment ( $t=.63$  two-tailed,  $p=.54$ ), thereby supporting the hypothesis.

Hypothesis 4 - Survivors utilize more emotion-focused

coping than problem-focused coping as measured by the Ways of Coping Questionnaire. The mean relative frequency for emotion-focused coping was 72.27 (SD=8.31), and the relative frequency mean for problem-focused coping was 24.32 (SD=8.19). A t-test of means indicated a significant difference ( $t=13.81$  two-tailed,  $p=.001$ ) which supported the hypothesis.

Hypothesis 5 - Female survivors utilize more emotion-focused coping strategies than male survivors as measured by the WCQ. This was evaluated by means of a univariate analysis of variance (ANOVA). These results are presented in Tables 2 and 3. Females were more likely to rely on emotion-focused coping than males,  $F(1,21)=4.85$ ,  $p=.04$ . However, this relationship became weaker when age was used as a covariate,  $F(1,21)=4.06$ ,  $p=.06$ . Conversely, males showed a nonsignificant trend towards greater use of problem-focused coping strategies  $F(1,21)=3.85$ ,  $p=.06$ . Again when age was used as a covariate, this relationship was not significant  $F(1,21)=2.94$ ,  $p=.10$ . These findings provided limited support of the hypothesis, and must be interpreted with caution.

Hypothesis 6 - The use of emotion-focused coping as measured by the WCQ increases with age. This was evaluated via Pearson product-moment correlations which revealed no significant relationship between emotion-focused coping and

Table 2  
Analysis of Variance - Coping by Gender

| Source of Variation              | Sum of Squares | df | Mean Square | F    | Signif. of F |
|----------------------------------|----------------|----|-------------|------|--------------|
| <u>Emotion-Focused by Gender</u> |                |    |             |      |              |
| Main Effects                     |                |    |             |      |              |
| Gender                           | 282.76         | 1  | 282.76      | 4.85 | .04          |
| Error                            | 1448.36        | 21 | 68.97       |      |              |
| <u>Problem-Focused by Gender</u> |                |    |             |      |              |
| Main Effects                     |                |    |             |      |              |
| Gender                           | 226.92         | 1  | 226.92      | 3.85 | .06          |
| Error                            | 1179.85        | 21 | 58.99       |      |              |

Table 3  
Analysis of Variance - Coping by Gender with Age

| Source of Variation                       | Sum of Squares | df | Mean Square | F    | Signif. of F |
|---|----------------|----|-------------|------|--------------|
| <u>Emotion-Focused by Gender with Age</u> |                |    |             |      |              |
| Covariates                                |                |    |             |      |              |
| Age                                       | 58.15          | 1  | 58.15       | .97  | .34          |
| Main Effects                              |                |    |             |      |              |
| Gender                                    | 244.73         | 1  | 244.73      | 4.06 | .06          |
| Error                                     | 1448.36        | 21 | 68.97       |      |              |
| <u>Problem-Focused by Gender with Age</u> |                |    |             |      |              |
| Covariates                                |                |    |             |      |              |
| Age                                       | 143.35         | 1  | 143.35      | 2.49 | .13          |
| Main Effects                              |                |    |             |      |              |
| Gender                                    | 169.26         | 1  | 169.26      | 2.94 | .10          |
| Error                                     | 1406.77        | 21 | 66.99       |      |              |

age  $r(20) = -.20$ ,  $p = .19$ . However, there was a nonsignificant trend for all subjects to use more problem-focused coping as they got older  $r(20) = .32$ ,  $p = .07$ . These findings did not support the hypothesis.

Hypothesis 7 - Survivors exhibit a wide range of psychological distress styles as measured by the Positive Symptom Distress Index (PSDI) of the Brief Symptom Inventory. This was evaluated by calculating standard t-scores on the PSDI, which yielded a mean of 49.44 ( $SD = 13.28$ ) with a range of 29 to 70 ( $SD = 13.28$ ). This fairly wide range provided limited support for the hypothesis, however only 6 subjects could be categorized as either repressors or sensitizers based on caseness criteria.

Hypothesis 8 - Male and female survivors report similar patterns of psychological distress style as measured by the PSDI. This was evaluated by means of a univariate ANOVA which indicated no significant difference in PSDI scores between males and females  $F(1,20) = .06$ ,  $p = .81$ . Age was also examined as covariate in these analyses and yielded no significant results  $F(1,20) = .77$ ,  $p = .39$ . These results supported the hypothesis.

Hypothesis 9 - Survivors who report a repressive style of psychological distress experience utilize more emotion-focused coping strategies. Pearson product-moment correlations between coping strategy and distress style were conducted to test this hypothesis. They indicated that as



PSDI score decreased (toward repression) the use of emotion-focused coping strategies increased,  $r(20)=.45$ ,  $p=.02$ . This supported the hypothesis.

Hypothesis 10 - Survivors who report a sensitizing style of psychological distress experience as measured by the PSDI utilize more problem-focused coping strategies. Pearson product-moment correlations between coping strategy and distress style were conducted to test this hypothesis. As the PSDI score increased (toward sensitization) the use of problem-focused strategies increased,  $r(20)=.43$ ,  $p=.02$ , thereby supporting the hypothesis.

Hypothesis 11 - Repressors who favor emotion-focused coping strategies and sensitizers who favor problem-focused coping strategies report better adjustment than repressors who favor problem-focused coping strategies and sensitizers who favor emotion-focused coping strategies. Based on the definition of caseness, 3 subjects were classified as sensitizers, 3 subjects were classified as repressors, with the remainder falling within the normative range. Consequently, due to the small number of subjects in the categories (repressor/sensitizer) the eleventh hypothesis was not testable. However, a Pearson product-moment correlation was conducted between CARS score and PSDI score yielding a significant positive relationship,  $r(20)=.38$ ,  $p=.04$ . This indicated that as survivors tended toward repression, perceived adjustment improved. Conversely, as survivors

tended towards sensitization, perceived adjustment  
diminished.

## CHAPTER 4

## DISCUSSION AND INTERPRETATION

The purpose of this study was to investigate the general level of adjustment in a cohort of survivors of pediatric leukemia, to examine characteristics of coping behavior and style of psychological distress experience, and to investigate interactions among these variables.

Results from this study support previous findings that survivors of ALL see themselves as being generally well adjusted. Why might these individuals see themselves as so psychologically healthy despite a traumatic childhood experience such as cancer? Having had the disease and its treatment may have encouraged the development of a greater appreciation of life. Interview data from prior assessments of this cohort (Kupst & Schulman, 1988) support this hypothesis. Most subjects reported that having had cancer had some positive aspect, such as making them psychologically stronger and/or enhancing personal relationships with family members or friends. An alternative explanation for this finding is that suggest that such reports of positive adjustment are defensive--a brave facade behind which these survivors hide a greater level of suffering and maladjustment. This hypothesis may be explored in future

research by using alternative sources of measuring adjustment in addition to self-report, such as parent, teacher, and/or independent observer reports. The finding that adjustment was positively related to age suggests that older survivors in this cohort see themselves as better adjusted. Older adolescents and young adults may be less likely to present themselves as unable to manage their life experience than younger children. However, it also may be interpreted that it is easier to adjust to a diagnosis of leukemia at an older age, enabling individuals to rebound with fewer long-term effects on perceived adjustment to life's responsibilities. In addition, younger children who were more affected by cranial irradiation and had more cognitive/academic problems may have had more adjustment difficulties. Finally, older survivors may have a greater intellectual understanding of the diminishing risks of having had cancer, and as they feel less fearful of recurrence or other consequences, may in turn feel generally better about their lives. Males and females reported equivalent levels of adjustment, supporting previous research.

As a whole, these survivors use more emotion-focused coping than problem-focused coping, indicating that these survivors expend more energy managing their emotional experience and expression than confronting or attempting to change external stimuli. This supports Folkman & Lazarus' (1985) contention that the relative use of problem- and

emotion-focused coping varies according to the type of situation. They identified health related situations as more likely to elicit emotion-focused coping, particularly as individuals tend to view health related problems as less amenable to change. In this case, survivors of pediatric cancer have had extensive opportunities to learn and practice internally-based/emotion-focused coping strategies when dealing with relatively uncontrollable illness-related stressors. They may see their cancer and its treatment as unchangeable, and may consequently shift coping efforts toward managing their internal affective experience. This may enhance the frequency of emotion-focused coping across a variety of situations.

Females in this study tended to use more emotion-focused coping than males. However, as survivors got older, this trend became less significant. A trend towards males using slightly more problem-focused coping disappeared in older survivors. As age increases, gender differences in preferred coping strategies diminishes. The majority of research in coping has failed to find gender differences in coping. However, two studies of coping in healthy children have identified a trend towards females using more emotion-focused coping for general life stress than males (Compas, et al, 1988; Wertlieb, Weigal, & Feldstein, 1987). The greater use of emotion-focused coping by younger female survivors may be explained in part by differences in the ways in which

children are taught to deal with problems. Young males may be encouraged to utilize action-oriented problem solving strategies, while young girls may be more encouraged to think through their distress (Compas et al, 1988). In adults, Folkman & Lazarus (1986) reported that health-related encounters evoke increased emotion-focused coping. They found that women in their sample reported more health encounters than men, and consequently utilized more emotion-focused coping. With regards to the survivors in this study, males may be more sensitized to health-related concerns, and consequently employ levels of emotion-focused coping comparable to female survivors.

Studies comparing younger children with adolescents have reported a positive relationship between age and emotion-focused coping (Bull & Drotar, 1991; Worchel, Copeland, & Barker, 1987). It was expected that older survivors would use more emotion-focused coping. However, this was not the case. In this cohort, all subjects were at the point of adolescence or older, and perhaps had acquired the greater cognitive maturity associated with increased use of emotion-focused coping.

Survivors demonstrated extensive variability in their style of psychological distress experience. While several survivors did evidence a strong tendency for one style over another (repression/sensitization), the majority of survivors fell within a normal distribution. Male and female

survivors demonstrated no significant differences in their style of psychological distress experience.

Whereas style of distress experience refers to the emotional reaction to a stressful situation, coping is concerned with the manner in which the individual deals with the stress. In this study, survivors who were greater sensitizers used more problem-focused coping than repressors, who utilized more emotion-focused coping strategies. One explanation is that sensitizers, having a more intensely felt emotional reaction to a stressor, are more likely to look for ways to directly confront and/or attempt to impact the stressor in an effort to alleviate their psychic distress. Conversely, repressors are intensely focused on the stressor itself, and consequently attempt to manage their emotional reaction. Instead of directly confronting or changing the stimulus, they focus on changing their internal reaction. The trend toward decreasing adjustment with those scoring higher on sensitization supports the contention of Harris, et al (1991) that a repressive style of distress management is a more adaptive response to the ongoing demands of a chronic illness.

As earlier stated, in this study the majority of individuals relied more on emotion-focused coping in general. This is probably related to their life-long focus on health related concerns. It is possible that coping with an ongoing, life-threatening illness affects more generalized

coping patterns, resulting in a reliance on one type. If a repressive style is more adaptive in dealing with the ongoing demands of a stressor such as ALL, survivors exhibiting this style and using more emotion-focused coping would be expected to report overall positive adjustment. Unfortunately, several things prevented a direct test of this hypothesis. Along the distress style continuum, only 25% of our sample could be categorized as either repressors/sensitizers. This small number made interpretation questionable at best. In addition, the restricted range of adjustment scores reported by this cohort made it difficult to differentiate patterns of distress style and coping as related to better adjustment. By increasing sample size, adding alternative sources of adjustment other than self report such as parent and teacher reports, and the use of independent observers to assess coping and adjustment, future research could provide more detailed information regarding the effects of coping strategy and distress style on adjustment.

Other design and sampling considerations should be kept in mind when interpreting our findings. This sample was with a homogeneous type of illness. Consequently, findings may not be generalizable across chronic illnesses, or even to other forms of cancer. ALL now has a higher survival rate than many other types of pediatric cancer, with fewer lasting visible sequelae. In addition, this cohort had a higher rate of death from ALL than is expected in current populations,



which underscores the need to conduct prospective research with currently diagnosed cancer patients. Finally, this sample was primarily Caucasian; the question of how minority survivors may differ in their coping strategies and distress experience remains unanswered, and emphasizes a need for their inclusion in future research.

Several other directions for future research are suggested by this study. The validity of survivors perceived adjustment needs to be demonstrated. It would be useful to document whether survivor's reports of adjustment correspond to parents' or others' (e.g. teachers, medical staff) reports. Finally, comparisons with survivors of other chronic conditions are necessary to determine to what extent the present findings are specific to pediatric leukemia.



|                                     |                       | Does not apply or not used | Used somewhat         | Used quite a bit      | Used a great deal     |  |
|-------------------------------------|-----------------------|----------------------------|-----------------------|-----------------------|-----------------------|--|
| <b>WAYS OF COPING QUESTIONNAIRE</b> |                       |                            |                       |                       |                       |  |
| 11.                                 | <input type="radio"/> | <input type="radio"/>      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | I hoped for a miracle.   |
| 12.                                 | <input type="radio"/> | <input type="radio"/>      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | I went along with fate; sometimes I just have bad luck.  |
| 13.                                 | <input type="radio"/> | <input type="radio"/>      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | I went on as if nothing had happened.  |
| 14.                                 | <input type="radio"/> | <input type="radio"/>      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | I tried to keep my feelings to myself.   |
| 15.                                 | <input type="radio"/> | <input type="radio"/>      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | I looked for the silver lining, so to speak; I tried to look on the bright side of things.         |
| 16.                                 | <input type="radio"/> | <input type="radio"/>      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | I slept more than usual.   |
| 17.                                 | <input type="radio"/> | <input type="radio"/>      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | I expressed anger to the person(s) who caused the problem.   |
| 18.                                 | <input type="radio"/> | <input type="radio"/>      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | I accepted sympathy and understanding from someone.  |
| 19.                                 | <input type="radio"/> | <input type="radio"/>      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | I told myself things that helped me feel better.   |
| 20.                                 | <input type="radio"/> | <input type="radio"/>      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | I was inspired to do something creative about the problem.   |
| 21.                                 | <input type="radio"/> | <input type="radio"/>      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | I tried to forget the whole thing.   |
| 22.                                 | <input type="radio"/> | <input type="radio"/>      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | I got professional help.   |
| 23.                                 | <input type="radio"/> | <input type="radio"/>      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | I changed or grew as a person.   |
| 24.                                 | <input type="radio"/> | <input type="radio"/>      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | I wanted to see what would happen before doing anything.   |
| 25.                                 | <input type="radio"/> | <input type="radio"/>      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | I apologized or did something to make up.  |
| 26.                                 | <input type="radio"/> | <input type="radio"/>      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | I made a plan of action and followed it.   |
| 27.                                 | <input type="radio"/> | <input type="radio"/>      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | I accepted the next best thing to what I wanted.   |
| 28.                                 | <input type="radio"/> | <input type="radio"/>      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | I let my feelings out somehow.   |
| 29.                                 | <input type="radio"/> | <input type="radio"/>      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | I realized that I had brought the problem on myself.   |
| 30.                                 | <input type="radio"/> | <input type="radio"/>      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | I came out of the experience better than when I went in.   |
| 31.                                 | <input type="radio"/> | <input type="radio"/>      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | I talked to someone who could do something concrete about the problem.                             |
| 32.                                 | <input type="radio"/> | <input type="radio"/>      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | I tried to get away from it for a while by resting or taking a vacation.                           |
| 33.                                 | <input type="radio"/> | <input type="radio"/>      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | I tried to make myself feel better by eating, drinking, smoking, using drugs, or medications, etc. |
| 34.                                 | <input type="radio"/> | <input type="radio"/>      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | I took a big chance or did something very risky to solve the problem.                              |
| 35.                                 | <input type="radio"/> | <input type="radio"/>      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | I tried not to act too hastily or follow my first hunch.   |
| 36.                                 | <input type="radio"/> | <input type="radio"/>      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | I found new faith.   |
| 37.                                 | <input type="radio"/> | <input type="radio"/>      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | I maintained my pride and kept a stiff upper lip.  |
| 38.                                 | <input type="radio"/> | <input type="radio"/>      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | I rediscovered what is important in life.  |
| 39.                                 | <input type="radio"/> | <input type="radio"/>      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | I changed something so things would turn out all right.  |
| 40.                                 | <input type="radio"/> | <input type="radio"/>      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | I generally avoided being with people.   |
| 41.                                 | <input type="radio"/> | <input type="radio"/>      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | I didn't let it get to me; I refused to think too much about it.                                   |
| 42.                                 | <input type="radio"/> | <input type="radio"/>      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | I asked advice from a relative or friend I respected.  |
| 43.                                 | <input type="radio"/> | <input type="radio"/>      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | I kept others from knowing how bad things were.  |
| 44.                                 | <input type="radio"/> | <input type="radio"/>      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | I made light of the situation; I refused to get too serious about it.                              |
| 45.                                 | <input type="radio"/> | <input type="radio"/>      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | I talked to someone about how I was feeling.   |
| 46.                                 | <input type="radio"/> | <input type="radio"/>      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | I stood my ground and fought for what I wanted.  |
| 47.                                 | <input type="radio"/> | <input type="radio"/>      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | I took it out on other people.   |
| 48.                                 | <input type="radio"/> | <input type="radio"/>      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | I draw on my past experiences; I was in a similar situation before.                                |
| 49.                                 | <input type="radio"/> | <input type="radio"/>      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | I knew what had to be done, so I doubled my efforts to make things work.                           |
| 50.                                 | <input type="radio"/> | <input type="radio"/>      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | I refused to believe that it had happened.   |
| 51.                                 | <input type="radio"/> | <input type="radio"/>      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | I promised myself that things would be different next time.  |
| 52.                                 | <input type="radio"/> | <input type="radio"/>      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | I came up with a couple of different solutions to the problem.                                     |
| 53.                                 | <input type="radio"/> | <input type="radio"/>      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | I accepted the situation, since nothing could be done.   |
| 54.                                 | <input type="radio"/> | <input type="radio"/>      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | I tried to keep my feelings about the problem from interfering with other things.                  |
| 55.                                 | <input type="radio"/> | <input type="radio"/>      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | I wished that I could change what had happened or how I felt.                                      |
| 56.                                 | <input type="radio"/> | <input type="radio"/>      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | I changed something about myself.  |
| 57.                                 | <input type="radio"/> | <input type="radio"/>      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | I daydreamed or imagined a better time or place than the one I was in.                             |
| 58.                                 | <input type="radio"/> | <input type="radio"/>      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | I wished that the situation would go away or somehow be over with.                                 |
| 59.                                 | <input type="radio"/> | <input type="radio"/>      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | I had fantasies or wishes about how things might turn out.   |
| 60.                                 | <input type="radio"/> | <input type="radio"/>      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | I prayed.  |
| 61.                                 | <input type="radio"/> | <input type="radio"/>      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | I prepared myself for the worst.   |
| 62.                                 | <input type="radio"/> | <input type="radio"/>      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | I went over in my mind what I would say or do.   |
| 63.                                 | <input type="radio"/> | <input type="radio"/>      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | I thought about how a person I admire would handle this situation and used that as a model.        |
| 64.                                 | <input type="radio"/> | <input type="radio"/>      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | I tried to see things from the other person's point of view.                                       |
| 65.                                 | <input type="radio"/> | <input type="radio"/>      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | I reminded myself how much worse things could be.  |
| 66.                                 | <input type="radio"/> | <input type="radio"/>      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | I jogged or exercised.   |

DO NOT FOLD

DO NOT MARK BELOW BAR

# Appendix B

## BRIEF SYMPTOM INVENTORY

BSI

SIDE 1

**INSTRUCTIONS:**

Below is a list of problems people sometimes have. Please read each one carefully, and circle the number to the right that best describes HOW MUCH THAT PROBLEM HAS DISTRESSED OR BOTHERED YOU DURING THE PAST 7 DAYS INCLUDING TODAY. Circle only one number for each problem and do not skip any items. If you change your mind, erase your first mark carefully. Read the example below before beginning, and if you have any questions please ask about them.

**SEX**

MALE

FEMALE

NAME: \_\_\_\_\_

LOCATION: \_\_\_\_\_

EDUCATION: \_\_\_\_\_

MARITAL STATUS: MAR. \_\_\_ SEP. \_\_\_ DIV. \_\_\_ WID. \_\_\_ SING. \_\_\_

| DATE |     |      |
|------|-----|------|
| MO   | DAY | YEAR |
|      |     |      |

| ID. NUMBER |  |
|------------|--|
|            |  |

| AGE |
|-----|
|     |

| EXAMPLE                          | NOT AT ALL | A LITTLE BIT | MODERATELY | OUTR A BIT | EXTREMELY |
|----------------------------------|------------|--------------|------------|------------|-----------|
| HOW MUCH WERE YOU DISTRESSED BY: |            |              |            |            |           |
| 1. Bodyaches                     | 0          | 1            | 2          | 3          | 4         |

VISIT NUMBER: \_\_\_\_\_

| HOW MUCH WERE YOU DISTRESSED BY:  | NOT AT ALL | A LITTLE BIT | MODERATELY | OUTR A BIT | EXTREMELY |   |
|---|------------|--------------|------------|------------|-----------|---|
| 1. Nervousness or shakiness inside  | 1          | 0            | 1          | 2          | 3         | 4 |
| 2. Faintness or dizziness   | 2          | 0            | 1          | 2          | 3         | 4 |
| 3. The idea that someone else can control your thoughts                             | 3          | 0            | 1          | 2          | 3         | 4 |
| 4. Feeling others are to blame for most of your troubles                            | 4          | 0            | 1          | 2          | 3         | 4 |
| 5. Trouble remembering things   | 5          | 0            | 1          | 2          | 3         | 4 |
| 6. Feeling easily annoyed or irritated  | 6          | 0            | 1          | 2          | 3         | 4 |
| 7. Pains in heart or chest  | 7          | 0            | 1          | 2          | 3         | 4 |
| 8. Feeling afraid in open spaces  | 8          | 0            | 1          | 2          | 3         | 4 |
| 9. Thoughts of ending your life   | 9          | 0            | 1          | 2          | 3         | 4 |
| 10. Feeling that most people cannot be trusted                                      | 10         | 0            | 1          | 2          | 3         | 4 |
| 11. Poor appetite   | 11         | 0            | 1          | 2          | 3         | 4 |
| 12. Suddenly scared for no reason   | 12         | 0            | 1          | 2          | 3         | 4 |
| 13. Temper outbursts that you could not control                                     | 13         | 0            | 1          | 2          | 3         | 4 |
| 14. Feeling lonely even when you are with people                                    | 14         | 0            | 1          | 2          | 3         | 4 |
| 15. Feeling blocked in getting things done  | 15         | 0            | 1          | 2          | 3         | 4 |
| 16. Feeling lonely  | 16         | 0            | 1          | 2          | 3         | 4 |
| 17. Feeling blue  | 17         | 0            | 1          | 2          | 3         | 4 |
| 18. Feeling no interest in things   | 18         | 0            | 1          | 2          | 3         | 4 |
| 19. Feeling fearful   | 19         | 0            | 1          | 2          | 3         | 4 |
| 20. Your feelings being easily hurt   | 20         | 0            | 1          | 2          | 3         | 4 |
| 21. Feeling that people are unfriendly or dislike you                               | 21         | 0            | 1          | 2          | 3         | 4 |
| 22. Feeling inferior to others  | 22         | 0            | 1          | 2          | 3         | 4 |
| 23. Nausea or upset stomach   | 23         | 0            | 1          | 2          | 3         | 4 |
| 24. Feeling that you are watched or talked about by others                          | 24         | 0            | 1          | 2          | 3         | 4 |
| 25. Trouble falling asleep  | 25         | 0            | 1          | 2          | 3         | 4 |
| 26. Having to check and double check what you do                                    | 26         | 0            | 1          | 2          | 3         | 4 |
| 27. Difficulty making decisions   | 27         | 0            | 1          | 2          | 3         | 4 |
| 28. Feeling afraid to travel on buses, subways, or trains                           | 28         | 0            | 1          | 2          | 3         | 4 |
| 29. Trouble getting your breath   | 29         | 0            | 1          | 2          | 3         | 4 |
| 30. Hot or cold spells  | 30         | 0            | 1          | 2          | 3         | 4 |
| 31. Having to avoid certain things, places, or activities because they frighten you | 31         | 0            | 1          | 2          | 3         | 4 |
| 32. Your mind going blank   | 32         | 0            | 1          | 2          | 3         | 4 |
| 33. Numbness or tingling in parts of your body                                      | 33         | 0            | 1          | 2          | 3         | 4 |
| 34. The idea that you should be punished for your sins                              | 34         | 0            | 1          | 2          | 3         | 4 |
| 35. Feeling hopeless about the future   | 35         | 0            | 1          | 2          | 3         | 4 |

**BSI**

**SIDE 2**

| HOW MUCH WERE YOU DISTRESSED BY:                                   | NOT AT ALL | A LITTLE BIT | MODERATELY | QUITE A BIT | EXTREMELY |   |
|--|------------|--------------|------------|-------------|-----------|---|
| 36. Trouble concentrating  | 36         | 0            | 1          | 2           | 3         | 4 |
| 37. Feeling weak in parts of your body                             | 37         | 0            | 1          | 2           | 3         | 4 |
| 38. Feeling tense or keyed up                                      | 38         | 0            | 1          | 2           | 3         | 4 |
| 39. Thoughts of death or dying                                     | 39         | 0            | 1          | 2           | 3         | 4 |
| 40. Having urges to beat, injure, or harm someone                  | 40         | 0            | 1          | 2           | 3         | 4 |
| 41. Having urges to break or smash things                          | 41         | 0            | 1          | 2           | 3         | 4 |
| 42. Feeling very self-conscious with others                        | 42         | 0            | 1          | 2           | 3         | 4 |
| 43. Feeling uneasy in crowds                                       | 43         | 0            | 1          | 2           | 3         | 4 |
| 44. Never feeling close to another person                          | 44         | 0            | 1          | 2           | 3         | 4 |
| 45. Spells of terror or panic                                      | 45         | 0            | 1          | 2           | 3         | 4 |
| 46. Getting into frequent arguments                                | 46         | 0            | 1          | 2           | 3         | 4 |
| 47. Feeling nervous when you are left alone                        | 47         | 0            | 1          | 2           | 3         | 4 |
| 48. Others not giving you proper credit for your achievements      | 48         | 0            | 1          | 2           | 3         | 4 |
| 49. Feeling so restless you couldn't sit still                     | 49         | 0            | 1          | 2           | 3         | 4 |
| 50. Feelings of worthlessness                                      | 50         | 0            | 1          | 2           | 3         | 4 |
| 51. Feeling that people will take advantage of you if you let them | 51         | 0            | 1          | 2           | 3         | 4 |
| 52. Feelings of guilt  | 52         | 0            | 1          | 2           | 3         | 4 |
| 53. The idea that something is wrong with your mind                | 53         | 0            | 1          | 2           | 3         | 4 |

## Appendix C

### CURRENT ADJUSTMENT RATING SCALE

#### RATING SCALE

Name \_\_\_\_\_

**DIRECTIONS:** Please complete the following scale by responding how you feel about your current adjustment in different aspects of your life. Rate yourself by circling the number which most describes you.

-----

1. Overall general estimate of your current overall functioning.

|           |   |   |   |   |   |   |   |           |
|-----------|---|---|---|---|---|---|---|-----------|
| 1         | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9         |
| Very Poor |   |   |   |   |   |   |   | Excellent |

2. What change has there been in your functioning in the past five years?

|                |   |   |   |           |   |   |   |                   |
|----------------|---|---|---|-----------|---|---|---|-------------------|
| 1              | 2 | 3 | 4 | 5         | 6 | 7 | 8 | 9                 |
| Great Decrease |   |   |   | No Change |   |   |   | Great Improvement |

3. Rate your current work or school adjustment.

|                                  |   |   |   |   |   |   |   |                              |
|----------------------------------|---|---|---|---|---|---|---|------------------------------|
| 1                                | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9                            |
| Very unhappy and<br>Unproductive |   |   |   |   |   |   |   | Very happy and<br>Productive |

4. Your current relationships with friends are:

|                   |   |   |   |   |   |   |   |                 |
|-------------------|---|---|---|---|---|---|---|-----------------|
| 1                 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9               |
| Very unsatisfying |   |   |   |   |   |   |   | Very satisfying |

5. Rate your current relationship with your husband or wife (or close friend of the opposite sex):

|                   |   |   |   |   |   |   |   |                 |
|-------------------|---|---|---|---|---|---|---|-----------------|
| 1                 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9               |
| Very unsatisfying |   |   |   |   |   |   |   | Very satisfying |

6. Where applicable: Rate your current relationship with your children:

|                   |   |   |   |   |   |   |   |                 |
|-------------------|---|---|---|---|---|---|---|-----------------|
| 1                 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9               |
| Very unsatisfying |   |   |   |   |   |   |   | Very satisfying |

(Continued on next page)

7. Where applicable: Rate your current relationship with your parents:

1        2        3        4        5        6        7        8        9

Very unsatisfying

Very satisfying

8. Rate your current likeability (how much you think others like you):

1        2        3        4        5        6        7        8        9

Very unlikeable

Very likeable

9. To what extent are you living up to your potential in your work or in school?

1        2        3        4        5        6        7        8        9

Not at all

Living up to full potential

10. To what extent are you living up to your potential as a person?

1        2        3        4        5        6        7        8        9

Not at all

Living up to full potential

11. Rate your current leisure time activities.

1        2        3        4        5        6        7        8        9

Very unsatisfying

Very satisfying

12. How well do you feel you have adjusted to having had leukemia?

1        2        3        4        5        6        7        8        9

Extremely difficult  
to adjust

Adjusted very well

Do you have any additional comments?

## Appendix D

### INFORMED CONSENT FORM

#### CHILDREN'S MEMORIAL HOSPITAL

#### Individual's Consent for Participation in Clinical Research Project

I/for my child \_\_\_\_\_

(Name of Patient or Parent/legal guardian)

voluntarily agree to participate in the study entitled: "10 Year Follow-up Study of Coping with Pediatric Leukemia."

#### THE PURPOSE OF THIS STUDY

The study will be carried out under the supervision of Mary Jo Kupst, Ph.D., John V. Lavigne, Ph.D., Lakshmi Das, M.D., & Jerome L. Schulman, M.D. The purpose of the study is to obtain further information from the patients and families who participated in the earlier Coping Project. Specifically, we are interested in how people are coping at ten years post-diagnosis, and what factors are related to long-term coping and adjustment. To our knowledge, this is the longest prospective study of coping and adjustment in pediatric leukemia survivors.

#### ROUTING PROCEDURES

I understand that no changes will be made in the usual routine medical procedures I encounter in my return visits to the clinic.

#### EXPERIMENTAL PROCEDURES

I understand that I will participate in an interview with a member of the project staff, which will take approximately 30-60 minutes. The content of the interview will include information about medical history, school, work, family, social, and personal issues, as well as what has been helpful to me, and what issues I feel are important in long-term coping. I will also complete some paper and pencil scales, all of which look at specific issues, concerns, and ways that people cope.

#### BENEFITS

I understand that, while there is no certain benefit to me, the primary benefit of the study is that more will be known about the needs and issues of pediatric leukemia survivors who are ten years post-diagnosis.

#### RISKS

I understand that there are no risks which are anticipated. If I have any questions about the interviews or the scales, the project staff will be available to discuss these questions further with me.

#### CONFIDENTIALITY

I understand that any information obtained from this project that can be identified with me will remain confidential, or will be disclosed only with my permission. All individual data will be coded to remove any identification, and the data will be combined in summary form to give a picture of group responses. However, I am in agreement that scientific data or information not identifiable with me resulting from the study may be presented at meetings and published so that the information can be useful to others.



I understand that it is my right to withdraw permission for any test or treatment at any time. In the event that I wish to withdraw permission, usual forms of care will be offered outside the research study protocol, with no influence on my relationship with the hospital or the quality of care provided.

SUBJECT'S ASSURANCES

Whereas no assurance can be made concerning the results that may be obtained (because results from investigational studies cannot be predicted with certainty), the principal investigator will take every precaution consistent with the best clinical practice.

By signing this consent form, I understand that my/my child's participation in this study is voluntary. I acknowledge that I have not waived any of my legal rights or released this hospital from liability for negligence.

I may revoke my consent and withdraw my child from this study at any time without penalty or loss of benefits. My child's treatment by, and relations with the physician(s) and staff at The Children's Memorial Hospital, now and in the future, will not be affected in any way if I refuse to participate, or if I enter my child into the program and withdraw later.

I understand that records of this study will be kept confidential with respect to any written or verbal reports making it impossible to identify me/my child individually.

If I have any questions about the research procedures, I will contact Dr. Kupst, (414) 266-4170 or Dr. Lavigne, by calling (312) 880-4877 during a workday or (708) 869-7533 at night or on weekends.

If I have any questions about my child's rights as a research subject, I may take them to the Mr. Steven B. Pulik, Research Administrator, Children's Memorial Institute for Education and Research, 2300 Children's Plaza, Chicago, Illinois 60615, telephone number (312) 880-4987.

\* \* \* \* \*

I have read this informed consent document. I understand its contents and I freely consent, without force, reward, or promise of reward, to have my child participate in this study under the conditions described in this document.

|       |   |
|-------|---|
| _____ | _____   |
| Date  | Signature of Child adult or patient<br>(only those 14-18 years)<br>(identify the signatory) |
| _____ | _____   |
| Date  | Signature of Parent(s) or Guardian(s)<br>(for minor)<br>(identify the signatory)            |
| _____ | _____   |
| Date  | Signature of the Witness<br>* * * * *   |

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The final copies have been examined by the director of the dissertation and the signature which appears below verifies the fact that any necessary changes have been incorporated and that the dissertation is now given final approval by the Committee with reference to content and form.

The dissertation is, therefore, accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy.

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