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A descriptive analysis of the social support perceptions and resources of children with cancer and their parents

Basili, Laura Anne, Ph.D.

Case Western Reserve University, 1991
A DESCRIPTIVE ANALYSIS OF THE SOCIAL SUPPORT PERCEPTIONS
AND
RESOURCES OF CHILDREN WITH CANCER AND THEIR PARENTS

by
LAURA ANNE BASILI

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

Thesis Advisor: Elizabeth J. Short, Ph.D.

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MAY 1991
We hereby approve the thesis of

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degree.*

Signed: Elizabeth Short (Chairman)

June 1990

*We also certify that written approval has been obtained for any proprietary material contained therein.
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A Descriptive Analysis of the Social Support Perceptions and Resources of Children with Cancer and their Families

Abstract

by

Laura Anne Basili

An important aspect of the psychosocial adjustment to cancer is to utilize available sources of social support. This includes support from family, friends, and medical staff. Children with cancer are unique in that they get additional support from programs such as one week summer camps. Yet children's and parents' perceptions of social support from each of these resources have not been directly examined. The present research had four primary purposes: 1) to describe and assess the satisfaction with social support resources used by children and their parents to cope with the cancer experience; 2) to assess overall satisfaction with the level of social support and perceptions of family functioning and competence in children with cancer and their parents; 3) to explore the demographic, illness, social support, and familial factors that predict psychosocial adjustment in children with cancer; and 4) to describe and assess children's and parents' perceptions of the cancer camp experience and their satisfaction with the services these camps provide.
Subjects were forty six children with cancer between the ages of 7 and 17, who attended one of two cancer camps, and their parents. Children were interviewed and given questionnaires to assess perceptions of social support, self-concept, and intelligence. Parents were interviewed and given questionnaires to assess perceptions of social support, family functioning, child behavior, demographic and medical information. All interviews took place in the participants’ homes. Frequency analyses, analyses of variance, and regression analyses were used to analyze the data. Findings from the interviews highlighted the resilience these families demonstrated in coping with the cancer experience. Both children and parents were found to be quite satisfied with the support they received from their families, friends, and medical staff during the illness experience. Younger children and adolescents relied on their parents and peers for their emotional and companionship support. Children’s and parents’ scores on measures of social support, self-concept, family functioning, and behavioral problems were found to be comparable with the normative data for each measure. Variables relating to the child and the family were found to be predictors of adjustment for children with cancer. Almost all children and parents were quite satisfied with the services the camps were providing them. Children
described themselves as using camp as a means of emotional and companionship support. Findings from the present research indicate that these children and families have adjusted well to their illness experience, and are well supported, both by formal and informal sources of support. Results are discussed in relation to the findings of other researchers in the area of social support and in relation to the limitations of the study.
Dedicated to
Clement Pease
(1937 - 1974)

Jim Zeigler
(1962 - 1984)

Niam Goryeb
(1926 - 1985)

Charlie Dumont
(1977 - 1988)
ACKNOWLEDGEMENTS

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INTRODUCTION

Childhood Cancer Overview

Although cancer in children is rare, in that approximately 12 out of 100,000 children are affected, it is the second leading cause of death in children (Siegel, 1980). Cancer is a generic term for abnormal or uncontrolled growth of cells in the body. Cancer actually refers to a variety of diseases which affect different tissues and organs in the body (Barbarin & Chesler, 1984). Leukemia, tumors of the central and sympathetic nervous systems, tumors of the kidneys and bone, and lymphoma are the most frequent types of childhood cancer (Pratt, 1985; see Table 1). Treatment varies depending on the type of cancer, with all forms of treatment aimed at inducing a remission or the absence of signs or symptoms of the disease. Treatment can include any combination of chemotherapy, radiation therapy, or surgery.

While all families are faced with their own individual dilemmas when coping with childhood cancer, there is consistency in the illness stages. Katz and Jay (1984) have identified seven stages in the course of the illness which families progress through. These include the following: 1) prediagnostic and diagnostic phase; 2) the initiation of treatment; 3) remission or illness stabilization; 4) completion of medical therapy; 5)
relapse or deterioration; 6) terminal phase; and 7) post
death adjustment. Research has delineated several
potential stressors associated with each phase of the
illness (e.g. vomiting and hair loss associated with
chemotherapy), as well as psychosocial interventions
useful for each phase (e.g. hypnosis, relaxation training
for treatment side effects; Katz, 1980; Kellerman, 1980).

While at one time childhood cancer was seen as an
acute fatal illness, improvements in diagnostic and
therapeutic techniques have rendered childhood cancer a
potentially life threatening illness (Siegel, 1980). In
the past, survival was measured in terms of months; today
many children survive for 5 years or longer (Spasto &
Hammond, 1985). While prognosis has improved and the
outcome is more hopeful, the child and the family must now
live with uncertain survival, with the threat of the
disease returning, and must accept regular and routine
hospital check-ups and diagnostic procedures. The child
and family facing cancer are confronted with numerous
stressors. These include painful and aversive diagnostic
and treatment procedures, side-effects of the treatment
which can alter physical and emotional well being,
repeated absences from normal experiences like school,
distress and upheaval of family relationships, and
general anxiety associated with a life threatening illness
(e.g. Katz & Jay, 1984; Van Dongen-Melman & Sanders-Woudstra, 1986; Varni & Katz, 1988).

**Psychosocial Adjustment**

With the advances in treatment and the prospect of long term survival, much research has focused on children’s psychosocial adjustment to cancer. Early studies indicated children with a chronic illness were at increased risk for developing emotional and behavioral problems (e.g. Diller, 1972; Gayton & Friedman, 1973; Knowles, 1971; Werry, 1972). However, more recent studies have shown that while children with chronic illnesses are at increased risk for adjustment problems, most children and families are characterized by a broad range of functioning and resilience (Tavormina, Kestner, Slater, & Watts, 1976; Longo & Bond, 1984; Garrison & McQuiston, 1989).

With respect to children with cancer, Teta, Delpo, Kasl, Meigs, Myers, and Mulvihill (1984, as cited in Chesler & Barbarin, 1987) found the frequency of major depressive disorders to be no greater for children with cancer than their siblings. Koocher and O’Malley (1981) studied 115 long term survivors of childhood cancer, with a mean survival time of 12 years since treatment was completed. Fifty three percent were judged to be well adjusted by independent ratings of a psychologist and psychiatrist. Forty seven percent were reported to have
residual difficulties in adjustment as reflected by depression, anxiety, and poor self-esteem. Yet only a small percentage had serious enough psychological distress to need professional help. Other researchers have found long term survivors to function well in school, work, and marriage (Fergusson, 1976; Holmes & Holmes, 1975; Li & Stone, 1976; Obetz, Swenson, McCarthy, Gilchrist, & Burgert, 1980). While providing support for the hypothesis that most survivors of childhood cancer demonstrate a great deal of resiliency, the majority of these studies were based on retrospective interviews with survivors.

Recent studies have attempted to make controlled comparisons between children with cancer and healthy children using standardized assessment measures. Spirito, Stark, Cubiella, Drigan, Androkites, and Hwett (1990) found children with cancer who had successfully completed treatment did not differ from healthy peers in self-perceptions of competence or in parental perceptions of social competence. Furthermore, children with cancer were rated higher on willingness to attend school and lower in negative classroom behavior by their teachers.

One group of researchers has recently conducted a series of studies of the social, behavioral, and academic adjustment of children with cancer using self, peer,
teacher, and parent ratings on a variety of standardized measures. Relatively few differences were found between healthy children and children with cancer, with no differences in self ratings of competence or loneliness. Parental reports of behavioral problems were no different for children with cancer than for healthy matched controls. However, children, whose families had rated themselves as higher in conflict, had higher scores on a measure of loneliness (LeRoy, Noll, & Mondoux, 1988). Peers of children with cancer rated them to be as popular as healthy agemates, although they were seen as having slightly fewer mutual friends than their peers. In addition, on a peer sociometric measure, children with cancer were nominated to more roles descriptive of greater sensitivity and isolation by themselves, as well as peers (Noll, LeRoy, Bukowski, Rogosch, & Kulkarni, 1990a). Teachers also nominated children with cancer to more roles descriptive of greater sensitivity and isolation than healthy peers (Noll, Bukowski, Rogosch, LeRoy, & Kulkarni, 1990b). While some subtle vulnerabilities have been found for children with cancer, findings from these controlled studies indicate that for the most part children with cancer have few social adjustment problems.

Another line of research has tried to focus on predictors of adjustment in childhood cancer. Family factors identified include: openness in family
communication concerning the illness (e.g. Fergusson, 1976; Spinetta & Deasy-Spinetta, 1981); quality of the marital relationship (Sourkes, 1977); family income and SES (Koocher & O'Malley, 1981); religious beliefs and philosophical outlook (Chodoff, Friedman, & Hamburg, 1964); positive outlook (e.g. Obetz et al., 1980); satisfaction with medical care (Koocher & O'Malley, 1981; Obetz et al., 1980). Personal factors identified include: using denial as a coping strategy, being young at diagnosis, early knowledge of the disease, being able to resume a normal lifestyle (Koocher & O'Malley, 1981), and having good quality social and peer interactions (Katz, 1980).

One group of researchers followed children diagnosed with leukemia for six years to explore factors related to adjustment (Kupst & Schulman, 1988; Kupst, Schulman, Honig Maurer, Morgan, & Fochtman, 1982; Kupst, Schulman, Maurer, Honig, Morgan, & Fochtman, 1984). Families were assessed at diagnosis, at one year post diagnosis (n = 64), at two years post diagnosis (n = 60), and at six years post diagnosis (n = 43). Subject attrition was due to the researchers inability to locate 15 of the families and because 6 families refused to participate (5 were families of children who had died). Of the families participating at the six year assessment, 27 children were still in
remission, 1 had relapsed, and 15 had died. Self, staff, and objective ratings of adjustment were obtained at each time interval. Both at the one and two year assessments, family coping was found to be stable and most families were found to be coping well.

The six year follow-up indicated that there was a significant increase in adjustment over time. Good coping tended to run in families, and those who were having problems coping had preexisting problems (e.g. marital discord, family communication difficulties). Antecedent predictors of adjustment included coping disposition, father's occupational level, and coping with earlier stages of the illness. Concurrent predictors of adjustment included level of family cohesion, quality of marital relationship, good coping of other family members, lack of concurrent stressors, and open communication within the family. Surprisingly, neither the medical status of the child nor the duration of the illness related to adjustment.

Thus, the research indicates that in general children with cancer and their families have adjusted fairly well and have demonstrated a great deal of resilience in the face of the serious stressors associated with this chronic illness. Furthermore, their adjustment increases over the course of the illness. While children with cancer are at increased risk for adjustment problems, most experience
subtle vulnerabilities and not major problems. The research also suggests that among other things, the quality of family relationships and how the illness is handled over time are important predictors of long term adjustment.

Overview of the Literature Review

While the studies reviewed thus far point to important factors in the childhood cancer experience, a greater understanding of the specific ways families adapt and cope with cancer is needed. Two primary ways people adapt to the stressors presented by a chronic illness are to use a variety of coping strategies and to utilize available sources of social support. The focus of the present research is on the social support resources of children with cancer and their parents. Although understanding the specific coping strategies used by children with cancer and their families is important, it is beyond the scope of the present study. As such, a review of the coping literature is not provided. The interested reader is referred to Bull (1990) for a recent review of the children’s coping literature and a study of the coping strategies used by children with cancer.

To adequately understand the concept of social support and the relationship of support to childhood cancer, a brief review of the main conceptual and
methodological issues in the social support literature are presented. The importance of social support has only recently been addressed in children, although it has been widely assessed in a variety of adult populations. Some recent research has begun to explore social support in other childhood chronic illness populations, although again there are relatively few studies. To fully understand the implications of social support for children with cancer and their families, this review drew on the social support literature from healthy children, adult cancer patients, children with other chronic illnesses, as well as the literature on children with cancer.

Social Support

Definitional Issues

Regardless of the different stressors and specific coping strategies employed to deal with childhood cancer, most parents and children reach out for some kind of social support. Social support can be viewed as the resources provided by others in the context of interpersonal relationships (Belle, 1989). An individual's social support system is that subset of people in a total social network that one relies on for socioemotional and instrumental aid (Thoits, 1982). Cobb (1976) defines social support as information leading a person to believe she or he is 1) cared for and loved; 2) esteemed and valued; and 3) belongs to a network of communication and
mutual obligation. Social support can come from a spouse or partner, child, other family members, friends, professional caregivers, social community ties, and social support groups. Caplan (1974) defined social support as providing informational and cognitive guidance, tangible resources, and emotional sustenance. Others have viewed social support as the provision of specific resources such as giving advice, sharing tasks, and teaching skills (e.g. Barrera, Sandler, & Ramsey, 1981).

What these various definitions illustrate is that there are many qualitatively different kinds of support, with each affecting stress and coping in a different manner. Recent reviews of the literature divide descriptions of support into four categories: esteem/emotional, informational, instrumental/tangible, and companionship support (Cohen & Wills, 1985). Esteem or emotional support refers to statements or actions that convince people of their own value or worth. Self-esteem is enhanced by communicating to people that they are valued for their own worth, and unconditionally accepted. Informational support is viewed as advice or guidance which is helpful in understanding and coping with problems. Instrumental or tangible support is defined as the provision of resources or services necessary to solve practical problems. Instrumental aid might reduce stress
by directly resolving a problem or by giving the recipient increased time for leisure activities. Finally, companionship support refers to the opportunity to share activities and have a companion. Companionship support may reduce stress by fulfilling affiliative needs, by distraction, or by facilitating positive mood. While these support functions can be conceptually distinguished, they are usually related in natural settings (Cohen & Wills, 1985).

Researchers in the field have come to recognize social support as a multidimensional construct. There are different ways to operationalize social support, and each provides different information about an individual’s social relationships. Advances and refinements in the assessment of social support have lead to greater precision in the definitions of social support (Depner, Wethington, Ingersoll, & Dayton, 1984; Heitzman & Kaplan, 1988). More recent conceptualizations have demarcated three important aspects of support: social embeddedness, perceived quality of support, and enacted support; measures have been developed to assess each of these (Barrera, 1986; Wolchik, Beals, & Sandler, 1989).

The concept of social embeddedness relates to the connections and links between a person and their environment. These links suggest a relationship exists, but do not necessarily specify the adequacy or frequency
of the helping exchanges that may occur. Some measures of social embeddedness assess the characteristics of the social network, without determining if support transactions occur within the relationships. Others assess the occurrence of support from network members. Examples of what embeddedness measures might assess include the presence or absence of support, the density of and conflict within the network, as well as descriptions of the structural aspects or patterns of social ties within the network (Wolchik, et al., 1989).

Perceived quality of support refers to a person's appraisal of the subjective dimensions of support. Measures of this type assess the satisfaction with support received or perceptions of whether adequate support would be provided if needed. Examples would include ratings of helpfulness of various supporters or satisfaction with the specific kinds of support received. These measures clearly tap cognitive appraisals of support but may be strongly influenced by psychological functioning. As a result, these measures may be confounding the assessment of support and distress (Wolchik et al., 1989).

Enacted support refers to the frequency of supportive interactions that have taken place over a specified time period. Measures of enacted support assess
the frequency of supportive exchanges. While these measures are unique, the meaning of different levels of enacted support is complex. For instance, high levels of enacted support may indicate the presence of greater amounts of stress. Yet high levels of enacted support under conditions of low stress may reflect a dependent orientation in relation to one's social network (Wolchik et al., 1989). Assessing all three types of support is important because intercorrelations among the measures of these three concepts are low (Barrera, 1986; Cohen & Wills, 1985), and because measures of psychological and physical health relate differentially to these dimensions of support (Cohen & Wills, 1985; Wolchik et al., 1989).

Research has shown social support to be an important variable mediating the relationship between stress and adjustment in adults (e.g. Cobb, 1976). Reviews of the literature suggest that social support decreases or buffers the negative psychological impact of exposure to stressful life events and ongoing life strains (Cohen & Wills, 1985; Kessler & McLeod, 1985; Turner, 1983). Social support has been shown to decrease psychological discomfort in times of stress (Billings & Moos, 1982; Lin, Ensel, Simeone & Kuo, 1979; Williams, Ware, & Donald, 1981) and to enhance prospects for recovery for people who are ill (Di Matteo & Hays, 1981; Wallston, Alagna, DeVellis, & DeVellis, 1983).
Mechanisms by Which Social Support Affects Adjustment

While much research has explored the relationship among social support, health, and adjustment, little is known about the mechanisms by which social support affects health and adjustment to date. However, social support is postulated to work in one of two ways (Cohen & Wills, 1985). The main-effect model hypothesizes social support to be beneficial in both nonstressful and stressful times. That is, social support is believed to produce a generalized positive effect on individuals, regardless of the level of stressors. The buffering model views social support to be related to well being only for persons under stress. Essentially the hypothesis is that high levels of supportive interactions moderate the negative effects of stress on adjustment.

At the present time there is support for both models in the literature (e.g., Cohen & Wills, 1985;Thoits, 1982). In their review of the social support literature, Cohen and Wills (1985) argue that both the main-effect and buffering models of social support are correct in some ways, but each represent a different process by which social support affects well being. Nevertheless both models help to understand the complex relationship between social support and health.
Furthermore, close examinations of the literature indicate that different aspects of social support relate to adjustment in separate ways. Embeddedness measures provide evidence for a main-effect model (Barrera, 1986; Cohen & Wills, 1985; Wolchik et al., 1987). Researchers postulate that a large social network provides more chances for positive experiences and helps people avoid negative experiences. Furthermore large networks provide positive affect, a sense of stability and predictability to life, and a recognition of self worth. Measures that assess perceived availability and satisfaction with supportive functions, especially esteem and informational support, provide evidence in support of the buffering model (Barrera, 1986; Cohen & Wills, 1985; Wolchik et al., 1987). Esteem support is hypothesized as letting the individual know he or she is valued by others, which may lead to enhanced self-esteem and feelings of mastery over stressors. Informational support may help an individual to understand and cope more effectively with stressors. Both informational and esteem support may lessen the impact of stressors by reducing their perceived threat and importance. Instrumental and companionship support are assumed to be effective in buffering stress when the resources they provide are closely linked to the needs elicited by the stressful event.
Other researchers have proposed models that explain the way social support affects stress and adjustment without explaining roles the various types of support may have on stress. Sandler, Miller, Short, and Wolchik (1989) propose one such model. Within their model, social support affects three important intervening variables, self-esteem, perceptions of control over the world, and perceived security of social relations, all three of which influence adjustment. Social support is proposed to affect adjustment via three alternative pathways: preventive, moderating, and counteractive.

In the preventive pathway support prevents the occurrence of stressful events. For example, following the diagnosis of a chronic illness, a supportive family network might prevent the occurrence of stressors related to medical and financial troubles. Within the moderating pathway, support decreases the negative effects of stress on variables leading to maladjustment. For instance, perceived support might increase the appraisal that one has the resources to cope with stressful events. In the counteracting pathway support is unrelated to stress but directly strengthens variables which lead to adjustment, counteracting the negative effects of stress. Thus, support may enhance self-esteem, increase perceptions of control over the world, and/or enhance perceptions of security of social ties.
Sandler et al. (1989) suggest that support can affect any combination of the three intervening variables or all three of them. For instance confiding in one’s parents may lead to increased self-esteem, greater control, and decreased loneliness. At the same time, support can affect just one specific area. For example family rituals may affect the security of social relations.

Sandler et al. (1989) also suggest that stress can have one of three effects on social support. Stress can increase support if it mobilizes a person’s network to meet the coping demands of a situation. Stress can also lead to a deterioration of a support network, thereby having a negative effect on adjustment. Finally, stress can have no effect on support but have an independent negative effect on adjustment. This model provides a synthesis of various mechanisms by which social support has been postulated to relate to stress and adjustment in the literature. Although there is no data to support the model at this point in time, researchers should attempt to test the model and assess its applicability.

One further issue to address is the relationship between social support and coping, since social support interfaces with most coping strategies in the stress and coping literature (e.g. Thoits, 1986). While coping and social support are related and influence one another, they
are distinct phenomena which both can have independent impacts on health. Social support can exist independent of general coping (i.e. gratification of affiliative needs, maintenance of self identity and self-esteem). In addition, positive coping resources (e.g. money, intelligence) and adaptive coping strategies (relaxation techniques) can occur in the absence of social support (Heller, Swindle, & Dusenbury, 1986; Shumaker & Brownell, 1984). Therefore, actions of people that enhance an individual's sense of well being or self-esteem can occur regardless of attempts to cope with stressful experiences. Furthermore, social support processes also make an independent impact because of people's interpersonal styles and the relationships they develop (Heller et al., 1986).

Although coping and social support are viewed as separate but related constructs, it is postulated that coping and social support are linked through the appraisal process (Heller et al., 1986). Within the coping literature, appraisal is seen as the cognitive process where one decides if a situation is potentially threatening or challenging, or involves loss or harm. Appraisal is influenced by one's view of the situation and one's resources to handle the situation (Cohen & Lazarus, 1979). Within the domain of social support, appraisal is the cognitive process where one decides whether a social
relationship or act of support is helpful or not helpful. Thus, it is the meaning of the social activity to the individual that determines how the support is perceived. The implication for research is not only to assess the impact of support on health or adjustment, but to also assess how the support is appraised.

Problems with the Social Support Research

While the quality of the research in the area of social support has improved, methodological problems remain within the literature. One criticism of the social support research to date is the lack of good or consistent operational definitions of social support. Although advances have been made in the precision of social support definitions, researchers often do not specify whether they are assessing embeddedness, enacted support, or satisfaction with support. To compound the problem, conclusions are drawn about social support in general, and not linked to the specific type of support assessed (Wolchik et al., 1989). Another problem is the potential confounding of the direct effect of life events upon support, and the interactive (buffering) effect of life events with support. Life events may alter the support available while support may decrease the likelihood of events occurring (Thoits, 1982). Furthermore, assessments of social support and adjustment may be confounded since
both are often assessed via self-report measures. Negative views of psychological states could lead to negative views of the people in one's life (Heller et al., 1986).

These methodological problems indicate that in the assessment of social support, researchers need to carefully select and specify the type of support to be assessed. Furthermore, outcome measures using different informants and different modes of assessment need to be used whenever possible.

**Social Support and Children**

While the literature on social support in adults is large, researchers have only recently identified social support as an important area to study in children. Exploring social support and support networks in children is important for several reasons. First, childhood is a period of social vulnerability and physical reliance on others. Second, children acquire a contextual sense of self across multiple sources and settings such as family, school, and peers. Third, the developmental literature on attachment in infancy stresses the importance of children’s relationships in widening their social worlds. Finally, as with adults, stressful life experiences have been shown to contribute to the mental and physical health problems of children and youth (Belle, 1989; Compas, 1987; Sandler et al., 1989). Thus, exploring children's
perceptions of social support and support networks will help in further understanding the role of social support and social relations in children's lives.

**Children's Descriptions of their Support Networks.**

Given that the various aspects of support relate to adjustment in different ways, initial research in the area sought to understand what aspects of support were most important to children. Early findings suggested that children might not conceptualize social support by the kind of behaviors provided by network members (e.g. self esteem support, tangible aid) but according to the source of the support such as family, peers, or nonfamily adults. As a result, in initial studies of children's support networks, researchers interviewed children, asking them about each person in their network, and then categorized the type of support described (Berndt & Perry, 1986; Dubow & Ullman, 1989; Wolchik et al., 1989).

To explore children's perceptions of social support, Reid, Landesman, Treder and Jaccard (1989) developed 12 semistructured dialogs. The dialogs assessed children's perceptions of availability of individuals in their networks to provide different types of social support, and assessed children's satisfaction with support received. Results from a study of 249 six to twelve year old children indicated that their self-reports did differ as a
function of who was being rated and the type of support being considered. Parents were reported to be the best multipurpose providers of social support in children’s networks; they were turned to most frequently and provided all types of support. Friends and teachers were seen as having a more specialized social value. Friends were rated as especially good in their companionship support and as skilled at providing emotional support. On the other hand, teachers were depicted as the best source of informational support to children. The investigators also described the children as being invested in having their informational needs met and as easily recalling memories for special acts of kindness and sensitivity others had shown them.

To assess children’s subjective appraisal of family, teacher, and peer support, and to assess the size of children’s social networks, Dubow and Ullman (1989) developed a scale, the Survey of Children’s Social Support. Three hundred and sixty one third through fifth grade children were administered the scale. Results indicated that both the frequency of supportive behaviors and the appraisal of support were positively related to global self-worth. As found with adults, the frequency of supportive behaviors available from the support network was only moderately correlated to subjective appraisals of support, and neither of the above were related to the size
of the child's social network. Children were able to
distinguish among some types of support (e.g. tangible
versus informational), yet they did not necessarily
distinguish between emotional and informational support,
although esteem enhancing support was viewed as a separate
function.

Consistent with Reid et al. (1989), other researchers
have also found parents to be important sources of support
to children. Positive relations with mothers and
frequency of confiding in them has been shown to be
related to high academic achievement, personality
adjustment, high level of self-esteem and internal locus
of control (Belle & Longfellow, 1984; Biller, 1986; Parke,
1981). Rutter (1979) found a good relationship with at
least one parent to be a protective factor buffering
children from the potential adverse effects of marital
discord, parental psychological disturbance, and social
disadvantage. Cauce (1986) explored perceived quality of
supports and found higher family support to be related to
higher scholastic self-concept. Perceived quality of
support and enacted support were assessed in children in
the second through eighth grades by Furman and Buhrmester
(1985). Family support was found to be important to
children in the second through fifth grades, but less so
with adolescents, who viewed friends as more important.
However, the greater the connections between adolescent’s parent and friend networks, the better the adjustment in adolescents.

Harter (1986) assessed third through eighth grade children’s perceptions of support and regard from four sources of support: parents, classmates, teachers, and close friends, using the Social Support Scale for Children and the Self-Perception Profile for Children. Results supported age-related differences in children’s perceptions of support. Elementary school children (i.e. third and fourth graders) did not appear to differentiate classmate support from close friend support, yet middle school children (i.e. sixth, seventh, and eighth graders) did. For young children, peers in general provided feedback about the self. However, for the adolescent, it was their network of close friends that became critical for providing feedback about the self (Harter, 1986). Perceptions of support were shown to be moderately related to global self-worth and perceptions of competence.

Developmental and Sex Differences.

Developmental shifts within children’s peer networks were also found using a global network inventory with fourth through tenth grade children and youth (Furman, 1989). Being part of a group was found to be more important to early adolescents (seventh through tenth graders) than to younger children or older adolescents.
Adolescents have also been shown to be more intimate and disclosing with peers about personal issues previously discussed only with parents, than younger children (Hunter, 1985). Furthermore, friendships are perceived as becoming more supportive relationships as children approach adolescence (Berndt, 1989).

Other researchers have also documented a developmental shift in both the structure and the size of children's social networks. Feiring and Lewis (1989) found children's social networks to change with age and developmental level. By the age of nine, children's networks have grown substantially, increasing in number and contact with adults and peers. Belle (1989) explored sex differences in children's support networks. Interviews revealed that boys had social networks that were larger and more active than girls. Girls tended to have more intimate, self-disclosing dyadic relations, whereas boys relied on groups and sports for their interactions. Boys turned to peers and nonfamily adults more than females, yet girls were more disclosing and intimate when they turned to confidants. Associating with members of one's own sex, was found to increase in the childhood years, peak in late childhood, and stabilize during adolescence.
Measurement Issues.

As found with the adult literature, refinements need to be made in the measurement of children's social support. At this point there are only a few social support inventories whose psychometric properties have been examined (Wolchik et al., 1989). In general, test-retest reliabilities are not as stable as those found for adult measures of social support. Yet, controlled studies need to be carried out to determine whether this lack of stability is due to problems in the inventories, fluctuations within the child, or true fluctuations in social support. Preliminary data on construct validity has found weak to moderate relations between social support and adjustment. These weak relations may be because researchers haven't assessed important moderator variables such as sex of the child or family size. Or, the construct of social support may not be as meaningful in a child population. The weak relationships could also be due to problems in the measures themselves. Measures with poor reliability could attenuate the relations between indices of support and adjustment (Wolchik et al., 1989). Regardless, these methodological limitations suggest further research in the area of children's social support is need to address these important issues.

Nevertheless, the findings from the studies on children's support resources and networks indicate
children and adolescents can describe their support networks, as well as differentiate among various types of support. In addition, many of the characteristics of children's networks are similar to those of adults.

**Relationships among Stress, Support and Adjustment**

In addition to studying descriptive characteristics of children's and adolescent's support networks, researchers have also explored the relationships among social support, stress, and children's adjustment. Wolchik et al. (1989) interviewed 285 eight to sixteen year old children about three types of social support: social embeddedness, enacted support, and perceived quality of support. Children in the study had either experienced a parental death or parental divorce in the past two years, were chronic asthma sufferers, or were part of a matched control group. Higher levels of enacted support were associated with greater satisfaction with support. Higher levels of satisfaction with family support were found to be associated with lower levels of depression and conduct problems. Higher levels of satisfaction with nonfamily members was related to lower levels of anxiety.

The relationship among stressful life events, social support, social problem solving, and behavioral and academic adjustment was explored in third through fifth
grade children (Dubow & Tisak, 1989). The researchers found higher levels of social support and social problem solving moderated the negative effects of stressful life events on teacher rated behavioral problems. Social support was found to be directly related to parent ratings of behavior problems and teacher’s perceptions of children’s competence. These findings suggest the protective influence of social support might depend on a match between the source of the support and the context in which support is being measured.

The relationship among personal, family, and peer resources and psychophysiological symptoms was examined in adolescents from an outpatient medical clinic (Walker & Greene, 1987). Perceived personal efficacy, peer support, and family cohesion were found to be related to psychophysiological symptoms. Low family cohesion was related to high symptom levels for males and females, regardless of stress level. This finding suggests a lack of family cohesion may be stressful in and of itself. Peer support buffered against life stress for males, whereas it had no effect for females. Results suggest that for females, peers may not discourage somatization when they are faced with negative life events.

The studies reviewed thus far suggest that social support is related to a variety of indices of adjustment in children and adolescents. As in the adult literature,
there is some initial evidence for both main and buffering effects of support on children's adjustment. Given the fact that children with cancer face many stressors, whether from the treatment they receive or from the difficulties associated with surviving a chronic illness, understanding the role social support plays in the adjustment process seems crucial.

The Cancer Patient

The studies reviewed thus far described children's social support resources and explored the relationship of support to the adjustment of healthy children. Before reviewing the literature on social support in children with cancer, the literature on social support in adult cancer patients and parents of children with cancer will be briefly reviewed. Then the literature on social support in children with cancer and other chronic illnesses will be reviewed.

Several researchers have examined the importance of social support to the adult cancer patient. Dunkel-Schetter (1984) interviewed 79 cancer patients 7 - 20 months post diagnosis to assess the types of support they were receiving and their perceptions of this support. Ninety five percent of her sample described receiving emotional support and perceived this support as helpful. Additionally, the types of support seen as helpful
depended on who was providing them. That is, informational support was seen as helpful when coming from medical staff, but not when it came from the family.

Other researchers have also found the majority of adult cancer patients perceive the degree of social support they receive as adequate or outstanding (Lichtman & Taylor, 1986; Smith, Redman, Burns, & Sagert, 1985). A positive relationship between emotional support from family members and the degree of psychological and physical adjustment by cancer patients with advancing disease has also been found (Weidman, Gibbs, & Achterberg-Lawlis, 1978). Patients with a good prognosis have also been shown to adjust better with high levels of social support (Bloom, 1982; Punch & Mettlin, 1982). Furthermore, longitudinal studies indicate social support at the time of diagnosis is associated with less emotional distress and a longer life (Weisman, & Worden 1976; Vachon, 1979).

Parents of Children with Cancer

Social support has also been shown to be related to adjustment in parents of children with cancer. Morrow, Hoagland, and Carnrike (1981) examined the relationship among perceptions of social support and psychosocial adjustment in 107 parents of children who had cancer. The parents participating either had a child on treatment, had a child who was finished with treatment, or had lost their
child. As expected, parents whose children had died showed poorer adjustment than parents whose children were in active treatment or had completed treatment. For parents with a child in treatment, satisfaction with support from spouses, relatives, friends, doctors, and other parents with sick children correlated positively and significantly with total psychosocial adjustment. For parents whose children were off treatment, only support from relatives related to psychosocial adjustment. No significant relationships were found for satisfaction with support and psychosocial adjustment for parents whose children had died. The authors suggest that social support is particularly beneficial to parents whose children are in active treatment. However, all parents were involved with a national support group for parents of children with cancer. Perhaps for those parents whose children had died or were off treatment, the support provided by the group was a more important predictor of psychosocial adjustment than the support of spouses, friends, doctors, or relatives.

The relationship between psychological distress and satisfaction with social support has also been explored in parents of children with cancer (Magni, Silvestro, Carli, & DeLeo, 1986). Twenty six parents whose child had recently been diagnosed with leukemia filled out social
support and psychological distress questionnaires. Greater satisfaction with support was found to be associated with lower levels of distress for parents during the early diagnostic phase of their child’s cancer treatment.

Other researchers have used interviews to assess satisfaction of support in parents of children with cancer. Chesler and Barbarin (1984; 1987) used semi-structured interviews to explore parents’ perceptions of the way friends did and did not help them during their child’s cancer experience. Ninety five parents from fifty five families with a child (aged 4 - 21) with cancer were interviewed about their perceptions of friends’ helping behavior. Interview data illustrated that parents turned to various sources of social support and help. Parents with more education reported more help from friends than parents with less education. Parents of children who had died reported more help from close friends than those with children who were alive. In general, parents described friends as helping them in many ways: by providing emotional and companionship support, by offering tangible support and problem solving assistance, and by helping to organize other support resources in the community. Yet, parents also felt that their friends’ compassion and desire to help was complicated by their own emotional distress. Parents’ described friends as not being helpful
in several ways: by invasion of family privacy, by the stigma associated with "nonnormality", and by attempts to try and find ways to be useful or helpful when help wasn’t needed. Thus, those who are sources of help may also be sources of added stress. Chesler & Barbarin’s (1984) findings illustrate that support can have drawbacks as well as benefits.

*Children with Chronic Illnesses.*

Most studies of chronically ill children have assessed parental perceptions of support. One exception is a study of the relationship among stress, satisfaction with support, and depressive symptomatology in children with congenital or acquired limb deficiency (Varni, Rubenfield, Talbot & Setoguchi, 1989). Overall satisfaction with support from parents, close friends, peers, and teachers were found to be comparable to findings for healthy children. In addition, children’s perceptions of social support from parents, teachers, and classmates were found to be directly related to depressive symptoms, regardless of the level of daily stress or life events. Thus, social support was found to be related to adjustment for children with limb deficiencies.

Studies of children with other chronic illnesses have explored the relationship of family factors to children’s adjustment, since the family is so important to children’s
development. Kazak, Reber, and Carter (1988) explored the qualitative and structural aspects of social networks in families with young children with PKU and matched control families. Results revealed few significant group differences in assessments of social network size and network density. However, differences were found for qualitative aspects of support. Parents of chronically ill children had a larger network of professional helpers. Mothers of ill children were also less likely to name their spouse and parents as members of their support network than comparison group mothers. Larger, less dense networks were associated with decreased experiences of psychological distress for parents with and without an ill child. The authors suggest these broad networks may provide advantages to families in the early child rearing stage of the family life cycle.

The role of practical and psychological family resources in the behavioral problems and social competence of handicapped children and children with chronic illnesses was studied by Wallander, Varni, Babani, Banis, and Wilcox (1989). Children whose families participated had juvenile diabetes, juvenile rheumatoid arthritis, chronic obesity, spina bifida, and cerebral palsy. Findings illustrated that both practical (maternal education and family income) and psychological family resources (cohesion, conflict, organization) were related
to variations in children’s psychosocial adjustment as assessed by behavior problems and social competence. Families with higher maternal education and income, along with high levels of family cohesion and organization, and low levels of family conflict, had children with fewer behavioral problems and higher social competence.

Other researchers have also found family relationship factors to be related to psychosocial adjustment in children with several different chronic illnesses. For children with sickle cell anemia, higher family cohesion was found to be related to better child adjustment (Moise, 1980). Diabetic children have been shown to have higher self-perceived competence in families who were high in independence, achievement, activity, and organization (Hauser, Jacobson, Wertlieb, Brink, & Wentworth, 1985).

Children with Cancer

The adult literature reviewed suggests that social support has been found to be important to parents of children with cancer, as well as to adults with cancer. In more descriptive research, adult cancer patients often describe themselves feeling isolated and as wanting more opportunities to discuss and talk about their feelings with other people, but especially similar others. These issues are equally as important for children with cancer,
since their social networks and supports are more limited than the networks of adults. To compound the problem, children with cancer are often cut off from their friends, classmates, and other means of support. The isolation (decreased contact) is due to treatment schedules, absences from school, and decreased opportunities to discuss feelings because of the social taboo surrounding discussion of illness. Parents aren’t always able to provide the support and help the child needs because they are concerned with the long term consequences of the illness and are trying to cope themselves (Wortman, 1984).

In exploring social resources in children with cancer, early studies indirectly assessed different aspects of social support. Research by Susman, Hollenbeck, Nannis, and Strope (1980) suggests that children with cancer want others to interact with them in ways which may be different from the ways others actually do react to them. Adults were often found to withdraw from a child with a relapse, yet the children indicated they wanted more contact. Deasy-Spinetta (1981) found children with cancer to be less likely to express freely their positive and negative feelings, and were more passive in social interactions. Links between communication and both mood and adaptive coping strategies have also been demonstrated in children with cancer (Kellerman, Rigler, Siegel, & Katz, 1977; Spinetta &

In a recent study, the relationship of social support, family adaptation, and psychosocial adjustment was explored in thirty five adolescent survivors of childhood cancer (Kazak & Meadows, 1989). Children with cancer, their parents, and a comparison group were assessed at two time intervals, six months apart. Cancer survivors did not differ from control children on measures of perceived competence, social support, behavioral problems, family adaptability or distress. There were, however, significant changes in cancer survivors’ perceptions of social support over time.

Survivors reported receiving less emotional support and caring from their families and friends, and less help and guidance from friends than matched control children. Both matched control and survivor children reported receiving less emotional support and caring, as well as less help and guidance from teachers and other nonfamily adults. Satisfaction with emotional support, age at time of diagnosis, family adaptability, and school changes were found to be important predictors of adjustment as reflected in adolescents’ perceptions of social acceptance. Consistent with other studies of social
support, satisfaction with support was an important predictor of well-being. Being young and not in school at the time diagnosis and treatment occurred, suggested a lessened impact of cancer on social relationships. School transitions that occurred also affected social acceptance, suggesting that stability in peer relationships and settings is important to those who have experienced cancer. As with other chronic illnesses, family adaptability was also found to be important, as adjustment of the family affects the adjustment of the ill child.

In another study, cancer survivors were interviewed about their perceptions of support during the time of their active treatment (Tebbi, Stern, Boyle, Mettlin, & Mindell, 1985). Twenty seven adolescents who had amputations as a part of their cancer treatment, participated in interviews about the social support they received at the time of their surgery. Most of the adolescents (80%) described their parents, and their mothers in particular, as being quite realistic and most helpful at the time of the surgery. Fifty nine percent of the adolescents viewed hospital staff as helpful, and 57% viewed siblings as being helpful at the time of the surgery. Friends, however, were described as less helpful at the time of the surgery. Some were characterized as displaying too much pity, while others were seen as avoiding the friendship or gradually drifting away.
Although the developmental literature suggests that peers become increasingly important to children, this study seems to suggest that the family is an even more critical source of support to adolescent cancer patients while they are undergoing treatment.

In a retrospective study of cancer survivors, Fritz, Williams, and Amylon (1988) explored factors predictive of psychosocial adjustment. Fifty two survivors, two or more years post-treatment, were given questionnaires and interviewed about their social support resources during their cancer experiences. Most illness related variables were not found to be significant predictors of psychosocial outcome. However, during treatment, communication patterns such as the directness of communication and the availability of support (e.g. how actively helpful peers were, best friend being available) were related to psychosocial outcome. That is, good psychosocial adjustment was associated with having direct communication and available supports.

As studies with healthy children and children with other chronic illnesses have illustrated, social support from peers and families, as well as the ability to communicate feelings to others, are both important to adjustment during the cancer experience. Although it is important to understand who people informally turn to for
social support, exploring the use of formal sources of support is also important to understanding the support resources of children with cancer and their families.

**Formal Sources of Support**

The literature reviewed thus far suggests that people who can maintain close interpersonal relationships with family and friends are more likely to cope effectively with their illness. Yet many cancer patients describe experiencing considerable difficulties in interpersonal relationships due to their illness (Wortman & Dunkel-Schetter, 1979). Many patients report that the feedback they receive is often inconsistent and mixed from those in their support networks. Friends and family often present conflicting verbal and nonverbal cues or retain an overly cheery and optimistic approach to the patient.

Although individuals with cancer are in need of support, others are not always supportive of them. As a result, the cancer patient is left in a confusing and ambiguous situation and in need of clarification and support. Social comparison theory (Festinger, 1954; Schachter, 1959) suggests that confusion and ambiguity is decreased by social comparison with others in a similar situation. For a person with cancer this could mean learning from others with cancer that it is normal to be angry or depressed when first diagnosed. In addition, this could mean getting feedback about the meaning and
appropriateness of one’s behavior since the experience being shared is the same (Revenson, Wolman, & Felton, 1983; Shinn, Lehman, & Wong, 1984).

Support Groups

As a result of this inadequate support, many individuals with cancer search out support groups for people with cancer. In a recent study by Taylor, Falke, Shoptaw, and Lichtman (1986), questionnaires were sent to 666 adults with cancer to assess use of organized social support resources. Sixty percent of the sample were found to attend some form of organized support group. Nonattenders were more recently diagnosed, and attenders tended to be female and of higher SES. In general, support group participants indicated that family and friends were perceived as supportive, suggesting communication problems alone were not the sole reason for joining the group. Furthermore, support group participants tended to use other social support resources at the same time. Therefore, these group were not their only form of support.

Parents of children with cancer have also been interviewed about their support group usage. Chesler, Barbarin, and Lebo-Stein (1984) and Barbarin and Chesler (1987) found those families participating in self help group were married, lived closer to the hospital, had
a child diagnosed one to four years earlier, and had a higher degree of perceived stress from their child’s illness than nonparticipants. As was found with adult cancer patients, parents of children with cancer in support groups also utilized and received social support from a variety of sources, especially coworkers, friends, and parents of other ill children. The findings suggest that parents may not participate in support groups within the first year of diagnosis because they need time to adjust to their new identity and may be too busy for group activities. Yet the research suggests that a fair number of parents will join support groups later on in the illness experience.

The nature and types of parents’ active roles in self-help groups for parents of children with cancer has also been explored (Yoak, Chesney, & Schwartz, 1985). Questionnaires were distributed to 131 parents participating in 43 groups. Parents reported being involved in groups at the interpersonal level, creating and sustaining one-to-one contacts for reciprocal support. Parents described their motivation for group involvement in terms of active help seeking and information seeking, for help with problem focused coping, and because of the desire to help others. Sixty eight percent of the parents were also involved at the organizational level, building and leading groups. Parents were also actively involved
at the institutional level, using the self-help group as a base for individual and group level advocacy. Thus, support groups provide parents with support, as well as active ways to cope with and have an impact on the illness experience.

Support groups have also been established for children with cancer. To date, no formal assessments of children’s perceptions of these groups have been published in the literature. Yet it would be important to explore whether the findings for adults are comparable for children.

**Religious Faith**

The literature also suggests that many families turn to their religion and their faith as a source of support during the illness experience. Many parents participating in Chesler and Barbarin’s (1987) study of families of children with cancer described having a coherent religious belief system to rely on. Other researchers have also found religious beliefs and philosophical outlook on life to be predictive of adjustment in long term survivors of childhood cancer (Chodoff et al., 1964). The implication for research would be to assess the extent to which a person relied on and perceived their faith as important.
Camps for Children with Cancer

The child with cancer is also in need of more social support. The result of the increased awareness of the emotional and social needs of the child with cancer has been the establishment of one to two week summer camps specifically for children with cancer. The overall goal of these camps is to have children with cancer participate in the same childhood activities as healthy children; the process described is generally known as therapeutic camping. The specific goals of these camps to help children 1) develop self confidence and independence; 2) develop new friendships, 3) develop a spirit of group identity; and 4) develop skills and explore interests (Shields, Abrams, & Siegel, 1985).

Research is just beginning to appear that evaluates the effectiveness of these camps. Smith, Gottlieb, Gurwich, and Blotcky (1987) evaluated the effects of a one week residential camp on the daily activity and family interactions among 18 children with cancer, their parents, and their siblings. They found children with cancer evidenced increased physical activity two weeks after camp but this increase was not maintained at the one month follow-up. The child’s social activities increased and self-engaged activities decreased at both two weeks post camp and at the one month follow-up. Parents spent more time with friends and family during the week of camp, and
maintained this increase at the two week and one month intervals. Siblings increased their activities with the family and decreased activities with their peers at all time intervals. The authors concluded that camps for children with cancer do have a positive impact on children by allowing them to engage in normal healthy activity, along with providing a reprieve for the family members to meet their own needs.

Yet camps for children with cancer are providing children with more than just the opportunity to engage in normal activities; they provide the opportunity for emotional, companionship, instrumental, and even informational support. These camps increase the child’s contact with other children who are sick, enabling them to develop a sense of belonging; increase the child’s social network (counselors, staff, campers); provide the opportunity for peer support; and provide the ability to participate in developmentally appropriate activities. Not only do these camps gratify children’s affiliative needs, help maintain and enhance self-identity and self-esteem, but they provide children with the opportunity to compare their behavior and feelings with an appropriate peer group.

While these camps are intuitively appealing, some researchers have suggested social comparison could be
damaging if the comparison results in a less favorable outcome for the self (Cohen & McKay, 1984). At a camp where children range in illness stage, these negative comparisons could potentially occur. Yet Taylor et al. (1986) found upward comparisons to be rare in adults with cancer. In fact, other researchers have found adult cancer patients usually seek patients to compare themselves to that they perceive as equals. In addition, people tend to shift their comparisons if beliefs are disconfirmed (Molleman, Pruyn, & Van Knippenberg, 1986; Spiegel, 1986). No research has looked at social comparison in children, but one would expect the findings to be similar. Nevertheless, when evaluating a means of social support such as a summer camp, it would be important to assess both the positive and negative consequences associated with the support (Wortman, 1984).

Furthermore, since appraisal has been shown to be central to people’s perceptions of support, it would be important to understand how these camps are perceived by the families that use them. That is, exploring what camp means to both the child who attends and his or her parent. To date researchers have explored the effects of camp on children’s and families’ activities, but have not examined their appraisals of these camp and the support they provide.
Research Implications

The review of the literature to date indicates that although we know a fair amount about the families of children with cancer, there is still a great deal to be learned about childhood cancer and family functioning. Specifically, we need to learn more about perceptions of social support and formal and informal support resources utilized by children with cancer and their families. Furthermore, these two areas need to be assessed within the context of the family since the family has such a large impact on the child's adjustment to cancer. Finally, with the establishment of psychosocial interventions such as cancer camps, important information about who uses and benefits from these services also needs to be assessed.

The literature reviewed suggests several important areas for further research regarding the social support perceptions and resources of children with cancer and their families. Presently there is a growing body of research concerning healthy children's descriptions and perceptions of support and their support networks. However, relatively little research has focused on the support resources of children with chronic illnesses, cancer in particular. Stress associated with the cancer experience could alter the support process, resulting in an increase or decrease in the support provided.
Therefore, researchers need to understand in detail what kinds of support children and parents receive in relation to the illness experience, along with their general perceptions of support. Although preliminary investigations of support in children with cancer report some findings which are similar to those in healthy children, the majority have been based on retrospective studies that either relied solely on interviews or were based on studies that relied on parental perceptions of support. As such, it would be important to describe the support providers and formal and informal resources children with cancer and their families utilize specific to the cancer experience, along with assessing their satisfaction with the support received.

While understanding support in relation to the illness is important, satisfaction with overall levels of social support should also be assessed. For children in active treatment for their cancer, these two assessments might be one in the same. However, for those children off treatment, they could potentially be quite different. Therefore, satisfaction with the overall level of social support and perceptions of family functioning should be examined. The recent advances in the assessment of social support in children allow for both qualitative assessments of support via interviews, and quantitative assessments of support using standardized measures.
Although most children and families have been shown to cope and adjust fairly well to the cancer experience, demonstrating a great deal of resilience, subtle variations in adjustment have been noted. What is still unclear is whether perceptions of satisfaction with support relate to adjustment in children with cancer, along with other illness, demographic, and family factors.

Finally, over the past five to ten years there has been a growing interest and popularity of camps for children with cancer. Although these camps meet children's recreational needs, they are also providing valuable opportunities for peer interactions and may potentially enhance the support networks of children with cancer. What remains to be explored is how children and their families perceive and describe these camps, to determine whether these camps are meeting their support needs.

The Present Study

Therefore, the present research had four primary purposes: 1) to describe and assess the satisfaction with social support resources used by children and their parents to cope with the cancer experience; 2) to assess satisfaction with the overall level of social support and perceptions of family functioning and competence in children with cancer and their parents; 3) to explore the
demographic, illness, social support, and familial factors that predict psychosocial adjustment in children with cancer; and 4) to describe and assess children's and parents' perceptions of the cancer camp experience and their satisfaction with the services these camps provide.

To this end, 46 children with cancer attending one of two cancer camps, and their parents, participated in home interviews. Children's social support resources, self-concept, intelligence, and perceptions of camp were assessed using semi-structured interviews and standardized questionnaires. Parents' social support resources, perceptions of family functioning, child behavior, and camp were assessed using semi-structured interviews and standardized questionnaires.

Rationale for the Research Measures and Design

The proposed study was exploratory in nature, as no comparisons were made between children with cancer who attend camps and those with cancer who don't attend such camps, nor were comparisons made with healthy children. While these comparisons are informative and necessary, they were beyond the scope of the present research. The proposed study took a preliminary step in the research process by fully assessing and describing the social support providers, resources, and perceptions of children with cancer and their parents. It is hoped that the information provided by the present study will be the
foundation for further controlled and comparative research with children with cancer.

Only studying children who attended cancer camps limits the generalizability of this research. However, since these camps have become more popular and widespread, a good proportion of children with cancer may now be attending them. Thus, the information obtained from this study should be generalizable to that subgroup of children with cancer who attend camps for children with cancer. Since children who attend two different camps were evaluated, comparisons were made between the camps where appropriate. These camp comparisons allowed for an examination of the characteristics of children attending each of the camps. Thus if there are/were "typical" profile(s) of children who attended these camps, they could be delineated via the camp comparisons. The information obtained from this study could then be the starting point for controlled comparisons among children at various other cancer camps.

The information collected in this study may also help in understanding what attracts families to camps for children with cancer. Given this information, future research could examine whether people choosing not to participate fail to recognize the positive attributes of camp attendance or simply just aren't interested.
Furthermore, the information collected in this study will help to determine what aspects of this specific psychosocial intervention are perceived as beneficial by children with cancer and their parents. Such information could then be used in designing other interventions for children with cancer.

The literature suggests that it is important to study children with cancer from a developmental perspective (Rutter, 1981; Susman et al., 1980). The belief is that developmental processes proceed under stress, however they are altered. This is particularly important when examining children who have undergone such an adverse experience as cancer. As Rutter (1981; 1987) has indicated, adverse experiences early in life may alter the course of subsequent development by sensitizing one to stress or by modifying patterns of coping. Therefore it would be important to examine social support as a function of the age of onset of the illness, the elapsed time since diagnosis, and the stage of the illness (Rolland, 1984).

However, within the chronic illness literature, few illness related variables have been shown to be related to psychosocial adjustment (e.g. Fritz et al., 1988; Kazak & Meadows, 1989; Kupst & Schulman, 1988). The sample of children with cancer used in the present study was relatively homogeneous in terms of illness characteristics. Most children were off treatment and in
remission or considered cured at the time of the study. Data was collected on a variety of illness variables (e.g. age of onset, duration of illness, stage of illness, treatments received). This illness information was used to describe the sample in detail, to inform decisions about data analysis, and in the analyses of predictors of adjustment.

Developmental factors were taken into consideration in the data analyses by examining differences, where appropriate between younger children (7 - 12) and adolescents (13 - 17). Although this developmental breakdown is rather broad, there were several reasons for dividing the age groups in this manner. Children participating in the study ranged in age from 7 to 17 years. Given a relatively small sample size and the distribution across each age, this split allowed for almost equal sample sizes in each group. Furthermore, this age breakdown has been used in one other study of children with cancer (Kupst & Schulman, 1988). Although this age split may be masking developmental differences, it did allow for a preliminary exploration of age differences.

The descriptive literature on children's social support networks and support perceptions indicates that males and females perceive and utilize support differently
(e.g. Belle, 1989). Therefore, where appropriate, the present study examined sex differences in order to determine whether these differential gender findings held true for children with cancer.

Assessing the family was considered essential to the study of social support in children, since the family is viewed as the child's primary social support group (Spinetta, 1983). In addition, because the family mediates the reactions of its members to a chronic illness or stressor, understanding how the family perceives and utilizes support may shed insight on the information obtained from the child (McCubbin, Joy, Cauble, Comeau, Patterson, & Needle, 1980).

The main construct to be explored in the present study was social support. As indicated in the literature review, the method by which support is assessed influences the impact it is found to have on adjustment. Embeddedness measures appear to relate to direct effects on adjustment, while enacted support and satisfaction with support seem to moderate the effects of stress on adjustment (e.g. Wolchik, et al., 1989). The primary intent of this research was to explore children's and parents' descriptions of helping behavior and support specific to the cancer experience, along with assessing perceptions of satisfaction with support received for the cancer experience and in general.
Therefore, standardized measures of support were used to assess general perceptions of support, and semi-structured interviews were conducted to understand support specific to the cancer experience.

To assess children's general perceptions of social support, the Social Support Scale for Children (Harter, 1986) was used. This scale provided information regarding children's perceptions of support and positive regard received from parents, teachers, classmates, and close friends. Additionally, use of this scale allowed for a comparison of the levels of perceived support of children with cancer with those of healthy children provided in the normative data on the scale.

This scale was selected for use in the present research for both theoretical and practical reasons. As the literature on children's social support indicates, children primarily describe social support by the source of the support (e.g. parent, friend) and not by the type of support (e.g. informational; emotional) received (e.g. Reid et al., 1989). This scale was selected because it provided an assessment of support across various sources of support (e.g. friends versus teachers). Furthermore, the scale is described as assessing perceptions of support. Although the scale does not assess enacted support or social embeddedness, perceptions of quality of support were the main interest in this study.
Practical considerations also influenced the selection of the scale. While several standardized measures were available to assess adolescent's perceptions of support at the time this study was designed, Harter's (1986) scale was the only standardized measure available that assessed younger children's support perceptions. Since the children participating in the study ranged in age from 7 to 17, a measure was selected which tapped the broadest range of children participating. However, it should be noted that the scale was not normed on adolescents as it was designed for children in the third through eighth grades. Therefore the use of the scale with the adolescents in the present research must be considered exploratory.

There is much debate in the adult social support literature on whether to assess functional (e.g. satisfaction) or structural (embeddedness) aspects of support. Recent reviews of the adult literature (e.g. Heitzman & Kaplan, 1988) indicate that network measures are more reliable yet less likely to be valid, as compared to support perception measures. The adult social support literature suggests that assessments of the quality of support are more important to the individual than assessments of the quantity of support. Furthermore, the research suggests it is the perception of support and not
the actual receipt of support which is essential. This has been found to be especially true when examining the effects of support on health and illness (Schaefer, Coyne, & Lazarus, 1982). Therefore, the Social Support Questionnaire (Sarason, Levine, Basham, & Sarason, 1983) was used as the standardized measure of social support for parents in this research. This measure was selected since it assesses both the number of supports, as well as the satisfaction with support, and because it is widely used in the adult social support literature.

Children’s and parents’ perceptions of support received during the cancer experience and from camp were assessed via semi-structured interviews designed by the author. The literature suggests that help or support can take many forms and can be defined differently by each person interviewed (e.g. Dubow & Ullman, 1989). Therefore interviews were designed using open-ended informant generated and close-ended pre-structured questions. The format of the interviews used by Chesler and Barbarin (1987), in their descriptive study of children with cancer and their families, was used to generate an initial format for the interviews. The interview was designed for the child and then modified to be used with parents.

Although the design of the present study is similar to that of Chesler & Barbarin (1987), there are important
differences. Chesler and Barbarin (1987) interviewed both children with cancer and their parents about the entire cancer experience, exploring coping, social support, medical utilization, and use of school and community resources. However, their work focused primarily on parents' reports, descriptions, and perceptions when assessing social support and support resources. The present study allowed for an in depth and examination of children’s as well as parents’ perceptions of support and support resources. Furthermore, this research allowed for a comparison between the responses given by children and those given by their parents.

The social support interview developed for this study assessed who the central characters of support were to the child or parent. Other studies of children's descriptions of support have found children to report relying on parents, siblings, peers, relatives, and school personnel for support (e.g. Reid et al., 1989). Therefore these categories of people were enumerated in the interviews. Yet because of their chronic illness experience, children with cancer also rely heavily on medical and mental health staff; therefore they were added to the list of people specified in the interviews. Understanding that others besides those specified could also be part of children's support networks, children were asked to generate and talk about other sources of support. As part of their
descriptions, children were asked to give specific examples of ways that various people in their lives helped them. Since assessing both the positive and negative aspects of support have been shown to be important, children were also asked to describe what people did that was not helpful.

Researchers have shown that many families turn to both formal and informal sources of support (e.g. Chesler & Barbarin, 1987) to cope with cancer. Therefore, children and their parents were also asked to describe help received from formal sources of support, such as support groups, mental health services, and camps for children with cancer. Again, children and parents were asked to discuss ways the support facilitated or hindered their coping with the cancer. Since many children with cancer and parents report relying on their faith or religious beliefs to cope (e.g. Chesler & Barbarin, 1987), participants were asked to discuss this area of support as well.

Although the interviews provided a wealth of qualitative information, they were also designed to provide quantitative information. Wherever possible information was quantified. For example ratings of perceived helpfulness of support and ratings of the frequency with which the illness was discussed with the
various members of the support network are two examples of the quantitative data obtained from the interview.

The present research also provided an exploration of the relationship of social support, family and demographic factors to adjustment. The study was not designed, however, to allow a test of the main-effect or buffering models of support, or other models of support reviewed (Sandler et al., 1989). However, the present research should provide some understanding of how children’s support perceptions relate to adjustment. The current study should also help identify variables that could be used in further predictive research with this population. In order to explore the relationship of support and other variables to psychosocial adjustment, two indices of adjustment were selected. Since self-esteem and behavior have been implicated as being important adjustment indices in the social support literature, they were assessed in the present research.

The Self-Perception Profile for Children (Harter, 1985), which assesses feelings of self-worth across five specific domains (scholastic competence, social acceptance, athletic competence, physical appearance, and behavioral conduct) as well as global self-worth, and the Self-Perception Profile for Adolescents (Harter, 1987a), were used as indices of adjustment. The Self-Perception Profile for Adolescents is an upward extension of the
Self-Perception Profile for Children; six of the scales are identical for the measures, with the adolescent scale having three additional scales (romantic, job, and friend competence). The global self-worth score was used as the index of adjustment in the present study. The use of these scales allowed for comparisons with the self-worth of healthy children provided in the normative data of the measures. Both scales have also been used in chronic illness research (e.g. DeStefano, 1989; Noll et al., 1990a; Spirito et al., 1990).

The Child Behavior Checklist (CBCL; Achenbach & Edelbrock, 1983) was used to assess child behavior via parent report. Like the Harter self-perception scales, this checklist has been used extensively with healthy children and children with chronic illnesses (e.g. Mulhern, Wasserman, Friedman, & Fairclough, 1980; Kazak & Meadows, 1989). Using this checklist also allowed for comparisons of the behavior of children with cancer with the behavior of healthy children provided in the normative data of the scale. The total behavior problem score, internalizing score, and externalizing score were used as indices of adjustment.

Although the CBCL is often used with children with chronic illnesses, problems have been identified in using this scale with chronic illness populations (Perrin,
Stein, & Drotar, 1990). Concerns are that the behavior scales tend to be biased with the data of physical symptoms associated with chronic illnesses, that the scale has limited sensitivity to detect mild adjustment problems associated with children with chronic illnesses, and that the scale provides a potentially biased assessment of social competence for children who have chronic illnesses. These factors were seriously considered in the choice of an instrument to assess behavioral problems. However, the CBCL was selected because of the empirical properties of the measure, and because comparisons could be made with normative data on healthy children.

The chronic illness literature suggests that a number of demographic family factors and psychological family factors are related to indices of adjustment in children with cancer and other chronic illnesses (e.g. Kazak & Meadows, 1989; Varni et al., 1989, Wallander et al., 1987). Information on demographic variables was obtained during the parent interviews. This information was used for the purposes of sample description and for exploring predictors of adjustment. The Revised Peabody Picture Vocabulary Test was used to obtain an estimate of children’s verbal intellectual ability.

Finally, the Family Environment Scale (Moos, 1974) was used to assess family functioning and support. The Relationship Dimension of the scale was chosen for this
study since it supplies an assessment of both positive and negative family relationships. Family cohesion, conflict, and expressiveness are assessed with the relationship dimension. This scale has also been widely used in the chronic illness literature. Inclusion of this scale in the measures of the study allowed for an evaluation of the family’s overall adaptation, and enabled an exploration of the relationship between child and family functioning.

**Study Hypotheses**

Four primary goals have been stated for this study of the perceptions of support and support resources of children with cancer and their parents. Within each of the primary goals, several hypotheses were tested. Although the literature on children’s social support perceptions and resources has grown steadily, there is little guidance on what to expect from children with cancer. Since the chronic illness literature emphasizes the resiliency of families with children with chronic illnesses (Garrison & McQuiston, 1989), the null hypothesis was used for many of the planned comparisons. Where possible, however, hypotheses formulated were based on the developmental and chronic illness literatures pertaining to social support.

The first goal of the present research was to describe and assess the satisfaction with social support
resources used by children and their parents to cope with the cancer experience. Overall, children and parents were expected to rely on a variety of sources of support and to be quite satisfied with the support they received. Furthermore children and parents were expected to describe several different types of support provided (e.g. instrumental support, emotional support).

Specific hypotheses were as follows: 1) there would be no developmental, sex, or camp differences in the frequency with which children discussed their illness experience with parents, siblings, relatives, and medical staff; 2) adolescents were expected to discuss their illness experience more frequently with friends and school staff than younger children; 3) there would be no developmental, sex, or camp differences in the ratings of helpfulness of parents, siblings, friends, relatives, medical and school staff.

The second goal of the proposed research was to assess overall satisfaction with social support, perceptions of competence, and perceptions of family functioning in children with cancer and their parents. In general children and parents were expected to be quite satisfied with the overall level of support received in their lives. Specific hypotheses were as follows: 1) children’s perceptions of support from parents, teachers, classmates, and close friends were expected to be
comparable to the normative data for healthy children provided with the scale; 2) there would be no sex or camp differences in children’s perceptions of support from parents, teachers, classmates, and close friends; 3) adolescents were expected to perceive greater support from close friends than younger children; 4) the overall satisfaction with social support and number of supports of parents of children with cancer would be comparable with the normative data provided for adults in the scale; 5) parents’ ratings of family expressiveness, cohesiveness, and conflict would be comparable with the normative data for the scale for families; 6) children’s and adolescents perceptions of competence would not differ from the perceptions of competence of healthy children and adolescents found in the normative data of the scale; 7) there would be no sex or camp differences in younger children’s or adolescents’ perceptions of competence for any of the domains assessed; 8) children’s internalizing, externalizing, and total behavior problem scores from the child behavior checklist would not differ from the normative data on the scale for healthy children.

The third goal of the present research was to explore the demographic, illness, social support, and familial factors that predict psychosocial adjustment in children with cancer. Theoretically, a number of variables within
each of the above mentioned areas were expected to influence psychosocial adjustment as reflected in behavioral problems and global self-worth. However, there were no a priori expectations for which factors would be more predictive of adjustment. Therefore, the intent was to explore which factors or combination of factors were most predictive of adjustment.

The fourth goal of the present research was to describe and assess children’s and parents’ perceptions of camps for children with cancer along with assessing their satisfaction with the services these camps provide. Overall, children and parents were expected to be quite satisfied with their camp experiences and the support camp provides them. They were also expected to describe several different types of support provided by these camps, along with describing ways they contributed to the camps. Furthermore their perceptions of the purposes and benefits of the camps were expected to be consistent with the overall goals and purposes of the camps. Specific hypotheses were as follows: 1) adolescents were expected to send and receive contact from campers and counselors more often than younger children; 2) no developmental differences were expected in the frequency with which counselors contacted campers; 3) no developmental differences were expected in the willingness to share problems with counselors or other campers at camp; 4)
adolescents were expected to talk about their illness experiences and hear about other's illness experiences more often than younger children; 5) adolescents were expected to talk about their illness experiences and be asked about their illness experiences more often by counselors than younger children; 5) no sex or camp differences were expected for any of the above mentioned comparisons.
METHOD

Subjects

The 46 subjects were recruited from a list of 104 7-17 year-old children with cancer who attended a one-week cancer camp in either Vermont or Connecticut. These children were part of a larger group of children with cancer who were being followed at four centers, University of Connecticut Medical Center (CT), Yale New Haven Hospital (CT), University of Vermont Medical Center (VT) and Dartmouth Mary Hitchcock Medical Center (NH). The medical and psychosocial care patterns were similar in each setting. On each visit, children generally saw a pediatric oncologist, a clinical nurse specialist and a social worker (optional). The two Connecticut centers were the largest, each with 30-40 new cases diagnosed per year and a total of approximately 250-300 cases seen annually at each setting. The Vermont center diagnoses 25-28 new cases each year and sees a total of 75-88 children annually, while the New Hampshire center treats 15-20 newly diagnosed children per year and sees a total of 50-60 children each year. Thus, subjects were part of a larger pool of between 625-750 children with cancer treated by these four centers.

Parents of these children were sent a letter explaining the purposes, requirements and description of the study (see Appendix A). Both the child and one
parent, preferably the mother, were requested to participate in the study. Originally, 49 child and parent pairs agreed to participate, 27 from the Connecticut camp, Camp Rising Sun, and 22 from the Vermont camp, Camp Ta-Kum-Ta. Of these 49 pairs, two (one from each camp) were unable to participate, and one (from Camp Ta-Kum-Ta) was eliminated after data collection since he had a blood disease and not cancer. Of the remaining 55 families, 27 declined participation in the study (14 from Vermont and 13 from Connecticut) and 28 did not return the consent form and were subsequently unreachable by phone (14 from each camp). Hence, 46 pairs comprised the study population, 26 from the Connecticut camp and 20 from the Vermont camp. While the camps were located in Vermont and Connecticut, subjects were from New Hampshire, New York, Connecticut, and Vermont.

Sample Demographics

Of the 46 children, 26 were male and 20 were female. All but one of the children were white, with the remaining child of Indian descent. Socioeconomic status, as measured by the Hollingshead Four Factor Index of Social Position, ranged from lower to upper class with the mean at the middle class level ($M = 2.85$, $SD = 1.26$). The mean age of the sample was 12.28 years ($SD = 3.34$), and the mean intelligence score was 103.2 ($SD = 12.8$).
Illness Characteristics

The mean age at diagnosis was 6.91 years ($SD = 4.03$), and the average duration of the illness was 5.44 years ($SD = 3.33$). Almost half (45.7%) of the children had some form of leukemia, 8.7% had brain tumors, and 8.7% had bone cancer, with the remaining children (36.9%) having one of 10 other types of cancer. Of the total sample, 41.3% of the children were considered cured (over five years in continuous remission), 43.5% were in remission (less than five years) and off treatment, and 15.2% were on treatment or terminal. Throughout the course of their illness, children were hospitalized overnight an average of 7.6 times ($SD = 9.3$), and 87.0% of the children had single (72.5%) or multiple (27.5%) surgeries for their cancer. The most frequently performed surgeries were tumor removals (38.8%) and biopsies (24.5%). More serious but less frequent surgeries included amputation ($n = 2$), open heart surgery ($n = 1$) and bone removal and graft ($n = 1$).

Children were asked to rate the extent to which they were comfortable and pain free (no pain to a great deal of pain) on most days. Eighty five percent reported feeling no pain and eleven percent described feeling a little pain as a result of their cancer. One child described feeling some daily pain and another child described feeling a great deal of daily pain as a result of the illness. When asked to rate how physically limiting (not at all to very
limiting) the illnesses were, most children ($M = 2.00, SD = 1.05$) indicated their cancer was only slightly limiting. Thirty seven percent indicated their cancer was not limiting, 39% said their cancer was slightly limiting, and 15% stated that their cancer was somewhat limiting. Two children reported that their cancer limiting and two others felt their cancer was very limiting. Children’s descriptions of their physical limitations as a result of their cancer are shown in Table 2. The most common responses were restrictions on activities and tiring easily.

The children from the two camps did not differ from each other on any of the following variables: age, age at diagnosis, race, sex, time lapsed since diagnosis, type of cancer, diagnostic status, SES, religion, number or length of remissions or intelligence as determined by $t$ test and chi-square analyses. Children from the two camps were distinguished only by number of siblings, with the children from the Vermont camp having more siblings ($M = 2.0, SD = 0.97$) than those from the Connecticut camp ($M = 1.4, SD = 0.90$), $t(44) = -2.08, p < .05$.

In addition to these between-camp comparisons, data were also gathered on 38 of the 55 children who declined participation in the study. Information was only available on the 38 children who declined participation in
the study but still returned to camp. These non-study children did not differ from the study children on age, sex, type of cancer, diagnostic status, or time lapsed since diagnosis, as determined by t test or chi-square analyses. They did differ, however, on race, with minorities representing a larger percent (21.1%) of the non-study group than the study group (2.2%) \( \chi^2(1, N = 84) = 7.76, p < .01 \).

**Family Characteristics**

Of the parents in the study, all but two were mothers. The two fathers that participated did so due to last minute conflicts with the mothers' schedules. The mean parent age was 39.30 years (SD = 5.39, range 27 - 53). Eighty percent of the parents were married, 66.7% for the first time and 13.3% were remarried. Of the remaining 20% of the parents, 13.3% were divorced, two were widowed and one was single. None of these variables (sex, age, or marital status) differentiated parents from either camp, as determined by t test and chi-square analyses.

Forty nine percent of the families participating in this research were Catholic and 37.8% were Protestant. Of the remaining families, one was Jewish, one was Hindu, one was Russian Orthodox, one was Fundamentalist, and two had no religion. Seventy three percent of the families reported attending religious services. Families participating in this study had moved an average of 1.87
times ($SD = 1.83$). The mean length of time spent in their current neighborhoods was 8.84 years ($SD = 5.7$; range 1 – 27). Many of the families lived by relatives; 64.4% lived near maternal parents, 48.9% lived near paternal parents, and 61.4% lived by parental siblings.

**School Information**

Thirty nine percent of the parents reported that their child had repeated a grade in school. The largest number of parents indicated that their children repeated either first, second, or third grade, the grade which the child was in when the illness was diagnosed. Fifty one percent of the parents reported that their children received special services from their schools and 56.5% of the parents stated that their children were currently having problems in school. According to their parents, 23.9% of the children were in special education classes and 28.3% received tutoring. Additionally 13% of the children were involved in gifted and talented programs. Parents’ reported that their children had been involved in these special school programs for an average of 32.43 months ($SD = 23.57$ months, range 1 – 96 months). Children participating in this study were also quite involved in extracurricular activities. The mean number of activities children participated in was 4.1 ($SD = 1.63$, range = 1 – 8).
Measures

A copy of all measures can be found in Appendix B. Tables 3 and 4 provide a summary of all the measures in the study along with the scores derived from each. Reliability and validity information of the measures employed in the study is presented in Appendix C. Appendix D contains instructions for administering each measure. Reliability information for the child and parent semi-structured interviews is presented Appendix E. Finally, Appendix F contains examples of children’s and parents’ responses to the social support and camp interview questions.

Child Measures

Social Support

The Social Support Scale for Children (SSSC; Harter, 1986) was administered to all children in the study. This scale is a 24 item questionnaire which assesses children’s views of perceived support and regard from significant others in their lives. Social support is assessed using four subscales: parents, teachers, classmates, and close friends. The parent, teacher, and classmate scales assume that these people exist in children’s lives. The close friend subscale asks whether children have close friends who respond with positive regard toward them. With this scale, the profile of a child’s perceived social support from these four sources can be examined. Low perceived
support is reflected in a score of one and high perceived social support is reflected in a score of four. Each subscale contains six items; mean scores are computed for each subscale. Normative data are provided for third through eighth grade children (Harter, 1986). Adequate reliability and validity have been demonstrated (see Appendix C).

**Social Support Interview.**

In addition to the SSSC, children’s perceptions of support received from camp and in daily life were assessed via a semi-structured interview designed by the author. Essentially the interview assessed the children’s perceptions of who the central characters of support were to them, what aspects of support were helpful/not helpful, and what support resources were available to and used by them. Children’s perceptions of camp, its purposes and benefits, and ways to change or improve camp were also assessed in the interview.

The format of the social support interviews used by Chesler and Barbarin (1987) in their descriptive study of families with children with cancer, was used to generate an initial format for the interviews. Interview questions were also generated from this author’s experiences with children with cancer and from suggestions made by the dissertation committee. The interviews were piloted on a young adult who had cancer and changed where necessary.
More specifically, children were queried about the support received from their parents, siblings, grandparents or other relatives, medical and mental health staff, friends, teachers and other school staff. The interviews were broken down into three parts. First, respondents were asked to specify how often they spoke with each person in their support network, rating the frequency of contact on a five point scale (never to very frequently). Then they were asked to indicate whether they spoke with the person about any of seven specified areas relating to their illness experience (treatment, side effects, feelings, sibling adjustment, parental adjustment, limitations, and school issues). Children were then asked to rate how helpful each person was on a five point scale (not helpful to very helpful) and also to give an example of how that person did and did not help them. Thus both qualitative and quantitative aspects of support were assessed (see Appendix B for Child Interview form).

Self-Concept

The Self-Perception Profile for Children (SPPC; Harter, 1985) was completed by each child. The SPPC is a 36 item questionnaire which examines six different components of children’s sense of competence and adequacy. The differential approach used in the SPPC reflects the
belief that children typically do not view themselves as equally competent and adequate in all areas. The six areas assessed include: 1) scholastic competence; 2) athletic competence; 3) social acceptance; 4) physical appearance; 5) behavioral conduct; and 6) global self-worth. With this scale the profile of a child’s perceived competence across the various domains can be examined, and each domain can be compared to the child’s general feelings of self-worth.

Scores on this scale range from one to four, with low perceived competence reflected in a score of one, and high perceived competence reflected in a score of four. The subscales contain six items each; means scores are computed for each scale. Normative data are provided for third through eighth grade children (Harter, 1985), and adequate reliability and validity have been demonstrated (see Appendix C).

The Self-Perception Profile for Adolescents (SPPA; Harter, 1987a) is an upward extension of the SPPC. Like the SPPC, the SPPA is based on the assumption that separate measures of competence in different domains, in addition to a measure of global self-worth, provides a fuller and more differentiated assessment of self-concept than a single self-concept score. This newer version was made appropriate for teenagers (ninth through twelfth graders) by altering the language of certain items from
the child version, and by adding three subscales: Romantic Appeal, Job Competence, and Close Friendship. This measure is scored in the same manner as the SPPC. Initial normative data are provided for fifth through twelfth graders (Harter, 1987a). Preliminary reliability information has been reported (see Appendix C).

**Behavioral Symptoms**

Indices of the child’s behavioral symptoms were obtained by the Child Behavior Checklist (CBCL; Achenbach and Edelbrock, 1983). The CBCL, completed by the parent, is a 118-item questionnaire that identifies multiple dimensions of behavioral symptoms. Parents rate each item from zero (not true) to two (very true) according to their child’s behavior over the past six months. Separate scores were determined for internalizing and externalizing behavior problems. A total problem score is also calculated. The authors have provided normative data, as well as demonstrating adequate reliability and validity for the checklist (see Appendix C).

**Intelligence**

General intellectual ability was estimated with the Revised Peabody Picture Vocabulary Test, Form L (PPVT-R; Dunn & Dunn, 1981). The PPVT-R is a receptive vocabulary test that employs an easel format with four pictures in each quadrant. It was employed in the present study as an
estimate of verbal ability and scholastic aptitude for children from 2 to 16. The child must choose one of four pictures which best indicates the meaning of the cue word read. Raw scores are converted into scaled scores. The PPVT-R has a mean scaled score of 100 and a standard deviation of 15. Normative data, reliability and validity are provided by Dunn and Dunn (1981) (see Appendix C).

**Parent Measures**

**Social Support**

The short form of the Social Support Questionnaire (SSQ; Sarason, Levine, Basham, & Sarason, 1983) was administered to parents to assess parental perceptions of social support. The short form of the SSQ is a six item questionnaire which taps two dimensions of social support: perceived number of social supports and satisfaction with the support that is available. Each item has two parts. The first part assesses the number of available others (SSQN) that the person can turn to in times of need, in each of a variety of situations (e.g. who helps you feel you have something positive to contribute to others). The second part of each item measures the person’s degree of satisfaction (SSQS) with the perceived available support on a 6 point likert scale (ranging from very dissatisfied to very satisfied). Mean scores are computed for each scale. Adequate reliability and validity have
been established for the SSQ (Sarason, et al., 1983; see Appendix C).

Social Support Interview.

Parents' perceptions of support received from camp and in daily life were also assessed via a semi-structured interview designed by the author. Essentially the interview assessed the parents' perceptions of who the central characters of support were to them, what aspects of support were helpful/not helpful, and what support resources were available to and used by them. Parents' perceptions of camp, its purposes and benefits, and ways to change or improve camp were also assessed in the interview. In general, the parent interviews were modified versions of the child interviews.

Parents were asked about the support received from their spouses, parents, siblings, medical or mental health staff, and friends. The interviews were broken down into three parts. First, respondents were asked to specify how often they spoke with each person in their support network, rating the frequency of contact on a five point scale (never to very frequently). Then they were asked to indicate whether they spoke with the person about any of seven specified areas relating to their illness experience (treatment, side effects, feelings, sibling adjustment, parental adjustment, limitations, and school issues). Parents were then asked to rate how helpful each person
was on a five point scale (not helpful to very helpful) and also to give an example of how that person did and did not help them. Thus both qualitative and quantitative aspects of support were assessed (see Appendix B for Parent Interview Form).

**Family Functioning**

The Relationship Dimension of the Family Environment Scale (FES; Moos, 1974) was administered to parent to assess family functioning. The FES is a 90 item true/false scale which assesses the social climate of all types of families. The relationship dimension of the FES is made up of three subscales, comprised of nine items each, which measure interpersonal relationships among family members. The relationship dimension includes views of cohesion, expressiveness, and conflict within the family. Cohesion is defined as the extent to which family members are concerned and committed to the family and the degree to which family members are helpful and supportive of each other. Expressiveness is defined as the extent to which family members are allowed and encouraged to act openly and to express their feelings directly. Conflict is defined as the extent to which the open expression of anger and aggression and generally conflictual interactions are characteristic of the family. True or false choices are summed for the three subscales. Raw
total scores for each subscale are then converted to standardized scores. Adequate reliability and validity have been demonstrated for the FES (Moos, 1974; see Appendix C).

**Background Information**

Background/demographic information about each child, and his or her siblings and parents was collected during the interview with the parent. Socioeconomic status was assessed using the Hollingshead Four Factor Index of Social Position (Hollingshead, 1975). Disease information was also collected, including diagnosis of the child with cancer, time since diagnosis, number and length of remissions, and treatment undergone. Information about children's school performance was also obtained during this interview (see Appendix B for Information Form).

**Medical Center Demographics**

Additionally information was obtained from the four medical centers where the children attending these camps were treated: the University of Vermont Medical Center, Dartmouth Mary Hitchcock Medical Center, the University of Connecticut Medical Center, and Yale New Haven Hospital. Information concerning the number of children treated, the frequency of children's visits to the clinic and whom they see during their clinic visits was collected.
Procedure

Data were collected two to four weeks before the start of the camps in August. Parents were contacted by the experimenter by telephone to arrange an appointment for testing in their home. Each appointment lasted approximately three hours. The purpose of the study and procedures were explained to the child and the parent again, and any questions or concerns were addressed.

Two experimenters were involved in carrying out this study. Each interviewed both the child and the parent. The primary experimenter interviewed the parent to obtain the background information, carried out the semi-structured camp/social support interview, and administered the social support questionnaire. At the same time the other experimenter interviewed the child. She administered the intelligence, social support, and self-concept measures. When these interviews were completed a planned break was taken. Afterward, the principal experimenter carried out the semi-structured camp/social support interview with the child. The other experimenter administered the child behavior scale and family functioning questionnaire to the parent. Breaks were taken whenever the child needed one.

Session One

During the initial parent interview, the information form was administered first. Verbatim recordings of
parents’ responses were taken during this interview. Parents’ were queried about their families, the course of their child’s illness, and their child’s schooling and outside activities. The interview proceeded as indicated by the Information Form in Appendix B. The Social Support Questionnaire was administered next. Parents were told to list the people in their lives whom they could count on for help or support and then were asked to rate their satisfaction with this support (see Appendix D for exact instructions). Next, the semi-structured camp/social support interview was conducted with verbatim recordings made of parents’ comments. The interview proceeded as indicated on the Parent Camp/Social Support Form in Appendix B.

During the initial child interview the PPVT-R was administered first. Children were shown a page with four pictures on it and were asked to identify a requested picture. Sample items were administered to ensure understanding of the task. Children were instructed to "Find the ______" by pointing to the correct picture. The remaining items were administered in the same manner until children incorrectly answered six out of eight consecutive responses.

The Self-Perception Profile was administered next. Two sample items were read to the children, and an
explanation of the scale was given. The following example was read: "Some kids often forget what they learn but other kids can remember things easily. Are you more like the kids who forget what they learn or like the ones who remember easily? Now is that really true for you or sort of true for you?". Once understanding was ensured, the experimenter proceeded with the remaining items on the scale (see Appendix D for exact instructions).

Session Two

In the second child interview, the Social Support Scale for Children was given first. Since the format is identical to the Self-Perception Profile, abbreviated instructions were given to the child. Once understanding was ensured, the scale was administered (see Appendix D for exact instructions).

Finally, children were interviewed about camp and social support in general with a semi-structured interview. This interview was tape-recorded and verbatim recordings of the child’s comments were taken. Each child was told:

Now I’d like to know a little more about camp and the things you like and don’t like about camp. I’m also going to ask you several questions about ways different people in your life do and don’t help you with your cancer experience. I’d like you to answer me as well as you can. Feel free to say anything that you feel. When we are done, if you think of something I didn’t ask you about that you’d like to tell me, you can tell me then, Ok?
This interview proceeded as indicated by the Child Camp/Social Support Interview form in Appendix B.

In the second parent interview the Family Environment Scale was administered first. Parents were instructed to read all the statements and select a true or false response for each item (see Appendix D for exact instructions). Finally, the parents were given the Child Behavior Checklist. Instructions were as follows:

Below is a list of items that describe children. For each item that describes your child now or within the past 6 months, please circle the 2 if the item is very true or often true of your child. Circle the 1 if the item is somewhat or sometimes true of your child. If the item is not true of your child, circle the 0. Please answer all items as well as you can, even if some do not seem to apply to your child.

When the child and parent had finished completing all procedures, any additional concerns or questions raised were answered. This procedure was then repeated for each child and parent participating in the study. At the conclusion of each session, the parent and child were thanked and were told that they would receive a letter explaining some of the findings of the study once the research was completed.

**Scoring**

Once the data were collected, all standardized questionnaires were scored as instructed in their manuals, and scores were entered into a computer database. This procedure was also followed for any and all of the camp
and social support interview questions which had quantified responses.

All interview tapes were transcribed onto index cards. The answers for each open ended question were written onto separate cards, with subject identification numbers on each to ensure confidentiality and eliminate bias. Index cards were then sorted by question. Responses for each question were then sorted into categories which were given names and coded numerically. When this process was completed the coded interviews were added to the computer database for analysis.

Reliability

Inter-rater reliability was collected on a random sample of 15% of the responses for each camp and each social support question from the parent and child interviews. Two independent raters coded the responses to both the child and parent interview questionnaires to obtain inter-rater reliability. Appendix E contains the percent agreement scores for each question from the child and parent interviews, and the inter-rater reliability coefficients for the different parts of the child and parent interviews. Percent agreement scores for all questions ranged from 86.7% to 100%. Overall, the two raters never disagreed on more than two responses for any question being coded. Inter-rater reliability coefficients ranged from .99 to 1.00.
RESULTS

Overview of Descriptive Analyses of Social Support

To understand who the central characters of support were in children’s and parents’ lives during the illness experience, a semi-structured social support interview was administered to each child and his or her parent. The quantitative and qualitative data from these interviews were initially analyzed using descriptive statistics to explore the frequency of various responses to the interview questions. Developmental and sex differences were then explored using chi-square analyses and oneway analyses of variance. Children were split into two age groups for developmental comparisons, young children (7 - 12) (n = 24) and adolescents (13 - 17) (n = 22).

Throughout this manuscript the term ‘younger children’ is used to denote 7 - 12 year-olds and the term ‘adolescents’ is used to denote 13 - 17 year-olds in the study. When the term ‘children’ is used, it refers to the entire sample of younger children and adolescents participating in the study.

Throughout the following analyses the number of children included in the data analyses fluctuates at times. Four children were not included in the social support analyses because they were infants when they had their cancer and could not remember the experience. They were however, included in the camp study analyses.
Therefore, unless otherwise specified, the n for children is forty two. Although 46 parent-child pairs participated in this study, only 45 parents are involved in the analyses of parent data because a brother and sister participated in the study. The number of children, parents, or families participating in each of the analyses is reported in each table presented.

Descriptions of Social Support

To Whom Did Children Talk

In describing whom they talked to about their illness experience, the greatest number of children reported talking to their parents. After parents, most children spoke with friends, then medical staff, siblings, relatives and school staff. Table 5 displays the frequency with which children talked to the different people in their lives about their illnesses. Children not only relied on their parents most, but spoke more often with parents ($M = 3.48$, $SD = 1.25$) than friends and others in their lives. When children were asked whether they spoke more with one parent versus the other, only 41% replied that they did, with mothers being the most likely candidate for conversation. This difference is not surprising in that the mothers in the present sample were usually more integrally involved in managing the day to day illness experience, while the fathers worked and managed the household.
What Children Shared With Others

In depicting what they talked about to the various members of their support system, most children stressed that they spoke about the treatment and side effects of their cancer with all members of their support networks. Children were generally more selective than their parents about which aspects of the illness experience they shared with the different people in their support systems.

Table 6 contains the percentage of children who spoke with the various members in their support system about each of the given illness topic areas. Treatment and side effects were talked about by most children with parents, medical staff, school staff, and then friends. Feelings about the illness ordeal, sibling adjustment, and parental adjustment were shared by more children with parents, friends, and siblings. Limitations of the illness were discussed by more children with parents than any other members in the support network. The greatest number of children reported sharing their feelings about school and school issues with friends and with school personnel as would be presumed. Other than parents, friends were the people most children choose to share the different aspects of the illness ordeal.
Developmental and Sex Differences.

As predicted, younger children and adolescents were equally as likely to turn to most members of their support system to discuss their illness experiences. One exception was found when talking with relatives. More adolescents (83.3%) reported talking to relatives about their illness experience than younger children (47.8%), $\chi^2(1, N = 41) = 4.06, p < .05$. When examining how frequently children discussed their cancer experience, adolescents, as expected, ($M = 3.53, SD = 1.26$) spoke more often with their friends than younger children ($M = 2.57, SD = 1.38$), $F(1, 40) = 5.46, p < .05$. While it was thought that older children would talk more frequently about their illness experience with school staff, this was not the case. No sex differences were found for any of the above comparisons.

To Whom Did Parents Talk

Parents' responses concerning the people they talked to in their support network were similar to their children's responses (see Table 7). All parents stated they discussed the illness experience with medical staff and their own parents. Although parents spoke frequently with most members of their support networks, they most often talked with their own parents and medical staff.
What Parents Shared With Others

In relating what they talked about with the different members of their social networks, parents’ responses were more consistent than their children’s responses (see Table 8). Most parents reported discussing the medical aspects of their child’s illness with all members of their support system. Feelings about the illness experience, the sick child’s adjustment, and sibling adjustment were spoken about by most parents with their spouses, their own parents, and their friends. Most parents talked about limitations imposed on their child from the illness and school issues with spouses and friends. In contrast to their children, parents were not as selective in what they talked about with the different people providing them support in their lives.

Children’s Satisfaction with Support Received

In general, all parts of children’s support system were perceived as somewhat to very helpful during the illness experience. Table 9 contains children’s helpfulness ratings for people in their support networks. Parents received the highest mean helpfulness ratings (five point scale) from their children ($M = 4.57$, $SD = .80$), followed by medical staff ($M = 4.21$, $SD = 1.0$) and then friends, siblings, school staff, and relatives. As in talking about their illness, children relied heavily on their parents for support and help with their illness.
Developmental and Sex Differences.

Developmental and sex differences in children's mean helpfulness ratings were explored using oneway analyses of variance. As expected, there were no developmental differences in children's mean ratings of helpfulness for the various people in their support networks. Children of all ages were fairly satisfied with the help they were receiving from the different members of their support system.

Parents' Satisfaction With Support Received

Like their children, parents were quite satisfied with the help they received from their spouse, parents, medical staff, friends, and siblings. Table 10 contains parents' helpfulness ratings of those people in their support networks. Medical staff (\(M = 4.87, \, SD = .40\)) received the highest mean rating from parents, followed by friends and parents. Although it may seem surprising that spouses received the comparatively lowest (\(M = 3.6, \, SD = .40\)) mean helpfulness rating, there were several divorced families participating in this study which might be in part responsible for this finding. Yet looking only at married families, spouses still had the lowest mean helpfulness rating (\(M = 4.13\)), although the rating did improve.
Children's Descriptions of Support Received

Children were asked to describe how parents, siblings, relatives, medical staff, friends, and school staff were and were not helpful to them. Their responses for each are displayed in Tables 11 - 19. Children provided a variety of responses for these descriptions, as they could give more than one response for each source of support. Examples of responses for each category of support within each source of support can be found in Appendix F. In their comments, children more often described ways people were helpful to them than ways people were not helpful to them. However, when relating ways people were not helpful, children more frequently talked about family members and medical staff than others in their support networks. This may be because the family and medical staff were relied on so heavily during the illness experience and were such an integral part of the day to day illness routine.

In discussing ways their parents helped them, children most frequently commented that their parents were with them throughout the illness experience. They described this in terms of being emotionally and physically present and by offering instrumental aid such as back rubs or help with the treatment side effects. Thirty three percent of the children spoke about ways their parents were not helpful to them. The most
frequently mentioned responses were those suggesting that the parent’s style of coping was not in line with the child’s style. For example, children described their parents talking too much about the illness with them, or expressing emotions such as crying that overwhelmed them (see Table 11).

Siblings were perceived as helping by providing instrumental aid such as helping with homework or illness related needs. The next most common response for siblings was the emotional support they provided, such as sharing feelings of love and caring. Fifty one percent of the children specified ways their siblings were not helpful. Comments made by the children centered around not getting along with their siblings, whether that was a function of the siblings’ negative attitudes and actions or simply general fighting and bothering each other (see Table 12).

In discussing ways their relatives helped them, children most often relied on grandparents for help (see Table 13). Relatives were perceived as helping by visiting children at home or in the hospital. Relatives were also seen as helpful because they provided material support such as gifts, money, or cards. Only 22.5% of the children spoke about ways their relatives were not helpful. Their responses centered on relatives being unavailable to them whether that was by not visiting or by not getting along with them (see Table 14).
For help from the medical staff children most often relied on nurses and doctors (see Table 15). Medical staff were most often depicted as helping children via the medical support they provided. This included comments about treating or curing the cancer or talking with the child while preparing him/her for different medical procedures. Children also frequently commented about the emotional support they received from medical staff. While children felt the medical staff helped them by treating them, they also viewed the actual treatments such as bone marrow aspirations and spinal taps as unhelpful since they were so painful. The medical staff was also described as not helping when they made medical mistakes such as not giving the correct pills at the correct time or puncturing veins when administering chemotherapy (see Table 16).

Children viewed their friends as providing emotional support, by talking and sharing their illness experiences with them. Friends were also described as helping by providing companionship support, whether that meant on the telephone or in person. Friends were most often perceived as not helpful when they did not accept the children for who they were or singled them out for their cancer by teasing them (see Table 17).

In relating their support experiences from school staff, most children commented that they turned to their
teachers and school nurses for assistance (see Table 18). Children commonly spoke about the assistance they received from teachers with their school work. Children also viewed teachers and school nurses as giving emotional support by talking with them about their cancer. Comments about ways school staff were not helpful centered on their lack of understanding or assistance with what the child was going through with the illness (see Table 19).

Children were also asked to discuss other sources of support besides those asked about in the interview. Table 20 presents the various responses given by the children, along with the percent and frequency of each. Children's comments suggest that they rely on people other than their families, friends, and teachers for support. Mental health professionals were mentioned most frequently, followed by neighbors and other friends of the family, as well as the family's religious community. From their interview responses, these children appear to have rich and varied support networks to rely on for assistance, and for the most part were satisfied with the support they received during the illness experience.

Parents' Descriptions of Support Received

Parents were asked to describe how their spouses, parents, siblings, medical staff, friends, and children were and were not helpful to them. Parents' responses for each are displayed in Tables 21 - 28. Parents provided a
variety of responses for these descriptions, as they could
give more than one response for each source of support.
Examples of responses for each category of support within
each source of support can be found in Appendix F. Like
their children, parents more often described ways people
were helpful to them than ways people were not helpful to
them. As was true for their children, when relating ways
people were not helpful, parents more frequently talked
about family members and medical staff than others in
their support networks. Again this may be because the
family and medical staff were relied on so heavily during
the illness experience and were such an integral part of
the day to day illness routine.

Spouses were characterized as helping by providing
emotional support such as being available to listen, talk,
and understand. Spouses were also frequently seen as
helping by managing the household and finances during the
course of the illness. Parents most often described their
spouses as not helping by not offering the emotional
support they needed such as sharing feelings or listening,
and by not helping with the treatment or illness related
decisions (see Table 21).

Parents related that their own parents gave support
by managing the household and caring for the healthy
siblings while they were at the hospital with the sick
child. Many parents indicated that their own parents or in-laws moved in to help out, and sent money to help with the medical bills. Parents were also commonly seen as helping by assisting in the care of the sick child. Parents were viewed as not helpful because of their lack of emotional support, either because they did not want to be involved with the illness situation or because of their negative attitudes about the child’s prognosis (see Table 22).

The siblings of parents were turned to with parents’ feelings about the illness experience and with requests for assistance. Siblings were characterized as helping by providing emotional support in the form of talking or listening, or in assistance with the healthy children and household. The most frequently given criticism of siblings was the lack of support from those who could not handle or deal with the emotional turmoil centered around the cancer (see Table 23).

Parents described themselves as relying heavily on their friends. Friends were seen as offering emotional support such as listening and being there to talk. Friends also provided families with instrumental support, whether that meant managing the household or going to the hospital. Parents most often related ways acquaintances were not helpful. Comments focused on them being too intrusive in their questions or views about the illness
situation. A few parents depicted close friends as not helpful because they pulled away from the parent and family once the child was diagnosed (see Table 24).

In turning to medical or mental health staff for help, most parents relied on nurses, doctors, and social workers (see Table 25). Parents reported relying on medical staff for emotional as well as medical needs. They described sharing emotions and feelings with the medical staff almost as frequently as in receiving medical support. Like their children, parents perceived medical staff as not helpful when they made medical mistakes and when they were unavailable or not emotionally supportive (see Table 26).

Parents also discussed ways their ill children supported them. All parents spoke in loving and admiring terms about their children's strengths and resilience in handling the illness experience. In talking about the child with cancer, all of the parents interviewed stressed that it was their child's positive attitude and strength that helped them through the ordeal. While very few parents gave examples of how their child was not helpful, three described their child's behavior while on chemotherapy as difficult to manage and one described their child's negative attitude as difficult to manage (see Table 27).
The siblings of the child with cancer were characterized by their parents as helping by providing them and the sick child with emotional support. Siblings were also seen as helping out at home and being flexible with the changes being made in their own lives. As is commonly found in the chronic illness literature, it was siblings resentment or jealousy of the sick child that was seen by many parents as troublesome (see Table 28).

When queried about support from their child's school, 62.8% of the parents described their school systems as quite supportive. Adjusting the child's school workload and providing extra assistance to their children were frequently mentioned by parents as types of support. Nine percent of the parents reported that their child's school was not supportive. These parents felt their school systems did not provide the special services their children needed or did not make appropriate adjustments in school procedures over the course of the illness. Twelve percent of the parents felt that their school systems were both supportive and nonsupportive. These parents described the schools as providing a mixture of helpful and unhelpful support or as initially being supportive and becoming less so over the course of the illness.

Parents were also asked to discuss other sources of support besides those specified and asked about in the interview. Table 29 presents the various responses
provided by parents, along with the percent and frequency of each. Parents' comments suggest that they rely on people other than their families and friends for support. In contrast to their children, parents most often mentioned information seeking as a source of support for them. Learning and reading about the illness was described as helping parents to cope with the experience and to manage their own emotions. The second most commonly mentioned source of support was the American Cancer Society or the Leukemia Society. These organizations assisted parents with the costs of transportation and medical supplies, in addition to providing information about cancer. Towns and communities were mentioned by many parents as helpful in terms of organizing family fund raisers, and providing household assistance (i.e. cooking meals, housework). Whereas only two adolescents and no younger children described relying on themselves and their own inner strength as support, several parents commented on themselves as sources of support. Parents in similar situations were also mentioned as helpful, particularly in terms of negotiating the medical system and forming realistic expectations about cancer. Like their children, these parents had large extended networks to rely on during the illness experience.
Satisfaction with Family Relationships

Children and their parents were asked to rate how satisfied they were with their family relationships on a five point scale (not satisfied to very satisfied). Their responses are presented in Table 30. Most children (M = 4.26, SD = .88) and parents (M = 4.13, SD = 1.11) were quite satisfied with their current family situation. When asked whether their families had changed as a result of the illness experience, 63% (n = 29) of the children felt their families had changed. Of those children, 26 (89.7%) felt their families had grown closer together, one felt his or her family had grown further apart, and two felt their families had grown closer in some ways and further apart in other ways.

Of the parents interviewed, 87% (n = 39) felt their families had changed as a result of the illness experience. Of those parents, 74.4% (n = 29) felt their families had grown closer, 5.1% (n = 2) felt their families had grown further apart, and 20.5% (n = 8) felt their families had grown closer in some ways and further apart in other ways.

Faith as Support

Parents and children were also asked to describe how their faith or religion helped them to cope with their illness experience. Their ratings of how helpful their faith was to them are presented in Table 31. Eighty three
percent of the children and 84.4% of the parents stated that they used their faith to cope with the illness experience. Children's and parents' descriptions of how their faith helped them are presented in Tables 32 and 33, respectively. Both children and their parents relied on individual prayer and going to church during their illness ordeal. They also relied on others praying for them and on support from their church community. Thus, many children and parents turned inward for spiritual support and relied on the spiritual support of others to aid them in coping with the cancer experience.

Offering Support to Others

Social support includes giving help, along with receiving help from others. Comments on ways parents and their families attempted to help others are shown in Table 34. Fund raising for the various cancer organizations and causes was mentioned most frequently. Attempts to organize parent support groups was another common way parents tried to help others.

Use of Formal Sources of Social Support

Children and parents were also questioned about the use of more formal or organized sources of support. Twenty four percent of the children (n = 11) indicated they were involved in support groups. Eight children described being members of cancer based groups such as
candlelighters (n = 5), hospital run cancer clinic groups (n = 2) and a group formed by the leukemia society (n = 1). Church youth groups (n = 2) and a teen support group (n = 1) were the two nonillness groups in which children participated. The frequency with which children spoke about their illness experiences at their support groups is presented in Table 35, and what they shared with the groups is shown in Table 36.

Children appear to have used the groups to share their feelings about the illness experience, as well as the medical aspects of their cancer. Children perceived the groups as helpful by allowing them to make friends with similar experiences, providing emotional support, and supplying fun activities. Three troublesome aspects of the groups included their organization and logistics, and depressing talks that occurred during group (see Table 37). All in all, children found the groups fairly helpful to them (see Table 38).

Thirty eight percent of the parents were also involved in support groups. Most parents were members of their cancer clinic's support group for parents (n = 11). Five parents were members of Candlelighters, and one parent was involved with a family nonillness support group. Five other parents expressed their desire to belong to cancer related support groups while being interviewed, but explained that there were not any
available where they lived. The frequency with which parents spoke about the illness experiences at their support groups is presented in Table 39, and what they shared with the groups is shown in Table 40.

Parents seemed to use the groups to talk about the emotional and medical aspects of the illness experience. Groups were characterized as supplying emotional support and educational opportunities to learn from others about cancer. Parents viewed the poor organization of these groups and group members attitudes as the least helpful aspects of the groups (see Table 41). Overall, parents were satisfied with the support received from these groups (see Table 42).

Parents were also asked to talk about any professional mental health services they, their child, or their families had received during the illness experience. Of the forty five families in the study, 68.9% (n = 31) used some type of professional mental health services. Table 43 presents the break down of family members involvement in the various types of therapy described by parents. Forty five percent (n = 14) of the families described being involved in short term therapy (less than one year/brief consultation) with a psychologist or psychiatrist. Forty two percent (n = 14) stated their families were involved in therapy with a psychologist or
psychiatrist for more than a year. Thirty six percent \((n = 11)\) of the parents indicated that had intermittent and brief contact with the hospital social worker assigned to the floor their child was staying on during their child’s hospitalizations. Finally, 9.7\% \((n = 3)\) received brief counseling from a minister. While not all families used mental health services, those that did often used them for several family members and not just the child with cancer. Again these comments suggest these families are well supported, both formally and informally.

**Standardized Assessment of Support and Adjustment**

**Children’s Social Support**

Children’s perceptions of social support received from parents, teachers, friends, and classmates were assessed using the Social Support Scale for Children (SSSC; Harter, 1986). Since this scale is normed for children 7 - 13 years old, separate descriptive statistics are provided for the 14 - 17 year old adolescents. The mean, standard deviation, and range for each subscale are presented in Table 44 for younger children and Table 45 for adolescents. Mean scores and standard deviations for children with cancer fell within the age appropriate norms provided with the scale. The various sources of social support were found to have low to moderate intercorrelations and the pattern of intercorrelations was generally consistent with those found for healthy children.
(see Table 46). No developmental differences were found for any of the subscales. Children's ratings suggest that they perceive a fair amount of support from their parents, friends, classmates, and teachers.

**Sex Differences.**

Sex differences in perceptions of social support were examined separately for younger children and adolescents using multivariate analyses of variance, with sex as the grouping factor. No sex differences were found for younger children on the social support scale. In contrast, a significant main effect for sex was obtained for adolescents, $F(4, 12) = 7.60, p < .01$. Univariate analyses of variance revealed that adolescent females ($M = 3.90, SD = .13$) perceived greater support from close friends than adolescent males ($M = 2.98, SD = .72$), $F(1, 14) = 10.95, p < .01$. Adolescent females ($M = 3.43, SD = .32$) also perceived more support from teachers than adolescent males ($M = 2.90, SD = .31$), $F(1, 14) = 11.58, p < .01$. The adolescent females in this study appear to either receive or elicit more support from their friends and teachers than the adolescent males. While interesting, these findings must be viewed as tentative for two reasons: 1) the scale was normed on younger children and not on adolescents, and 2) the sample size was quite small ($n = 16$).
Children's Perceptions of Competence

Children's perceptions of themselves across several
domains of competence were assessed using the Self
Perception Profile for Children and the Self-Perception
Profile for Adolescents (Harter, 1985; 1987a). Tables 47
and 48 presents the mean scores, standard deviations, and
range of scores for the six subscales of the children's
questionnaire and the nine subscales of the adolescent
questionnaire. Means and standard deviations for both
groups fell within the age appropriate limits provided in
the normative data of the scales. These findings are
consistent with the literature that suggests that children
with cancer do not perceive themselves differently than
healthy children on standardized assessments of self-
concept (e.g. DeStefano, 1988).

Sex Differences.

Differences in self-perception were explored in
younger children and adolescents using multivariate
analyses of variance, with sex as the grouping factor.
For younger children, there was a significant main effect
for sex, $F(6, 23) = 3.05, p <.05$. Univariate analyses of
variance revealed that young males ($M = 3.0$, $SD = .77$) had
significantly higher athletic self-concept than young
females ($M = 2.01$, $SD = .70$), $F(1, 28) = 12.72, p <.001$.
For adolescents a significant main effect was also found
for sex, $F(9, 6) = 8.50, p <.01$. Univariate analyses of
variance indicated that females ($M = 3.6$, $SD = .40$) had higher friend self-concept than males ($M = 2.53$; $SD = .85$) \( F(1, 14) = 9.22, p < .01 \). Thus, adolescent females not only perceived more support from friends than their male counterparts, but they also felt more confident in their perceptions of these friendships.

**Behavioral Symptoms**

The Child Behavior Checklist ratings by parents yielded an overall total behavior score ($M = 27.9$, $SD = 20.1$), as well as internalizing ($M = 56.4$, $SD = 8.9$) and externalizing ($M = 54.3$, $SD = 9.9$) behavior scores. These means fell within the normal range of scores, as defined by the CBCL. Of the 35 children who were rated on the CBCL, 8 children (6 boys, 2 girls; 23.0%) had a total behavior score that fell in the clinical range. On the internalizing scale, 9 children (7 boys, 2 girls; 29%) made the clinical cutoff score while 4 children (3 boys, 1 girl; 11.4%) were classified in the clinical range for the externalizing scale (see Table 49 for breakdown by age and sex). While as a group the children were well adjusted behaviorally, a small subset of children were having difficulty with their behavior.

**Parents' Perceptions of Social Support and Family Functioning**

Parental perceptions of social support were assessed with the Social Support Questionnaire (Sarason et al.,
1983). Mean satisfaction with support was measured on a six point scale, and number of supports were summed and averaged across the items of the scale. Parents were very satisfied with the support received from people in their lives (M = 5.31, SD = .85). Parents reported relying on several different people for support (M = 4.31, SD = 2.09), and their scores were comparable to the norms for adults. Like their children, parents were quite satisfied with the support they were receiving from others in their lives.

The Family Environment Scale was administered to assess parental perceptions of family relationships and family support. Means, standard deviations, and ranges for the family cohesion, expressiveness, and conflict subscales are shown in Table 50. Intercorrelations of the subscales revealed family expressiveness to be minimally related to family cohesion (r = .15) and family conflict (r = -.08). Family cohesion had a significant inverse relationship with family conflict (r = -.42). Parents' scores on the subscales fell within the norms for families provided by the scale, suggesting these families perceive adequate levels of expressiveness and cohesion, with low levels of family conflict.

Overall, data from the family environment scale and the social support scale suggests that these parents feel
well supported by their families and others in their lives. These findings are consistent with the ratings of satisfaction with family relationships that children and parents gave during their social support interviews.

**Predictors of Adjustment**

One of the four goals of this research was to explore the demographic, illness, social support, and familial factors that predict psychosocial adjustment in children with cancer. To do so, multiple regression analyses were performed on the two indices of adjustment, global self-worth and behavioral problems. Four analyses were performed altogether; one with global self-worth as the criterion variable, and one each for total, externalizing and internalizing behavior problems.

A number of variables were thought to influence adjustment as reflected in behavioral problems and global self-worth. Demographic variables included age, sex, ses, marital status, and intelligence. Illness variables considered were diagnostic status and time lapsed since last remission. Child social support variables included perceived support from parents, friends, classmates, and teachers. Parental social support variables included satisfaction with and number of supports, family expressiveness, cohesiveness, and conflict, and living by maternal or paternal siblings and parents.
Given the small n of the study, predictors of adjustment were selected after examining pearson product-moment correlations computed on the predictor variables and global self-worth and behavioral problems. For each criterion measure, variables that correlated significantly were than used as predictors in its regression analysis. Table 51 presents the intercorrelations of the variables used in the regression analyses.

The multiple regression analysis to predict total global self-worth scores included marital status, level of family conflict, and children's perceived support from friends as predictor variables. All variables were entered simultaneously; only marital status and level of family conflict were found to be significant predictors of children’s perceptions of self-worth ($R = .67; F(5, 38) = 6.34, p < .001$. Taken together, these variables accounted for 38% (adjusted $R^2$) of the variance in children’s self-worth scores. Thus, having parents who were married and having families with higher levels of perceived conflict was associated with higher global self-worth in children with cancer.

The three multiple regression analyses to predict total, externalizing, and internalizing behavior problem scores from the CBCL included sex, level of family cohesion, and children’s perceived support from friends as predictor variables. Since sex differences have
consistently been found when using the CBCL, hierarchical regression analyses were performed, entering sex into each regression equation first. Family cohesion and support from friends were entered simultaneously on the second step of each analysis to determine whether they accounted for any additional variance above and beyond that accounted for by sex. Results for the analyses for the total, externalizing, and internalizing behavior problem scores are presented in Tables 52, 53, and 54 respectively.

Sex, family cohesion, and social support from friends were found to be significant predictors of total behavior problem scores, accounting for a total of 35% of the variance. Alone, sex accounted for 14% of the variance, with social support from friends and family cohesion together accounting for 21% of the variance in the total behavior problem score. Thus, being male, having high levels of perceived support from friends, and a family with low levels of perceived cohesion was associated with higher total behavior problem scores for children with cancer.

For externalizing behavior problems, sex, social support from friends, and family cohesion were found to be significant predictors, accounting for a total of 30% of the variance. Alone, sex accounted for 14% of the
variance with social support from friends and family cohesion together accounting for 16% of the variance in externalizing behavior problem scores. Being male, having high levels of perceived support from friends, and having a family with low levels of perceived cohesion was associated with higher externalizing behavior problem scores for children with cancer.

For internalizing behavior problems, sex was the only significant predictor, accounting for a total of 17% of the variance. Although family cohesion and support from friends accounted for an additional 10% of the variance in internalizing behavior scores, their contribution to the regression equation was not statistically significant. Being male was associated with having higher internalizing behavior problem scores for children with cancer. This finding is at odds with the typical finding that being female is associated with more internalizing problems when using the scale with healthy children (Achenbach & Edelbrock, 1983).

**Overview of Descriptive Camp Analyses**

The quantitative and qualitative data from the camp study was initially analyzed using descriptive statistics to explore the frequency of various responses to the interview questions. Developmental, sex, and camp differences were then explored using chi-square analyses and oneway analyses of variance. Children were split into
two age groups for the developmental comparisons, younger children (7-12) \(n = 24\) and adolescents (13-17) \(n = 22\).

**Descriptive Information**

Children had attended the two camps involved in this study for an average of 2.1 years \(SD = 1.04\). Thirty seven percent of the children also attended other camps for children with cancer. Of the children interviewed, 52.2% reported hearing about camp from the medical staff where they had received treatment. Children less frequently learned about camp from advertisements (21.7%), parents (10.9%), mental health staff (10.9%), and other children with cancer (4.3%). Like their children, parents most often learned of camp from medical staff (71.7%). Parents also learned about camp from mental health staff (17.4%) and from advertisements for the camps (10.9%).

Eighty five percent of the parents in the study let their child attend camp the first year they learned of the camp. Of the seven parents who did not initially let their children attend camp, five stated their child was too sick. The remaining two reported they did not inform their child about camp because they were not "mentally" ready to let their child attend.

Of the children at camp, 35% had been to camp one time, 26% had been to camp two times, and 39% had attended camp three or more times. Of the children attending these
camps for the first time \( (n = 16) \), \( 62.5\% \) \((n = 10)\) were in active treatment for their cancer.

While 84% percent of the sample was in remission by the time of this study and the following camp session, many had been in treatment the first year they attended camp. Of the entire sample, 67.4% were on treatment the first year they ever attended camp. Twenty eight percent were too young to attend camp when their treatment was completed, and 4.3% had just completed treatment when camp began.

**Post-Camp Contact**

Since these camps are conceptualized as providing a means of social support for those who attend them, children were questioned about the extent to which they keep in touch with their new found support network. Sixty seven percent of the children stated they are the recipients of contact from other campers (see Table 55). Fifty seven percent reported they contact other campers. (see Table 56). An even larger percentage of the children (87%) reported receiving and initiating contact from the counselors at camp (see Tables 57 and 58). Thus, the children appear to continue to contact the friends they make at camp during the time between camp sessions. While some children did receive visits and telephone calls, the largest percentage reported staying in touch with other campers and counselors via letters.
**Developmental, Sex, and Camp Differences**

Developmental, sex, and camp differences in children's frequency of contact with campers and counselors were explored using chi-square analyses. As expected, adolescents were more likely to send (77.3%) and receive (86.4%) contact than younger children (37.5% and 50%), $\chi^2(1, N = 46) = 5.86, p < .05$ and $\chi^2(1, N = 46) = 5.35, p < .05$ respectively. Although more adolescents (95.5%) reported contacting counselors than younger children (75%), the difference was not statistically significant. As hypothesized, there were no significant differences in counselors contacting younger children (79.2%) or adolescents (95.5%). No sex or camp differences were found for any of the above comparisons. These findings suggest adolescents are more active in keeping in contact with their new found friends.

**Sharing of Illness Experiences**

Children were also queried about their experiences talking and sharing with other children and counselors at camp. Ninety six percent of the children stated they would feel comfortable talking to someone from camp if they were upset about something. Of those children, 60.9% indicated they would talk with a counselor or a camper, 26.1% said they would only talk to a counselor and 2.2% said only a camper.
Parents were not as certain that their children would share their problems with people from camp. Seventy percent of the parents thought their child would rely on others from camp, 17.4% said their child would not share problems, and 13% replied they did not know what their child would do. Of the parents indicating their child would rely on others, 43.8% thought he or she would talk only to counselors, 34.4% thought he or she would talk to both campers and counselors, 6.3% thought he or she would talk only to campers and 15.6% did not know who their child would talk to if they had a problem.

When asked specifically about sharing their cancer experiences, 71.1% of the children replied they had talked about their illness with other campers and 78.3% stated that other campers shared their own illness experiences with them. Seventy percent of the campers reported talking about their cancer experiences with counselors at camp.

There was some variability in children’s descriptions of what they talked about with other campers and counselors. The majority of children described talking (89.4%) and hearing (41.7%) most frequently about the medical aspects of having cancer (e.g. diagnosis and treatment). A smaller number of children described talking (39.4%) and hearing (30.6%) about all aspects of the illness experience (e.g. treatment, feelings).
Developmental and Sex Differences.

Developmental differences in the mean frequency with which children talked and heard about illness experiences were explored using one way analyses of variance. As expected, adolescents ($M = 3.05, SD = 1.17$) were found to speak more frequently than younger children ($M = 2.08, SD = 1.10$) about their cancer experience with other campers, $F(1, 44) = 10.31, p < .01$. In addition, adolescents ($M = 3.23, SD = 1.15$) reported hearing about other children’s illness experiences more frequently than younger children ($M = 2.08, SD = 1.10$), $F(1, 44) = 11.87, p < .01$, as presumed. Furthermore, adolescents ($M = 2.82, SD = 1.05$) talked more frequently about their cancer with counselors than younger children ($M = 1.67, SD = 0.82$), $F(1, 44) = 17.35, p < .001$. Finally, adolescents ($M = 2.23, SD = 1.23$) perceived counselors as asking about their illness experience more frequently than younger children ($M = 1.38, SD = .65$), $F(1, 44) = 8.84, p < .01$. No sex differences were found for any of the above comparisons. Thus, adolescents appear to use camp as a time to process and discuss their illness experiences with other campers and counselors more often than younger children.

Camp Differences.

To determine whether differences existed between the two camps, comparisons of the responses of children from each camp were performed on the above mentioned questions.
Children from the Connecticut camp were found to speak more frequently about their illness experiences with other campers ($M = 2.85, SD = 1.22$), $F(1, 44) = 5.62, p < .05$, and with counselors ($M = 2.5, SD = 1.07$) than children from the Vermont camp ($M = 2.0, SD = 1.17$; $M = 1.85, SD = 1.04$ respectively), $F(1, 44) = 4.28, p < .05$. No significant differences were found in the mean frequency that other children or counselors spoke with children from either camp about their illness experiences.

Children were also questioned about having boyfriends or girlfriends at camp. Surprisingly, younger children (45.8%) were equally as likely to have boy or girlfriends at camp as adolescents (41%). However, as predicted, adolescents did talk ($M = 2.2, SD = .67$) and hear ($M = 2.2, SD = .83$) about illness experiences with their significant other more frequently than younger children ($M = 1.46, SD = .69$; $M = 1.36, SD = .67$), $F(1, 18) = 6.34, p < .05; F(1, 18) = 6.5, p < .05$ respectively. Again, although both younger children and adolescents use their time at camp to share feelings with friends and boy/girlfriends, adolescents do so more often.

Satisfaction with the Camp Experience

Overall, ratings of camp experiences were quite positive. On a five point scale, seventy eight percent of the children indicated they liked being at camp very much
(score of 5), with the remaining 22% stating that they liked being at camp a lot (score of 4). Children’s mean satisfaction rating for camp was 4.78 (SD = .42). Parents were also quite satisfied with their children’s camp experiences. Eighty five percent stated they liked camp very much, 13% stated they liked camp a lot, and 2.2% stated they liked camp somewhat (score of 3). Parent’s mean satisfaction rating was 4.83 (SD = .44).

**Children’s Qualitative Camp Responses**

Semi-structured interviews were also used to collect children’s and parents’ qualitative perceptions of camp. The categories formed for each of the questions, and the percent and frequency of responses for each question are presented in Tables 59 - 68). Children and parents provided a variety of responses to these questions, as they could give more than one response for each camp question. Examples of responses for each support category within each question can be found in Appendix F.

Camp seems to provide children with a variety of positive feelings. In talking about how they felt at camp, most described a sense of belonging and feeling good and happy (see Table 59). While most children felt good, a few did express feeling bad or sad as well, since so many children at camp were sick. Children were well aware of their own needs for support and for a break from the medical routine. When asked the purposes of special
camps, children most frequently responded that camp allowed them to be with others experiencing the same thing, as well as providing them with a vacation and some fun (see Table 60).

Children described receiving a great deal from camp. The most frequently mentioned responses were new friends, fun, and positive feelings such as hope, enthusiasm, and spirit (see Table 61). Children felt they not only received things from camp, but felt they contributed to camp as well. Giving their friendship was the most frequently stated response when asked what they contributed to camp. Children also described being a role model and providing understanding to others, as well as offering a good sense of humor and fun to the experience (see Table 60).

Since most of the children had attended these camps at least one other year, they were easily able to enumerate their likes and dislikes about the camp experience. Sports, special events such as carnivals and hot air ballooning, and the campers and counselors at camp were frequently mentioned by the children as their favorite parts of the camp experience. Activities which were against the camp rules such as water balloon fights and night raids were also favorites among the children (see Table 63). Many different responses were given for
ideas of what to add to camp. Responses most frequently included adding sports such as waterskiing and horseback riding along with adding animals to camp (see Table 64).

When asked what they would change about camp, 76.1% of the children indicated they would change something about camp. The most frequent response was to make camp longer or make specific changes in the food or some of the programs and activities at camp (see Table 65). When queried about unrealistic rules at camp, only 32.6% of the children felt there were any. Comments given by children centered around rules pertaining to sports and teams. Like most children, they felt they should be allowed to go to bed and wake up later than required at camp (see Table 66).

Children were also asked to describe the aspects of camp that may have been more difficult for them to handle. In explaining what was hard for them to get used to at camp, children discussed some of the readily apparent negative aspects of camps for children with cancer. While only 54.3% of the children responded to the question, responses most frequently given included seeing so many other children with cancer and meeting so many new people, along with leaving home and family (see Table 67). When questioned about the things that made them feel bad or sad at camp, 50% of the children responded. Children most often described leaving camp as making them feel bad,
along with seeing other children who were sick (see Table 68). While they could identify the positive aspects of camp, these comments suggest many children could also identify the negative aspects of camp.

Both the Vermont and Connecticut camps provide opportunities for the children to see other campers and staff during the year. Many of the children from both camps take advantage of this opportunity to see friends. The Vermont camp had a reunion in the fall which 50% of the children attended. The Connecticut camp had a weekend in the fall where campers could bring a buddy to camp. Sixty five percent of the children attended this weekend, with 58.8% bringing friends and 17.7% bringing siblings as buddies for the weekend. Children not only made new friends at camp, but their parents did as well. Forty four percent of the parents indicated they became friendly with other parents from camp as a result of their child’s camp attendance. These findings suggest that seeing and being with others from camp is important to both the children at camp and their parents, who enable them to attend these extra activities.

**Parents’ Qualitative Camp Responses**

Parents’ responses to the semi-structured camp interview are presented in Tables 69 - 77. In general parents’ perceptions of camp were quite consistent with
those of their children. Like their children, parents most often viewed the purpose of camp as allowing their children to be with others undergoing the same experience and as an escape from treatment regimens (see Table 69). Parents felt their children made new friends from camp. They also frequently commented on changes that they noticed in their child’s self-esteem, personality, or style of interacting such as increased confidence or becoming more outgoing, as a result of attending camp. Like their children, parents saw camp as providing their children with role models to learn how to cope with their cancer (see Table 70).

In discussing what their children contribute to camp, most parents described qualitative aspects of their child’s personality or interactional style. The breakdown of these qualities can be found in Table 71. Parents most frequently depicted their children as giving their compassion and comfort, positive attitude and enthusiasm, and charisma and out-going personality to others at camp.

While children listed sports and other camp activities as their favorite parts of camp, parents most often responded that the break they themselves received was their favorite part of camp. Parents also stated they liked the fun their child had at camp, as well as the dedication of the staff and caring and sharing that went on at camp (see Table 72).
Although their children had numerous responses for what they would add to camp, only 40% of the parents responded to this question. Parents' comments focused on different activities they would like to see at camp such as overnight camping experiences or waterskiing (see Table 73). Only 55.6% of the parents expressed any changes they would like to see in camp. The largest number of parents wanted camp to be longer, as did their children. Several parents wanted to be able to attend camp, explaining they wanted to see some of the fun too (see Table 74). A few parents felt that the camps should address, in a formal or informal manner, the more psychological aspects of having a chronic illness such as cancer. Most parents were quite satisfied with the rules at camp (see Table 75).

In contrast to their children, a larger percentage of the parents commented on what was hard for them to get used to at camp (75.6%) or what made them feel bad at camp (71.1%) than their children. Although parents indicated that they liked the break from their children, the hardest thing for them to get used to was letting their children go to camp and then being away from them for a week (see Table 76). And like their children, parents also found seeing sick children and children dying as two of the saddest aspects of camp. Parents also stated that making
their child leave camp at the end of the week as quite sad for them as well (see Table 77).

Thus both children and parents were able to describe and discuss the positive and negative aspects of the camp experience. Yet both viewed the positive effect and the enduring relationships made from camp as making the experience worthwhile, one they would not have wanted to miss.
DISCUSSION

Purposes of the Study

The present research had four primary purposes: 1) to describe and assess the satisfaction with social support resources used by children and their parents to cope with the cancer experience; 2) to assess the overall level of satisfaction with social support and perceptions of family functioning and competence in children with cancer and their parents; 3) to explore the demographic, illness, social support, and familial factors that predict psychosocial adjustment in children with cancer; and 4) to describe and assess children’s and parents’ perceptions of the camp experience and their satisfaction with the services these camps provided.

Descriptions of Social Support

The first goal of the present research was to describe the support providers and support resources used by children with cancer and their parents, and to assess their satisfaction with the support received in relation to the cancer experience. Consistent with the literature on children’s social support resources, children with cancer relied heavily on their parents for support. This reliance on parents was not only true for the children in this study, but for their parents as well. This finding suggests that the family and parents in particular continue to be a stable source of social support.
throughout the lifespan (e.g. Belle & Longfellow, 1984; Furman & Buhrmester, 1985). Children reported discussing their illness situation most often with their parents, and a fair number of children reported talking with their mothers more often than their fathers. This finding was consistent with Tebbi et al.'s (1985) finding that mothers were viewed as the most helpful person in the support network of adolescents with cancer. In the present study, this finding may have been due in part to the fact that the mother was almost always the parent who took responsibility for the daily management of the illness. The fathers in this study were usually responsible for running the household and taking care of their other children, while their wives were at the hospital.

After parents, children most often talked about their illness experiences with peers. Furthermore, older children reported talking with their friends more frequently than younger children did. As researchers have found with healthy children, peers are an important source of support for children with cancer, and become even more so as they get older (e.g. Furman & Buhrmester, 1985; Harter, 1986). Parents also described talking about the illness experience frequently with their friends.

For both children and parents, the medical staff was also an important source of support in talking about the disease process. Parents, in fact, turned to medical
staff for support almost as often as they turned to their own parents for support. While parents also turned to their spouses to discuss the illness experience, they did so less frequently than with other sources of support in their lives. This finding was in part influenced by the fact that in 16 of the 45 families in the study, parents were either divorced, widowed, or single. Yet, even when exploring the reports of married parents alone, spouses were turned to least often of all people in the support network, although still talked to often. Perhaps because of the intensity of the shared experience, parents needed to talk with other adults to get a different perspective on their thoughts and feelings.

Children also turned to siblings and relatives to discuss their illness experiences, but less frequently. While siblings may be a source of support, there is often a strain in sibling relationships since the sick child receives so much attention for the illness (Tritt & Esses, 1988). Contrary to expectation, adolescents were found to discuss their cancer with relatives more often than younger children. Reid et al. (1989) found adolescents to have increased contact with relatives if they lived with them. Since approximately seventy percent of the families in this sample lived near their grandparents, adolescents may have been more likely to contact them to share thoughts and feelings.
Children were more selective than their parents in what they discussed with the various people in their support networks. Both children and parents talked with most people about the medical aspects (e.g. treatment, side effects) of the cancer experience. However, children usually shared the more emotional aspects (e.g. feelings, family adjustment) of their experience with parents and peers. Parents shared the more intimate aspects of the illness with all members of their support networks.

The developmental literature indicates that as children get older they tend to turn to their peers to share issues they used to discuss only with their parents (Berndt, 1989; Hunter, 1985). The findings that adolescents in this study turned to friends more often than younger children to discuss their cancer experience is consistent with the developmental literature. Yet most younger children and adolescents reported sharing most of the more emotional aspects of their illness with friends. This finding may in part be related to the nature of the cancer experience. Children with cancer have been found to be quite aware of the seriousness of their illnesses, even when parents have not shared this information with them (Bluebond-Langer, 1978). Thus, in an effort to avoid upsetting their parents, younger children and adolescents may also turn to their peers to share more of their fears
and feelings. An alternative explanation may be that children with cancer just need the extra support during an experience that is so overwhelming, and their friends can provide this support. As one would expect, most children discussed school issues pertaining to their illness with their teachers and peers.

Overall, children and parents were quite satisfied with the support they received from others. Parents were perceived as most helpful to children followed by medical staff, friends, siblings, school staff, and relatives. Parents viewed their own parents as most helpful, followed by medical staff, friends, siblings, and spouses.

When describing the ways people did and did not help them, children and parents were less likely to discuss ways that people did not help them. There are several possible explanations for this pattern of responding. Approximately eighty four percent of the children participating in this research were in remission or considered cured. Many were not describing current experiences of support but were recalling events from the past, although for many it was the recent past. As a result, it may have been easier to recall acts of kindness or remember generalized positive feelings as the literature on memory recall has demonstrated (Matlin, 1989). Memories for behaviors that weren’t helpful may fade or be harder to recall unless they are tied to a particularly memorable incident. Or, the
parents and children in the study may not have felt comfortable describing "negative" aspects of friends' and loved ones' behaviors with a "stranger", viewing it as socially unacceptable, or responding in socially desirable ways. An alternative explanation is that there truly were few ways people were not helpful during the illness ordeal. Yet, when describing ways that people were not helpful, more parents and children provided examples for family members and medical staff than any others in their support networks. This may be because people are often most critical of those most integrally involved in their daily lives. With childhood cancer, that would be family members and the medical staff.

**Children's Descriptions of Support**

Children's descriptions of the types of support provided by their support networks were varied and rich. In addition, children described receiving a variety of types of support. Emotional, companionship, and instrumental support were mentioned most often, which is consistent with other findings in the literature (e.g. Dubow & Ullman, 1989).

Parents were characterized as the mainstay of children's support networks during the cancer experience. They were children's multipurpose support providers, supplying all different types of support, but especially
emotional and companionship support. This too is consistent with the findings in the literature on children’s support networks (e.g. Reid, et al., 1989). One informative way parents were not helpful was in their attempts to impose their own coping style on the child, such as talking about the illness when the child did not want to talk. Parents need to appraise how their child perceives the support they are providing, and must consider both the child’s style of coping and the developmental age of the child in their appraisal.

Friends, like parents, provided emotional and companionship support to children. As is seen with healthy children, the peers of children with cancer seem to validate their sense of worth by caring for them and spending time with them (e.g. Reid et al., 1989). While parents also provide this function, spending time with peers may help to normalize the illness experience even more, since spending time with friends is what children are expected to and want to do. The issue of fitting in and being seen as normal characterized children’s responses for how friends and peers were not helpful to them. Children viewed being teased or treated differently because they had cancer as not helpful.

Siblings were most often characterized by children as supplying instrumental assistance and less often as providing emotional support. Developmentally, one might
expect to see this; by being active or doing something for the sick child, siblings might feel useful. Children described their siblings as not helpful because they displayed negative emotions such as jealousy and resentment. Feelings such as these have consistently been found in the siblings of children with other chronic illnesses (e.g. Drotar & Crawford, 1986; Tritt & Esses, 1988).

People on the periphery of children's lives such as grandparents and other relatives were described as providing less emotional types of support and more material (e.g. presents) or companionship (e.g. visiting at hospital) support. Relatives were viewed as not helpful when they were not able to visit or had negative attitudes about the illness prognosis.

As would be expected, medical staff were primarily viewed as supplying children with "medical" support by treating or curing their cancer. It is encouraging that children also perceived the medical staff as supplying emotional support. With the reduced contact with peers and family that often accompanies the hospitalizations for treatment, the medical staff often becomes a "family" for the child with cancer. They provide some of the support resources that children would normally get from peers or family members but cannot while they are hospitalized or
sick. Their descriptions of the medical staff imply they are aware of this support.

Children’s descriptions of how medical staff were not helpful reflect the complexity of providing support. Although children viewed the medical treatment staff gave them as helpful because it cured their cancer, they also viewed it as not helpful because it was painful or made them sick. This illustrates the dilemma faced by both the child and the health care provider when dealing with cancer. While the short term consequences of cancer treatment are negative, in the long run they will most likely have life sustaining benefits. Although children understand the implications of the medical assistance doctors and nurses are giving them, they do not necessarily like them. This example is consistent with the finding of Chesler and Barbarin (1984) that those who are sources of help can also be sources of added stress.

Teachers were described as being children’s primary support providers at school. As would be expected, they were usually seen as providing instrumental support with school work. Some children described teachers as also giving emotional support by listening to them and trying to understand what they were going through. Lack of understanding or assistance with what a child was going through with the illness experience were two of the ways teachers were seen as unhelpful. Many cancer centers now
have psychosocial treatment teams to help the child with adjustment back to school (e.g. Katz & Ingle, 1987). Team members come into the schools, and talk with school staff and classmates about cancer and what to expect from the sick child. The comments from the children in the present study suggest this type of intervention needs to be available to more children with cancer.

Children also described turning to others, above and beyond the central support figures already discussed, for support. Many stated they received support from mental health professionals, from adults such as neighbors or friends of the family, as well as from their religious communities. As Chesler and Barbarin (1987) conclude, cancer impacts both the near and far support networks of children.

Parents' Descriptions of Support

For parents, spouses were quite important in the support process. Spouses were depicted as furnishing emotional support, as well as instrumental support in managing the household and family in the mother's absence. Conversely, spouses were viewed as not helpful if they did not provide emotional support and by not helping with medical decisions and management of their children's cancer.
Like their children, parents viewed their own parents as offering emotional and instrumental support. This sample of families may be unique in that approximately seventy percent lived near maternal or paternal parents, and forty nine percent lived near siblings. Thus, the extended family was often accessible and available to these families. Many of the grandparents moved in or stayed with the families for several weeks during the illness ordeal, helping to run the household. Parents were seen as unhelpful when they were not emotionally supportive of the parent of the sick child. Siblings of parents also supplied emotional and instrumental support. They were viewed as unhelpful when they did not provide emotional support such as listening or caring. In general, the families participating in the present study appear to have had a core of extended family members to rely on for assistance with their support needs.

The medical staff was also quite important to the parents of children with cancer. Medical staff was seen as providing emotional support as well as medical support. Consistent with the findings in the literature, during the cancer experience the medical staff is one of the main sources of social support for the child with cancer and his or her family (Chesler & Barbarin, 1987). Both parents and their children viewed medical mistakes made by hospital staff as not helpful.
Friends were described as very important to parents during the cancer ordeal. They supplied parents with both emotional support such as listening, as well as providing instrumental aid such as assisting in managing the remaining children in the family. Friends were seen as unhelpful when they altered their relationship with the parent(s) and child, becoming emotionally and/or physically unavailable. These descriptions were consistent with those obtained by Chesler and Barbarin (1984) in their interviews of parents with children with cancer. Parents described acquaintances as unhelpful because they were too intrusive or too free with advice for the family. These comments illustrate the point that it is the meaning of a "supportive" behavior to an individual that is important (Thoits, 1986). Acquaintances may have thought that they were expressing concern by asking about the child’s progress or offering advice, but it was often perceived to be intrusive and annoying.

When describing how the sick child helped them, all parents described their child’s resilience and positive attitude as giving them the strength they needed. Their comments illustrate the notion that the support process is a reciprocal one (Belle, 1989). Parents are not only supporting their children, but they are receiving support
from them as well. Siblings of the sick child were characterized as being emotionally supportive to the parent, as well as quite flexible and understanding about changes in family routines. Like their sick children, parents found their healthy children’s jealousy and resentment toward the sick child to be unhelpful.

Parents also used a variety of other sources of social support. Unlike their children, parents not only turned to others for support but turned inward. Informational support, that is learning as much as they could about cancer, was one of the most commonly described types of additional support used by parents. Obtaining information about their children’s cancer may have increased parents’ perceptions of control over the illness (Sandler et al., 1989). In addition, parents talked about relying on their own inner reserves and strength as a means of support, as have others who have experienced cancer (Chodoff et al., 1964). Parents also belonged to one of the various cancer societies, as well as turning to their towns and communities for support. Thus, there is evidence to suggest that these parents relied on a fairly large number of people for support, along with relying on themselves to get through the illness experience.

**Additional Sources of Support**

The families in this study were involved with a variety of other supportive relationships. Interviews
suggest that parents turned to internal and external sources of support. For most families, internal support meant relying on their faith and religion to cope. Parents also turned to external sources of support. For several parents this included being part of support groups; for others it meant attempts to help other people with some aspect of the cancer experience. Still, for other families, external support meant participating in individual child or parent therapy, as well as family therapy. Like other families studied in the literature, these families turned to a variety of sources of support to aid them with the cancer experience (Chesler & Barbarin, 1987; Chodoff et al., 1964, Yoak et al., 1985).

Family Relationships

Both children and parents reported feeling quite satisfied with their current level of family relationships. Most children described their families as having grown closer as a result of the illness experience. Most parents perceived their families as having grown closer in some ways and further apart in other ways. Since they were responsible for managing the illness and for maintaining a sense of normalcy within the family, parents may have been more aware of the fluctuations and changes in family relationships over the course of the illness experience.
From their descriptions, one can conclude that these families received a variety of types of supports during the cancer experience. Parents and children's perceptions and descriptions of their support experiences were quite similar. Given that parents are the primary source of children's social support, one might expect similarities in the way the illness experience is approached and perceived.

Parents described receiving all types of support from each of the central support figures in their lives. For many of the children, emotional support was depicted as being received from parents and friends, with most other support figures providing various forms of instrumental support. Thus, children's descriptions of support for the cancer experience appear to be specific and tied to different people in their support networks. These findings are consistent with those of other researchers using interview formats to assess support (Dubow & Tisak, 1989; Reid et al., 1989). In general, children's responses were also consistent with those of healthy peers. Although these children suffered from chronic illnesses, the ways they described the social support they received were the same as their healthy agemates.

Overall, few sex differences were found in the descriptive portion of this study. Although the literature suggests that males often have more nonfamily
adult and peer support resources, while females are often more satisfied with their support, and more intimate with those in their networks (Belle, 1989; Berndt 1989), this was not the case in the present study. Perhaps the cancer experience is perceived as so stressful that males and females alike seek or receive additional support, and learn to rely on more people than their immediate families and friends for help. Nevertheless, males and females with cancer appear to describe their support networks similarly, which is different from their healthy peers.

Summary of Descriptive Findings

The use of available formal and informal sources of social support suggests that these families were well supported during the illness experience. The general findings of satisfaction with familial and extrafamilial support implies that these families have adjusted fairly well to the cancer experience. Since eighty four percent of the children involved in this study were in remission for an average of four years, these descriptive findings were to be expected given the cancer literature that indicates adjustment increases over time (Kazak & Meadows, 1989; Kupst & Schulman, 1988). Nevertheless, these findings highlight the point that these children and parents demonstrate a great deal of resilience in the face of the enormous stressors associated with childhood cancer.
Limitations of the Descriptive Findings

The families in the present study chose to participate in this project. Therefore, there is no way to discern whether those willing to participate were also those most involved in other formal or informal support services. Furthermore, those in the study may have also been more satisfied with the support they were receiving as compared to those families from camp who did not participating in the study. The fact that these families were included in this study because they participate in a camp suggests a willingness to be involved in supportive interventions. However, information was not collected as to whether families chose to seek out these support services or were referred for services by people in their lives.

Furthermore, some of the children in the sample were on treatment. As a result, their responses were based on current experiences, while the rest of the children were giving retrospective reports, although for many these reports were of the recent past. This mixing of children on and off treatment may also have influenced the findings. Given the small number of children receiving treatment, comparative analyses were not performed. Furthermore, this study explored children’s and parents’ perceptions of support. What was actually received or available (enacted support) was not assessed. Therefore,
these results should be interpreted cautiously and replicated. Nevertheless, the general findings appear to reflect both the resilience and strength of these families, as well as the advances that have been made in the psychosocial care of children with cancer.

**Implications for Further Research in the Social Support of Children with Cancer**

Given the limitations of the present study, more controlled research in this area is warranted. Future research could assess support resources at the time of diagnosis and assess how social support resources and perceptions of satisfaction change over the course of the illness. Comparisons should also be made of children who attend camps for children with cancer with children who do not attend such camps, to illuminate any differences in perceptions of support and support resources. In both cases, standardized measures of social support should be used along with interviews to provide different assessments of social support. And, assessments of enacted as well as perceived support, should be provided. There are currently several well standardized questionnaires which assess enacted, perceived, and structural aspects of support which can be used with children (e.g. Dubow & Ullman, 1989; Reid et al., 1989), that were not available at the outset of this study.
Standardized Assessment of Social Support, Family Functioning, and Adjustment

The second goal of the present research was to assess overall satisfaction with social support and perceptions of family functioning in children with cancer and their parents. On all standardized measures, children with cancer and their parents did not differ from the normative data for healthy children, adults, or families. Overall, the findings on these measures suggest that this sample of families has adjusted well to the illness experience. Again, given the fact that most of the children were off treatment and in remission or considered cured, these findings are not surprising and also consistent with other studies of families with children with cancer (e.g. Chesler & Barbarin, 1987).

Social Support

As expected, children with cancer were quite satisfied with the general level of social support obtained from parents, friends, classmates, and teachers. Although Harter (1986) found developmental differences in perceptions of support, with adolescents perceiving more support from close friends than younger children, that was not the case in this sample. This finding may be due to the fact that the children she used for comparison ranged in age form 8 to 13 with the developmental groups being split from this age range. The children in the present
study ranged in age from 7 to 17. Therefore, some of the middle school children who were in the older group in Harter’s study were in the younger group for the present research. As such, the present grouping may have masked developmental differences.

Although Harter’s (1986) social support scale was not designed to be used with adolescents, it was piloted on them in the present study. Sex differences were found for adolescents females, who perceived more support from friends and teachers than adolescent males. This trend is consistent with developmental research that suggests females are more intimate with and more satisfied with the support they receive from close friends than adolescent males (Berndt, 1989; Furman, 1989). However, the perception of greater support from teachers is at odds with the developmental literature on support from nonfamily adults, which has found adolescent males to report more support (Belle, 1989; Bryant, 1985). This finding appears to suggest that adolescent females with cancer perceive more support from friends and teachers than adolescent males.

These developmental differences must be viewed as tentative for three reasons. First, the scale was not designed for adolescents; it was constructed and normed on younger children. Thus is not clear what the scale is
measuring, as it could be tapping a similar but different construct in the population. Second, the size of the sample of adolescents on all of these comparisons was small (n = 16). Finally, although the difference were statistically significant, they may not reflect practical differences.

These findings also raise some important questions about the use of the Social Support Scale for Children (Harter, 1986) in the present research. While the scale does not measure social embeddedness or enacted support, it was described as assessing perceptions of support and regard, and thought to reflect perceptions of quality of support. However, more recent use of the scale has described it as a measure of social acceptance (Harter, 1987b). While perceptions of social acceptance may be related to perceptions of quality of support, they are not the same thing. Given the definitional problems within the social support literature, using a measure with a more precise definition of the type of support it assesses would be critical for further research with children with cancer. More recently developed measures (e.g. Reid et al., 1989; Wolchik et al., 1989) assess social embeddedness, enacted support, and perceived quality of support, all three of which may be more useful for comparative research.
Self-Concept

Children and adolescents with cancer do not perceive their competence or global sense of worth differently than healthy children do. These findings are in line with a growing number of studies in the literature that suggest that children with cancer do not differ from their healthy agemates on standardized assessments of self-concept (DeStefano, 1989; Noll et al., 1990a; Spirito et al., 1990). Differences according to gender were found for both younger children and adolescents. As reported by others in the literature, male children had significantly higher perceptions of athletic competence than female children (Harter, 1986). However, adolescent females had higher perceptions of competence in close friendships than males. Therefore, adolescent females were not only found to perceive more support from close friends, but they felt more confident in their perceptions of competence in close friendships. One might expect these two findings to be related. For example, if a person does not feel confident in his or her close friendships, one would not expect him or her to feel he or she could rely on these friends for support. Again these results must be interpreted cautiously and should be replicated given the previously mentioned problems with the sample.
Behavioral Symptoms

Children's scores on the child behavior checklist suggest that as a group they are functioning well within the average behavioral range for their age. As a group, the children were well adjusted behaviorally. Yet a small number of children had behavior problem scores that fell within the range of clinical significance. These children were primarily boys, which is a typical finding for most populations of girls and boys on this scale (Achenbach & Edelbrock, 1983). Those scores that fell within the range of clinical significance must be interpreted cautiously due to problems reported in using the scales with children with chronic illnesses (Perrin et al., 1990). Overall, the findings using this scale and the self-competence scale are in line with others in the childhood cancer literature which suggest most children are adjusting and functioning well, with subtle individual differences (e.g. Noll et al., 1990a; Spirito et al., 1990).

Parental Perceptions of Social and Familial Support

Like their children, parents were also quite satisfied with the general level of support in their lives, and parents reported relying on several different people for support. Parents also perceived their families as functioning well, viewing adequate levels of cohesiveness and expressiveness, and low levels of conflict within the family. These findings from the
Family Environment Scale are consistent with parents ratings of satisfaction with their families from the clinical interviews. Caution must be taken in interpreting these self-report findings, as parents may have been influenced by social desirability when responding.

Predictors of Adjustment in Children with Cancer

The third goal of the present research was to explore the demographic, illness, social support, and familial factors that predict psychosocial adjustment in children with cancer. Theoretically, several variables within each of the above mentioned areas were expected to influence psychosocial adjustment, as reflected in behavioral problems and global self-worth. However, there were no a priori expectations for which factors or combination of factors would be most predictive of adjustment. Therefore, the analyses which will be discussed were exploratory in nature. As a result, findings should be interpreted cautiously.

Both marital status and degree of family conflict were found to be significant predictors of children's global self-worth, accounting for thirty eight percent of the variance in self-worth scores. Having married parents was associated with higher self-worth in children with cancer. However, higher family conflict was associated with higher
self-worth in children with cancer. In examining marital status as a predictor of adjustment, it may be that having two parents involved in day to day life enhances or protects the self-worth of children with cancer. Given the life threatening nature of the illness, support from both parents may be necessary for children with cancer to feel better about themselves. The finding that marital status was related to global self-worth is consistent with findings from the literature on children from divorced families (Hodges, 1986).

However, it should be noted the children in this study whose parents weren't married were a varied group. Thirty six children had parents who were married, and the remaining ten children either had single parents, parents who were divorced, or came from families where a parent had died. As such, it is hard to discern what aspects of having or not having married parents affect children's perceptions of self-worth.

The finding that higher levels of perceived family conflict were predictive of global self-worth initially appears puzzling. However, a certain amount of conflict is to be expected in most families. Perceiving little or no conflict in the family may be associated with denial that conflict exists or may be reflecting a disengaged, noncommunicative family style. Alternatively, for children with cancer, having conflict in the family may help them
to feel like "normal" children along with taking the focus off of them for a while. As the children described in their interviews, parents and siblings provide a great deal of support during the illness experience. Yet, family members may be afraid of upsetting the sick child, and as a result may attempt to avoid or limit the expression of conflict. Therefore, the acknowledgement of conflict may help reassure the child that life is returning to normal. As a result, children with cancer may feel better about themselves.

In regard to level of perceived family conflict as a predictor, it should be noted that the mean level of conflict within the sample was found to be comparable with the normative data on families provided with the scale. Parents were not reporting an excessive amount of family conflict. The implication is that there may be an altogether different relationship among conflict and self-worth when there is a wider range of conflict scores.

For the indices of behavioral adjustment, sex, perceptions of social support from friends, and perceived level of family cohesion were significant predictors of total behavior problems and total externalizing behavioral problems. Sex was the only significant predictor for total internalizing behavior problems. Being male, perceiving more social support from friends, and having lower levels
of family cohesion were associated with more total behavioral problems and more externalizing behavior problems. Being male was associated with more internalizing behavior problems. The finding that being a male was associated with externalizing and total behavioral problems is consistent with Achenbach and Edelbrock’s (1983) findings for sex differences in behavior problems on the CBCL scale. However, girls usually show more internalizing behavior problems than boys do. Perhaps dealing with a serious illness such as cancer places boys, who are at greater risk for developing externalizing problems (e.g. hyperactivity), at risk for developing internalizing problems (e.g. depression) as well. Why girls weren’t reported as having more internalizing problems may be explained in the interrelationships of sex, family cohesion, and behavioral adjustment.

Family cohesion was shown to be inversely related to behavioral problems. Thus, children with cancer from families with lower levels of perceived cohesion had more reported behavioral difficulties. Yet, family cohesion was also correlated with sex; girls’ families reported higher levels of family cohesion. Although in general girls are at increased risk for developing internalizing behavior problems, family cohesion may operate as a protective factor for them.
The third predictor, perceptions of social support from close friends, related directly to behavioral adjustment. Higher perceptions of support from close friends was associated with more externalizing behavior problems and more total behavior problems. Close friends may be providing support, but that does not necessarily imply positive support. The support could be for a variety of aggressive or negative behaviors. Furthermore, children who perceived less support from their friends also had higher levels of perceived family cohesion. Perhaps those who look less to their friends for support turn more to their families for support. As a result their behavior may be viewed more positively by their parents. Findings for all three regression analyses using the Child Behavior Checklist must also be interpreted tentatively, given the previously mentioned problems of using the scale with children with chronic illnesses (Perrin et al., 1989).

Summary of Predictive Analyses of Adjustment

Overall, the findings from the predictive analyses are consistent with those of other researchers that suggest familial and child factors play a role in the psychosocial adjustment of children with cancer (e.g. Fritz et al., 1988; Kazak & Meadows, 1989). Familial factors such as perceived level of cohesion and conflict, along with marital status related to indices of adjustment in the
present study. Furthermore, the sex of the child and his or her perceptions of support from close friends were related to psychosocial adjustment as well. Further research is warranted to understand the exact nature of the relationships among these variables and psychosocial adjustment in children with cancer.

**Limitations of the Predictive Findings**

The findings from all four regression analyses are difficult to interpret for several reasons. First, this was a mixed sample of children with cancer who were on and off treatment, and represented a large age range. As such, it is difficult to understand how these predictors differentially relate to disease status or developmental level. Marital status, sex, support from friends, and family cohesion and conflict may influence self-worth and behavioral adjustment in different ways for children with cancer who are on and off treatment, as well as influencing younger children and adolescents in different ways. Given the small number of children on treatment and the large age range in this study, these issue could not be explored using the current data set.

Second, analyzing child and adolescent global self-worth scores together may not be appropriate. Several potential predictor variables correlated with the separate child and adolescent self-worth scores in the opposite
direction. Any relationships these variables may have had in predicting self-worth may have been washed out as a result of a differential relationship for younger children and adolescents. Therefore, other demographic, illness, and social support variables that were not identified in this research, along with other untapped variables such as life stress, may have moderated the relationship among family conflict, marital status, and self-worth.

Third, this sample was a nonrandom, highly supported and satisfied group of children with cancer. As a result, many of the variables considered for use in the regression analyses had restricted ranges. There may have been other significant predictors of adjustment, but the limited sample size and range of scores did not allow a valid assessment of their predictive utility. Furthermore, the findings for children's social support as a predictor may have been different if a scale more appropriate for the sample had been used. Since the scale was not constructed to be used with adolescents, it is not certain what the scale was assessing, as it could have been measuring a similar but different construct in the population. This may have seriously influenced its predictive utility.

Implications for Further Predictive Research

Further controlled research needs to be carried out to more fully and accurately assess the role social support, demographic, illness, and family factors play in the
adjustment of children with cancer. Controlling for illness factors such as status of the disease along with controlling for developmental factors would be important to such endeavors, along with a larger sample size of children with cancer. Furthermore, measures of life stress should be included so that one could test the main-effect model versus the buffering model of social support. It would also be important to use measures that assess other aspects of social support such as social embeddedness or enacted support in addition to assessing perceived satisfaction with support. Finally, more appropriate indices of adjustment for children with cancer should be used.

**Descriptive Assessments of Camp**

The fourth goal of the present research was to describe and assess children's and parents' perceptions of camps for children with cancer along with assessing their satisfaction with the services these camps provide.

Overall, children and parents were quite satisfied with their camp experiences and the support camp provides them. Most families heard about camp from medical staff. Most children had been to camp an average of two times. A fair number of children had also attended other camps for children with cancer.

Children who attended the Vermont and Connecticut camps did not differ on any illness or demographic
variables except for the number of siblings in their families. However, they did differ from those children not participating in the study by race. That is, 2% of the study participants and 21% of the nonstudy participants were minorities.

Approximately 84% of the children in this sample were off treatment and in remission or considered cured at the time this study and camp began. Since many of the children return to camp for several summers, this figure is misleading as to the number of children who are on treatment the first year they attend camp. For this study, 16 children had attended camp for the first time, and 10 of them were being treated when they went to camp. In general, approximately 10 to 20 new children attend these camps for the first time each year, with many of these children on treatment. Thus, the camps are serving a varied group of children with cancer.

Children appear to benefit from camp by having their support networks expanded. Most children put effort into keeping their new friendships, especially with counselors. As was expected, adolescents contacted campers and counselors more frequently than younger children. Since the youngest children attending camp were seven and the oldest were seventeen, one would expect the adolescents to keep in contact with their new found friends more than the younger children. Counselors were viewed as keeping in
touch with all children at camp. Thus, children appear to
gain not only the support of other children who have
undergone a similar experience, but they also gain the
support of young adult counselors.

The strength of these new friendships can be seen in
most children's comments that they would discuss problems
with either other campers or counselors at camp. They are
also reflected in the fact that approximately seventy five
percent of the children reported hearing and talking about
their illness experiences with others at camp. As
expected, adolescents shared their cancer "stories" with
campers and counselors and heard about others' cancer
"stories" more frequently than younger children did. These
findings suggest similar patterns of sharing of illness
experiences for younger children and adolescents, however
adolescents appear to do so more frequently.

One interesting finding appeared in the comparisons
of the two cancer camps. Children from the Connecticut
camp were found to talk about their illness experiences
more often with counselors and other campers than children
from the Vermont camp. Furthermore, only children
attending the Connecticut camp were involved in illness
related support groups. Since the camps were comparable on
all demographics, one could speculate that children from
the Connecticut camp engaged in more support seeking
behavior or required more support than children from the Vermont camp.

To understand the finding for the differential use of support groups, there are two plausible explanations. First, the Vermont campers come from New York, New Hampshire, and Vermont. Many travel two to three hours to reach the University of Vermont Medical Center as their homes are spread out over a large rural area. These children may not have as easy access to support groups as the children from Connecticut. While the Connecticut campers come from all over the state, the largest percentage live in the greater metropolitan New York City area. Many live in suburbs that are fairly close to one another and the Yale New Haven Medical Center. As a result, they may have easier access to support groups. Another possible explanation can be derived from an examination of the groups to which the children from Connecticut belong. Almost all of the Connecticut campers are involved in a Candlelighters group. All of these children live near each other and all reported influencing each others participation in the group. Thus, the findings are most likely due to a combination of these two factors.

In general, most children and parents were quite satisfied with their camp experiences. Children described camp as providing them first and foremost emotional and
companionship support. The support received is critical for them since it provides them the opportunity to interact with others who have experienced the same thing and allows them to develop a sense of belonging. Thoits (1986) argues that this "empathy support" from similar others is one of the most helpful types of support. Children’s and parents’ responses about camp would support her contention.

As researchers have suggested, the recipients’ appraisal of the support received is crucial to understanding and interpreting attempts at social support (e.g. Heller et al., 1986). From children’s and parents’ responses, their views of the purposes of these camps are consistent with the stated goals of the camps. Both children and parents felt the camps provided them the chance to be with similar others, to have a break and escape from treatment, and to have fun.

These camps also provided children with both companionship support and emotional support. Children and parents felt they received a great deal from these camps. Children described gaining new friends, having fun, and sharing positive feelings. Thus, they were aware that camp expanded their social networks, which in turn may have enhanced their positive feelings. Children also described coming to understand others’ experiences with cancer and
learning from them at camp. Thus, while children learned how other children with cancer are similar, they also had the opportunity to learn how other types of cancer are different. Therefore camp provided them with the opportunity to evaluate their own experiences. Parents also viewed the effect of the experience on their child as an important benefit of camp. Many talked about changes in their child’s personality, self-esteem, and style of interaction as a result of going to camp.

Social support is a reciprocal process; both receiving and giving help are important (Yoak et al., 1984). Camp provides a good example of this since what children feel they receive and contribute can be assessed. Children’s responses indicate they were aware of the ability to help others at camp. Some said they helped by providing understanding and empathy, while others stated they were a role model to other children. Parents’ overall descriptions of ways their children contributed to camp were consistent with their children’s descriptions. Yet within the overall categories, children gave more instrumental ways of providing assistance while parents described more emotional ways of helping, by describing qualitative aspects of their children’s personalities.

The fact that children were aware that they were role models to others at camp implies that these camps should continue to allow children on and off treatment to attend
them. Camp administrators have grappled with the issue of limiting the number of years a child can attend these camps, especially if the child is in long term remission. Yet, the reports from these children suggest that it is that diversity in disease status and prognosis that is so important to the children who attend these camps.

Both children and parents enumerated a variety of things they liked about camp. Children’s comments centered around the normal activities at camp along with the special events such as hot air ballooning. While parents views were similar to those of their children, their favorite part of camp was the break it provided the family from the illness routine. Parents talked about the chance to take a "breather" and spend more time with friends and family. These parents’ descriptions are consistent with the findings of the Smith et al. (1988) study where parents of children with cancer were shown to spend more time with friends and family while their children were at camp. Although camp is important to the children who attend, it is equally important to the children’s families.

In describing ways to change camp, both children and their parents stressed that camp should be longer than a week. Children also wanted to add some more sports and special events to camp along with changing the bedtime and wake-up rules. Many parents also emphasized wanting to
attend camp, to be as they said, "part of the fun". A few parents felt camp should address, formally or informally, the more psychological aspects of having cancer.

Although the majority of parents and children viewed camp as a positive experience, they also described ways that camp was difficult for them. Responses essentially focused around the issue of saying goodbye and letting go, whether that be saying goodbye to parents and children before camp, or children saying goodbye to campers after camp. Responses also centered on the issues of seeing sick children and/or children dying. While children and their parents were aware that camp has both positive and negative experiences, overall it was viewed as worthwhile. Although this study was not designed to test social comparison theory, or to assess the impact of camp on children’s self-esteem or adjustment, children’s responses imply that the "positive" aspects of camp outweighed the "negative". Perhaps that is because the reality of cancer is sad, but children are well aware of that. While not hiding the negative, camp provides the chance to see hope and the positive side of life.

Given that children described seeing other sick children and children dying as aspects of camp that were difficult for them to handle, the suggestion from parents to have psychological issues addressed at camp may be an important one. Findings from the children’s interviews
imply they utilize peer support at camp, discussing their illness experiences informally amongst themselves. The programmatic implication would be to allow younger children or adolescents who are interested to organize a group for discussing these issues and others that may arise in a more organized manner. The group could be supervised by a counselor or other staff member at camp. From this author’s experiences at camp, this is a needed activity.

Summary of the Camp Findings

Overall the findings of the present study suggest that these camps for children with cancer are achieving their stated goal of providing children with a normal camping experience, as well as supplying them with a source of emotional social support. Children’s perceptions of camp and those of their parents were quite consistent. Both children and parents were able to recognize that these camps increase the child’s contact with other children who are sick, enabling them to develop a sense of belonging, increase their social networks, provide peer support, and the ability to participate in normal camp activities. While the majority of the children and parents were satisfied with the camp programs, most wished the camps could be longer than one week. Children reported using their time at camp to have fun as well as share their illness experiences with others at camp. And, many of
those children reported keeping in touch with their new
friends, both campers and counselors after camp.

Limitations of the Camp Findings

In discussing the findings from the camp interviews,
one must take into consideration two sources of possible
influence on children’s responses. First, the timing of
the interviews may have affected children’s responses.
Families were interviewed almost a full year after camp
ended and approximately one month before the new camp
session. Children may have given more generalized positive
responses because their memories faded over time, or
because they were anticipating the upcoming camp session.
Yet their anticipation of camp may have also helped them to
remember what they had experienced. If children had been
interviewed after camp, their responses may have been
different, possibly more evaluative. A second source of
influence may have been the investigator. Being a
counselor at these camps and being acquainted with many of
these children may have influenced their responses. It may
have made them less willing to discuss negative or
embarrassing issues or their familiarity with the
investigator may have helped them to feel more comfortable.
An examination of the range and variety of responses given
by the children suggests that they seem to have been fairly
evaluative, discussing both negative and positive aspects
of the camp experience. Therefore, these influences did
not seem to threaten the validity of the findings.

**Implications for Research on Camps**

Although the present research was a descriptive study and not a formal program evaluation, the findings nevertheless raise important questions to be addressed for further controlled research. Children who attended the two camps in this study were similar on most of the dimensions assessed. Therefore, it would be important to understand how these children who attend camps differ from those children with cancer who do not attend such camps, using matched controls. One might suspect children who don’t attend camp might be less satisfied with the social support they receive in their lives, less connected to broad social networks, and possibly sicker than children attending camp, yet this remains an open question. Research should also compare the perceptions of children attending camp for the first time with those who have attended more than once. Findings from the present interviews also indicated that children and their parents were perceptive informants about camp. Controlled program evaluations should be performed on these camp programs to obtain a formal assessment of their strengths and weaknesses, and should include child, parental, and counselor appraisals.
General Conclusions

The strengths of this investigation center on the fact that this sample provided rich information about children’s and parents’ perceptions of social support. This study gave an in depth examination of social support in relation to the cancer experience. Furthermore, the information collected from this study should enable further exploration of social support resources in children with cancer using more controlled research designs.

A few important limitations of this study should be reiterated. One limitation was the restriction of data analysis to a descriptive and correlational method. All of the information about these children was assessed in terms of characteristics of the child or the child’s family at the time of the study. Neither experimental manipulation or controls were feasible. Another shortcoming was the fact that the sample was small, covered a broad age range, and included children who came from one of two camps for children with cancer. As a result, there were unequal distributions of children with cancer on treatment and those off treatment. Therefore, the findings may not be generalizable to children with cancer who don’t attend this type of camp.

Taken together, the findings from the present research suggest that social support is important to understanding the illness experiences of children with cancer. Overall,
the findings highlight the resilience these families demonstrate in the face of a stressful chronic illness. While the present research provides a wealth of information about the specific support resources provided to and used by children with cancer, further research needs to clarify the relationship of these resources to children's psychosocial adjustment.
REFERENCES


### Table 1

**Common Forms of Childhood Cancer**

<table>
<thead>
<tr>
<th>Type of Childhood Cancer</th>
<th>Cell System of Origin</th>
<th>Percent of All Childhood Cancers</th>
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<td>Leukemias</td>
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<td>33</td>
</tr>
<tr>
<td>Brain and spinal cord</td>
<td>Central nervous system</td>
<td>20</td>
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<tr>
<td>Lymphomas (e.g. Hodgkin’s disease)</td>
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<tr>
<td>Soft tissue (e.g. rhabdomyosarcoma)</td>
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<td>6</td>
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<tr>
<td>Neuroblastoma</td>
<td>Sympathetic nervous system</td>
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</tr>
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<td>Wilm’s tumor</td>
<td>Kidney</td>
<td>6</td>
</tr>
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Table 2

Children's Perceptions of their Physical Limitations

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<td>Tire easily</td>
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</tr>
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<td>Sensitivity/Weakness of body part</td>
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<td>5</td>
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<td>Taking medicine for life</td>
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<td>Glasses/eye problems</td>
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<td>Memory problems</td>
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<td>Sleep problems</td>
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Table 3

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</tr>
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<td>Friends</td>
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<td>Classmates</td>
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<td>Teachers</td>
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<tr>
<td><strong>Child Social Support/Camp Interview</strong></td>
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<tr>
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<td><em>Self-Perception Profile for Children</em></td>
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<td>Athletic Competence</td>
</tr>
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<td>Behavioral Conduct</td>
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<td>Physical Appearance</td>
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<tr>
<td>Scholastic Competence</td>
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<td>Social Acceptance</td>
</tr>
<tr>
<td>Global Self-Worth</td>
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<td><em>Self-Perception Profile for Adolescents</em></td>
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<td>Athletic Competence</td>
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<td>Job Competence</td>
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<td>Global Self-Worth</td>
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<td>Externalizing Behavior Score</td>
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<td>Total Behavior Problem Score</td>
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<tr>
<td><strong>Intelligence:</strong></td>
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<td>Peabody Picture Vocabulary Test</td>
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Table 4

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<td><em>Social Support Questionnaire</em></td>
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<td>Family Expressiveness</td>
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<td>Family Conflict</td>
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<td><em>Hollingshead Four Factor Index of SES</em></td>
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<td><strong>Background Information Interview</strong></td>
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Table 5

Whom Children Talked to About Illness and Frequency of Talking

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<th></th>
<th>Yes</th>
<th>No</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
<th>Very Often</th>
<th>Mean</th>
<th>SD</th>
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<td>30.8</td>
<td>3.4</td>
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<td>(6)</td>
<td>(13)</td>
<td>(8)</td>
<td>(12)</td>
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<tr>
<td>Friends %</td>
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<td>28.6</td>
<td>17.1</td>
<td>25.7</td>
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</tr>
<tr>
<td>n (35)</td>
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<td>(10)</td>
<td>(10)</td>
<td>(6)</td>
<td>(9)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medical %</td>
<td>76.2</td>
<td>23.8</td>
<td>40.6</td>
<td>31.3</td>
<td>12.5</td>
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<td>(10)</td>
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<td>Sibling %</td>
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<td>7.9</td>
<td>5.3</td>
<td>2.2</td>
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<td>(11)</td>
<td>(14)</td>
<td>(8)</td>
<td>(3)</td>
<td>(2)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relatives %</td>
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<td>36.6</td>
<td>9.8</td>
<td>24.4</td>
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<td>14.6</td>
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<td>(10)</td>
<td>(6)</td>
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<td></td>
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<tr>
<td>School %</td>
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Table 6

What Aspects of Cancer Experience Children Talked About

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Table 7
Whom Parents Talked to About Illness and Frequency of Talking

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<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>Rarely</th>
<th>Sometimes</th>
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<th>Very Often</th>
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Table 8
What Aspects of Cancer Experience Parents Talked About

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Table 9

Children's Perceptions of Helpfulness of their Support System

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<td>-</td>
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<td>12.8</td>
<td>7.5</td>
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<td>19.0</td>
<td>23.7</td>
<td>35.9</td>
<td>47.5</td>
</tr>
<tr>
<td>4 Quite</td>
<td>23.8</td>
<td>21.4</td>
<td>19.0</td>
<td>26.3</td>
<td>10.3</td>
<td>10.0</td>
</tr>
<tr>
<td>5 Very</td>
<td>69.0</td>
<td>38.1</td>
<td>54.8</td>
<td>31.6</td>
<td>35.9</td>
<td>32.5</td>
</tr>
<tr>
<td>Mean</td>
<td>4.57</td>
<td>3.79</td>
<td>4.21</td>
<td>3.66</td>
<td>3.59</td>
<td>3.55</td>
</tr>
<tr>
<td>SD</td>
<td>.80</td>
<td>1.20</td>
<td>1.00</td>
<td>1.20</td>
<td>1.25</td>
<td>1.18</td>
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</table>

Table 10

Parents' Perceptions of Helpfulness of their Support System

<table>
<thead>
<tr>
<th>Helpful</th>
<th>Spouse</th>
<th>Parents</th>
<th>Friends</th>
<th>Medical</th>
<th>Siblings</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Not</td>
<td>11.4</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>2 A little</td>
<td>15.9</td>
<td>8.9</td>
<td>-</td>
<td>16.3</td>
<td>6.8</td>
</tr>
<tr>
<td>3 Somewhat</td>
<td>13.6</td>
<td>17.8</td>
<td>2.2</td>
<td>16.3</td>
<td>11.4</td>
</tr>
<tr>
<td>4 Quite</td>
<td>15.9</td>
<td>22.2</td>
<td>8.9</td>
<td>25.6</td>
<td>20.5</td>
</tr>
<tr>
<td>5 Very</td>
<td>43.2</td>
<td>51.1</td>
<td>88.9</td>
<td>41.9</td>
<td>61.4</td>
</tr>
<tr>
<td>Mean</td>
<td>3.60</td>
<td>4.17</td>
<td>4.87</td>
<td>3.93</td>
<td>4.36</td>
</tr>
<tr>
<td>SD</td>
<td>1.46</td>
<td>1.02</td>
<td>.40</td>
<td>1.11</td>
<td>.93</td>
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Table 11
Children's Perceptions of Parent Support

<table>
<thead>
<tr>
<th>Helpful</th>
<th>Comments: 100% (42)</th>
<th>%</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Being with me</td>
<td></td>
<td>42.9</td>
<td>18</td>
</tr>
<tr>
<td>Instrumental aid</td>
<td></td>
<td>42.9</td>
<td>18</td>
</tr>
<tr>
<td>Talking to me/encouraging me</td>
<td></td>
<td>31.0</td>
<td>13</td>
</tr>
<tr>
<td>General caring and support</td>
<td></td>
<td>7.1</td>
<td>3</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Not Helpful</th>
<th>Comments: 33.3% (14)</th>
<th>%</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Talking about illness too much</td>
<td></td>
<td>28.6</td>
<td>4</td>
</tr>
<tr>
<td>Parent emotion overwhelming child</td>
<td></td>
<td>28.6</td>
<td>4</td>
</tr>
<tr>
<td>Pushing child to do things</td>
<td></td>
<td>21.4</td>
<td>3</td>
</tr>
<tr>
<td>Told other people about illness</td>
<td></td>
<td>14.3</td>
<td>3</td>
</tr>
<tr>
<td>Babying child</td>
<td></td>
<td>14.3</td>
<td>2</td>
</tr>
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</table>
Table 12

Children's Perceptions of Sibling Support

<table>
<thead>
<tr>
<th>Helpful</th>
<th>Comments: 92.3% (36)</th>
<th>%</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Instrumental Aid</td>
<td></td>
<td>47.2</td>
<td>17</td>
</tr>
<tr>
<td>Emotional Assistance</td>
<td></td>
<td>41.7</td>
<td>15</td>
</tr>
<tr>
<td>Played with me</td>
<td></td>
<td>16.7</td>
<td>6</td>
</tr>
<tr>
<td>Visited/stayed with me when ill</td>
<td></td>
<td>11.1</td>
<td>4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Not Helpful</th>
<th>Comments: 51.3% (20)</th>
<th>%</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Negative attitudes and actions</td>
<td></td>
<td>40.0</td>
<td>8</td>
</tr>
<tr>
<td>General bothering</td>
<td></td>
<td>30.0</td>
<td>6</td>
</tr>
<tr>
<td>Beating me up/fighting</td>
<td></td>
<td>15.0</td>
<td>3</td>
</tr>
<tr>
<td>Not emotionally supportive</td>
<td></td>
<td>15.0</td>
<td>3</td>
</tr>
</tbody>
</table>

Table 13

Which Relatives Children Turned to for Help

<table>
<thead>
<tr>
<th>Relative</th>
<th>%</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Grandmother</td>
<td>69.0</td>
<td>29</td>
</tr>
<tr>
<td>Grandfather</td>
<td>52.4</td>
<td>22</td>
</tr>
<tr>
<td>Aunt</td>
<td>21.4</td>
<td>9</td>
</tr>
<tr>
<td>Uncle</td>
<td>16.7</td>
<td>7</td>
</tr>
<tr>
<td>Cousin</td>
<td>4.8</td>
<td>2</td>
</tr>
</tbody>
</table>
Table 14

Children's Perceptions of Relative Support

<table>
<thead>
<tr>
<th>Helpful</th>
<th>Comments: 97.5% (39)</th>
<th>%</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Visited at home/hospital</td>
<td></td>
<td>43.6</td>
<td>17</td>
</tr>
<tr>
<td>Material Assistance</td>
<td></td>
<td>35.9</td>
<td>14</td>
</tr>
<tr>
<td>Emotional Support</td>
<td></td>
<td>33.3</td>
<td>13</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Not Helpful</th>
<th>Comments: 22.5% (9)</th>
<th>%</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do not see or visit</td>
<td></td>
<td>33.3</td>
<td>3</td>
</tr>
<tr>
<td>Not getting along/bothering</td>
<td></td>
<td>33.3</td>
<td>3</td>
</tr>
<tr>
<td>Bought/did things didn’t need</td>
<td></td>
<td>22.2</td>
<td>2</td>
</tr>
<tr>
<td>Worrying too much</td>
<td></td>
<td>11.1</td>
<td>1</td>
</tr>
</tbody>
</table>

Table 15

Which Medical Staff Children Turned to for Help

<table>
<thead>
<tr>
<th></th>
<th>%</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nurse</td>
<td>76.2</td>
<td>32</td>
</tr>
<tr>
<td>Doctor</td>
<td>54.8</td>
<td>23</td>
</tr>
<tr>
<td>Social Worker</td>
<td>9.5</td>
<td>4</td>
</tr>
<tr>
<td>Psychologist</td>
<td>2.4</td>
<td>1</td>
</tr>
<tr>
<td>Recreational Therapist</td>
<td>2.4</td>
<td>1</td>
</tr>
</tbody>
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Table 16

Children's Perceptions of Medical Staff Support

<table>
<thead>
<tr>
<th>Helpful</th>
<th>Comments: 100% (42)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>%</td>
</tr>
<tr>
<td>Treated/cured my cancer</td>
<td>33.3</td>
</tr>
<tr>
<td>Talked and prepared for procedures</td>
<td>26.2</td>
</tr>
<tr>
<td>General emotional support</td>
<td>19.0</td>
</tr>
<tr>
<td>Played/spent time with me</td>
<td>16.7</td>
</tr>
<tr>
<td>Material Aid</td>
<td>11.9</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Not Helpful</th>
<th>Comments: 38.1% (16)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>%</td>
</tr>
<tr>
<td>Medical mistakes</td>
<td>31.3</td>
</tr>
<tr>
<td>Treatment involved in cancer</td>
<td>25.0</td>
</tr>
<tr>
<td>Not seeing/talking to Dr. enough</td>
<td>25.0</td>
</tr>
<tr>
<td>Hospital routines/group rounds</td>
<td>18.8</td>
</tr>
<tr>
<td>Intrusive/upsetting illness talk</td>
<td>12.5</td>
</tr>
<tr>
<td>Losing relationships when left</td>
<td>6.3</td>
</tr>
</tbody>
</table>
Table 17

**Children's Perceptions of Friend Support**

<table>
<thead>
<tr>
<th>Helpful</th>
<th>Comments: 95.2% (40)</th>
<th>%</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional Support</td>
<td>52.5</td>
<td>21</td>
<td></td>
</tr>
<tr>
<td>Visited/called me</td>
<td>27.5</td>
<td>11</td>
<td></td>
</tr>
<tr>
<td>Material Aid</td>
<td>17.5</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>Played with me</td>
<td>15.0</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>Protected me</td>
<td>15.0</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>Helped with school work/issues</td>
<td>7.5</td>
<td>3</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
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<th>Comments: 42.9% (18)</th>
<th>%</th>
<th>N</th>
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</thead>
<tbody>
<tr>
<td>Teased me</td>
<td>61.1</td>
<td>11</td>
<td></td>
</tr>
<tr>
<td>Treated &quot;specially/differently&quot;</td>
<td>22.2</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Changed relationship/didn’t see</td>
<td>16.7</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Brought school work home</td>
<td>5.6</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Insensitive comments</td>
<td>5.6</td>
<td>1</td>
<td></td>
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</tbody>
</table>

Table 18

**Which School Staff Children Turned to for Help**

<table>
<thead>
<tr>
<th>Comments: 83.3% (35)</th>
<th>%</th>
<th>N</th>
</tr>
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<tbody>
<tr>
<td>Teacher</td>
<td>85.7</td>
<td>30</td>
</tr>
<tr>
<td>Nurse</td>
<td>22.9</td>
<td>8</td>
</tr>
<tr>
<td>Counselor</td>
<td>17.1</td>
<td>6</td>
</tr>
<tr>
<td>Principal</td>
<td>2.9</td>
<td>1</td>
</tr>
<tr>
<td>Class</td>
<td>2.9</td>
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</tr>
</tbody>
</table>
Table 19

**Children’s Perceptions of School Support**

<table>
<thead>
<tr>
<th>Helpful</th>
<th>Comments:</th>
<th>100%</th>
<th>(38)</th>
<th>%</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Helped with school work/learning</td>
<td></td>
<td>52.6</td>
<td>20</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Emotional support</td>
<td></td>
<td>15.8</td>
<td>6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Helped with illness needs</td>
<td></td>
<td>13.2</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Talked to class about cancer</td>
<td></td>
<td>10.5</td>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Material aid</td>
<td></td>
<td>7.9</td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stopped kids’ teasing</td>
<td></td>
<td>5.3</td>
<td>2</td>
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</table>

<table>
<thead>
<tr>
<th>Not Helpful</th>
<th>Comments:</th>
<th>34.2%</th>
<th>(13)</th>
<th>%</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not emotionally supportive</td>
<td></td>
<td>46.2</td>
<td>6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Didn’t adjust school procedures</td>
<td></td>
<td>46.2</td>
<td>6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Allowed teasing</td>
<td></td>
<td>15.4</td>
<td>2</td>
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Table 20

**Other Sources of Support for the Child**

<table>
<thead>
<tr>
<th>Comments:</th>
<th>59.5% (25)</th>
<th>%</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mental health professionals</td>
<td>36.0</td>
<td>9</td>
<td></td>
</tr>
<tr>
<td>Family friends/neighbours</td>
<td>32.0</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>Religious community</td>
<td>10.9</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Other people with cancer</td>
<td>6.5</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Myself</td>
<td>4.3</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Family dog</td>
<td>2.2</td>
<td>1</td>
<td></td>
</tr>
</tbody>
</table>
Table 21

**Parents' Perceptions of Spouse Support**

<table>
<thead>
<tr>
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<th>%</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional Support</td>
<td>39.5</td>
<td>17</td>
</tr>
<tr>
<td>Managed household/finances</td>
<td>23.3</td>
<td>10</td>
</tr>
<tr>
<td>Managed illness &amp; medical info</td>
<td>18.6</td>
<td>8</td>
</tr>
<tr>
<td>Came to/Stayed at hospital</td>
<td>18.6</td>
<td>8</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Not Helpful</th>
<th>%</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lack of emotional support</td>
<td>44.0</td>
<td>11</td>
</tr>
<tr>
<td>Lack of aid in illness management</td>
<td>31.6</td>
<td>7</td>
</tr>
<tr>
<td>Spouse coping poorly/falling apart</td>
<td>12.0</td>
<td>3</td>
</tr>
<tr>
<td>Conflicting coping expectations</td>
<td>10.5</td>
<td>2</td>
</tr>
<tr>
<td>Annoying habits</td>
<td>10.5</td>
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</tr>
</tbody>
</table>
Table 22

Parents' Perceptions of Parent Support

<table>
<thead>
<tr>
<th>Helpful</th>
<th>Comments: 97.8% (44)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>%</td>
</tr>
<tr>
<td>Household/instrumental aid</td>
<td>56.8</td>
</tr>
<tr>
<td>Support in caring for sick child</td>
<td>31.8</td>
</tr>
<tr>
<td>Emotional support</td>
<td>27.3</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Not Helpful</th>
<th>Comments: 64.4% (29)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>%</td>
</tr>
<tr>
<td>Lack of emotional support</td>
<td>58.6</td>
</tr>
<tr>
<td>Negative attitude/criticism</td>
<td>27.6</td>
</tr>
<tr>
<td>Parents coping with own problems</td>
<td>10.3</td>
</tr>
<tr>
<td>Spoiled sick child</td>
<td>6.9</td>
</tr>
<tr>
<td>Gave laundry to neighbors to do</td>
<td>2.3</td>
</tr>
</tbody>
</table>
Table 23

Parents' Perceptions of Sibling Support

<table>
<thead>
<tr>
<th>Helpful</th>
<th>Comments: 100% (43)</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional support</td>
<td>48.8</td>
<td>21</td>
<td></td>
</tr>
<tr>
<td>Household/sibling assistance</td>
<td>20.9</td>
<td>9</td>
<td></td>
</tr>
<tr>
<td>Hospital visits &amp; stays</td>
<td>16.3</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>Family visits</td>
<td>16.3</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>Cared for sick child</td>
<td>14.0</td>
<td>6</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Not Helpful</th>
<th>Comments: 32.6% (14)</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Not emotionally supportive</td>
<td>71.4</td>
<td>10</td>
<td></td>
</tr>
<tr>
<td>Spoiled children</td>
<td>14.3</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Disagreements</td>
<td>7.1</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Having to pretend things were OK</td>
<td>7.1</td>
<td>1</td>
<td></td>
</tr>
</tbody>
</table>
Table 24

Parents' Perceptions of Friend Support

<table>
<thead>
<tr>
<th>Helpful</th>
<th>Comments: 97.8% (44)</th>
<th>%</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional support</td>
<td>72.7</td>
<td>32</td>
<td></td>
</tr>
<tr>
<td>Material aid to family</td>
<td>45.5</td>
<td>20</td>
<td></td>
</tr>
<tr>
<td>Letting child play with sick child</td>
<td>6.8</td>
<td>3</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Not Helpful</th>
<th>Comments: 38.6% (17)</th>
<th>%</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intrusiveness of acquaintances</td>
<td>47.1</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>Lack of emotional support</td>
<td>29.4</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Keeping child away from sick child</td>
<td>11.8</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Too much pity</td>
<td>11.8</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Not taking child to hospital after an accident</td>
<td>5.9</td>
<td>1</td>
<td></td>
</tr>
</tbody>
</table>

Table 25

Which Medical Staff Parents Turned to for Help

<table>
<thead>
<tr>
<th>Comments: 100% (45)</th>
<th>%</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nurse</td>
<td>91.1</td>
<td>41</td>
</tr>
<tr>
<td>Doctor</td>
<td>84.4</td>
<td>38</td>
</tr>
<tr>
<td>Social Worker</td>
<td>24.4</td>
<td>11</td>
</tr>
<tr>
<td>Psychologist</td>
<td>2.2</td>
<td>1</td>
</tr>
<tr>
<td>Minister</td>
<td>2.2</td>
<td>1</td>
</tr>
</tbody>
</table>
Table 26

**Parents’ Perceptions of Medical Staff Support**

<table>
<thead>
<tr>
<th>Helpful</th>
<th>Comments: 100% (45)</th>
<th>%</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional support</td>
<td></td>
<td>51.1</td>
<td>23</td>
</tr>
<tr>
<td>Medical support</td>
<td></td>
<td>46.7</td>
<td>21</td>
</tr>
<tr>
<td>Extraordinary assistance</td>
<td></td>
<td>6.7</td>
<td>3</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Not Helpful</th>
<th>Comments: 60.0% (27)</th>
<th>%</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical mistakes</td>
<td></td>
<td>51.9</td>
<td>14</td>
</tr>
<tr>
<td>Lack of emotional support</td>
<td></td>
<td>33.3</td>
<td>9</td>
</tr>
<tr>
<td>Hospital routines</td>
<td></td>
<td>14.8</td>
<td>4</td>
</tr>
</tbody>
</table>

Table 27

**Parents’ Perceptions of Ill Child’s Support**

<table>
<thead>
<tr>
<th>Helpful</th>
<th>Comments: 100% (20)</th>
<th>%</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child’s strength and positive attitude</td>
<td></td>
<td>100</td>
<td>20</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Not Helpful</th>
<th>Comments: 15% (3)</th>
<th>%</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Behavior on drugs</td>
<td></td>
<td>15.0</td>
<td>3</td>
</tr>
<tr>
<td>Complying with treatment</td>
<td></td>
<td>5.0</td>
<td>1</td>
</tr>
</tbody>
</table>
Table 28

Parents' Perceptions of their Other Children's Support

<table>
<thead>
<tr>
<th>Helpful</th>
<th>Comments: 100% (20)</th>
<th>%</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Material assistance</td>
<td></td>
<td>45.8</td>
<td>11</td>
</tr>
<tr>
<td>Emotional support</td>
<td></td>
<td>33.3</td>
<td>8</td>
</tr>
<tr>
<td>Flexibility to family changes</td>
<td></td>
<td>20.8</td>
<td>5</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Not Helpful</th>
<th>Comments: 55.0% (11)</th>
<th>%</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jealousy/resentment</td>
<td></td>
<td>90.9</td>
<td>10</td>
</tr>
<tr>
<td>Not visiting sib in hospital</td>
<td></td>
<td>9.1</td>
<td>1</td>
</tr>
</tbody>
</table>
Table 29

**Other Sources of Support**

<table>
<thead>
<tr>
<th>Comments: 77.8% (35)</th>
<th>%</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information seeking</td>
<td>34.3</td>
<td>12</td>
</tr>
<tr>
<td>American Cancer/Leukemia Society</td>
<td>25.7</td>
<td>9</td>
</tr>
<tr>
<td>Town/community</td>
<td>22.9</td>
<td>8</td>
</tr>
<tr>
<td>Wish granting foundation</td>
<td>20.0</td>
<td>7</td>
</tr>
<tr>
<td>Myself</td>
<td>17.1</td>
<td>6</td>
</tr>
<tr>
<td>Other parents at the hospital</td>
<td>11.4</td>
<td>4</td>
</tr>
<tr>
<td>Coworkers</td>
<td>8.6</td>
<td>3</td>
</tr>
<tr>
<td>Nonillness support groups</td>
<td>5.7</td>
<td>2</td>
</tr>
<tr>
<td>Acquaintances</td>
<td>5.7</td>
<td>2</td>
</tr>
<tr>
<td>Writing in a journal</td>
<td>2.9</td>
<td>1</td>
</tr>
<tr>
<td>Board of education</td>
<td>2.9</td>
<td>1</td>
</tr>
<tr>
<td>Insurance company</td>
<td>2.9</td>
<td>1</td>
</tr>
</tbody>
</table>
### Table 30

**Children's and Parents' Satisfaction Ratings of their Families**

<table>
<thead>
<tr>
<th></th>
<th>Child %</th>
<th>Child N</th>
<th>Parent %</th>
<th>Parent N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not</td>
<td>-</td>
<td>-</td>
<td>4.4</td>
<td>2</td>
</tr>
<tr>
<td>Alittle</td>
<td>4.3</td>
<td>2</td>
<td>4.4</td>
<td>2</td>
</tr>
<tr>
<td>Somewhat</td>
<td>15.2</td>
<td>7</td>
<td>15.6</td>
<td>7</td>
</tr>
<tr>
<td>Quite</td>
<td>30.4</td>
<td>14</td>
<td>26.7</td>
<td>12</td>
</tr>
<tr>
<td>Very</td>
<td>50.0</td>
<td>23</td>
<td>48.9</td>
<td>22</td>
</tr>
<tr>
<td>Mean</td>
<td>4.26</td>
<td></td>
<td>4.13</td>
<td></td>
</tr>
<tr>
<td>SD</td>
<td>.88</td>
<td></td>
<td>1.11</td>
<td></td>
</tr>
</tbody>
</table>

### Table 31

**Children's and Parents' Ratings of Helpfulness of their Faith**

Comments: Child: 83.3% (38)  Parent: 84.4% (38)

<table>
<thead>
<tr>
<th></th>
<th>Child %</th>
<th>Child N</th>
<th>Parent %</th>
<th>Parent N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not</td>
<td>-</td>
<td>-</td>
<td>2.6</td>
<td>1</td>
</tr>
<tr>
<td>Alittle</td>
<td>25.7</td>
<td>9</td>
<td>13.2</td>
<td>5</td>
</tr>
<tr>
<td>Somewhat</td>
<td>11.4</td>
<td>4</td>
<td>13.2</td>
<td>5</td>
</tr>
<tr>
<td>Quite</td>
<td>34.3</td>
<td>12</td>
<td>23.7</td>
<td>9</td>
</tr>
<tr>
<td>Very</td>
<td>28.6</td>
<td>10</td>
<td>47.4</td>
<td>18</td>
</tr>
<tr>
<td>Mean</td>
<td>3.66</td>
<td></td>
<td>3.57</td>
<td></td>
</tr>
<tr>
<td>SD</td>
<td>1.16</td>
<td></td>
<td>1.54</td>
<td></td>
</tr>
</tbody>
</table>
### Table 32
**Ways Children Used their Faith to Help Them**

<table>
<thead>
<tr>
<th>Comments: 83.3% (35)</th>
<th>%</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individual prayer</td>
<td>68.8</td>
<td>22</td>
</tr>
<tr>
<td>Individual prayer &amp; church going</td>
<td>25.4</td>
<td>8</td>
</tr>
<tr>
<td>Others prayed for family</td>
<td>18.8</td>
<td>6</td>
</tr>
<tr>
<td>Support from church community</td>
<td>9.4</td>
<td>3</td>
</tr>
<tr>
<td>Talking with priest/minister</td>
<td>9.4</td>
<td>3</td>
</tr>
<tr>
<td>Christian music</td>
<td>3.1</td>
<td>2</td>
</tr>
</tbody>
</table>

### Table 33
**Ways Parents Used their Faith to Help Them**

<table>
<thead>
<tr>
<th>Comments: 93.3% (42)</th>
<th>%</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individual prayer &amp; church going</td>
<td>45.2</td>
<td>19</td>
</tr>
<tr>
<td>Individual prayer</td>
<td>35.7</td>
<td>15</td>
</tr>
<tr>
<td>Support from church community</td>
<td>31.0</td>
<td>13</td>
</tr>
<tr>
<td>Others prayed for family</td>
<td>23.8</td>
<td>10</td>
</tr>
<tr>
<td>Talking with priest/minister</td>
<td>11.9</td>
<td>5</td>
</tr>
<tr>
<td>Healing</td>
<td>4.8</td>
<td>2</td>
</tr>
</tbody>
</table>
Table 34

How Parents Helped Others

<table>
<thead>
<tr>
<th>Comments</th>
<th>%</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fundraising for cancer causes</td>
<td>66.7</td>
<td>8</td>
</tr>
<tr>
<td>Starting a support group</td>
<td>33.3</td>
<td>4</td>
</tr>
<tr>
<td>Board member: Cancer Society/ Ronald McDonald House</td>
<td>16.7</td>
<td>2</td>
</tr>
<tr>
<td>Talking to new parents</td>
<td>8.3</td>
<td>1</td>
</tr>
<tr>
<td>Educating school about cancer</td>
<td>8.3</td>
<td>1</td>
</tr>
<tr>
<td>Writing a book about experience</td>
<td>8.3</td>
<td>1</td>
</tr>
</tbody>
</table>

Table 35

Children's Ratings of How Often They Spoke at Group

<table>
<thead>
<tr>
<th>Comments</th>
<th>%</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>2 Rarely</td>
<td>50</td>
<td>5</td>
</tr>
<tr>
<td>3 Sometimes</td>
<td>30</td>
<td>3</td>
</tr>
<tr>
<td>4 Often</td>
<td>20</td>
<td>2</td>
</tr>
<tr>
<td>Mean</td>
<td>2.55</td>
<td></td>
</tr>
<tr>
<td>SD</td>
<td>.93</td>
<td></td>
</tr>
</tbody>
</table>
Table 36

<table>
<thead>
<tr>
<th>What Children Talked About at Support Groups</th>
<th>%</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Treatment</td>
<td>90</td>
<td>9</td>
</tr>
<tr>
<td>Side Effects</td>
<td>80</td>
<td>8</td>
</tr>
<tr>
<td>Feelings about illness</td>
<td>70</td>
<td>7</td>
</tr>
<tr>
<td>Siblings Adjustment</td>
<td>30</td>
<td>3</td>
</tr>
<tr>
<td>Parent Adjustment</td>
<td>40</td>
<td>4</td>
</tr>
<tr>
<td>Limitations</td>
<td>50</td>
<td>5</td>
</tr>
<tr>
<td>School</td>
<td>40</td>
<td>4</td>
</tr>
</tbody>
</table>

Table 37

Children's Perceptions of Support Groups

Helpful Comments: 81% (9)

<table>
<thead>
<tr>
<th></th>
<th>%</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Making friends</td>
<td>44.4</td>
<td>4</td>
</tr>
<tr>
<td>Talking/sharing</td>
<td>44.4</td>
<td>4</td>
</tr>
<tr>
<td>Fun activities</td>
<td>22.2</td>
<td>2</td>
</tr>
</tbody>
</table>

Not Helpful Comments: 81.9% (9)

<table>
<thead>
<tr>
<th></th>
<th>%</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Logistics</td>
<td>22.2</td>
<td>2</td>
</tr>
<tr>
<td>Depressing talks</td>
<td>11.1</td>
<td>2</td>
</tr>
<tr>
<td>Not enough cancer information</td>
<td>11.1</td>
<td>1</td>
</tr>
<tr>
<td>Power struggles</td>
<td>11.1</td>
<td>1</td>
</tr>
<tr>
<td>Group falling apart</td>
<td>11.1</td>
<td>1</td>
</tr>
</tbody>
</table>
### Table 38

**Children’s Ratings of Helpfulness of Support Groups**

<table>
<thead>
<tr>
<th>Comments</th>
<th>%</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>2 Alittle</td>
<td>10</td>
<td>1</td>
</tr>
<tr>
<td>3 Somewhat</td>
<td>40</td>
<td>4</td>
</tr>
<tr>
<td>4 Quite</td>
<td>30</td>
<td>3</td>
</tr>
<tr>
<td>5 Very</td>
<td>20</td>
<td>2</td>
</tr>
</tbody>
</table>

Mean: 3.6  
SD: .97

### Table 39

**Parents’ Ratings of How Often They Spoke at Group**

<table>
<thead>
<tr>
<th>Comments</th>
<th>%</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Never</td>
<td>5.9</td>
<td>1</td>
</tr>
<tr>
<td>2 Rarely</td>
<td>17.6</td>
<td>3</td>
</tr>
<tr>
<td>3 Sometimes</td>
<td>26.3</td>
<td>5</td>
</tr>
<tr>
<td>4 Often</td>
<td>23.5</td>
<td>4</td>
</tr>
<tr>
<td>5 Very Often</td>
<td>17.6</td>
<td>3</td>
</tr>
</tbody>
</table>

Mean: 3.31  
SD: 1.20
Table 40

**What Parents Talked About at Support Groups**

<table>
<thead>
<tr>
<th>Topic</th>
<th>%</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Treatment</td>
<td>82.4</td>
<td>14</td>
</tr>
<tr>
<td>Side Effects</td>
<td>82.4</td>
<td>14</td>
</tr>
<tr>
<td>Feelings about illness</td>
<td>64.7</td>
<td>11</td>
</tr>
<tr>
<td>Siblings Adjustment</td>
<td>58.8</td>
<td>10</td>
</tr>
<tr>
<td>Parent Adjustment</td>
<td>52.9</td>
<td>9</td>
</tr>
<tr>
<td>Limitations</td>
<td>52.9</td>
<td>9</td>
</tr>
<tr>
<td>Death</td>
<td>58.8</td>
<td>10</td>
</tr>
</tbody>
</table>

Table 41

**Parents' Perceptions of Support Groups**

<table>
<thead>
<tr>
<th>Helpful</th>
<th>Comments: 70.6% (12)</th>
<th>%</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional support</td>
<td></td>
<td>58.3</td>
<td>7</td>
</tr>
<tr>
<td>Being a role model for others</td>
<td></td>
<td>33.3</td>
<td>4</td>
</tr>
<tr>
<td>Educational info about illness</td>
<td></td>
<td>33.3</td>
<td>4</td>
</tr>
<tr>
<td>Understanding experience and child</td>
<td></td>
<td>33.3</td>
<td>4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Not Helpful</th>
<th>Comments: 41.2% (7)</th>
<th>%</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not very organized/fell apart</td>
<td></td>
<td>25.0</td>
<td>3</td>
</tr>
<tr>
<td>People's attitudes</td>
<td></td>
<td>16.7</td>
<td>2</td>
</tr>
<tr>
<td>Emotions group stirred up</td>
<td></td>
<td>8.3</td>
<td>1</td>
</tr>
<tr>
<td>Distance</td>
<td></td>
<td>8.3</td>
<td>1</td>
</tr>
</tbody>
</table>
Table 42

Parents' Ratings of Helpfulness of Support Groups

<table>
<thead>
<tr>
<th>Comments</th>
<th>%</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Not</td>
<td>5.9</td>
<td>1</td>
</tr>
<tr>
<td>2 A little</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3 Somewhat</td>
<td>17.6</td>
<td>3</td>
</tr>
<tr>
<td>4 Quite</td>
<td>17.6</td>
<td>3</td>
</tr>
<tr>
<td>5 Very</td>
<td>58.8</td>
<td>10</td>
</tr>
</tbody>
</table>

Mean 4.24
SD 1.15
Table 43

**Professional Help for the Family:**

<table>
<thead>
<tr>
<th></th>
<th>%</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Comments: 68.9% (31)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Short term therapy with psychologist</td>
<td>45.2</td>
<td>14</td>
</tr>
<tr>
<td>Family:</td>
<td>N</td>
<td></td>
</tr>
<tr>
<td>Child:</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Couple</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Parent:</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Sibling:</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Long Term therapy with psychologist</td>
<td>41.9</td>
<td>13</td>
</tr>
<tr>
<td>Family:</td>
<td>N</td>
<td></td>
</tr>
<tr>
<td>Parent:</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Child:</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Intermittent contact with hospital social worker</td>
<td>35.5</td>
<td>11</td>
</tr>
<tr>
<td>Brief counseling with priest/minister</td>
<td>9.7</td>
<td>3</td>
</tr>
<tr>
<td>Parent:</td>
<td>N</td>
<td></td>
</tr>
<tr>
<td></td>
<td>3</td>
<td></td>
</tr>
</tbody>
</table>
### Table 44

**Means, Standard Deviations, and Range of Scores for Younger Children (7 - 13) on the Social Support Scale for Children**

<table>
<thead>
<tr>
<th></th>
<th>Mean</th>
<th>SD</th>
<th>Range</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parents</td>
<td>3.68</td>
<td>.40</td>
<td>2.00 - 4.00</td>
<td>30</td>
</tr>
<tr>
<td>Friends</td>
<td>3.51</td>
<td>.82</td>
<td>1.50 - 4.00</td>
<td>30</td>
</tr>
<tr>
<td>Classmates</td>
<td>3.18</td>
<td>.75</td>
<td>1.50 - 4.00</td>
<td>30</td>
</tr>
<tr>
<td>Teachers</td>
<td>3.33</td>
<td>.87</td>
<td>1.00 - 4.00</td>
<td>30</td>
</tr>
</tbody>
</table>

### Table 45

**Means, Standard Deviations, and Range of Scores for Adolescents (14 - 17) on the Social Support Scale for Children**

<table>
<thead>
<tr>
<th></th>
<th>Mean</th>
<th>SD</th>
<th>Range</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parents</td>
<td>3.46</td>
<td>.52</td>
<td>2.50 - 4.00</td>
<td>16</td>
</tr>
<tr>
<td>Friends</td>
<td>3.39</td>
<td>.72</td>
<td>2.17 - 4.00</td>
<td>16</td>
</tr>
<tr>
<td>Classmates</td>
<td>3.32</td>
<td>.40</td>
<td>2.17 - 3.67</td>
<td>16</td>
</tr>
<tr>
<td>Teachers</td>
<td>3.13</td>
<td>.41</td>
<td>2.50 - 3.83</td>
<td>16</td>
</tr>
</tbody>
</table>
Table 46

**Intercorrelations Among the Four Social Support Variables**

<table>
<thead>
<tr>
<th></th>
<th>Parents</th>
<th>Friends</th>
<th>Classmates</th>
<th>Teachers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parents</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Friends</td>
<td>.20</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Classmates</td>
<td>.52</td>
<td>.43</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Teachers</td>
<td>.47</td>
<td>.36</td>
<td>.43</td>
<td></td>
</tr>
</tbody>
</table>

Table 47

**Means, Standard Deviations, and Range of Scores for Younger Children (7 - 13) on the Self-Perception Profile for Children**

<table>
<thead>
<tr>
<th></th>
<th>Mean</th>
<th>SD</th>
<th>Range</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Athletic Competence</td>
<td>2.57</td>
<td>.88</td>
<td>1.00 - 4.00</td>
<td>30</td>
</tr>
<tr>
<td>Behavioral Conduct</td>
<td>3.11</td>
<td>.63</td>
<td>1.50 - 4.00</td>
<td>30</td>
</tr>
<tr>
<td>Physical Appearance</td>
<td>3.12</td>
<td>.69</td>
<td>1.67 - 4.00</td>
<td>30</td>
</tr>
<tr>
<td>Scholastic Competence</td>
<td>2.83</td>
<td>.91</td>
<td>1.00 - 4.00</td>
<td>30</td>
</tr>
<tr>
<td>Social Acceptance</td>
<td>3.04</td>
<td>.72</td>
<td>1.50 - 4.00</td>
<td>30</td>
</tr>
<tr>
<td>Global Self-Worth</td>
<td>3.40</td>
<td>.51</td>
<td>2.33 - 4.00</td>
<td>30</td>
</tr>
</tbody>
</table>
Table 48
Means, Standard Deviations, and Range of Scores for Adolescents (13 - 17) on the Self-Perception Profile for Adolescents

<table>
<thead>
<tr>
<th></th>
<th>Mean</th>
<th>SD</th>
<th>Range</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Athletic Competence</td>
<td>2.64</td>
<td>.84</td>
<td>1.00 - 4.00</td>
<td>16</td>
</tr>
<tr>
<td>Behavioral Conduct</td>
<td>2.72</td>
<td>.35</td>
<td>2.00 - 3.40</td>
<td>16</td>
</tr>
<tr>
<td>Physical Appearance</td>
<td>2.83</td>
<td>.52</td>
<td>2.00 - 3.60</td>
<td>16</td>
</tr>
<tr>
<td>Scholastic Competence</td>
<td>2.71</td>
<td>.60</td>
<td>1.40 - 3.60</td>
<td>16</td>
</tr>
<tr>
<td>Social Acceptance</td>
<td>3.18</td>
<td>.49</td>
<td>2.20 - 4.00</td>
<td>16</td>
</tr>
<tr>
<td>Romantic Appeal</td>
<td>2.68</td>
<td>.60</td>
<td>1.60 - 3.80</td>
<td>16</td>
</tr>
<tr>
<td>Job Competence</td>
<td>3.14</td>
<td>.42</td>
<td>2.20 - 3.80</td>
<td>16</td>
</tr>
<tr>
<td>Close Friendship</td>
<td>3.00</td>
<td>.87</td>
<td>1.60 - 4.00</td>
<td>16</td>
</tr>
<tr>
<td>Global Self-Worth</td>
<td>3.21</td>
<td>.38</td>
<td>2.60 - 4.00</td>
<td>16</td>
</tr>
</tbody>
</table>
Table 49

Frequencies, Means and Standard Deviations of Child Behavior
Checklist Total Behavior, Internalizing and Externalizing Scores
in the Normal and Clinical Ranges: Breakdown by Age and Sex

<table>
<thead>
<tr>
<th>Age</th>
<th>Boys</th>
<th>Girls</th>
<th>Boys</th>
<th>Girls</th>
<th>M</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>7 - 12</td>
<td>4</td>
<td>2</td>
<td>7</td>
<td>9</td>
<td>29.82</td>
<td>20.96</td>
</tr>
<tr>
<td>13 - 16</td>
<td>2</td>
<td>0</td>
<td>7</td>
<td>4</td>
<td>24.77</td>
<td>18.85</td>
</tr>
<tr>
<td>%</td>
<td>23.0</td>
<td>%</td>
<td>77.0</td>
<td>SD</td>
<td>20.17</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Age</th>
<th>Boys</th>
<th>Girls</th>
<th>Boys</th>
<th>Girls</th>
<th>M</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>7 - 12</td>
<td>4</td>
<td>2</td>
<td>7</td>
<td>6</td>
<td>57.63</td>
<td>9.51</td>
</tr>
<tr>
<td>13 - 16</td>
<td>3</td>
<td>0</td>
<td>5</td>
<td>4</td>
<td>56.42</td>
<td>7.85</td>
</tr>
<tr>
<td>%</td>
<td>29.0</td>
<td>%</td>
<td>71.0</td>
<td>SD</td>
<td>8.78</td>
<td></td>
</tr>
</tbody>
</table>

Table continues
## Externalizing Score

<table>
<thead>
<tr>
<th>Age</th>
<th>Clinical</th>
<th>Normal</th>
<th>M</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Boys</td>
<td>Girls</td>
<td>Boys</td>
<td>Girls</td>
</tr>
<tr>
<td>7 - 12</td>
<td>2</td>
<td>1</td>
<td>9</td>
<td>10</td>
</tr>
<tr>
<td>13 - 16</td>
<td>1</td>
<td>0</td>
<td>8</td>
<td>4</td>
</tr>
<tr>
<td>N = 4</td>
<td></td>
<td></td>
<td>N = 31</td>
<td></td>
</tr>
<tr>
<td>% = 11.4</td>
<td></td>
<td></td>
<td>% = 88.6</td>
<td></td>
</tr>
</tbody>
</table>

"a" - Child Behavior Checklist was not applicable for the 17 year-olds in the study.

"b" - Data to calculate the Internalizing score was missing for four children.
Table 50
Means, Standard Deviations, and Range of Scores for the Three Subscales of the Family Environment Scale

<table>
<thead>
<tr>
<th></th>
<th>Mean</th>
<th>SD</th>
<th>Range</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family Expressiveness</td>
<td>51.30</td>
<td>11.67</td>
<td>16.00 - 64.00</td>
<td>44</td>
</tr>
<tr>
<td>Family Cohesion</td>
<td>52.55</td>
<td>12.62</td>
<td>16.00 - 64.00</td>
<td>44</td>
</tr>
<tr>
<td>Family Conflict</td>
<td>47.11</td>
<td>10.54</td>
<td>27.00 - 71.00</td>
<td>44</td>
</tr>
</tbody>
</table>

Table 51
Correlations Among the Predictor and Criterion Variables in the Multiple Regression Analyses

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Friend Support</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 Family Conflict</td>
<td>.09</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3 Family Cohesion</td>
<td>-.03</td>
<td>-.42</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4 Marital Status</td>
<td>-.44</td>
<td>.01</td>
<td>-.33</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5 Sex</td>
<td>-.08</td>
<td>.13</td>
<td>-.27</td>
<td>-.004</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6 Self-Worth</td>
<td>.29*</td>
<td>.42*</td>
<td>-.14</td>
<td>-.44*</td>
<td>.18</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7 Behavior Score</td>
<td>.33*</td>
<td>.36*</td>
<td>-.47*</td>
<td>-.13</td>
<td>.42*</td>
<td>.41*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8 Internal Score</td>
<td>.25*</td>
<td>.26*</td>
<td>-.37*</td>
<td>-.21</td>
<td>.44*</td>
<td>.29*</td>
<td>.86*</td>
<td></td>
</tr>
<tr>
<td>9 External Score</td>
<td>.29*</td>
<td>.20</td>
<td>-.42*</td>
<td>-.02</td>
<td>.41*</td>
<td>.30</td>
<td>.93*</td>
<td>.79*</td>
</tr>
</tbody>
</table>

* - p < .05
Table 52

Hierarchical Multiple Regression Analyses Predicting Total Behavior Problem Scores from Friend Support, Family Cohesion, and Sex

<table>
<thead>
<tr>
<th>Predictor Variable</th>
<th>R</th>
<th>Adj R2</th>
<th>Adj R2 Change</th>
<th>F Change</th>
<th>Signif F Change</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td>.41</td>
<td>.143</td>
<td>.143</td>
<td>6.54</td>
<td>.05</td>
</tr>
<tr>
<td>Family Cohesion and Friend Support</td>
<td>.65</td>
<td>.35</td>
<td>.21</td>
<td>6.40</td>
<td>.005</td>
</tr>
</tbody>
</table>

Table 53

Hierarchical Multiple Regression Analyses Predicting Externalizing Behavior Problem Scores from Friend Support, Family Cohesion, and Sex

<table>
<thead>
<tr>
<th>Predictor Variable</th>
<th>R</th>
<th>R2</th>
<th>Adj R2 Change</th>
<th>F Change</th>
<th>Signif F Change</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td>.41</td>
<td>.14</td>
<td>.14</td>
<td>6.50</td>
<td>.05</td>
</tr>
<tr>
<td>Family Cohesion and Friend Support</td>
<td>.60</td>
<td>.30</td>
<td>.16</td>
<td>4.66</td>
<td>.05</td>
</tr>
</tbody>
</table>
Table 54

Hierarchical Multiple Regression Analyses Predicting Internalizing Behavior Problem Scores from Friend Support. Family Cohesion, and Sex

<table>
<thead>
<tr>
<th>Predictor Variable</th>
<th>R</th>
<th>R²</th>
<th>Adj R² Change</th>
<th>F Change</th>
<th>Signif F Change</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td>.44</td>
<td>.17</td>
<td>.17</td>
<td>7.12</td>
<td>.05</td>
</tr>
<tr>
<td>Family Cohesion and Friend Support</td>
<td>.58</td>
<td>.27</td>
<td>.10</td>
<td>2.90</td>
<td>.07</td>
</tr>
</tbody>
</table>

Table 55

Frequency and Type of Contact Children Receive From Campers

<table>
<thead>
<tr>
<th>Comments: 67.4% (31)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Frequency</td>
</tr>
<tr>
<td>Never</td>
</tr>
<tr>
<td>Rarely</td>
</tr>
<tr>
<td>Sometimes</td>
</tr>
<tr>
<td>Often</td>
</tr>
<tr>
<td>Very Often</td>
</tr>
</tbody>
</table>
Table 56

**Frequency and Type of Contact Children Initiate with Other Campers**

Comments: 56.5% (26)

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Phone</th>
<th>Letters</th>
<th>Visits</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never</td>
<td>34.6</td>
<td>34.6</td>
<td>38.5</td>
</tr>
<tr>
<td>Rarely</td>
<td>26.9</td>
<td>19.2</td>
<td>57.7</td>
</tr>
<tr>
<td>Sometimes</td>
<td>34.6</td>
<td>26.9</td>
<td>3.8</td>
</tr>
<tr>
<td>Often</td>
<td>3.8</td>
<td>7.7</td>
<td>-</td>
</tr>
<tr>
<td>Very Often</td>
<td>-</td>
<td>11.5</td>
<td>-</td>
</tr>
</tbody>
</table>

Table 57

**Frequency and Type of Contact Children Receive From Counselors**

Comments: 87% (40)

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Phone</th>
<th>Letters</th>
<th>Visits</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never</td>
<td>52.5</td>
<td>10.0</td>
<td>40.0</td>
</tr>
<tr>
<td>Rarely</td>
<td>32.5</td>
<td>50.0</td>
<td>55.0</td>
</tr>
<tr>
<td>Sometimes</td>
<td>12.5</td>
<td>30.0</td>
<td>7.5</td>
</tr>
<tr>
<td>Often</td>
<td>2.5</td>
<td>17.5</td>
<td>-</td>
</tr>
<tr>
<td>Very Often</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>
Table 58

Frequency and Type of Contact Children Initiate with Counselors

<table>
<thead>
<tr>
<th>Comments: 87% (40)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Frequency</strong></td>
</tr>
<tr>
<td>Never</td>
</tr>
<tr>
<td>Rarely</td>
</tr>
<tr>
<td>Sometimes</td>
</tr>
<tr>
<td>Often</td>
</tr>
<tr>
<td>Very Often</td>
</tr>
</tbody>
</table>

Table 59

How Children Felt Being at Camp

<table>
<thead>
<tr>
<th>Comments: 100% (46)</th>
<th>%</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sense of belonging</td>
<td>41.3</td>
<td>19</td>
</tr>
<tr>
<td>Happy/Good</td>
<td>39.1</td>
<td>18</td>
</tr>
<tr>
<td>Normal</td>
<td>13.0</td>
<td>6</td>
</tr>
<tr>
<td>Bad/Sad</td>
<td>6.5</td>
<td>3</td>
</tr>
<tr>
<td>Special/Loved</td>
<td>4.3</td>
<td>2</td>
</tr>
<tr>
<td>Strange</td>
<td>4.3</td>
<td>2</td>
</tr>
</tbody>
</table>
Table 60

Children's Views of Purpose of Camp

<table>
<thead>
<tr>
<th>Comments</th>
<th>%</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Being with others experiencing the same thing</td>
<td>47.8</td>
<td>22</td>
</tr>
<tr>
<td>To have a vacation and a good time</td>
<td>45.7</td>
<td>21</td>
</tr>
<tr>
<td>Not able to go to other camps</td>
<td>19.6</td>
<td>9</td>
</tr>
<tr>
<td>Take mind off illness/to look forward to</td>
<td>13.0</td>
<td>6</td>
</tr>
<tr>
<td>Talk and share feelings</td>
<td>10.9</td>
<td>5</td>
</tr>
<tr>
<td>Raise money</td>
<td>4.3</td>
<td>2</td>
</tr>
<tr>
<td>Give parents a break</td>
<td>4.3</td>
<td>2</td>
</tr>
</tbody>
</table>
Table 61

**Children's Views of What They Receive From Camp**

<table>
<thead>
<tr>
<th>Comments</th>
<th>%</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>New friends</td>
<td>43.5</td>
<td>20</td>
</tr>
<tr>
<td>Fun</td>
<td>39.1</td>
<td>18</td>
</tr>
<tr>
<td>Positive feelings</td>
<td>26.1</td>
<td>12</td>
</tr>
<tr>
<td>Love &amp; caring</td>
<td>19.6</td>
<td>9</td>
</tr>
<tr>
<td>Material things</td>
<td>15.2</td>
<td>7</td>
</tr>
<tr>
<td>Understanding of other's experiences</td>
<td>13.0</td>
<td>6</td>
</tr>
<tr>
<td>Special experience</td>
<td>13.0</td>
<td>6</td>
</tr>
<tr>
<td>Learn things</td>
<td>13.0</td>
<td>6</td>
</tr>
<tr>
<td>Time away from family</td>
<td>10.9</td>
<td>6</td>
</tr>
</tbody>
</table>

Table 62

**Children's Views of What They Contribute to Camp**

<table>
<thead>
<tr>
<th>Comments</th>
<th>%</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Friendship</td>
<td>52.2</td>
<td>24</td>
</tr>
<tr>
<td>Understanding/Role model</td>
<td>28.3</td>
<td>13</td>
</tr>
<tr>
<td>Sense of humor/fun</td>
<td>15.2</td>
<td>7</td>
</tr>
<tr>
<td>Happiness/niceness</td>
<td>15.2</td>
<td>7</td>
</tr>
<tr>
<td>Love</td>
<td>13.0</td>
<td>6</td>
</tr>
<tr>
<td>Myself</td>
<td>10.9</td>
<td>5</td>
</tr>
<tr>
<td>Talents/abilities</td>
<td>10.9</td>
<td>5</td>
</tr>
<tr>
<td>Nothing</td>
<td>2.2</td>
<td>1</td>
</tr>
</tbody>
</table>
Table 63

**Children's Favorite Parts of Camp**

<table>
<thead>
<tr>
<th>Comments: 100% (46)</th>
<th>%</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sports</td>
<td>84.8</td>
<td>39</td>
</tr>
<tr>
<td>Special events</td>
<td>52.2</td>
<td>24</td>
</tr>
<tr>
<td>People</td>
<td>43.5</td>
<td>20</td>
</tr>
<tr>
<td>Waterballoon fights/Raids</td>
<td>43.5</td>
<td>20</td>
</tr>
<tr>
<td>Arts &amp; crafts</td>
<td>37.0</td>
<td>17</td>
</tr>
<tr>
<td>Positive atmosphere</td>
<td>32.6</td>
<td>15</td>
</tr>
<tr>
<td>Dances/Music</td>
<td>30.4</td>
<td>14</td>
</tr>
<tr>
<td>Freedom/Lack of rules</td>
<td>17.4</td>
<td>8</td>
</tr>
<tr>
<td>Camp grounds/Facilities</td>
<td>15.2</td>
<td>7</td>
</tr>
<tr>
<td>Being away from home/Hospital</td>
<td>13.0</td>
<td>6</td>
</tr>
<tr>
<td>Food</td>
<td>4.3</td>
<td>2</td>
</tr>
</tbody>
</table>
### Table 64
**What Children Would Add to Camp**

<table>
<thead>
<tr>
<th>Comments</th>
<th>%</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Different sports</td>
<td>42.4</td>
<td>14</td>
</tr>
<tr>
<td>Animals</td>
<td>36.4</td>
<td>12</td>
</tr>
<tr>
<td>Special events/Programs</td>
<td>24.2</td>
<td>8</td>
</tr>
<tr>
<td>Special things</td>
<td>18.2</td>
<td>6</td>
</tr>
<tr>
<td>Better food</td>
<td>15.2</td>
<td>5</td>
</tr>
<tr>
<td>Physical aspects of campsite</td>
<td>9.1</td>
<td>3</td>
</tr>
<tr>
<td>More free time</td>
<td>6.1</td>
<td>2</td>
</tr>
<tr>
<td>More children</td>
<td>6.1</td>
<td>2</td>
</tr>
<tr>
<td>Longer week</td>
<td>6.1</td>
<td>2</td>
</tr>
<tr>
<td>Camp year book</td>
<td>6.1</td>
<td>2</td>
</tr>
<tr>
<td>Allow night raids</td>
<td>6.1</td>
<td>2</td>
</tr>
</tbody>
</table>

### Table 65
**What Children Would Change About Camp**

<table>
<thead>
<tr>
<th>Comments</th>
<th>%</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Length</td>
<td>48.6</td>
<td>17</td>
</tr>
<tr>
<td>Food</td>
<td>25.7</td>
<td>9</td>
</tr>
<tr>
<td>Programs/Activities</td>
<td>25.7</td>
<td>9</td>
</tr>
<tr>
<td>Wake-Up/Bed-time</td>
<td>14.3</td>
<td>5</td>
</tr>
<tr>
<td>Physical aspects of campsite</td>
<td>14.3</td>
<td>5</td>
</tr>
<tr>
<td>Personnel</td>
<td>11.4</td>
<td>4</td>
</tr>
</tbody>
</table>
### Table 66

**Children's Views of Unrealistic Rules at Camp**

<table>
<thead>
<tr>
<th>Comments</th>
<th>%</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sports/Team rules</td>
<td>33.3</td>
<td>5</td>
</tr>
<tr>
<td>Wake-Up/Bed-time</td>
<td>13.3</td>
<td>2</td>
</tr>
<tr>
<td>Not allowing night raids</td>
<td>13.3</td>
<td>2</td>
</tr>
<tr>
<td>Things aren't allowed to do</td>
<td>13.3</td>
<td>2</td>
</tr>
<tr>
<td>No rules - broke them all</td>
<td>13.3</td>
<td>2</td>
</tr>
</tbody>
</table>

### Table 67

**What at Camp Was Hard for Children to Get Used to**

<table>
<thead>
<tr>
<th>Comments</th>
<th>%</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>New people/Sick children</td>
<td>36.0</td>
<td>9</td>
</tr>
<tr>
<td>Leaving home &amp; family</td>
<td>28.0</td>
<td>7</td>
</tr>
<tr>
<td>Physical aspects of camp</td>
<td>16.0</td>
<td>4</td>
</tr>
<tr>
<td>Emotional openness</td>
<td>12.0</td>
<td>3</td>
</tr>
<tr>
<td>Wake-Up/Bed-time</td>
<td>12.0</td>
<td>3</td>
</tr>
<tr>
<td>Activities</td>
<td>12.0</td>
<td>3</td>
</tr>
<tr>
<td>Personnel</td>
<td>12.0</td>
<td>3</td>
</tr>
</tbody>
</table>
Table 68
What Made Children Feel Bad/Sad at Camp

<table>
<thead>
<tr>
<th>Comments</th>
<th>%</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Leaving camp</td>
<td>43.5</td>
<td>10</td>
</tr>
<tr>
<td>Seeing sick children</td>
<td>34.8</td>
<td>8</td>
</tr>
<tr>
<td>Memorial/Closing services</td>
<td>17.3</td>
<td>4</td>
</tr>
<tr>
<td>Children dying</td>
<td>13.0</td>
<td>3</td>
</tr>
<tr>
<td>Scary stories told at night</td>
<td>4.3</td>
<td>1</td>
</tr>
</tbody>
</table>

Table 69
Parents' Views of Purpose of Camp

<table>
<thead>
<tr>
<th>Comments</th>
<th>%</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Be with others with same experiences</td>
<td>40.0</td>
<td>18</td>
</tr>
<tr>
<td>Escape from treatment</td>
<td>37.8</td>
<td>17</td>
</tr>
<tr>
<td>Provide a normal camp experience</td>
<td>26.7</td>
<td>12</td>
</tr>
<tr>
<td>Break for family/independence for child</td>
<td>22.2</td>
<td>10</td>
</tr>
<tr>
<td>Provides medical protection</td>
<td>17.8</td>
<td>8</td>
</tr>
<tr>
<td>Sharing problems and feelings</td>
<td>13.3</td>
<td>6</td>
</tr>
<tr>
<td>Make new friends</td>
<td>8.9</td>
<td>4</td>
</tr>
<tr>
<td>Positive atmosphere</td>
<td>8.9</td>
<td>4</td>
</tr>
</tbody>
</table>
Table 70
Parents' Views of What Child Receives From Camp

<table>
<thead>
<tr>
<th>Comments: 100% (45)</th>
<th>%</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>New friends/friends with cancer</td>
<td>40.0</td>
<td>18</td>
</tr>
<tr>
<td>Change in self-esteem/interactional style</td>
<td>35.6</td>
<td>16</td>
</tr>
<tr>
<td>Learns about coping from others</td>
<td>33.3</td>
<td>15</td>
</tr>
<tr>
<td>Break from illness routine/fun</td>
<td>22.2</td>
<td>10</td>
</tr>
<tr>
<td>Something to look forward to</td>
<td>15.6</td>
<td>7</td>
</tr>
<tr>
<td>Friendships with counselors</td>
<td>11.1</td>
<td>5</td>
</tr>
<tr>
<td>Sharing and caring</td>
<td>11.1</td>
<td>5</td>
</tr>
</tbody>
</table>

Table 71
Parents' Views of Child's Contribution to Camp

<table>
<thead>
<tr>
<th>Comments: 100% (45)</th>
<th>%</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Compassion and comfort</td>
<td>24.4</td>
<td>11</td>
</tr>
<tr>
<td>Positive attitude/enthusiasm</td>
<td>22.2</td>
<td>10</td>
</tr>
<tr>
<td>Self as gift</td>
<td>20.0</td>
<td>9</td>
</tr>
<tr>
<td>Charisma/outgoing personality</td>
<td>20.0</td>
<td>9</td>
</tr>
<tr>
<td>Inspiration/role model</td>
<td>17.8</td>
<td>8</td>
</tr>
<tr>
<td>Fun/joy</td>
<td>15.6</td>
<td>7</td>
</tr>
<tr>
<td>Talents and abilities</td>
<td>15.6</td>
<td>7</td>
</tr>
<tr>
<td>Challenge/hard time</td>
<td>13.3</td>
<td>6</td>
</tr>
<tr>
<td>Sense of humor</td>
<td>11.1</td>
<td>5</td>
</tr>
<tr>
<td>Friendship</td>
<td>4.4</td>
<td>2</td>
</tr>
</tbody>
</table>
Table 72

Parents' Favorite Parts of Camp

<table>
<thead>
<tr>
<th>Comments: 100% (45)</th>
<th>%</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Break for family</td>
<td>37.8</td>
<td>17</td>
</tr>
<tr>
<td>Fun for child</td>
<td>31.1</td>
<td>14</td>
</tr>
<tr>
<td>Counselors' dedication</td>
<td>28.9</td>
<td>13</td>
</tr>
<tr>
<td>Caring and sharing</td>
<td>22.2</td>
<td>10</td>
</tr>
<tr>
<td>New friends and experiences</td>
<td>17.8</td>
<td>8</td>
</tr>
<tr>
<td>Activities and programs</td>
<td>8.9</td>
<td>4</td>
</tr>
<tr>
<td>Respect child learns for people's differences</td>
<td>6.7</td>
<td>3</td>
</tr>
<tr>
<td>Learning to let child try new things</td>
<td>2.2</td>
<td>1</td>
</tr>
<tr>
<td>Gifts child receives</td>
<td>2.2</td>
<td>1</td>
</tr>
</tbody>
</table>

Table 73

What Parents Would Add to Camp

<table>
<thead>
<tr>
<th>Comments: 40.0% (18)</th>
<th>%</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Longer session</td>
<td>38.9</td>
<td>7</td>
</tr>
<tr>
<td>Different activities</td>
<td>27.8</td>
<td>5</td>
</tr>
<tr>
<td>Overnight camping in the woods</td>
<td>11.1</td>
<td>2</td>
</tr>
<tr>
<td>Better food</td>
<td>5.6</td>
<td>1</td>
</tr>
<tr>
<td>Peer counseling</td>
<td>5.6</td>
<td>1</td>
</tr>
<tr>
<td>Parent support group</td>
<td>5.6</td>
<td>1</td>
</tr>
<tr>
<td>Allow parents to go</td>
<td>5.6</td>
<td>1</td>
</tr>
</tbody>
</table>
Table 74

What Parents Would Change About Camp

<table>
<thead>
<tr>
<th>Comments: 55.6% (25)</th>
<th>%</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Length</td>
<td>36</td>
<td>9</td>
</tr>
<tr>
<td>Fact that parents can't attend</td>
<td>20</td>
<td>5</td>
</tr>
<tr>
<td>Some of the rules</td>
<td>20</td>
<td>5</td>
</tr>
<tr>
<td>Food</td>
<td>16</td>
<td>4</td>
</tr>
<tr>
<td>Camp celebrity guests</td>
<td>12</td>
<td>3</td>
</tr>
<tr>
<td>Address more psychological aspects</td>
<td>8</td>
<td>2</td>
</tr>
<tr>
<td>Place hold camp</td>
<td>4</td>
<td>1</td>
</tr>
</tbody>
</table>

Table 75

Parents' Views of Unrealistic Rules at Camp

<table>
<thead>
<tr>
<th>Comments: 11.1% (5)</th>
<th>%</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not allowing child to call home</td>
<td>40</td>
<td>2</td>
</tr>
<tr>
<td>Allowing children out of cabins at night</td>
<td>40</td>
<td>2</td>
</tr>
<tr>
<td>Activities schedule</td>
<td>20</td>
<td>1</td>
</tr>
</tbody>
</table>
Table 76

What at Camp Was Hard for Parents to Get Used to

<table>
<thead>
<tr>
<th>Comments</th>
<th>%</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Letting child go</td>
<td>67.6</td>
<td>23</td>
</tr>
<tr>
<td>Being away from child for a week</td>
<td>26.5</td>
<td>9</td>
</tr>
<tr>
<td>Child's worries about camp</td>
<td>2.9</td>
<td>1</td>
</tr>
<tr>
<td>Having free time</td>
<td>2.9</td>
<td>1</td>
</tr>
<tr>
<td>Seeing children die</td>
<td>2.9</td>
<td>1</td>
</tr>
</tbody>
</table>

Table 77

What at Camp Made Parents Feel Bad

<table>
<thead>
<tr>
<th>Comments</th>
<th>%</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Seeing sick children</td>
<td>40.6</td>
<td>13</td>
</tr>
<tr>
<td>Children dying</td>
<td>34.4</td>
<td>11</td>
</tr>
<tr>
<td>Making child leave at end of week</td>
<td>18.9</td>
<td>6</td>
</tr>
<tr>
<td>Fact have to go to a cancer camp</td>
<td>15.6</td>
<td>5</td>
</tr>
<tr>
<td>Fears the camp would be (-) for child</td>
<td>6.3</td>
<td>2</td>
</tr>
</tbody>
</table>
APPENDICES
APPENDIX A

Letters of Permission
TO: Dr. Elizabeth J. Short/Laura Basilii
DEPARTMENT OR SCHOOL: Psychology
SUBJECT: Notice of: [X] Review and Approval
[ ] Exception

The Committee has reviewed your proposal entitled: An Exploratory Analysis of Social Support Resources & Coping Strategies in Children with Cancer

Please be advised that with respect to (1) the rights and welfare of the individual(s) involved; (2) the appropriateness of the methods to be used to secure informed consent; and (3) the risks and potential benefits of the investigation, the Committee considers your project:

[ ] Exempt
[X] Fully acceptable
[ ] Acceptable with reservations noted*
[ ] Not acceptable for reasons noted*

Follow-up: The Committee wishes to have a status report on this project on July 17, 1990 (date)

Remarks:

Date July 17, 1989
Signed
For the Committee
Gerald M. Parker

For ORA Use
Type Project: [ ] New [ ] Renewal: Human Risk [ ] Yes [ ] No
Source of Support: [ ] Outside Funding [ ] Departmental or Other
Agency (Potential) Agency No.
Are any of the following involved: [ ] Yes [ ] No
[ ] Minors, [ ] Fetuses, [ ] Abortuses, [ ] Pregnant Women, [ ] Prisoners,
[ ] Mentally Retarded, [ ] Mentally Disabled Subjects

If "yes" please mark the appropriate category.

cc: Faculty Advisor
Dean
Department Chairman (or Investigator)
May 9, 1988

Laura Basili
3256 Redwood Rd.
Cleveland Heights, OH 44118

Dear Laura:

Sorry for the long delay. Enclosed is last year's list of campers to be used in your graduate study.

As I understand from your letter, this list will not be shared with any other organization or person, but used solely to obtain information for your doctoral dissertation.

I would very much like to have you share the information with our "Division Childhood Cancer Committee."

See you this summer at camp.

Cordially,

Jane S. Bemis
Director Service and Rehabilitation

JSB/ew
Enclosure
Dear Parents, May 31, 1988

Hello! We have been counselors at camps for children with cancer for the past 3 years. We are doctoral students in Child Clinical Psychology at Case Western Reserve University, in Cleveland, Ohio. Since working at Camp Rising Sun and Camp Ta Kum Ta for the past several years we've become particularly interested in the positive effects of camp on the emotional development of children with cancer.

Although there are several camps such as Rising Sun and Ta Kum Ta around the country, little research has been done to study their beneficial effects. One study that was recently published found attendance at a one week cancer camp to have positive effects on the behavior of the children after camp. However, no one has done a study which looks at the descriptive characteristics of the children or families who attend these camps. Therefore, for my dissertation and for Beth Anne's master's thesis we've designed a study to learn more about the children and families who attend these camps. We view such camps as providing a means of emotional and social support for the children who attend, and as such believe them to have a positive effect on the children who attend.

We are writing to ask your participation in this study. This study has been approved by both the Vermont and Connecticut Cancer Societies as well as by the Human Research Committee at Case Western Reserve University. Basically we will be collecting information from you and your child before camp, during the month of July or at the beginning of August. Beth Anne and I will travel to your home at your convenience to interview you and your child. The interview will last approximately two hours, with one of us interviewing either one or both parents and the other interviewing your child.

During the parent interview we will collect demographic information (e.g. parent education, occupation, religion, etc.) and medical information (e.g. type of cancer, duration, current treatment, etc.). We will also ask you as parents to fill out questionnaires concerning your 1) child's behavior, 2) current life events, 3) coping style and resources, 4) current level of social support, and 5) family functioning as well as to answer questions to a semi-structured interview. During your child's interview we will collect information regarding your child's perceptions of camp (e.g. favorite activities, number years attended, etc.). Your child will also fill out questionnaires concerning their 1) affect (e.g. depression, anxiety) 2) self concept, 3) current level of social support, and 4) coping style. Your child will also be given a pictorial vocabulary test as an estimate of their cognitive ability.

All data will be collected in one session, one month before camp, and in no way will the study be conducted at camp. The only connection between camp and the study is that we will be counselors at camp. All information collected will be kept completely
confidential and if at any time you or your child wishes to
discontinue participation you may do so. After all the data has been
coded and analyzed we will send you a letter explaining the findings
of the study.

We realize the tremendous stress and struggle you, your family,
and your child have undergone since the diagnosis of your child's
illness. We will be asking a few questions about sensitive issues.
However, having worked closely with children with cancer and other
chronic illnesses, we feel prepared to handle such delicate topics.
Furthermore, if at any time you or your child does not feel
comfortable answering a question, you won't be asked to do so.

We feel the significance of this study to be substantial in its
potential for drawing attention to the emotional and social support
needs of children with cancer. Not only will we understand more
about the emotional, social support, and coping resources of the
children and their families who attend such camps, but we will also
learn about how they view camp. Any information collected could be
used by the Cancer Society for fund raising, etc.

We feel this project to be an important and worthwhile one and
we hope you will as well. If you would like to participate in this
study please detach and fill out the permission slip below, enclose
it in the addressed and stamped envelope, and mail it back to us.
We will contact you once we receive the letter to find out your
schedule for the summer and to set up a time for the interview.
We would appreciate your sending the permission slip back to us
as soon as possible, even if you do not wish to participate in
the study. If you need any further information, feel free to contact
us at 216-321-7910. Thank you for your time and consideration.

Sincerely,

Laura Basili, M.A.  Beth Anne Bull

__________________________  ____________________________
Laura Basili, M.A.  Beth Anne Bull

I have read the above letter and I (we), _______________________
agree to participate in the study described as well as to allow my
child, ________________________ to participate.

We do not wish to participate in this study at this time.
APPENDIX B

Measures Employed in the Study

Child Social Support/Camp Interview

Parent Social Support/Camp Questionnaire

Information Form
PLEASE NOTE

Copyrighted materials in this document have not been filmed at the request of the author. They are available for consultation, however, in the author's university library.

240-257

University Microfilms International
APPENDIX C

Reliability and Validity of the Measures Employed in the Study

Social Support Scale for Children (SSSC)
Self Perception Profile for Children (SPPC)
Revised Peabody Picture Vocabulary Test (PPVT-R)
Social Support Questionnaire (SSQ)
Family Environment Scale (FES)
Child Behavior Checklist (CBCL)
Social Support Scale for Children (SSSC)

Reliability and validity data were obtained on 1137 children in the third through eighth grades in two school districts in Colorado (Harter, 1986). The sample was lower to upper class, and 90% Caucasian. Cronbach’s Alpha was used to determine internal consistency for the sample. Cronbach’s alpha for subscales ranged from .78 to .88 for parent support; .74 to .79 for classmate support; .81 to .84 for teacher support; and .72 to .83 for close friend support. A factor analysis with oblique rotation was performed and resulted in a 4 factor solution for middle school children (sixth through eighth). A three factor solution for elementary school children was obtained, with support from classmates and friends not separating out as distinct factors. Factor loadings ranged from .27 to .71 for classmates; .33 to .77 for close friends; .54 to .79 for parents; and .54 to .80 for teachers. Intercorrelations among the subscale scores were low to moderate, ranging from .27 to .57. The highest intercorrelation was between close friends and classmates for elementary school children.

Validity data was obtained by correlating each source of social support with the global self worth scale of the Self-Perception Profile for Children (SPPC). Correlations for elementary and middle school samples were respectively, .43, .46 for parent support; .48, .42 for
classmate support; .38, .49 for friend support; and .35, .28 for teacher support. Additionally, the classmate support score was correlated with the social acceptance domain of the SPPC; correlations were .62 and .69 for elementary and middle school children respectively. And, close friend support for middle school children was correlated .46 with the child’s score on the Social Skills Scale for Children (Harter, 1985).

Self Perception Profile for Children (SPPC)

Reliability and validity data on the SPPC were based on four samples of children in the third through eighth grade, living in Colorado (Harter, 1985). The samples were from a range of SES but were primarily (90%) Caucasian. Cronbach’s Alpha was used to determine internal consistency for the four samples. The range of reliabilities for the six scales were as follows: scholastic competence ranged from .80 to .85; social acceptance ranged from .75 to .80; athletic competence ranged from .80 to .86; physical appearance ranged from .76 to .82; behavioral conduct ranged from .71 to .77; and global self-worth ranged from .78 to .84.

A factor analysis with oblique rotation was performed for the five specific subscales to determine the factor structure of the scale. The factor pattern was clear with each of the five subscales defining their own factor for 6th & 7th, 6th, 7th, & 8th, and 5th & 6th grade samples of
children. The factor loadings for each subscale were substantial; scholastic competence ranged from .52 to .70, social competence ranged from .41 to .70, athletic competence ranged from .41 to .81, physical competence ranged from .33 to .77, and behavioral competence ranged from .33 to .82. There were also no cross loadings greater than .18 with the average ranging from .04 to .08. Intercorrelations of subscales ranged from .01 to .58. The findings indicated there was a tendency for scores to be more highly related among the younger children (3rd and 4th graders), as compared to the older children (5th through 8th graders).

Findings for the Self-Perception Profile for Adolescents were similar to those for the SPPC. Cronbach’s alpha’s ranged from .74 to .92. There were no cross-loadings greater than .30. A factor analysis with oblique rotation was performed for the eight specific subscales to determine the factor structure of the scale. The factor pattern was clear with each of the eight subscales defining their own factors for 9th through 12th graders. The average factor loadings for each scale were substantial; scholastic competence was .64; athletic competence was .76; social competence was .45; friendship competence was .63; romantic competence was .58; physical competence was .62; behavioral conduct was .57; and job competence was .51.
Revised Peabody Picture Vocabulary Test (PPVT-R)

Split-half reliability coefficients on Form L of the PPVT-R for children from 2 1/2 to 18 ranged from .67 to .88 (median .80). Immediate and delayed retest reliability, using forms L and M, were also determined for this age group. Immediate retest coefficients ranged from .71 to .89 (median .79), while delayed retest coefficients ranged from .54 to .90 (median .77). No validity information is available for the PPVT-R, but correlations with the PPVT are high enough to refer to validity studies between the PPVT and other tests of intelligence. The standard score correlation coefficients between the PPVT-R and the PPVT range from .50 to .85 (median .68). The PPVT and Stanford Binet Vocabulary subtest correlation coefficients range from .68 to .76 (median .72), and that of the PPVT and the WISC-R Vocabulary subtest range from .37 to .83 (median .69) (Dunn & Dunn, 1981).

Social Support Questionnaire (SSQ)

The reliability and validity of the SSQ was obtained in a series of studies by Sarason, Levine, Basham, and Sarason (1983). For a sample of 602 undergraduates, coefficient alpha was .94 for the support score (SSQS) and .97 for the number score (SSQN). Administering the scale to a group of 277 undergraduates revealed test-retest correlations over a 4 week period to be .90 for the SSQN score and .83
for the SSQS score, suggesting the scale is stable with high internal consistency. A modest correlation of .34 was found between the 2 parts of the scale suggesting the importance of analyzing social support into its component parts. For validity, negative correlations of (-.22) for SSQN and (-.43) for SSQS were found with the Multiple Affect Adjective Checklist. And a negative correlation of (-.22) for SSQS and (-.32) for SSQN was found with the Lack of Protection Scale. A group of 38 female undergraduates was administered the SSQ and correlations of .35 between SSQN and -.37 with SSQS were found with the Extroversion and Neuroticism scales of the Eysenck Personality Inventory. And, no correlation was found between the SSQ and the Marlowe-Crowne Measure of Social Desirability.

Family Environment Scale (FES)

The initial form of the FES, which contained 200 items, was administered to 1000 individuals comprising 285 families from community church groups, Black and Mexican American families, and disturbed families from a clinic population (Moos, 1974). The initial data was used to obtain the 90 item scale. A factor analysis revealed 10 factors which comprise the 10 subscales. Each subscale was found to have moderate to high internal consistency (.64 - .79) using the Kuder-Richardson Formula 20.
The item to subscale correlations varied from .45 to .55. Average subscale intercorrelations were approximately .20, suggesting the subscales measure distinct yet somewhat related aspects of family social environments. Test-retest reliabilities of individual scores on the 10 subscales were calculated on 47 family members in 9 families who took the FES 2 times within an 8 week interval between testing. Reliabilities ranged from .68 to .86 (Moos, 1974).

**Child Behavior Checklist (CBCL)**

Reliability and validity of the CBCL was established in a number of studies (Achenbach & Edelbrock, 1983). Intraclass correlations between item scores were obtained from a group of mothers filling out the CBCL at 1 week intervals, from mothers and fathers filling out the CBCL on a group of clinically referred children, and from 3 different interviewers obtaining CBCLs from the parents of demographically matched triads of children. All intraclass correlations were in the .90 range. The intraclass correlation for 3 month stability of mother ratings of individual items was .838 for behavior problems and .974 for social competence items. For internalizing and externalizing scale scores and total problem scores social and competence scores, median Pearson correlations for 1 week test-retest reliabilities of mother ratings was .89. Median Pearson correlations between mother and
father ratings on these scale scores was .66. Test-retest correlations for inpatient scores over a 3 month period averaged .74 for parents and .73 for child care worker ratings. Test-retest correlations for outpatient scores over 6 months were .60 for the behavior problems and competence scores. Over 18 months the mean correlation ranged from .46 to .76 for the behavior problems and competence scores for a variety of sex and age groups.

Content validity was assessed by whether items related to clinical concerns of mental health workers and parents. One hundred sixteen of 118 behavior problem items and all 20 social competence items were significantly associated with a separate evaluation of clinical status. Construct validity was assessed by correlations between the CBCL behavior problem score and total scores on the Conners Parent Questionnaire (r = .77 for males, .91 for females) and the Quay-Peterson Revised Behavior Problem Checklist (R = .71 for males, .92 for females). Criterion related validity was assessed by the relationship between CBCL score and referral for mental health services. Significant differences were found between demographically matched and referred and nonreferred children on all profile scores for all sex and age groups.
APPENDIX D

Instructions to be Read for Measures Employed in the Study

Social Support Questionnaire (SSQ)

Family Environment Scale (FES)

Self Perception Profile for Children and Adolescents (SPPC, SPPA)

Social Support Scale for Children (SSSC)

Family Inventory of Life Events (FILE)

Child Behavior Checklist (CBCL)
Social Support Questionnaire Instructions:

The following questions ask about people in your environment who provide you with help or support. Each question has two parts. For the first part, list all the people you know, excluding yourself, whom you can count on for help or support in the manner described. You may either give the person's initials or their relationship to you. Do not list more than one person next to each of the letters beneath the question. For the second part, circle how satisfied you are with the overall support you have. If you have no support for a question, check the word "No one", but still rate your level of satisfaction. Do not list more than nine persons per question. Please answer all questions as best you can. All your responses will be kept confidential.

Family Environment Scale Instructions:

There are 90 statements in this booklet. They are statements about families. You are to decide which of these statements are true of your family and which are false. Make all your marks on the separate answer sheets. If you think the statement is T or mostly T of your family, make an X in the box labeled T. If you think the statement is F or mostly F of your family, make an X in the box labeled F.

You may feel that some of the statements are true for some family members and false for others. Mark T if the statement is true for most members. Mark F if the statement is false for most members. If the members are evenly divided, decide what is the stronger overall impression and answer accordingly. Remember, we would like to know what your family seems like to you. So do not try to figure out how other members see your family, but do give us your general impression of your family for each statement.

Self Perception Profile for Children and Adolescents Instructions:

We have some sentences here and, as you can see from the top of your sheet where it says "What I am Like" we are interested in what you are like, what kind of person you are like. This is a survey, not a test. There are no right or wrong answers. Since kids are very different from one another, you will be putting down something different from other kids.
First let me explain how these questions work. There is a sample question at the top, marked (A). I’ll read it out loud and you follow along with me. (READ SAMPLE QUESTION). This question talks about two kinds of kids, and we want to know which kids are most like you.

1) So, what I want you to decide first is whether you are more like the kids on the left side who would rather play outdoors, or whether you are more like the kids on the right side who would rather watch T.V. Don’t mark anything yet, but first decide which kind of kid is most like you, and go to that side of the sentence.

2) Now, the second thing I want you to think about, now that you have decided which kind of kids are most like you, is to decide whether that is only sort of true for you or really true for you. If its only sort of true for you then put an X in the box under sort of true; if its really true for you, then put an X in that box.

3) For each sentence you’ll check only one box. Its important not to check both sides, just the one side most like you. Now we have some more sentences which I’m going to read out loud to you. For each one just check one box, the one that goes with what is true for you, what you are most like.

Social Support Scale for Children Instructions:

We have some sentences here and, as you can see from the top of your sheet where it says "People in My Life" we are interested in several kinds of people in your life. This is a survey, not a test. There are no right or wrong answers. Since kids are very different from one another, you will be putting down something different from other kids.

First let me explain how these questions work. There is a sample question at the top, marked (A). I’ll read it out loud and you follow along with me. (READ SAMPLE QUESTION). This question talks about two kinds of kids, and we want to know which kids are most like you.

1) So, what I want you to decide first is whether you are more like the kids on the left side who would rather do fun things with alot of other people, or whether you are more like the kids on the right side who would rather do fun things with just a few people. Don’t mark anything yet, but first decide which kind of kid is most like you, and go to that side of the sentence.
2) Now, the second thing I want you to think about, now that you have decided which kind of kids are most like you, is to decide whether that is only sort of true for you or really true for you. If its only sort of true for you then put an X in the box under sort of true; if its really true for you, then put an X in that box.

3) For each sentence you’ll check only one box. Its important not to check both sides, just the one side most like you. Now we have some more sentences which I’m going to read out loud to you. For each one just check one box, the one that goes with what is true for you, what you are most like.

Child Behavior Checklist Instructions:

Below is a list of items that describe children. For each item that describes your child now or within the past 6 months, please circle the 2 if the item is very true or often true of your child. Circle the 1 if the item is somewhat or sometimes true of your child. If the item is not true of your child, circle the 0. Please answer all items as well as you can, even if some do not seem to apply to your child.
APPENDIX E

Inter-rater Reliability for the Social Support and Camp Interviews

Child Social Support Questions
Parent Social Support Questions
Child Camp Questions
Parent Camp Questions
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APPENDIX F

Examples of Children’s and Parents’ Interview Responses

Children’s Social Support Responses

Parents’ Social Support Responses

Children’s Camp Responses

Parents’ Camp Responses
CHILDREN’S SOCIAL SUPPORT RESPONSES

Parents: Helpful

Being with me at home or hospital
My mom was always there. She totally shifted her life around mine which was totally demanding.

Actual/Material assistance: did things bought things
My mother rubbed my back when I was throwing up.

Talking to me/encouraging me
Told me that I was going to live and that I wouldn’t die – that I’d be all right and it would be over soon.

General caring and support
Helped me by caring about me.

Parents: Not Helpful

Talking about illness too much
Talked about everything when I was tired – just kept talking.

Parent emotion overwhelming child
My dad cried with me once for a long time. It scared me a little bit. I knew he was trying to help. I’d never seen him like that before. It scared me a little bit.

Pushing child to do things
They expect too much from me. Like for me to exercise, and my knee is shot.

Told other people about illness
My mom tried to do good but bothered me. She told people things I didn’t want them to know. She told the whole world. She called everyone she knew.

Babying child
I told my mom not to take out the garbage or cat litter because it’s my job. She did it anyway and got me mad.

Siblings: Helpful

Material assistance: did things, gave things
When I get bone marrow aspirations my sisters let me lie in their beds because they have soft beds.

Emotional support: talking, listening, understanding
Comforted me by asking questions about how I felt.
Played with me
   She would play games with me.

Visited/stayed with me when ill
   When I was in the hospital I kind of wanted to see them.

   I didn’t tell my mom and dad but they kind of knew and
   came to see me. It made me feel better.

**Siblings Not Helpful**

Negative attitudes and actions such as teasing, jealousy
   Teased me and got jealous cause I got more presents.

General bothering
   Small things like putting my shoes away when I didn’t
   want them to.

Beating me up/fighting
   Beat me up all the time.

Not emotionally supportive: not there to listen or talk to
   Not being around or there for me.

**Relatives: Helpful**

Visited at home/hospital
   Came to the hospital almost as much as my mom came.

Material assistance: did things for me, gave gifts
   Brought books for me to read in the hospital.

Emotional support: talking and reassuring
   If I called them up at whatever time they talked to me.

**Relatives: Not Helpful**

No see or visit
   I didn’t see my dad’s parents at all.

Not getting along/bothering
   My grandma could be a bitch. When I wasn’t sick she
   was on my back.

Bought/did things didn’t need
   Bought toys that I didn’t really need or want.

Worrying too much
   Fact that grandma worried so much made me scared.
Medical Staff: Helpful

Treated/cured my cancer
   Kept me alive. I was sick and they helped.
Talked and prepared for medical procedures
   Telling me what it would feel like, preparing me.

General emotional support: optimism, just being there
   Helped me to feel that I would get over it someday and
   I would be a normal person.

Played/spent time with me
   They played and entertained me when I was bored.

Material aid: special favors, bought things
   They didn’t let me go into the playroom and play with
   the other kids. Lucy snuck toys into my room so I
   could play with them.

Medical Staff: Not Helpful

Medical mistakes
   Sometimes the nurses gave me the wrong pills or they’d
   be under my plate and I wouldn’t see them.

Treatment involved in cancer
   The needles and treatment were painful!

Not seeing/talking to doctor enough
   The doctors were not that available to talk to.

Hospital routines/group rounds
   Twelve medical students came in to check me. Each one
   made me do the same thing!

Intrusive/upsetting illness talk
   Doctor tried to talk with me about cancer prognosis from
   a magazine article. I didn’t want to.

Losing relationships when left
   The resident I was close to left the hospital. I don’t
   hear from him. I have no idea now what he’s doing.
   He’s not involved in my life now – it hurts.

Friends: Helpful

Emotional support: listening, caring, understanding
   My friend listened to me and stuff, understood me –
   always has and always will.
Visited/called me
   Came to visit, called me and everything.

Material aid: wrote letters, did nice things
   Sent cards and gifts.

Played with me
   My friend would come over and play games with me.

Protected me, didn’t tease me
   Beat up others - so they stood up for me if someone
   came by and I had no hair or a hat. They’d say,
   "What did you say about my friend?".

Helped with school work/issues
   Told me what was happening at school, kept me up on
   things.

Friends: Not Helpful

Teased me
   Kids teased me and talked about me.

Treated "specially/differently"
   I don’t feel people knew me - they just knew my problem.
   I was not Jesse but "the girl with cancer". It was
   awful to deal with.

Changed relationship/no see
   Once when I was sick a really good friend stopped
   talking to me for awhile.

Brought school work home
   They brought my school work home.

Insensitive comments
   Dumb comments. One friend asked if I had ALL or AIDS.

School/Teachers: Helpful

Helped with school work/learning
   Helped me with my work so I didn’t have to stay back.

Emotional support: talking, caring, made feel better
   Talked to me and helped me to feel better.

Helped with illness needs: sent to nurse, let rest
   Sometimes in school if I felt sick she told me to put
   my head down.
Talked to class about cancer
   Explained to kids what was happening to me to prepare
them. She told the kids I had cancer, that I was normal
and the treatment was normal.

Material aid: sent cards, gifts
   My English teacher wrote to me all the time.

Stopped kids' teasing
   If kids teased me about my cancer they would help me.

School Staff: Not Helpful

Not emotionally supportive: didn't care, weren't sensitive
   Told kids about my cancer but the kids didn't know me
first. I'm still trying to get kids to recover from
that today.

Didn't adjust school procedures to accommodate illness
   Made me take gym when I was feeling sick.

Teased me
   They teased me all the time.
PARENTS’ SOCIAL SUPPORT RESPONSES

Spouse: Helpful

Emotional support: talking, understanding, (+) attitude
Just being there and offering to do whatever he can.
Putting up with how I felt.

Managed household/finances
He handled all the bills and housework.

Managed illness & medical information
Because of husband’s efforts gained medical resources
in the greater Hartford area.

Came to/Stayed at hospital
He was at the hospital the whole time, every time we
went whether it was a spinal or bone marrow he was
there.

Spouse: Not Helpful

Lack of emotional support: didn’t talk or share feelings
We were on the outs already in our marriage. The
hardest thing was not being able to sit down and talk
about how we really felt.

Lack of aid in illness management: decisions, hospital
Wasn’t involved. He couldn’t handle hospitals at the
time. I handled it all and I had a hard time with the
hospital.

Spouse coping poorly/falling apart: drinking, drugs
My husband went bonkers and took sleeping pills and
tranquilizers.

Conflicting coping expectations
He wanted me to do what he does best, like comfort her
and be patient.

Annoying habits
My wife tried to give me advice on how to do the laundry
or run the water. She didn’t need to tell me.

Parents: Helpful

Household/material support: kids, house, money; gifts
My mom moved in and took care of the laundry, cleaning,
getting the kids ready while I was helping Mark.
Support in caring for sick child
My mom came up at Christmas to be with him. She got Walter walking again.

Emotional support: talking, listening, calling
My mom was just there when I needed her to talk to.

Parents: Not Helpful

Lack of emotional support: denial, uninvolved
My husband’s family didn’t talk about it or didn’t tell other relatives. They couldn’t cope.

Negative attitude/criticism
My mom was too bitter about it.

Parents coping with own problems
My mother-in-law was an alcoholic at the time.

Spoiled sick child
My mom would give into my daughter more than I would have liked. She wouldn’t discipline her.

Specific incident:
Gave laundry to neighbors to do.

Siblings: Helpful

Emotional support: talking, encouraging, understanding
She thinks like I do and was good to talk to. It was easy to share with her.

Household/sibling assistance:
My sister came and helped on weekends. She took the kids for the weekend and brought them to visit Robin in the hospital.

Hospital visits & stays
Came up to see me and keep me company in the hospital.

Family visits
Came and visited the family for weekends.

Cared for/spent time with sick child
Took care of Brian after his chemotherapy if he was too sick to go to school, so I could go to work.

Siblings: Not Helpful

Not emotionally supportive: not there, didn’t understand
They were scared of the situation and left me all alone.
Spoiled children
They spoiled my kids.

Disagreements
We had a run-in when Tommy relapsed, we were going
crazy.

Having to pretend things were ok
Darren had to act like things were ok. He had to put
on a show for relatives who couldn’t handle it.

Friends: Helpful

Emotional support: listening, encouraging, talking
I talked to each friend about different things. It felt
good to dump my feelings.

Material aid to family: meals, fund raising, housework
My friends drove with us to NY for radiation therapy to
keep us company, they fed Dick and Dan, they came over
in the middle of the night.

Letting child play with sick child
Accepted Shallon’s illness. Let the kids play
together, let her sleep at her house even on chemo.
They made me feel I had a normal child.

Friends: Not Helpful

Intrusiveness of acquaintances: tactless, offered advice
One lady kept trying to have serious discussions with
me. She wasn’t close, just an acquaintance. I didn’t
have the time or the desire.

Lack of emotional support: pulled away, didn’t keep
promises
One friend, I thought she was my best friend, abruptly
stopped calling. She was like a sister to me and it
was really hard.

Keeping child away from sick child
Thought kids would catch it or she’d die anyway so
didn’t let her play with her kids.

Too much pity
Too much sympathy and pity.

Specific incident
Not taking child to hospital after an accident.
Medical Staff: Helpful

Emotional support: compassion, listening, calling
They were there at night to talk to them. I felt better afterward because staying there made me feel depressed.

Medical support
Dr.'s helped with managing the illness. I'd call them to get her counts, etc.

Extraordinary assistance
One orthopedic surgeon picked up our medical bills and helped us to get a tutor too - he was really supportive.

Medical Staff: Not Helpful

Medical mistakes
Some nurses were negligent, they were so busy. They knocked him out once with thorazine. Another time they forgot to clamp his brovic.

Lack of emotional support: not available, don't understand
We don't get the attention we really need. Our phone calls are not returned - they're not checking for a transplant.

Hospital routines: rotating staff, personality conflicts
Medical students doing exams made me very nervous.

Sick child: Helpful

Child's strength and positive attitude
He was one thing that kept me going, he was so courageous and strong. I couldn't have done it without him. He never complained or was angry. Never was miserable with his life.

Sick Child: Not Helpful

Behavior on drugs
His behavior while on prednisone - terrible mood swings.

Complying with treatment
Had a hard time with him complying with his treatment.

Other Children: Helpful

Material assistance: chores, errands, raise each other
Helped with dinner while Walter was getting his treatment. The dishes were done and they took care of each other.
Emotional support: caring, understanding
   The kids instinctively were good. They hugged and kissed Heather, asked questions and talked a lot.

Flexible adjustment to family changes
   They were great. Went to clinic and were good about being watched by other people.

Other Children: Not Helpful

Jealousy/resentment
   She was not helpful. She was jealous of Jenna and did not have much sympathy for her except when she was sick.

Not visiting sib in hospital
   Didn’t like to go to the hospital, only came 1-2 times.
CHILDREN’S CAMP RESPONSES

How children felt being at camp

Sense of belonging
Like I’m not the only one in the world that has a problem. You don’t find too many kids that have had cancer. No one else can relate to me except adults who had cancer or know people that had cancer.

Happy/Good
Good, because it just made me feel good; happy

Normal
Fine; all right; I don’t know, ok I guess.

Bad/Sad
I felt bad too. Everyone using their two hands except me and Matt.

Depressing at times cause you see new sick kids and don’t know whether you’ll see them again or not.

Special/Loved
The best. Made me feel kind of special and feel special and just like a regular kid.

I think camp is so important because for 1 week you feel totally special. I think that is one of the things that is so important. The first year I was just done with cancer and done fighting it. I was so fed up with everything - not too "positive" about myself, self-esteem, my relationships. After just one week thinking "ok - somebody thinks I’m special is so important especially if you’re just getting started with life again. I think it’s great for everybody.

Strange
I felt kind of strange - not used to it. I didn’t have all the cancer problems so it was kind of different.

Children’s views of the purpose of camp

Being with others experiencing the same thing:
So we all have a place to go where people don’t discriminate, where we don’t have to explain ourselves and can be ourselves. We don’t have to be what they want us to be.
To have a vacation and a good time
Because a lot of the kids don’t see much happiness through the time they go through cancer. You’re free of meds, free of being sick. It’s a great place - a lot of fun - it makes kids happy.

Not able to go to other camps:
Because maybe a normal camp wouldn’t accept them.
Wouldn’t want the responsibility of taking care of them if they had cancer or leukemia.

Take mind off illness/to look forward to:
To take their minds off of their cancer.

Talk and share feelings:
So they can get together and talk about what they had - share the same feelings.

Raise money:
For money to help people.

Give parents a break:
Lets parents have a vacation.

Children’s views of what they receive from camp

New friends:
To be in a group with my friends - my other friends.

Fun:
A whole week of fun. I just want to go back because it’s so much fun.

Positive feelings:
Some hope from the camp - lets you let go of everything. Enthusiasm and spirit to get better.

Love & caring:
Lots of love from everyone; caring.

Material things:
Shirts & hats; lots of presents.

Understanding of other’s experiences:
Get an understanding of what others are going through since I didn’t know what I went through.

Special experience:
I don’t feel like I get anything. It isn’t anything given. It’s an experience that is shared - one of those things you can’t explain. You have to experience it for
yourself. You just get camp.

Learn things:
Learn stuff like arts and crafts. I’m not very good in art in school. Now I’m good at art.

Time away from family:
Vacation away from home.

Children’s views of what they contribute to camp

Friendship:
I’m a friend - someone to talk to.

Understanding/Role model:
Help. Well most of the kids are just starting or still on meds. I’m all finished so I talk to them about it. I help other kids to have fun.

Sense of humor/fun:
A good time - some laughs.

Happiness/niceness:
Make kids feel happy and proud.

Love:
Love definitely. You don’t have to know them.

Myself:
Myself - encompasses it all.

Talents/abilities:
Dancing lessons.

Nothing
I don’t know - nothing.

Children’s favorite parts of camp

Sports:
Fishing; doing things like archery and playing ball.

Special Events:
Special activities like the renaissance fair and food booths.

People:
Counselors and how they can understand with the kids and where they are coming from. They’re good. Don’t treat kids like kids - respect them. Counselors notice and respect you for things that you do. Treat you like
humans and not like a kid who is sick. It’s neat the way they treat us.

Waterballoon Fights/Raids:
I like the waterballoon and shaving cream fights and midnight wanderings.

Arts & Crafts:
I like the arts and crafts. I love art.

Positive Atmosphere/attitudes:
The relaxed attitude of everyone and the atmosphere. I feel like I know everyone and can talk to them. It’s hard to explain - like you’re in a totally different world, completely different.

Dances/Music:
When we went to the dances.

Freedom/Lack of Rules:
That there aren’t really any rules. You just have to be conservative at times. I like the flexible changing of rules for each situation.

Camp Grounds/Facilities:
The camp grounds and the way they keep them up; the lake.

Being Away From Home/Hospital:
You get away from your parents. It doesn’t mean that you don’t like them. When you live with someone for a long time sometimes you have to get away from them. Little things do annoy you and get on your nerves. It’s much better after a separation.

Food:
The food at the cookouts.

What children would add to camp

Different Sports:
Waterskiing; golfing; sailing.

Animals:
Bring rabbit to camp; a petting zoo.

Special Events/Programs:
Hot air balloons that really go up.

Special Things:
Golfcarts; video arcade & electric air hockey.
Better Food:
  Change the food!

Physical Aspects of Campsite:
  Add fireplaces to cabins.

More Free Time:
  Have more free time.

More People:
  More guys my age.

Longer Week:
  Make camp longer.

Camp Year Book:
  Memory book for all kids.

Allow night raids:
  More raids at night.

What children would change about camp

Length:
  Make it longer. Make it a whole month.

Food:
  The food. I didn’t like it - it wasn’t like home.

Programs/Activities:
  Need to have more things to do when it rains.

Wake-Up/Bed Time:
  Getting up at 8:00 and having to eat breakfast. Let them skip breakfast if don’t want to.

Physical Aspects of Campsite:
  New cabins with bathrooms, beds, and showers.

Personnel:
  Change the camp director.

What at camp was hard for children to get used to

New People/Sick Children:
  Getting used to seeing a whole bunch of kids who were like me. When I was really little I used to think I was the only one in the world with cancer.

Leaving Home & Family:
  Missing my dog and mom and dad.
Physical Aspects of Camp:
The showers and problems with the showers. They were gross and hard to get into without slipping.

Emotional Openness:
It was tough the first year. I was homesick by Wed. It was a hard period. It was hard to open up when I was just done with chemo. I had no leg, no hair. I was leaving myself vulnerable. It was hard to put myself in the position to be there and do these things.

Wake-Up/Bed Time:
Breakfast - to get up at that time when I’m out doing mischievous things late.

Activities:
How to go about swimming on treatment.

Personnel:
The camp director.

What made children feel bad or sad at camp

Leaving Camp:
When you have to say goodbye. I feel worstest when I gotta leave. I hate leaving camp.

Seeing Sick Children:
I felt sorry for the kids that had to go through more than me. I went through the least.

Hard to see other kids on meds and having disabilities like not swimming or doing activities when I was feeling better.

Memorial/Closing Services:
Well, sad cause when I went to the memorial service at the chapel it was pretty sad. The candlelight service is pretty sad, yet all good too.

Children Dying:
When people die it makes me feel sad.

Scary stories told at night:
Some of the time they tell stories I’m ashamed to hear about - scary stories.
Children’s views of unrealistic rules at camp

Sports/Team Rules:
When I had to get out of the water when they blew the whistle during swimming.

Wake-Up/Bed Time:
The 7:00 wake-up time.

Not Allowing Night Raids:
They don’t let you raid another person’s cabin. That is totally unrealistic. There’s a time and a place for raiding and that’s at camp.

Things aren’t allowed to do:
Kids should be able to be let free with water balloons. It helps with loosening up and smiling. It makes people smile in their everyday lives. To get them smiling is kind of a job. It made things funnier and kids forgot about what they had.

No Rules – Broke Them All:
What rules? We broke them all.
PARENTS’ CAMP RESPONSES

Parents’ views of purpose of camp

Be with others with same experiences:
So kids won’t feel different—real, like any other kids with the same needs and love. They can be bald, one handed, one legged and can not be different.

For kids to see they are not singled out or being punished or in pain. A chance to be with kids with the same or related problems. They can’t focus on their illness so they have to move on to another level.

Escape from treatment:
So that these kids can forget for a little bit of time all of the hell they’re going through.

Give kids an escape. To get away from the routine of the hospital/medicine. Being free from all of that stuff and feel like they felt before they were sick.

Provide a normal/camp experience:
To provide a place for kids to feel normal.

Break for family/independence for child:
Great for parents—more one on one time with your other children.
Kids in treatment—you open so much time day and night with them. It can be a sick relationship. Your child needs a sense of being free and independent.

Provides medical protection:
For a lot don’t get a chance to go to a regular camp, with the special problems with meds. Here they understand their problems.

Sharing problems and feelings:
Have them so kids can get together and discuss their problems, share with each other and know that they’re not alone.

Make new friends:
To relate to other people, the counselors and campers.

Positive atmosphere:
To get kids going, bring up their spirit.
Parents' views of what child receives from camp

New friends/friends with cancer:
Her friends couldn't deal. Life went on without her. Life was treatment, sickness, hospital. She made friends with kids who could understand her. No one else could.

Change in self-esteem/interactional style:
More outgoing after camp - better with people after having an opportunity to be at camp. Chance to be in charge, he got a sense of being at the center of things.

Learns about coping from others:
I think she really benefits. I think she sees the other kids who are really sick and how they cope with life. I think she really appreciates how well she really is.

Break from illness routine/fun:
A sense of fun - a good outlet to be more carefree. There are few places he could go and not have them make a big deal about his scars, his hair, his hickman.

Something to look forward to:
Shows her the good part of having cancer cause it's special, something to look forward to you.

Friendships with counselors:
He developed a close relationship with one of the counselors. He came and visited, took my son skiing and provided him opportunities to broaden his horizons, opportunities to enjoy life.

Sharing and caring:
I have the feeling in privacy he talks to other kids. This is very important for him since he doesn't talk to us. The giving that goes on at camp is great.

Parents' view of child's contribution to camp

Compassion and comfort:
Compassion. If a kid is feeling sick she'll take care of them. She's real sincere with her honesty and mellowness.

Positive attitude/enthusiasm:
Enthusiasm & courage; she gives a lot of spirit - very outgoing, like a ball of fire or a ray of sunshine.
Self as gift:
They give themselves as a gift, they have a lot to offer.

Charisma/outgoing personality:
Always had a kind of charisma about him – don’t know what
that gives – draws people to him. People enjoy his
personality and the sweetness about him – his easy going
fun.

Inspiration/role model:
It’s good for someone like Robin whose in remission to
go to camp. It gives other kids hope for the future.

Fun/joy:
Always a nappy go lucky kid, a fun person.

Talents and abilities:
His dancing; her ideas – she’s very imaginative.

Challenge/hard time:
A run for their money.

Sense of humor:
He’s a clown at camp, gives laughter.
Comical – made people laugh. A bubbly type of person
who helps people to not be sad.

Friendship:
Friendship to other kids.

Parents’ favorite parts of camp

Break for family:
A good break for us and him.
He’s gone for a week. I don’t have to worry or take him
anywhere. He’s in a safe place, having fun and I don’t
have to be the big bad parent; I don’t have to entertain.

Fun for child:
I thought it was all great from what I heard. A week
filled with fun from start to finish.

Counselors’ dedication:
I thought it was great to see the love the counselors
have for the kids – so patient. A great bunch of people
with the kids. Great for kids to see adults can let
their hair down.

Caring and sharing:
I’m impressed with the emotions shared. It’s only one
week yet they're so busy with each other and the things going on, real comraderie.

The close personal contact, how they run and hug one another - the loving atmosphere.

**New friends and experiences:**
Meet new people, had new experiences which allow her to grow outside the family unit.

**Activities and programs:**
The opportunities Robin had to do things. She learned things like boating, swimming, and horseback riding.

**Respect child learns for people's differences:**
Learn more respect for people who are different. Treated as an individual regardless of differences.

**Learning to let child try new things:**
It helped me. I was more relaxed. I was afraid of leaving her because I didn't want to see her grow up.

**Gifts child receives:**
Send something at Christmas like the teddy bears or videotapes.

**What parents would add to camp**

**Longer session:**
Make it longer, an extra week or a couple times a year.

**Different activities:**
Powerboats for waterskiing; horseback riding.

**Overnight camping in the woods:**
Some sort of outward bound in the forest.

**Better food:**
Change the food.

**Peer counseling:**
A type of counseling, maybe best from other kids.

**Parent support group:**
Would have been nice to form a support group through the campers parents.

**Allow parents to go:**
I (mom) would like to go and be able to do something at camp that week.
What parents would change about camp

Length:
Make it longer.

Fact that parents can’t attend:
Letting parents go. My husband wants to be a counselor.

Some of the rules:
The schedule is a bit rigid at camp. There’s not enough
time between activities, it seemed rushed or pressured.

Food:
Change the food.

Camp celebrity guests:
Better celebrities to visit camp.

Address more psychological aspects:
I think camp should tell the parents about the illnesses
and kids who die. Richie got very depressed when a
counselor from camp died, it really hurt him. The kids
know why others don’t come back. They need to let kids
know who did die, its reality and they need to know.
They should be honest with them.

They’re sophisticated about illness knowledge yet don’t
know enough to deal with concerns that come up at camp.
How to move on and incorporate uncertainty ("Am I a
person with cancer? Will I ever have it again?").

Add more psychological components for the older kids.
Get the older kids, 16-17 year olds, to form it
themselves. Listen to their ideas, see what they want.
And work with the leadership - how to take what they
learned about life and adapt.

Place hold camp:
Have it at a more rustic campsite.

What at camp was hard for parents to get used to

Letting child go:
Letting him go cause I knew he was sick. I was more
protective of him, I almost lost him.

Being away from child for a week:
Getting used to being away from him for a week.
Child’s worries about camp:
I was kind of worried about it because he was worried.

Having free time:
It was hard to get used to having a day off, since cancer is such an all consuming thing. I didn’t have to do anything.

Seeing children die:
Seeing kids dying and dealing with kids dying and helping them to handle it.

What at camp made parents feel bad

Seeing sick children:
Seeing other kids that are going through the treatment. I see the pain deep down inside through their eyes even though they try to cover up. I feel guilty - she’s healthy and running around. I wish they’d have the same miracle happen to them.

When you see some of the kids with missing limbs, hair, or see their broviacs. I hate to see it. I try to act as normal as possible but I don’t feel normal.

I cry every time I go there from seeing what those kids go through. I feel happy/sad. At the slides and award presentation I cry. I can’t deal with the fact children have to be sick. It’s tough enough for adults. But kids shouldn’t have to deal with it although they handle it well.

Children dying:
Kids leave at the end of the week and you find out some of them won’t come back. As a parent, that is the hardest thing.

You realize that some of the kids won’t be back the next year because they’re doing bad with their cancer. It was hard for Lizzy to have Shannon die. It makes me cry. Life is really tough for some of these kids.

Making child leave at end of week:
Picking him up the last day is a heartbreak. I hate to leave, knowing they won’t see each other till next year.

Fact have to go to a cancer camp:
I guess the part of you that wishes your kid went to normal camp. You don’t want to be part of a club of illness and cancer. It’s very real.
Fears the camp would be (−) for child:
I was scared about all these kids with cancer getting
together and being sick kids together. Like if Shallon
was in a bad mood others might be too.

Parents’ views of unrealistic views of camp

Not allowing child to call home:
Said younger kids could call home yet didn’t let them.

Allowing children out of cabins at night:
Letting kids out of cabins at night.

Activities schedule:
The schedule of getting up early and things being
regimented and planned out. Be a little more lax.