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FAMILY ADAPTATION TO CHRONIC CHILDHOOD ILLNESS

By

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ABSTRACT

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The process of family adaptation to chronic childhood illness was investigated after the diagnostic period. Participants were 28 families of school age children with asthma, congenital heart disease, cystic fibrosis, or insulin dependent diabetes mellitus and 17 matched comparison families with healthy children. Using an adaptation of the FAAR Model to conceptualize demands, resources, perception of demands, coping, and family functioning, data was collected from the parents, target children, and siblings. Families with chronically ill children reported a greater number of positive life events, total life events, and uplifts, with negative life events approaching significance. Demands were perceived by the chronic illness group as being more intense. The families with chronically ill children reported a greater number and broader range of coping responses than the comparison families and scored significantly higher on family cohesion and religious emphasis. The conceptual model predicted a significant amount of the variance in perception of demands, coping, and the nine dimensions of family functioning. Of particular interest was the stronger predictive value of uplifts intensity for coping and adaptive dimensions of family functioning relative to the intensity of life events and hassles. These findings suggest that families with chronically ill children have strengths in coping skills and family functioning that facilitate their adaptation to the high number and

intensity of demands they face. Uplifts, which are infrequently studied, appear to play an important role in this process. Greater knowledge of effective family adaptation to chronic childhood illness would contribute to the identification of precursors of maladaptation and preventive intervention strategies.

THIS DISSERTATION IS DEDICATED TO
MARSHA F. WORBY
WHO GAVE ME THE COURAGE TO PURSUE MY DOCTORATE
AND
THE STRENGTH TO PERSEVERE

AND
CYRIL M. WORBY
WHO WILL ALWAYS BE AN INSPIRATION
TO MY COMMITMENT TO
FAMILIES AND CHRONICALLY ILL CHILDREN

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INTRODUCTION

Biomedical advances in recent decades have extended the lifespan and decreased the mortality of chronically ill children. Although actual data are not available, estimates indicate that 10%-20% of the children in the United States have a chronic illness (Gortmaker & Sappenfield, 1984; Harkey, 1983; Hobbs, Perrin, Ireys, Moynihan, and Shayne, 1984; Perrin & MacLean, 1988). Moreover, the incidence of chronic illness in childhood appears to be increasing (Newacheck, Budetti, & Halfon, 1986; Pless & Perrin, 1985). Of this group approximately 1,000,000 children (1%-2% of the child population) have severe physical involvement. Another 9,000,000 children have less severe involvement (Harkey, 1983; Hobbs et al., 1984; Perrin & MacLean, 1988). Using two parents and one sibling as an average one could estimate that 3,000,000 family members or more are living and dealing daily with severe chronic childhood illness and another 27,000,000 are dealing with children who have mild to moderate limitations. The effects of chronic illness on the family include: the need for daily care; the high cost of treatment; the often unpredictable future course of the illness; and potential disruption of family life, family development, and the development of individual family members.

Chronically ill children and their families merit public attention for several reasons (Pless & Perrin, 1985). They are the recipients of a sizeable public investment of total dollars and professional time for

child health care and medical services. Chronically ill children constitute 50% of pediatric practice (Magrab & Calcagno, 1978). These children and their families present special needs that are not likely to be met through any existing or proposed programs for general child health care. Technological and health care advances have resulted in prolongation of life in children who would have died in years past. Currently about 80% of children with severe long term illness survive to young adulthood (Perrin & MacLean, 1988). As the number of these survivors increases it might be found that they have a relatively greater frequency of physical and developmental handicaps.

Common Characteristics of Chronic Childhood Illness

Common characteristics of chronic childhood illness include: long duration, need for specialized health care services, on-going management in the home and health care settings, frequently shortened life expectancy, and no known cure or uncertain prognosis (Stein, 1983). For research and service purposes a strong case can be made for viewing all chronic conditions as one group having many problems in common regardless of their individual characteristics (Pless & Perrin, 1985). Utilizing the combined data from an institutional sample (N=134) and a national probability sample (N=329) of chronically ill children, Stein and Jessop (1989) found greater variability within diagnostic groups than between diagnostic groups on multiple psychological, social and developmental measures. Needs and problems cannot be predicted from the type and/or severity of the disability alone. From a psychosocial perspective, chronicity itself is thought to have a powerful effect on child development and family functioning. The empirical literature supports the belief that the presence of a disorder which makes the

child 'different' from peers and persists for a significant period of time creates a potential risk for normal psychosocial development. Studies of self-reports of chronically ill children and their parents indicate that there are a limited number of difficulties experienced frequently by many if not most families that have a child with a chronic disorder. These difficulties vary little from disorder to disorder and from family to family. The nature of the family rather than the nature of the disorder is likely to determine the frequency with which certain problems are experienced. Early research linked specific personality profiles with specific illnesses in a cause-effect paradigm. Recent research suggests that where there are apparent patterns of psychosocial maladaptation, factors related to the family and the social circumstances of the child are the important determinants of who has problems and who does not. There is little evidence that the type of difficulties experienced by the child or family is related to the specific medical condition. The impact of chronic childhood illness on a family is extremely variable but the types of family problems documented are similar across conditions (Pless & Perrin, 1985; Stein & Jessop, 1982). It has been documented consistently that the psychosocial impact of chronic illness on the child and family is determined largely by factors not intrinsic to any particular diagnostic category. Determinants of ultimate function are to a large degree demographic, psychosocial, and developmental and include such factors as age, developmental level, family characteristics, personality characteristics, and community resources (Korsch, 1985).

Statement of the Problem

The purpose of this study was to examine adaptation of families with chronically ill children after the initial diagnostic period. Adaptation as reflected in the quality of family functioning was examined in the context of a conceptual model of family adaptation (Figure 1, page 76). The adaptation process is viewed as a process that families are continuously involved in as they develop across time. The quality of family functioning is influenced by the demands, resources, perception of the demands, and coping skills of the family. In this study family functioning and the influencing factors will be examined in families with chronically ill children and comparison families with healthy children. Asthma, congenital heart disease, cystic fibrosis, and diabetes mellitus were selected as representative chronic childhood illnesses based on their frequency. These are also frequently researched diagnoses which will facilitate comparison of the findings of this study with previous research. The focus of this study will be the overall functioning of the family rather than the outcome of coping with a specific event or crisis such as diagnosis or death. The majority of the research on chronic childhood illness has focused on individual family members, usually the chronically ill child or the child's mother, psychopathology/maladaptation, and the time periods surrounding diagnosis and death. There have been a limited number of studies of families with chronically ill children. Typically the data from these studies have been collected from one family member, usually the mother. Studies of individual family members indicate that mothers, fathers, siblings, and the chronically ill child respond differentially to the illness and its related effects. Consequently it would seem that each

family member contributes to the family unit's experience. This study will use data from parents, target children, and siblings to investigate family adaptation to chronic childhood illness after the diagnostic period and prior to the terminal phase of illness (in illnesses where that may occur).

CHAPTER 1 REVIEW OF LITERATURE

Family adaptation is an on-going process that involves not only the inter-related family members but also factors internal and external to the family. It is not static nor is it a simple cause-effect phenomenon. A conceptual model provides a theoretical and organizational framework for the examination of family adaptation. The conceptual model for this study will be described in detail later. It involves five constructs: demands on the family, family resources, the family's perception of the demands, family coping responses, and styles of family functioning. This model will be used to examine the demands faced by families with chronically ill children and how these families perceive or define the demands in terms of intensity. Family resources allows for the exploration of family and individual characteristics that may influence the family's coping responses and style of family functioning. Family coping responses and styles of family functioning provide a means of exploring the relationship of these two parameters with each other as well as how these constructs are influenced by the demands, perception of demands, and resources of the family.

The review of literature will begin with a description of the conceptual model. This will be followed by examination of the chronic childhood illness literature related to each of the five model constructs. Within those five sections the research will be examined according to the focus of the study beginning with research related to the total family followed by studies focusing on the mother, father, chronically ill child, and siblings respectively when available.

CONCEPTUAL MODEL

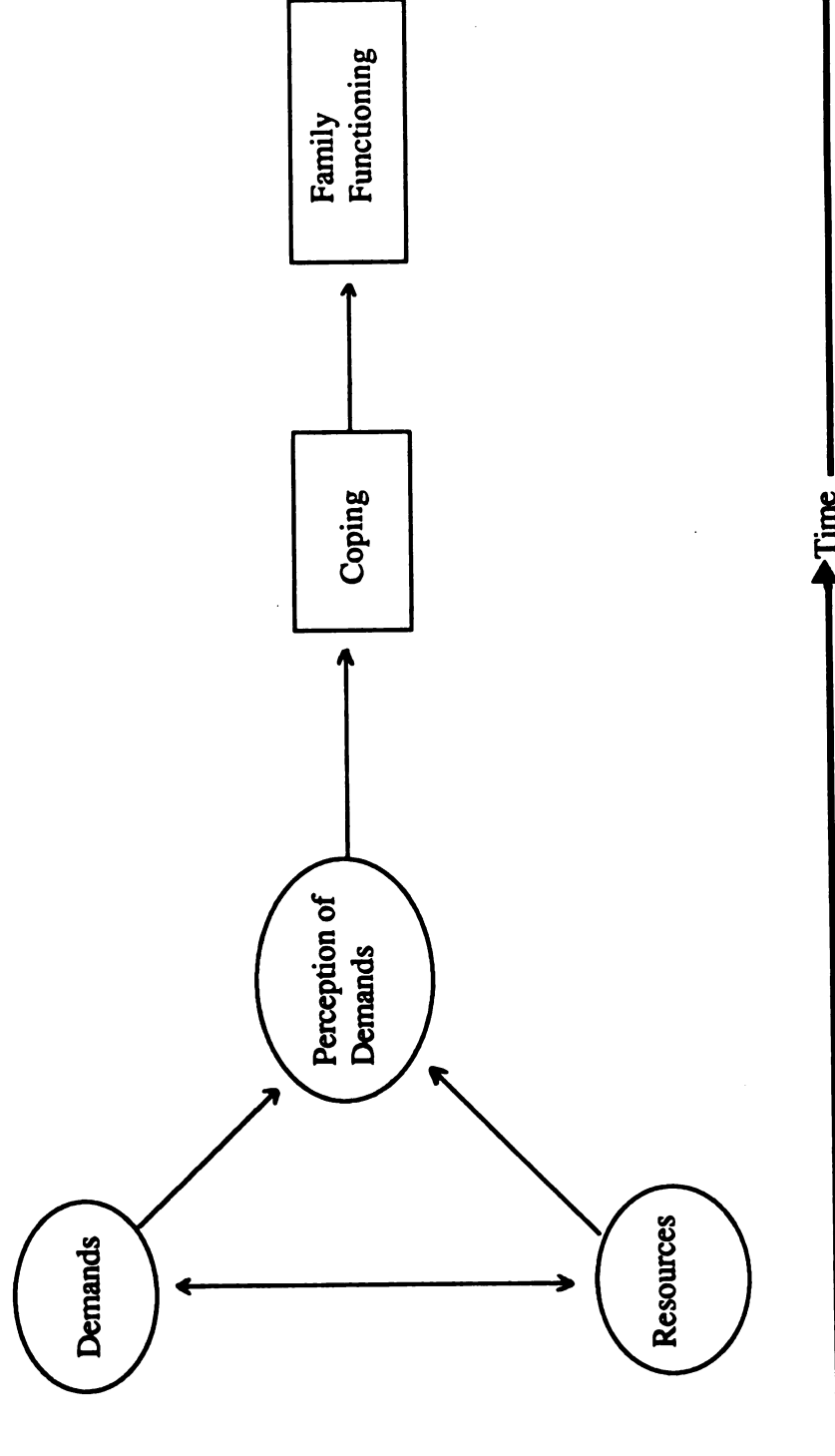
The conceptual model of family adaptation for this study (Figure 1) was based on the model developed by McCubbin and his colleagues (Patterson & McCubbin, 1983a; McCubbin & Patterson, 1983b; McCubbin & Thompson, 1987) from Hill's (1958) classic work on family vulnerability to crisis. The model includes the interaction of demands and resources leading to the family's perception of the demands. The family as a unit and the individual family members respond cognitively and behaviorally to their perception of the demands in order to restore stability. These coping responses lead to varying degrees of change in family functioning. In the McCubbin model (McCubbin & Patterson, 1983b, McCubbin & Thompson, 1987) when the family is able to restore stability without changing the structure of its patterns of interaction it is considered adjustment. When changes in patterns of interaction and/or structure are needed to restore stability it is considered adaptation. Chronic childhood illness requires adaptation on the part of the family.

Demands

Each of the components in the model (Figure 1) directly or indirectly influences the family's functioning. The overall model conceptualizes family adaptation. Demands are stressors that place pressure on the family to restore stability. They include the initial stressor (chronic illness), hardships from the initial stressor which have persisted or increased over time, prior strains, additional life changes and events including normative transitions, and stresses that have emerged from specific coping behaviors used by the family (McCubbin & Patterson, 1983b; McCubbin & Thompson, 1987). In families with a chronically ill child, hardships from the initial stressor are often

Figure 1

Family Adaptation



increased by the financial, temporal, and emotional demands on the family, and exacerbation of the illness. Marital dysfunction or conflicts with extended family members are stressors that may precede the illness. Coping behaviors such as taking a second job and moving closer to medical care can also result in demands on the family. The degree of pressure resulting from the demands will be influenced by the family's resources.

Resources

Resources are the capabilities of individual family members, the family system, and the community for meeting the demands. These capabilities include psychological, social, and interpersonal characteristics as well as material resources. Perceived self competence, locus of control, cognitive capacity, and psychological well-being of family members are individual characteristics that can serve as resources for the family. Within the family system, the quality of relationships, communication, and organization can be valuable resources. Material resources such as time and money also influence the family's capability to meet demands. Instrumental and psychological support from neighbors and agencies within the community are further resources for a family.

Perception of Demands

Perception of demands is the family's subjective definition or perception of the total situation. It will be influenced by the actual demands and the family's resources. The perception of the demands will change as a family copes with and adapts to on-going and new experiences.

Coping

In this model coping is defined as the cognitive and/or behavioral responses of the family unit and individual family members. The coping responses are made in an effort to eliminate and/or avoid the stressors and strains, to manage the hardships of the situation, and to acquire and develop social, psychological, and material resources to meet the demands. Efforts to avoid or eliminate the stressors are often an initial response. However, avoidance/elimination is ineffective with many stressors such as family conflict or developmental transitions. Families may then attempt to utilize their current resources to manage the demands. The most challenging of the coping responses is the development of new or strengthened social, psychological, and material resources. Not all families have the capacity for all three types of coping responses. Different types of coping responses will have different effects on family functioning.

Adaptation and Family Functioning

Adaptation is a continuous process in which demands, resources, and the perception of demands interact, leading to the family's coping responses which influence the characteristics of family functioning. At a given point in time family adaptation is reflected in the characteristics of family functioning in areas such as family cohesion and organization, sense of control over environmental influences, and the promotion of individual and family development. Demands and resources interact leading to the family's perception of demands and the family's coping responses which influence the level of family adaptation through family functioning.

REVIEW OF LITERATURE

Demands

Demands consist of: a) the initial stressor (chronic illness) and its hardships that have increased or persisted over time; b) prior strains; c) additional life changes; and d) the stresses that have emerged from specific coping behaviors used by the family (McCubbin, McCubbin, Patterson, Cauble, & Wilson, 1983a). The diagnosis of a long term and sometimes life-threatening illness is a threat to the child's well-being as well as to the parents' hopes, competence, and security (Lavigne & Burns, 1981). In families of children with cystic fibrosis, strained family relationships were reflected in a number of ways (McCubbin, et al., 1983a). Overprotection of the ill child led to strained family relationships and jeopardized the ill child's development. In addition to overprotection, scapegoating, and blaming, overt or covert rejection of the ill child was also found. In some families coalitions developed between the primary caregiver and the ill child resulting in other family members feeling left out. The parents reported guilt and anger about genetic responsibility and experienced worry or resentment regarding possible extended caregiving responsibilities. Comparison of the ill child with siblings and discrepancies regarding uneven physical, social, and intellectual development added further to the family strain. Strained family relationships were also reflected in sibling competition for parent time and attention as well as an overall increase in intrafamily tension and conflict.

Hardships may be created by modifications in the family activities and goals that result from reduced flexibility in the use of leisure

time and vacation, decreased career opportunities for both parents, and worry and uncertainty about having more children. Hardships reported by families of children with cystic fibrosis included: increased tasks, time commitment, financial needs, limitations in parental occupation, and alteration in the home environment to accommodate special equipment when needed. These hardships resulted in further demands on the family (McCubbin, et al., 1983a, Meyerowitz & Kaplan, 1967). The families in the study by Meyerowitz and Kaplan (1967) reported that the mothers were not able to work outside of the home due to the complicated routines and difficulty finding adequate child care. The fathers were often unable to take advantage of occupational opportunities due to limited family mobility. The families in the study by McCubbin (1983a) reported experiencing social isolation due to friends' and/or relatives' reactions to and expectations of the chronically ill child, family embarrassment, limited mobility of the ill child, unavailability of adequate child care, and fear of accidents or exposure to infection. Social isolation may result in further modification of the families' activities and goals. Families of children with congenital heart disease reported similar demands. These families described upset family balance, modification of social life, extra expense, and somatic and behavior problems in siblings (Apley, Barbour, Westmacott, 1967). Residual family tension is created by unresolved prior stressors or intrinsic strains in the on-going roles of family members. These strains are often exacerbated by stress and tend to be insidious, often making the onset and resolution unclear to the family (McCubbin & Patterson, 1983b). Prior marital problems were found to be exacerbated by the diagnosis of a chronic childhood illness. Closed communication

in families of chronically ill children led to increased family stress and resentment (Kaplan, Grobstein, & Smith, 1976). The pile-up of demands particularly in areas of intrafamily development and relationships, family management and decisions, and family finances can effect the health of the chronically ill child and the family (Patterson and McCubbin, 1983b).

Frydman (1981) found a direct effect for life stress on the psychological symptomatology in families of chronically ill children. This finding is supported by Bedell and his colleagues (Bedell, Giordani, Amour, Tavormina, & Boll, 1977) who found that chronically ill children with low life stress scores had significantly higher self-concept scores and rated themselves as better behaved, more intelligent, more physically attractive, socially popular, happier, and satisfied with themselves than the high life stress group. The life stress scores in the low stress group were comparable to the average for healthy children while the scores for the high stress group were significantly higher. A significant relationship also has been reported between family life stress scores and the physical health of children with cystic fibrosis (VanOs, Clark, Turner, & Herbst, 1985).

Demands on the family are further added to by the consequences of the family's efforts to cope, ambiguity about roles and structure, and social ambiguity when social guidelines for coping are not clear. Parents reported increased demands related to their efforts to cope with medical concerns such as obtaining competent care; understanding, clarification, and verification of medical information; ability to follow-up with prescribed home treatment; the child's compliance; helping the child endure or minimizing the child's pain; and worry and

uncertainty about the prognosis (McCubbin et al., 1983a). Unfulfilled parental expectations of the health care system may also contribute to the pile-up of demands. When presented with ten psychosocial issues 76% of parents with chronically ill children expected these issues to be discussed in physician interaction. Eight of the ten issues were discussed in less than 50% of the interactions. Six of the ten issues were discussed in less than 20% of the interactions. Unfulfilled expectations were associated with lower satisfaction with medical care (Lau, Williams, Williams, Ware, & Brook, 1982). These psychosocial issues would then need to be addressed either within the family or through other social groups in the community.

Summary

All families are faced with demands that have an impact on the family unit and the individual family members. The research related to demands in families with chronically ill children has primarily been descriptive and without comparison groups. The care of a chronically ill child was consistently found to place additional demands on the physical and emotional energy of the family as well as their temporal and material resources. Families of chronically ill children reported complex caregiving responsibilities, difficulty finding child care, and limited family mobility. The limited family mobility resulted in decreased career opportunities, alterations in the family's leisure and recreational activities and in some families social isolation. The families reported that negative attitudes of extended family and friends contributed further to the experience of social isolation.

Generic demands such as intrafamilial and extrafamilial conflict, normative transitions, and the consequences of specific coping efforts

add to the demands on all families. Families with chronically ill children faced both generic demands and demands resulting from the management of the their child's illness. Intrafamilial tension and conflict was increased in families where overprotection of the ill child, scapegoating, and the formation of family coalitions were found. Familial tension was also contributed to by medical concerns such as acquiring knowledge of the illness and its treatment, obtaining adequate medical care, and unfulfilled expectations of the health care system.

Resources

Resources refer to the family's ability to meet the demands and needs of the family unit and its individual members. Resources include psychological, social, material, and interpersonal characteristics of the individual members, the family system, and the community. Family system resources include cohesion, adaptability, open communication, conflict resolution skills, and open expression of affect (McCubbin & Patterson, 1983b). Resources of individual family members include self-esteem, effective communication, mutual assistance and support, problem-solving ability, physical and emotional health, and sense of mastery over events. Because resources include characteristics of individual family members this has been the most widely studied component of the model. This section of the literature review will address family resources followed by resources of the mother, father, chronically ill child, and siblings respectively.

Family Resources

Resources can decrease family conflict, aid in the prevention of crisis, and facilitate family adaptation. Psychosocial characteristics of the family may serve as resources. In one study family cohesion and

expressiveness was positively related to the social competence of chronically ill and handicapped children while child adjustment as measured by behavior problems was positively related to family conflict and negatively related to family cohesion and organization (Wallander, Varni, Babani, Banes, Wilcox, 1989). A study of communication style found that families of hemophiliacs who used open communication prior to the diagnosis of a child's chronic illness tended to use and retain clear, open, and functional communication during adaptation to the chronic illness. In contrast blurred and closed communication tended to be exacerbated when a child was diagnosed with a chronic illness. The families with closed communication tended to form internal alliances and displace conflict inside of the family resulting in impoverishment of their social, affective, and intellectual lives. Initial dysfunctional communication was associated with severe conflicts and major opposition (Kaplan, Grobstein, & Smith, 1976; Pacquay-Weinstock, Appelboom-Fondu, & Dopchie, 1979). Residual family tension, created by unresolved prior stressors or intrinsic strains in the on-going family roles is often exacerbated by stress and tends to be insidious making the onset and resolution unclear to the family (McCubbin & Patterson, 1983b).

A common misperception is that there is a higher rate of divorce in families with chronically ill children. Research supports a higher rate of marital distress but not a higher divorce rate in these families (Kaplan et al., 1976; Lansky, Cairns, Hassanein, Wehr, & Lowman, 1978; Maddison & Raphael, 1971; Sabbeth & Leventhal, 1984; Salk, Hilgartner, & Granich, 1972; Silbert, Newburger, & Fyler, 1982). No significant difference in divorce rates was found between families with cardiac children, control families, and the national divorce rate. The divorce

rate in both groups was related to younger maternal age and lower SES (Silbert, et al, 1982). Marital and family conflict may result from parental overcommitment and overcaring for the ill child (Maddison & Raphael, 1971). Marital distress has also been found to be related to diagnosis and severity of illness but not the prolonged survival or death of the child (Steinhausen, Schindler, & Stephan, 1983a). Despite the marital distress reported in many studies, fifteen of sixteen couples with hemophiliac sons reported that having a chronically ill child brought them closer together or did not change their marital relationships (Markova, MacDonald, & Forbes, 1980). Even in the presence of marital distress having two parents in the home may serve as a resource for the families of chronically ill children.

Social support has been investigated as a resource in family adaptation. One study of social support in families with chronically ill children found that crisis support, neighborhood interaction, and coping style correlated significantly with anxiety and psychiatric symptoms in the parents. In general, support mediated the incidence of psychiatric symptoms in the presence of high life stress but had little effect with low life stress (Frydman, 1981). In another study mothers who perceived more social support were found to provide more stimulation for their infants who had been in the NICU (Pascoe & Earp, 1984). The age of the parents and child may influence social support. One study found that although younger parents of leukemics were more able to call on relatives for assistance, when the child was younger there was a greater decrease in social activity (Meyerowitz & Kaplan, 1967).

In families of diabetic children the capacity of family members to enjoy each other, family stability, intact generational boundaries, home

adjustment, IQ, and SES were associated with good diabetic control, increased self-esteem and independence. Poor diabetic control was associated with adverse family psychosocial factors such as low parental self-esteem, indifferent parental attitude, poor coping abilities of the family, and poor quality of family functioning (Gath, Smith, & Baum, 1980; Klusa, Habbick, Abernathy, 1983; Sullivan, 1979; Swift, Seidman, Stein, 1967). The diabetic families in the study by Swift and his colleagues (1967) showed significantly more extreme emotional tone in the home, maternal overprotection-neglect, and parental dominance-submission than control families.

In families of children with cystic fibrosis sharing the burdens of the illness within and outside of the family was positively associated with family functioning. There was no significant relationship between sociodemographic variables, financial stress, and family functioning (Venters, 1981). Family functioning was found to be a better predictor of the ill child's adjustment than the presence of illness. When family functioning was controlled the behavior problems reported by mothers of children with cystic fibrosis and asthma were no longer significant (Lewis & Khaw, 1982). Parents of children with cystic fibrosis reported closeness to the medical center, adequacy of the physical environment, resources to meet the expenses and mastery of the therapeutic techniques as important resources (McCollum & Gibson, 1970). Family adjustment was significantly related to asthmatic children's adjustment in a 10-12 year follow-up (McLean & Ching, 1973).

Summary

Family adjustment and relationships are not necessarily poor in families with chronically ill children. The quality of family

adjustment is related to the family's psychosocial, material, and interpersonal resources. As with demands the research on resources in families of chronically ill children has been descriptive and with few comparison groups. Although these studies do not provide a basis for the comparison of families with chronically ill children and families of healthy children, they do provide many consistent findings related to the adaptation of families with chronically ill children. Specific factors that have been found to serve as resources are family cohesion, family organization, and open, effective family communication. Adverse family psychosocial factors such as closed or dysfunctional communication, low parental self-esteem, poor family coping skills, and ineffective family functioning have been found to negatively effect family adaptation, child adjustment, and illness management. Although marital and family conflict may result from the overinvolvement of one or both parents in the care of the ill child, research has consistently found no increase in the divorce rate of parents with chronically ill children. Having two parents, even in the presence of marital distress, may serve as a resource in these families. One study found that particularly in the presence of high life stress, social support facilitated positive parental adaptation. Thus the quality of the marital relationship and social support can serve as resources for the family.

Resources of the Mother

Much of the research on chronic childhood illness focuses on the ill child's mother. Although maternal psychosocial functioning can serve as a positive family resource, most research to date has focused on deficits in maternal functioning. In two early studies, the mothers

of chronically ill children were found to have significantly lower general self-esteem and significantly higher social introversion than mothers of healthy children but not mothers of mentally retarded children (Cummings, Bayley, & Rie, 1966; Gayton, Friedman, Tavormina, & Tucker, 1977). Their general self-esteem in the first study fell between that of mothers with healthy children and mothers with mentally retarded children. Although the mothers of chronically ill children were found to have lower self esteem than the mothers of healthy children in this study, both of these groups of mothers had lower levels of expressed depressive affect than the mothers of mentally retarded and neurotic children. The mothers of the chronically ill children did report less enjoyment of the ill child than mothers of healthy children. This diminished enjoyment did not generalize to their other children, their husbands, or their neighbors (Cummings et al., 1966). In contrast the second study found a greater frequency of emotional disturbance and higher scores on depression for mothers of chronically ill children compared to fathers and parents of healthy children (Gayton et al., 1977). A more recent comparison of mothers of healthy children and mothers of children with cystic fibrosis, diabetes, or moderate mental retardation found no significant difference in the level of depression reported by mothers of healthy children and those with chronically ill children. Maternal employment outside of the home was a significant predictor of maternal depression but not the child's condition (Walker, Orteiz-Valdes, & Newbrough, 1989). In a second study by Walker, mothers of school age children with cystic fibrosis rated themselves as significantly more competent at parenting and discipline than mothers of healthy children (Walker, Ford, & Donald, 1987).

Depression and parenting have also been examined in mothers of diabetic children. A longitudinal study of children with diabetes from the time of diagnosis found that the mother's distress shortly after the diagnosis was the best predictor of later maternal symptomatology. Maternal depressive symptoms decreased over the first year then increased over time but remained below the levels generally considered to be clinically significant. Maternal symptoms were not significantly related to the child's compliance with the medical regimen, metabolic control, or rehospitalization (Kovacs, Iyengar, Goldston, Obrosky, Stewart, & Marsh, 1990). In terms of parenting, mothers of diabetics in one study showed extreme scores on protection-neglect (Swift et al., 1967). For the diabetic children but not their healthy siblings the mother's behavior had a positive relationship with the child's self-esteem and satisfaction with his/her own behavior. The mother's behavior had a negative relationship with the diabetic child's academic achievement (Crain, Sussman, & Weil, 1966).

In an early study of families of children with congenital heart disease maternal immaturity was related to a number of factors that could create difficulties for the families. For the mothers themselves immaturity was related to below average intelligence, anxiety proneness, and over-reacting to situations and events. On the family level maternal immaturity was related to paternal immaturity, lack of outside interests, decreased social life, and not leaving the child with neighbors (Apley et al., 1967).

Summary

Mothers have an important role in the development of their children. The effects of this role may be even greater with a

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chronically ill child. Studies focusing on the maladaptation of mothers with chronically ill children found that these mothers experienced depressive affect, social introversion, conflicts regarding protection of the ill child, and in some cases diminished self-esteem. The findings related to maternal depression and depressive affect have been inconsistent. Two studies (Cummings et al., 1966; Gayton et al., 1977) found greater levels of depressive symptomatology in mothers of chronically ill children than mothers of healthy children, however, one of these studies (Cummings et al., 1966) found the same mothers to have lower levels of depressive affect than mothers of mentally retarded or emotionally impaired children. A third study (Walker et al., 1989) found no significant differences in depression between mothers of chronically ill and healthy children. In this study, employment was a better predictor of the level of maternal depression than the child's condition. A longitudinal study found that depression in mothers of diabetic children decreased over the first year then increased but remained below clinically significant levels (Kovacs et al., 1990). The mother's maturity also appears to play a role in the impact of chronic illness on the family and family functioning. The research with comparison groups suggest that the maladaptive maternal characteristics may not be as great in mothers of chronically ill children as in mothers of mentally retarded children. Only one study included positive characteristics of mothers with chronically ill children. In this study these mothers rated themselves significantly higher on both parenting and discipline than mothers of healthy children (Walker et al., 1987). The timing of the above studies in relation to the diagnosis was reported in only one of the studies and may have influenced the

findings. The importance of time since diagnosis is discussed further with the literature on coping. The role assumed by the father may also serve to attenuate some of the stressful effects of caring for a chronically ill child experienced by the mothers but was not included in any of these studies.

Resources of the Father

Fathers of chronically ill children have been studied far less frequently than mothers. As was the case with mothers the focus of the research has been maladaptation and/or psychopathology. Studies of the personality characteristics and emotional adjustment of fathers of chronically ill children has resulted in varied findings. In one study 32% of the fathers of children with cystic fibrosis obtained scores suggestive of emotional disturbance on personality tests. These fathers scored significantly higher than controls on the hysteria, lie, hypochondriasis, and psychopathic deviance scales of the MMPI (Gayton et al., 1977). On a different set of personality tests fathers of diabetics had extreme scores on dominance-submission (Swift et al., 1967). In a study of fathers with healthy, chronically ill, or retarded children, having a chronically ill child was found to have a significant negative effect on fathers but not as great an effect as mental retardation. Fathers of chronically ill children showed significantly more depression, a lower sense of paternal competence, and a lower level of gratification in their relationship with the ill child, other children, and neighbors than fathers of healthy children but not fathers of mentally retarded children. This stress was greater with younger children (Cummings, 1976).

A relationship between intellectual understanding of the illness and parental adjustment has been found in some studies of families with chronically ill children. In families of children with cancer parental (mothers and fathers) adjustment was significantly related to education, intellectual understanding of the disease, occupation, parent-parent relationships, and parent-child relationships. Intellectual understanding of the disease was related to the emotional adjustment of both parents, the parent-child relationships, the parent-parent relationship, and adjustment to hospital routines (Murstein, 1960). A second study however found that knowledge of the illness had differential effects on mothers and fathers. Knowledge of the illness was negatively related to maternal depression and depression in hemophiliacs under 15 years of age but there was no relationship between knowledge and psychological distress for fathers or for hemophiliacs over 15 years of age (Klein & Nimorwicz, 1982). Fathers in these families participated more in child care and saw their role as head of household more in terms of care and protection than masculinity (Markova et al., 1980). Family relationships (parent-parent and parent-child) appear to play an important role in both parental adjustment and intellectual understanding of the illness.

Summary

The studies of fathers are limited in number and limited in their focus on psychopathology. Chronic childhood illness can clearly have a negative impact on fathers. In comparison with the published norms on personality tests, fathers of chronically ill children in two studies were found to have scores suggestive of emotional disturbance (Gayton et al., 1977; Swift et al., 1967). A comparison of fathers with healthy,

chronically ill, and mentally retarded children found that the fathers of chronically ill children reported higher levels of depression and lower levels of paternal competence and gratification from interactions within and outside of the family than fathers of healthy children but not fathers of mentally retarded children (Cummings, 1976). Findings regarding the relationship of intellectual understanding of the illness and parental adjustment conflict. One study found a positive relationship between intellectual understanding of the illness and the adjustment of both mothers and fathers (Murstein, 1960). A second study found this relationship to be present only for mothers (Markova et al., 1980). Examining the findings of these two studies together suggests that the parent-parent relationship and the role the father assumes in the family may be more important factors in parental adjustment. The resources that the father may bring to the family situation and the possible personal growth that may result from this experience have not been addressed by the studies to date.

Resources of the Chronically Ill Child

Chronically ill children have been studied more extensively than their parents or siblings. The methodology of these studies varies but many are based on maternal report. Fewer studies have used the child's self report. Consistent with the research on other family members, studies of chronically ill children have focused on identifying maladaptation and psychopathology. None of the research to date has examined the strengths of the chronically ill child. For example, positive self-esteem and adequate psychosocial functioning of the chronically ill child could serve as a resource for the family. Because of the extent of the literature on chronically ill children, this

section will be divided into general adjustment, self-concept, and locus of control. For organizational purposes the literature within each area will be reviewed by diagnostic category.

General Adjustment

In chronically ill school age children functional status may influence psychological adjustment. In one study, there was no significant relationship between psychosocial adjustment and days in bed, days hospitalized, or number of hospital days. Number of days absent from school was significantly correlated with poor adjustment. Family composition altered the correlation between each morbidity measure and psychological adjustment. These relationships are the weakest with both parents in the home and strongest when the mother is living with an adult other than the father (Stein & Jessop, 1984). In a five year follow-up study, children with cystic fibrosis followed the trend toward better adjustment seen among the general population. In contrast, children with conditions involving the brain, the majority of whom were classified as severely psychologically impaired, remained at the same level of adjustment 5 years later (Breslau & Marshall, 1985).

The findings from one study of chronically ill adolescents have particular relevance to the long term adjustment of chronically ill school age children. Although most chronically ill adolescents dated and attended school full time, some did report dating less frequently and being less likely to be in school full time. Multidimensional scaling suggests that in moderate to severe illness there is less adequate social functioning and slower progress into the adult role. Age, age of onset, age may marry, dating often, age may become a parent, close to another, and opposite sex friends do not strongly relate to

health status. The majority of the youths appeared psychosocially well. The mere presence of a chronic illness eight years earlier did not alone seem to place the child at risk for subsequent psychosocial problems (Orr, Weller, Satterwhite, & Pless, 1984).

Cystic fibrosis. The functioning of children with cystic fibrosis has been examined in a number of studies. One study found that parental adjustment ratings of their children with cystic fibrosis indicated normal adjustment. These children did show higher but normal scores on infantile aggression, hyperactivity, inhibition, social withdrawal, sensitivity, fear, and irritability than their siblings and healthy controls. The authors point out that these differences may reflect parent perception of the ill child and heightened sensitivity to the ill child's state and behavior (Drotar, Doershuk, Stern, Boat, Boyer, & Matthews, 1981). Children and adolescents with cystic fibrosis have shown many adaptational strengths. In a group of preadolescents and adolescents with cystic fibrosis 85% were in the appropriate school grade, 69% participated in physical education class, and 81% had future plans for college and/or a career. Self report indicated good adjustment in terms of self-concept and lack of defensive distortions of self-image. They perceived adequate social support from family and friends, with more support from family than friends. High levels of perceived social support were related to high levels of total self-esteem (Smith, Gad, & O'Grady, 1983). Adolescents with cystic fibrosis appeared able to maintain good self-concept, to be socially competent, and perceived they had control of their health. Females with cystic fibrosis relied heavily on denial and were behaviorally more compliant. Males used less denial, showed more behavior problems and immature

behavior, and appeared to integrate having a physical disorder into their self concept more than females. The males did not function as well socially as male peers or females with cystic fibrosis. Physical self-concept scores were significantly related to pulmonary function tests. Locus of control was significantly related to overall psychosocial functioning (Simmons, Corey, Cowen, Keenan, Robertson, & Levison, 1985). Breslau (1983) found no significant difference in psychiatric symptoms between children with cystic fibrosis and healthy controls. In contrast, neurologically and orthopedically handicapped children showed a significantly increased incidence of psychiatric symptoms. This suggests that handicapped children may respond differently to their situation than chronically ill children. This would be an important difference since chronically ill and handicapped children are often grouped together in theoretical literature, research, service provision, and education of health care professionals.

Asthma. Examination of asthmatic children showed that anxiety was the greatest in an inpatient subsample. In the inpatient subsample increased debilitation was related to increased despair over social debilitation, bad quality of life, dread of illness, and little orientation to compliance. All patients showed significant and comparable reductions in debilitation after hospitalization (Staudenmayer, 1982). In a second study mothers of asthmatic sons more frequently described their sons as depressed than mothers of healthy controls. This view correlated with the asthmatic son's anxiety and depression. The mothers also showed more depression and anxiety. Asthmatic boys themselves scored significantly lower than controls on commitment to parents, overprotection by mother, and overindulgence by

mother. There were no differences for mothers with asthmatic daughters or fathers with asthmatic children of either sex (Meijer, 1976). A study focusing on the effects of the family on the asthmatic child found a significant relationship between family adjustment and child adjustment but neither family adjustment nor family situation were related to the severity of the asthma at two year and ten year follow-up visits (McLean & Ching, 1973). One study compared asthmatic children and children with cystic fibrosis using parental interview. For asthmatics it was found that the most important predictor of psychopathology was disturbance in family functioning followed by other family variables, recent life events, and prior undesirable life events. For children with cystic fibrosis in this study the severity of illness was the most important predictor of psychopathology followed by disturbed parental behavior, paternal emotional disorder, and past psychiatric history of the child (Steinhausen et al., 1983b). In other studies of cystic fibrosis and asthma no significant correlations were found between severity of illness and psychosocial variables (Kashani, Konig, Shepperd, Wilfley, & Morris, 1988; Simmons, Corey, Cowen, Keenan, Robertson, and Levison, 1987). In both cystic fibrosis and asthma these studies found that family variables are better predictors of poor adjustment than the presence of the disease.

Diabetes mellitus. Studies of children with diabetes have found both strengths and limitations. On Family Kinetic Drawings diabetic children showed increased isolation compared to controls. Isolation was associated with aggression for the diabetic children but not the controls. Neither general body distortion nor denial of body parts appeared significantly more often in the drawings of the diabetic

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children (Sayed & Leaverton, 1974). Comparison of diabetic and acutely ill control preadolescents and early adolescents on psychosocial dilemmas about parent-child issues revealed that the diabetics had higher focusing, problem-solving, and active understanding scores and markedly higher overall enabling scores than the acutely ill controls. Diabetics did express more devaluing and higher levels of affective constraining than the controls (Hauser, Jacobson, Wertlieb, Weiss-Perry, Follansbee, Wolfsdorf, Herskowitz, Houlihan, & Rajaparik, 1986). A group of well controlled diabetics was found to have fewer youths with interpersonal and noninterpersonal conflicts than a group of poorly controlled diabetics or healthy controls, although anxiety and depression were significantly more frequent by parent reports in the poorly controlled group. The poorly controlled group was not significantly different from the healthy controls. Of the three groups, the well controlled group seemed to be in the best mental health (Simonds, 1977).

Cancer. Research related to children with cancer has focused more often on the diagnosis or death of the child than the child's functioning during the illness. The stage of the illness (diagnosis, remission, exacerbation, end stage) is often not controlled in the research. Parental reports on children with cancer in various stages indicated problems related to cognitive development, high anxiety scores that decreased with age, delinquency scores that increased with age, and depression scores that were significantly above normal. Twenty-six percent of the children exhibited profiles indicating problems of sufficient magnitude for professional intervention (Armstrong, Wirt, Nesbit, & Martinson, 1982). These findings may have been influenced by

the stage of the illness which was not described. In a second study using a drawing task few differences were found between children with cancer and healthy controls. Age, sex, and group interacted indicating that all males and healthy females viewed themselves as healthier at intermediate rather than younger or older ages, whereas sick females viewed themselves as healthier at younger and older ages (Burns & Zweig, 1980). One study examined children successfully treated for cancer. These children were not significantly different from healthy children in perceived self-competence, although a higher percentage of the post-treatment children reported spending more time alone and having more friends of ages different than their own (Spirito, Stark, Cobiella, Dregan, Androkites, & Hewett, 1990). The timing (near diagnosis or death) and focus of these studies make it difficult to identify the resources that may be present in children with cancer.

Self-Concept

Asthma. Over the years various maladaptive personality characteristics have been attributed to asthmatic children in the theoretical literature. The research findings however have been inconsistent. Based on self-report measures one study found that asthmatics did not differ significantly on total self concept from the instrument norms and there were no significant differences due to severity of illness. Severe asthmatics saw themselves as generally less anxious than an emotionally disturbed group and exhibited a slight tendency to see themselves as happier (Heilveil & Schimmel, 1982). Semistructured interviews with asthmatics did not reveal the hypothesized lack of emotional expression. The main pattern of reaction was of directly and indirectly expressed anger and statements of

helplessness. There were many expressions of competence and good feelings. Both of these patterns were significant. Preadolescent asthmatics showed more depression and fewer good feelings than younger asthmatic children (Viney & Westbrook, 1985). Using both a structured interview and a self report self concept measure no significant differences were found between asthmatic and healthy children on psychiatric symptoms (Kashani et al., 1988).

A study comparing asthmatic, cystic fibrosis, emotionally disturbed, and healthy children did find some differences between these groups of children. Asthmatics and emotionally disturbed children had significantly lower self-concept scores than healthy controls. The cystic fibrosis children were between these 2 groups and the healthy controls. Adequacy and worth as a family member, self-satisfaction, and acceptance were significantly lower in asthmatics. Physical self scores were significantly lower in asthmatics and children with cystic fibrosis (Margalit, 1982). Another study compared asthmatic, diabetic, and healthy children. The ill children scored significantly higher on empathy, emotional responsiveness, and depression. The asthmatic children had significantly lower scores on self esteem than the diabetic and healthy children who had similar scores. The asthmatic children also had significantly lower aggression scores than the diabetic children with the healthy children falling in between (Nelms, 1989).

Cystic fibrosis. In two studies of the psychological testing of children with cystic fibrosis and their healthy siblings, no significant differences were found in self-concept or personality functioning (Gayton et al., 1977; Simmons et al., 1987). In the study by Simmons and his colleagues (1987), the cystic fibrosis children and their

healthy siblings had significantly higher self concept scores than the published norms; however, parents rated their sons with cystic fibrosis as having significantly more behavior problems than the published norms. Positive self-concept, personality functioning, and adjustment in children with cystic fibrosis would serve as resources for the child and family.

Diabetes mellitus. Most of the controlled studies seem to support the concept that there are no psychiatric differences between diabetics and nondiabetics. Good psychosocial functioning has been reported in diabetics over time. One study found that although self-esteem and body image were found to be somewhat poorer in school age and adolescence this seemed to resolve in adulthood (Klusa et al., 1983). Two studies however found that diabetic children scored significantly higher than the published norms on the Piers-Harris Self Concept Scale (Evans & Hughes, 1987; Saucier, 1984). A three year longitudinal study of diabetic children beginning at diagnosis found no differences in mental state, social problems, or intelligence between the diabetic children and the healthy controls. Diabetics showed a tendency toward aggression, higher degrees of mental activity, emotional lability, and decreased social contact. They initially showed a higher degree of anxiety concerning their own health which decreased over time. The authors felt the few abnormal patterns were due to the traumatic experience of onset (Ahnsjo, Humble, Larsson, Sattergren-Carlsson, & Sterky, 1981). In spite of their normal intelligence diabetic children did seem to have a distorted perception or incomplete knowledge of their disease in one study. Low self-esteem when it did occur in this study was thought to serve as a catalyst for adjustment difficulties

(Greydanus & Hofmann, 1979). Although poor diabetic control has been associated with lower self-concept and abnormal psychiatric classification an increase in the latter has not always been found (Gath et al., 1980; Swift et al., 1967). Diabetics were found to score more extremely in both directions on independence-dependence, higher on latent and manifest anxiety, constriction of sexual identity, extreme hostility, and lower on self-perception in one study (Swift et al., 1967). The positive self-esteem and psychosocial functioning found in the majority of studies of diabetic children are individual resources that contribute to the family's capability.

Locus of Control

Research related to locus of control in chronically ill children is more limited than that on adjustment and self-concept. Although the findings related to locus of control in chronically ill children have been inconsistent, locus of control appears to have an important relationship with adjustment in chronic childhood illness. In severe asthmatics it was found that external locus of control decreased with age in better adjusted patients. Children with extreme scores at either end of the locus of control scale tended to have emotional and management problems (Matus, Kinsman, & Jones, 1978). Significantly lower externality scores were found in two studies of school age and early adolescent children with a variety of chronic illnesses (Simmons et al., 1987; Steinhausen, 1982). In contrast significantly higher externality scores have been found in a number of studies of adolescents with a variety of chronic illnesses compared to healthy controls. The scores of adolescents with diabetes and cystic fibrosis however were comparable to the controls. An inverse relationship was found between

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self-esteem, social support, and both external locus of control and anxiety (Kellerman, Zeltzer, Ellenberg, Dash, & Rigler, 1980; Evans & Hughes, 1987; Smith et al., 1983). In a separate study self-report and the report of teachers and parents indicated that adolescents with cystic fibrosis were able to maintain a good self-concept, be socially competent, and perceived that they had control of their health. Locus of control correlated significantly with overall psychosocial functioning (Simmons et al., 1985). It is possible that the adolescents with diabetes and cystic fibrosis are assuming more responsibility for self-care. This may lead to greater internality, self-esteem, and less anxiety. Locus of control may be influenced more by style of medical management (authoritarian versus patient and family as partners) and nondisease variables (e.g. developmental level, self-esteem) than the presence of a chronic illness. The perception that one has control and can influence realistic aspects of his/her life would serve as a resource.

Summary

Studies of children with a variety of chronic illnesses, physically handicapped children, and healthy children have supported the normalcy of the chronically ill child's psychosocial functioning across multiple measures (Kellerman et al., 1980; Steinhausen, 1981; Tavormina, Kastner, Slater, & Watt, 1976). These studies do suggest that there may be an increased risk for maladaptation in chronically ill children but not an increased incidence. In contrast the physically handicapped children showed impaired ability to become emotionally integrated into their environment and a tendency to withdraw (Breslau, 1985; Steinhausen, 1981). The chronically ill children's strengths and coping abilities

noticeably outweighed their weaknesses. Their self-concept was significantly higher than or comparable to the standardized norms in the majority of studies and there were no consistent significant differences from the norms on personality testing or locus of control for chronically ill children (Tavormina et al., 1976). Although the locus of control findings with chronically ill adolescents are inconsistent, no evidence of psychopathology was found by self report in adolescents with a variety of chronic illnesses. The adolescents did report that the illness disrupted relationships with parents and siblings (Zeltzer, Kellerman, Ellenberg, Dash, & Rigler, 1980).

Parental ratings provide stronger although insufficient support for the presence of psychopathology in chronically ill children. Parental ratings in the majority of studies were completed by mothers. By maternal rating chronically ill and handicapped children were found to have significantly more behavior problems and lower social competence than healthy children (Wallander et al., 1989). Research suggests that clinical depression affects mothers' perceptions or tolerance of their child's behavior making it more likely for them to label their children as disordered or to refer them for treatment (Breslau, Davis, & Prabucki, 1988). Higher levels of maternal depression have been reported in some studies of families with chronically ill children. Although maternal depression has been associated with mothers' reporting increased behavioral problems in children with chronic illnesses, one study found that this relationship was attenuated by maternal employment (Walker et al., 1989). Since the time constraints of having a chronically ill child may limit the mother's opportunity to work, the relationship between maternal depression, employment, and the mother's

reporting increased behavior problems in chronically ill children may explain in part the discrepancy in findings between studies using parental report versus teacher report and child self report to examine the psychosocial functioning of chronically ill children.

Actual assessment of the chronically ill children and children's self reports support only potential risk. Using the Diagnostic Interview for Children and Adolescents, Kashani and his colleagues (1989) found no significant differences in psychiatric symptoms between children and adolescents with cystic fibrosis and matched healthy controls. In contrast, using the parent version of the same interview schedule with the same sample, parents reported significantly more symptoms in cystic fibrosis children than the healthy controls (Kashani, Barbero, Wilfley, Morris, & Shepperd, 1988). Self-concept, age-appropriate locus of control, and coping abilities are resources that chronically ill children bring to their families.

Resources of Siblings

Siblings of chronically ill children have received limited attention in the literature. Siblings have been used more often as a comparison group for the chronically ill child than as the focus of the research. Much of the research on siblings has utilized maternal report alone. These studies tend to reveal a more negative perspective on sibling functioning than those using sibling self-report and other sources (Lobato, Faust, & Spirito, 1988).

Sibling relationships are characterized by intensity, complexity, and ambiguity. They span a longer period of time than most other relationships and include an involvement where children spend hours, days, and years together. Thus siblings may have a powerful influence

on shaping each other's identity. Siblings serve many roles for each other including mentor, supporter, comforter, protector, and socializer. The sibling subsystem as a whole is affected by an ill or handicapped child. There is evidence that particular children within that system are especially vulnerable to difficulties. Siblings who are in the midst of developmental transitions, have few or ineffective coping skills, and/or have poor relationships with their parents leading to inadequate nurturance are at increased risk for psychosocial sequelae. "Protecting" siblings from information and excluding them from full participation in family problems increased feelings of loneliness and anxiety (McKeever, 1983; Siemon, 1984).

Illness alters the quality of sibling interaction by complicating natural combat and conflict among siblings leading healthy siblings to question their right to be angry. In addition parents must make difficult decisions about the distribution of emotional and material resources which often place the good of all family members against the needs of one member. Siblings may feel or be short changed in these decisions leading to a perceived or actual lack of needs being met. Siblings in the role of explaining, defending, or mediating are torn between their own needs for friends and protection of their ill sibling. Older sisters and siblings closest in age to the ill child seem to be at greatest risk for role strains and shifts. An important risk is that siblings will make reactive decisions about themselves based on overidentification with the ill child and consequently sacrifice their own needs and abilities. This may lead to bitterness, resentment, and feelings of lack of control in later years. Having a chronically ill siblings may also have positive effects including maturity,

responsibility, altruism, compassion, and appreciation of their own good health. Within the family these siblings may demonstrate greater sensitivity to and tolerance of another's point of view, empathy for their parents, appreciation of the family's bonds, and more family pride and loyalty (McKeever, 1983; Siemon, 1984).

Much of the research on siblings of chronically ill children has focused on maladjustment. Overall there does not seem to be a direct relationship between a child's illness and sibling psychopathology. Adverse psychological outcomes that have been reported such as anxiety, poor peer relationships, somatization, and depression have been more strongly related to general family factors than illness related variables. Many siblings appear to benefit psychologically and socially from having a chronically ill sibling (Lobato et al., 1988). In one study siblings of epileptic children were found to be significantly more self-directed and had higher self-esteem than the epileptics (Long & Moore, 1979). In another study, interviews with siblings of children with cancer found both positive and negative effects of having a chronically ill sibling (Iles, 1979). The siblings of cancer patients described losses in terms of disruption of family and peer relationships, physical changes in the ill sibling, disturbance in routine family life, and alterations in the environment. The sibling interviews also revealed gains in empathy for parental needs, cognitive understanding, respect for the ill sibling, and self-esteem. The majority of these siblings found a peer that they could share the experience with (Iles, 1979).

There has been more research on siblings of handicapped children than siblings of chronically ill children. Siblings of handicapped and

Chronically ill children grouped together have been reported to be higher on fighting and delinquency than siblings of healthy children. However, there was no significant difference between the two groups in the number of siblings with serious psychological impairments. A greater impact has been reported on the psychological functioning and physical health of older female and younger male siblings (Breslau, 1982; Breslau, Weitzman, & Messenger, 1981; Vadasy, Fewell, Meyer, & Schnell, 1984). However, these findings have since been found to be more true of siblings of handicapped than chronically ill children (Breslau, 1982). In an early study, siblings of chronically ill children who asked disease related questions and were active in extra-family activities led to increased parental distress (Meyerowitz & Kaplan, 1967). If the family attenuated relationships with the broader community the siblings were aware of this and avoided further loss of family contact by keeping thoughts, feelings, and questions regarding the illness to themselves (McKeever, 1983). As normalization of the family and chronically ill child's life and open communication have increased in emphasis in the medical management of chronic childhood illness, the parental distress related to these sibling behaviors may have decreased.

Maternal ratings give a different impression of these siblings. Siblings of children with a variety of chronic illnesses were rated by their mothers as being significantly higher on social withdrawal and irritability than healthy controls (Lavigne & Ryan, 1979). In one study, semistructured interviews and self report questionnaires revealed no significant differences in self esteem and self appraisal between siblings of chronically ill children and those of healthy children but

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Parents of the chronically ill children perceived the siblings as having significantly more behavior problems of a personality nature such as shyness and withdrawal than siblings of healthy children (Tritt & Esses, 1988). In a study using maternal and teacher ratings, siblings of children with nephrotic syndrome were rated to be in poorer emotional and physical health by parents and to have poorer academic achievement by teachers than healthy controls (Vance, Fazan, Satterwhite, & Pless, 1980).

Summary

Siblings serve an important function for each other in self-appraisal, support if parents are disorganized, forming alliances, and socialization. There is considerably more theoretical literature based on clinical observation than actual research on siblings of chronically ill children. Although behavior problems and social withdrawal have been found using maternal ratings, the majority of studies support good psychosocial functioning and self concept that is comparable to or higher than siblings of healthy children. The majority of siblings of chronically ill children appear able to adjust to the changes that occur within their families and in some studies have reported positive effects of this experience. Although at risk for psychosocial problems, most siblings of chronically ill children do not appear to develop them (Lavigne & Burns, 1981). The adequacy of siblings' self-esteem and psychosocial functioning will contribute to family resources.

Perception of Demands

The perception of demands is the family's subjective definition or perception of the total situation. It includes the subjective definition of the seriousness of the demands. It also reflects the

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family's values and prior experience with change and crisis. The family's subjective definition will usually focus on concrete demands such as time, money, and fatigue. These definitions are influenced by the affective responses of the family as a unit and individual members. The family's perception can range from seeing the situation as uncontrollable to seeing the demands as a challenge to be met. The prognosis, availability of treatment, complex time-consuming management, and severity of the disease affect the definition (Klusa et al., 1983; Lavigne & Burns, 1981). The family's perception will change over time as the family copes with and adapts to on-going and new experiences (McCubbin & Patterson, 1983b).

The accuracy of the parent's perception of the illness has been related to a number of factors. Examination of parental perception of illness severity in children with cystic fibrosis and leukemia revealed three groups: overestimators, underestimators, and accurate perceivers. Overestimation of disease severity was associated with increased psychiatric symptoms, accurate perception with decreased symptoms, and underestimation was intermediate. Parental distortion of illness severity was related to the sex of the child, younger children, older parents, and lower occupational status (Frydman, 1980). In families of children with cystic fibrosis, mother's ratings of illness severity whether accurate or not correlated significantly with limits on family opportunity, financial strain, personal burden, lifespan worries, and terminal illness concerns. In terms of total family stress, there was no significant difference in perception of total stress between the mothers of children with cystic fibrosis and mothers of healthy control children (Walker et al., 1987).

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Overreactions of mothers with children with congenital heart disease correlated significantly with maternal immaturity, upset family balance, maternal proneness to anxiety, extra expense, and modification of social life (Apley et al., 1967). Maternal perception of congenital heart disease was a crucial factor in the effect of illness on family life. Overestimation and underestimation both related to overprotection of the ill child with overestimation having a stronger relationship and leading to greater disruption in family life. Distortion of severity was negatively related to the father's occupational status. There was no relationship between maternal distortion of illness severity and maternal age, child age, or number of children. There was no difference in effects of distortion by levels of symptomatic versus asymptomatic children (Offord & Aponte, 1967). Significant misunderstanding of prognosis has been found between mothers, fathers, and physicians of children with leukemia. Both parents accurately predicted the child's perception of the prognosis. Fathers accurately predicted the mother's perceptions. Mothers however underestimated the father's perceptions of the prognosis, thus the fathers saw the prognosis as poorer than the mothers realized. The physicians significantly underestimated both parent's perceptions but not the children's perceptions. Children were more optimistic than mothers and physicians but not fathers. Misperceptions and misunderstandings were related to increased stress (Mulhern, Criso, & Camitta, 1981).

Parents of epileptic children expected more emotional problems, unpredictable behavior, and emotional reactivity in epileptic children. Siblings were expected to have better school performance, more sports, more power of concentration, and a wider choice of occupations.

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Parental attitudes toward epilepsy were positively related to parental adjustment (Long & Moore, 1979). Parental perception of seizure control was positively related to actual seizure control and parental adjustment (Austin, MacBride, & Davis, 1984)

Summary

Parental perceptions of the illness and demands have an important impact on the family. Maternal perceptions of the demands have been studied the most extensively. Maternal overestimation of illness severity had the greatest effect and was associated with increased parental maladjustment and psychological symptoms as well as the illness having a greater negative impact on family functioning. Accurate maternal perception was related to decreased parental symptoms and underestimation was in between. The mother's perception of illness severity whether accurate or not related significantly to the impact of the illness on the family. Parental perceptions of illness severity have not shown a consistent relationship with the actual severity of symptoms. Two studies identified a relationship between parental distortion of illness and demographic variables, however, lower SES was the only demographic variable that was related to illness distortion in both studies (Frydman, 1980; Offord & Aponte, 1967). Parental perceptions of illness can influence their expectations of the ill child as well as the healthy siblings (Austin et al., 1979). Differences in perceptions among family members have been related to increased family stress (Mulhern et al., 1981). Over time families develop new definitions of their situation. New definitions usually involve defining the illness and its severity as well as relinquishing and/or modifying fantasies and goals for the child's future development

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(Maddison & Raphael, 1971). The perceptions of the ill child and his/her siblings and the effect of the children's perceptions on parent, child, and family adjustment have not been examined.

Coping

When existing resources including family structure are not adequate the family comes to a new shared definition of the total situation. They search for and agree upon solutions the implementation of which (coping) leads to restructuring (McCubbin & Patterson, 1983b). Coping is the cognitive and/or behavioral response of the family unit and individual family members in an effort to eliminate and/or avoid stressors, manage the hardships of the situation, and to acquire and develop social, psychological, and material resources to meet the demands. The interaction of demands, resources, and perception of demands influence the family's demand-capability balance. The family responds behaviorally and/or cognitively to restore equilibrium. The problem-solving and coping strategies of the family are aimed at making changes in the system to meet new demands and restore balance and organization to the family system. Three initial coping strategies have been identified. One strategy, avoidance, is the family's effort to deny or ignore the stressor. A second, elimination, is the family's active effort to get rid of the stressor. A third general strategy, assimilation, is the family's efforts to accept the demands into the existing family structure and pattern of behavior. These initial coping strategies are not always sufficient for achieving equilibrium. When these strategies are not sufficient three additional coping strategies may be needed: synergizing which involves the family pulling together and increasing their coordination as a unit, interfacing with the

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community to achieve a new fit, and compromising through realistic appraisal and willingness to accept a less than perfect solution (McCubbin & Patterson, 1983b).

Vulnerability to stressors is a continuum affected by both constitutional and acquired factors. For children the behavioral processes needed for coping and adaptation include seeking information, maintaining autonomy, and utilizing intrapsychic processes. Coping consists of both active efforts and defense mechanisms. Children may exhibit inactive coping with silent, nonparticipating behavior, pre-coping with orienting behavior or active coping. Children may use active coping by attempting to control, resisting, cooperating, and/or complying with demands (Rose, 1984).

The majority of the research on coping in families of chronically ill children has focused on the time surrounding the diagnosis with fewer studies examining coping beyond this period. In contrast to the research on demands, resources, and the perception of demands, the research on coping has most often looked at families using data from both parents rather than isolated family members such as the mother or the chronically ill child. In addition the majority of the research has focused on parental coping not that of the chronically ill child or the siblings. Because the primary difference in the research is the time period examined rather than the subjects, this section of the review of literature will be divided into initial reactions and on-going coping.

Initial Reactions

In a classical theoretical article Solnit and Stark (1961) proposed a mourning process following the birth of a defective child. This theory and process of mourning has been supported by a number of authors

following the diagnosis of chronic illness in a child (Lavigne & Burns, 1981; Maddison & Raphael, 1971; Maghi Messina, DeLeo, Mosconi, & Carli, 1983; McCollum & Gibson, 1970; Pacquay-Weinstock et al., 1979; Salk et al., 1972). The initial reactions to the diagnosis of a chronic childhood illness have been extensively studied. An initial grief response to the diagnosis of the chronic illness including shock, disbelief, and anger has been reported in congenital heart disease, hemophilia, leukemia, and cystic fibrosis (Apley et al., 1967; Grossman, 1975; Lavigne & Burns, 1981; Salk et al., 1972). Initial anger, decreased self-esteem, and parental resentment were reported by parents of hemophiliacs (Mattson & Gross, 1966a). Mothers of children with hemophilia initially felt intensely guilty about being carriers, depressed, tearful, anxious, and resentful or fearful about having been punished. The reactions of the fathers varied. The family dynamics reflected the mothers guilt, the father's ambivalence, and the child's conflict about movement (Browne, Mally, & Kane, 1960). Family guilt about a child's chronic illness may eventually lead to excessive anxiety about their healthy children and issues about reproduction (Maddison & Raphael, 1971; McCollum & Gibson, 1970). In a study of families of children with cystic fibrosis, differences in perceptions of the amount of stress influenced parental response to the diagnosis of cystic fibrosis. The cystic fibrosis families initially reported moderate to severe negative emotional responses as well as negative definitions and interpretations of the illness (Meyerowitz & Kaplan, 1967; Venters, 1981). Parents' anticipation of the severity of the illness at the time of diagnosis was significantly related to family functioning. Over time parents of children with cystic fibrosis reported giving the illness a

more positive interpretation. This interpretation was positively associated with family functioning (Venters, 1981). In an early study when leukemia was more frequently fatal, reactions to the diagnosis of leukemia ranged from loss of control to outward calm and resignation. Most of the parents suspected that something serious was wrong. The first days or weeks after the diagnosis the parents experienced physical distress, depression, inability to function, anger, hostility, self blame, and anticipatory grief. From the initial diagnosis through illness and subsequent death parents manifested all aspects of anticipatory and subsequent grief reactions including: intellectualization, irritability, depression, somatization, denial, and frenzy. Fathers found ways to absent themselves from their troubled families. Persistent denial was encountered in relatives especially grandparents but not parents (Binger, Ablin, Feuerstein, Kushner, Zoger, & Mikkelsen, 1969).

On-going interviews revealed a natural history of parental response to the diagnosis of cancer. These responses were shock, intellectual acceptance/emotional nonacceptance, denial, and anticipatory mourning. The anticipatory mourning included somatic signs and preoccupation with thoughts of the child. Pathological grief reactions were not prominent and there were no major depressive reactions. Parents utilized intellectualization with marked affective isolation. Denial varied greatly in intensity. The greater the intensity the more removed the degree of relationship with the child. Parents also exhibited increased motor activity. Parents actively searched for meaning, mastery, and competence in the situation (Chodoff, Friedman, & Hamburg, 1964). In families of children with other chronic illnesses denial, anxiety, and

mastery attempts led to misinterpretation of explanations, multiple repetitive questions, searching for information, and intellectualization (Lavigne & Burns, 1981; Maddison & Raphael, 1971).

Other studies have found comparable but more intense initial responses with evidence of ineffective coping efforts (Chodoff et al., 1964; Magni et al., 1983). Initially parents may try to eliminate the stressor through isolation, detachment, decreased affect, avoidance, and repression (Mattson & Gross, 1966a; Mattson & Gross, 1966b; McCollum & Gibson, 1970). Compulsive caring for the child and performance of domestic tasks, sleep disturbances, and increased motor activity were reported in parents of children with a variety of chronic illnesses (Lavigne & Burns, 1981; Maddison & Raphael, 1971; Magni et al., 1983). Overprotection and overdependence of the child led to overcommitment of the mother with her adopting a martyr role. These dynamics were related to decreased family integration in two studies (Friedrich & Friedrich, 1981; Meijer, 1976) and to anxiety and depression in the child in one of the studies (Meijer, 1976).

The effects of initial family coping with childhood leukemia have been described in longitudinal studies. In an early longitudinal study (Kaplan, Smith, Grobstein, & Fischman, 1973) 87% of the families failed to cope adequately with the consequences of childhood leukemia resulting in a variety of individual and interpersonal problems that were superimposed on the stressors created by the disease itself. The most common maladaptive responses included: denial of the reality of the diagnosis leading to rejection of the facts, clinging to the possibility of misdiagnosis, denying obvious symptoms, taking elaborate precautions to keep the child unaware of the diagnosis, and fear that the child

knowing would lead to a disaster. Parents who refused to accept the diagnosis occasionally displayed overt and massive hostility toward members of the health team. In families that achieved adequate coping parents understood that leukemia was a serious, ultimately fatal illness (in the early 1970's) involving remissions and exacerbations but moving progressively toward a terminal state. The family's ability to manage the illness depended on successful coping by both parents in the tasks that followed diagnosis. Successful early resolution of the tasks following diagnosis was considered a most critical coping assignment because achievement of further coping tasks depended on the effectiveness of this initial effort (Kaplan et al., 1976; Kaplan et al., 1973). In more recent longitudinal study of family response to childhood leukemia, mother's and father's self-reported adjustment to diagnosis were significantly correlated. Parents saw little change in their own adjustment from one year before the diagnosis. Staff ratings of family coping were generally at the high end of the coping scale. There was good agreement between nurses, physicians, and mental health professionals. Typical initial reactions included: anxiety, sadness, searching for information, focus on intellectual details, and cognitive but not emotional acceptance (Kupst & Schulman, 1980).

It was important for both parents to inform the family about the true nature of the illness. Communicating the nature of the illness within the family led to a period of grief that involved many if not all members. The diagnosis ushered in a phase of shared family mourning and mutual consolidation that included the ill child. It was important for each family member to have the opportunity to experience grief for the current and anticipated losses. The family as a group can offer its

members the potential of mutual support and access to its collective coping experience (Kaplan et al., 1976; Kaplan et al., 1973). Many losses are associated with a child's serious illness so the mourning may extend over a long period and be an intermittent process in which all family members participate.

The mourning process may also occur in the chronically ill child. Two initial modes of coping were found in children with newly diagnosed insulin dependent diabetes. A subdued reaction with mild sadness, anxiety, feelings of friendlessness, irritability, and social withdrawal was found in 64% of the children. Depressive symptoms that met the DSM III criteria for psychiatric disorder were identified in 36% of the children. An increased incidence of psychiatric reactions was found in families with lower SES and marital distress. The children's coping was not directly related to the parents' initial response. Children's coping took 7-9 months no matter how severe the initial reaction (Kovacs, Feinberg, Paulauskas, Finkelstein, Pollock, & Crouse-Novak, 1985).

On-Going Coping

In one study of families of children with cystic fibrosis, three patterns of coping were identified in families of children with cystic fibrosis (McCubbin et al., 1983b). These patterns were: a) maintaining family integration, cooperation, and an optimistic definition of the situation; b) maintaining social support, self-esteem, and psychological stability; and c) understanding the medical situation through communication with other parents and consultation with the medical staff. When used by the mother all three coping patterns were associated with the interpersonal relationship dimensions of family

life. Mother's coping efforts directed at family integration, cooperation, optimism, and medical communication and consultation were associated with family cohesion. Her efforts at maintaining social support, self-esteem, and emotional stability were associated with family expressiveness. Two coping patterns used by the father were associated primarily with the system maintenance dimensions of family life. Father's coping efforts directed at integration, cooperation, and optimism were associated with family organization and family interpersonal relationships. These efforts were positively related to family cohesion and inversely related to family conflict. His efforts at medical communication and consultation were associated with both family organization and family control. Father's and mother's coping efforts had differential effects on the family. The coping efforts of both parents had a positive effect on the chronically ill child's height/weight index and pulmonary function tests. Of the sociodemographic variables only income and age of the child with cystic fibrosis were related to the mother's and father's coping patterns (McCubbin et al., 1983b). In a second study similar coping patterns and relationships to family functioning were found in families of children with cerebral palsy, myelomeningocele, and additional families of children with cystic fibrosis (Patterson & McCubbin, 1983a). Encounters with other families through clinic and inpatient experiences were used overtly and covertly for information appraisal, affective appraisal, and support (McCubbin et al., 1983a). In another study eighty-nine percent of the families of children with cystic fibrosis reported some degree of reorganization and decreased negative emotion after one year (Venters, 1981).

One study examined specific coping behaviors of parents of children with cystic fibrosis. The coping strategies reported most often were asking a physician (92%) or a nurse (88%) for information; questioning other parents of children with cystic fibrosis (63%); speaking to clergy (61%); seeking information from others (48%); and questioning friends and relatives (55%). When they had more concerns than usual parents reported praying (47%); talking with someone (38%); busying themselves with other things (27%); crying (26%); asking for help (21%); smoking (14%); blaming oneself (13%); yelling, screaming, slamming doors (12%); getting away (24%); exercising (15%); ignoring (12%); alcohol (16%); medicine (13%); and blaming others (12%). Only 19% of the parents belonged to an association related to cystic fibrosis. Of those who did 48% went occasionally; 17% never went, and 35% went frequently. One third of the parents who attended found the meetings helpful while 17% did not find the meetings helpful (Hymovich & Baker, 1985).

Ineffective coping efforts have been reported in families of children with cystic fibrosis. Adolescents with cystic fibrosis reported inadequate communication between mothers and fathers. They described their mothers as overprotective and fathers as withdrawn. It seemed the closer the mothers were to the CF adolescent the more distant the fathers. Adolescents with mothers who worked outside of the home were better adjusted (Boyle, diSant Agnese, Sack, Millican, & Kulczycki, 1976). Families of children with cystic fibrosis reported difficulty maintaining a relationship with a potentially dying child. Anticipatory grief fluctuated with denial of prognosis. Parents expressed difficulty meeting the physical and emotional needs of the ill child while meeting the needs of other family members (McCollum & Gibson, 1970).

Sharing burdens within and outside of the family was significantly related to family functioning (Venters, 1981). Role changes for siblings however can increase the demands for independence and lead to feelings of anxiety and abandonment (Lavigne & Burns, 1981). When parents perceived the attitudes of friends, relatives, and/or the community as negative they responded by withdrawing from these relationships (Maddison & Raphael, 1971; McKeever, 1983). In parents of children with leukemia and cystic fibrosis, crisis support, neighborhood interaction, and community participation had a direct effect on parental psychiatric symptoms (Frydman, 1981). Thus withdrawing from extrafamilial relationships as a coping response could have negative consequences for the family.

Summary

The research on coping supports an initial grief process in response to the diagnosis of a child's chronic illness. This grief process may explain the inconsistent findings related to depression in parents of chronically ill children as well as some of the other findings of emotional disturbance. Studies done during this initial grief process would be more likely to find an increased incidence of depressive symptomatology and other behavior indicative of emotional maladjustment in a nongrieving population. After this initial period the majority of families appeared to develop effective coping strategies that facilitate on-going adaptation and development. The literature does suggest however that the effectiveness of the ongoing family adaptation is related to the family's effectiveness in dealing with the initial stressors. The use of open communication within and outside of the family, acquisition and maintenance of social support, and

management of the medical situation were important coping skills for these families. The use of these coping behaviors by mothers and fathers appears to have differential effects with the mother's efforts having a greater effect on the interpersonal dimensions of family functioning and the father's efforts having a greater effect on the system maintenance dimensions. Clarity of roles and open communication within the family facilitated effective coping. Outside of the family, crisis support, neighborhood interaction, and community participation facilitated effective coping. Over time families often reorganized their values and goals in life developing a philosophy of life that placed more emphasis on human values (e.g. love and sharing) than future goals (e.g. academic achievement, athletic prowess, occupational opportunity). They could thus develop a sense of worthwhileness of the child's life despite the disease imposed limitations (Lavigne & Burns, 1981). Defining the illness situation within an existing philosophy (e.g. biological, religious) was positively associated with family functioning (Venters, 1981).

Adaptation and Family Functioning

Adaptation is a continuous process that reflects family functioning in the areas of family cohesion and organization, sense of control over environmental influences, and promotion of individual member and family development. Family adaptation to stress involves at least two major components. First, the family must have or develop such internal resources as integration and adaptability in order to withstand social and psychological stresses. Second, the family must have or develop a range of coping behaviors directed at strengthening its internal organization and functioning, at procuring community and social

supports, and in some cases at diverting, reducing, or eliminating the sources of stress. The development of interpersonal relationships outside the family system appears to be an important coping pattern and contributes to self-development and self-esteem. In severely stressful situations family members must devote effort to maintaining integration and stability. Spiritual support contributes to maintaining the family unit, individual self-esteem, and serves as a reference point for social norms and expectations which may guide families in stressful situations (McCubbin, 1979). The clarity of community norms and expectations regarding family behavior under stress also influences the vulnerability of families under stress. The degree of family adherence to community norms and the strength of the family's interpersonal relationships is inversely related to vulnerability under stress.

Family functioning has not been examined comprehensively in families with chronically ill children. It has been assessed either as a generic concept that is rated for general quality or a specific aspect of family functioning has been singled out in the study of other variables. Examination of these studies together however does provide insight into the relevance of family functioning in the on-going adaptation of families to chronic childhood illness as well as the effects of some of the specific aspects of family functioning. Poor quality of family life as measured by an index of family functioning was found to place the chronically ill child at the highest risk for psychological maladaptation (Pless et al., 1972). In addition, if the chronically ill child is older and his personality and role in the family have developed, an even greater sense of loss may be experienced by all family members (Steinhauer, Mushin, & Rae-Grant, 1974). The

increased emotional, time, and financial demands resulting from the illness can lead to decreased family cohesion with relative neglect of siblings as well as sibling rivalry and guilt if the child dies. The husband also may receive relatively less emotional and practical attention if the mother is the primary caregiver (Maddison & Raphael, 1971). The greatest psychological or social problems are likely to develop when serious chronic illness occurs within an already disturbed family situation (Steinhauer et al., 1974).

In a 2 year follow up of families with a leukemic child current family adjustment was within normal range. Multiple, pre-existing marital, family, and/ or emotional problems were a common factor in the 9 of 60 families who had below normal family coping scores at 6 months and 2 years. Sixty-five percent of the families were considered to have good marital and family relations. The predominant emotional reactions were anxiety and apprehension, sadness with a depressive affect, cheerful affect, and anger. The most difficult times as reported by the parents were diagnosis, medical procedures, feelings of helplessness, dealing with the reactions of other people, and watching changes in the child's physical appearance (Kupst, Schulman, Maurer, Honig, Morgan, & Fochtment, 1984). Follow-up of the same families 6-8 years post-diagnosis revealed that the families' coping continued to be high and appeared to increase. The adequacy of coping at diagnosis was significantly related to coping six years later. Families who coped well tended to have better family support, higher quality of marital relationships, fewer concurrent stressors, and more open communication (Kupst & Schulman, 1988). In a second longitudinal study, classification of early coping reactions in families of children with

leukemia were also found to be predictive of later adaptational level (Kaplan et al., 1976). Powazek and his colleagues (1980) studied families of children with leukemia longitudinally. One year after diagnosis 33% of the mothers were highly anxious, 17% showed high depression scores, 11% high psychoticism scores, and 44% high neurotic maladjustment scores. These levels were lower than at the time of diagnosis. Six months after diagnosis less than 11% of the children were highly anxious. Forty-six per cent of the patients discussed the fear or possibility of death. Fifty-five per cent of these children talked to their mother; 18% to their fathers; and 27% with other relatives or friends. After one year families were well educated regarding leukemia and its treatment, used the word 'cancer' or 'leukemia', and told family and friends about the disease. The illness was not kept secret or denied. All families knew that leukemia was serious, chronic, and sometimes fatal. Serious psychiatric disturbance was not apparent in the first year although there were increased scores on anxiety, depression, and occasionally disturbed thinking. Mothers reported that family disruption declined in 6 months and the majority of the patients returned to prior level of functioning (e.g. school). Approximately 20% of the parents reported increased use of alcohol and tranquilizers. Adaptation seemed particularly difficult for fathers and siblings. While 75% of the mothers discussed the disease at home only 54% of the fathers and 26% of the siblings did so. Lack of discussion by fathers and siblings may reflect a lack of open, effective family communication. For fathers and siblings this could result from less participation in the treatment process. Siblings showed evidence of a variety of behavior problems including: fear of going to school, fear

of being left alone, achievement and behavior problems in class, increased anger and jealousy toward the ill sibling, and somatic complaints. The siblings understanding of the disease process was noticeably deficient (Powazek et al., 1980).

Changes in boundaries, roles, values, and patterns of interaction affect family functioning. Families who used open communication prior to the diagnosis tended to maintain an open communication style within the family and in relationships outside of the family. In contrast a blurred, closed communication style tended to be exacerbated by stress with members withdrawing into themselves or subgroups. This resulted in a fixed, anxious atmosphere characterized by confusion and diffuse depression. The family system was fixed in a closed way of functioning characterized by withdrawal from the outside world and consequent affective and intellectual impoverishment (Pacquay-Weinstock et al., 1979). Open family boundaries and communication style would enhance the availability of support to the family and its members whereas closed family boundaries and communication style would decrease the amount of available support. In families with diabetic children, intact boundaries between 2 generations, family stability, and the capacity of family members to enjoy each others company was positively related to diabetic control (Klusa et al., 1983). The findings of these studies support the importance of clear, open communication and boundaries in family adaptation.

Family communication style has been examined in families of children with a variety of chronic illnesses. Using a family problem solving task, families of epileptics showed increased conformity to group opinion, greater acknowledgement of interruptions, less conflict,

and more rapid decision-making than matched controls. The mothers in these families were more dominant than the fathers and the family structure was a more rigid dominance hierarchy than the control families. The strength of their problem-solving skills may have been in the clarity of the roles, boundaries, and patterns of interaction (Ritchie, 1981). In one study families of asthmatic children scored significantly lower on family expressiveness than matched healthy control families. This may reflect the extent to which feelings are openly and directly expressed and could negatively affect the level of adaptation (Hilliard, Fritz, & Lewiston, 1982). In a second study of families of asthmatics in a standard communication situation one third of the asthmatic's parents communicated ineffectively, could not take each others perspective, seemed to listen but did not, and were egocentric. In comparison with parents of children with congenital heart disease the couples with asthmatic children seemed to have a high tolerance for vague, unclear communication with the pretense that they understood. They demonstrated high anxiety for open conflict and did everything possible to avoid conflict (Wikran, Faleide, & Blakar, 1978). These findings are consistent with the subset of families with asthmatic and diabetic children that Minuchin and his colleagues (1975) identified as 'psychosomatogenic.' This subset of families develops a manner of functioning after the disease onset that maintains the symptomatology. Psychosomatogenic families are characterized by enmeshment, rigidity, overprotection, and poor conflict resolution.

Family factors involved in the adaptation to cystic fibrosis have been described. Mother's rating of illness severity was positively related to limits on family opportunity. The greater the severity of

the illness rating the greater the sense of reward mothers derived from caretaking tasks (Walker et al., 1987). These findings suggest that the mother's overestimation of illness severity may lead to over involvement in child care with a consequent decrease in family cohesion and communication. Gayton and his colleagues (1977) found no significant differences in family adjustment and family satisfaction between families of children with cystic fibrosis and healthy controls. The family's perception of severity again seemed to be a crucial factor. Over time parents of children with cystic fibrosis reported giving the illness a more positive interpretation. This re-interpretation was associated with positive family functioning and adaptation. The ability to share the burdens within and outside of the family which is related to clear, flexible boundaries was also positively related to family functioning (Venters, 1981).

A 13 year longitudinal study examined family and individual factors that influenced the outcome for children with end stage renal disease. Vulnerability to poor outcome was strongly increased with the following factors: poor family support, complex medical course, low income and other practical problems, and the experience of renal failure and treatment for end stage renal disease occurring in adolescence. In the patients, vulnerable personality before the illness including poor self-esteem and high anxiety related to poor outcome. Poor family functioning with family disorganization was also strongly related to poor outcome (Korsch, 1985). Thus a large number of the factors influencing poor outcome in end stage renal disease were related to the family functioning.

Studies of children with diabetes revealed that their adaptation was related to a number of family functioning factors. The perceived self competence of diabetics was significantly related to the family dimensions of organization, independence, and activities. Family orientation toward personal growth and family system maintenance predicted multiple types of diabetic adjustment and total diabetic adjustment (Hauser, Jacobson, Wertlieb, Brink, & Wentworth, 1985). Based on parental report a significantly greater proportion (75%) of families of adolescent diabetics fell in the structured or rigid range of adaptability. This style of adaptability was significantly related to poor metabolic control of diabetes of short duration. The relationship between family adaptability and metabolic control was attenuated as the duration of the diabetes increased (Hanson, Henggler, Harris, Burghen, & Moore, 1989). Although families of diabetics do not appear to differ from families of healthy children on family cohesion, cohesion has shown a significant relationship to metabolic control (Evans & Hughes, 1987; Hanson et al., 1989).

A variety of family dynamics and styles of family functioning were found in studies of families of hemophiliacs. In one study the families' functioning reflected the mother's guilt, the father's ambivalence, and the child's conflict about movement. These mothers constantly questioned their ability to rear children and carried out the suggestions of the doctor literally and to extremes. For the mothers, activity was seen as equivalent to injury and school was thus seen as a threat. Although most of the children were overtly docile and passive, they did rebel in subtle ways against restrictions. Anticipation of increased activity or independence was the theme most commonly

associated with spontaneous bleeding episodes. The reactions of the fathers in this study varied (Browne, et al., 1960). These findings suggest that the interaction of the mother's feelings with the child's behavior and symptoms has an important influence on family functioning. While a second study of families of hemophiliacs found that some families reported withdrawal of the husband and decreased attention for the other children (Salk et al., 1972), a third study found that fathers of hemophiliacs participated more in childrearing than fathers of healthy controls and saw their role more in terms of care and protection than masculinity. Fifteen of the sixteen couples reported that having a chronically ill child brought them closer together (Markova et al., 1980). The inconsistency of these findings support the impression that the presence of a chronic illness alone does not predict a specific pattern of family functioning and the pattern of family functioning is not disease specific.

Cross-disease studies have examined a number of characteristics of chronically ill children and their families that relate to family functioning. One study of chronically ill adolescents provides some insight into the longer term implications of family functioning for chronically ill children. It was found that chronically ill adolescents frequently did not have their drivers license. In some cases this was due to their illness but in others it was due to parental refusal. There were no significant differences between the ill and well adolescents on psychosocial items including: intactness of family, satisfaction with parents and self, types and number of outside interests, number and type of school activities, number and reported closeness of friends, days missed from school, or ability to talk to

adults. Fewer of the chronically ill adolescents perceived home life to be good. They reported doing things less frequently with their families and shared problems more often with their siblings than the healthy adolescents did (Orr et al., 1984).

In 1962 Olshansky proposed that parents who have a mentally defective child experience chronic sorrow that varies in intensity across time. This theory appears applicable to many long term health problems in children including chronic illness. A later review of this theory supported chronic sorrow and suggested that final acceptance may not be realistic (Kornblum & Anderson, 1977). Many parents of leukemic children report periodic onset of depressive symptoms associated with the child's hospitalization or appointments. During remissions most parents attempted to lead as normal a life as possible. They acknowledged the urge to overindulge the child. Changes in work habits and social lives indicated the parents were not entirely successful. The occurrence and effects of cyclical upheaval cannot be assessed by one time cross-sectional studies (Eiser, 1979). In one study parents of chronically ill children reported increased demands on time and energy and pressure to take 'proper' care of the ill child. They expressed an increased need for approval as a 'good' parent. The parents scored lower on parental confidence and extroversion and higher on social desirability and neuroticism than the standardized norms (Pacquay-Weinstock et al., 1979). Over time families reorganized their values and goals in life and were thus able to develop a sense of worthwhileness of the child's life despite the disease imposed limitations (Lavigne & Burns, 1981).

Summary

Adaptive behavior is more likely in families that are intact and well integrated, families with open channels of communication, families with clear but flexible roles, boundaries, authority and status structures, and families that have successfully met past disasters. In some studies, coping responses such as overinvolvement in the care of the ill child resulted in decreased family communication and communication. Lack of family organization as well as ineffective communication may impair the family's ability to share both the instrumental and psychosocial demands of having a chronically ill child. The strength of the family's interpersonal relationships both within and outside of the family is positively related to a family's regenerative powers (McCubbin, 1979).

Conclusion

The impact of chronic childhood illness on the family is extremely variable. A variety of methodological issues make it difficult to reach definitive conclusions about family adaptation. The majority of the studies have focused on maladaptation of the family or specific family members. Furthermore, conclusions regarding the family were often based on data from one parent usually the mother. In an increasing number of the more recent studies data from both parents was utilized. Data from the chronically ill child were included only in those studies where the affect of family variables on the chronically ill child's psychosocial adjustment or disease management was the focus of the study. Data from siblings were rarely included. Studies of coping and adjustment in families with chronically ill children have focused primarily on the initial response to the diagnosis and specific family characteristics at

one point in time (e.g family expressiveness). The research to date does provide insight into some of the issues which influence family adaptation. Although the medical treatment for different diseases is quite different, the other needs and problems of the chronically ill children and their families have more features in common than features that distinguish them. Families and children have both generic and specific needs. The research supports that family adaptation is neither disease specific nor specific to the presence of a chronically ill child alone.

In both families with healthy children and families with chronically ill children family adaptation appears to be a generic process that is a function of the relationships among demands, resources, perception of demands, coping skills and attributes of family functioning such as structure and communication. The model (Figure 1) for this study is proposed as a means for conceptualizing the family adaptational process and investigating factors which may influence the process and the relationships among the factors. The present study focuses on describing the adaptational process rather than the identification of psychopathology and maladaptation. Since family responses during the initial diagnostic period have been described in previous research, this study will examine family adaptation after the diagnostic period. In order to obtain a more comprehensive view of the family, data from the parents, the chronically ill children, and siblings will be used. In this study families of chronically ill children and comparison families with healthy children will be used to test the model. Differences between the chronic illness families and

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the comparison families on each of the model components will also be examined.

CHAPTER 2 METHODOLOGY

Sample

The sample consisted of 45 families. There were 28 families with a school age (8-12 years) child who had been diagnosed with a chronic illness for at least one year and 17 comparison families with healthy children. There were 8 families of children with asthma, 6 with congenital heart disease, 8 with cystic fibrosis, and 6 with insulin dependent diabetes mellitus. In the comparison families the children had no known physical abnormalities or developmental deficits. Families with chronically ill children were recruited through the pediatric subspecialty clinics in the Department of Pediatrics and Human Development at Michigan State University. Recruitment was limited to these clinics in an effort to control the philosophical approach to the medical management of chronic childhood illness. These clinics encourage patient and family participation in management which may not be true in other settings and could influence the family's adaptation. Due to the limited number of chronically ill children in some of the diagnostic categories all families coming to the respective pediatric subspecialty clinic who met the criteria were asked to participate successively. The comparison families were recruited through university, neighborhood, and community agency announcement.

Family was defined as the parent(s) (biological, adoptive, or step-parents), the target child, and siblings (biological, half, or step-siblings) eight years of age or older, who were living currently in the home. The minimum age of eight years was selected in an effort to avoid the cognitive transitional period that generally occurs between 5-7

years and thus facilitate the children's ability to understand and respond to the instruments. Four families were randomly selected from each of the four chronic illness categories for purposes of matching. The comparison families were matched to one of the selected chronic illness families on: age, sex, and birth order of the target child; number of parents in the home; approximate family size, and income. Birth order of the target child was matched on oldest, middle, or youngest. Family size was matched for 1-2 children, 3-5 children, 6 or more children. Income was matched for <\$20,000, \$20,000-34,999, \$35,000-49,999, \$50,000-74,999, and >\$75,000. Thirteen of the comparison families were able to be matched to the randomly selected chronic illness families. The other four comparison families were matched to four non-randomly selected chronic illness families that were evenly distributed across the diagnostic categories. The final sample consisted of 160 subjects. In the 28 target families there were 47 parents (28 mothers, 19 fathers), 28 target children, and 27 siblings (17 children, 10 adolescents). In the 17 comparison families there were 28 parents (17 mothers, 11 fathers), 17 target children, and 13 siblings (4 children, 9 adolescents).

Chi square analysis revealed no significant differences between the chronic illness and comparison families on the target child characteristics (age, sex, and birth order), family characteristics (number of parents, number of children, and income) or the parent characteristics of father's education, occupation, or full/part time work. Mothers in the comparison families had significantly more education, were significantly more likely to work outside of the home and in graduate professional positions than mothers in the chronic

illness families. Significantly more mothers in the comparison group worked full time. Specific information describing the sample characteristics is provided in Table 1 (Family Member Characteristics) and Table 2 (Family Characteristics).

Procedures

All procedures were the same for the chronically ill families and the comparison families. Families meeting the criteria received a letter explaining the study and inviting their participation. The letter contained a return postcard indicating willingness to participate, most convenient times for participation, and family composition. Families who returned the postcards received a follow-up phone call from the investigator to answer any questions and schedule an appointment for a home visit with the entire family. At the home visit the study was explained to the entire family, questions answered, and informed consent obtained. Sociodemographic and illness demographic (for families with chronically ill children) information were obtained from the parents by interview. Each family member was then asked to complete the appropriate instruments. The investigator answered questions and assisted the younger children with completion of the instruments.

Instruments

The instruments used to assess the model constructs follow. Some of the instruments were revised in order to be age-appropriate. These revisions are described later.

Demands

Demands were assessed by the Life Events Questionnaire (LEQ), the Hassles Scale, and the Uplifts Scale (Kanner, Coyne, Schaefer, and

Table 1

Family Member Characteristics

<u>Variable</u>	<u>Target</u>		<u>Comparison</u>	
Target Child	Mean		Mean	
Age	9.93 yrs.		10.45 yrs.	
Sex	<u>N</u>	<u>%</u>	<u>N</u>	<u>%</u>
female	13	46	8	47
male	15	54	9	53
Birth Order	Mean		Mean	
	Oldest		Middle	
Youngest	8	29	7	41
Middle	4	14	2	12
Oldest	11	39	4	23.5
Mother	Mean		Mean	
Education	some college		college	
less than high school	1	4	0	0
high school	6	22	0	0
business, trade, jr. college	5	18	2	13
some college	10	37	1	6
college	4	15	9	56
postgraduate	1	4	4	25
Occupation	Median		Median	
	trade, clerical technical		graduate professional	
no work outside home	9	33	2	12
unskilled labor	2	7	0	0
trade, clerical, technical	7	26	4	23
sales	3	11	0	0
management	1	4	0	0
graduate professional	5	19	11	65
Amount of work	Mean		Mean	
	full-time		full-time	
none outside of home	9	33	2	12
full-time	8	30	12	70
part-time	10	37	3	18
Father	Mean		Mean	
Education	some college		college	
less than high school	1	4	0	0
high school	5	22	0	0
trade, business, jr. college	4	17.4	2	18

Table 1 (cont.)

<u>Variable</u>	<u>Target</u>		<u>Comparison</u>	
	<u>N</u>	<u>%</u>	<u>N</u>	<u>%</u>
some college	5	22	1	9
college	4	17.4	3	27
postgraduate	4	17.4	5	46
Occupation		Median		Median
no work outside home	1	4	0	0
unskilled labor	3	13	0	0
trade, clerical, technical	7	30	6	50
sales	5	22	0	0
management	2	9	1	8.3
graduate professional	5	22	4	33.3
postgraduate prof.	0	0	1	8.3
Amount of Work		Mean full-time		Mean full-time
no work outside home	1	4.3	0	0
full-time	21	91.3	12	100
part-time	1	4.3	0	0

Table 2

Family Characteristics

<u>Variable</u>	<u>Target</u>			<u>Comparison</u>		
	<u>N</u>	<u>%</u>	<u>Mean</u>	<u>N</u>	<u>%</u>	<u>Mean</u>
Number of Families	28			17		
Number of Parents			2			2
one parent	4	14		5	29	
two parents	22	79		12	71	
one parent plus sign. other	2	7		0	0	
mothers	27	96		17	100	
fathers	19	68		11	65	
Number of Children			2			2
one child	5	18		4	23.5	
two children	14	50		8	47	
three children	3	11		4	23.5	
four children	3	11		1	6	
five children	2	7		0	0	
six children	1	3		0	0	
Income			\$35,000-44,999			\$45,000-54,999
under \$12,000	5	18		0	0	
\$12,000-24,999	5	18		4	23	
\$35,000-34,999	5	18		3	18	
\$35,000-44,999	3	10.7		1	6	
\$45,000-54,999	3	10.7		1	6	
\$55,000-64,999	4	14		1	6	
\$65,000-74,999	1	3.6		5	29	
over \$75,000	2	7		2	12	

Lazarus, 1981). The Life Events Questionnaires were based on the Life Experiences Survey (LES)(Sarason, Johnson, & Siegel, 1978) with some questions added from the Children's Life Event Record (Coddington, 1972). The Life Experiences Survey (Sarason et al., 1978) was designed to eliminate some of the consistent criticisms of previous life stress measures by including a list of events experienced with some degree of frequency, allowing the respondents to rate the desirability or undesirability of the event, and allowing the respondents themselves to rate the personal impact of each event experienced. In his comprehensive review of methodological issues in life events research, Zimmerman (1983) found that group-derived weights generally do not improve the stress-illness relationship. There was substantial evidence of interindividual and intergroup variability in the perception of an event's impact. Assessment of this variability in perception is of particular importance in the current study in order to examine the family's perception of the demands. There are also indications that individually derived weights are more highly correlated with psychiatric symptoms than consensus weights (Zimmerman, 1983). Zimmerman (1983, p. 360) concluded that "a largely unrecognized value of subjective weights may be in their ability to identify individuals at high-risk for becoming ill after an event has occurred." Thus the design of the LES was a major reason for its selection for this study.

The reliability and validity of the LES are comparable with other life events questionnaires (Sarason et al., 1978; Zimmerman, 1983). The psychometric properties of the LES have been examined for the direction (positive or negative) and intensity of the impact but not the frequency of events. Although together the life events items provide a

quantitative measure of major stressors, the individual life events are not necessarily stably or highly inter-related. For example, the 'death of a family member' and a family member 'being in jail' may not be highly or consistently correlated. This instability of inter-item correlations makes internal consistency a less meaningful measure of reliability with life events measures than test-retest reliability which examines the consistency of events reported over time. Test-retest reliabilities of the LES at 5- and 6- week intervals were .19 and .53 for the positive change scores; .56 and .88 for the negative change scores; and .63 and .64 for the total change scores (Sarason et al., 1978). The validity of the LES has been demonstrated with a number of outcome measures. Total and negative change scores have shown significant correlations with state and trait anxiety, lower grade point average, self-rated depression, and measures of personal adjustment (Kale & Stenmark, 1983; Sarason et al., 1978).

Instruments assessing life events have been designed for adults in studies of the epidemiology of the stress-illness relationship. The Children's Life Event Record (Coddington, 1972) was the first such instrument developed to assess life events in children. Although research that includes the assessment of life events in children is not frequent, the Children's Life Event Record has been the instrument used most often. It was designed for parents to complete. The items were developed from a survey of professionals working with children. To examine life events in the family for the present study it was felt that the LES approach of having the children themselves identify which events had occurred and rate their impact was important to retain. In order to be age appropriate the LES needed to be supplemented with life events

that are specifically relevant to the children and adolescents in the family. The items on the Children's Life Event Record were compared with those on the LES and the events not previously covered by the LES were added. Children as young as nine years of age have demonstrated the ability to make distinguishing judgments of perceived stressfulness of life events on 5 and 7 point Likert scales. These judgments often differed from those of professionals and adult respondents (Brown & Cohen, 1988; Yamamoto, 1979). The children's subjective ratings of perceived stressfulness that have occurred in their family are considered to be of particular value when examining the family's perception of the demands in the present study.

Three forms of the Life Events Questionnaire were used in this study: child (8yrs.-12yrs.), adolescent (13yrs.-19yrs.), and adult. The first 46 questions are the same on all three forms. Questions 47-50 are identical on the adolescent and adult forms. These questions relate to sexual difficulties, abortion, and outstanding personal achievement. The adult form has 3 additional questions (51-53) which are related to major financial issues. The Life Events Questionnaires ask which events happened in the family in the past 6 months, to whom it happened, and what that event was like for the respondent. The respondent rates the impact of the event on a 5 point scale from Very Negative to Very Positive (Very Bad to Very Good on children's form). The wording and print size on the children's form were adapted for easier reading. For the purposes of this study the 46 items that are present on all three forms of the Life Events Questionnaire were used for the analysis.

The Hassles and Uplifts Scales (Kanner et al., 1981) are designed to assess positive and negative experiences that characterize everyday

transactions with the environment. Age-appropriate adaptations were made in the format and wording of the adult scales to develop the child and adolescent forms used in this study. The respondent is asked to indicate which hassles and uplifts he/she experienced and rate each experience on a 3 point scale from somewhat hassled to very hassled (Hassles Scale) or somewhat pleasurable to very pleasurable (Uplifts Scale). There are 118 potential Hassles and 134 potential Uplifts on the adult form. The children's form contains 96 Hassles and 119 Uplifts derived from the adult form. The adolescent version contains 111 Hassles and 129 Uplifts drawn from the adult forms. Thus there were 96 Hassles and 119 Uplifts responded to be all family members. For purposes of this study the Hassles and Uplifts responded to by all family members were used in the analysis.

The psychometric properties of the Hassles and Uplifts Scales were determined with adult samples from early through middle adulthood (Kanner et al., 1981). As was true for the life events measure, individual items on the Hassles and Uplifts Scales may not be consistently or highly inter-related making examination of internal consistency less meaningful than test-retest reliability. Test-retest correlations of each monthly administration with every other administration over a ten month period were calculated. For the Hassles Scale the average correlations were .79 for frequency and .48 for intensity. For the Uplifts Scale the average correlations were .72 for frequency and .60 for intensity (Kanner et al., 1981). The Hassles and Uplifts Scales were positively related to each other. The correlation of their frequency scores was .51 and of their intensity scores .28. This relationship may reflect either a common response style or a

tendency for people who experience many hassles to also experience many uplifts (Kanner et al., 1981).

The validity of the Hassles and Uplifts Scales has been examined. Frequency of hassles was related ($r = .34$) to negative affect and psychological symptoms. Intensity of hassles was not significantly related to affect or psychological symptoms. Frequency and intensity of uplifts were related to positive affect. The correlations were .33 and .25 respectively. When these data were examined by gender, uplifts frequency and negative affect tended to be negatively correlated for men but positively correlated for women. This suggests that for women Uplifts may contribute to the level of stress. The positive relationship between uplifts and measures of stress for women was found throughout the analysis (Kanner et al., 1981).

Hassles and Uplifts intensity scores were not significantly related to life events. There was a significant positive relationship between life events that occurred during the 10 month study and frequency of hassles for women. This relationship was not significant for men. When significant relationships did occur life events were positively related to hassles and negatively related to uplifts for men. For women life events were positively related to both hassles and uplifts. In regression analyses hassles were a more powerful predictor of psychological symptoms than life events. Hassles continued to contribute significantly to the variance in psychological symptoms when the variance due to life events was partialled out. Hassles were also a better predictor of psychological symptoms than uplifts for the total sample as well as for men and women separately. These results suggest

that hassles contribute to psychological symptoms independent of major life events (Kanner et al., 1981).

Perception of Demands

Perception of demands was measured by using the intensity responses of the family members to each of the events identified on the Life Events Questionnaire and on the Hassles and Uplifts Scales. The psychometric properties related to intensity have been discussed with the respective scales.

Resources

Resources were assessed by administering Harter's Self Perception Profiles for Children, Adolescents, and Adults (1982b, 1985, 1986a, 1986b, and 1988), the Multidimensional Locus of Control Scale (Levenson, 1981) for parents, the Nowicki-Strickland Locus of Control Scale (1973) for children and adolescents, and the Family Inventory of Resources for Management (FIRM) for parents (McCubbin and Thompson, 1987). The Self Perception Profiles for Children, Adolescents, and Adults were developed by Susan Harter (1982a, 1982b, 1985, 1986a, 1986b, 1988). All three profiles use a structured alternative format which allows for four potential choices. The Self Perception Profile for Children contains 36 items and six subscales. The subscales are Scholastic Competence, Social Acceptance, Athletic Competence, Physical Appearance, Behavioral Conduct, and Global Self Worth. For children from third through eighth grades the internal consistencies of the subscales were Scholastic Competence .80-.85, Social Acceptance .75-.80, Athletic Competence .80-.86, Physical Appearance .76-.82, Behavioral Conduct .71-.77, and Global Self Worth .78-.84. Factor analysis revealed that each of the five specific subscales (Global Self Worth excluded) defined their own

factor. The range of average cross-loadings was .04-.08 with no cross-loading greater than .18 (Harter, 1985). Correlations of the Scholastic Competence Subscale with teacher ratings of scholastic competence ranged from .28-.73 and with achievement test scores .27-.54. The lowest correlations were in the third grade. The Social Acceptance Subscale correlated .59 with sociometric peer ratings. The correlation between Athletic Competence and gym teachers' ratings was .62 (Harter, 1982b).

The Self Perception Profile for Adolescents contains 45 items and nine subscales (1986b, 1988). This is the most recent of Harter's Self-Perception Profiles. The subscales are Scholastic Competence, Social Acceptance, Athletic Competence, Physical Appearance, Job Competence, Romantic Appeal, Behavioral Conduct, Close Friendship, and Global Self-Worth. The internal consistency of the subscales for four samples of seventh through twelfth graders was .77-.91 for Scholastic Competence, .77-.90 for Social Acceptance, .86-.92 for Athletic Competence, .84-.89 for Physical Appearance, .55-.93 for Job Competence, .75-.85 for Romantic Appeal, .79-.85 for Close Friendship, .58-.78 for Behavioral Conduct, and .80-.89 for Global Self Worth.

Factor analysis revealed that each of the eight specific subscales define their own factors. The range of average cross factor loadings was .08-.12 with no cross loadings greater than .30. Intercorrelations among domain specific subscales demonstrated several patterns. Scholastic Competence was moderately related to Behavioral Conduct (.41-.45). Social Acceptance, Close Friendship, Romantic Appeal, and Physical Appearance appeared to form a moderately related cluster (.34-.58). Across all samples Physical Appearance was consistently and highly related to Self Worth (.66-.73). Scholastic Competence, Romantic

Appeal, and Behavioral Conduct were moderately related to Self Worth (.39-.59).

The Adult Self Perception Profile contains 50 items and 12 subscales (Harter, 1986a). The subscales are Sociability, Job Competence, Nurturance, Athletic Abilities, Physical Appearance, Adequate Provider, Morality, Household Management, Intimate Relationships, Intelligence, Sense of Humor, and Global Self-Worth. The internal consistency of the subscales was .87-.92 for Global Self Worth, .65-.75 for Job Competence, .75-.90 for Intelligence, .84-.91 for Athletic Abilities, .81-.87 for Physical Appearance, .63-.86 for Sense of Humor, .74-.82 for Sociability, .72-.88 for Intimate Relationships, .63-.88 for Morality, .67-.87 for Nurturance, .82-.90 for Household Management, and .83-.90 for Adequate Provider. Factor analysis of the eleven specific subscales (General Self-Worth excluded) revealed a clear ten factor solution. The only subscale not to define its own factor was Job Competence which had weak cross-loadings on Nurturance. It was felt that this may have been due to half of the sample being mothers/homemakers whose primary job responsibility was childrearing. The average loadings for the ten factors ranged from .65-.89. The average cross-loadings ranged from .05-.09. The Self Perception Profiles (Harter 1985, 1986a, 1986b, 1988) were selected for this study because of their sound psychometric properties and the logical upward extension from school age to adulthood which allows administration of comparable instruments to all family members.

The Multidimensional Locus of Control Scale developed by Levenson (1981) was used with the parents. This scale contains 24 items with three subscales: Internal, Powerful Others, and Chance. Internal

consistency with college student and adult samples was .51-.64 for the Internal Subscale; .72-.77 for the Powerful Others Subscale; and .73-.78 for the Chance Subscale. Test-retest reliabilities for a one week period were in the .60-.79 range and for a seven week period ranged from .62 to .73. Factor analysis revealed that the first factor was composed entirely of Powerful Other Subscale items. The second factor was composed entirely of Internal Subscale items. The third factor was composed entirely of Chance Subscale items. Control by powerful others correlated .54 with the Chance Subscale and both were negligibly correlated ($r = .04$ & $.03$) with the Internal Subscale. Correlations with Rotter's I-E Scale were .25 and .56 with the Powerful Others and Chance Subscales respectively and $-.41$ with the Internal Subscale. Correlations with social desirability were negligible. The original six point Likert scale used by Levenson was modified to a four point Likert scale for purposes of the current study to keep the across instrument response formats as consistent as possible. This scale was selected primarily because the response format provides a continuum rather than dichotomous response allowing greater flexibility in data analysis.

The Nowicki-Strickland Locus of Control Scale (1973) was used with children and adolescents. This Scale contains 40 items. The original yes-no response format was modified to a 4 point Likert scale from very untrue to very true to maintain response format consistency and flexibility in data analysis. Estimates of the internal consistency of the unmodified scale using the split-half method corrected by the Spearman-Brown formula ranged from .63 to .81 in third through twelfth grade students. Test-retest reliabilities six weeks apart were .63 for third grade students, .66 for seventh grade, and .71 for tenth grade.

The locus of control scores were not significantly correlated with social desirability scores. Internal scores were positively related to self esteem. External locus of control scores were negatively related to achievement scores. This relationship was stronger for males. Scores on the Nowicki-Strickland scale were significantly related to two other measures of children's locus of control the Intellectual Achievement Responsibility scale and the Bialer-Cromwell score.

The respective locus of control scale, one developed for adults and the other for children and adolescents, identifies the respondent's perception of internal and external control over individual and family situations.

Family Inventory of Resources for Management (FIRM) was designed by McCubbin and Comeau (McCubbin & Thompson, 1987) to assess the family's repertoire of resources. It contains 69 self-report items which ask the respondents to rate how well the items describe their family on a 0-3 scale. The internal reliability was .89. There are four subscales: Esteem and Communication, Mastery and Health, Extended Family Support, and Financial Well-Being. The internal consistency for the subscales was .85 for Esteem and Communication, .85 for Mastery and Health, .62 for Extended Family Support, and .85 for Financial Well-Being. FIRM was moderately and significantly related to all four subscales of the Family Environment Scale (FES). Using the Conflict Scale from the FES to divide two samples (families of children with myelomeningocele and families of children with cerebral palsy) in half, the high conflict families had a significantly lower level of resources using the scores on the FIRM. This instrument was only administered to the parents as much of the content was assessed to be age-inappropriate and/or probably

unknown to children and adolescents. Parents completed FIRM to assess the repertoire of resources available to the family. Due to a substantial number of significant subscale intercorrelations and low factor loadings only the total scale was used in this study.

Coping

Coping was assessed with the Family Crisis Oriented Personal Evaluation Scales (F-COPES) (McCubbin & Thompson, 1987). F-COPES was designed to identify problem-solving and behavioral strategies used by families in difficult or problematic situations. It consists of 30 items which ask the respondent to rate on a five point scale from very untrue to very true how well each statement describes their own family. The internal consistency of the scale was .86. Test-retest reliability over a four week period was .81. Factor analyses revealed five factors: acquiring social support, reframing the family problem, seeking spiritual support, mobilizing the family to acquire and accept help, and passive appraisal. The internal consistency for each of the factors was .83, .82, .80, .71, and .63 respectively. For purposes of the current study the wording was adapted for the children's form of F-COPES. Adolescents and parents responded to the original form. Thus F-COPES was administered to all family members.

Family Functioning

Family functioning was measured by the Family Functioning Questionnaire (Bloom, 1985). The Family Functioning Questionnaire was developed from four well-known self report family measures: the Family Environment Scale (Moos & Moos, 1981), the Family Concept Q Sort (van der Veen, 1965), the Family Adaptability and Cohesion Scales (Olson, Sprenkle, & Russell, 1979), and the Family Assessment Measure (Skinner,

Steinhauer, & Santa-Barbara, 1983). The Family Functioning Questionnaire was developed to identify a limited set of reliable concepts describing family functioning. The respondent is asked to rate on a four point scale how true each statement is of his/her family. The Questionnaire consists of 75 items and 15 dimensions of family functioning. The dimensions and their respective internal consistencies as measure by coefficient alpha were cohesion .78, expressiveness .77, conflict .76, intellectual-cultural orientation .71, active-recreational orientation .57, religious emphasis .88, organization .74, family sociability .71, external locus of control .67, family idealization .85, disengagement .66, democratic family style .65, laissez-faire family style .71, authoritarian family style .40, and enmeshment .78. Scale score intercorrelations ranged from .03 to .73 with a mean of .28. Factor analyses revealed 13 factors which accounted for 88.4% of the variance. Second order factor analysis of the 15 scale scores revealed heavy loadings of Cohesion, Expressiveness, and Family Idealization in one more general factor. For purposes of the current study the wording for the children and adolescent forms was adapted to make the questions more easily understood in these age groups. All family members completed the questionnaire.

Data Analysis

After the testing was completed, total and subscale scores as appropriate were calculated on each instrument for each subject. The mean, variance, and distribution of the scores for each measure were examined. Histograms of the raw scores derived for the Life Events Questionnaire and Hassles Scale revealed a positive skewness with outliers. In order to retain all of the cases and avoid the outliers

carrying undue weight in the data analysis logarithmic transformations were performed on these scores (Winer, 1971). No excessive skewness was found in the histograms of the other measures.

Internal consistency, using Cronbach's alpha, was calculated for each of the total and subscale scores. The results were examined and compared with the reported values. The Life Events Questionnaire, Hassles and Uplifts Scales, F-COPES, and the Family Functioning Questionnaire were administered to all family members. Internal consistency for these measures was calculated using the scores of children, adolescents, and adults together. This was done to determine if it was appropriate to utilize these scores together in data analysis. An alpha greater than .60 was selected a priori as the criterion to determine if family member scores (child, adolescent, adult) would be used together in analyses where the family was the subject/unit of study. A lower alpha was chosen due to the developmental differences in the respondents and the conceptual importance of using data from all family members (Cronbach, Gleser, Nanda, & Rajaratnam, 1972). This level of internal consistency was reached on all relevant measures.

Based on the internal consistency analysis, two of the subscales from F-COPES and the majority of subscales from the Family Functioning Questionnaire needed further examination. This was true when alpha was computed with child, adolescent, and adult scores separately and together. The two subscales from FCOPES that were evaluated further were: Mobilization of the Family to Acquire and Accept Help and the Passive Appraisal subscales. Although the alpha for the Mobilization subscale was .65, the subscale correlated highly with the Acquiring Social Support subscale. Correlational and factor analysis of the items

did not support two separate subscales. The Mobilization subscale was combined with the Acquiring Social Support subscale.

Cronbach's alpha for the Passive Appraisal subscale was .29. Three of the four items on this subscale had correlations below .30 with all of the other items on the total instrument. The fourth item had one correlations of .37 with an item on another subscale. This subscale was dropped from further analysis. These revisions resulted in four scores being used for coping in the data analysis: FCOPES total score, Acquiring Social Support, Reframing, and Seeking Spiritual Support.

The internal consistency of the original subscales from the Family Functioning Questionnaire are presented in Table 3. They ranged from .24 to .77 with nine of the original fifteen subscales having alphas below .60. Correlational and factor analyses were used to further examine the items and subscales. These analyses resulted in nine subscales. Three of the original subscales, Religious Emphasis, Family Organization, and Family Idealization, were retained. The Cohesion, Conflict, Sociability, and Disengagement subscales were revised based on inter-item correlations, item-total correlations, and factor loadings. Two new subscales were constructed: Open Communication and Chaotic Family Style. The Open Communication subscale primarily contains items from the original Expressiveness subscale and the Democratic Family Style subscale with additional items that had high factor loading and item-subscale correlations. The Chaotic Family Style subscale contains items from the External Locus of Control Subscale, Laissez-Faire Family Style subscale, and additional items identified from the correlational and factor analyses. The internal consistencies of the new subscales are presented in Table 4.

Table 3

Family Functioning Questionnaire--Original Subscales

Subscale	Cronbach's Alpha
Cohesion	.71
Expressiveness	.74
Intellectual-Cultural Orientation	.54
Active-Recreational Orientation	.49
Religious Emphasis	.77
Organization	.61
Family Sociability	.57
External Locus of Control	.57
Family Idealization	.73
Disengagement	.25
Democratic Family Style	.49
Laissez-Faire Family Style	.51
Authorization Family Style	.24
Enmeshment	.45

Table 4

Family Functioning Questionnaire--New Subscales

Subscale	Cronbach's Alpha
Cohesion	.75
Open Communication	.76
Conflict	.70
Religious Emphasis	.77
Organization	.61
Family Sociability	.67
Family Idealization	.73
Disengagement	.64
Chaotic Family Style	.62

Following the examination of the psychometric properties of the measures, all of the scores were standardized. Standardization of scores was performed to provide consistent units of measure across instruments and across subject groups (child, adolescent, adult) in the data analysis. Varying units of measure across 36 variables and 160 subjects from three age groups could result in spurious findings.

Correlational Analysis

Correlations were calculated to examine the relationships among the instruments measuring the model variables. Demands included frequency scores for positive, negative, and total life events, hassles, and uplifts. Perception of demands included intensity scores for positive, negative, and total life events, hassles, and uplifts. Resources included the MFIRM total score external locus of control scores and the scores from the six subscales of the Self Perception Profiles that are consistent across age groups. These subscales are General Self Worth, Scholastic Competence, Social Acceptance, Athletic Competence, Physical Appearance, and Conduct/Morality. Coping included the total score and three subscale scores from F-COPES. Family functioning was represented by the nine subscale scores from the Family Functioning Questionnaire. Correlations between scale and subscale scores within each of the model constructs were examined to facilitate data reduction for analysis of variance and multiple regression. Correlations between scale and subscale scores across each of the model constructs were examined for relationships between the model constructs. The Bonferroni procedure was used to control the risk of findings spurious results due to the multiple comparisons (Keppel, 1982). This resulted in a criterion of $p \leq .001$.

Analysis of Variance

Analysis of variance was performed to assess for significant between group differences. One group was composed of the families with chronically ill children and the other group was composed of the comparison families with healthy children. Differences were assessed on each of the variables since the correlational analysis did not support data reduction. Power for the analysis of variance with a medium effect size (.30), 36 variables, and 160 subjects was .94 (Cohen, 1988). The Tukey (HSD) procedure was used to maintain the family-wise significance rate at $p \leq .05$ (Winer, 1971).

Multiple Regression Analysis

Hierarchical multiple regression analyses were used to look at the significance of each of the model constructs and their relative position in the model in order to evaluate the role of each of the constructs for future statistical tests of the model. These analyses were used to examine the contribution of the model constructs in predicting perception of demands, coping, and family functioning respectively. The first analysis examined the independent and interactive contributions of demands and resources in predicting perceptions of demands. Then the contributions of perception of demands, demands, resources, and the interaction of demands and resources in predicting family coping (FCOPES) was examined. Lastly a series of multiple regression were run to examine the contributions of demands, perception of demands, resources, and coping to the variance in each of the dimensions of family functioning. The variables within each model construct were entered as a set in the order predicted by the model. To control the level of significance individual variables were only examined if the

increment in R^2 for the construct was significant (Cohen & Cohen, 1983). Power with a medium effect size for the multiple regression analysis of perception of demands was .99, for FCOPES the power was .98, and for the family functioning dimension .96 (Cohen, 1988).

HYPOTHESES

The following relationships among the variables in the family adaptation model were hypothesized:

Correlational Analyses

A summary of the correlational hypotheses for each of the model constructs is presented in Tables 5 through 9.

Analysis of Variance

The following hypotheses will be used to compare the chronic illness and comparison families:

1. The chronic illness families will have significantly higher scores on life events and hassles (demands) than the comparison families.
2. The chronic illness families will score significantly higher on family resources (FIRM) than the comparison families.
3. The chronic illness families will score significantly higher than the comparison families on the total intensity of negative life events and total intensity of hassles.
4. The mean intensity of negative life events and hassles will be significantly lower in the chronic illness families than in the comparison families.
5. The chronic illness families will score significantly higher on coping (FCOPES) than the comparison families.
6. Consistent with the conceptual model and previous studies that concluded the incidence of maladaptive individual and family

Table 5

Summary of Correlational Hypotheses for Demands

Demands	Demands				
	NLE	PLE	TLE	HF	UF
NLE	+				
PLE	-	+			
TLE	+	+	+		
HF	+	-	+	+	
UF	-	+	-	-	+
Resources					
	NLE	PLE	TLE	HF	UF
ELOC	+	+	+	+	+
PSC	-	+	-	-	+
PSA	-	+	-	-	+
PAC	-	+	-	-	+
PPA	-	+	-	-	+
PCM	-	+	-	-	+
GSW	-	+	-	-	+
FIRM	-	+	-	-	+
Perception of Demands					
	NLE	PLE	TLE	HF	UF
NLEI	+	-	+	+	-
PLEI	-	+	-	-	+
TLEI	+	+	+	+	+
HI	+	-	+	+	-
UI	-	+	+	-	+
Coping					
	NLE	PLE	TLE	HF	UF
FCTOT	-	+	-	-	+
FCREF	-	+	-	-	+
FCSS	-	+	-	-	+
FCASS	-	+	-	-	+
Family Functioning					
	NLE	PLE	TLE	HF	UF
FFCOH	-	+	-	-	+
FFOC	-	+	-	-	+
FFCON	+	-	+	+	-
FFSOC	-	+	-	-	+
FFID	-	+	-	-	+
FFREL	-	+	-	-	+
FFDIS	+	-	+	+	-
FFORG	-	+	-	-	+
FFCHA	+	-	+	+	-

Table 6

Summary of Correlational Hypotheses for Resources

Resources	Resources							
	ELOC	PSC	PSA	PAC	PPA	PCM	GSW	FIRM
ELOC	+							
PSC	-	+						
PSA	-	+	+					
PAC	-	+	+	+				
PPA	-	+	+	+	+			
PCM	-	+	+	+	+	+		
GSW	-	+	+	+	+	+	+	
FIRM	-	+	+	+	+	+	+	+
Perception of Demands								
	ELOC	PSC	PSA	PAC	PPA	PCM	GSW	FIRM
NLEI	+	-	-	-	-	-	-	-
PLEI	-	+	+	+	+	+	+	+
TLEI	+	-	-	-	-	-	-	-
HI	+	-	-	-	-	-	-	-
UI	-	+	+	+	+	+	+	+
Coping								
	ELOC	PSC	PSA	PAC	PPA	PCM	GSW	FIRM
FCTOT	-	+	+	+	+	+	+	+
FCREF	-	+	+	+	+	+	+	+
FCSS	-	+	+	+	+	+	+	+
FCASS	-	+	+	+	+	+	+	+
Family Functioning								
	ELOC	PSC	PSA	PAC	PPA	PCM	GSW	FIRM
FFCOH	-	+	+	+	+	+	+	+
FFOC	-	+	+	+	+	+	+	+
FFCON	+	-	-	-	-	-	-	-
FFSOC	-	+	+	+	+	+	+	+
FFID	-	+	+	+	+	+	+	+
FFREL	-	+	+	+	+	+	+	+
FFDIS	+	-	-	-	-	-	-	-
FFORG	-	+	+	+	+	+	+	+
FFCHA	+	-	-	-	-	-	-	-

Table 7

Summary of Correlational Hypotheses Perception of Demands

Perception of Demands	NLEI	PLEI	TLEI	HI	UI
NLEI	+				
PLEI	-	+			
TLEI	+	+	+		
HI	+	-	+	+	
UI	-	+	+	-	+
Coping	NLEI	PLEI	TLEI	HI	UI
FCTOT	-	+	-	-	+
FCREF	-	+	-	-	+
FCSSS	-	+	-	-	+
FCASS	-	+	-	-	+
Family Functioning	NLEI	PLEI	TLEI	HI	UI
FFCOH	-	+	-	-	+
FFOC	-	+	-	-	+
FFCON	+	-	+	+	-
FFSOC	-	+	-	-	+
FFID	-	+	-	-	+
FFREL	-	+	-	-	+
FFDIS	+	-	+	+	-
FFORG	-	+	-	-	+
FFCHA	+	-	+	+	-

Table 8

Summary of Correlational Hypotheses for Coping

Coping	FCTOT	Coping FCREF	FCSS	FCASS
FCTOT	+			
FCREF	+	+		
FCSSS	+	+	+	
FCASS	+	+	+	+
Family Functioning	FCTOT	FCREF	FCSS	FCASS
FFCOH	+	+	+	+
FFOC	+	+	+	+
FFCON	-	-	-	-
FFSOC	+	+	+	+
FFID	+	+	+	+
FFREL	+	+	+	+
FFDIS	-	-	-	-
FFORG	+	+	+	+
FFCHA	-	-	-	-

Table 9

Summary of Correlational Hypotheses for Family Functioning

Family Functioning	Family Functioning									
	FFCOH	FFOC	FFCON	FFSOC	FFID	FFREL	FFDIS	FFORG	FFCHA	
FFCOH	+									
FFOC	+	+								
FFCON	-	-	+							
FFSOC	+	+	-	+						
FFID	+	+	-	+	+					
FFREL	+	+	-	+	+	+				
FFDIS	-	-	+	-	-	-	+			
FFORG	+	+	-	+	+	+	-	+		
FFCHA	-	-	+	-	-	-	+	-	+	

functioning was not increased based solely on the presence of chronic childhood illness, no differences have been hypothesized between the chronic illness and comparison families in the present study on perceived self competence, locus of control, or family functioning.

Multiple Regression

1. The demands followed by resources and then the interaction of resources and demands will predict a significant amount of the variance in perception of demands.
2. Perception of demands followed by demands, resources, and then the interaction of resources and demands, will predict a significant amount of the variance in FCOPES.
3. FCOPES followed by perception of demands, demands, resources and then the interaction of resources and demands will predict a significant amount of the variance on each of the nine dimensions of family functioning.

CHAPTER 3 RESULTS

The results are organized by the three major types of analyses. The correlational analysis is presented first, followed by the analysis of variance and the multiple regression analyses respectively. Within each of the major analysis sections the results are presented by model construct beginning with the within construct results followed by the between construct results.

Correlational Analysis

Correlational analysis was used to provide an initial examination of the relationships among the variables. Because of the number of comparisons the Bonferroni procedure was used resulting in a criterion of $p \leq .001$ (Winer, 1971). In addition to examination of the relationships among the variables, the within construct correlations were examined to determine if data reduction was appropriate. With the exception of subscale-total scale correlations, the correlations were small to moderate. Thus all variables were retained for further analysis.

Demands

The variables included in demands were the frequency of Negative Life Events (NLE), Positive Life Events (PLE), Total Life Events (TLE), Hassles (HF), and Uplifts (UF). Total Life Events is the sum of the Negative and Positive Life Events used to represent the overall number of major events experienced by the family. The correlation matrix for the variables in demands is presented in Table 10.

Within Construct

Negative life events, positive life events, total life events, and hassles were positively interrelated. This supports the hypothesized

Table 10

Correlation Matrix for Demands

Demands	Demands				
	NLE	PLE	TLE	HF	UF
NLE	1.00				
PLE	.37**	1.00			
TLE	.79**	.74**	1.00		
HF	.39**	.20	.30**	1.00	
UF	.07	.15	.14	.44**	1.00
Resources					
	NLE	PLE	TLE	HF	UF
ELOC	.16	.02	.12	.16	.06
PSC	-.06	-.01	-.08	-.12	.09
PSA	-.07	.01	-.05	-.16	.12
PAC	-.11	.04	-.04	-.10	-.02
PPA	-.18	-.02	-.15	-.33**	.03
PCM	-.21	-.05	-.16	-.16	-.03
GSW	-.24	-.03	-.18	-.32**	.08
FIRM	-.32	-.17	-.26	-.26	.21
Perception of Demands					
	NLE	PLE	TLE	HF	UF
NLEI	.99**	.38**	.80**	.38**	.11
PLEI	.36**	.99**	.73**	.21	.18
TLEI	.81**	.78	.94**	.35**	.17
HI	.43**	.10	.27**	.79**	.20
UI	.08	.16	.14	.24	.78**
Coping					
	NLE	PLE	TLE	HF	UF
FCTOT	.00	-.08	-.11	.06	.25**
FCREF	-.08	-.16	-.21	-.07	.01
FCSS	-.07	.05	-.04	.06	.19
FCASS	.09	-.02	.01	.13	.31**
Family Functioning					
	NLE	PLE	TLE	HF	UF
FFCOH	-.25**	.00	-.16	-.09	.22
FFOC	-.01	.00	-.08	.05	.29**
FFCON	.29**	.11	.28**	.17	-.20
FFSOC	-.13	-.09	-.11	-.02	.23
FFID	-.12	-.03	-.07	.00	.27**
FFREL	-.12	.03	-.10	.02	.18
FFDIS	.19	.06	.16	.12	-.14
FFORG	-.09	-.01	-.11	-.09	.09
FFCHA	.11	.17	.22	.20	.21

** $p \leq .001$

relationships between negative life events, total life events, and hassles. The relationship of positive life events with these variables was hypothesized to be negative. The results are in the opposite direction. The only significant relationship found for uplifts was with hassles. This relationship was positive and in the opposite direction of the hypothesis. Thus both variables that reflect positive experiences related positively with the variables measuring negative experiences.

Between Construct

Resources were represented by family resources (FIRM), external locus of control (ELOC), and six dimensions of perceived self competence: scholastic competence (PSC), social acceptability (PSA), athletic competence (PAC), physical appearance (PPA), conduct-morality (PCM), and global self worth (GSW). The relationships between demands and the variables measuring resources were scattered and did not support the hypotheses. There were only two significant relationships and those involved Hassles. Hassles were negatively related to global self worth as well as to perceived physical appearance. Negative life events, positive life events, total life events, and uplifts were not significantly related to any of the resource variables.

The variables in perception of demands reflected the total intensity of negative life events (NLEI), positive life events (PLEI), total life events (TLEI), hassles (HI), and uplifts (UI). The hypotheses for negative life events, total life events, and hassles were supported, while the hypotheses for positive life events and uplifts received limited support. Each of the demands variables showed a high correlation with its respective variable in perception of demands. All

three life event measures significantly related to the positive and negative life event intensity variables. Only negative life events, total life events, and hassles were related to total life event and hassles intensity. Positive life events were not significantly related to the intensity of hassles or uplifts. Again the relationships of the positive experience variables were in the opposite direction of the hypotheses and uplifts was not significantly related to any of the life event intensity variables.

Coping was measured by a total score (FCTOT) and three specific types of coping responses, reframing (FCREF), seeking spiritual support (FCSS), and acquiring social support (FCASS). The relationship between demands and coping were limited in number and did not support the hypotheses. There were three significant relationships and those involved Uplifts. Uplifts was positively related to the total coping score and acquiring social support. None of the other demand variables were significantly related to coping.

Nine dimensions of family functioning were examined: cohesion (FFCOH), open communication (FFOC), conflict (FFCON), sociability (FFSOC), idealization (FFID), religious emphasis (FFREL), disengagement (FFDIS), organization (FFORG), and chaotic style (FFCHA). The hypotheses received limited support with four significant relationships. Negative life events were positively related to family conflict and negatively related to family cohesion. Total life events were also positively related to family conflict. Uplifts was positively related to open communication and idealization. Positive life events and hassles were not significantly related to the characteristics of family

functioning. Of the demands variables, uplifts showed the highest overall correlations with family functioning.

Resources

Resources included external locus of control (ELOC), family resources (FIRM), and six dimensions of perceived self competence. The dimensions of perceived self competence were scholastic competence (PSC), social acceptability (PSA), athletic competence (PAC), physical appearance (PPA), conduct-morality (PCM), and global self worth (GSW). The correlation matrix for resources is presented in Table 11.

Within Construct

The six dimensions of perceived self competence were all positively related as hypothesized. Only the relationships between athletic competence and conduct-morality and social acceptability respectively failed to reach significance. External locus of control was negatively related to all six dimensions of perceived self competence and to family resources as hypothesized however the relationships with social acceptability and physical appearance did not reach significance. Family resources were positively related to perceived self competence as hypothesized but only the relationships to physical appearance and global self worth reached significance. External locus of control was negatively related to family resources, perceived scholastic competence, athletic competence, conduct-morality, and global self worth as hypothesized. The relationships of external locus of control with perceived social acceptability and perceived physical appearance were negative but not significant.

Table 11

Correlation Matrix for Resources

Resources	ELOC	PSC	PSA	PAC	PPA	PCM	GSW	FIRM
ELOC	1.00							
PSC	-.27**	1.00						
PSA	-.10	.34**	1.00					
PAC	-.31**	.28**	.19	1.00				
PPA	-.16	.29**	.34**	.30**	1.00			
PCM	-.26**	.33**	.22	.13	.32**	1.00		
GSW	-.33**	.40**	.36**	.28**	.66**	.49**	1.00	
FIRM	-.31**	.20	.01	.08	.38**	.32	.56**	1.00
Perception of Demands								
NLEI	.16	-.06	-.04	-.09	-.14	-.20	-.21	-.33
PLEI	.02	.02	.04	.04	-.01	-.03	-.02	-.16
TLEI	.12	-.02	-.01	-.02	-.10	-.13	-.14	-.26
HI	.14	-.11	-.15	-.07	-.31**	-.17	-.35**	-.45**
UI	.08	.13	.16	.04	.19	.01	.15	.24
Coping								
FCTOT	.01	.07	.23	-.01	.06	.06	.15	.40**
FCREF	-.13	.21	.21	.08	.20	.29**	.25**	.51**
FCSS	.09	-.07	.02	-.19	-.07	-.11	.02	.09
FCASS	.13	-.03	.23	.01	.03	-.04	.08	.22
Family Functioning								
FFCOH	-.06	.12	.07	-.01	.25**	.15	.36**	.54**
FFOC	-.12	.17	.16	.12	.24	.20	.32**	.52**
FFCON	.20	-.40**	-.23	-.09	-.18	-.20	-.33**	-.47**
FFSOC	-.07	.15	.23	.19	.13	.11	.25**	.39**
FFID	-.06	.08	.06	-.01	.11	.07	.27**	.38**
FFREL	.09	-.02	.09	-.16	.00	-.08	.04	.05
FFDIS	.20	-.31**	-.18	-.08	-.29**	-.38**	-.47**	-.66**
FFORG	-.04	.25**	.04	-.09	.17	.14	.15	.33**
FFCHA	.48**	-.21	-.12	-.01	-.18	-.31**	-.30**	-.53**

** $p \leq .001$

Between Constructs

The variables within resources showed a number of significant relationships with perception of demands, coping, and family functioning. The hypothesized relationships between resources and perception of demands were not supported. There were three significant relationships. Family resources, global self worth, and perceived physical appearance were negatively related to hassles intensity.

The hypothesized relationships between resources and coping were partially supported. Family resources were positively related to the total coping responses. Family resources and two dimensions of perceived self competence, conduct-morality and global self worth, were significantly related to the use of reframing as a coping response. External locus of control, perceived scholastic competence, social acceptability, athletic competence and physical appearance were not significantly related to any of the measure of coping.

The hypothesized relationships between resources and family functioning were supported on the whole for global self worth and family resources but received limited support for external locus of control and the other five dimensions of perceived self competence. Three of the family functioning characteristics: conflict, disengagement and chaotic style, represent maladaptive patterns of functioning. Family resources and global self worth were negatively related to all three of these dimensions. There were scattered relationships between other resource variable and maladaptive family functioning. External locus of control was positively related and perceived conduct-morality negatively related to chaotic family style. Perceived physical appearance, conduct-morality, and scholastic competence were all negatively related to

family disengagement. Perceived scholastic competence and social acceptability were negatively related to family conflict.

The other six dimensions of family functioning represent adaptive family functioning. Of the dimensions of perceived self competence, global self worth showed the largest number of relationships with positive characteristics of family functioning. Global self worth was positively related to family sociability, cohesion, open communication, and idealization. Perceived physical appearance was positively related to family cohesion. Perceived scholastic competence was related to family organization. Family resources were positively related to family organization, sociability, cohesion, open communication, and idealization. External locus of control, perceived social acceptability, athletic competence, and conduct-morality showed no significant relationships with the adaptive dimensions of family functioning.

Perception of Demands

Perception of demands included the intensity of negative life events (NLEI), positive life events (PLEI), total life events (TLEI), hassles (HI), and uplifts (UI). The correlation matrix for perception of demands is presented in Table 12.

Within Construct

The intensity of the three types of life events and hassles were positively interrelated as hypothesized. The intensity of uplifts was related positively to the other intensity variables but none of these relationships was significant. The intensity of negative life events and total life events showed the strongest relationships with all of the intensity variables. The intensity of positive life events was

Table 12

Correlation Matrix for Perception of Demands

Perception of Demands	Perception of Demands				
	NLEI	PLEI	TLEI	HI	UI
NLEI	1.00				
PLEI	.37**	1.00			
TLEI	.83**	.78**	1.00		
HI	.44**	.10	.32**	1.00	
UI	.13	.18	.18	.16	1.00
Coping					
	NLEI	PLEI	TLEI	HI	UI
FCTOT	.00	-.08	-.04	-.01	.33**
FCREF	-.10	-.17	-.14	-.06	.12
FCSSS	-.07	.05	-.01	.01	.25**
FCASS	.11	-.02	.05	.03	.37**
Family Functioning					
	NLEI	PLEI	TLEI	HI	UI
FFCOH	-.19	.00	-.13	-.16	.30**
FFOC	.01	.01	.01	-.07	.34**
FFCON	.28**	.08	.23	.28**	-.15
FFSOC	-.10	-.07	-.13	-.04	.29**
FFID	-.08	-.02	-.08	-.02	.31**
FFREL	-.10	.03	-.05	-.01	.18
FFDIS	.18	.06	.13	.18	-.22
FFORG	-.10	-.02	-.06	-.15	.25**
FFCHA	.17	.17	.20	.20	.18

**p ≤ .001

significantly related to only the intensities of negative and total life events.

Between Constructs

The relationships of perception of demands with coping and family functioning are generally consistent with the relationships found with their respective demands variables. In contrast to what the model would predict, the intensities of major life events and hassles were not significantly related to the coping measures. Thus the majority of hypothesized relationships were not supported. Uplifts intensity was positively related to total coping and the specific coping responses of seeking spiritual support and acquiring social support as hypothesized.

Overall the hypotheses related to uplifts intensity and family functioning were supported while the hypothesized relationships between the other intensity variables and family functioning received scattered support. Uplifts intensity also showed the largest number of significant relationships with family functioning. It was positively related to cohesion, open communication, sociability, idealization, and organization. The intensity of major life events and hassles did show one significant relationship with family functioning. The intensities of negative life events and hassles were positively related to family conflict.

Coping

The variables included in coping were total coping responses (FCTOT), and three specific types of coping responses reframing (FCREF), seeking spiritual support (FCSS), and acquiring social support (FCASS). The correlation matrix for coping is presented in Table 13.

Table 13

Correlation Matrix for Coping

Coping	Coping			
	FCTOT	FCREF	FCSS	FCASS
FCTOT	1.00			
FCREF	.70**	1.00		
FCSSS	.51**	.04	1.00	
FCASS	.88**	.40**	.40**	1.00
Family Functioning				
	FCTOT	FCREF	FCSS	FCASS
FFCOH	.21	.13	.19	.17
FFOC	.43**	.36**	.17	.40**
FFCON	-.20	-.08	-.18	-.17
FFSOC	.33**	.24	.14	.30**
FFID	.27**	.20	.16	.25**
FFREL	.35**	.01	.74**	.24**
FFDIS	-.33**	-.48**	-.02	-.18
FFORG	.26	.17	.22	.21
FFCHA	-.12	-.30**	.17	.02

** $p \leq .001$

Within Construct

The four variables in coping were all positively interrelated as predicted but all of the relationships did not reach significance. Total coping responses were significantly related to all three specific types of coping responses. Acquiring social support and seeking spiritual support were significantly related and acquiring social support was also significantly related to reframing. Reframing and seeking spiritual support were not significantly related.

Between Constructs

The hypothesized relationships between coping and family functioning were partially supported. The total coping responses were positively related to four of the six adaptive characteristics of family functioning: open communication, sociability, idealization, and religious emphasis. Total coping responses were negatively related to disengagement but not significantly related to a chaotic family style or family conflict. Reframing was positively related to open communication and negatively related to disengagement and a chaotic family style. Acquiring social support was positively related to open communication, sociability, idealization, and religious emphasis. There were no significant relationships between acquiring social support and family cohesion, organization, conflict, disengagement, or a chaotic family style. Seeking spiritual support was significantly correlated with only one of the family functioning characteristics, religious emphasis.

Family Functioning

Within Construct

Family functioning included nine characteristics of family functioning: family cohesion (FFCOH), open communication (FFOC),

conflict (FFCON), sociability (FFSOC), idealization (FFID), religious emphasis (FFREL), disengagement (FFDIS), organization (FFORG), and a chaotic style (FFCHA). The within construct correlations are presented in Table 14. The between construct correlations have been presented in earlier tables. The relationships among the nine family functioning characteristics were in the predicted direction but not all reached significance. Family cohesion, open communication, sociability, idealization, and organization were positively intercorrelated and negatively related to family conflict and disengagement. There were no significant relationships between religious emphasis and any of the other family functioning dimensions. Chaotic family style was positively related to family conflict and disengagement and negatively related to organization. Overall family cohesion, open communication, and conflict showed the largest number of significant relationships with the other dimensions of family functioning. The relationships between family functioning and the variables in the other model constructs have been presented in previous sections.

Analysis of Variance

Analysis of variance was used to compare the families of chronically ill children with families with healthy children on the variables within each of the model constructs. For the family variables analysis by group was performed first. When there was a significant difference by group further analysis was done using the Tukey (hsd) procedure to maintain the level of significance at $p \leq .05$ (Winer, 1971) for all pairwise comparisons. Further analysis was performed by age group, sex, and family role. Age group was examined using adult (parents), adolescents (all of whom were siblings), and children (target

Table 14

Correlation Matrix for Family Functioning

Family Functioning	Family Functioning								
	FFCOH	FFOC	FFCON	FFSOC	FFID	FFREL	FFDIS	FFORG	FFCHA
FFCOH	1.00								
FFOC	.56**	1.00							
FFCON	-.40**	-.37**	1.00						
FFSOC	.42**	.43**	-.22	1.00					
FFID	.65**	.37**	-.25**	.39**	1.00				
FFREL	.18	.22	-.15	.18	.18	1.00			
FFDIS	-.55**	-.58**	.38**	-.44**	-.42**	-.03	1.00		
FFORG	.40**	.45**	-.43**	.29**	.26**	.22	-.39**	1.00	
FFCHA	-.08	-.21	.27**	-.07	-.03	.16	.32**	-.31**	1.00

**p ≤ .001

children and school age siblings). Thus age group provided three general subgroups. More specific analysis was performed using family role. In terms of family role parents had been analyzed by group and sex with the adult age group. Offspring were examined by target children and siblings (both school age and adolescent) to determine if it was age group or family role that resulted in differences. The individual variables, the six dimensions of perceived self concept and external locus of control, in the resources construct were analyzed by age group, sex, and family role again using the Tukey Test to control the level of significance.

Demands

The results of the analyses of variance by group for negative life events, positive life events, total life events, hassles frequency, and uplifts frequency are presented in Table 15. Three of the five variables in demands showed a main effect for group. The findings for positive life events, total life events and uplifts support the hypothesis related to greater demands in the chronic illness families. The families with chronically ill children reported a significantly greater number of positive life events, total life events, and uplifts. No differences by group were hypothesized for uplifts. There were no significant differences on negative life events or hassles although negative life events approached significance. The lack of a significant difference on negative life events fails to support the hypothesis. Thus the hypothesis related to demands was only partially supported.

Further analysis was performed to identify more specifically the sources of variance. The analysis of positive life events by age group, sex, and family role is presented in Table 16. Children, both target

Table 15

Demands-Analysis of Variance by Group

Source of Variance	Mean Squares	Degrees of Freedom	F	P ≤
<u>NLE</u>				
Group	3600480.10	1	3.66	.06
Residual	983474.31	158		
Total	999933.47	159		
<u>PLE</u>				
Group	8538070.62	1	8.97	.003*
Residual	952154.77	158		
Total	999864.94	159		
<u>TLE</u>				
Group	3971434.84	1	4.05	.05*
Residual	981404.62	158		
Total	1000209.84	159		
<u>HF</u>				
Group	2461952.16	1	2.49	.12
Residual	990758.29	158		
Total	1000011.08	159		
<u>UF</u>				
Group	6417927.15	1	6.69	.01*
Residual	959749.88	158		
Total	994078.04	159		

* $p \leq .05$

Table 16

Positive Life Events-Analysis of Variance

Source of Variance	Mean Squares	Degrees of Freedom	F	P ≤
<u>Parents/Adults</u>				
Group	1123345.33	1	1.04	.31
Sex	1165924.36	1	1.08	.30
Group X Sex	247614.72	1	.23	.63
Explained	837137.58	3	.77	.51
Residual	1077578.54	71		
Total	1067830.94	74		
<u>Adolescents</u>				
Group	1003681.05	1	1.06	.32
Sex	909.07	1	.00	.98
Group X Sex	512435.97	1	.54	.47
Explained	505446.28	3	.54	.67
Residual	943122.64	15		
Total	870176.58	18		
<u>Children</u>				
Group	68829525.77	1	8.63	.01*
Sex	43962.97	1	.05	.82
Group X Sex	403352.28	1	.51	.48
Explained	2485535.91	3	3.12	.03
Residual	797464.40	62		
Total	875375.40	65		
<u>Target Children</u>				
Group	4061436.73	1	5.94	.02*
Sex	1105014.95	1	1.62	.21
Group X Sex	342637.39	1	.50	.48
Explained	1827776.93	3	2.67	.06
Residual	683671.64	41		
Total	761678.82	44		
<u>Siblings</u>				
Group	4363327.22	1	4.61	.04*
Sex	1336749.28	1	1.41	.24
Group X Sex	541721.03	1	.57	.45
Explained	2316498.22	3	2.45	.08
Residual	946390.64	36		
Total	1051783.53	39		

* Significant using the Tukey Procedure

children and their siblings, in the chronic illness families reported significantly more positive life events than children in the comparison families. There were no significant differences for parents (adults) or adolescents. The analysis for total life events by age group, sex, and family role is presented in Table 17. Again the children in the chronic illness families reported more total life events. There was a significant group by sex interaction for chronically ill children with chronically ill girls reporting significantly more total life events than healthy target girls. There were no significant differences for parents, adolescents, or siblings. The results of the analysis of uplifts by age group, sex, and family role are presented in Table 18. For parents there was a main effect for sex with mothers in both groups reporting significantly more uplifts than fathers. The children in the chronic illness families reported significantly more uplifts than children in the comparison families, this difference was particularly true for target children. There were no significant differences for siblings or adolescents.

Resources

Resources included one family variable, family resources (FIRM), and seven individual resources, external locus of control and six dimensions of perceived self competence. The results for the analysis of variance on each of the eight variables are presented in Tables 19 through 26. The hypothesis that the chronic illness families would have a higher level of family resources was not supported. There was no significant difference between family resources in the chronic illness versus the comparison families (Table 19). On the seven individual resource variables no differences by group had been hypothesized. The

Table 17

Total Life Events-Analysis of Variance

Source of Variance	Mean Squares	Degrees of Freedom	F	P ≤
<u>Parents/Adults</u>				
Group	592726.00	1	.51	.48
Sex	3969271.17	1	3.39	.07
Group X Sex	565830.95	1	.48	.49
Explained	1697959.52	3	1.45	.24
Residual	1172499.39	71		
Total	1193801.83	74		
<u>Adolescents</u>				
Group	18619.64	1	.01	.91
Sex	166583.67	1	.12	.73
Group X Sex	924844.90	1	.67	.43
Explained	368468.85	3	.27	.85
Residual	1386164.39	15		
Total	1216548.47	18		
<u>Children</u>				
Group	3834035.22	1	7.34	.01*
Sex	578227.53	1	1.11	.30
Group X Sex	1780967.24	1	3.41	.07
Explained	2149976.59	3	4.12	.01
Residual	522332.59	62		
Total	597454.62	65		
<u>Target Children</u>				
Group	2101351.08	1	3.45	.07
Sex	61440.26	1	.10	.75
Group X Sex	2910334.46	1	4.78	.04*
Explained	1692536.23	3	2.77	.05
Residual	608967.49	41		
Total	682847.18	44		
<u>Siblings</u>				
Group	1621209.01	1	1.80	.19
Sex	526860.60	1	.59	.45
Group X Sex	350012.92	1	.39	.54
Explained	922790.07	3	1.02	.39
Residual	901348.30	36		
Total	902997.67	39		

* Significant using the Tukey Procedure

Table 18

Uplifts Frequency-Analysis of Variance

Source of Variance	Mean Squares	Degrees of Freedom	F	P ≤
<u>Parents/Adults</u>				
Group	146489.23	1	.20	.66
Sex	3780840.08	1	5.11	.03*
Group X Sex	1488283.26	1	2.03	.16
Explained	1799785.85	3	2.43	.07
Residual	739468.66	71		
Total	782454.49	74		
<u>Adolescents</u>				
Group	2180639.52	1	1.13	.30
Sex	297361.22	1	.16	.70
Group X Sex	2587449.62	1	1.35	.26
Explained	1714333.41	3	.89	.47
Residual	1924266.02	15		
Total	1889277.25	18		
<u>Children</u>				
Group	4506703.50	1	9.74	.003*
Sex	404017.33	1	.87	.35
Group X Sex	94690.21	1	.21	.65
Explained	1608602.84	3	3.47	.02
Residual	462935.03	62		
Total	515812.00	65		
<u>Target Children</u>				
Group	5912693.93	1	15.33	.00*
Sex	5019.90	1	.01	.91
Group X Sex	297285.69	1	.77	.39
Explained	2075444.67	3	5.37	.003
Residual	386183.76	41		
Total	501360.64	44		
<u>Siblings</u>				
Group	4396728.27	1	3.28	.08
Sex	1230945.83	1	.90	.35
Group X Sex	1557522.33	1	1.14	.29
Explained	2227223.71	3	1.64	.20
Residual	1362020.70	36		
Total	1428574.78	39		

* Significant using the Tukey Procedure

Table 19

Family Resources-Analysis of Variance

Source of Variance	Mean Squares	Degrees of Freedom	F	P $\leq$
<u>Parents/Adults</u>				
Group	2135938.28	1	2.17	.15
Sex	3743.07	1	.00	.95
Group X Sex	2142185.37	1	2.18	.15
Explained	1426708.33	3	1.45	.24
Residual	985108.24	71		
Total	1003010.95	74		

* Significant using the Tukey Procedure

analyses of variance revealed two main effects for group and seven group by sex interactions. The group differences were on perceived conduct-morality and perceived athletic competence in children. Thus with the exception of perceived conduct-morality and perceived athletic competence, no significant between group differences were found on perceived self competence and external locus of control was supported. Although a null hypothesis cannot be proved, the lack of significant differences is important to the conceptual basis of the present study.

Individual variables were analyzed by group, age group, sex, and family role differences. There were no significant differences between the groups on perceived scholastic competence (Table 20). There was a significant group by sex interaction for parents on perceived social acceptability (Table 21). Fathers and mothers from the chronic illness families and mothers from the comparison families rated themselves significantly higher than comparison fathers on perceived social acceptability. There were no significant differences for children, adolescents, target children, or siblings. For perceived athletic competence there was a significant group by sex interaction for parents (Table 22). Fathers in the chronic illness group rated themselves higher than fathers in the comparison group while mothers in the comparison group rated themselves higher on perceived athletic competence than mothers in the chronic illness group. There was also a main effect for group for children on perceived athletic competence with children in the comparison families rating themselves higher than children in the chronic illness families. There were no significant differences for adolescents, target children, or siblings. There was a significant group by sex interaction for parents on perceived physical

Table 20

Perceived Scholastic Competence-Analysis of Variance

Source of Variance	Mean Squares	Degrees of Freedom	F	P ≤
<u>Parents/Adults</u>				
Group	1023271.73	1	1.01	.32
Sex	172909.09	1	.17	.68
Group X Sex	1039635.28	1	1.03	.31
Explained	742166.33	3	.73	.54
Residual	1011168.94	71		
Total	1000263.43	74		
<u>Adolescents</u>				
Group	705292.50	1	.62	.44
Sex	172336.17	1	.15	.70
Group X Sex	6407.00	1	.01	.94
Explained	284802.91	3	.25	.86
Residual	1142794.75	15		
Total	999796.11	18		
<u>Children</u>				
Group	793950.44	1	.82	.37
Sex	1445292.52	1	1.49	.23
Group X Sex	1136.00	1	.00	.97
Explained	695974.28	3	.72	.55
Residual	970752.58	62		
Total	958070.51	65		
<u>Target Children</u>				
Group	12273.64	1	.01	.91
Sex	2306842.94	1	2.43	.13
Group X Sex	2079287.01	1	2.19	.15
Explained	1465476.42	3	1.54	.22
Residual	950440.93	41		
Total	985556.98	44		
<u>Siblings</u>				
Group	2817334.22	1	3.84	.07
Sex	184476.22	1	.22	.64
Group X Sex	2973377.30	1	3.57	.07
Explained	1946436.48	3	2.34	.09
Residual	832474.22	36		
Total	918163.63	39		

* Significant using the Tukey Procedure

Table 21

Perceived Social Acceptability-Analysis of Variance

Source of Variance	Mean Squares	Degrees of Freedom	F	P ≤
<u>Parents/Adults</u>				
Group	557406.07	1	.64	.43
Sex	802647.95	1	.93	.34
Group X Sex	10092363.83	1	11.65	.001*
Explained	3812511.14	3	4.40	.01
Residual	866013.59	71		
Total	985466.19	74		
<u>Adolescents</u>				
Group	856.64	1	.00	.98
Sex	1085538.46	1	.96	.34
Group X Sex	628.21	1	.00	.98
Explained	363989.77	3	.32	.81
Residual	1127272.22	15		
Total	1000058.48	18		
<u>Children</u>				
Group	2850808.23	1	2.83	.10
Sex	178047.59	1	.18	.68
Group X Sex	289111.28	1	.29	.59
Explained	1075245.05	3	1.07	.37
Residual	1007738.66	62		
Total	1010854.34	65		
<u>Target Children</u>				
Group	648459.68	1	.69	.41
Sex	6984.41	1	.01	.93
Group X Sex	580894.41	1	.62	.44
Explained	412395.84	3	.44	.73
Residual	933895.11	41		
Total	898338.35	44		
<u>Siblings</u>				
Group	1597561.07	1	1.41	.24
Sex	1603237.85	1	1.42	.24
Group X Sex	58875.31	1	.05	.82
Explained	967512.39	3	.85	.47
Residual	1132407.35	36		
Total	1119723.12	39		

* Significant using the Tukey Procedure

Table 22

Perceived Athletic Competence-Analysis of Variance

Source of Variance	Mean Squares	Degrees of Freedom	F	P ≤
<u>Parents/Adults</u>				
Group	335811.34	1	.43	.51
Sex	14589080.01	1	18.84	.00*
Group X Sex	4121085.72	1	5.32	.02*
Explained	6332681.00	3	8.18	.00
Residual	774468.83	71		
Total	999801.75	74		
<u>Adolescents</u>				
Group	274389.48	1	.28	.61
Sex	689516.34	1	.70	.42
Group X Sex	2235766.15	1	2.27	.15
Explained	1080267.65	3	1.10	.38
Residual	984292.00	15		
Total	1000287.94	18		
<u>Children</u>				
Group	4572844.05	1	4.46	.04*
Sex	2754374.80	1	2.68	.11
Group X Sex	44082.45	1	.04	.84
Explained	2288553.04	3	2.23	.09
Residual	1026522.86	62		
Total	1084770.41	65		
<u>Target Children</u>				
Group	2402784.01	1	2.35	.13
Sex	2811280.46	1	2.75	.11
Group X Sex	33654.04	1	.03	.86
Explained	1738691.73	3	1.70	.18
Residual	1022316.62	41		
Total	1071160.38	44		
<u>Siblings</u>				
Group	354783.83	1	.33	.57
Sex	669623.64	1	.62	.44
Group X Sex	1435843.56	1	1.32	.26
Explained	784092.25	3	.72	.55
Residual	1084208.81	36		
Total	1061122.92	39		

* Significant using the Tukey Procedure

appearance (Table 23). Fathers in the chronic illness group rated themselves significantly higher than fathers in the comparison group and mothers in the chronic illness group on perceived physical appearance. There were no significant differences for children, adolescents, target children, or siblings. On perceived conduct-morality (Table 24) for children there was a main effect for group with the comparison group perceiving their behavior to be more positive. For siblings there was a group by sex interaction such that male siblings of chronically ill children rated themselves significantly lower on perceived conduct morality than male siblings in the comparison families. There were no significant differences for parents, adolescents, or target children. There was also a significant group by sex interaction for siblings on global self worth (Table 25). Female siblings of chronically ill children rated themselves significantly higher on global self worth than female siblings in the comparison families. Male siblings of chronically ill children rated themselves significantly lower on global self worth than male siblings in the comparison families. There were no significant differences for parents, adolescents, children, or target children. On external locus of control there was a significant group by sex interaction for adolescents (Table 26). Female adolescents in chronic illness families were significantly less external than adolescent females in the comparison families. Male adolescents in the chronic illness families were significantly higher on externality than male adolescents in the comparison families. Consistent with all of the adolescents being siblings, the group by sex interaction for siblings approached significance. Male siblings of chronically ill children were also significantly more external than male siblings in the comparison

Table 23

Perceived Physical Appearance-Analysis of Variance

Source of Variance	Mean Squares	Degrees of Freedom	F	P ≤
<u>Parents/Adults</u>				
Group	39835.74	1	.04	.84
Sex	4178922.03	1	4.50	.04*
Group X Sex	3819352.91	1	4.11	.05*
Explained	2676486.88	3	2.88	.04
Residual	928921.10	71		
Total	999768.36	74		
<u>Adolescents</u>				
Group	80186.64	1	.08	.79
Sex	1269593.82	1	1.22	.29
Group X Sex	12895.40	1	.01	.91
Explained	464716.12	3	.45	.72
Residual	1043475.76	15		
Total	947015.82	18		
<u>Children</u>				
Group	2177157.87	1	2.06	.16
Sex	1070752.06	1	1.02	.32
Group X Sex	290773.82	1	.28	.60
Explained	1107239.54	3	1.05	.38
Residual	1055249.51	62		
Total	1057649.05	65		
<u>Target Children</u>				
Group	1292219.05	1	1.53	.22
Sex	1489851.84	1	1.76	.19
Group X Sex	1366692.45	1	1.61	.21
Explained	1377290.03	3	1.63	.20
Residual	845886.50	41		
Total	882118.56	44		
<u>Siblings</u>				
Group	116987.43	1	.10	.76
Sex	438350.70	1	.37	.55
Group X Sex	2903155.03	1	2.44	.13
Explained	1136533.40	3	.95	.43
Residual	1192501.05	36		
Total	1188195.85	39		

* Significant using the Tukey Procedure

Table 24

Perceived Conduct-Morality-Analysis of Variance

Source of Variance	Mean Squares	Degrees of Freedom	F	P ≤
<u>Parents/Adults</u>				
Group	2234784.47	1	2.30	.13
Sex	2484366.33	1	2.55	.12
Group X Sex	101719.47	1	.10	.75
Explained	1624836.15	3	1.67	.18
Residual	973466.93	71		
Total	999873.79	74		
<u>Adolescents</u>				
Group	1284454.77	1	1.54	.23
Sex	1368341.37	1	1.64	.22
Group X Sex	2975732.70	1	3.57	.08
Explained	1838160.98	3	2.21	.13
Residual	832701.04	15		
Total	1000277.70	18		
<u>Children</u>				
Group	4723589.73	1	4.63	.04*
Sex	84445.10	1	.08	.78
Group X Sex	2083.75	1	.00	.96
Explained	1580331.24	3	1.55	.21
Residual	1020554.46	62		
Total	1046390.31	65		
<u>Target Children</u>				
Group	1736039.90	1	2.02	.16
Sex	3592.45	1	.00	.95
Group X Sex	2326068.99	1	2.71	.11
Explained	1355578.02	3	1.58	.21
Residual	857308.90	41		
Total	893145.43	44		
<u>Siblings</u>				
Group	193674.23	1	.17	.68
Sex	237426.35	1	.21	.65
Group X Sex	4978836.26	1	4.35	.04*
Explained	1823857.16	3	1.59	.21
Residual	1144081.54	36		
Total	1196371.97	39		

* Significant using the Tukey Procedure

Table 25

Global Self Worth-Analysis of Variance

Source of Variance	Mean Squares	Degrees of Freedom	F	P ≤
<u>Parents/Adults</u>				
Group	1386451.11	1	1.40	.24
Sex	628473.64	1	.64	.43
Group X Sex	1778616.47	1	1.80	.18
Explained	1257594.65	3	1.27	.29
Residual	989022.59	71		
Total	999910.64	74		
<u>Adolescents</u>				
Group	310994.59	1	.30	.59
Sex	19060.84	1	.02	.89
Group X Sex	2245145.20	1	2.18	.16
Explained	860934.62	3	.84	.49
Residual	1027936.21	15		
Total	1000102.61	18		
<u>Children</u>				
Group	1190955.64	1	1.10	.30
Sex	433503.40	1	.40	.53
Group X Sex	321047.68	1	.30	.59
Explained	614657.88	3	.57	.64
Residual	1084070.51	62		
Total	1062405.31	65		
<u>Target Children</u>				
Group	1330137.95	1	1.45	.24
Sex	658754.57	1	.72	.40
Group X Sex	690436.47	1	.75	.39
Explained	889312.12	3	.97	.42
Residual	915234.78	41		
Total	913467.33	44		
<u>Siblings</u>				
Group	156136.99	1	.14	.71
Sex	11927.73	1	.01	.92
Group X Sex	5201099.33	1	4.60	.04*
Explained	1786947.98	3	1.58	.21
Residual	1130008.01	36		
Total	1180541.86	39		

* Significant using the Tukey Procedure

Table 26

External Locus of Control-Analysis of Variance

Source of Variance	Mean Squares	Degrees of Freedom	F	P ≤
<u>Parents/Adults</u>				
Group	2034232.13	1	1.94	.17
Sex	4040.56	1	.004	.95
Group X Sex	1302385.48	1	1.24	.27
Explained	1112958.51	3	1.06	.37
Residual	1047082.43	71		
Total	1049753.08	74		
<u>Adolescents</u>				
Group	135969.86	1	.29	.60
Sex	570554.92	1	1.20	.29
Group X Sex	4119473.37	1	8.67	.01*
Explained	1617505.64	3	3.40	.05
Residual	475197.03	15		
Total	665581.80	18		
<u>Children</u>				
Group	27597.07	1	.02	.89
Sex	42025.46	1	.03	.86
Group X Sex	157165.49	1	.12	.73
Explained	77491.02	3	.06	.98
Residual	1330751.77	62		
Total	1272908.97	65		
<u>Target Children</u>				
Group	32112.58	1	.03	.87
Sex	146754.49	1	.12	.73
Group X Sex	9.74	1	.00	.99
Explained	59347.52	3	.05	.99
Residual	1225723.52	41		
Total	1146197.88	44		
<u>Siblings</u>				
Group	184627.81	1	.18	.68
Sex	944028.68	1	.91	.35
Group X Sex	4061675.72	1	3.91	.06
Explained	1771655.01	3	1.71	.18
Residual	1038116.41	36		
Total	1094542.46	39		

* Significant using the Tukey Procedure

families. The differences for female siblings were not significant. There were no significant differences for parents, children, or target children.

Perception of Demands

The variables included in perception of demands included the total and mean intensity of negative life events (NLEI, MNLEI), positive life events (PLEI, MPLEI), total life events (TLEI, MTLEI), hassles (HI, MHI), and uplifts (UI, MUI). The total scores provide a measure of the subject's perception of the total intensity of demands being experienced by the family. The mean score provides a measure of the subjects perception of the intensity of a particular type of demands. The analysis of variance by group for these variables is presented in Table 27. The hypotheses of higher total intensity of hassles, and lower mean intensity on negative life events and hassles for the chronic illness group were not supported. On all of the variables except hassles there were significant main effects for group with the chronic illness families rating both the total and mean intensity of demands significantly higher than the comparison families. The chronic illness families scored significantly higher on total and mean uplifts intensity which had not been hypothesized.

Further analysis was performed for the intensity scores on negative life events, positive life events, total life events, and uplifts. On negative life events (Table 28) for parents there was a significant main effect for sex on total intensity with mothers in both groups rating the intensity higher. There was no significant difference for mean intensity of negative life events for parents. Children in the chronic illness group rated the total intensity of negative life events as

Table 27

Perception of Demands-Analysis of Variance by Group

Source of Variance	Mean Squares	Degrees of Freedom	F	P $\leq$
NLEI				
Group	4805721.87	1	4.92	.03*
Residual	975926.59	158		
Total	1000013.36	159		
MNLEI				
Group	20363127.91	1	4.87	.03*
Residual	4182589.24	157		
Total	4284997.71	158		
PLEI				
Group	9188246.07	1	9.69	.002*
Residual	947980.82	158		
Total	999806.38	159		
MPLEI				
Group	15360534.99	1	3.84	.05*
Residual	3999423.90	157		
Total	4071329.66	158		
TLEI				
Group	7279183.58	1	7.58	.01*
Residual	960135.18	158		
Total	999877.62	159		
MTLEI				
Group	10365775.80	1	6.82	.01*
Residual	1519992.14	157		
Total	1575978.11	158		
HI				
Group	994274.61	1	.99	.32
Residual	999980.69	158		
Total	999944.81	159		
MHI				
Group	182570.67	1	.18	.67
Residual	1010232.94	157		
Total	1004994.57	158		
UI				
Group	8565061.99	1	8.98	.003*
Residual	953986.46	158		
Total	1001854.86	159		
MUI				
Group	5337260.85	1	5.51	.02*
Residual	968592.17			
Total	996241.98			

* p $\leq$.05

Table 28

Negative Life Events Intensity-Analysis of Variance

Source of Variance	Mean Squares	Degrees of Freedom	F	P ≤
<u>Parents/Adults</u>				
Total Intensity				
Group	365050.67	1	.35	.56
Sex	5091286.39	1	4.84	.03*
Group X Sex	1930429.44	1	1.83	.18
Explained	2452256.46	3	2.33	.08
Residual	1052370.21	71		
Total	1109122.36	74		
Mean Intensity				
Group	4150783.08	1	1.07	.31
Sex	10402105.38	1	2.68	.11
Group X Sex	2409929.31	1	.62	.43
Explained	5513156.25	3	1.42	.25
Residual	3889224.30	71		
Total	3955961.23	73		
<u>Adolescents</u>				
Total Intensity				
Group	313143.48	1	.23	.64
Sex	64428.02	1	.05	.83
Group X Sex	63297.05	1	.05	.83
Explained	151475.71	3	.11	.95
Residual	1339583.79	15		
Total	1141565.78	18		
Mean Intensity				
Group	8044495.73	1	1.20	.29
Sex	5491662.22	1	.82	.38
Group X Sex	2305472.87	1	.34	.57
Explained	5489242.93	3	.82	.51
Residual	6722117.84	15		
Total	6516638.69	18		
<u>Children</u>				
Total Intensity				
Group	3955864.97	1	6.33	.01*
Sex	167901.92	1	.27	.61
Group X Sex	1258894.48	1	2.02	.16
Explained	1844446.34	3	2.95	.04
Residual	624832.03	62		
Total	681121.92	65		

Table 28 (cont'd)

	Mean Squares	Degrees of Freedom	F	P ≤
<u>Children</u>				
Mean Intensity				
Group	3635812.11	1	1.34	.25
Sex	1594114.17	1	.59	.45
Group X Sex	12972571.85	1	4.78	.03*
Explained	6202073.53	3	2.86	.09
Residual	2713893.38	62		
Total	2874886.31	65		
<u>Target Children</u>				
Total Intensity				
Group	2138545.97	1	2.85	.10
Sex	310796.29	1	.42	.52
Group X Sex	575155.58	1	.77	.39
Explained	1011525.66	3	1.35	.27
Residual	749220.71	41		
Total	767105.13	44		
Mean Intensity				
Group	3617219.14	1	.98	.33
Sex	4190102.99	1	1.13	.29
Group X Sex	11450191.12	1	3.10	.09
Explained	6435166.16	3	1.74	.17
Residual	3695322.93	41		
Total	3882130.43	44		
<u>Siblings</u>				
Total Intensity				
Group	4705332.75	1	4.47	.04*
Sex	155619.79	1	.15	.70
Group X Sex	17815.49	1	.02	.90
Explained	1579428.38	3	1.50	.23
Residual	1053247.38	36		
Total	1093722.84	39		
Mean Intensity				
Group	21518005.21	1	4.61	.04*
Sex	274478.95	1	.06	.81
Group X Sex	767285.73	1	.16	.69
Explained	7429596.37	3	1.59	.21
Residual	4672963.93	36		
Total	4885012.57	39		

* Significant using the Tukey Procedure

significantly higher than the children in the comparison group. For mean intensity of negative life events there was no main effect but a group by sex interaction with girls in the chronic illness families perceiving negative life events in general as more being more intense than girls in the comparison families. There was a main effect for siblings on both total and mean negative life events intensity with siblings in the chronic illness families scoring higher. There were no significant differences for total or mean intensity of negative life events for adolescents.

Further analysis of the intensity of positive life events (Table 29) revealed no significant differences for parents, adolescents, or siblings on either mean or total scores. On total intensity but not mean intensity of positive life events there was a significant main effect with children in the chronic illness group rating their total positive life events intensity higher than children in the chronic illness group. In contrast to negative life events, the group by sex interaction for target children on positive life events showed that chronically ill boys rated the mean intensity of positive life events significantly higher than the target boys in the comparison families. For positive life events this interaction was present for the target children only, while for negative life events the group by sex interaction was present for all children. There were no significant differences on total or mean intensity of positive life events for parents, siblings, or adolescents.

The analysis of total life event intensity is presented in Table 30. On total life event intensity but not the mean intensity of total life events there was a significant main effect for children with

Table 29

Positive Life Events Intensity-Analysis of Variance

Source of Variance	Mean Squares	Degrees of Freedom	F	P ≤
<u>Parents/Adults</u>				
Total Intensity				
Group	1768762.52	1	1.63	.21
Sex	1166889.27	1	1.07	.30
Group X Sex	243509.64	1	.22	.64
Explained	1049064.65	3	.96	.42
Residual	1088348.99	71		
Total	1086756.38	74		
<u>Mean Intensity</u>				
Group	10657613.29	1	2.43	.12
Sex	2695882.57	1	.61	.44
Group X Sex	6978.38	1	.00	.97
Explained	4338928.55	3	.99	.40
Residual	4387321.92	71		
Total	4385333.15	73		
<u>Adolescents</u>				
Total Intensity				
Group	590923.47	1	.65	.43
Sex	9276.19	1	.01	.92
Group X Sex	800192.68	1	.88	.36
Explained	464979.46	3	.51	.68
Residual	906234.34	15		
Total	832699.36	18		
<u>Mean Intensity</u>				
Group	1495687.50	1	.44	.52
Sex	904922.34	1	.27	.61
Group X Sex	4969066.40	1	1.46	.25
Explained	2493109.55	3	.73	.55
Residual	3405290.79	15		
Total	3253260.59	18		
<u>Children</u>				
Total Intensity				
Group	6664653.19	1	9.16	.004*
Sex	45427.54	1	.06	.80
Group X Sex	97527.43	1	.13	.72
Explained	2310902.49	3	3.18	.03
Residual	727171.94	62		
Total	800267.20	65		

Table 29 (cont'd)

	Mean Squares	Degrees of Freedom	F	P ≤
<u>Children</u>				
Mean Intensity				
Group	7663702.80	1	3.03	.09
Sex	61842.72	1	.02	.88
Group X Sex	9413220.87	1	3.72	.06
Explained	5763766.32	3	2.28	.09
Residual	2528672.98	62		
Total	2677984.98	65		
<u>Target Children</u>				
Total Intensity				
Group	4862309.29	1	8.29	.01*
Sex	834438.86	1	1.42	.24
Group X Sex	75071.07	1	.13	.72
Explained	1915785.79	3	3.27	.03
Residual	585984.27	41		
Total	676652.56	44		
Mean Intensity				
Group	17100982.49	1	11.36	.002*
Sex	529158.28	1	.35	.56
Group X Sex	7387737.90	1	4.91	.03*
Explained	8327229.61	3	5.53	.003
Residual	1505490.35	41		
Total	1970608.94	44		
<u>Siblings</u>				
Total Intensity				
Group	3043442.85	1	3.19	.08
Sex	911887.97	1	.96	.34
Group X Sex	659899.04	1	.69	.41
Explained	1701256.99	3	1.78	.17
Residual	954564.75	36		
Total	1012002.61	39		
Mean Intensity				
Group	996582.57	1	.249	.62
Sex	19654.49	1	.005	.94
Group X Sex	1037829.10	1	.260	.61
Explained	678211.59	3	.170	.92
Residual	3994368.94	36		
Total	3739279.92	39		

* Significant using the Tukey Procedure

Table 30

Total Life Events Intensity-Analysis of Variance

Source of Variance	Mean Squares	Degrees of Freedom	F	P ≤
<u>Parents/Adults</u>				
Total Intensity				
Group	1004095.70	1	.84	.36
Sex	5502810.18	1	4.61	.04
Group X Sex	907254.03	1	.76	.39
Explained	2454023.74	3	2.05	.11
Residual	1194798.98	71		
Total	1245848.63	74		
Mean Intensity				
Group	3050102.19	1	1.67	.20
Sex	5967698.70	1	3.26	.08
Group X Sex	1665236.79	1	.91	.34
Explained	3469227.27	3	1.90	.14
Residual	1829441.80	71		
Total	1896830.24	73		
<u>Adolescents</u>				
Total Intensity				
Group	242087.51	1	.19	.67
Sex	2995.41	1	.00	.96
Group X Sex	242440.71	1	.19	.67
Explained	161864.71	3	.12	.94
Residual	1305239.49	15		
Total	1114677.03	18		
Mean Intensity				
Group	1899752.20	1	.75	.40
Sex	1037344.06	1	.41	.53
Group X Sex	182881.02	1	.07	.79
Explained	999824.59	3	.40	.76
Residual	2534125.96	15		
Total	2278409.06	18		
<u>Children</u>				
Total Intensity				
Group	5923714.60	1	12.52	.001*
Sex	148561.45	1	.31	.58
Group X Sex	951864.96	1	2.01	.16
Explained	2401823.94	3	5.07	.003
Residual	473324.37	62		
Total	562332.04	65		

Table 30 (cont'd)

	Mean Squares	Degrees of Freedom	F	P ≤
<u>Children</u>				
Mean Intensity				
Group	4882185.16	1	5.60	.02*
Sex	1306602.24	1	1.50	.23
Group X Sex	379313.97	1	.44	.51
Explained	2071351.42	3	2.38	.08
Residual	872213.81	62		
Total	927558.63	65		
<u>Target Children</u>				
Total Intensity				
Group	3848443.29	1	7.23	.01*
Sex	449.07	1	.00	.98
Group X Sex	509221.10	1	.96	.33
Explained	1452922.37	3	2.73	.06
Residual	531992.73	41		
Total	594783.39	44		
Mean Intensity				
Group	2982579.59	1	3.56	.07
Sex	321428.17	1	.38	.54
Group X Sex	5444824.81	1	6.49	.02
Explained	2912320.63	3	3.48	.02
Residual	837735.37	41		
Total	979184.36	44		
<u>Siblings</u>				
Total Intensity				
Group	3912720.86	1	4.15	.05
Sex	1918.84	1	.00	.96
Group X Sex	463772.59	1	.49	.49
Explained	1487753.61	3	1.58	.21
Residual	943621.42	36		
Total	985477.74	39		
Mean Intensity				
Group	7245096.34	1	4.80	.04*
Sex	4183884.84	1	2.77	.11
Group X Sex	914799.49	1	.61	.44
Explained	3707282.76	3	2.46	.08
Residual	1508748.51	36		
Total	1677866.53	39		

* Significant using the Tukey Procedure

children in the chronic illness group rating the total intensity of all of their life events as higher. Although the mean intensity was not higher for children as a group it was higher for siblings with the siblings of chronically ill children perceiving the mean intensity of life events either positive or negative as more extreme than the siblings in the comparison group. While chronically ill children viewed the impact of their total life events as more intense than the target children in the comparison families, the mean intensity showed a group by sex interaction with chronically ill boys perceiving any given life event as more intense. There were no significant differences on total or mean intensity of total life events for parents or adolescents.

Further analysis of uplifts is presented in Table 31. For both total and mean intensity of uplifts there was a main effect for sex but not group for parents. Mothers perceived their overall uplifts and rated a given uplift higher than fathers. Both total and mean intensity of uplifts were also rated higher by the chronically ill children than the target children in the comparison families. There were no significant differences for adolescents, children as a group, or siblings.

Coping

Coping included four variables, total coping (FCTOT), and three specific types of coping responses: seeking spiritual support (FCSS), acquiring social support (FCASS), and reframing (FCREF). The analysis of variance for these four variables by group is presented in Table 32. The findings supported the hypothesis that the chronic illness families would score higher on coping than the comparison families. There were significant main effects for group on total coping, seeking spiritual

Table 31

Uplifts Intensity-Analysis of Variance

Source of Variance	Mean Squares	Degrees of Freedom	F	P ≤
<u>Parents/Adults</u>				
Total Intensity				
Group	823861.38	1	1.58	.21
Sex	6866521.01	1	13.16	.001*
Group X Sex	1044928.17	1	2.00	.16
Explained	2894248.28	3	5.55	.002
Residual	521751.58	71		
Total	617933.88	74		
Mean Intensity				
Group	1698793.91	1	2.92	.09
Sex	6312784.49	1	10.85	.002*
Group X Sex	845858.79	1	1.45	.23
Explained	2882433.10	3	4.96	.004
Residual	581671.95	71		
Total	676223.78	73		
<u>Adolescents</u>				
Total Intensity				
Group	4421915.31	1	3.27	.09
Sex	15510.51	1	.01	.92
Group X Sex	1214586.69	1	.90	.36
Explained	1879135.13	3	1.39	.29
Residual	1354426.25	15		
Total	1441877.73	18		
Mean Intensity				
Group	3688853.54	1	2.76	.12
Sex	305818.80	1	.23	.64
Group X Sex	4459.26	1	.00	.96
Explained	1303848.77	3	.98	.43
Residual	1337639.09	15		
Total	1332007.37	18		
<u>Children</u>				
Total Intensity				
Group	3882091.85	1	3.58	.06
Sex	170940.64	1	.16	.69
Group X Sex	654568.62	1	.60	.44
Explained	1535217.54	3	1.42	.25
Residual	1084659.39	62		
Total	1105454.38	65		

Table 31 (cont'd)

	Mean Squares	Degrees of Freedom	F	P ≤
<u>Children</u>				
Mean Intensity				
Group	1169352.35	1	.94	.34
Sex	83739.22	1	.07	.80
Group X Sex	1780722.28	1	1.43	.24
Explained	997614.54	3	.80	.50
Residual	1244916.22	62		
Total	1233502.30	65		
<u>Target Children</u>				
Total Intensity				
Group	9718901.92	1	8.13	.01*
Sex	50377.16	1	.04	.84
Group X Sex	172823.27	1	.15	.71
Explained	3317013.56	3	2.77	.05
Residual	1195993.82	41		
Total	1340608.80	44		
Mean Intensity				
Group	6794632.76	1	4.32	.04
Sex	56225.23	1	.04	.85
Group X Sex	812797.48	1	.52	.48
Explained	2552113.57	3	1.62	.20
Residual	1572906.93	41		
Total	1639671.02	44		
<u>Siblings</u>				
Total Intensity				
Group	2229623.54	1	1.86	.18
Sex	1607163.88	1	1.34	.26
Group X Sex	310742.73	1	.26	.61
Explained	1241972.09	3	1.03	.39
Residual	1201254.20	36		
Total	1204386.34	39		
Mean Intensity				
Group	61017.71	1	.07	.80
Sex	291441.38	1	.31	.58
Group X Sex	336250.71	1	.36	.55
Explained	220108.52	3	.24	.87
Residual	929369.55	36		
Total	874811.01	39		

* Significant using the Tukey Procedure

Table 32

Coping-Analysis of Variance by Group

Source of Variance	Mean Squares	Degrees of Freedom	F	P $\leq$
<u>ECTOT</u>				
Group	4107791.69	1	4.08	.05*
Residual	1007757.31	158		
Total	1027254.38	159		
<u>ECASS</u>				
Group	8532497.31	1	8.91	.003*
Residual	957292.17	158		
Total	1004934.97	159		
<u>ECSS</u>				
Group	22724945.64	1	22.40	.00*
Residual	1014365.59	158		
Total	1150910.12	159		
<u>ECREF</u>				
Group	3226886.10	1	2.98	.09
Residual	1081430.31	158		
Total	1094923.75	159		

* p $\leq$.05

support, and acquiring social support with the chronic illness families scoring higher on each of these measures. There was no significant difference on reframing.

Further analysis of total coping (Table 33) revealed no significant differences for subgroups. All subgroups for both age and family role had a significant main effect for group on seeking spiritual support (Table 34) with the members of the chronic illness families using this coping response significantly more than the members of the comparison families. Additional analysis of acquiring social support (Table 35) revealed a significant group by sex interaction with fathers in the chronic illness group using this coping response significantly more than fathers in the comparison group.

Family Functioning

Family functioning included nine dimensions of family functioning: cohesion (FFCOH), open communication (FFOC), conflict (FFCON), sociability (FFSOC), idealization (FFID), religious emphasis (FFREL), disengagement (FFDIS), organization (FFORG), and chaotic style (FFCHA). The analysis of variance for the nine variables in family functioning is presented in Table 36. No significant differences by group had been hypothesized for family functioning. There were significant main effects for two of the dimensions. The chronic illness families scored significantly higher on cohesion and religious emphasis. These findings on the whole support a lack of difference on family functioning based solely on the presence of a chronically ill child.

Further analysis of cohesion is presented in Table 37 and revealed no significant differences by subgroups. Further analysis of religious emphasis is presented in Table 38. There was a main effect for group

Table 33

Total Coping-Analysis of Variance

Source of Variance	Mean Squares	Degrees of Freedom	F	P ≤
<u>Parents/Adults</u>				
Group	1631068.99	1	2.53	.12
Sex	4201743.45	1	6.51	.01*
Group X Sex	1282891.85	1	1.99	.16
Explained	2352504.55	3	3.65	.02
Residual	645080.90	71		
Total	714300.78	74		
<u>Adolescents</u>				
Group	716078.47	1	1.17	.30
Sex	1606505.41	1	2.61	.13
Group X Sex	12047.81	1	.02	.89
Explained	747574.06	3	1.22	.34
Residual	614499.79	15		
Total	636678.83	18		
<u>Children</u>				
Group	1286767.11	1	1.01	.32
Sex	896101.55	1	.70	.41
Group X Sex	187280.01	1	.15	.70
Explained	849776.89	3	.66	.58
Residual	1279007.10	62		
Total	1259196.48	65		
<u>Target Children</u>				
Group	2758716.59	1	2.31	.14
Sex	716074.73	1	.60	.44
Group X Sex	117251.17	1	.10	.76
Explained	1203130.27	3	1.01	.40
Residual	1196937.67	41		
Total	1197359.89	44		
<u>Siblings</u>				
Group	981736.10	1	.90	.35
Sex	882145.89	1	.81	.37
Group X Sex	28007.45	1	.03	.87
Explained	561420.52	3	.52	.67
Residual	1085928.50	36		
Total	1045581.73	39		

* Significant using the Tukey Procedure

Table 34

Seeking Spiritual Support-Analysis of Variance

Source of Variance	Mean Squares	Degrees of Freedom	F	P ≤
<u>Parents/Adults</u>				
Group	10110900.81	1	8.22	.01*
Sex	263705.29	1	.21	.65
Group X Sex	1215563.36	1	.98	.32
Explained	3851575.63	3	3.13	.03
Residual	1229909.80	71		
Total	1336193.55	74		
<u>Adolescents</u>				
Group	3063830.02	1	7.50	.02*
Sex	572868.28	1	1.40	.26
Group X Sex	53253.88	1	.13	.72
Explained	1192659.86	3	2.92	.07
Residual	408358.46	15		
Total	539075.36	18		
<u>Children</u>				
Group	7277242.42	1	7.80	.01*
Sex	24703.71	1	.03	.87
Group X Sex	95621.77	1	.10	.75
Explained	2502217.80	3	2.68	.05
Residual	932663.16	62		
Total	1005104.15	65		
<u>Target Children</u>				
Group	9094394.87	1	9.73	.003*
Sex	1379787.64	1	1.48	.23
Group X Sex	208814.09	1	.22	.64
Explained	3575594.92	3	3.83	.02
Residual	934590.03	41		
Total	1114658.55	44		
<u>Siblings</u>				
Group	5235252.55	1	7.28	.01*
Sex	3704054.38	1	5.15	.03*
Group X Sex	300990.85	1	.42	.52
Explained	2753242.98	3	3.83	.02
Residual	719452.61	36		
Total	875898.02	39		

* Significant using the Tukey Procedure

Table 35

Acquiring Social Support-Analysis of Variance

Source of Variance	Mean Squares	Degrees of Freedom	F	P ≤
<u>Parents/Adults</u>				
Group	2985154.79	1	4.57	.04*
Sex	4147920.82	1	6.35	.01*
Group X Sex	2513958.75	1	3.85	.05
Explained	3189575.95	3	4.88	.004
Residual	653345.73	71		
Total	756165.88	74		
<u>Adolescents</u>				
Group	1975292.63	1	2.92	.11
Sex	1260943.62	1	1.87	.19
Group X Sex	12548.09	1	.02	.89
Explained	1037726.04	3	1.54	.25
Residual	676175.46	15		
Total	736433.89	18		
<u>Children</u>				
Group	2594638.06	1	2.13	.15
Sex	453628.17	1	.37	.54
Group X Sex	803942.52	1	.66	.42
Explained	1346085.83	3	1.10	.36
Residual	1219748.60	62		
Total	1225579.55	65		
<u>Target Children</u>				
Group	4228682.77	1	3.24	.08
Sex	75872.42	1	.06	.81
Group X Sex	226358.98	1	.17	.68
Explained	1512671.54	3	1.16	.34
Residual	1304642.03	41		
Total	1318825.86	44		
<u>Siblings</u>				
Group	2965679.91	1	3.46	.07
Sex	575754.82	1	.67	.42
Group X Sex	51459.73	1	.06	.81
Explained	1105388.67	3	1.29	.29
Residual	857491.83	36		
Total	876560.82	39		

* Significant using the Tukey Procedure

Table 36

Family Functioning-Analysis of Variance by Group

Source of Variance	Mean Squares	Degrees of Freedom	F	P ≤
<u>FFCOH</u>				
Group	4742337.14	1	3.83	.05*
Residual	1238941.61	158		
Total	1260975.55	159		
<u>FFOC</u>				
Group	1958335.71	1	1.65	.20
Residual	1189153.53	158		
Total	1193991.15	159		
<u>FFCON</u>				
Group	11613.30	1	.01	.92
Residual	1158676.75	158		
Total	1151462.52	159		
<u>FFSOC</u>				
Group	349952.35	1	.31	.58
Residual	1145955.36	158		
Total	1140949.05	159		
<u>FFID</u>				
Group	717267.21	1	.58	.45
Residual	1227674.06	158		
Total	1224463.96	159		
<u>FFREL</u>				
Group	11542905.46	1	10.62	.001*
Residual	1087230.41	158		
Total	1152989.38	159		
<u>FFDIS</u>				
Group	695666.47	1	.61	.44
Residual	1138851.66	158		
Total	1136064.33	159		
<u>FFORG</u>				
Group	1273729.18	1	1.01	.32
Residual	1263691.88	158		
Total	1263755.00	159		
<u>FFCHA</u>				
Group	2351394.28	1	2.05	.15
Residual	1147059.25	158		
Total	1154633.68	159		

* p ≤ .05

Table 37

Family Cohesion-Analysis of Variance

Source of Variance	Mean Squares	Degrees of Freedom	F	P ≤
<u>Parents/Adults</u>				
Group	1825258.66	1	1.58	.21
Sex	328740.28	1	.29	.60
Group X Sex	264966.73	1	.23	.63
Explained	800600.53	3	.69	.56
Residual	1154770.43	71		
Total	1140412.19	74		
<u>Adolescents</u>				
Group	499052.31	1	.38	.55
Sex	1012606.41	1	.77	.39
Group X Sex	846551.43	1	.64	.44
Explained	765745.97	3	.58	.64
Residual	1315481.14	15		
Total	1223858.61	18		
<u>Children</u>				
Group	1394478.87	1	1.03	.31
Sex	43823.32	1	.03	.86
Group X Sex	1554188.03	1	1.15	.29
Explained	1013103.52	3	.75	.53
Residual	1353617.16	62		
Total	1337901.14	65		
<u>Target Children</u>				
Group	62401.10	1	.08	.78
Sex	451488.34	1	.56	.46
Group X Sex	64750.90	1	.09	.78
Explained	193571.94	3	.24	.87
Residual	813892.30	41		
Total	771597.73	44		
<u>Siblings</u>				
Group	6802460.62	1	3.52	.07
Sex	3079945.86	1	1.60	.21
Group X Sex	84760.96	1	.04	.84
Explained	2985798.37	3	1.55	.22
Residual	1927464.14	36		
Total	2008874.46	39		

* Significant using the Tukey Procedure

Table 38

Family Religious Emphasis-Analysis of Variance

Source of Variance	Mean Squares	Degrees of Freedom	F	P ≤
<u>Parents/Adults</u>				
Group	6665793.43	1	6.70	.01*
Sex	253221.19	1	.26	.62
Group X Sex	282192.48	1	.28	.60
Explained	2390946.03	3	2.41	.08
Residual	994249.05	71		
Total	1050871.90	74		
<u>Adolescents</u>				
Group	1793232.04	1	1.25	.28
Sex	1437061.59	1	1.00	.33
Group X Sex	334429.23	1	.23	.64
Explained	1142221.39	3	.80	.52
Residual	1437380.91	15		
Total	1388187.66	18		
<u>Children</u>				
Group	2015736.11	1	1.87	.18
Sex	198562.32	1	.18	.67
Group X Sex	2789095.77	1	2.59	.11
Explained	1639554.25	3	1.52	.22
Residual	1077166.06	62		
Total	1103122.44	65		
<u>Target Children</u>				
Group	1912923.21	1	2.04	.16
Sex	437347.09	1	.47	.50
Group X Sex	47820.55	1	.05	.82
Explained	803128.00	3	.86	.47
Residual	936543.53	41		
Total	927447.02	44		
<u>Siblings</u>				
Group	4646843.83	1	3.35	.08
Sex	6588414.37	1	4.75	.04*
Group X Sex	4286800.85	1	3.09	.09
Explained	4763341.43	3	3.43	.03
Residual	1387366.29	36		
Total	1647056.69	39		

* Significant using the Tukey Procedure

with parents of chronically ill children scoring significantly higher on this dimension than parents in the comparison families. For siblings there was a significant main effect for sex but not group. Female siblings viewed their families as having a greater religious emphasis than male siblings did.

Summary

In summary the analysis of variance resulted in fourteen main effects for group on thirty six variables. Families of chronically ill children reported significantly more demands than the comparison families. The chronic illness families reported more positive life events, total life events, and uplifts. Negative life events approached significance. There were no differences on hassles. The hypothesis of a greater number of life events was supported. The hypothesis of greater hassles was not supported, however the chronic illness families did report a greater number of uplifts which had not been hypothesized.

On resources there were two significant main effects for group out of the nine variables. Children in the comparison group scored significantly higher on perceived athletic competence and perceived conduct morality. There were no significant main effects for the other subgroups on the other four dimensions of perceived self competence or external locus of control. No differences had been hypothesized between the chronic illness and comparison families on perceived self competence and external locus of control, and in general no differences were found. There were no significant group differences on family resources. Thus the hypothesis of higher resources in the chronic illness families was not supported.

On perception of demands there were four main effects for group out of five variables. The chronic illness families reported significantly higher total and mean intensities on all demands except hassles. Thus the hypotheses of higher total intensities and lower mean intensities for negative life events and hassles in the chronic illness families were not supported.

On coping the analysis of variance resulted in three main effects with the chronic illness families scoring significantly higher on total coping responses and two of the three specific types of coping responses. The chronic illness families scored higher on seeking spiritual support and acquiring social support but not reframing. The hypothesis of higher coping scores in the chronic illness group was for the most part supported.

Analysis of variance for family functioning resulted in two main effects for group out of the nine dimensions of family functioning. Families with chronically ill children scored significantly higher on family cohesion and religious emphasis. Further analysis of cohesion by subgroups revealed no additional significant differences. Further analysis of religious emphasis resulted in a main effect for parents by group with the parents in the chronic illness group scoring higher. For siblings there was a main effect for sex with female siblings in both groups scoring higher. No significant differences in family functioning based solely on the presence of a chronically ill child had been hypothesized and for the most part no differences were found.

Multiple Regression

Hierarchical multiple regression was used to provide an initial statistical examination of the conceptual model. The amount of variance

accounted for by each of the model constructs was evaluated to determine whether it should be retained and its position in the model for future statistical tests of the model. The multiple regression analysis was performed with perception of demands, coping, and each of the nine dimensions of family functioning respectively as dependent variables. For each equation a set of covariates including group (chronic illness versus comparison), mother's work (MW), mother's education (ME), and mother's occupation (MO) was entered first to control for the significant differences found on these variables in earlier analyses. The constructs were then entered in the order predicted by the model with the interaction of demands and resources entered last. In the analysis of family functioning and coping, perception of demands was entered with the total intensity scores for the variables and then was rerun with the mean intensity scores to determine which set was a better predictor. For the family functioning dimensions the same procedure was also carried out with coping, using the total coping score first and then rerunning the analysis with the three subscale scores. A summary of the multiple regression analyses is presented in Table 39.

Perception of Demands

The findings support the hypothesis predicting a significant amount of the variance in perception of demands. However, the model predicted a main effect for resources, a prediction that was not supported. With perception of demands as the dependent variable the model accounted for 79.1% of the variance. The covariates accounted for 9% of the variance in perception of demands which was significant. Group was the only variable in the set that contributed significantly. Demands accounted for 68% of the variance. All of the variables within the set except

Table 39

Summary of Multiple Regression

	Dependent Variables					
	Perception of Demands	Coping	Cohesion	Open Communication	Open Communication	
	beta	beta	beta	beta	F	F
Step 1						
Covariates						
Group	-.27	-.19	-.16		-1.96*	
MW	-.03	.15	-.07		-.35	
ME	.25	.21	-.45		-2.70*	
MO	-.08	-.06	.50		2.20*	
R ² change	.09	.11	.07	.01	2.86*	.50
Step 2						
Coping						
FCTOT			.23		2.80*	
FCSS				.04		.47
FCASS				.28		3.13*
FCREF				.27		3.25**
R ² change			.05	.20	7.83*	13.00**
Step 3						
Perception of Demands						MEAN
NLEI	-.06	-.30	-.02	.05	-.07	.63
PLEI	-.18	-.95	.15	-.12	.75	-1.46
TLEI	.07	.23	-.25	.24	-.77	2.69*
HI	-.10	-1.27	-.11	-.21	-1.33	-2.78*
UI	.34	4.47**	.27	.22	3.37**	2.85*
R ² change	.12	4.68**	.10	.10	3.70*	4.29**
Step 4						
Demands						
NLE	.29		-1.57		-3.23*	
PLE	.15		.54		1.12	

Table 39 (cont'd)

Table 39 (cont'd)

Step 6									
Demands X Resources									
R ² change	.00	.58	.00	.25	.01	1.39	.00	.10	
Constant	2196.68		-2667.18		7128.95		7137.73		
R ²	.36		.31		.30		.44		
Overall F	3.19**		2.54**		2.39**		4.10**		
Dependent Variables									
Step 1									
Covariates									
Group	-.23	-2.91*					-.06	-.70	
MW	.22	1.13					-.11	-.59	
ME	-.07	-.41					-.19	-1.17	
MO	-.13	-.55					-.03	-.15	
R ² change	.07	2.87*		1.19			.11	4.78*	
Step 2									
Coping									
FCIOT			.18	2.05*			.16	1.90	
FCSS	.77	12.34**	.07	.74			.14	1.60	
FCASS	-.07	-1.11	.12	1.30			-.30	-3.56**	
FCREF	.00	.14	.06	3.48*			.10	6.09**	
R ² change	.48	54.69**							
Step 3									
Perception of Demands									
NLEI			-.16	-1.87			-.08	-.37	
PLEI			-.14	-1.53			-.08	-.46	
TLEI			.21	2.17*			.25	.83	
HI			-.21	-2.58*			.18	2.25*	
UI			.33	4.08**			.12	1.51	
R ² change	.00	.12	.14	5.39**			.08	3.24*	

Table 39 (cont'd)

Step 4									
Demands									
NLE									
PLE									
TLE									
HF									
UF									
R ² change	.03	1.92	.00	.08	.02	.61			
Step 5									
Resources									
FIRM			.04	.38	-.09	-1.19			
ELOC			-.06	-.66	.41	5.74**			
PSC			.26	3.04*	-.04	-.51			
PSA			-.09	-1.04	.00	-.13			
PAC			-.19	-2.21*	.19	2.59*			
PPA			.13	1.20	-.05	-.61			
PCM			.09	.94	-.03	-.45			
GSW			-.13	-1.05	-.11	-1.13			
R ² change	.01	.40	.08	1.97*	.20	6.88**			
Step 6									
Demands X Resources									
R ² change	.01	2.70	.00	.06	.00	.94			
Constant	7166.61		3662.81			-2323.94			
R ²	.60		.32			.51			
Overall F	7.68**		2.36**			5.26**			

* p ≤ .05 ** p ≤ .001

total life events contributed significantly. Neither resources nor the interaction of resources and demands contributed significantly, however, the interaction term did approach significance.

Coping

In this analysis total coping was used as the dependent variable. The role of perception of demands, resources, and the interaction term in predicting coping is consistent with the model and the hypothesis. The covariates and model constructs accounted for 37.3% of the variance in coping. The covariates, perception of demands, resources, and the interaction each contributed significantly to the prediction of coping. The covariates accounted for 11% of the variance. Group was the only significant variable in the covariate set. Perception of demands accounted for 23% of the variance. Uplifts intensity was the only significant variable in the perception of demands set. Within resources which accounted for 8% of the variance, family resources and individual perceived social acceptability were both significant. The interaction demands and resources accounted for 3% of the variance. Although the model predicted an effect size for demands that is more comparable with that of resources, the findings do support the hypothesis.

Family Functioning

Cohesion

The findings related to cohesion support the hypothesis. The covariates and each of the model constructs except the interaction term contributed to the prediction of 38% of the variance in family cohesion. The covariates accounted for 7% of the variance with group, mother's education, and mother's occupation having significant effects. Group and mother's education related negatively to family cohesion indicating

that being in the chronic illness group and lower maternal education were associated with higher levels of family cohesion. Mother's occupation related positively to cohesion. Total coping and perception of demands accounted for 5% and 10% of the variance respectively with uplifts intensity having a significant effect in the latter construct. Demands accounted for 6% of the variance with negative life events having a significant negative effect. Family resources and the global self worth of family members made significant contributions to the 10% of the variance accounted for by resources. Overall the findings are consistent with the model content, although the model would predict that coping would account for a greater amount of the variance than the constructs that precede it.

Open Communication

The findings are consistent with the model content and the relative contribution of constructs. Constructs early in the model may not have main effects if the constructs closer in proximity to the dependent variable account for a large proportion of the variance. The model accounted for 39.3% of the variance in open communication which supports the hypothesis. The coping subscales accounted for 20% of the variance with both reframing and acquiring social support making significant contributions. Mean perception of demands was a better predictor of open communication than the total intensity scores and accounted for 10% of the variance. Mean hassles intensity had a significant negative effect on open communication. The mean intensities of total life events and uplifts made significant positive contributions. Covariates, demands, resources, and the interaction term did not make significant contributions to the prediction. Although the first three constructs in

the model did not make significant contributions individually, together they accounted for 8.5% of the variance in open communication.

Conflict

The model accounted for 36.2% of the variance in family conflict which supports the hypothesis. Total coping, mean perception of demands, and resources all contributed significantly. Coping had a significant negative effect on family conflict and accounted for 4% of the variance. As with open communication, mean perception of demands was a better predictor of family conflict and accounted for 11% of the variance. In contrast to the significant variables in open communication, mean intensities of hassles and negative life events showed significant positive effects on family conflict. Within demands hassles had a significant positive effect and uplifts had a significant negative effect. Demands accounted for 9% of the variance. Resources accounted for 10% of the variance with only perceived scholastic competence having a significant effect and it was negative. The findings are consistent with the model content but the model would not predict the earlier constructs (demands and resources) to have stronger predictive value than the constructs closer in proximity to family functioning.

Sociability

The model accounted for 31% of the variance in family sociability. Although this is lower than the previous family functioning dimensions it was significant ($p \leq .0004$) and thus supports the hypothesis. Total coping accounted for 14% of the variance and perception of demands 6% of the variance. Within perception of demands uplifts intensity was the only variable with a significant effect. Demands, resources, and the

interaction term did not make significant individual contributions but together accounted for 10.2% of the variance. The findings are consistent with the model in both content and relative contributions of the constructs.

Idealization

Family idealization was the most poorly predicted of the family functioning dimensions. The model accounted for 30% of the variance ($p \leq .0009$) which supports the hypothesis. Total coping and perception of demands were both significant predictors accounting for 9% and 6% of the variance respectively. Within perception of demands uplifts intensity was the only significant variable. Although not significant individually, demands, resources, and the interaction term together accounted for 9.5% of the variance. The results support the model even though the significant constructs do not account for a large percentage of the variance in idealization.

Disengagement

Forty-four per cent of the variance in disengagement was accounted for by the model. Thus the hypothesis was supported. The coping subscales, mean perception of demands, and resources were significant predictors of disengagement. The coping subscales accounted for 21% of the variance and were better predictors than the total coping score with reframing having a significant negative effect. Mean perception of demands was also a better predictor than the total intensity scores accounting for 7% of the variance. Mean hassles intensity made a significant positive contribution while mean uplifts intensity made a significant negative contribution. Resources accounted for 10% of the variance. Within resources, global self worth was the only significant

variable and it was negatively related to disengagement. Demands and the interaction term did not contribute significantly. The findings are consistent with the model content and relative contribution of the constructs although resources has a somewhat larger effect than would be anticipated.

Religious Emphasis

Sixty percent of the variance in religious emphasis was accounted for by the model which supports the hypothesis. The covariates made a significant contribution with group being the only significant variable. Although significant the covariates accounted for only 7% of the variance while the coping subscales accounted for 48% of the variance. This was clearly related to the large contribution of the subscale for seeking spiritual support. These findings are consistent with the analysis of variance finding that the chronic illness group uses the coping strategy of seeking spiritual support significantly more than the comparison group. None of the other constructs were significant. A clear main effect for coping with lesser effects from the other constructs is consistent with the model in content and relative contribution of constructs.

Organization

The model accounted for 31.6% of the variance in family organization which support the hypothesis. The coping subscales, mean perception of demands, and resources were significant predictors. The coping subscales accounted for 6% of the variance with seeking spiritual support having a significant effect. Mean perception of demands accounted for 14% of the variance. The mean intensity of total life events and uplifts had significant positive effects. The mean intensity

of hassles had a significant negative effect. Resources accounted for 8% of the variance with perceived scholastic competence having a significant positive effect and perceived athletic competence having a significant negative effect. The findings are consistent with the model in content but the model would predict a greater contribution from coping.

Chaotic Family Style

The model accounted for 51% of the variance in chaotic family style which supports the hypothesis. The covariates, coping subscales, perception of demands, and resources were significant predictors. The covariates accounted for 11% of the variance with no single variable being significant. The coping subscales accounted for 10% of the variance with reframing making a significant negative contribution. Perception of demands accounted for 8% of the variance. Hassles intensity was the only significant variable. Resources accounted for 20% of the variance with external locus of control and perceived athletic competence making significant positive contributions. The findings are consistent with the model content and relative contributions of coping and perception of demands however resources are a stronger predictor than would be expected from the model.

Summary

It was hypothesized that the model constructs entered in the order of the model would predict a significant amount of the variance in perception of demands, coping, and each of the nine dimensions of family functioning. The hypotheses were supported. The significance of the constructs in predicting the dependent variables supports the content of the model. The relative contribution of individual constructs in terms

of their position in the model was not consistently supported in the prediction of each of the dependent variables. This may in part be due to the significant correlations that were found between variables in different constructs. Examination of the constructs across dependent variables revealed that coping was significant in predicting all nine dimensions of family functioning. Thus it was significant in all nine of the equations into which it was entered. Perception of demands was a significant predictor of coping and eight of the nine dimensions of family functioning, making it significant in nine out of ten of the equations into which it was entered. The findings for the variables within perception of demands is also of importance. Life event intensities were significant in only three of the ten equations while hassles intensity was significant in five and uplifts intensity was significant in seven. Demands were significant predictors of perception of demands and two dimensions of family functioning. This is consistent with the construct's early position in the model. With the exception of the prediction of perception of demands where all of the demands variables except total life events were significant, negative life events, hassles, and uplifts were each significant in one but different dimensions of family functioning. Resources were significant predictors in six of the eleven equations into which they were entered including coping and five dimensions of family functioning. This construct in particular showed high correlations with family functioning which may have resulted in its accounting for a larger proportion of the variance in some of the dimensions of family functioning than would be predicted by the model. Of the variables within this construct perceived conduct-morality and perceived physical appearance were the only two variables

that were not significant in any of the equations. The interaction of demands and resources approached significance in the prediction of perception of demands and was a significant predictor of coping.

Overall the model and its effectiveness in examining family adaptation was supported. The findings support the retention of each of the five model constructs for future research. However, the significance of the interaction of demands and resources and the position of resources in the model are weakly substantiated. The interaction does not appear to play a crucial role in the predictions and could be dropped from the equations with minimal effect. The findings suggest that resources have a direct effect on coping and may mediate the effect of perception of demands on coping. This would place resources later in the model which is more consistent with the findings.

CHAPTER 4 DISCUSSION

The discussion will be organized by the model constructs. Within the constructs major findings from the three types of analysis will be integrated and discussed as they relate to one another, other constructs, previous research, and the implications for future research. The discussion concludes with a summary.

Demands

Much research has been done on the effect of major life events on the psychological adjustment of adults. Research related to the impact of life events on children has been sparse (Burt, Cohen, & Bjorck, 1988). The life events research in all age groups has focused almost exclusively on the relationship between negative life events and psychopathology with the inclusion of few positive events. When a sufficient number of positive events were included they were found to be related to life satisfaction and unrelated to disorder (Zimmerman, 1983). The introduction of hassles and uplifts into the stress-coping paradigm is more recent (Kanner et al., 1981). The pattern of research with hassles and uplifts parallels that of the life events research. Although there is less research on hassles and uplifts, what there is focuses on adults and the relationship of hassles with negative psychological outcomes. The inclusion of uplifts in the research is rare (Kanner, Feldman, Weinberger, & Ford, 1987). In the current study the three life event measures and hassles were positively and significantly related to one another. This is consistent with a unitary construct of demands and the concept of "pile up" of demands (McCubbin et al., 1983a). In addition they showed highly significant relationships with the perception of demands variables and were the only

significant predictors of overall perception of demands. Consistent with previous research, negative life events and total life events were significantly related to less adaptive characteristics of family functioning, although these relationships were few. These variables had limited predictive value in relation to family functioning or coping. In contrast to the interrelationships of the other four demands variable, uplifts were significantly related only to hassles. Uplifts were positively related to the life event measures but the relationships were not significant. The possibly unique role of uplifts will be discussed separately. Based on the previous research it had been hypothesized in the current study that families with chronically ill children would report significantly more life events and hassles. This was partially supported. These families reported more positive life events, uplifts, and total life events but not hassles. Negative life events approached significance. Overall the chronic illness families reported more positive than negative experiences. Although this findings was not anticipated, it is consistent with the idea that families redefine their total situation in a more positive manner over time (Venters, 1981). If chronic illness families have developed additional and more effective coping behaviors through their experiences with the illness, they may not appraise some life events and hassles as being a threat to their well being (Folkman, Lazarus, Gruen, & DeLonogis, 1986). Specific events such as illness and hospitalization might have a less negative effect on families who are knowledgeable about the illness and hospitalization particularly if the chronically ill child's condition improves considerably with hospitalization or if the hospitalization is an expected and predictable part of the

management of the child's illness. This process of coping affecting cognitive appraisal is supported by the negative relationship found between total life events and coping.

The families with chronically ill children did experience significantly more major life events than families with healthy children. Even though the incidence of life events was higher there seems to be a relative equilibrium between positive and negative life events with the occurrence of positive events being somewhat more frequent. This positively skewed balance may be a function of the adaptation process that provides the family with the energy to go forward in spite of the high level of demands.

Uplifts frequency showed a different pattern of relationships than the other variables in demands. Uplifts were significantly related to measures of coping and adaptive family functioning which suggests that in comparison to life events and hassles, uplifts may have a unique role in adaptation. In one of the few studies of uplifts in children, the frequency of uplifts was found to have a significant relationship to good adaptational outcome (Kanner et al., 1987). For the families in the present study the frequency of uplifts was related to total coping and acquiring social support as well as to the family functioning dimensions of open communication and idealization. These relationships suggest that positive experiences support positive family functioning. This may occur through their relationships with coping responses as well as adaptive family functioning leading to a higher frequency of uplifts. The higher level of uplifts in the families with chronically ill children could result from their more effective use of coping responses such as enhancing their social support network which, in turn, would

lead to enriched social interactions. Increased social interaction and support could not only result in a direct increase in uplifts but may also increase the family's awareness of the small positive things that happen in their lives.

The higher level of family demands (primarily positive) reported by children in the chronic illness families could result from the interaction of family experience and developmental level. Children in the chronic illness families reported more uplifts, positive life events, and total life events. Chronic illness in the family may increase the child's awareness of and experience with major life events and smaller experiences that can be either hassles or uplifts and thus affect their cognitive appraisal of these events relative to the cognitive appraisal of children in families where no illness is present. This awareness and experience could occur through direct communication among family members, the family's philosophical style, and changes the children experience in their lives such as when a sibling is hospitalized. This interpretation is supported by earlier research findings suggesting that families of chronically ill children in addition to redefining their total situation also redefine their values and goals developing a philosophy of life that places more emphasis on human values such as love and sharing rather than future achievement (Lavigne & Burns, 1981; Venters, 1981). Both the chronically ill children and their school age siblings may define more events as positive due to their experience with them, particularly if they have experienced their family dealing effectively with major life events and identifying smaller positive experiences. As the family redefines its total situation and specific situations this redefinition may increase

the frequency of within family uplifts. Children in the chronic illness families may have wider social contacts in terms of age groups, professionals, and nonprofessionals as a result of both social support and professional contacts related to the illness. These contacts may increase uplifts for children in the chronic illness families compared to children in families with healthy children.

The significant interaction between group and sex for target children showing chronically ill girls reporting more total life events than healthy target girls is more difficult to interpret. It may be a result of their direct experience with life events related to their illness as well as increased time with their parents due to treatments and health care visits. A gender effect for frequency of life events has not been reported in previous life events research with children (Brown & Cowen, 1988). The gender effect could potentially result if parents tended to overprotect and restrict chronically ill girls more than chronically ill boys. This would be enhanced if the chronically ill girls were more willing than the boys to comply with this role. Developmentally the chronic illness itself as well as the future implications of the chronic illness are abstract and often not well understood by school age children due to their level of cognitive functioning. This limited understanding would influence how children view major life events related to the illness as well as other life events with abstract components (Dunn, 1986). Thus when a chronically ill child becomes acutely ill, the ill child may view the positive one-to-one attention from parents as positive. But the siblings may also view increased time with parents while the ill child is sleeping or in the hospital as positive. Thus cognitive functioning, family

experience, and the illness related social contacts may all influence a child's awareness of demands and definition of them as positive or negative.

Resources

Resources include both the family's resources and the resources of individual members. Individual and family resources together were significant predictors of both coping and adaptive family functioning. Family resources include psychological, social, interpersonal, and material resources. The positive relationship between family resources and global self worth indicates that one's global self worth may influence as well as be influenced by the family's resources. In addition fewer family resources, particularly in combination with lower global self worth, is associated with higher levels of externality of control. This sense of lack of control in one's life could lead the individual and family to use fewer coping responses and consequently not develop an increased sense of competence or acquire increased family resources (Folkman, 1984). Even though there were no significant differences between families of chronically ill children and comparison families on family resources, it is still important to note that despite the high level of demands they did not have fewer resources than the comparison families suggesting that the demands are not depleting the resources of the chronic illness families. The negative relationship of family resources with the intensity of hassles and the positive relationship with coping and adaptive dimensions of family functioning indicates that in the presence of greater family resources hassles are viewed as less severe and coping strategies and adaptive family functioning are increased. This relationship was further supported by

the significance of family resources and five of the individual resources in predicting coping and adaptive family functioning which supports the importance of resources in family adaptation.

Individual resources included perceived self competence and locus of control. Higher levels of global self worth, perceived conduct-morality, and perceived scholastic competence were associated with lower levels of family conflict, disengagement, and chaotic family style. These findings illustrate the importance of the relationship between individual resources and family functioning for on-going family adaptation. If an individual believes in his/her capability and the family resources give the family a perception of competence, demands may be defined more in terms of challenges that can be met rather than as insurmountable obstacles. Family resources, individual resources, and adaptive family functioning work reciprocally in promoting individual development and facilitating family adaptation (McCubbin & Patterson, 1983b).

In the analyses of individual resources there were only two main effects for group. On the whole these findings support a lack of difference on perceived self competence and external locus of control between the chronic illness and comparison groups and suggest that chronic illness alone neither impairs nor facilitates perceived self competence and external locus of control. This is consistent with previous research on chronically ill children that found no differences from healthy children when self report was used to examine self concept and with sibling research that identified strengths in the siblings of chronically ill children (Breslau, 1983; Gayton et al., 1977; Simmons et al., 1987). The lack of research on nonpathological aspects of parents

does not allow for comparison of these findings, but in the present study there were no significant differences in the individual resources of parents based solely on the presence of a chronically ill child.

The findings do suggest that the presence of a chronically ill child in a family does interact with the gender and developmental level of members in effecting perceived self competence and locus of control. This is evidenced by the seven group by sex interactions. Perceived self competence accounted for the two main effects for group and five of the group by sex interactions. External locus of control accounted for the other two group by sex interactions.

Three of the interactions involved the parents. Fathers in the comparison group rated themselves lower on perceived social acceptability than both groups of mothers and the fathers from the chronic illness group. The near equal means on this subscale for both parents in the chronic illness family may reflect that when a chronic illness is present both parents are involved more equally in individual and family social interactions. This may be a result of the family coping responses that involve social interaction and the extent of social support outside of the family. This is consistent with the importance of extra-familial support that has been described by a number of authors (Frydman, 1981; Patterson & McCubbin, 1983a; Venters, 1981). In families with healthy children the mothers may play a larger role in the family's social interactions.

On perceived athletic competence there was a group by sex interaction for parents. Fathers of chronically ill children rated themselves higher on athletic competence than comparison fathers and comparison mothers rated themselves higher than mothers of chronically

ill children. For fathers in the chronic illness group athletics may serve as a means of coping through increasing interpersonal interaction and self esteem. Physical activity may provide an outlet for the frustration and stress of having a chronically ill child. The mothers of chronically ill children may have moved more toward social interaction and nurturing activities that can be incorporated with their increased caregiving responsibilities. Participation in athletic activities outside of the home could serve to detract from the time available for caregiving for mothers of chronically ill children. In addition mothers may find social activity to be a more effective means of dealing with their frustration and stress than physical activity.

Perceived physical appearance resulted in the same findings for fathers as athletic competence. Again the fathers of chronically ill children rated themselves higher than fathers in comparison families and mothers in the chronic illness families. Although depressive affect might be used to explain the mother's lower scores that interpretation would not be consistent with the lower scores of the comparison fathers. When paired with the athletic competence findings, it may be that maintaining one's physical appearance and athletic skills or at least perceiving them to be good supports the fathers identity which may be negatively affected by having a chronically ill child. This explanation would be consistent with Cummings (1976) findings related to negative impact on fathers of having a chronically ill child.

For the school age children (both siblings and target children) having a chronically ill child in the family did have significant effects. On perceived athletic competence both target children and siblings in the chronic illness group rated themselves lower than the

children in the comparison group. For children this may reflect lack of experience due to limited time, finances, and parental support for pursuing these activities (McCubbin et al., 1982a; Meyerowitz & Kaplan, 1967). It may be more difficult for the parents to find time to go out and do sports with the children or to transport them to organized sports activities. Both chronically ill children and their school age siblings also reported lower perceived conduct-morality indicating they were less satisfied with their behavior or viewed their behavior as less 'good' than children in the comparison families. The increased demands in families with a chronically ill child may result in increased role and behavioral expectations of the children. The parents may also not have as much time for positive reinforcement and may be spending considerably more time performing treatments and getting the child to health care agencies. Increased role and behavioral expectations can lead to a sense of mastery if the child's efforts are recognized. Conversely, lack of parental feedback can diminish the child's sense of competence (Harter, 1982a).

In the present study no differences on perceived self competence were found for the target children. A difference specific to the target children, not including the siblings, might have been anticipated on perceived physical appearance and athletic competence based on the presence of illness but this does not appear to be the case. This could indicate either a realistic appraisal of their physical appearance and motor skills with acceptance of the differences or the use of denial. The data from this study do not provide information to address this issue. Specific domains of perceived self competence have not been examined in previous research on chronically ill children but the

present findings are consistent with prior findings of no differences in self concept between chronically ill and healthy children (Gayton et al., 1977; Simmons et al., 1987).

Having a chronically ill child in the family does appear to interact with the gender of siblings in relation to perceived self competence. For both school age and adolescent siblings of chronically ill children, the male siblings reported lower perceived conduct morality than the male siblings in the comparison families. There was also a significant group by sex interaction for siblings on global self worth. Again the male siblings of chronically ill children scored significantly lower than the males siblings of healthy children. In contrast, the female siblings of chronically ill children scored significantly higher on global self worth than the female siblings of healthy target children. Global self worth would certainly be effected by the siblings perception of their behavior. Female siblings may take on more tasks at home and receive both more feedback and positive reinforcement than their male counterparts leading to a sense of mastery (Harter, 1982a). Female siblings of chronically ill children may also receive more positive reinforcement within the family for helping with extra demands than female siblings in healthy families where there are less demands. For the female siblings in the chronic illness group, being more involved at home may increase their contact with their mother in a positive way that is developmentally consistent. Male siblings may be more interested in peer group and sports activities outside of the family. There may be less support and guidance at home for the developmental interests of the male siblings and decreased opportunities for these siblings to be involved with peers in organized and informal

activities outside of the family. This could result in less positive reinforcement and support for the male siblings leading to a diminished perception of conduct-morality. Their fathers may have less time or be less inclined to do something extra with them as found by Cummings (1976). The development of sex role is a prominent process in the school age years. In this age group the children tend to be traditional and conservative in terms of sex role. They identify with and imitate same sex models and the same sex parent. After starting school the children also receive considerably more feedback from peers and adults based on behavioral expectations for their sex (Bandura, Ross, & Ross, 1983; Maccoby & Jacklin, 1974). This aspect of development may be more difficult for the male siblings of chronically ill children to accomplish leading to a diminished sense of competence in terms of their behavior as well as their global self worth.

Adolescent males and male siblings (including school age) in the chronic illness families both showed greater externality in locus of control than their counterparts in the comparison families. The lower levels of global self worth and perceived conduct-morality may lessen the boys confidence in decision making and problem solving thus diminishing the development of a sense of control. If developmentally consistent activities have been blocked by family demands, decreased parental time, and/or finances, this could increase the feelings of external control. Adolescent females who were siblings of chronically ill children scored significantly lower on externality than adolescent females in the comparison group. This relationship was not significant for the chronic illness group when female siblings of all ages were compared. If the older female siblings have indeed participated more in

family tasks related to the chronic illness over time, their participation with the family in dealing with the increased demands may increase their sense of internal control. The findings on individual resources indicate that male siblings of chronically ill children may be at increased risk for psychosocial difficulties while the female siblings may benefit from the experience of having a chronically ill sibling.

Perception of Demands

Prior life events research and to a lesser extent the research involving hassles and uplifts have focused on the relationship between these experiences and psychological dysfunction. The majority of the researchers have concluded that standard or subjective weighing of these events does not add to their predictive ability and in some cases detracts from it (Zimmerman, 1983). Because of the focus on psychological disorder and the lack of subjective weights there is little research with which to compare perception of demands in the current study. Although the number of negative life events, positive life events, hassles, and uplifts significantly predicted the perception of demands in the present study, the additional findings related to perception of demands suggest that the inclusion of subjective weights may be an important parameter in studying adaptation.

Negative life events, positive life events, hassles, and uplifts predicted greater than two thirds of the variance in perception of demands. This supports the concept of pile up of demands and a total intensity of demands for families. The significant positive intercorrelations of the intensity of life events and hassles further support the unified construct of perception of demands in the model

reflecting the intensity of the overall situation. As was true in demands, the intensity of uplifts showed a different pattern of relationships than the other variables within perception of demands.

The inclusion of the intensity of uplifts is supported by its theoretical relationships with hassles and life events. However, its role in this construct seems to be more complex and obscure than the other variables. The intensity of uplifts is the only variable in perception of demands that has a significant relationship with coping. Uplifts intensity is positively related to total coping, seeking spiritual support, and acquiring social support. These findings suggest that perceiving small events as opposed to major life events as being very positive may facilitate the implementation of coping responses in general and specific coping responses aimed at seeking spiritual support and acquiring social support. High levels of uplifts intensity may be associated with viewing the world external to the family as positive and supportive. This would lead to a greater likelihood of seeking help outside of the family when demands increase beyond the family's capacity. This interpretation is supported by uplifts intensity being a significant predictor of total coping. Uplifts intensity also shows more relationships with family functioning than the other perception of demands variables. Uplifts intensity contributed significantly to the prediction of adaptive family function including positive contributions to the prediction of cohesion, open communication, sociability, positive attitudes about one's family, and organization and negative contributions to the prediction of family conflict. The relationships with family functioning may result through the relationship between uplifts intensity and coping and/or a more direct relationship between

uplifts intensity and family functioning. These findings are consistent with the findings of previous research on uplifts in children and adolescents that found uplifts to be associated with a number of indicators of emotional well-being and social adjustment regardless of gender (Kanner et al., 1987). The findings of research on the effect of uplifts on adaptational outcomes in adults has been less clear. For men uplifts have been unrelated to adaptational outcomes while for women they have shown a positive relationship with negative outcomes (Kanner et al., 1981). The findings in the present study are not consistent with the previous findings with adults. Although psychological symptoms were not measured there is no evidence of lower perceived self competence in the mothers.

In contrast to uplifts intensity, high levels of intensity for negative life events and hassles were associated with increased family conflict. These findings are consistent with the uplifts findings of the current study if they are interpreted to indicate that the intense negative perception of life events and hassles is associated with maladaptive, nonsupportive characteristics of family functioning. The lack of significant relationships between intensity of life events, hassles, and coping may reflect a static rather than a diminished level of coping responses when faced with an increased number and intensity of negative demands. Not increasing coping responses to deal with these demands could then result in maladaptive family functioning characteristics. For example, previous research with individuals has found a positive relationship between negative demands and maladaptive outcomes (Kanner et al., 1981; Kanner et al., 1983; Zimmerman, 1983).

Families with chronically ill children describe the total demands they are experiencing as more intense as reflected in the total intensity scores. The mean intensity scores indicate that these families also perceive demands in general to be more intense. The differences between the chronic illness families and the comparison families rather than being tied to the intensity of negative experiences as hypothesized involved all types of demands except hassles. Although the intensity of both positive and negative life events was significantly higher in the chronic illness families, the significance of uplifts but not hassles suggests that positive experiences both major and minor may have greater relevance to the chronic illness families' perception of their total situation and their adaptation. This is an area that has not been addressed in previous family or chronic illness research but may relate to redefining their total situation in a more positive manner and to changes in their cognitive appraisal through experience (Venters, 1981; Folkman et al., 1986).

Examination of the analyses of each of the intensity variables provides further insight into the effects of age, gender, and family role on the perception of demands. Mothers in both groups perceived the total intensity of negative life events as being more extreme than fathers. This is consistent with previous life event research findings that females view negative events as more upsetting than males (Kale & Stenmark, 1983). Chronically ill children and their siblings rated the total intensity of the negative life events they were experiencing as significantly more intense than their counterparts in the comparison group. The developmental level, particularly in relation to cognitive functioning, of these children and siblings may limit their

understanding of major life events particularly as they relate to the chronic illness (Dunn, 1986). Children also have more limited coping responses related to their developmental level which may also make the experience of negative life events more intense (Rose, 1984; Spirito et al., 1988). The main effect for siblings on mean intensity of negative life events indicates that all siblings (both school age and adolescent) of chronically ill children perceive negative life events in general to be significantly more severe. The group by sex interaction for children indicates that this perception is particularly true for school age girls whether siblings or chronically ill. This general perception of negative life events as being extremely intense may reflect their experience with these events in the past, their limited understanding of them, and their coping abilities. The findings do raise the question of whether the school age girls are at risk for a negative attribution style and psychosocial problems (Kaslow, Rehm, & Siegel, 1984).

For positive life events, the higher total intensity for the chronic illness families is related in part to the larger number of positive life events reported by these families. However, the significantly higher mean intensity of positive life events indicates that the high total intensity is not solely a result of the number of positive life events. The high mean intensity suggests that the perceived intensity of positive events may provide equilibrium for the family. Although it could be interpreted as overestimation by the chronic illness families or use of denial by the comparison families the most parsimonious and least pathological interpretation would be that this intensity is a result of coping responses and maintaining homeostasis. Chronically ill children and their school age but not

adolescent siblings in particular experience a high total intensity of positive life events. As with the intensity of negative life events, this may be related to developmental level and coping abilities. Chronically ill boys in particular perceived positive life events in general as more intense than their siblings or the children in the comparison families. Chronically ill children may have more experience with a broader range of life events which may increase their awareness of and responsiveness to these events. For the chronically ill boys in particular, perceiving positive events as intensely positive may provide an equilibrium in the valence of the demands that they experience. In contrast, chronically ill girls and their school age female siblings perceived negative life events as being significantly more intense than the boys did. These gender differences could reflect the gender differences that have been described in the attributional style of boys and girls in general. This could place the girls at risk for depression. The attributional style associated with depression includes not only viewing events as negative but also a negative self concept but there was no evidence of decreased self concept in the chronically ill girls in this study or in their siblings (Dweck, Goetz, & Strauss, 1980; Kaslow et al., 1984).

The findings for the total intensity of all life events are consistent with summing the results for positive and negative life events and indicate that the chronic illness families and their children in particular are experiencing a high intensity of demands in their families even though the positive and negative life events may be in relative balance. Siblings in the chronic illness families perceived life events in general as being more intense. This is consistent with

the finding for siblings of higher intensity of negative life events and the trend for all children including siblings in the chronic illness group to perceive higher mean intensity for positive life events. The group by sex interaction with chronically ill boys rating total life events significantly higher than target boys in the comparison families suggests that the intensity with which chronically ill boys rated positive events is greater than the intensity with which the girls rated negative events resulting in the group by sex interaction for total life events. If this is true then the girls may be at less risk than would be predicted from examining the results of negative life event intensity alone.

The significance of the intensity of uplifts but not hassles suggests that for the chronic illness families the intensity of uplifts may provide a positive skew to the balance between the intensity of positive and negative experiences. In contrast to major life events, for chronically ill children uplifts showed no group by sex interaction. This suggests that the gender differences for major life events may relate more to coping abilities and cognitive functioning than to a generalized attribution style. Small positive events may not only be more noticed but also more appreciated when families are dealing with a large number of major life events that are experienced as being very intense. Since the model of adaptation is continuous across time, the prior use of all three types of coping responses could result in increased uplifts and consequently an increase in the total intensity of uplifts. Reframing of the total situation and major events over time could lead to a cognitive set that includes more small positive occurrences and defines more new occurrences as positive. Seeking

social and spiritual support could lead to positive personal and social experiences that are experienced as particularly positive due to the number of demands the family faces. The awareness of these small events and the perception of them as intensely positive may be heightened as the family goals are redefined in terms of humanitarian rather than achievement oriented goals. The high level of total uplifts intensity in the chronic illness families may lead over time to the general tendency to rate uplifts as intensely positive as reflected in the higher mean uplifts intensity in the chronic illness families. In combination with the positive life event intensity findings, this is suggestive of a positive attribution style which would be counter to the many discussions of depression in families of chronically ill children.

Coping

In this study a significant amount of the variance in coping was predicted by perception of demands, resources, and the interaction of demands and resources but not demands themselves. This supports the position of coping in the model as well as the use of the families' subjective perception of the demands they are experiencing. Within the construct of coping, the positive relationship between acquiring social support and seeking spiritual support may be a result of both the social interactional nature of these coping strategies as well as their potential for assisting the family in reducing the demands and tolerating the distress created by aspects of the illness that cannot be controlled (Folkman, 1984). Acquiring social support clearly involves interaction with other people. While spiritual support typically involves belief or faith in a higher being, it also involves interaction with the clergy and one's religious institution. In contrast, reframing

was not related to the other two types of coping. This lack of relationship may result from reframing being primarily related to cognitive activity that does not necessarily involve social interaction.

Consistent with the model, total coping was positively related to adaptive family functioning characteristics including open communication, sociability, idealization, and religious emphasis, and was negatively related to the maladaptive pattern of disengagement. Chaotic family style showed the weakest relationships with total coping. It may be the case that in chaotic families, unpredictability limits family coping responses and demands are adapted to more in relation to individual needs. Acquiring social support was positively related to open communication, sociability, idealization, and religious emphasis. Acquiring social support as a means of coping involves the use of both communication and social skills and may indeed facilitate the family's use of open communication and social interaction both within and outside of the family. These findings also suggest that some of the family's social support is sought within their religious framework. If the acquisition of social support is a positive experience for the family, family members may develop or increase their positive attitudes about themselves as a unit. The strength of the relationship between coping and family functioning is further supported by the finding that coping was a significant predictor of all nine dimensions of family functioning, a finding that once again illustrates that coping is related to both adaptive and maladaptive dimensions of family functioning. This supports the position of coping in the model relative to family functioning.

Based on the above findings, the families with chronically ill children would need to have significantly higher scores on coping to deal with their perceived demands adaptively. The findings indicate that this is true. The families with chronically ill children made use of significantly more coping responses than the comparison families. The significantly higher scores on total coping indicate both a greater number and a broader range of coping responses. In view of the large number of demands and the intensity of these demands, the greater number and broader range of coping responses are important assets for effective adaptation (Pearlin & Schooler, 1978). Reframing was the only specific coping response that was not significantly higher in the chronic illness families. Previous research has found that families with chronically ill children usually redefine the illness and their total situation within the first year after the diagnosis. The diagnosis of the chronic illness in all of the families that participated in the current study had been made at least one year prior to the study. By definition chronic illness is long term and the course and prognosis of the illness are uncertain. Once families have redefined the illness and their total situation, they may find that acquiring social support and seeking spiritual support are more effective coping mechanisms. Redefining and acquiring more knowledge about the illness will not shorten its duration nor affect the course and prognosis. Although redefining and increasing one's knowledge about the illness may decrease anxiety, the long term nature of a chronic illness and the inherent uncertainties make it seem likely that the level of demands and demand intensity will remain high. Therefore the family needs to develop and use coping strategies that can provide long term support. Social and spiritual support can be the

basis for such long term support strategies. The chronic illness families did make greater use of acquiring social support than the comparison families. In particular fathers in the chronic illness families indicated a greater use of this coping response than fathers in the comparison families. It may be that at the higher level of both demands and demands intensity fathers need to be more actively involved in acquiring social support for the family whereas with a lower level of demands and demands intensity fathers may play less of a role in the acquisition of social support. In particular families with chronically ill children sought spiritual support in response to the demands. This finding was significant for all subgroups by age and family role which indicates that all family members clearly recognized this as a means of coping and suggests that they may do this together as a family. The high use of spiritual support in these families may be particularly effective for dealing with the uncertainties of these illnesses.

Previous research on families with chronically ill children and other families facing other long term stressors has found a greater use of spiritual support in these families than families without a long term stressor (McCubbin, 1979; Olson, McCubbin, Barnes, Larsen, Muxen, & Wilson, 1983; Powers, Dill, Hauser, Noam, & Jacobson, 1985; Shapiro, 1983). When there is social ambiguity related to the stressful situation religious faith may provide a reference point for social norms and expectations (McCubbin, 1979; Olson et al., 1983).

Family Functioning

All nine dimensions of family functioning were successfully predicted by the model which supports its use as a conceptual framework for studying family adaptation. Of the six adaptive dimensions of

family functioning religious emphasis showed a unique prediction pattern, with the only significant predictor being the use of spiritual support as a coping strategy. Religious emphasis also had fewer significant interrelationships with the other dimensions of family functioning than was found for the other dimensions. Religious emphasis was positively related only to open communication and organization. These findings suggest that this characteristic is associated with adaptive family functioning but may be present more strongly in some families than others. It may be the case that when present it supports overall adaptive family functioning but that it is not a necessary dimension for adaptive family functioning. This would be consistent with earlier research findings of greater use of spiritual support in families facing chronic stressors (Olson et al., 1983; Powers et al., 1985; Shapiro, 1983).

The other five adaptive dimensions of family functioning were predicted by coping and perception of demands with resources having a significant predictive value for cohesion and organization. In contrast, the lack of resources had significant predictive value for all three maladaptive dimensions of family functioning. The multiple regression findings suggest that when resources are present they support a greater number and wider range of coping strategies leading to adaptive family functioning while the lack of resources appears to not only have a negative effect on coping but also have a greater and more direct effect on maladaptive family functioning. Another important difference in the prediction of family functioning was found in perception of demands. Uplifts intensity had significant predictive value for the five adaptive dimensions excluding religious emphasis.

Hassles intensity had significant predictive value for all three maladaptive dimensions. In contrast the predictive value of the intensity of life events was scattered and sparse. This supports the contention that day-to-day demands have an important impact on adaptation (Kanner et al., 1987; Lazarus, 1980) and suggests that they may be more relevant predictors of overall family adaptation than life events.

The findings related to family functioning indicate that there are few differences based solely on the presence of a chronically ill child. On nine dimensions of family functioning there were only two significant differences by group. The chronic illness families scored higher on family cohesion and religious emphasis. These findings would certainly appear to be strengths in family functioning. High scores on family cohesion in the measure used do not reflect enmeshment but positive feelings about one another, being together, family interaction, and doing things together without the rigid boundaries and interpersonal intrusiveness present in an enmeshed family (Bloom, 1985). The cohesiveness may reflect a talking and working together to deal with the demands including such aspects as flexible family roles and expansion of individuals roles when needed to meet the demands. Cohesion was positively related to open communication, sociability, idealization, and organization and negatively related to family conflict and disengagement which illustrates its integral role in family adaptation. This would be consistent with previous findings that effective parental coping led to increased family cohesion and that family cohesion was an important parameter in evaluating the effectiveness of the family's adaptation particularly as it related to the maintenance of family stability and

integration (McCubbin et al., 1983a). It has also been found that families who described high levels of stress as challenging rather than overwhelming have higher scores on mutuality and more positive feelings toward members of their families (Lowenthal & Chiriboga, 1975) which further supports the adaptive quality of the high cohesion scores in the chronic illness families of the present study. The higher levels of religious emphasis are most likely a result of the high levels of seeking spiritual support as a coping strategy for chronic stressors. Spiritual support seems to contribute to maintaining the family unit, individual self esteem, and aiding families in tolerating more chronic conditions (McCubbin, 1979; Olson et al., 1983). Religion has also shown a positive relationship with subjective well-being for individuals (Diener, 1984). These findings support previous theoretical and research conclusions that psychosocial problems in families with chronically ill children are most likely to occur in families where problems were present prior to the illness (Pless et al., 1972; Steinhauer et al., 1974). Prior psychosocial problems would likely be exacerbated by the demands of having a chronically ill child. For families who are at high risk for psychosocial problems, the diagnosis of a chronic illness and the subsequent demands may create enough additional stress that psychosocial problems become apparent.

Limitations of the Study

The findings of the current study are limited by a number of factors. Although the measures for demands ask for retrospective information, the data used in the current study is still cross-sectional. In order to study family adaptation more effectively, longitudinal data needs to be obtained. With longitudinal data,

demands, resources, perception of demands, and coping at one point in time could be used to predict family functioning at a later point in time. The relationship of family functioning at one point in time to demands, resources, perception of demands, and coping at a later point in time could be examined. This would provide a more accurate investigation of the model and family adaptation as an on-going process.

The current study is also limited by the small number of families. Originally, the study included the computation and examination of family scores. However, this analysis was not performed since there was not a large enough number of families to meaningfully examine the variables. Additional data is still being collected so that an analysis of family scores can be performed. It would also be ideal to have a larger number of comparison families so that the matching can be accomplished without any significant differences between the groups.

The style of medical management was purposely controlled in the current study by recruiting the chronic illness group from the same site. Style of medical management includes variables such as the amount of information, input, and decision-making power given to the chronically ill child and his family. This was felt to be an important variable in relation to family adaptation and one that would confound the current study. Investigation of the effect of style of medical management on family adaptation to chronic childhood illness would be a valuable contribution to both the research and intervention literature. This type of study would need to be carried out with a large sample that represents a broad geographic base.

The findings of the current study are further limited by the reliability of the family functioning subscales. This was evidenced by

the need to restructure the original subscales to obtain acceptable levels of internal consistency. Although the reliabilities of the new subscales were adequate, the internal consistency as measured with Cronbach's alpha was not strong. Future studies of family adaptation may benefit from adopting a family functioning instrument that has been used more extensively in this type of research and found to be sound.

Summary

The overall findings of the analysis of variance support functional adaptation in the families of chronically ill children. These families report a higher level of demands and intensity of demands than families with healthy children but the positive and negative demands and their respective intensities seem to have a relative equilibrium with a slightly positive skew. The chronic illness families appear to be dealing with these intense demands with their high level of coping responses. Their coping responses are both greater in number and broader in range than those used by the comparison families. In particular, families with chronically ill children used coping responses aimed at seeking spiritual support and acquiring social support. These types of responses have the potential of providing long term support as well as sharing the burden within and outside of the family. The minimal differences on resources and family functioning between the two groups of families suggests that the high number of intense demands is not depleting the families' resources nor is it leading to dysfunctional family functioning in the majority of families. The high level of coping appears to be effective in maintaining positive family functioning. Based on the findings, there is no evidence to suggest

that the presence of the chronic illness alone necessarily leads to maladaptive family functioning.

Although research on effective adaptation is slowly beginning to increase, it still accounts for a disproportionately small amount of the literature relative to maladaptation. Research into family adaptation is increasing even more slowly than that on individual adaptation. A comprehensive understanding of the adaptation process for both families and individuals would provide a basis from which to examine the deviations that lead to psychological disorders and dysfunctional families. Longitudinal research would provide a more accurate picture of adaptation over time including the impact of developmental transitions and coping outcomes for the family and its individual members. Although costly in terms of time and money, continued use needs to be made of self report measures from all family members to clarify father's and children's perception of and roles in this process. Pathology focused research has made limited use of positive life events and uplifts. The significant findings for uplifts in the current study and the lack of knowledge about positive life events indicates that positive experiences need to be included when investigating adaptation as an on-going developmental process. In the current study the controllability of demands was not measured. This may be of particular importance in families with chronically ill children. The area of controllability of demands has not been addressed in the family adaptation research and could provide insight into whether families use different coping strategies when faced with uncontrollable demands. A clearer understanding of the complex relationships within the adaptation process would provide guidance for preventive and promotive intervention

strategies for all health care providers. As the cost of health care in the United States continues to rise, the focus upon as well as the need and funding for prevention and health promotion will also continue to rise.

LIST OF REFERENCES

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