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PARENTING STRESS AND COPING PATTERNS OF MOTHERS
WITH YOUNG, HOSPITALIZED CHRONICALLY ILL CHILDREN

by

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THESIS

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ABSTRACT

Mothers with hospitalized chronically ill toddlers and preschoolers face a very challenging parenting situation. Mothers participated in a descriptive correlational study concerning their parenting-related stress and patterns of coping.

Hospitalization represents an acute phase of the longstanding chronic illness and chronically ill children are often repeatedly hospitalized. The young children are vulnerable to negative behavioral responses from hospitalization, and rely heavily on their mothers to cope. How the mother copes with stress directly affects how the child copes. Pre-existing parenting stresses may be aggravated by the stress of hospitalization. Very little is known about the parenting stresses of mothers or ways the mother copes when her chronically ill child is hospitalized.

The subject population consisted of a convenience sample of 30 mothers with hospitalized, chronically ill children between 20 and 66 months. Children were intellectually normal, and had been previously diagnosed with cardiac/pulmonary disease, cancer/leukemia, or GI/musculoskeletal illness.

Two questionnaires with established validity and reliability were used to collect data on parenting stress (Parenting Stress Index (PSI) and coping behaviors of mothers (Coping Health Inventory for Parents (CHIP)).

The findings demonstrated that parenting the hospitalized child is difficult because mothers perceive their child as excessively demanding, less able to adapt to changes, and as being moody and depressed. Marital stresses of mothers were high, as well as problems with their own health. Mothers worried about their competency as parents. However, despite the numerous stresses, mothers actively coped with the situation through a variety of coping strategies. Positive personal affirmations and beliefs about themselves and their child, believing in God, and reliance on the health care team were most helpful to mothers when coping with their hospitalized child. Less available to mothers were coping strategies related to social support and self-esteem.

Nurses can help meet both the emotional and educational needs of mothers with hospitalized, chronically ill children, thus becoming an important source of support. Since some mothers under the highest stress had the lowest coping scores, the coupled use of the PSI and CHIP allows a richer understanding of which mothers may be at risk and in most need for effective intervention.

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CHAPTER I

THE STUDY PROBLEM

Introduction

Mothers with hospitalized, chronically ill children experience a set of unique stresses. Mothers must respond to repeated medical intrusions into their child's life as they cope with the stresses of caring for a child with a long-term chronic illness in the hospital setting. Yet, little is known about the stresses of mothers who have chronically ill children in the hospital, or what coping strategies assist mothers in managing the stress of having the ill child hospitalized. This investigation is focused on the parenting-related stresses of mothers as well as coping behavior patterns used by mothers with hospitalized, chronically ill toddlers or preschool children.

Statement of the problem

Hospitalization is stressful for both children and parents. Children, especially toddlers and preschoolers, are vulnerable to emotional disturbances as consequences of hospital related events such as separation from home and family, painful experiences, and invasive procedures (Roskies, Mongeon, & Gagnon-Lefebvre, 1978). Most mothers perceive participation during a child's hospitalization as an expectation or obligation (Algren, 1985; Knafl, 1985) and mothers are important mediators in helping their children cope with hospitalization. Maternal participation may

reduce the negative effects of separation and hospitalization on the young child and hasten the child's recovery (Skipper, Leonard, & Rhymes, 1968; Visintainer & Wolfer, 1975). However, since the hospital environment is often threatening and anxiety provoking, the mother's ability to provide care to the child may be reduced (Mahaffy, 1965; Prugh, Staub, Sands, Kirschbaum, & Lenihan, 1953; Wolfer & Visintainer, 1975). Supportive intervention by nurses has been shown to decrease mothers' anxiety, thus increasing mothers' availability to help their children (Jaskula, 1985; Skipper, Leonard, & Rhymes, 1968; Wolfer & Visintainer, 1975).

Research on the hospital-associated stress and anxiety of mothers has usually focused on mothers with previously healthy, but acutely ill and hospitalized children. However, the hospital related stresses for mothers with chronically ill children may be quite different than for mothers with previously healthy children. Compared to mothers with healthy children, mothers with chronically ill children experience special problems related to the day-in and day-out burden of chronic worry and stress (Mattsson, 1972; Swartz, 1984). The stresses associated with a child's hospitalization are layered onto the existing stresses of caring for a chronically ill child. Existing intervention plans for parents with hospitalized, previously healthy children may not meet the needs of parents with chronically ill hospitalized children.

Parenting the chronically ill child in the hospital is particularly challenging and stressful (Chan & Leff, 1982; Ferraro & Longo, 1985; Hayes & Knox, 1984). When home management becomes inadequate or advanced invasive procedures are required, the child becomes hospitalized. Hospitalization represents an acute phase of the longstanding chronic illness and pre-existing stresses may be aggravated by the additional stress of hospitalization. The parent role changes when mothers must relinquish some of their caregiving responsibilities to the hospital staff (Knox & Hayes, 1983). Parental competence may be threatened by the parenting role changes related to the child's hospitalization (Knox & Hayes, 1983; Robinson, 1985). Little is known about the parenting-related stresses of mothers with hospitalized chronically ill children.

Certain coping strategies have been identified by parents caring for chronically ill children in the home. Coping of parents with hospitalized, chronically ill children has not been systematically explored. The coping behaviors related to finding meaning in the child's illness, seeking understanding of the illness and care requirements, sharing the burdens with others, using social supports, maintaining self-esteem, and making efforts to "normalize" the effects of illness (Holaday, 1984; McCubbin, 1984; Venters, 1981) need to be evaluated with parents coping with the hospitalization of their chronically ill child.

This investigation was based on a framework of family stress

and adaptation theory (McCubbin & Patterson, 1981) and Lazarus coping theory (Lazarus & Folkman, 1984). Stress is a product of cumulative events, an individual's perception, and the straining or taxing of resources available to manage a demanding situation (McCubbin & Patterson, 1981). Stresses are modified through the process of coping. Coping involves choosing and implementing behaviors or strategies designed to reduce the threat of a confronting situation (Lazarus & Folkman, 1984). Parenting the young toddler or preschooler with a chronic illness in the hospital is marked by stress, with a subsequent demand for mothers to develop coping behaviors to manage the stress. Yet, little systematic research has been conducted on mothers' stress or coping when the chronically ill young child is hospitalized. This descriptive study will examine the parenting-related stresses of mothers with hospitalized chronically ill young children. The mothers' coping behaviors and coping patterns will also be assessed. Additionally, the relationships between the stresses and the coping behavior patterns will be examined.

Purposes of the Study

The purposes of this study are to:

- 1.0 Determine the degree of parenting-related stress in mothers with hospitalized, young chronically ill children.
 - 1.1. Determine the degree of mother's stress arising from her perceptions of her child; specifically related to child characteristics of adaptability, acceptability to

the mother, demandingness, mood, distractibility, and reinforcement of the mother.

- 1.2. Determine the degree of mother's stress arising from her role functioning; specifically related to her feelings of depression, unhappiness and guilt, her attachment to the child, sense of restrictions imposed by the parent role, sense of parental competence, degree of social isolation, her relationship with her spouse, and her physical health.
- 2.0 Determine the pattern of coping behaviors used by mothers with hospitalized, young children with chronic illnesses.
- 3.0 Determine the relationship between the parenting-related stresses and identified coping behavior patterns.
- 4.0 Determine the relationship between the family demographic information and the parenting-related stresses or behavior coping patterns.

Significance

Childhood chronic illness has particular relevance to pediatric nurses. Between 10 and 15% of all American children suffer from a chronic medical condition (Hobbs, Perrin, & Ireys, 1985; Pless & Roghmann, 1971). Chronic illness in children imposes an increased care requirement, threatens a child's normal growth and development, and is often characterized by remissions and exacerbations (Hobbs, Perrin, & Ireys, 1985). Children with chronic illness utilize a greater percentage of health-related

services than normal, with a significant increased use of in-patient hospital beds (Gortmaker & Sappenfield, 1984).

Additionally, many children with chronic illnesses undergo repeated hospitalizations (Mattsson, 1972). Thus, children with chronic illnesses make up a significant percentage of the hospital population cared for by a pediatric nurse.

Nurses on pediatric units must interact with the families of hospitalized children. Mothers particularly, room-in or spend significant time with their hospitalized chronically ill toddler or preschool child (Knox & Hayes, 1983; Robinson, 1984). Nurses are in a unique position to be able to assess and modify the hospital related stresses on mothers, while providing support for the coping behaviors of mothers. However, since little is known about parenting-related stresses of mothers or their coping behaviors with hospitalized, chronically ill children, interventions by nurses may not be appropriate.

This study will extend nursing knowledge of child and parenting related stresses and coping patterns of mothers with hospitalized, young chronically ill children. This knowledge can lead to methods which identify mother-child dyads at risk for dysfunction, and towards the development of effective intervention programs designed to support mothers coping. Improved coping would benefit the mother and foster successful coping in her child.

Research Questions

1. What are the parenting-related stresses of mothers with hospitalized, chronically ill young children?
2. What is the relationship between family demographic information and the parenting-related stresses of mothers with hospitalized chronically ill young children?
3. What coping behavior patterns are used by mothers of hospitalized, young children with chronic illnesses?
4. What is the relationship between family demographic information and coping patterns used by mothers of hospitalized, young chronically ill children?
5. What is the relationship between parenting-related stresses and mothers' coping patterns with young, chronically ill hospitalized children?

Definition of terms

The independent variable is a chronically ill, hospitalized child between two and five years old.

Intervening variables include the mother's relationship with her ill child prior to hospitalization, her marital status, the family's socioeconomic background, the hospital environment, and any previous experiences with a child's hospitalization.

The dependent variables are the mother's parenting-related stress related to her perception of her child in the hospital setting, stress associated with her parent role functioning, and

the coping behavior patterns identified by mothers of hospitalized chronically ill young children.

Significant terms pertinent to this investigation are defined in the following list:

chronic illness = A physical condition which interferes with daily functioning for greater than three months in a year, causes hospitalization of more than one month in a year (or is likely to do so), and threatens the normal growth and development of the child (Hobbs & Perrin, 1985). Intellectual functioning of the child is normal.

child with a chronic illness = The subject's dependent child between eighteen months and five years of age, with a chronic physical illness diagnosed prior to this hospital admission.

mother = Subjects who are the primary caretaker of the affected child; may be biological mother, stepmother, or adoptive mother.

coping = Behavior or actions taken by mothers and designed to maintain integrity in the face of threat, identified by subjects through the questionnaire Coping-Health Inventory for Parents (CHIP).

stress = The perception of aspects of a situation which tax or exceed available coping resources.

parenting-related stress = Stress arising from the perception of characteristics of the child, and stress arising from the mothers' functioning in the parenting role. Child characteristics

include the child's adaptability to situations, the mother's acceptance of the child, the child's demandingness, the child's mood, the child's level of distractibility or hyperactivity, and the child's ability to positively reinforce the mother. Role functioning characteristics include the mother's feelings of depression, unhappiness and guilt, her attachment to the child, her feelings of restrictions imposed by the parent role, her sense of competence, the degree of her social isolation, her relationship with her spouse, and her own physical health.

CHAPTER II

CONCEPTUAL FRAMEWORK AND RELEVANT LITERATURE

This chapter describes the conceptual framework that guided this research study, and discusses the literature-based themes of stress and coping pertinent to mothers with chronically ill children. Finally, the available research relating to mothers with hospitalized, chronically ill youngsters is reviewed.

Conceptual Framework

The conceptual framework for this study was drawn from the work of family stress and coping theorists and consists of the Double ABCX family adaptation model (McCubbin & Patterson, 1981) and Lazarus' theory of stress and coping (Lazarus & Folkman, 1984). Each theory will be briefly described and then related to the study of mothers' stress and coping with hospitalized, chronically ill young children.

Double ABCX Model

The need to understand why some families seem to endure and cope with severe life hardships, while other families suffer and falter while experiencing apparently identical stresses, has led to the development of family stress theories (McCubbin & Patterson, 1981). One conceptual model designed to explain the varying family responses to stress is the Double ABCX model of family adaptation advanced by McCubbin and Patterson (1981) and modified from Hill's original ABCX family crisis model (1949).

The ABCX model (Hill, 1949) focuses on a family's response to a crisis, where the pre-crisis variables of a stressor event (A), interact with the pre-existing family resources which are available to meet the crisis (B), and create the family's perception or definition of the stress event (C). A crisis (X) occurs when the demands of the stressor event exceeds the family's coping resources.

The Double ABCX model adds post-crisis variables to explain family adaptation, or the outcome of family efforts over time to manage its stresses. The aA factor is termed "pile-up" and recognizes that multiple family crises evolve and resolve over time, and that families usually deal with multiple stressors at once. The bB factor refers to the psychological, social, interpersonal and material resources available to the family members to meet the needs and demands of the crisis situation. Resources may already exist or be newly developed in response to the crisis situation or "pile-up" of stressors. The resources may be found in the individual, the family or the community. The family's perception of the stress situation refers to the cC factor. The family's perception includes the cumulative stressors, the family's definition of the major stressor event, and an estimation of available resources and efforts which can redefine the situation and bring the family back into balance. Behavioral responses, or family coping, result from the interaction of perceptions and resources and serve to eliminate

or reduce stressors, manage the hardships, resolve family tension and conflicts, and develop or strengthen resources. Family adaptation, or the xX factor, is the outcome of family efforts to achieve a balance of demands and capabilities between individual family members and the family system, and between the family unit and the community. Figure 1 illustrates the variables of this model.

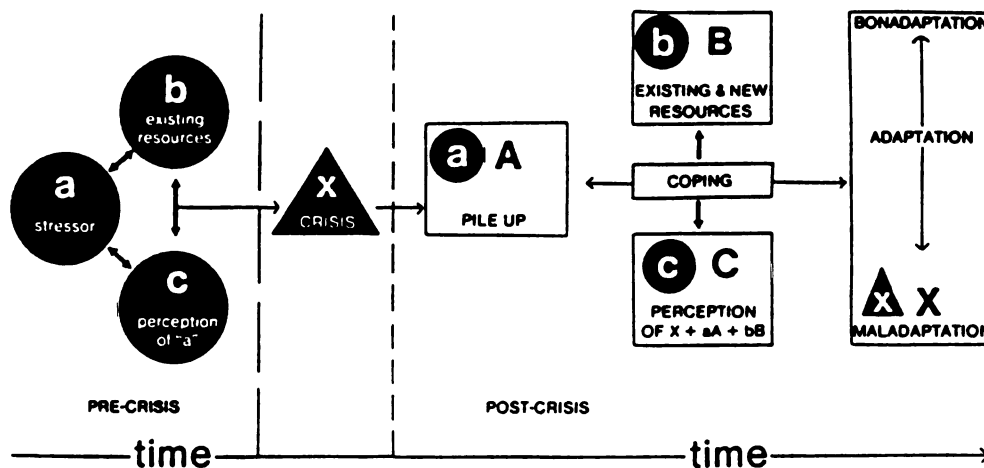


Figure 1. Double ABCX Model of Family Adaptation

Note. From Systematic assessment of family stress, resources and coping (p. 9) by H. McCubbin & J. Patterson, 1981. St. Paul: University of Minnesota.

The components of McCubbin's Double ABCX family stress and adaptation model strongly rely on the concept of social support, particularly the bB factor, or available resources to meet the emerging demands, often involve the use of social support. Cobb (1976) declared that "social support facilitates coping with

crisis and adaptation to change" (p. 302) and identifies three types of social support. Emotional support makes people believe they are loved and cared about, esteem support leads people to believe they are valued or worthy, and network support creates a sense of belongingness to a social network where mutual obligation and sharing of information exists. Social support may be protective against the negative consequences of environmental stress. Support is derived from others throughout the life span, and although friends and community are integral to support, the family is often the primary source of social support.

The Double ABCX family stress model provides a framework for understanding how families respond to crisis and change. The family response is modified based on experience with prior stressors, the responses that developed in order to meet those stressors, how the current situation is perceived, and the resources within the family framework available to meet the current situation. Thus, each family member will have their own unique history, and develop responses based on that history and current challenge.

Lazarus Theory of Coping

The theory of family adaptation, as described under the Double ABCX family stress model, is quite consistent with Lazarus' (1981) theory of individual coping. Lazarus, however, focuses on an individual's appraisal of psychological stress and subsequent coping efforts, while the Double ABCX model focuses on the family

as a unit.

Lazarus defines psychological stress as an individual's perception of a situation that is appraised as taxing or exceeding individual resources, thus endangering one's well being (Lazarus & Folkman, 1984). Stress involves the relationship of an individual's perception to an external event. Both perceiving and responding to stress requires a prior assessment of the situation, termed cognitive appraisal. Cognitive appraisal, although not always conscious, consists of a continuously changing set of judgements about the significance of the flow of events for the person's well-being (Lazarus & Folkman, 1984). Primary cognitive appraisal evaluates the actual, imagined, or anticipated environment with regards to personal threat or jeopardy. Secondary appraisal evaluates the available resource options to moderate the stress, including the possible consequences of those options (Lazarus & Folkman, 1984). Appraisal results in judgements that situations are irrelevant, benign-positive, or stressful. If deemed stressful, environmental situations are appraised for any harm or loss, including where injury or damage has already been done. Thus, the stressful situation could present a threat with the anticipation of harm, or could be perceived as a challenge where there is a potential for harm, but also an opportunity for growth, mastery or gain (Lazarus, 1981). Cognitive appraisal of stressful situations may lead to the perception that the stress taxes or exceeds the appraised

available resources, and psychological stress occurs. The individual with deficient coping resources may be considered more vulnerable to psychological stress.

Coping involves individual attempts to alter an unpleasant and threatening situation. Lazarus (1981) believes that coping has two basic functions; either improving the situation directly through changing the threatening environment or changing one's action, or by altering the stress-related somatic and subjective emotions themselves. Coping responses, which serve both functions of problem-solving and emotion-regulation, are classified into four modes: (1) information-seeking, (2) direct action, (3) inhibition of action, and (4) intrapsychic (Lazarus, 1981). Coping consists of both cognitive and behavioral efforts aimed at mastering a stressful situation by dealing with the actual problem, or in managing the unpleasant emotions aroused by the problem. Coping should be viewed as a process that unfolds over time rather than existing as an isolated characteristic in an individual.

Lazarus' theory of stress and coping provides a guideline for understanding how an individual perceives and responds to stress. The coping response of the individual lies in the perception of the event as stressful, and a mobilization of individual resources designed to modify the stress. Coping responses may be better understood when considered as a means to decrease the stress situation for the individual.

Summary

The Double ABCX family stress and adaptation model and the Lazarus theory of coping helps us to understand the stress and response patterns of families when caring for a chronically ill child. Although the family unit is a system, family behavior is comprised of individual responses by family members. Often, the study of families with ill children only focuses on an individual parent and some "families" consist of only a mother and a child. Therefore, the use of family stress theory and individual coping theory is not incongruent.

This study focused on the mother for two reasons. The mother traditionally is the primary caregiver of young children, and research suggests the stress of the mother is greater than the father during early childhood (Abidin, 1986; Kazak & Marvin, 1984). Additionally, mothers are more available to researchers, given their enhanced protective role when their child is sick and/or hospitalized.

Mothers with chronically ill and hospitalized children certainly experience a "pile-up" of stresses. The ongoing chronic illness, by definition, consists of a multitude of stressful situations for the mother and family. Thus, behavioral responses to cope with such situations must have been developed. The hospitalization of the previously ill child now adds to stresses experienced by the mother and the family. How the mother copes will be dependent upon her perception of the stresses, the meaning

of the hospitalized child's situation, and her available resources. This study will describe the individual parenting-related stresses of the mother arising from her family role as a parent to a chronically ill and hospitalized child. Also, her coping efforts to manage family life when the chronically ill child is hospitalized will be evaluated.

Literature Review

This section discusses issues pertinent to mothers with hospitalized, young chronically ill children. The literature review leads to the consideration of the important variables of parental role, multifaceted stresses, and coping with chronically ill children in the hospital setting.

The stresses of mothers with hospitalized, young chronically ill children, and their coping behaviors, cannot be explored without an examination of mothers' stresses and coping patterns prior to the hospitalization of the ill child. It is that aspect of chronicity, or the daily impact of the child on the mother's life, that distinguishes mothers with chronically ill and hospitalized children from others. Unfortunately, less is known about the stresses and coping of mothers with hospitalized chronically ill children. Therefore, this review will discuss the effects of a childhood chronic illness on families at home, before consideration of hospitalization, in order to "set the stage" for these mothers in the hospital environment. Specifically, this review will (1) discuss the parenting role with a chronically ill

child, (2) consider the difficulties of parenting an ill and hospitalized toddler or preschooler, (3) evaluate the developmental implications of chronic illness on a child, (4) enumerate the stresses affecting mothers with affected children, and (5) review what is known about how mothers cope with chronically ill children in order to understand the stresses of mothers with hospitalized, chronically ill children.

Parental Role

Parenting a child involves learning a societal role. Roles are defined as "distinct expectations, responsibilities, and privileges associated with a position in a social structure" (Fife, 1985, p. 108). The parent role requires meeting the many obligations of care for a child. The parent, through the development of attachment, nurtures and fosters the child's growth and development by fulfilling the child's needs, and protecting the child from harm (Ainsworth, 1973). The difficult maternal role requires finding a balance between the need to protect the child and the need to foster a child's exploration and independent growth. A mother must exercise some level of control over the environment and events surrounding her child, especially when the child is young and lacks the cognitive ability to understand situations. Yet, when a young child has a chronic illness, the mother may not be able to control many of the illness-related circumstances and events pertaining to her child, thus increasing her parenting role stress.

The worry over how to parent a child with a chronic illness appears repeatedly in the literature on chronic childhood illness (Holaday, 1978; Stein, 1983; Sperling, 1978; Swartz, 1984; Tavormina, Boll, Dunn, Luscomb, & Taylor, 1981). Societal guidelines do not exist for mothers on how to care for a chronically ill child (Mardiros, 1982; Shapiro, 1983). Without established criteria by which mothers can evaluate their performance in their role as a mother of a chronically ill child, mothers may feel uncertain and anxious. Mothers of children with cerebral palsy (Mardiros, 1982) cited the lack of these societal customs as contributing to their parenting role stress. Similarly, a decreased sense of confidence in parenting ability was reported by Tavormina et al. (1981). Concerns over competency in the parenting role makes the task of raising a child even more difficult.

Developmental effects of chronic illness on children

In the early childhood years children begin to differentiate themselves as separate individuals. Ambivalently dependent upon their mothers, young children strive for independence. Toddlers, from 18 months to three years old, seek to develop autonomy and manipulate their world. In the preschool years from three to five, children are quite physically active in their widening social world. Through the mastery of tasks, children seek approval from others and develop a sense of competence and initiative (Hughes & Horowitz, 1985). Mothers must encourage

the child's exploration while maintaining clear rules and protective limits.

The presence of a chronic illness has the potential to increase the difficulty or even prevent the child's normal progression through social and physical developmental stages. Perrin and Gerrity (1984) reviewed the effects of chronic illness on a child's development and found that children under six years are particularly vulnerable to limitations and restrictions imposed by illness. A child's physical mobility may be restricted by the effects of illness or functional limitations, or by maternal overprotection. Mothers may be overprotective or become impatient with the child's efforts, and end up doing for the child rather than allowing the child increased responsibility. Illness-related episodes of pain, immobility, and separation robs children of control, and may lead to a child feeling defeated, becoming passive and clinging. When a child has a sense of doubt about her own effectiveness in the world and is deprived of feelings of competence and mastery, poor self-esteem develops (Perrin & Gerrity, 1984). Chronic illness, then, imposes an enduring stress on both the physical and emotional development of the child.

Chronically ill children often undergo repeated episodes of hospitalization, which means separation from home and family. Hospitalization presents a life crisis for toddlers and preschoolers, as these young children are especially vulnerable to negative effects of separation and hospitalization (Cerreto, 1986;

Hobbs, Perrin & Ireys, 1985; Goslin, 1978; Sperling, 1978). Hospitalized chronically ill toddlers and preschoolers experience developmental threats toward the establishment of autonomy, and their opportunity to explore the environment. Additionally, they grapple with concerns over intrusions into their bodies (Ritchie, Caty, & Ellerton, 1982). Separation, or fear of separation from the parent increases the child's anxiety. Developmentally, young children have no concept of time and are dependent upon others, especially their mothers, to understand events. Fear of abandonment, and fantasies that their illness and its treatment are punishments for "bad thoughts or behaviors" characterize this developmental period (Bibace & Walsh, 1981). Thus, the chronically ill child who is hospitalized has increased threats to her emotional and physical development.

Although much has been written about the psychological adjustment of chronically ill children (Breslau, 1985; Drotar, 1981; Mattsson, 1972; Pless & Roghmann, 1971; Stein & Jessop, 1984; Steinhaurer, Mushin, & Rae-Grant, 1974) few believe there is any substantial increase in psychiatric disorder above the norm. The recurrent episodes of pain, activity restrictions, and hospitalization lead more to difficulty in social adjustment. The child's development of self-concept, self-esteem, and coping capacity is believed to be directly related to the parent's coping and perception of the chronic condition (Hobbs, Perrin & Ireys, 1985; Mattsson, 1972). The mother and the entire family influence

the psychological adjustment of the child with chronic illness (Drotar, 1981). Therefore, the stresses and factors that influence the mother's ability to cope has direct implications on how the young child adapts to a chronic illness and hospitalization.

Stresses on mothers

According to Sperling (1978), families who are raising a chronically ill child live in an atmosphere of stress. This stress atmosphere, acute after diagnosis, becomes chronic when coping with the day-to-day aspects of living. Stresses may become acute again with hospitalization of the child for illness or surgery. The diagnosis of a chronic ongoing physical illness in a child precipitates a state of crisis for the parents (Steinhauer, Mushin, & Rae-Grant, 1974). Accepting this diagnosis often involves a grief process similar to stages of death and dying, and has been termed chronic sorrow (Drotar et al., 1975; Solnit & Stark, 1961; Olshansky, 1962). Parents may experience denial, followed by intense longings for the normal child, which may frequently lead to feelings of anger or resentment. Resolution involves accepting the child's condition and moving forward. However, acceptance of the ill child may be marked with fluctuating periods of continued sorrow and feelings of loss, which occur throughout the illness or child's life, especially during periods of illness exacerbation (Young, 1977).

Many other factors also influence the stress level in mothers

with chronically ill children. Aspects such as the visibility of the child's illness, the child's age at onset or diagnosis, the family's socioeconomic status, the amount of daily care required, including medications, treatments, and special diets all contribute to a mother's stress (Cluff, 1985; Stein, 1983; Steinhauer, Mushin & Rae-Grant, 1974; Thomas, 1984). Parenting the chronically ill child may mean an expanded role for mothers when they are providing technical home care to their children (Ferraro & Longo, 1985). One survey (Andrews & Nielson, 1988) reported on mothers caring for children at home with apnea monitors, oxygen use, respiratory treatments, ventilatory assistance, tracheostomies, enteral feeding pumps, phototherapy, intravenous antibiotics, and renal dialysis. Mothers reported problems related to the equipment and decreased availability of in-home service by the companies, as well as increased financial problems. Mothers become quite proficient at providing sophisticated medical care, which become both a source of stress and pride when they perceive themselves as competent health care providers at home (Robinson, 1985).

Another area of difficulty for mothers with chronically ill children, is their relationship with their spouse. Although a review of 34 studies of marital adjustment in families with chronically ill children (Sabbeth & Leventhal, 1984) did not find the often presumed increased divorce rate, there definitely was increased stress in all the marital relationships. The presence

of a chronic illness in the child imposes a strain on the parents which impacts on the marriage.

Mothers may find a major source of their stress comes from their own emotional feelings. Feelings of guilt are common, arising from fears that mothers may have "caused" their child's congenital defect or illness (Mattsson, 1972). Continuing worries over the illness severity, prognosis, illness exacerbation and the child's future (Swartz, 1984) may lead to depression and a decreased self-esteem (Mardiros, 1982; Mattsson, 1972).

Psychological stress in mothers was evaluated by Cummings, Bayley and Rie (1966) when mothers of chronically ill children, mentally retarded children, and neurotic children were compared to a group of mothers with healthy children. The four samples consisted of 60 mothers each with similar demographic characteristics, and the children were between four and thirteen years. A battery of measures examined parent attitudes, a parent personality inventory, and considered interpersonal relationships. The mothers of the chronically ill children had fewer problematic areas compared to the mothers of mentally retarded or neurotic children, but had significantly more problems than the mothers of healthy children. Mothers of chronically ill children had lower self-esteem, had less enjoyment of their child, and had poorer relationships with their neighbors.

Using a qualitative participant observation design, Mardiros (1982) studied the stress of twelve mothers whose children had

cerebral palsy. Six major sources of stress were identified and ranked in priority. All agreed the role of mother was most stressful, with stresses related to the difficult feelings of guilt at having an abnormal child, feeling isolated and stagnated, being burdened as the only caregiver, having inadequate energy, having unrealistic expectations of themselves and others, and having a low self-concept. Stress related to the child ranked second, with concerns over the child's illness, care and future. Problems of communication and support from the husband were ranked third. Difficulty with the health care professionals or services was the fourth ranked stress. Social isolation, lack of societal guidance, and lack of understanding and support from family and friends were the fifth and sixth identified sources of stress.

Holroyd and Guthrie (1986) compared the stress in families (primarily mothers) with school aged children with neuromuscular disease, cystic fibrosis, and renal disease using a shortened non-validated version of the Questionnaire on Resources and Stress. The quality and quantity of stress differed among the groups. The parents of wheelchair-dependent children and mentally retarded children of the neuromuscular group differed significantly from both the cystic fibrosis and renal disease group. Findings suggested family stress with chronically ill, but intellectually normal children was different than stresses in families with retarded children. Additionally, the degree of physical impairment and reliance on assistive devices, such as wheelchairs,

may present different stresses to families.

Kazak (1987) compared three categories of families with disabled children, matched with normal control groups, on measures of anxiety and depression, marital satisfaction, and social network size. Sample one consisted of 33 families with mentally retarded children with behavior problems. Sample two consisted of 43 families with chronically ill children who had phenylketonuria (PKU), and sample three had 46 families with children with spina bifida. Overall, fewer differences between families with and without a disabled child were found than expected. Differences between the families with the three categories of handicapped children samples were not reported. Both mothers and fathers of disabled children had differences in their social network size compared to the normal control groups. The personal stress scores and marital satisfaction scores did not differ for mothers and fathers compared to the normal group. However, when the scores of only the mothers were examined, the mothers of handicapped or chronically ill children experienced significantly higher levels of stress compared to mothers of normal children. Additionally, the mothers had higher levels of marital dissatisfaction compared to fathers. These findings suggest that mothers of chronically ill children have higher stress, and experience more marital strain than the fathers of affected children.

In summary, the stresses for mothers with chronically ill children are complex and multifaceted, and consistently higher

than for mothers with normal children (Kazak, 1987). It seems that the area of greatest concern for mothers lies in their attempt to parent, or fulfill the parenting role to a child with a persistent medical illness, without clear guidance from family, friends, or society. The literature repeatedly emphasizes how uncertain the mothering role becomes (Holaday, 1978; Stein, 1983; Mardiros, 1982), with a heightened responsibility of trying to do the right thing for the ill child. Through the eyes of the mother, we grasp the difficulty of watching a child struggle with development, only to be set back by illness or hospitalized-imposed restrictions. Mothers grapple with many emotions, both from feelings about themselves, and about their child. Social isolation is common, coupled with increased stress in their relationship with their spouse (Kazak, 1987; Mardiros, 1982; Sabbeth & Leventhal, 1984).

Family coping with chronic illness

Families under the stress of raising a child with a chronic illness should not be considered dysfunctional. Although few studies provide insight into what parents actually do to cope with raising a chronically ill child, it is clear that many families do quite well. When the family does well, it seems to relate less to the child's illness severity, but more to the parents' perception of the child and the situation (Mattsson, 1972; Pless & Satterwhite, 1973; Stein & Reissman, 1980; Tavormina et al., 1981). However, research efforts have been more exploratory in

trying to find effective coping strategies, rather than directed toward how the parent perceives the child and illness. Although both parents in intact families contribute to family stress and coping, often only mothers are available to researchers. Consequently, many research reports refer to family coping, but in actuality only mothers comprised the sample. Therefore, the following reported studies pertinent to mothers coping may refer to either families or mothers, depending upon the research report.

In an exploratory, qualitative study of how families functioned with cystic fibrosis, Venters (1981) found two effective coping strategies through interviews with parents. "Sharing the burdens" or the use of family and social support, and "endowing the illness with meaning" were most associated with effective family functioning.

Another strategy that may help some mothers meet the stress of raising a chronically ill child is the phenomena called "normalization" where parents re-define the pathological aspects of illness and treatment as being a normal part of their child's life. Anderson (1981), Krulik (1980), and Robinson (1984) all interviewed parents of chronically ill children and found that parents voiced the strategy of normalization as a way to minimize the stress from their child's chronic illness. This reconstruing the abnormal, as normal, promoted a life as normal as was possible for the family, reduced the feelings of being different, and decreased the child's vulnerability. In turn, mothers could cope

better with the stresses of raising their ill child.

One of the first quantitative, descriptive study of parents (Tavormina et al., 1981) used a battery of psychosocial measures with established validity and reliability. Participating in the study were 144 parents (133 mothers and 93 fathers) with chronically ill children (diabetes, asthma, cystic fibrosis, & hearing-impaired) between 5 and 19 years. Scores were obtained on parent attitudes towards their child and parenting role; a personality scale that tapped dimensions of social desirability, neuroticism, and sociability; a child behavior problem checklist; a special problem area checklist designed for the study; and a family functioning inventory scale. Problematic areas were related to decreased social support, family routine disruptions, a tense home atmosphere, and pressure to take proper care of the ill child. Parents had doubts about their abilities as parents, and the insecurity in their parental roles was significant. Overall, the measures demonstrated significant stress and strain on the parents, but found that the parents had the ability to cope. However, specific coping strategies were not identified or reported. This study was important because it was one of the first studies to emphasize that families did cope with the stress of raising chronically ill children. Limitations of the study lie in the sparse reporting of the sample population and the demographic characteristics.

Recognizing that social support appears to be an important

variable in a family's ability to respond to stress (Stein, 1983), Kazak and Marvin (1984) examined family stress and social support in 56 families with a child with spina bifida compared to 53 matched normal families. The study used the Parenting Stress Index (Abidin, 1986) to measure parenting related stresses and how the parent perceived their ill child. Interestingly, compared to normal controls, the families with spina bifida children did not have increased marital stress. This supported the contention that in some cases having a handicapped child may actually strengthen the marital relationship. Mothers were found to be under more personal stress than were fathers, and the increased stress was related to parenting issues. Mothers were considerably more stressed by seeing their children as being poorly adaptable, more demanding, and less adequately fulfilling the mothers' expectations for her children. Mothers were also more depressed and felt less competent as mothers compared to the normal controls. In the analysis of social support, the networks of the parents of the handicapped children were significantly smaller than the comparison group. However, the family network size comparison was the same. This suggests that the social network of affected families was more dense, meaning more members knew and interacted with each other, compared to the density of networks in the control group. Such findings suggested that the families of ill children found support from a small, often familial, social network rather than a larger community. No correlations between

the social support measures and the stresses were reported. This study contributes to our understanding of both the parenting stresses and the use of social support by families with a chronically ill child.

Continuing the search for specific coping strategies that promote family adjustment to chronic childhood illness, McCubbin (1984) evaluated coping behaviors of 100 families of children (aged 3 months to 28 years) with cystic fibrosis using the Coping Health Inventory for Parents (CHIP). The CHIP measured coping in three areas called (1) maintaining family integration, cooperation, and an optimistic definition of the situation, (2) maintaining social support, self-esteem, and psychological stability, and (3) understanding the medical situation through communication with other parents and consultation with the medical staff. There were no significant differences in the coping patterns between mothers and fathers. Both parents used all three coping patterns, with the family integration pattern most emphasized. The demographic variables of family income and the child's age were significantly correlated with scores on the coping scales. The older the child, the less the mother was able to maintain social support and psychological stability. Fathers were more likely to be involved in health care aspects related to the child when the child got older. Fathers of higher income also scored higher on the coping measures. This study presented some patterns of coping found to be helpful to families and was useful

as an assessment measure of coping patterns used by parents with chronically ill children.

Gibson (1986) also evaluated the coping of 56 parents (46 mothers and 10 fathers) with children under ten years of age with cystic fibrosis. The vast majority of the parents with children treated at an outpatient specialty clinic felt they were coping very well. Social support was identified as the most helpful factor in helping them cope. Using the CHIP, the mothers scored higher than the reference mean for all three coping patterns. The high level of social support identified by this sample of parents contributed to their positive coping while caring for a chronically ill child.

In summary, families do adapt to the burdens of caring for a chronically ill child. Several coping strategies for managing the stresses have been uncovered through qualitative research, and reiterated through some quantitative measures. Among the coping strategies that have been identified as contributing to successful coping and subsequent adaptation to the demands of parenting a chronically ill child are the efforts at normalization of the medical effects and treatment procedures (Anderson, 1981; Robinson, 1984). Similarly, seeking and finding meaning in the child's illness (Tavormina et al., 1981; Venters, 1981) has proved to be quite beneficial to families when grappling with their ill child. The use of social supports (Gibson, 1986; Kazak & Marvin, 1984; Venters, 1981) is an important mediator of how families

respond to stress, and promote the ability to cope. McCubbin's (1984) work with the family underscores the importance of maintaining family stability, which is vital to the concept of social support. However, these studies have only focused on families with children out of the hospital setting. The effects of hospitalization on these coping strategies has not yet been systematically considered.

Effects of hospitalization on families

Hospitalization for any ill child has implications for both child, mother, and family. The deleterious effects on the child were discussed earlier, and this section will focus on the effects on the mother and family. Again, the term family most frequently refers to the mother, due to her availability and often continuing presence during a hospitalization of a young child.

Studies on the maternal response to a child's hospitalization have usually focused on the acutely ill, previously healthy child. When describing the hospital as an overwhelmingly strange environment, full of threats and unknowns, writers have emphasized the need for information and intervention programs designed to lower parental anxiety, in an effort to improve the parents ability to help their hospitalized children (Algren, 1985; Hunsberger, Love & Byrne, 1984; Mahaffy, 1965; Miles & Carter, 1985; Wolfer & Visintainer, 1975). Although such interventions could be helpful to parents of chronically ill children, they may not meet the family's needs when the chronically ill child becomes

hospitalized.

Hospitalization of a chronically ill child certainly disrupts family routine and is stressful for both child and family. However, the hospital may not be the overwhelmingly strange environment for families with chronically ill children that it is for families with previously healthy children. Ferraro and Longo (1985) emphasize that parents of chronically ill children may be quite knowledgeable about their child's care and condition. Staff assumptions that parents and children will assume the sick, dependent role and relinquish control and care to the "competent medical team", fail to recognize the parental competence and ability to provide care for their child. Johnston and Salazar (1979) suggest there may be a need to detoxify a family from a prior hospital experience. If prior hospitalizations have occurred, and chronically ill children often are repeatedly hospitalized, parents know too well the problems of communication, staff turnover, and understaffing. Both the nursing and medical staff may feel threatened when vigilant parents observe their care and procedures, and may try to prohibit parents from being present during procedures, at a time when their children most need them (Chan & Leff, 1982). Families of chronically ill children often look to the hospital staff for additional knowledge and help. However, they expect to share control and decision-making regarding their child with the health care team (Kodadek, 1979).

A qualitative exploratory study was conducted with 40 parents

of chronically ill, hospitalized children (Knox & Hayes, 1983; Hayes & Knox, 1984) with a variety of illnesses, including cardiac, neurological, renal, and cancer (beyond induction phase and not terminally ill). The dominant concern found to be most stressful for parents was the parental role in the hospital. Mothers entered the hospital setting with previously established expectations of themselves as caregivers of the ill child. Once in the hospital, many of their usual parenting tasks were taken over by others and their previous caregiving tasks were altered by the hospitalization of their child. Mothers willingly relinquished medical and treatment matters to the health care team, but they expected to be consulted and to work with the health care providers, considering themselves experts regarding their child and their child's care. Instead, parents found great discrepancies between their expectations and the hospital staff's expectations of their role. The hospital staff expected a rather passive, dependent parent role, rather than an active, competent and involved parent role. Thus, the parenting role in the hospital became an area of uncertainty and stress.

Another qualitative, ethnographic study on parents with hospitalized chronically ill children was done by Robinson (1984, 1985, 1987) who reported similar findings. Nine parents from six families with children ranging in ages from 3 to 21 years, were the informants for the study. Families stated their efforts at normalizing the illness experience were not respected in the

hospital setting. Parents focused on viewing the hospitalization as a small, often repeated part of their child's life, trying to keep it in the context of the day-to-day illness experience for their child. On the other hand, the health professionals focused on procedures required to "cure" the illness, often disregarding the inconvenience or effect of multiple intrusions by multiple individuals examining and treating the child. Parents learned they had to fight for what was meaningful for them and often become more assertive, aggressive, and even non-compliant.

The only study using quantitative measures of either stress or coping in mothers with hospitalized, chronically ill children, was most concerned with the child's response to hospitalization. Wells and Schwebel (1987) examined the level of the mother's parenting stress before hospitalization of their chronically ill child, as a predictor of the child's vulnerability to the stresses of hospitalization and surgery. The findings suggested that children of mothers with very high or very low parenting stress were at much greater risk for in-hospital and post-hospital psychological disturbances. However, since the mothers' stress was not the focus of this study, the parenting-related stresses of mothers in the hospital setting was not discussed.

Summary

This literature review demonstrated the multi-faceted stresses impinging upon mothers with hospitalized chronically ill children. The parent role represents a repeated stressful experience for

mothers of chronically ill children, both during home management, and during hospitalization. The parental role was cited as the greatest stressor in the qualitative study of Madiros (1982) and in the quantitative study by Tavormina et al. (1981). Perrin and Gerrity (1984) discussed the difficult issues when parenting the developing child who has a chronic illness. Kazak and Marvin (1984) found increased parenting-role associated stresses in mothers when caring for a child at home with spina bifida. Further studies which tease out the aspects of a mother's stress as arising from the parenting of her child are warranted.

Mothers had problems with their parent role in the hospital setting, particularly because hospital staff were uncomfortable about the competencies of care the mothers possessed. The uncertainty over what mothers can continue to do for their children in the hospital setting, and the desire to continue home-developed ways of managing their children pose significant role-related stress for mothers. Most of the research on mothers with hospitalized chronically ill children has been exploratory in nature, using qualitative techniques which yield vast information about a very few people. These ethnographic studies document the unique stresses of mothers and families with hospitalized chronically ill children. However, study designs using instruments with quantitative measures of stress or coping are conspicuously lacking for mothers with hospitalized, chronically ill children.

Quantitative measures of stress and coping behaviors are needed for larger populations of parents with hospitalized, chronically ill children. Through such investigations, the stress variables that account for the greatest source of stress could be determined. Additionally, more information is needed about what is helpful to mothers and families in helping them cope with their hospitalized, chronically ill children. The discovery of the stresses and coping efforts could lead to the identification of parents and families at risk for dysfunction, and to the development of effective intervention programs designed to modify stress and support coping efforts in parents with hospitalized, chronically ill children. This quantitative study on mother's parenting-related stress and coping effort with hospitalized, chronically ill children is a beginning towards gathering that information.

CHAPTER III

METHODOLOGY

This chapter reviews the study design and describes the sampling method and eligibility criteria. Each research instrument will be described, with a review of the reliability and validity of the measures. The data collection procedure used for this study will then be presented, followed by a discussion of the data analysis.

Research Design

This study used a nonexperimental design with correlational analysis of two quantitative measures and demographic information. This approach was chosen when the literature review found no other studies which used a quantitative measure to evaluate the parenting-stress or coping efforts of mothers with hospitalized, chronically ill children.

Previous research has documented the difficulty of parenting a chronically ill child (Mardiros, 1982), yet little attention has been paid to what child characteristics makes the parenting so difficult. Since chronic childhood illness often results in hospitalization, mothers are frequently confronted with parenting the child in the hospital setting. Qualitative research using interview techniques has reported on the magnitude of mothers' stress with hospitalized, chronically ill children (Hayes & Knox, 1984). Although both qualitative research (Venters, 1981) and

quantitative research (McCubbin, 1984) have described some coping strategies of parents caring for children in the home, much less is known about how mothers cope when caring for a hospitalized, chronically ill child. The qualitative research done with parents of hospitalized, chronically ill children has opened the door for further exploration of this population of mothers. By moving to a quantitative approach, areas of maternal stress and coping can be consistently explored using larger numbers representing this population of mothers.

This study represents one of the first inquiries to use quantitative measures to evaluate stress and coping in mothers with hospitalized, chronically ill children. Through the use of quantitative instruments, the research questions can be uniformly answered by all representatives of the population of mothers with hospitalized, chronically ill children, generating a larger data base from which conclusions may be drawn. The two instruments chosen for this inquiry have not been previously used with mothers of hospitalized, chronically ill children. However, both measures have been used on populations of parents who had chronically ill children. Therefore, a convenience sample from one hospital setting was chosen to examine the utility of these measures with this population. Only mothers who had children hospitalized on the pediatric ward were included in this study since the stresses and coping of mothers may be different when their children are in the pediatric intensive care unit (Miles & Carter, 1983).

Further, given this trial of these quantitative instruments with this population, there was no reason to include a control group at this stage of exploration. Using these instruments with this sample population can lay the groundwork for future investigations using more complicated research designs.

Sample

Research Setting

This study was conducted on the pediatric unit of a large 450 bed tertiary care multi-specialty University teaching hospital. The pediatric unit has 28 ward beds and 8 special care beds. The hospitalized children came from a large geographic area which included the metropolitan area of Sacramento, extending north to the Oregon border, south to Modesto, and east to Nevada. The referral area excludes the San Francisco bay area and north coast. Families may travel over three hundred miles for either inpatient or outpatient care. Parent participation in hospital life is encouraged through open visiting hours, facilities for entire families to stay on the hospital grounds, and in-hospital provisions for any parent wishing to room-in with the hospitalized child.

Eligibility Criteria

The independent variable for this investigation was a hospitalized, chronically ill young child. The dependent variables consisted of the mothers' parenting-related stress and her coping behaviors. In an effort to control variability in the

sample, inclusion and exclusion criteria was specified for both mother and child.

The inclusion criteria for the mother consisted of:

1. The mother must be the child's primary caretaker, either biological or adoptive.
2. The mother's child must meet the child inclusion criteria.
3. The mother must speak and understand english.
4. The mother could be of any ethnic background, marital status or socioeconomic status.

Mothers were excluded from the study if they did not meet the above criteria. Only mothers who regularly and routinely cared for the child were studied to evaluate parenting-related stress and coping. Only one of the mothers was not the biological mother, but had adopted the child, knowing about the chronic illness. One mother withdrew from the study, stating the child's maternal grandmother was the primary caretaker. No mother expressed difficulty with reading, and all questionnaires were completed appropriately. Mothers of any ethnic or socioeconomic background were included in an effort to make the sample more representative of the general population.

The inclusion criteria for the child consisted of:

1. The child was at least 18 months old and had not reached the sixth birthdate.

2. The child had to have a chronic physical illness that threatened the child's normal growth or development.
3. The child had to have been diagnosed with the chronic illness prior to the current hospitalization.
4. The child could be hospitalized for any medical or surgical reason.
5. The child with cancer or leukemia must have been out of the initial induction therapy phase.
6. The child could not be considered terminally ill.
7. The child needed to be of normal or near normal intellect.

Mothers were excluded from the study if their child did not meet the above inclusion criteria. The age of the child was limited to toddlers or preschoolers so that the parenting-related stresses of mothers were consistently applied to children at similar developmental levels. This developmental age was chosen in part because the young, cognitively immature child is dependent on the mother, particularly during hospitalization.

Although children with multiple medical diagnoses might suggest too much variability within the sample, research has found that the stresses of parents are related more to the chronicity of their child's condition rather than to the medical aspects of the child's illness (Hobbs, Perrin & Ireys, 1985). Thus, children with varied medical diagnoses which were long-term in nature, and that had an impact on the child's daily functioning for at least

three months of the year, met the chronic illness criteria.

Other studies have found high anxiety and shock in parents with the diagnosis of a long-term illness in a child (Young, 1977). To appreciate how the chronicity affected the mothers perception of the child, and the subsequent parenting-related stresses, children had to have been diagnosed prior to the current hospitalization. Once treatment for childhood cancer or leukemia has been induced, the child enters a long-term chronic treatment phase. Therefore, children with cancer or leukemia who had passed the initial induction phase were accepted into this study.

Many of the childhood chronic illnesses can result in premature death of a child. To avoid confusing the stress of dealing with the chronic illness with the acute stress of impending death in a child, no child felt to be in the terminal illness phase was accepted into this study.

The stresses for parents with a mentally retarded child have been shown to be different than for parents of a chronically ill children (Cummings, Bayley & Rie, 1966). Therefore, only mothers of children with normal or near normal intellect were accepted in this study.

The above controls represent efforts to decrease the variability within the sample and control confounding variables which may compound the parenting-stresses and coping efforts of the mothers. The research subjects consisted of a sample of 30 mothers who met the inclusion criteria.

Data Collection

Sample Selection Process

Potential subjects were identified by the investigator through consultation with the nursing staff and use of the ward patient roster, nursing cardex, and the medical record. All mothers meeting the inclusion criteria on the data collection days were approached by the investigator. The mother was approached in the child's room when she was at the child's bedside, and not involved with another health care worker. Mothers were only approached during daytime or early evening hours, and not approached on the day of admission, but rather any day prior to discharge.

Mothers were informed that the investigator was conducting a research study on mothers' experiences when their young, chronically ill child was hospitalized. The study was explained, and if mothers agreed to participate, a detailed written informed consent was obtained (Appendix D). A copy of the consent and the Experimental Subject's Bill of Rights was given to each subject (Appendix E). Each mother was assured that both confidentiality and anonymity would be maintained.

Human Subjects Assurance

Approval for the study was granted by the Human Subjects Review Committee of the University of California, Davis; the Committee on Human Research at the University of California, San Francisco; and the Nursing Research Committee at the University of California, Davis Medical Center, Sacramento. Confidentiality of

each subject was ensured by the numerical coding of all data pieces, with the master coding list and subject names kept locked in separate files.

Instrumentation

The Parenting Stress Index (Appendix B) and the Coping Health Inventory for Parents (Appendix C) were used to address the research questions of this study. Each questionnaire and the variables it measures will be described, and the reliability and validity of each will be reviewed. The demographic data sheet (Appendix A) was specifically designed for this study by the investigator.

Parenting Stress Index

The Parenting Stress Index (PSI) (Abidin, 1986) is a 101 item self-report questionnaire designed for either parent, and measures the relative magnitude of parental stress arising from the parent-child relationship. The instrument assesses parental, child and situational characteristics contributing to family and child-rearing stresses.

The PSI has been used in several studies of parents with children experiencing special problems. Abidin (1986) reported on 19 studies where the PSI was used, including studies with populations of parents of children with attachment problems, attention deficit disorders (Mash & Johnston, 1983), autism, child abuse, chronic illness (Wells & Schwebel, 1987), developmental delays, divorced parents, Down syndrome, gifted intelligence,

hearing impaired, hyperactive, apneic infants, premature infants with single parents, traumatic injuries, spina bifida (Kazak & Marvin, 1984), unwanted pregnancy, and new parents.

Unfortunately, only a few of these studies have been published.

The PSI has been used for researching the effects of stress on parenting behavior, as an individual diagnostic stress assessment tool, to screen for dysfunctional parenting which can impair a child's normal development, and to measure the effectiveness of intervention programs using a pre-post design (Abidin, 1986). This study used the PSI to measure the parenting-related stresses of mothers with a hospitalized, chronically ill young child.

Stress subscales.

The PSI instrument is divided into two separate areas or "domains" of stress. The child domain relates to how the parent perceives the child and the parent domain relates to stresses which affect the functioning of the parent in the parenting role. Each domain and its attendant subscales will be discussed, followed by a discussion of the scoring of the instrument.

The child domain measures stress associated with the parent's perception of child characteristics which tend to make parenting more or less difficult (Abidin, 1986). There are six areas of stress subscales making up the child domain. The first subscale, "child adaptability", involves the parent's perception of the child's ability to adapt or adjust to changes in the physical or social environment. High stress scores may indicate the child

becomes emotionally upset when changing from one task to another, overreacts, is difficult to calm once upset, or may unduly avoid strangers. Parents may become frustrated with their child, and may feel rejected by the child when the attachment scale and child reinforcement of parent scale are both elevated.

The second subscale "acceptability of child to parent" produces high scores when the child does not meet the parents hoped-for ideal of physical, intellectual or emotional characteristics. Poor attachment and/or rejection may unconsciously be present with the parent who scores high on this subscale.

The third subscale "child demandingness" involves how many demands the child makes of the parent, including crying, physically hanging on, frequent requests for help, or many minor problem behaviors. High scores may suggest an overly dependent child who has not achieved the developmental task of individuation.

"Child mood" is the fourth subscale, and high scores may suggest a child who is depressed and unhappy. The crying is different from the whining dependency suggested by the demandingness subscale.

The next subscale is called "child distractibility or hyperactivity". High scores are associated with hyperactive children who have an attention deficit disorder. However, high scores could reflect a parent who lacks the energy to keep up with

the child, and may be elevated with older parents who are having difficulty adjusting to the child. Also, parents who have unreasonable expectations of overly mature behavior may score high on this subscale.

The last subscale, "child reinforces parent" is elevated when the parent does not experience the child as a source of positive reinforcement. The parent may feel rejected by the child. High scores may suggest a child who could be neurologically impaired, or who may be depressed. Conversely, the parent may be depressed and project a negative response onto the child. Also, the parent who may not be able to correctly read the child's cues and is misinterpreting the child's behavior may score high in this area.

The second major stress area of the PSI is the parent domain with seven areas of stress related to parent functioning in the parent role (Abidin, 1986). The first parent domain subscale is "parent depression, unhappiness, guilt" and high scores suggest significant depression in the mother. The mother may be dissatisfied with herself and her life, and may find difficulty in mobilizing energy to fulfill the parental role.

"Parent attachment" is the second stress subscale, and high scores may reveal that the parent does not feel emotionally close to the child. Also, the parent may not be able to accurately read and understand the child's feelings or needs.

The third area of stress is called "restrictions imposed by parental role". Parents who feel the parental role overly

restricts their freedom or frustrates their attempts to maintain their own identity may have elevated scores on this subscale. Parents may see themselves as dominated by the child's demands and needs.

The "parent's sense of competence" is the fourth domain, and high scores may be related to numerous factors. Parents may find the parental role very difficult, possibly related to a lack of knowledge about child development, or a limited range of child management skills. Younger parents tend to earn higher scores than parents of many children. Parents who are criticized by the other parent may also have higher scores. Parents of children with either physical or mental handicaps often have elevated scores in this subscale.

The fifth subscale relates to "social isolation" and high scores demonstrate parents under considerable stress. These parents are socially isolated from their emotional support systems including peers and relatives.

The "relationship with spouse" is the sixth stress subscale, and high scores are earned by parents who lack the emotional and active support of the other parent. Usually the lack of mutual support in the area of child care is a symptom of a dysfunctional relationship between the mother and father.

The last subscale is called "parental health" and when elevated suggests poor health in the parent. The health deterioration of the parent may either represent an additional

stressor, or may be a result of the cumulative stress on the parent.

Scoring.

Mothers or fathers rate statements about their child and themselves using a five point scale with a range of strong agreement to strong disagreement (Appendix B). Each question pertains to one specific stress subscale, which results in individual stress scores for each stress subscale. The scores of the six subscales related to the child domain are summed together to make a child domain stress score. Similarly, the scores of the seven subscales related to the parent's role functioning are summed together to make a parent domain stress score. Both child and parent domain stress scores are summed together to make an overall total stress score.

There are normal percentile ranges for each individual stress subscale, the stress domain scores and the total stress score, each ranging from 15 to 80 percentile. There may be significant stress in only one subscale, with overall normal stress levels. Multiple subscales may be elevated resulting in high stress in one domain, but the other domain may continue to show normal stress levels. When both domains are elevated, the total stress score may be elevated above normal.

High child domain scores reflect that the parent perceives the child in such a way that increases the difficulty of fulfilling the parental role. High scores in the parent domain suggest that

parents may feel overwhelmed and inadequate to the task of parenting. Extremely high total scores suggest significant stress within the parent-child relationship, and intervention is indicated.

Low scores may reflect either low levels of stress, or when very low, parent-child dysfunction. Very low scores could be false negatives, representing very defensive parents, who are fearful and mildly paranoid, and unable to admit their problems. Conversely, low scores may reveal individuals with little investment in the role of parent, and thus minimally involved with their children. Parents with extremely low total scores should also be considered as having significant stress and intervention is again indicated.

Reliability.

The current PSI (form 6) has established good reliability. The alpha reliability coefficients for each subscale, each domain, and the total score were computed based on a normative sample of 534 parents (Loyd, 1986; Loyd & Abidin, 1985). Demonstrating high internal consistency, the subscale coefficients ranged from .62 to .80, with the child domain score being .89, the parent domain .93, and the total stress score .95. Nearly identical alpha reliabilities were reported in a cross-cultural sample (Loyd, 1986).

Test-retest reliabilities suggest stability of the PSI scales, and were obtained from four different studies (cited in Loyd,

1986) with Spearman coefficients of .817 and .706 ($p < .01$) achieved for scores across a 3 week interval in one study, and Pearson correlations of .63 Child, .91 Parent, and .96 Total across a 3 month interval in another study.

Content Validity.

The PSI was developed from a comprehensive literature review of relevant child, parent, and stress research and 95% of the constructed items were directly related to other research studies of parental stress (Loyd & Abidin, 1985). The initial instrument was then pilot tested and field tested. The instrument was further developed using varimax rotation and factor analysis which yielded six child factors and seven parent factors. The factor loadings demonstrated distinct discrimination between the two separate child and parent domains and their particular stress subscales (Loyd, 1986).

Construct Validity.

Concurrent and construct validity with other measures have been established through sixteen studies (many unpublished doctoral dissertations, Abidin, 1986) comparing the PSI, or its subscales to other measures. Studies using the Child Behavior Problem Checklist and the State-Trait Anxiety Scale (Lafiosca & Loyd, 1987) found concurrent validity for both the child and the parent domain of the PSI.

Coping Health Inventory for Parents

The Coping Health Inventory for Parents (CHIP) (McCubbin & Patterson, 1981) is a 45 item self-report questionnaire designed to measure parental coping when caring for a chronically ill child. Mothers under the stress of caring for a chronically ill child develop behaviors to manage the multiple demands of the situation. The CHIP was standardized using 185 parents of children with cystic fibrosis (McCubbin, McCubbin, Patterson, Cauble, Wilson, & Warwick, 1983). The CHIP measures specific coping behaviors and patterns of coping related to family integration, social support and emotional well-being, and coping through understanding the medical-related aspects of caring for a chronically ill child.

A recent survey (McCubbin, 1987) cited 22 investigations which used the CHIP. Parents of children with cystic fibrosis (Gibson, 1986), epilepsy, myelomeningocele, osteogenesis imperfecta, diabetes, renal disease, oncology, sickle cell anemia, autism, mental retardation and affective disorders have completed the CHIP. Unfortunately, very few of these studies have been published, although McCubbin (1987) briefly discussed many of the studies. The majority of the studies included both parents in the data collection, yet mothers outnumbered fathers by about a 3:1 ratio. The age of the affected child ranged from infants to young adults. Several of the study designs used a second measure, but no study used a measure of stress. With the exception of one study of

families with premature infants, all studies looked at families whose chronically ill child had been diagnosed for at least six months. No study included a child who was in the terminal phase of the illness. No study evaluated parental coping during the hospitalization of the chronically ill child.

The CHIP may be used either for research or for clinical assessment to determine if parents are adapting successfully to the stresses of caring for a chronically ill child. Low scores in the face of high stress suggest the need for professional assistance and intervention to enhance coping and improve family life. The utility of the CHIP in evaluating maternal coping seems evident by the number of investigators who are using this measure. The fact that no study has been conducted on the population of mothers with hospitalized children, nor correlated with a stress measure underscores the importance of this present investigation. Determining the effects of the child's hospitalization on the mothers coping behaviors and coping patterns may lead to the ultimate formulation of intervention plans designed to bolster the coping and emotional well-being of mothers with hospitalized, chronically ill children. This study used the CHIP to measure mothers coping when caring for hospitalized, young chronically ill children.

Scoring.

The individual coping behaviors are presented in a list (Appendix C), with instructions for a mother or father to indicate

how helpful that behavior is in managing their situation, with a score range from 0 (not helpful) to 3 (extremely helpful). Behaviors which are not used are either marked "not possible", or "choose not to". Each coping behavior is associated with a coping pattern and the separate coping behavior scores are combined into a pattern score.

There are three coping patterns measured by the CHIP. The first pattern, called "family integration, cooperation, and an optimistic definition of the situation" consists of 19 individual behaviors that involve strengthening family relationships and the parents' outlook on life when caring for a chronically ill child. Coping strategies representative of this pattern may be "trusting my spouse (or former spouse) to help support me and my child" or "doing things together as a family (involving all members of the family)".

The second coping pattern is called "maintaining social support, self esteem and psychological stability" and consists of 18 behaviors related to efforts to develop relationships with other people, and efforts to manage psychological tension and self esteem. Items such as "engaging in relationships and friendships which help me to feel important and appreciated" or "becoming more self reliant and independent" comprise this emotional and social support pattern.

The third coping pattern is labeled "understanding the health care situation through communication with other parents and

consultation with the health care team". Eight behaviors pertaining to understanding the child's medical condition comprise this pattern. Representative items consist of "talking with the medical staff (nurses, social workers, etc) when we visit the medical center" or being sure prescribed medical treatments for child are carried out at home on a daily basis".

Thus, the CHIP gives a wide range of information related to how mothers do or do not cope when caring for a chronically ill child. The means and standard deviations for each coping pattern were formulated from a sample of 308 parents whose children had cystic fibrosis or cerebral palsy (McCubbin & Patterson, 1981). Mothers and fathers have demonstrated slightly different coping behavior patterns, and norms are available for either the mother or father. Parents under high stress from their chronically ill child should earn high coping scores when actively trying to manage and adapt to the situation. In stressful situations, scores should be above the mean, and there should be a balance between all three coping patterns, rather than over-reliance on one pattern (McCubbin, 1987).

Reliability.

Reliability was determined after factor analysis determined three separate factors, or coping patterns (McCubbin et al., 1983). The three factors represented 71.1% of the variance from the correlation matrix. Internal consistency was represented by Cronbach's coefficient alphas of each behavior within the factor,

and found to be .79 for Pattern I, .79 for Pattern II, and .71 for Pattern III. This indicates the CHIP to be internally reliable.

Content and construct validity.

The CHIP was developed based on a review of pertinent literature, theories, and research of family stress, family and individual coping, social support, and chronic illness. The initial 80 item CHIP was developed and tested on 185 parents of children with cystic fibrosis (McCubbin et al., 1983), along with the Family Environment Scale, and two indices of child health (Height/Weight Index and Pulmonary Functioning Index). The use of all three coping patterns was associated with results on the Family Environment Scale and with improvements in the child's health status. The CHIP results were also compared between low conflict and high conflict families with a child with cerebral palsy (McCubbin & Patterson, 1981). High conflict families had higher coping pattern scores compared to the low conflict families. This finding is consistent with the understanding that coping behaviors develop in response to stressful situations and families with higher stress call upon a wider range of coping behaviors. Thus, the CHIP has demonstrated adequate validity as a research tool documenting the use of coping behavior patterns by parents when managing family life with a chronically ill child (McCubbin, 1987).

Data Collection Procedure

Consenting mothers were given a folder with the two questionnaires and a family data sheet. The investigator reviewed the forms with each of the mothers and each mother was shown how to fill in the answer sheets. The family data sheet was discussed first, followed by the PSI, then the CHIP. However, since the forms were left with the mothers, they could fill them out in any order they chose.

Mothers were asked to complete the study that day, either in their child's room, or at a nearby conference room. Mothers were told the investigator would return within four hours, and they were given information on how they could reach the investigator, prior to the investigator's return if they desired. No one contacted the investigator prior to her return. The mothers were told the investigator would like to speak with them upon completion of the questionnaires, if possible. A large manilla envelope was provided for the completed questionnaires.

All mothers preferred to fill out the questionnaires at the child's bedside. Although most mothers completed the questionnaires within the allotted time frame, many mothers requested more time, citing interruptions by their child or hospital procedures. The folders were requested to be kept overnight by five mothers, and were all returned either directly to the investigator, or via the manilla envelope to the nursing station on the following day.

After completing the questionnaires, the investigator attempted to speak with the mothers, giving her the opportunity for comments, and to discuss any concerns with the investigator. Six mothers who completed the forms were not available for discussion due to a variety of reasons ranging from early discharge, to being away from the hospital, often leaving another relative with the child. None of these mothers made an effort to contact the investigator, although the investigator unsuccessfully tried to contact the mothers.

The mothers who did engage in a discussion with the investigator often spoke about specific items on the questionnaires. Discussion periods ranged from five to thirty minutes, with the average around ten minutes. Mothers spoke about their stresses with balancing their home and family life with their need to be in the hospital with their sick child. Many mothers commented on aspects of the hospitalization and interactions with staff that were sometimes helpful and sometimes stressful. None of the mothers suggested the process of filling out the questionnaires was stressful to them, and many stated they found themselves thinking about things they had never previously considered.

Data analysis

The findings from this study were analyzed using descriptive statistics and correlational analysis. The computer program CRUNCH Interactive Statistical Package was used to for the

statistical analysis. The sample was described using descriptive statistics. Relationships amongst the demographic variables related to the mother or child were analyzed using chi-square analysis.

Each research question was addressed in the following manner. The first question, "what are the parenting-related stresses of mothers with a hospitalized, chronically ill young child?" was answered using descriptive statistics for the components of the Parenting Stress Index. The second question, "What is the relationship between family demographic information and the parenting-related stresses of mothers?" was answered using Pearson product moment correlations and analysis of variance between the components of the PSI and the demographic variables.

The third research question, " What coping behavior patterns are used by mothers of hospitalized, young children with chronic illnesses?" was answered using descriptive statistics for the Coping Health Inventory of Parents. The fourth question, "What is the relationship between family demographic information and coping patterns used by mothers of hospitalized, young chronically ill children?" was answered using Pearson product moment correlations and analysis of variance between the demographic parent/child information and the CHIP.

Finally, the last research question, " What is the relationship between parenting-related stresses and mothers coping patterns with young, chronically ill hospitalized children?" was

examined using Pearson correlations, analysis of variance, and chi-square analysis between the findings of the PSI subscales and the CHIP patterns.

The findings from this study with the answers to the research questions are subsequently described in Chapter 4. The data is presented in both discussion and table form.

CHAPTER IV

RESULTS

This section will present the research study findings. Demographic characteristics of the sample will be described, followed with a presentation of the results of the two quantitative measures, the Coping Health Inventory for Parents, and the Parenting Stress Index. The appropriate statistical analysis of each measure, including descriptive statistics, Pearson product moment correlations, analysis of variance, and chi-square analysis, will be presented.

Demographic Data

Mothers

The study sample consisted of 30 mothers with hospitalized chronically ill young children between the ages of 20 and 66 months. The sample was predominately White (70%), with 23% Hispanic and 7% Black women (Table 1). There were no Asian mothers who met the study criteria. Mothers ranged in age from 18 years to 42 years, with four women (13%) under 21 years, eighteen women (60%) between 22 and 30, and eight women (27%) between 31 and 42 years (Table 1). Most of the women (73%) lived in a couple relationship, with 16 mothers married to the child's father, and another three mothers who lived with the child's father, but were not married to him. Eight of the women were single mothers, four having never married, and the other four were separated or divorced. Three women lived with a

man who was not the father of the chronically ill child (Table 1).

Table 1

<u>DEMOGRAPHIC CHARACTERISTICS OF MOTHERS</u>		
	(n)	(%)
Race		
White	21	70%
Hispanic	7	23%
Black	2	7%
Mothers Ages		
18 to 21 years	4	13%
22 to 30 years	18	60%
31 to 42 years	8	27%
Marital Status		
Single	8	27%
Married, or with child's father	19	63%
Married, or with child's stepfather	3	10%

Socioeconomic background

Seventy percent of the sample mothers were housewives and did not work outside the home. Twenty three percent worked outside in semi-skilled employment, and 7% were employed as professionals. Of the mothers' partners, only one (3%) was unemployed, while 76% worked at semi-skilled jobs, and 19% were professionally employed (Table 2).

The mean family annual income was approximately \$26,000/year. Two families (7%) had an annual incomes under \$6,000/year, seven families (24%) earned between \$6,000 and \$10,000/year, three families (10%) earned between \$10,000 to \$20,000/year, nine families (31%) were in the \$20,000 to \$30,000 range, four families (14%) earned between \$30,000 to \$40,000/year, and four families (14%) earned over \$40,000/year (Table 2).

The educational background of mothers included 2 mothers (7%)

who attended school only up to 8th grade, 13 mothers (43%) were high school graduates, 10 mothers (33%) attended some college or vocational school, and 5 mothers (17%) were college graduates. The mothers reported on the educational level of the father of the chronically ill child where 14 (48%) attended high school only, 10 (35%) attended some college or vocational school, 3 (10%) were college graduates, and 2 (7%) attended graduate school (Table 2).

Table 2

DEMOGRAPHIC CHARACTERISTICS OF MOTHERS

Socioeconomic Background

	(n)	(%)
Mother's employment		
Housewife	21	70%
Semi-skilled	7	23%
Professional	2	7%
Father's employment		
Unemployed	1	3%
Semi-skilled	16	76%
Professional	4	19%
Annual Family Income		
0 to \$6,000/year	2	7%
\$6 - \$10,000/year	7	24%
\$10 - 20,000/year	3	10%
\$20 - 30,000/year	9	31%
\$30 - 40,000/year	4	14%
over \$40,000/year	4	14%
Mothers' Educational background		
Up to 8th grade	2	7%
9 to 12th grade	13	43%
Attended some college or vocational school	10	33%
College graduate	5	17%
Fathers Educational background		
9 to 12th grade	14	48%
Attended some college or vocational school	10	34%
College graduate	3	10%
Graduate education	2	7%

Distance from hospital

The distance from home to the multi-specialty hospital was varied. Many families (47%, n=14) lived within 30 miles of the hospital ($M=14.7$ miles). However, 40% of the families (n=12) lived between 42 to 90 miles away ($M=60.8$), and 13% (n=4) lived between 150 to 300 miles ($M=217.5$ miles) from the hospital (Table 3).

Hours spent at the hospital by the mother

The majority of the mothers (60%) reported that they were "rooming-in" with their sick child, and were there 24 hours a day. About one third (30%) of the mothers spent between 12 and 16 hours each day at the hospital. The fewest number of hours reported by any mother was eight. Only 10% of the mothers reported staying between eight and ten hours a day (Table 3).

Other children

Ten families (33%) did not have any other children besides the hospitalized ill child. However, 17 families (57%) had one other child besides the hospitalized child and three families (10%) had two other children. The siblings ranged in age from 8 months to 13 years, with a mean age of five years. Six of the families (20% of the sample) reported having another child with a chronic illness (Table 3).

Characteristics of the chronically ill children

The children of the study mothers were hospitalized toddlers and preschoolers consisting of nearly equal numbers of boys (57%, n=17) and girls (43%, n=13). They ranged in age from 20 to 66 months, with a mean age of 43 months. Eleven children (37%) were between 20 months and three years, ten children (33%) were between 37 months and four years, and nine children (30%) were between 49 months and five and a half years of age (Table 4).

Table 3

DEMOGRAPHIC CHARACTERISTICS

Distance from hospital	Mean # miles	(n)	(%)
1 to 30 miles	14.7	14	47%
42 to 90 miles	60.8	12	40%
150 to 300 miles	217.5	4	13%
Daily hours in hospital	Mean # hours	(n)	(%)
8 to 10 hours	9	3	10%
12 to 16 hours	13.2	9	30%
24 hours; rooming-in	24	18	60%
Other children in the family		(n)	(%)
None		10	33%
One		17	57%
Two		3	10%

Table 4

DEMOGRAPHIC CHARACTERISTICS OF CHILD

Child Sex and Age			
N=30			
	(n)	(%)	Mean age
Sex			
Female	13	43%	
Male	17	57%	
Ages			
Sample mean age in months	30	100%	42.8 months
20 months to 3 years	11	37%	30.6
37 months to 4 years	10	33%	43.2
49 months to 5 1/2 years	9	30%	57.2

Chronic conditions

The ill children had varied diagnoses, and these were arbitrarily grouped into one of three categories (Table 5). The first category, cardiopulmonary, consisted of 12 children (40%). Five had cardiac problems including one child with an atrial septal defect awaiting surgery, a child with tetralogy of fallot, one child with congestive cardiomyopathy anticipating a heart transplant, one child with pulmonary atresia, and one child with coarctation of the aorta. The children's pulmonary problems included two children with cystic fibrosis, one child with a tracheostomy and a repaired cleft lip and palate, one child with subglottic stenosis and tracheostomy, one child with congenital agenesis of the left lung and chronic lung disease, one child with recurrent tracheal papillomas and respiratory distress, and one child with asthma.

The second category consisted of eight children (27%) with leukemia or cancer, out of the induction phase, and in remission or relapse. Most were hospitalized for fever or infection. One child had Burkett's lymphoma, one child had rhabdomyosarcoma, and six children had leukemia.

The third category consisted of ten children (33%). Five children had problems with their GI tract including one child with gastroschisis, short bowel syndrome and home broviac TPN, one child had had a liver transplant from biliary atresia, one child had cirrhosis of the liver and was awaiting a liver transplant, one

child was born with an imperforate anus and retrovaginal fistula and was having a colostomy takedown, and one child had fetal alcohol syndrome and significant gastroesophageal reflux requiring surgery. Five other children had various musculoskeletal problems including one child with a congenital blood dyscrasia and cerebral palsy from a cerebral aneurysm, one with infantile spinal muscular atrophy, one had Furuyama muscular dystrophy, one child had severe hypospadias with penile reconstruction, and one child had a nonrepaired cleft palate with speech impediment.

Table 5

DEMOGRAPHIC CHARACTERISTICS OF CHILD

		N=30			
Diagnostic Categories:	(n)	(%)	Age	Age at dx	
Cardiopulmonary	12	40%	(38.9 mean)		
Atrial septal defect			45	36	
Tetralogy of Fallot			36	0	
Congestive cardiomyopathy			30	11	
Pulmonary atresia			45	10	
Coarctation of the aorta			59	36	
Cystic fibrosis			43	4	
Cystic fibrosis			49	2	
Tracheostomy & cleft palate/lip			32	0	
Tracheostomy & subglottic stenosis			22	1	
Congenital left lung agenesis			44	15	
Tracheal papillomas			30	10	
Asthma			32	12	
Cancer/Leukemia	8	27%	(50.4 mean)		
Burketts lymphoma			59	55	
Rhabdomyosarcoma			44	30	
Leukemia			36	34	
Leukemia			62	42	
Leukemia			50	36	
Leukemia			53	36	
Leukemia			66	42	
Leukemia			33	13	
GI/Musculoskeletal	10	33%	(41.4 mean)		
Gastroschisis			20	0	
Biliary atresia & liver transplant			66	1.5	
Liver cirrhosis			40	10	
Imperforate anus			31	0	
Fetal alcohol syndrome & GE reflux			45	4	
Cerebral aneurysm & cerebral palsy			48	2	
Spinal muscular atrophy			41	8	
Furuyama muscular dystrophy			35	12	
Hypospadias with penile reconstruction			37	0	
Cleft palate & speech impediment			51	30	

Children in all three categories had normal or nearly normal intellect according to the mother's report and chart audit. All of the children were diagnosed with their chronic illness prior to this hospitalization. Eleven children (37%) were diagnosed under six months of age (mean age 1.4 mos), eight children (27%) were diagnosed between 6 and 15 months of age (mean age 11.4), and eleven children (37%) were diagnosed over two years of age (mean age 36.3 mos) (Table 6).

Consequently, most of the children had been diagnosed with a chronic illness for quite some time prior to this hospitalization. About half (47%, n=14) of the children had been diagnosed for over two years, 40% (n=12) had been diagnosed between one and two years prior, and 13% (n=4) of the children had been diagnosed within the year prior to this hospitalization (Table 6).

Only two children (7%) had never been previously hospitalized, while 93% of the children had experienced previous hospitalizations. Previous hospitalization frequency varied among the children, with 40% (n=12) having been hospitalized less than three times, 40% (n=12) having been hospitalized between four and nine times, and 20% (n=6) of the children had been hospitalized between 10 and 21 times (Table 6). Together, the mothers and their chronically ill child had been hospitalized 187 times.

Table 6

DEMOGRAPHIC CHARACTERISTICS OF CHILD
Related to Illness

Age at diagnosis	(n)	(%)	Age in months
< 6 months	11	37%	1.4 mean
6 to 15 months	8	27%	11.4 mean
over 2 years	11	37%	36.3 mean
Time since diagnosis			
> 2 years	14	47%	37.8 mean
between 1 and 2 years	12	40%	19.0 mean
less than 1 year	4	13%	5.3 mean
Previous hospitalizations			
No	2	7%	
Yes	28	93%	
Number of Hospitalizations	(n)	(%)	Mean # hosp
One to three	12	40%	2.2
Four to nine	12	40%	5.7
over ten	6	20%	15.5

**Relationships Between Demographic Variables
of Mother and Child**

Age at diagnosis and diagnostic category

When the children were separated into the three diagnostic categories of cardiopulmonary disease, cancer/leukemia, and GI/musculoskeletal, there was a statistical relationship between the age of a child at diagnosis and the chronic illness category ($\chi^2=13.4$, $p < .01$, df 4) (Table 7). Children diagnosed under six months of age (36.7% of the sample children) had either cardiac or pulmonary disease ($n=5$), or the category of GI and musculoskeletal problems ($n=6$). Similarly, children diagnosed with illnesses between six and 15 months of age (26.7%) also had cardiac and pulmonary disease ($n=4$) or GI/musculoskeletal ($n=3$). Only one child in this age group was diagnosed with cancer or leukemia.

Children who were diagnosed later than two years of age (36.7%) suffered primarily from cancer or leukemia (n=7), with another three children in this age group having cardiopulmonary disease, and just one child with a musculoskeletal problem (cleft palate).

Table 7

<u>AGE AT DIAGNOSIS AND DIAGNOSTIC CATEGORY**</u>			
N=30			
Diagnostic Category			
	<u>Cardiopulmonary</u>	<u>Cancer/Leukemia</u>	<u>GI/musculoskeletal</u>
Age at	n=12 (40%)	n=8 (27%)	n=10 (33%)
Diagnosis			
< 6 mos	5	0	6
6 to 15 mos	4	1	3
over 2 yrs	3	7	1

** $p < .01$; $X^2=13.4$, 4 *df*

Mothers age and marital status

There was a relationship between the mother's age and her marital status ($X^2=11.44$, $p < 0.02$, *df* 4) (Table 8). None of the four young mothers aged 18 to 21 years lived with the child's father, either being single (50%) or living with a man who was not the father of the chronically ill child (50%). The eight older mothers between 31 and 42 years primarily lived with the child's father (75%), or were single (25%). Most of the group of mothers aged 22 to 30 years (n=18) lived with the child's father (72%), although 22% were single, and 5% lived with a child's stepfather.

Marital status and time since diagnosis

The length of elapsed time from the diagnosis of the child's illness also correlated with the mother's marital status (X^2

$=10.0$, $p < 0.04$, $df\ 4$) (Table 9). The mothers of children most recently diagnosed (13%) did not live with the child's father, although mothers of children diagnosed longer than one or two years primarily did live with the child's father (Table 9). Although the data may suggest that the group of the youngest mothers, who were not living with the child's father, also had the children most recently diagnosed, this was not the case (Table 10). Rather, it suggests the young mothers had the most tenuous relationships with their partners.

Table 8

MOTHERS AGE AND MARITAL STATUS*

Age	n (%)	Single	Married or lives with child's father	Married or lives with child's stepfather
		n (%) 8 27%	n (%) 19 63%	n (%) 3 10%
18 to 21	4 (13%)	2	0	2
22 to 30	18 (60%)	4	13	1
31 to 42	8 (27%)	2	6	0

* $p < .02$; $X^2=11.4$, 4 df

Table 9

TIME SINCE DIAGNOSIS AND MARITAL STATUS*

Length of time since diagnosis		Single n=8 (27%)	Married or lives with child's father n=19 (63%)	Married or lives with child's stepfather n=3 (10%)
< 1 year	4 (13%)	3	0	1
> 1 year	12 (40%)	2	8	2
> 2 years	14 (47%)	3	11	0

* $p < .04$; $X^2=10.0$, 4 *df*

Table 10

MOTHERS AGE, MARITAL STATUS, & TIME SINCE DIAGNOSIS

Mother's Age	Dx <1 yr	Dx 1-2 yr	Dx >2 yrs	Single	With Father	With Stepfather
18 to 21	1	2	1	2	0	2
22 to 30	2	9	7	4	13	1
31 to 42	1	1	6	2	6	0

Nonsignificant Demographic Variables

There was no relationship between the mother's marital status and the child's diagnostic group, the child's age at diagnosis, the number of secondary diagnoses, the number of hospitalizations, the age of the child, mothers's level of education, mother's employment, or the sex of the child. There was no relationship between the diagnostic group (cardiopulmonary, cancer/leukemia, GI/musculoskeletal) and the number of hospitalizations, nor was there was any relationship between the age at diagnosis and the number of hospitalizations.

Coping Health Inventory for Parents (CHIP)

The CHIP instrument was used to measure coping behaviors of mothers and their efforts to manage family life when their chronically ill child was hospitalized. Mothers' use of the three CHIP coping behavior patterns will be reported. The specific coping behaviors comprising each Coping Pattern are listed in Table 11. Specific coping behaviors felt to be particularly helpful or non-helpful to mothers will be discussed. Finally, any differences in coping related to demographic variables will be presented.

Table 11

COPING HEALTH INVENTORY FOR PARENTSCoping Pattern I Behaviors

Family Integration, Cooperation, and an Optimistic
definition of the situation

Trying to maintain family stability
 Trusting my spouse (or former spouse) to help support me and
 my child
 Believing that my child will get better
 Showing that I am strong
 Taking good care of all the medical equipment at home
 Getting other members of the family to help with chores and tasks
 at home
 Believing that the medical center has my family's best interest
 in mind
 Believing in God
 Doing things together as a family (involving all members of
 the family)
 Believing that my child is getting the best medical care possible
 Doing things with family relatives
 Telling myself that I have many things I should be thankful for
 Encouraging child with medical condition to be more independent
 Building a closer relationship with my spouse
 Investing myself in my child(ren)
 Talking over personal feelings and concerns with spouse
 Having my child with the medical condition seen at the
 clinic/hospital on a regular basis
 Believing that things will always work out
 Doing things with my children

Table 11 continued

COPING HEALTH INVENTORY FOR PARENTSCoping Pattern II Behaviors

Maintaining social support, self esteem,
and psychological stability

Engaging in relationships and friendships which help me to feel
important and appreciated
Sleeping
Working, outside employment
Purchasing gifts for myself and/or other family members
Eating
Getting away by myself
Building close relationships with people
Develop myself as a person
Investing time and energy in my job
Entertaining friends in our home
Becoming more self reliant and independent
Concentrating on hobbies (art, music, jogging, etc.)
Keeping myself in shape and well groomed
Involvement in social activities (parties, etc.) with friends
Going out with my spouse on a regular basis
Allowing myself to get angry
Talking to someone (not professional counselor/doctor) about
how I feel
Being able to get away from the home care tasks and
responsibilities for some relief

Coping Pattern III Behaviors

Understanding the medical situation through communication
with other parents and consultation with medical staff

Talking with the medical staff (nurses, social working, etc) when
we visit the medical center
Talking with other individuals/parents in my same situation
Talking with the doctor about my concerns about my child with the
medical condition
Talking with other parents in the same type of situation and
learning about their experiences
Reading about how other persons in my situation handle things
Explaining our family situation to friends and neighbors so they
will understand us
Being sure prescribed medical treatments for child are carried out
at home on a daily basis
Reading more about the medical problem which concerns me

Coping Patterns

This sample of mothers had scores within the normal range on all three of the CHIP coping patterns (Table 12). This was not surprising, since the normal range for each of the patterns is nearly equal to the total possible score. If each coping item was rated only minimally helpful, the lowest possible score on Coping Pattern I would be 19. The highest possible score would be 57, compared to the normal Pattern I range of 25 to 55. Similarly, Coping Pattern II would have a low score of 18 if each item was scored as minimally helpful. The highest score would be 54 compared to the normal Pattern II range of 16 to 40. Finally, Coping Pattern III could yield a low score of 8 if each item was scored as minimally helpful, and the highest score would be 24, compared to the normal range of 8 to 22. However, if a coping behavior was not used or indicated that it was not helpful, the score for that item would be zero, thus lowering the total possible Pattern score.

The CHIP reflects the repertoire of coping behaviors available to an individual under stress. Studies suggest (McCubbin, et al, 1983) that the greater the stress, the greater the number of coping efforts used to cope with the stress. Therefore, higher coping scores would be expected for mothers under the stress of caring for a hospitalized child. Since the normal ranges of the CHIP are broad, attention will be paid to the sample mean scores

of each Pattern compared to the normal mean scores. Scores below the mean suggest that mothers have fewer coping resources available to them. Scores above the mean suggest mothers are active in their efforts to find ways to manage the stresses of having a hospitalized, chronically ill child.

Coping Pattern I, the pattern of "family integration, co-operation, and an optimistic definition of the situation", has a normal mean of 40 with a range of 25 to 55 (Table 12). The sample mean was 40.8 and 97% of the sample fell within the normal range. The majority (57%) had Pattern I scores elevated above the normal mean of 40. Only 3% (n=1) had a lower than normal range score.

Coping Pattern II, "maintaining social support, self esteem and psychological stability", has a normal mean of 28, with a range of 16 to 40. Pattern II was the coping pattern used least frequently by this sample. The sample mean on this coping pattern was 26.9 and 87% of the sample fell within the normal range. Slightly less than half (47%) had scores higher than the normal mean. A few mothers scored outside the normal range, with 3% (n=1) below and 7% (n=2) above the normal range.

Coping Pattern III, "understanding the medical situation through communication with other parents and consultation with medical staff", has a normal mean score of 15, with a range of 8-22. Pattern III was the coping pattern most frequently used by this sample. The sample mean was 16.4, and again 97% of the sample scored in the normal range. No one scored below normal,

and only one mother (3%) scored above the normal range. The majority of the sample (60%) had Pattern III scores elevated above the normal mean of 15.

Table 12

<u>COPING HEALTH INVENTORY FOR PARENTS</u>				
Range and Mean Scores				
Coping Pattern	Range	Mean	% sample > mean	% sample < mean
Pattern I				
Normal	25 to 55	40		
Sample	20 to 55	40.8	57%	43%
Pattern II				
Normal	16 to 40	28		
Sample	6 to 45	26.9	47%	53%
Pattern III				
Normal	8 to 22	15		
Sample	9 to 23	16.4	60%	40%

Statistical Relationship of Coping Patterns

There were some significant relationships between the three Coping Patterns. Coping Pattern I, family integration, cooperation, and optimism was related to Coping Pattern II, support, esteem, and stability ($r=0.41$, $p < .02$, $df\ 28$). Coping Pattern I was also related to Coping Pattern III, medical communication and consultation ($r=0.55$, $p < .002$). However, Coping Pattern II and Coping Pattern III were not related ($r=0.24$, $p < .20$). This suggests there is some overlap between the coping patterns and they may not be measuring distinctly separate coping efforts.

Coping behaviors

Certain coping behaviors were identified by this sample as being extremely helpful in coping with family life when they had a hospitalized chronically ill child. Each of the 45 coping behaviors were analyzed to determine the percentage of the sample that rated that item as extremely helpful (Table 13). Items rated as moderately helpful or minimally helpful were not calculated in this analysis. Not every mother answered every item, so some variability exists between the percent of the sample and the number of mothers choosing a particular item. The most frequently used behavior (83.3%) was the belief that their child was getting the best medical care possible. "Believing that my child will get better" was rated as extremely helpful by 76.7% of the mothers. The coping behavior which ranked third in frequency was "believing in God", with 75% indicating this behavior as extremely helpful. Mothers also coped by believing that the medical center/hospital had the family's best interest in mind (73.3%). Also, "doing things with my children" was rated as extremely helpful by 73.3% of the sample. The belief that things will always work out was identified as extremely helpful by 70% of the sample.

Other coping behaviors identified as extremely helpful by at least half of the sample included: "telling myself that I have many things I should be thankful for (60%), "having my child with the medical condition seen at the clinic/hospital on a regular basis (56.7%), talking to the doctor about their concerns with

their ill child was listed 56.7%, and "talking with the medical staff (nurses, social worker, etc.) when we visit the medical center" was cited as extremely helpful by 55.2% of the sample (Table 13).

Only six coping behaviors were identified as being helpful to some degree by 100% of the sample. These six behaviors were (1) the belief that their child was getting the best medical care, (2) doing things with their children, (3) believing that the medical center had the family's best interest in mind, (4) thinking of all the things they had to be thankful for, (5) talking with the Doctor, and (6) having the child seen regularly by the medical staff. Not a single mother reported they did not use these behaviors to cope, and no one said it wasn't helpful to them in coping with their hospitalized child.

Certain coping behaviors were rated as being the least helpful by a large percentage of the sample (Table 14). The behavior identified least frequently as being helpful by 72% of the mothers was "working, outside employment". Most of these mothers chose not to work (48%), or stated working was not possible (21%), or not helpful (3.5%). In contrast, 21% of the mothers identified working as being extremely helpful, while 30% of the mothers worked outside the home. Purchasing gifts for the family or the mother herself, was not done or not helpful for 48% of the sample. Sadly, 41% of the sample stated that "getting other members of the family to help with chores and tasks at home" was not possible

(21%), chose not to (7%) or found it was not helpful (14%). Only a few mothers (14%) found getting others to help at home was extremely helpful, while 35% of the mothers found it to be moderately helpful, and 14% only minimally helpful.

Table 13

COPING HEALTH INVENTORY FOR PARENTS

Coping Behaviors Rated Extremely Helpful

Pattern	Behavior	n	%
I	Belief that the child was getting the best medical care possible	25	83.3%
I	Belief that the child will get better	23	76.7%
I	Belief in God	21	75.0%
I	Belief that the medical center has the family's best interest in mind	22	73.3%
I	Doing things with the children	22	73.3%
I	Belief that things will always work out	21	70.0%
I	Telling myself that I have many things I should be thankful for	18	60.0%
I	Having the child with the medical condition seen at the hospital on a regular basis	17	56.7%
III	Talking with the doctor about my concerns about my child with the medical condition	17	56.7%
III	Talking with the medical staff (nurses, social worker, etc) when we visit the medical center	16	55.2%

Table 14

COPING HEALTH INVENTORY FOR PARENTS

Coping Behaviors Rated Least Helpful

Behavior	Rating	n	%
Working, outside employment		21	72.4%
	Choose not to	14	48.3%
	Not possible	6	20.7%
	Not Helpful	1	3.5%
Purchasing gifts for self/family		13	48.2%
	Choose not to	3	11.1%
	Not possible	5	18.5%
	Not helpful	5	18.5%
Getting family to help with home chores		12	41.1%
	Choose not to	2	6.9%
	Not possible	6	20.7%
	Not helpful	4	13.8%

Influence of Demographic Variables on CHIP Scores

Certain demographic characteristics accounted for differences in the coping behaviors and patterns used by mothers. Variables which led to significantly different scores on the coping patterns, as well as those which suggest clinical significance will be discussed. Demographic variables which led to significantly different scores on individual coping behaviors will be presented.

Sex of child

Differences were noted in the mothers' coping scores depending on whether the ill children were boys or girls (Table 15). Mothers

with female children had significantly higher coping scores on the Coping Pattern II of social support, esteem and psychological stability ($M=30.3$) compared to mothers with boys ($M=24.2$, $F=4.4$, $p<0.05$, $df\ 1$). There were no significant differences in the other two Coping Patterns based on the sex of the ill child.

Time since diagnosis

There was a relationship between the length of time since the child was diagnosed with the chronic illness and the coping scores (Table 15). Coping Pattern I, family integration, cooperation, and optimism, was used significantly less frequently by mothers of children diagnosed less than one year compared to mothers of children diagnosed over one or two years prior to this hospitalization ($F=8.3$, $p<.001$, $df\ 2$). Mothers with children diagnosed under a year also tended to use both Coping Pattern II, social support, self esteem, and stability, and Coping Pattern III, medical consultation and communication, less than the other mothers.

Specific coping behaviors reported to be significantly less helpful to mothers with children diagnosed for under a year ($p<.05$) included doing things together as a family, being sure home medical treatments were carried out, talking with other parents about their experiences, talking about their concerns with the child's father, trusting the child's father for support, or building a closer relationship with the child's father (Table 15). Although not statistically significant, mothers of children

diagnosed but a few months tended to be less sure that the medical center had their family's best interest in mind ($p < .08$).

Marital status

Sample scores were computed based on the marital status of mothers (Table 15). Score variances were found for single mothers ($n=8$), for coupled women either married ($n=16$) or unmarried ($n=3$) who lived with the father of the ill child, and for those women who lived with a man who was not the father of the ill child (stepfather, $n=3$).

Whether or not there was a father figure in the home resulted in significantly different scores on the CHIP Coping Pattern I of family integration, cooperation, and optimism ($F=14.5$, $p < 0.001$, df 1). Single mothers used Coping Pattern I less ($M=33.3$) compared to mothers living with the child's father ($M=43.4$) or mothers living with the child's stepfather ($M=44.3$) ($F=7.0$, $p < 0.05$, df 2). There was no difference in Coping Pattern II, social support, self-esteem, and emotional stability, between the single mothers and those living in a couple relationship. Similarly, there was no difference in the use of Coping Pattern III, medical communication and consultation, between single mothers, and coupled mothers. However, although not statistically significant, the mothers living with the child's stepfather found the coping behaviors associated with Coping Pattern III more helpful ($M=19.0$) compared to single mothers ($M=16.1$) or mothers who lived with the child's father ($M=16.1$).

Mothers' employment

The helpfulness of coping behaviors associated with Coping Pattern II, social support, self-esteem and emotional stability, were significant for mothers based on their employment status (Table 15). The small group of mothers with professional employment found this Pattern significantly more helpful ($M=47$) compared to the mothers who were housewives ($M=40.5$) or mothers employed at semi-skilled positions ($M=39.8$) ($F=8.3$, $p < .005$, $df\ 2$). Although not statistically significant, the women with professional employment also found Coping Pattern I, family integration, cooperation, and optimism, and Coping Pattern III, medical communication and consultation, more helpful.

Mother's age

There was no statistical relationship between the age of the mother and the three CHIP coping patterns (Table 15). However, younger mothers tended to use the medical communication and consultation coping pattern more frequently than did older mothers. Mothers aged 18 to 21 years had a mean score of 17.5, mothers aged 22 to 30 years had a mean score of 16.4, and older mothers aged 31 to 42 years had a mean score of 15.9.

Income

Mothers were separated into three groups based on their annual family income (Table 15). There were 12 mothers with an annual family income of \$6,000 to \$20,000/year (low), 9 mothers with an income of \$20,000 to \$30,000/year (middle), and 8 with an annual

income over \$30,000/year (high). Although not statistically significant, certain trends were noted in their coping scores based on income.

The Coping Pattern III of medical communication and consultation seemed to be more helpful for mothers with a lower income, with scores of 17.2 for the low group, 16.7 for the medium group, and 15.2 for the high income group. However, mothers of the lowest income group found the Coping Pattern II of support, esteem and stability ($M=23.1$) less helpful than the middle income group ($M=29.7$) or high income group ($M=29.0$). Further, the low income mothers used behaviors from the Coping Pattern I of family integration, cooperation and optimism less frequently ($M=37.6$) than the group of middle ($M=42.9$) or high income mothers ($M=42.8$).

Time spent in the hospital by mothers

Mothers spent varying amounts of time in the hospital with their sick child (Table 15). Although there were no significant differences in the coping scores of mothers based on the amount of time spent in the hospital, there were some suggestive trends. The mothers who spent the fewest hours with their sick child had higher scores on the family integration and cooperation Pattern I, while the mothers who stayed full time at the hospital had the lowest Pattern I support. The same mothers who spent the fewest bedside hours had the lowest scores for the social support, esteem and psychological stability Pattern II. There was virtually no

difference in the medical communication and consultation Pattern III scores.

Number of child's hospitalization

Mothers were divided into groups based on the number of times their child had been hospitalized (Table 15). There was a trend across all three coping patterns for the mothers of children hospitalized between four and nine times to have the highest scores. Mothers of children hospitalized with the greatest frequency, between 10 and 22 times, had the lowest scores across all measures. None of the scores were statistically significant.

Other children

Scores were analyzed according to whether the ill child was the only child, or whether the mother had another one or two children (Table 15). Mothers with an only child, with a chronic illness, had the highest score on the social support Pattern II, but the lowest scores on both the family integration and cooperation Pattern I and the medical consultation Pattern III. Mothers with two other children had the lowest scores on the social support Pattern II. None of the scores reached statistical significance.

Table 15

COPING HEALTH INVENTORY FOR PARENTS
DIFFERENCES BASED ON DEMOGRAPHICS

		Pattern I		Pattern II		Pattern III	
		M	(S.D.)	M	(S.D.)	M	(S.D.)
Sample	N=30	40.8	(7.8)	26.9	(8.4)	16.4	(3.7)
Sex of child							
boys	n=17	40.1	(8.4)	24.2	(7.6)	16.5	(3.3)
girls	n=13	41.7	(7.3)	30.3	(8.3)	16.2	(4.2)
		F=4.4*					
Time since dx							
< one year		30.0	(7.4)	23.8	(3.3)	15.0	(2.9)
> one year		45.0	(6.8)	27.1	(7.7)	18.0	(3.4)
> two years		40.3	(5.7)	27.6	(10.1)	15.4	(3.6)
		F=8.3***					
Marital Status							
single		33.3	(6.7)	27.1	(5.5)	16.1	(3.1)
with father		43.3	(6.6)	26.8	(10.0)	16.1	(3.9)
with stepfather		44.3	(6.0)	26.7	(4.5)	19.0	(3.6)
		F=7.0*					
Mother's Job							
housewife		40.5	(8.2)	23.8	(6.3)	16.4	(3.5)
semi-skilled		39.8	(7.2)	32.3	(8.8)	15.6	(4.4)
professional		47.0	(7.1)	40.5	(3.5)	19.5	(0.7)
		F=8.3***					
Mothers age							
18-21 yr		41.5	(8.1)	27.0	(2.9)	17.5	(4.1)
22-30 yr		40.4	(8.4)	26.5	(9.7)	16.4	(3.7)
31-42 yr		41.2	(7.4)	27.6	(7.7)	15.9	(3.6)
Annual Income							
0 -\$20,000		37.6	(9.4)	23.2	(7.4)	17.2	(4.0)
\$20-30,000		42.9	(4.3)	29.7	(9.3)	16.7	(3.2)
> \$30,000		42.8	(8.1)	29.0	(8.3)	15.2	(3.8)
In-hospital Time							
8-10 hrs		44.0	(2.6)	22.3	(14.1)	16.7	(6.7)
12-16 hrs		41.6	(7.3)	28.0	(8.1)	16.5	(3.1)
24 hrs/day		39.8	(8.7)	27.0	(7.8)	16.3	(3.6)
Number of Hosp.							
1- 3 times		40.2	(8.2)	26.2	(6.2)	16.0	(3.9)
4- 9 times		42.6	(6.3)	30.1	(8.8)	17.1	(3.7)
10-22 times		38.3	(10.4)	21.6	(9.6)	15.8	(3.2)

Table 15 continued

	Pattern I		Pattern II		Pattern III	
	M	(S.D.)	M	(S.D.)	M	(S.D.)
Sample N=30	40.8	(7.8)	26.9	(8.4)	16.4	(3.7)
Age at dx						
< 6 months	39.6	(5.3)	23.2	(9.5)	15.5	(3.1)
6 to 15 mos.	44.8	(6.0)	31.1	(8.9)	17.6	(4.3)
> 2 years	39.0	(10.4)	27.3	(5.3)	16.4	(3.7)
Other children						
none	40.1	(7.0)	30.1	(8.3)	15.9	(4.5)
one	41.0	(8.1)	25.6	(8.2)	16.4	(3.0)
two	42.0	(11.5)	22.9	(9.0)	17.7	(4.7)

* $p < .05$ ** $p < .01$ *** $p < .005$ Specific coping behaviors

Scores from each individual coping behavior from the three CHIP patterns were analyzed for variance based on the demographic variables and only significant differences are presented. The demographic variables which accounted for the greatest variation in specific coping behaviors were the length of time since the child was diagnosed with a chronic illness (Table 16) and the mother's marital status (Table 17).

Table 16

COPING HEALTH INVENTORY FOR PARENTS

Coping Behavior Differences: Time Since Diagnosis

Behavior	<i>n</i>	<i>M</i>	<i>S.D.</i>	<i>F</i>
Doing things together as a family (involving all family members)				4.6*
< one year	4	1.0	1.15	
> one year	12	2.3	1.0	
> two years	14	2.3	0.5	
Being sure prescribed home medical treatments are carried out daily				3.8*
< one year	4	1.5	1.0	
> one year	12	2.6	0.7	
> two years	14	2.4	0.6	
Talking with other parents in similar situations about their experiences				3.8*
< one year	4	1.5	1.0	
> one year	12	2.6	0.7	
> two years	14	2.4	0.6	
Talking over personal feelings and concerns with the child's father				4.1*
< one year	4	0.3	0.5	
> one year	12	2.0	0.9	
> two years	14	1.4	1.3	
Trusting the child's father to help support the mother and child				3.5*
< one year	4	0.3	0.5	
> one year	12	2.1	1.3	
> two years	14	2.0	1.4	
Building a closer relationship with the child's father				4.9*
< one year	4	0.3	0.5	
> one year	12	2.1	1.2	
> two years	14	1.9	1.0	

Note. Scores range from 3 (extremely helpful) to 0 (not helpful).

* $p < .05$

Table 17

COPING HEALTH INVENTORY FOR PARENTS

Coping Behavior Differences: Marital Status

Behavior	<i>n</i>	<i>M</i>	<i>S.D.</i>	<i>F</i>
Trust spouse (or former spouse) to help support me & my child				36.2****
single	8	0.1	0.4	
w/ father	19	2.6	0.8	
w/ stepfather	3	0.3	0.6	
Building a closer relationship with my spouse				24.1****
single	8	0.2	0.5	
w/ father	19	2.4	0.8	
w/ stepfather	3	2.0	1.0	
Talking over personal feelings and concerns with spouse				10.0****
single	8	0.2	0.7	
w/ father	19	2.0	1.0	
w/ stepfather	3	1.7	0.6	
Doing things together as a family				7.8***
single	8	1.2	1.2	
w/ father	19	2.5	0.5	
w/ stepfather	3	2.3	0.6	

Note. Scores range from 3 (extremely helpful) to 0 (not helpful).

*** $p < .005$

**** $p < .001$

Parenting Stress Index

The Parenting Stress Index was used to measure the degree of parenting-related stress of mothers with hospitalized, chronically ill children. The Child and Parent Domain scores will be reported, followed by the numerous subscales comprising each Domain. Differences in scores related to demographic variables will then be presented for each Domain.

Total scores

The scores of the sample mothers were graphed onto the PSI "Profile Sheet and Norms-Form 6" (Abidin, 1986, p.48)(Table 18). The sample scores were compared to the established norms for the Child Domain and the Parent Domain, as well as the combined Total stress score. The mean sample scores for the Child Domain ($M=70$), Parent Domain ($M=60$) and Total stress ($M=65$) scores were within the normal range of 15% to 80% (Table 19). However, variability within the sample resulted in a large percentage of mothers having individual stress scores outside the normal range. Within the Child Domain, 43% of mothers had abnormally high scores. One third of the mothers (33%) had abnormally high Parent Domain scores. Overall, 40% of the sample mothers had Total stress scores outside the normal range (Table 19).

Parenting Stress Index
Profile Sheet and Norms—Form 6
R. R. Abidin—University of Virginia

Table 18

Parents Name Study Sample N = 30 Parents Sex _____ Parents Date of Birth _____
 Childs Name _____ Childs Sex _____ Childs Date of Birth _____
 Normal Percentile range _____ Date _____

TOTAL STRESS SCORE Raw Score 234.7 S.D. Score 40.5

CHILD DOMAIN SCORE Raw Score 214 S.D. Score 27.9

Adaptability	6.7	27.9
Acceptability	3.5	13.2
Demandingness	5.5	22.4
Mood	4.3	10.4
Disrupt/Hyper	4.7	24.2
Reinforces Parent	3.6	9.4

PARENT DOMAIN SCORE Raw Score 24.7 S.D. Score 25.8

Depression	5.1	20.6
Attachment	4.0	12.3
Restic of Role	4.1	18.5
Sense of Competence	5.8	30.1
Social Isolation	4.6	14.0
Relat Spouse	5.7	18.6
Parent Health	3.5	12.6

LIFE STRESS
 (Optional Scale)

1	5	10	15	20	25	30	35	40	45	50	55	60	65	70	75	80	85	90	95	99+
131	157	170	178	188	196	201	208	214	217	221	224	228	233	239	244	249	258	267	293	320

Percentile Ranks*

1	5	10	15	20	25	30	35	40	45	50	55	60	65	70	75	80	85	90	95	99+
1	5	10	15	20	25	30	35	40	45	50	55	60	65	70	75	80	85	90	95	99+

Percentile Ranks*

1	5	10	15	20	25	30	35	40	45	50	55	60	65	70	75	80	85	90	95	99+
1	5	10	15	20	25	30	35	40	45	50	55	60	65	70	75	80	85	90	95	99+

**MOTHERS WITH HOSPITALIZED
 CHRONICALLY ILL CHILDREN**
 N = 30

*When two raw scores were equidistant from the percentile interval, the higher number was selected.

Table 19

Domain N=30	PARENTING STRESS INDEX Frequency Statistics				
	M	S.D.	Normal 15-80%	Very Low < 15%	Very High > 80%
Child Domain	70	30	50%	7%	43%
Parent Domain	60	30	57%	10%	33%
Total Stress	65	30	57%	3%	40%

Child Domain

The Child Domain subscale scores are reported in Table 20. The area of the ill child's behavior most distressing to mothers was the perception that their child was very demanding, where 47% of mothers had abnormally high scores. Other highly stressful areas where a large percentage of mothers had abnormally high scores included the child's poor adaptability to new situations (43%), the moodiness of the child (37%), difficulty with accepting the ill child's behavior (23%), and a lack of positive reinforcement of their maternal role by the child (23%). Few mothers perceived their children as excessively distractible or hyperactive (13%).

Scores were then examined to determine which area of the Child Domain carried the greatest stress for each individual mother, regardless of their actual percentile score. The six subscales were ranked in descending order of stress, with the first holding the highest stress for the greatest number of mothers, and the sixth carrying the least stress for the greatest number of mothers (Table 21). Equal scores received an equal ranking. Arbitrarily,

the first and second stressors for mothers were calculated together to determine which child stressor was the greatest for this sample population. Demandingness of the child emerged as the highest stressor, being first for 13 mothers and second for 6 mothers. The second highest stress for this sample population was stress around the child's adaptability to situations, being first for five mothers and second for seven. The child's moodiness was third, being first for six mothers and second for five. Acceptability of the child appears fourth, being only first for two mothers, but second for seven. Next, was whether the child could positively reinforce the mothers' role as parent, being first for five mothers, and second for three. Finally, distractibility or perceived hyperactivity of the child was the least stressful for most mothers, with only three mothers ranking this as the first stressor, and only two the second.

Table 20

PARENTING STRESS INDEX

Child Domain Subscale Scores, Frequency Statistics

Child Domain N=30	M	S.D.	Normal 15-80%	Very Low < 15%	Very High > 80%
Adaptability	80	28	54%	3%	43%
Acceptability	60	28	74%	3%	23%
Demandingness	85	25	50%	3%	47%
Moodiness	75	32	56%	7%	37%
Distractibility	55	26	80%	7%	13%
Role Reinforcement	65	29	77%	--	23%

Table 21

PARENTING STRESS INDEX

Subscale Ranking of Child Domain Stress
Highest to lowest individual stress

Subscale	Subscale stress frequency						n
	1st	2nd	3rd	4th	5th	6th	
Demandingness	13	6	5	3	2	1	30
Adaptability	5	7	8	5	3	2	30
Moodiness	6	5	4	6	6	3	30
Acceptability	2	7	5	8	5	3	30
Reinforces Parent	5	3	3	6	8	5	30
Distractibility	3	2	8	3	6	8	30

Note. Subjects with equal subscale scores received equal ranking, (i.e. two 1st's, etc.) resulting in uneven frequency of ranking.

Parent Domain

The Parent Domain subscale scores are reported in Table 22. There were three areas of parent functioning most distressing, where 33% of mothers had abnormally high stress scores. The areas involved worries over their competency as parents, concerns over their own personal health, and relationship problems with their spouse. Other highly stressful areas included maternal depression, social isolation, and their attachment to the child, where 23% of mothers had excessively high scores. Few mothers felt excessively restricted by the imposition of the parent role (13%).

Table 22

PARENTING STRESS INDEX

Parent Domain Subscale Scores, Frequency Statistics

Parent Domain N=30	M	S.D.	Normal 15-80%	Very Low < 15%	Very High > 80%
Depression	55	30	74%	3%	23%
Attachment	55	33	57%	20%	23%
Role Restrictions	50	26	80%	7%	13%
Competency	60	28	67%	--	33%
Social Isolation	70	29	64%	13%	23%
Spouse Relationship	70	29	60%	7%	33%
Mothers Health	70	30	60%	7%	33%

Individual scores were then calculated to determine which area in the Parent Domain carried the greatest stress for each mother. Similar to the Child Domain, the seven subscales were ranked in descending order of stress, with the first holding the highest stress for the greatest number of mothers, and the seventh carrying the least stress for the greatest number of mothers (Table 23). Again, the first and second stressors for mothers were counted together to achieve the parent stressors ranking. The subscale carrying the highest stress for the most mothers was concerns over the mother's personal health, being first for seven mothers and second for six mothers. The mother's relationship with the child's father ranked second as carrying the greatest stress, being first for six mothers and second for seven. Stress around feeling competent in the parent role ranked third, being the highest stressor for six parents, and second highest for four mothers. Close to competency stress, was stress from social

isolation, with five mothers reporting this as their highest stress, and in second place for another five mothers. The stressor ranked fifth for the sample population was depression, with five mothers indicating depression as their primary stressor, and second for another four mothers. Feeling restricted as a result of the parenting role was the primary stressor for only one mother, but the second stressor for eight. Finally, stress associated with the mother's attachment to her child was most stressful for five mothers, and second-most stressful for three mothers.

Table 23

PARENTING STRESS INDEX

Subscale Ranking of Parent Domain Stress
Highest to Lowest Individual Stress

Subscale	Subscale stress frequency							n
	1st	2nd	3rd	4th	5th	6th	7th	
Parent Health	7	6	4	4	6	3		30
Spouse Relationship	6	7	5	6	4	2		30
Competency	6	4	6	7	4	2	1	30
Social Isolation	5	5	11	1	4	3	1	30
Depression	5	4	4	7	6	2	2	30
Role Restrictions	1	8	5	7	4	3	2	30
Attachment	5	3	4	4	4	9	1	30

Note. Subjects with equal subscale scores received equal ranking, (i.e. two 1st's, etc.) resulting in uneven frequency of ranking.

Inter-relationships of PSI subscales

There was a significant relationship between the Parent and Child Domain ($r=.61$, $p < .001$). Many subscales within each Domain were inter-related. Pearson correlations are reported first for subscales of the Child Domain and then for subscales of the Parent Domain. Finally, subscales of the Child Domain which were related to subscales of the Parent Domain are presented.

Child Domain

Several of the Child Domain subscales were related to each other (Table 24). The highest stressor for mothers within this Domain, demandingness of the child, was significantly related to all other subscales, consisting of the child's adaptability to situations ($r=.61$, $p < .001$), to the mother's acceptance of the child ($r=.59$, $p < .001$), to the child's moodiness ($r=.55$, $p < .001$), to the child's positive reinforcement of the mother's role ($r=.45$, $p < .01$), and to the distractibility of the child ($r=.40$, $p < .05$). There were also relationships between the child's ability to adapt to situations and to the child's moodiness ($r=.81$, $p < .001$), level of distractibility ($r=.64$, $p < .001$), and acceptance by the mother of the child's behavior ($r=.46$, $p < .01$). Moodiness in the child was also strongly associated with the child's level of distractibility ($r=.54$, $p < .005$) and the mother's acceptance of the child ($r=.43$, $p < .05$). Acceptance by the mother was also related to whether the child could positively reinforce the mother's parent role ($r=.43$, $p < .05$).

Table 24

PARENTING STRESS INDEX

Pearson Correlations Between PSI Child Domain Subscales

	<u>Child Domain</u>				
	Adapt	Mood	Accept	Reinforce	Distract
Demand	.61****	.55****	.59****	.45**	.40*
Adapt	-	.81****	.46**	.24	.64****
Mood	-	-	.41*	.22	.54***
Accept	-	-	-	.43*	.30
Reinforce	-	-	-	-	.16

* $p < .05$
 ** $p < .01$
 *** $p < .005$
 **** $p < .001$

Parent Domain

Similar to the Child Domain, many of the Parent Domain subscales were significantly related to each other (Table 25). The mothers' concerns over their competency as parents were significantly related to nearly all other subscales with stress around social isolation ($r=.68$, $p<.001$) and depression ($r=.57$, $p<.001$) being very strongly associated, followed by worries about their personal health ($r=.55$, $p<.005$), problems with the child's father ($r=.52$, $p<.005$), and feeling restricted by virtue of their parent role ($r=.48$, $p<.01$). Complaints about the mother's personal health were also associated with social isolation ($r=.62$, $p<.001$), relationship problems ($r=.57$, $p<.005$), depression ($r=.53$,

$p < .005$), and the perception of imposed parent-role related restrictions ($r = .47$, $p < .01$). Spousal problems were strongly related to maternal role restrictions ($r = .56$, $p < .001$), as well as social isolation ($r = .49$, $p < .01$), depression ($r = .43$, $p < .05$), and concerns over attachment to the child ($r = .38$, $p < .05$). Social isolation was also associated with feelings of depression ($r = .56$, $p < .001$), worries about the attachment to the child ($r = .41$, $p < .05$), as well as the imposed role-related restrictions ($r = .40$, $p < .05$). Finally, depression was also related to concerns over attachment to the child ($r = .46$, $p < .05$), as well as feeling restricted by the parental role ($r = .43$, $p < .05$).

Table 25

PARENTING STRESS INDEX

Pearson Correlations Between PSI Parent Domain Subscales

	<u>Parent Domain</u>					
	Health	Spouse	Isolation	Depress	Restrict	Attach
Competency	.55***	.52***	.68****	.57****	.48**	.18
Health	-	.57***	.62****	.53***	.47**	.29
Spouse	-	-	.49**	.43*	.56****	.38*
Isolation	-	-	-	.56****	.40*	.41*
Depress	-	-	-	-	.43*	.46**
Restrict	-	-	-	-	-	.22

* $p < .05$ ** $p < .01$ *** $p < .005$ **** $p < .001$

Child & Parent Domain Relationships

Relationships between the subscales of the Child Domain and Parent Domain also existed and are reported in table 26. The greatest child stressor of mothers, demandingness of the child, was related to nearly every stress subscale of the Parent Domain. Problems with the mother's personal health was related to nearly every stress subscale of the Child Domain. Concerns over parental competency was also strongly associated with stress over acceptance of the child's behavior.

Table 26

PARENTING STRESS INDEX

Correlations Between PSI Child and Parent Domain Subscales

Parent Domain	Child Domain					
	Demand	Adapt	Mood	Accept	Reinforce	Distract
Competency	.61****	.33	.34	.64****	.30	.18
Health	.61****	.56****	.52***	.44**	.35*	.25
Spouse	.58****	.27	.36*	.34	.32	.30
Isolation	.54***	.41*	.30	.39*	.30	.30
Depressed	.51***	.18	.24	.37*	.18	.12
Restrict	.54***	.29	.26	.15	.01	-.16
Attach	.30	.24	.18	.11	.42*	.18

* $p < .05$

** $p < .01$

*** $p < .005$

**** $p < .001$

Influence of Demographic Variables on PSI Scores

Variances in the PSI scores arose from several demographic variables. Nine demographic variables are examined in relationship to the PSI Domains and subscale scores. Scores based on demographics are first presented for the Child Domain, Parent Domain and Total stress score (Table 27). Subscale score differences related to demographics are then presented for the Child Domain (Table 28) and the Parent Domain (Table 29).

The nine demographic variables consist of the mothers' age, her marital status, the annual family income, her employment status, the age the child was diagnosed with the chronic illness, the length of time the mother had dealt with the child's diagnosis, the presence of other siblings, the distance the mother lived from the hospital, and the number of hours the mother spent with her child in the hospital. Demographic variables which resulted in no observable differences in the PSI scores included the sex of the child, the mother's ethnic background, the father's employment, the child's diagnosis or diagnostic group, and the number of times the child had been previously hospitalized.

Domain and Total Stress Scores

This section reports the influence of specific demographic variables on the Child Domain, Parent Domain, and Total stress scores (Table 27). Few scores are statistically significant. However, considering the small sample size, interesting trends that may have clinical significance are reported.

Mother's age.

Although not statistically significant, the Child Domain stress score was slightly elevated above normal only for the youngest group of mothers aged 18 to 21 years, with a mean score of 81. Mothers between 22 and 30 years had the lowest score of 61, and mothers between 31 and 42 years had a mean score of 69.

The Parent Domain scores also suggested that the youngest mothers were under the highest stress ($M=79$) compared to mothers aged 22 to 30 ($M=52$) or the older mothers ($M=66$). However, these scores were not statistically significant.

Considering the Child Domain and Parent Domain together, only the youngest mothers had their total stress score elevated above normal, at 82. The older group of mothers followed, with a mean score of 75, and the medium age group of mothers had the least overall stress ($M=56$).

Marital status.

The Child Domain stress score was lowest for women who lived with the child's father ($M=59$). Women who lived with a man who was not the child's father had severely high stress ($M=95$). The stress level of single mothers was in-between ($M=70$).

Stress related to Parent Domain functioning approached statistical significance for mothers based on their living situation ($F=2.7$, $p<0.08$, $df2$). Intact parents had the lowest stress score ($M=51$) compared to the single mothers ($M=66$).

Similar to the Child Domain, the mothers who lived with the child's stepfather had extremely high stress ($M=90$).

Overall, the total stress score was significant for mothers based on their marital status ($F=3.8$, $p<0.05$, $df2$). Mothers living with the child's stepfather had the highest overall stress ($M=96$), followed by single mothers ($M=77$), and mothers who lived with the child's father had the lowest overall stress ($M=55$).

Income.

There were no differences in the scores of mothers based on their annual family income. None of the groups had abnormal scores in either the Child Domain, Parent Domain, or Total stress score.

Mother's employment.

Since the majority of the mothers were housewives, without outside employment, scores were not statistically significant. However, some interesting score differences were noted.

Mothers who stayed home full-time with their chronically ill children scored the lowest Child Domain stress ($M=63$). Mothers who worked outside the home at semi-skilled jobs scored somewhat higher ($M=70$). However, the mothers who were employed in professional positions were on the verge of extremely high stress related to their child ($M=80$).

Stress related to parent functioning was much lower for mothers with semi-skilled employment ($M=46$) compared to the full-time housewives ($M=62$) or the mothers with professional

employment ($M=70$). Again, the professional mothers scored the highest stress.

Overall, mothers who were either housewives or had semiskilled employment had nearly the same stress ($M=64$, $M=63$). The mothers with professional employment had somewhat higher combined stress ($M=74$).

Age of child at diagnosis.

Child related stress was lowest for mothers whose children were "normal" until after their second birthday ($M=59$) or who were diagnosed under six months of age ($M=63$). However, the mothers of children who were diagnosed during late infancy or early toddlerhood had quite high child-related stress ($M=80$).

Mothers of children diagnosed with the chronic illness under six months of age had the least stress around their parent functioning ($M=48$), followed by the mothers of children diagnosed after the second birthday ($M=63$). Again, mothers of children diagnosed between six and fifteen months had somewhat higher stress ($M=69$).

Mothers of children diagnosed under six months of age had the lowest overall stress ($M=57$). Mothers of children diagnosed over two years of age were slightly higher stressed ($M=65$), and the mothers of children diagnosed between six and fifteen months had the highest stress ($M=74$).

Time since diagnosis.

Mothers of children who had known about their child's

diagnosis of a chronic illness for greater than one or two years had little differences in their child stress score ($M=63$, $M=67$). The mothers of children diagnosed within the past year had higher stress ($M=70$).

Stress related to parent functioning was also higher for mothers of children diagnosed for less than a year ($M=76$). The stress of mothers with children diagnosed over one year ($M=57$) or over two years was very similar ($M=56$).

The overall combined stress was very high for mothers who had known about their child's long-term illness for less than one year ($M=87$). The stress of mothers with children diagnosed over one year ($M=59$) was slightly lower than the stress of mothers with children diagnosed over two years of time ($M=63$). Stresses related to the child, as well as to the mother's functioning in her parent role, seem to be accentuated during the first year after the diagnosis of a long-term chronic childhood illness.

Other siblings.

Mothers who had no children other than the chronically ill youngster reported the highest child-related stress ($M=81$). Mothers with one other child seemed to have the lowest stress ($M=57$), with mothers of two other children reporting slightly higher stress ($M=63$).

Fewer differences were apparent in the parent functioning stress scores of mothers depending on whether or not there was another child in the family compared to the child domain. Mothers

with only the chronically ill child scored 62, while mothers with one other child scored 57, and those with two other children scored 58.

The overall stress of mothers with one or two other children was the same ($M=60$). Mothers who had only the chronically ill child had higher stress, but still within the normal stress range ($M=73$).

Distance.

There were no differences in the Domain scores for mothers based on the distance they lived from the hospital. No discernible trends were noted related to living close or far from the hospital.

Hours in the Hospital.

Mothers who spent the least time with their ill and hospitalized child reported the highest child-related stress ($M=75$). Mothers who spent large amounts of time at the hospital, between 12 to 16 hours per day had the lowest child-related stress ($M=57$). Those who roomed-in with their child by spending 24 hours per day in the hospital reported somewhat higher child-related stress ($M=69$).

Again, the mothers who spent the fewest number of hours with their hospitalized child had the highest parent functioning related stress ($M=68$), followed by the mothers who were rooming-in with their ill child ($M=64$). Mothers who spent large amounts of time, but were also able to leave for 8 to 12 hours each day had

the lowest parent-functioning stress ($M=46$).

Mothers who spent the least time at the hospital ($M=73$) had slightly higher overall stress compared to the mothers who spent the most time in the hospital with their child ($M=71$). The mothers who spent between 12 and 16 hours each day with their hospitalized child had the lowest overall stress ($M=50$).

Table 27

PARENTING STRESS INDEX
DIFFERENCES IN DOMAIN AND TOTAL SCORES
BASED ON DEMOGRAPHICS

Means and Standard Deviations

	Child Domain Score		Parent Domain Score		Total Stress Score	
	(M)	(S.D.)	(M)	(S.D.)	(M)	(S.D.)
Sample N=30	70	(30)	60	(30)	65	(30)
Mothers age						
18-21 yr	81	(34)	79	(32)	82	(34)
22-30 yr	61	(29)	52	(29)	56	(31)
31-42 yr	69	(31)	66	(27)	75	(26)
Marital Status						
Single	70	(29)	66	(33)	77	(31)
With Father	59	(30)	51	(28)	55	(29)
With Stepdad	95	(04)	90	(09)	96	(05)
			$F=2.7c$		$F=3.8*$	
Annual Income						
\$0 - 20,000	58	(34)	59	(30)	62	(34)
\$20-30,000	73	(27)	67	(31)	74	(28)
> \$30,000	72	(28)	55	(30)	62	(30)
Mothers Job						
Housewife	63	(33)	62	(30)	64	(33)
Semi-skilled	70	(23)	46	(29)	63	(25)
Professional	80	(14)	70	(28)	74	(35)

Table 27 Continued

	Child Domain		Parent Domain		Total Stress	
	(M)	(S.D.)	(M)	(S.D.)	(M)	(S.D.)
Sample N=30	70	(30)	60	(30)	65	(30)
Age at Dx.						
< 6 mos.	63	(27)	48	(27)	57	(30)
6-15 mos.	80	(30)	69	(26)	74	(30)
> 2 yrs.	59	(32)	63	(34)	65	(33)
Time Since Dx.						
< one year	70	(31)	76	(25)	87	(12)
> one year	63	(33)	57	(35)	59	(33)
> two years	67	(29)	56	(26)	63	(31)
Siblings						
None	81	(20)	62	(33)	73	(29)
One	57	(33)	57	(30)	60	(32)
Two	63	(25)	58	(32)	60	(34)
Distance						
<30 miles	61	(31)	62	(31)	64	(30)
40-90 miles	72	(27)	62	(26)	70	(30)
150-300 miles	62	(38)	39	(38)	50	(39)
Hosp hours						
8-10 hrs	75	(39)	68	(42)	73	(46)
12-16 hrs	57	(29)	46	(26)	50	(25)
24 hrs	69	(30)	64	(30)	71	(30)

Note. c = $p < .08$

* $p < .05$

Demographics and Child Domain Subscales

This section discusses the score differences in the six subscales of the Child Domain and the seven subscales of the Parent Domain. Only the scores which were statistically significant, abnormally high, or those with obvious trends will be presented. The Child Domain subscale scores are presented in Table 28 and the Parent Domain subscale scores are presented in Table 29.

Mother's age.

There were no significant differences in the child stress subscales related to mothers age. However, the younger and older mothers tended to have higher stress scores than the mothers between 22 and 30 years. Also, the younger mothers had abnormally high stress related to the child's adaptability to situations ($M=86$), and they tended to see their children as more distractible or hyperactive. The oldest mothers tended to perceive their child as the most moody (Table 28).

Stress around feeling competent in the parental role approached statistical significance for mothers based on their ages ($F=2.7$, $p<.08$, $df\ 2$). The competency stress exceeded the normal range for only the youngest group of mothers ($M=81$), with the older mothers having moderate stress ($M=66$), and the middle group of mothers with the lowest stress ($M=50$).

Overall, the youngest mothers tended to have the highest

stress scores on each of the Parent Domain subscales, followed by the older mothers. Mothers between 22 and 30 had the lowest stresses across the measures (Table 29).

Marital status.

The only subscale of the Child Domain with statistically significant scores was the acceptability subscale ($F=3.7$, $p<.05$, $df\ 2$). Mothers who lived with the child's stepfather had abnormally high stress with accepting their child ($M=85$). Single mothers had lower stress ($M=74$), and mothers in intact parent relationships had the lowest stress for child acceptability ($M=51$).

Mothers who lived with the child's stepfather also had excessively high stress around the perception of their child's demandingness ($M=94$), adaptability ($M=93$), and moodiness ($M=80$). Single mothers tended to see their child as less moody ($M=54$) compared to others (Table 28).

Only the stress subscale related to parental role competency was statistically significant for mothers based on their marital status ($F=3.5$, $p<.05$, $df\ 2$). Women who lived with a man who was not the child's father had abnormally high competency stress ($M=90$) compared to single mothers ($M=67$) or mothers who lived with the child's father ($M=50$).

Mothers who lived with the child's stepfather also had abnormally high stress scores related to social isolation ($M=90$), their own physical health ($M=90$), and their relationship with

their spouse ($M=82$). Again, mothers who lived with the child's father had lower stress across all stress measures compared to the single mothers, or the women living with the child's stepfather (Table 29).

Income.

Mothers with the highest family income perceived their child as most demanding, with a mean score that exceeded the normal range ($M=81$). The women with the lowest income had less stress related to the demandingness of their child ($M=71$). The highest income mothers also were the most stressed regarding their perception of their child's adaptability, moodiness, and distractibility (Table 28).

Mothers with the highest annual incomes tended to have the lowest stress scores around maternal depression, competency as parents, social isolation, personal physical health problems, and spouse relationship problems. The mothers with the lowest income had the least stress with attachment to their child and felt less restricted by the parental role (Table 29).

Mothers Employment.

Mothers who were full-time housewives were less stressed by the demandingness of their child ($M=71$) compared to mothers who worked, either those professionally employed ($M=82$), or those with semi-skilled jobs ($M=83$). Full-time housewives also found their child was more acceptable ($M=56$) compared to working mothers, both semi-skilled ($M=69$) and professionally employed ($M=75$). The women

with professional employment tended to have the highest stress related to their child positively reinforcing their role as parent ($M=77$) compared to the housewives ($M=58$) or women with semi-skilled jobs ($M=51$) (Table 28).

Differences in stress over attachment to the ill child approached statistical significance ($F=3.0$, $p<.06$, $df\ 2$) for mothers based on their employment status. Women who were professionally employed had severely high stress regarding their attachment to their child ($M=97$) compared to housewives ($M=46$) or mothers with semi-skilled jobs ($M=36$). The only other stress area with abnormally high stress scores was the spouse relationship stress, where professionally employed women were quite stressed ($M=82$) compared to housewives ($M=63$) or women with semi-skilled jobs ($M=53$) (Table 29).

Age at child's diagnosis.

There were significant differences in the distractibility stress for mothers based on how old the children were at diagnosis of the chronic illness ($F=3.4$, $p<.05$, $df\ 2$). Mothers had quite low stress if the child was diagnosed under six months of age ($M=48$), or over two years of age ($M=42$). However, if the child was diagnosed in late infancy to early toddlerhood between six and fifteen months of age, the mothers found their children much more distractible or hyperactive ($M=70$). When diagnosed in that age range, the mothers also were much more stressed by their child's demandingness ($M=84$) compared to mothers of children diagnosed as

small infants ($M=72$) or after two years of age ($M=71$). Mothers of children diagnosed in that middle range also tended to have the highest stress with their child's adaptability and moodiness (Table 28).

Attachment to the ill child was significant for mothers based on the child's age at diagnosis ($F=3.6$, $p<.05$, $df\ 2$). Mothers of children diagnosed with a long-term illness less than six months of age had very low stress with attachment to the child ($M=28$). Mothers of children diagnosed late, over two years of age, had mild stress ($M=54$) which varied little for mothers of children diagnosed in late infancy or early toddlerhood ($M=64$). Mothers of early diagnosed children also tended to be less depressed, had less sense of parental role-related restrictions, reported less concerns with their personal health, had fewer problems with their spouse and were somewhat less stressed over social isolation compared to the other mothers.

Time since child's diagnosis.

The length of time since the child was diagnosed with the chronic illness approached significance for mothers' stress around the acceptability of the child for the mother ($F=3.2$, $p<.06$). The mothers who knew about their child's diagnosis for less than one year were considerably stressed ($M=87$) compared to mothers whose child had been diagnosed for between one and two years ($M=50$) or greater than two years ($M=62$).

Children were also seen as having more difficulties with

adaptability ($M=86$) and more demanding ($M=81$) by mothers when diagnosed less than a year (Table 28).

Mothers of children who were diagnosed less than one year had higher stress in every area of the parent functioning subscales compared to the mothers of children diagnosed between one and two years, or over two years. Further, the stress of these mothers exceeded the normal levels for social isolation ($M=85$), role competency ($M=84$) and was borderline for their own personal health problems ($M=80$) (Table 29).

Siblings.

Mothers who had no other children than the chronically ill child were significantly more stressed around perceiving their child as highly distractible ($M=69$) compared to mothers with one other child ($M=43$) or two other children ($M=45$) ($F=4.0$, $p<.05$, df 2). Mothers with an only child also found the child excessively demanding ($M=86$) compared to mothers with other children ($M=67$, $M=76$). However, mothers with two other children were very stressed regarding the adaptability ($M=82$) of the ill child, compared to mothers of an only child ($M=79$) or mothers with one other child ($M=63$). In general, mothers without other children tended to have higher stress levels on all the subscales regarding the perception of their child compared to mothers with other children (Table 28).

There were no appreciable differences or trends regarding parent functioning stress for mothers with or without other

children (Table 29).

Distance from the hospital.

There were no appreciable differences in stress of mother's perception of their child based on the distance the mother lived from the hospital (Table 28).

There was significantly varying amounts of stress for mothers depending on whether they lived over 150 miles from the hospital ($M=30$), or much closer ($M=67$) ($F=3.2$, $p<.05$, $df\ 2$). Mothers who lived quite far from the hospital tended to have lower stress on the parent functioning subscales compared to mothers who lived closer (Table 29).

Hours in hospital.

Mothers who spent only between eight and ten hours each day at the hospital reported their child as excessively demanding ($M=91$) compared to mothers who roomed-in with their ill child ($M=77$) or those mothers who spent between twelve and sixteen hours each day ($M=65$). The mothers who spent the fewest hours also tended to have higher stress levels concerning their perception of their child's adaptability, distractibility, and the acceptability of their child compared to mothers who spent more time with their hospitalized child (Table 28).

There was a relationship between the number of hours spent by mothers with their hospitalized child, and their own personal physical health complaints ($F=3.0$, $p<.05$, $df\ 2$). Mothers who spent the fewest hours with their hospitalized child reported

excessively high personal health problems ($M=83$). Mothers who roomed-in with their child had much lower health problems ($M=67$), and the mothers who spent between 12 and 16 hours each day with their child had the lowest degree of health problems ($M=41$) (Table 29).

TABLE 28
PARENTING STRESS INDEX
CHILD DOMAIN STRESSES AND DEMOGRAPHICS

	Adaptability (M) (S.D.)		Acceptability (M) (S.D.)		Demandingness (M) (S.D.)	
Sample N=30	80	(28)	60	(28)	85	(25)
Mothers' Age						
18-21 yr	86	(24)	68	(37)	77	(44)
22-30 yr	66	(28)	54	(29)	73	(23)
31-42 yr	72	(28)	71	(16)	76	(20)
Marital Status						
Single	78	(21)	74	(25)	76	(31)
With Father	63	(29)	51	(26)	71	(23)
With Stepdad	93	(07)	85	(21)	94	(08)
			$F=3.7*$			
Annual Income						
\$0 - 20,000	68	(32)	59	(30)	71	(24)
\$20-30,000	66	(26)	66	(27)	77	(29)
> \$30,000	78	(23)	55	(29)	81	(22)
Mothers Job						
Housewife	71	(31)	56	(31)	71	(27)
Semi-skilled	74	(15)	69	(19)	83	(17)
Professional	50	(00)	75	(07)	82	(24)
Age at Dx.						
< 6 mos.	70	(22)	60	(26)	72	(28)
6-15 mos.	76	(29)	57	(31)	84	(23)
> 2 yrs	66	(32)	63	(29)	71	(23)
Time Since Dx.						
< one year	86	(15)	87	(18)	81	(14)
> one year	70	(32)	50	(25)	75	(24)
> two years	66	(25)	62	(28)	72	(28)
			$F=3.2a$			
Siblings						
None	79	(22)	72	(19)	86	(17)
One	63	(30)	57	(31)	67	(27)
Two	82	(03)	40	(26)	76	(22)

Distance					
<30 miles	64	(31)	60	(25)	73 (23)
40-90 miles	76	(21)	63	(30)	80 (26)
150-300 miles	74	(31)	55	(37)	66 (31)
Hosp. Hours					
8-10 hrs	80	(26)	72	(36)	91 (25)
12-16 hrs	67	(27)	53	(27)	65 (30)
24 hrs	70	(29)	62	(27)	77 (22)

Note. a = $p < .06$

* $p < .05$

Table 28, continued

	Child Domain, PSI					
	Moodiness		Distractibility		Role Reinforcement	
	(M)	(S.D.)	(M)	(S.D.)	(M)	(S.D.)
Sample N=30	75	(32)	55	(26)	65	(29)
Mothers' Age						
18-21 yr	67	(36)	70	(24)	64	(35)
22-30 yr	54	(32)	48	(21)	57	(29)
31-42 yr	73	(31)	52	(36)	56	(30)
Marital Status						
Single	54	(35)	55	(23)	68	(33)
With Father	60	(32)	48	(26)	52	(25)
With Stepdad	80	(26)	68	(38)	63	(42)
Annual Income						
\$0 - 20,000	54	(33)	54	(29)	47	(28)
\$20-30,000	62	(33)	52	(28)	57	(28)
> \$30,000	68	(34)	56	(17)	51	(22)
Mothers Job						
Housewife	61	(33)	51	(28)	58	(29)
Semi-skilled	63	(30)	54	(24)	51	(29)
Professional	45	(42)	57	(32)	77	(31)
Age at Dx.						
< 6 mos.	63	(28)	48	(25)	61	(21)
6-15 mos.	73	(29)	70	(29)	57	(34)
> 2 yrs	49	(37)	42	(18)	54	(34)

$F=3.4*$

Time Since Dx.

< one year	75	(33)	40	(24)	65	(38)
> one year	47	(34)	57	(24)	48	(28)
> two years	68	(28)	51	(29)	63	(26)

Siblings

None	72	(29)	69	(19)	73	(27)
One	54	(35)	43	(27)	50	(28)
Two	60	(25)	45	(17)	47	(18)

F=4.0*

Distance

<30 miles	53	(31)	50	(28)	56	(29)
40-90 miles	66	(31)	59	(24)	58	(29)
150-300 miles	70	(41)	37	(24)	60	(33)

Hosp. Hours

8-10 hrs	58	(38)	63	(25)	47	(42)
12-16 hrs	55	(30)	51	(29)	54	(17)
24 hrs	64	(34)	50	(26)	61	(32)

* $p < .05$

Table 29

PARENTING STRESS INDEX
PARENT DOMAIN STRESSES AND DEMOGRAPHICS

	Depression (M) (S.D.)		Attachment (M) (S.D.)		Role Restriction (M) (S.D.)	
Sample N=30	55	(30)	55	(33)	50	(26)
Mothers' Age						
18-21 yr	61	(38)	44	(17)	67	(10)
22-30 yr	47	(30)	42	(36)	46	(26)
31-42 yr	62	(29)	61	(32)	53	(30)
Marital Status						
Single	62	(34)	58	(37)	58	(28)
With Father	47	(29)	43	(34)	45	(26)
With Stepdad	65	(28)	45	(17)	68	(13)
Annual Income						
\$0 - 20,000	61	(20)	42	(33)	47	(28)
\$20-30,000	52	(34)	47	(32)	57	(28)
> \$30,000	44	(29)	60	(36)	51	(22)
Mothers Job						
Housewife	55	(32)	46	(33)	50	(26)
Semi-skilled	51	(32)	36	(29)	50	(22)
Professional	40	(07)	97	(03)	55	(50)
F=3.0a						
Age at Dx.						
< 6 mos.	39	(28)	28	(16)	42	(27)
6-15 mos.	63	(30)	64	(35)	55	(26)
> 2 yrs	60	(29)	54	(38)	56	(25)
F=3.6*						
Time Since Dx.						
< one year	74	(26)	62	(25)	67	(13)
> one year	55	(33)	49	(40)	44	(27)
> two years	47	(28)	41	(30)	51	(27)
Siblings						
None	62	(28)	42	(30)	44	(24)
One	48	(31)	52	(37)	51	(28)
Two	50	(40)	37	(27)	68	(23)

Distance					
<30 miles	57	(30)	58	(40)	52 (28)
40-90 miles	53	(33)	36	(18)	51 (27)
150-300 miles	40	(28)	45	(40)	45 (23)
Hosp. Hours					
8-10 hrs	62	(41)	38	(35)	50 (40)
12-16 hrs	36	(21)	37	(29)	42 (18)
24 hrs	60	(31)	54	(35)	55 (28)

Note. a = $p < .06$

* $p < .05$

Table 29, continued

	Parent Domain, PSI							
	Competency		Isolation		Spouse		Health	
	(M)	(S.D.)	(M)	(S.D.)	(M)	(S.D.)	(M)	(S.D.)
Sample N=30	60	(28)	70	(29)	70	(29)	70	(30)
Mothers' Age								
18-21 yr	81	(18)	78	(36)	76	(11)	76	(37)
22-30 yr	50	(28)	57	(28)	53	(29)	55	(31)
31-42 yr	66	(26)	61	(29)	76	(29)	66	(23)
	F=2.7c							
Marital Status								
Single	67	(21)	62	(34)	72	(21)	66	(34)
With Father	50	(29)	56	(27)	54	(32)	54	(28)
With Stepdad	90	(05)	90	(09)	82	(10)	90	(09)
	F=3.5*							
Annual Income								
\$0 - 20,000	58	(28)	66	(28)	63	(24)	69	(30)
\$20-30,000	63	(26)	63	(32)	77	(26)	61	(26)
> \$30,000	57	(34)	57	(26)	49	(31)	47	(34)
Mothers Job								
Housewife	60	(28)	64	(29)	63	(30)	67	(29)
Semi-skilled	59	(34)	49	(33)	53	(26)	47	(29)
Professional	45	(28)	65	(07)	82	(24)	50	(42)
Age at Dx.								
< 6 mos.	61	(25)	54	(32)	49	(33)	54	(26)
6-15 mos.	52	(36)	67	(26)	67	(23)	69	(30)
> 2 yrs	61	(28)	63	(29)	71	(27)	62	(34)

Time Since Dx.

< one year	84	(09)	85	(10)	79	(09)	80	(21)
> one year	52	(29)	59	(31)	55	(30)	61	(34)
> two years	57	(28)	55	(29)	63	(31)	55	(28)

Siblings

None	63	(28)	58	(35)	61	(29)	66	(32)
One	56	(29)	61	(28)	62	(31)	58	(30)
Two	60	(33)	70	(26)	62	(31)	60	(32)

Distance

<30 miles	56	(28)	67	(28)	67	(25)	60	(33)
40-90 miles	68	(25)	61	(25)	67	(28)	65	(25)
150-300 miles	39	(35)	38	(42)	30	(34)	54	(38)

 $F=3.2^*$

Hosp. Hours

8-10 hrs	72	(40)	58	(28)	60	(36)	83	(16)
12-16 hrs	57	(25)	54	(33)	51	(24)	41	(32)
24 hrs	57	(29)	65	(28)	68	(30)	67	(26)

 $F=3.9^*$

Note. c = $p < .08$

* $p < .05$

Relationships between Stress and Coping

Levels of mothers' stress were compared to their coping behaviors used to manage family life when their chronically ill child was hospitalized. Correlations between the PSI Child Domain and the three Coping Patterns of the CHIP are presented, followed by correlations between the PSI Parent Domain and the CHIP Coping Patterns. Analysis of low, normal, and high PSI stress scores compared to the three CHIP Coping Patterns using Chi-square are then discussed.

CHIP Coping Patterns and PSI Domains

PSI Domains and CHIP

The three Coping Patterns of the CHIP were correlated with the Child Domain, Parent Domain, and Total stress scores of the PSI. No significant relationships amongst the measures were found (Table 30).

Table 30

RELATIONSHIPS BETWEEN STRESS AND COPING

<u>CHIP</u> Coping Patterns	Child Domain	<u>PSI</u> Parent Domain	Total Stress
Pattern I	-.10 $p < .61$	-.31 $p < .10$	-.27 $p < .15$
Pattern II	.21 $p < .27$	-.03 $p < .86$	.09 $p < .64$
Pattern III	.01 $p < .98$	-.13 $p < .49$	-.06 $p < .76$

PSI Child subscales and CHIP Patterns

The six subscales of the Child Domain were compared to the three Coping Patterns of the CHIP. The stress subscale, acceptability of the child, was inversely related to Coping Pattern I, family integration, cooperation and optimism ($r = -.38$, $p < .04$). This means that when there is high stress associated with accepting the child, the coping behaviors related to integrating a cooperative family life or an maintaining an optimistic outlook become less useful or helpful to mothers in helping them cope. The stress subscale of degree of distractibility or hyperactivity of the child may possibly be related to Coping Pattern II, social support, self-esteem and emotional stability ($r = .34$, $p < .07$). Although not significant, there was a tendency to suggest that how the mother perceives the activity level of her child may influence her use of social support and how she feels about herself. None of the other areas of stress associated with the mother's perception of her child were related to the coping patterns (Table 31).

PSI Parent subscales and CHIP Patterns

The seven subscales of the Parent Domain were compared to the three Coping Patterns of the CHIP. The level of mothers' depression was inversely related to Coping Pattern I, family integration, cooperation and optimism ($r = -.35$, $p < .05$). This suggests that the higher the mothers' depression, the less helpful were her efforts to maintain the family, and be optimistic.

Conversely, mothers who were not depressed, found coping efforts directed toward family life and a positive outlook to be quite helpful.

Another area of mothers' stress related to coping efforts involved the sense of maternal competence in the parental role. Competency was strongly and inversely related to the Coping Pattern I ($r = -.45$, $p < .01$). Similar to depression, when mothers were quite distressed over their ability to parent the hospitalized, chronically ill child, efforts directed towards maintaining family life were not helpful. Yet, when mothers felt more confident of their ability, family integration and fostering an optimistic outlook were much more useful. None of the other areas of stress associated with the mother's functioning were related to the coping pattern (Table 32).

Table 31

RELATIONSHIPS BETWEEN STRESS AND COPING
CHIP and Child Domain Subscales

CHIP	PSI Child Domain					
	Adapt	Accept	Demand	Mood	Distract	Reinforce
Pattern I	-.12 $p < .53$	-.38* $p < .04$	-.16 $p < .41$	-.14 $p < .47$	.16 $p < .39$	-.22 $p < .23$
Pattern II	.11 $p < .56$	.11 $p < .56$	.13 $p < .49$	.07 $p < .72$	.34 $p < .07$	.08 $p < .67$
Pattern III	.01 $p < .95$	-.28 $p < .13$	.13 $p < .49$	-.16 $p < .40$	.21 $p < .23$	-.19 $p < .31$

* $p < .05$

Table 32

RELATIONSHIPS BETWEEN STRESS AND COPING
CHIP and Parent Domain Subscales

CHIP	PSI Parent Domain						
	Depress	Attach	Restrict	Competency	Isolation	Spouse	Health
Pattern I	-.35* $p < .05$	-.05 $p < .77$	-.23 $p < .23$	-.45* $p < .01$	-.28 $p < .14$	-.28 $p < .27$	-.21 $p < .27$
Pattern II	-.01 $p < .98$	.22 $p < .25$	.02 $p < .92$	-.22 $p < .23$	-.23 $p < .22$	.15 $p < .44$	-.05 $p < .79$
Pattern III	-.12 $p < .52$	-.13 $p < .49$	.05 $p < .80$	-.26 $p < .17$	-.01 $p < .95$	.02 $p < .90$	-.02 $p < .91$

* $p < .05$

PSI Stress scores and CHIP Coping Patterns

The stress scores of mothers were separated into groups of very low stress scores, stress within the normal score ranges, and abnormally high stress scores. The low, normal, and high stress scores were contrasted with the scores on three CHIP Coping Patterns. Since coping scores have been shown to be higher with high-conflict families under greater stress (McCubbin, et al, 1983), mothers demonstrating high stress should have coping scores higher than the established reference mean scores. Yet, mothers with higher stress scores generally had lower coping scores compared to mothers under lower stress (Table 33).

Child Domain and CHIP.

Individual analysis of Child Domain stress and coping scores were as follows for Coping Pattern I, family integration, cooperation and optimism. Two mothers had very low Child Domain stress ($M=10$) and had Coping Pattern I scores slightly below the reference mean (39.5). Half of the mothers ($n=15$) had both stress scores ($M=49$) and Coping Pattern I scores ($M=42.2$) within the normal range. However, there were 13 mothers with abnormally high Child Domain scores ($M=94$), and whose Coping Pattern I scores dropped below the reference mean (39.4) (Table 33).

The comparison of stress and coping scores related to Coping Pattern II, social support, self-esteem, and emotional stability, were similar. The two mothers with low child stress had low coping scores below the reference mean (20.5). The 15 mothers with normal child stress scores ($M=49$) had coping scores very close to the reference mean (27.9). Yet again, the 13 mothers with abnormally high child stress scores ($M=94$) scored the lowest on the coping measure falling below the reference mean ($M=26.6$) (Table 33).

Only on the Coping Pattern III of medical consultation and communication, did the mothers regardless of their stress level, score above the reference mean. Coping efforts associated with this coping pattern was felt to be most helpful for the sample as a whole. However, once again, the mothers with the abnormally high stress had the lowest coping score on this pattern (Table 33).

Table 33

RELATIONSHIPS BETWEEN STRESS AND COPING

PSI Stress Scores			CHIP Coping Scores					
			Pattern I norm 40		Pattern II norm 28		Pattern III norm 15	
	(M)	(n)	(M)	(S.D.)	(M)	(S.D.)	(M)	(S.D.)
Child Domain								
Low	10%	2	39.5	7.8	20.5	3.5	17.0	2.8
Normal	49%	15	42.2	2.1	27.9	10.4	16.5	3.8
High	94%	13	39.4	5.9	26.6	5.8	16.1	3.8
Parent Domain								
Low	10%	3	42.9	8.9	31.3	5.5	15.2	3.0
Normal	48%	16	41.6	7.4	25.8	10.2	17.3	3.5
High	93%	11	39.0	8.6	27.2	5.8	15.4	4.0
Total Stress								
Low	10%	1	51.7	0.0	26.0	0.0	18.7	0.0
Normal	45%	17	42.4	7.3	27.1	10.2	16.7	3.5
High	97%	12	37.5	7.6	26.6	5.8	15.8	4.0

Note. Scores not statistically significant

Parent Domain and CHIP.

The analysis of Parent Domain stress and coping patterns were quite similar to the Child Domain findings. There were three mothers with very low parent functioning stress scores ($M=10$), but who had rather high Coping Pattern I scores (42.9). The 16 mothers under a normal degree of parenting stress ($M=48$) had normal Coping Pattern I scores above the reference norm (41.6). However, there were 11 mothers with abnormally high parenting stress ($M=93$), and this group had the lowest score on Coping Pattern I (39.0), falling below the normal reference mean (Table 33).

The comparison of coping scores from Pattern II, social support, self esteem and emotional stability, to Parent Domain stress scores were somewhat different than Pattern I comparisons. The mothers with the least stress concerning their parent functioning had the highest coping scores (31.1), well above the reference mean. Mothers under a moderate, but normal amount of parent functioning stress, actually scored the lowest coping score in Pattern II (25.8), falling well below the normal reference. The mothers under abnormally high parent functioning stress scored lower than the reference mean (27.2). Why the mothers under a normal amount of stress scored the lowest on this coping pattern remains unclear (Table 33).

Consistent with the helpful focus of the Coping Pattern III, medical communication and consultation, for the entire sample, was that all three stress groups of mothers scored above the reference norm. In this case, the mothers under moderate, but normal parent functioning stress, scored the highest (17.3) on Coping Pattern III compared to mothers under very low parent functioning stress (15.2) or abnormally high parent functioning stress (15.4) (Table 33).

Total stress and CHIP.

The cumulative stress for mothers arising from both perception of the child characteristics measured by the Child Domain, as well as stress around functioning in the parent role as measured by the

Parent Domain was also compared to the three Coping Patterns of the CHIP. The total parenting stress scores and coping efforts reinforced the finding that when stress gets abnormally high, coping efforts falter. Since only one mother fell into the very low stress category, comparison of only the mothers under normal overall stress to mothers under abnormally high overall stress seems more pertinent. The mothers under the abnormally high stress had much lower coping scores than the mothers under a moderate amount of parenting stress (Table 33). Further, individual analysis of the mothers with the most extreme stress scores revealed that many had the absolutely lowest coping scores of the entire group.

Summary

This research study focused on 30 mothers with hospitalized, chronically ill young children. Mothers came from a variety of ethnic backgrounds, with a diversity of ages, and varying socioeconomic status. Some mothers had no other children, others had one or at the most two. Many mothers lived with the child's father, but some were single, and some lived with a man unrelated to the hospitalized child. Their children had a variety of chronic illnesses, including heart disease, pulmonary problems, leukemia, cancer, gastrointestinal disorders and musculoskeletal disease.

Mothers of children with similar developmental status were included in the study. The toddler and preschool children were

considered intellectually normal, but at risk for delay related to their ongoing physical illness. The child's chronic illness imposed an increased care demand on the mother when the mothers were confronted with caring for their children in the hospital. Hospitalization was a repeated event for the overwhelming majority of the mothers. Mothers struggled with meeting the needs of their hospitalized child as well as the needs of the rest of their family.

The stresses for this group of mothers were significant. Forty percent of the mothers had abnormally high parenting-related stress, measured by the Parenting Stress Index. Almost half of the mothers (43%) experienced dramatic stress around their child, where the child was seen as being incredibly demanding, as well as poorly adaptable, moody, and not a source of positive reinforcement for the mother. Another third (33%) experienced excessive stress related to their own functioning in the parent role, with problems with their spouse, personal health difficulties, worry over competence and social isolation contributing to their stress.

Yet despite the significant stresses, mothers evidenced a wide range of coping behaviors. Most vital to mothers in helping them cope was a trust and belief in the medical care delivery system, as well as a belief in God. Mothers relied on communication and consultation with health care professionals regarding the care and treatment of their child.

CHAPTER V

DISCUSSION

This study focused on the parenting-related stresses and family coping patterns of mothers with hospitalized toddlers or preschoolers who had chronic, long-term illnesses. The original research questions asked: (1) What were the mothers' parenting-related stresses with their hospitalized children? (2) What was the relationship between the parenting-stresses and family demographic information? (3) What pattern of coping behaviors did the mothers use? (4) What was the relationship between the coping behaviors and the family demographic information? and (5) Was there a relationship between the parenting-related stresses and coping behavior patterns? The pertinent findings for each question will be discussed in relation to the existing literature on mothers with chronically ill children, followed by a consideration of the implications of this information for nursing practice. Areas to be explored in potential future research will be suggested, and limitations of the study will be presented.

The literature on childhood chronic illness emphasizes the strain imposed on parents who care for a child with a chronic illness (Cummings, Bayley & Rie, 1966; Mattsson, 1972; Swartz, 1984; Thomas, 1984). The stress on parents and families is multifaceted and efforts to discern the overall impact on these families (Hymovich, 1981, 1983, 1984) present an overwhelming

array of information, perhaps too broad or cumbersome to be clinically useful to health care professionals working with families who have a child with a chronic illness. Consequently, this study narrowly explored only the parenting-related stresses and coping patterns of mothers with hospitalized, chronically ill children. Hopefully, smaller areas of inquiry will ultimately lead to a better understanding of the diverse responses of families to childhood chronic illness.

The two instruments used in this study, the Parenting Stress Index and the Coping Health Inventory for Parents, relied upon the mother's perception of herself and her child. Both Lazarus coping theory and McCubbin's Double ABCX family adaptation model emphasize that stress and coping responses are dependent on how the stress situation is perceived. It is the mother's interpretation of her child and herself which defines her stress and how she responds. Further, her responses or coping behaviors are a result of her perceptions from her previous experiences, the culmination of her present stresses, and her perception of current resources available to manage the stressful situation of caring for the chronically ill child in the hospital setting.

Parenting Stress

Mothers of hospitalized children with long-term chronic illnesses evidenced significant stress related to parenting issues. Caring for the chronically ill child in the hospital setting certainly represents McCubbin's description of family

stress and adaptation arising from the accumulation of many crisis events. The previous and current family stresses pile-up on the mother as she faces the current challenge of parenting the hospitalized child. Although the sample group generally had scores within the normal ranges of the PSI stress instrument, 40% of the mothers had total stress scores elevated above the norm. The areas of highest stress were most concerned with how they perceived their child, but also strongly related to their functioning in the maternal role.

Child Characteristics

Most striking was how very demanding the ill child was on the mother. The mothers' stress related to their children's demandingness was significantly elevated above normal stress levels. This finding is consistent with previous research which documented significant stress related to additional demands imposed by the ill child on the parents (Gallagher, Beckman & Cross, 1983; Holroyd, 1974). Additionally, high scores in this area may suggest the child is quite dependent on the mother, and has not achieved the normal separation from the mother (Abidin, 1986). This lack of individuation is consistent with the developmental effects of chronic illness on children, where progression through the normal stages is hindered and challenged by the imposition of illness, restrictions, and hospitalization (Perrin & Gerrity, 1984).

Mothers also perceived their children as less adaptable,

meaning the children had difficulty adjusting to changes in their environment. Children who poorly adapt to changes make the mothering tasks more difficult, particularly in the hospital setting. Toddlers and preschoolers are most vulnerable to negative behavioral responses when separated from their home and family (Cerreto, 1986; Sperling, 1978). Nearly one half of the study mothers (43%) were very stressed by the poor adaptability of their children, which persisted despite the prolonged number of hours spent by the mothers at their child's bedside.

Children were seen as quite moody by their mothers, suggesting that the children were unhappy and depressed. Depression in chronically ill children is not uncommon (Breslau, 1985; Mattsson, 1972) and may be accentuated when the young child becomes hospitalized and is separated from home.

The other child characteristics measured by the PSI were less stressful to mothers as a group, but were very stressful for some mothers within the group. Accepting the ill child was difficult for almost one quarter of the sample (23%) and decreased acceptance of a chronically ill child has been previously reported (Tavormina et al., 1981). Similarly, about one quarter (23%) of the mothers reported that the child did not positively reinforce their mother role. This finding suggests there may be problems with maternal attachment to the child as well as problems with accepting the hospitalized chronically ill child.

Parent Characteristics

Several areas related to functioning in the parental role were stressful for mothers as a group. The three highest stressors involved the mothers' own personal health, their relationships with their spouse, and worries over their competency as parents. One third of the sample mothers had extremely high stress in each of these three areas.

The prevalent finding of maternal health problems within this sample suggests that the stress and strain of caring for a chronically ill child may evidence itself in physical aches and ills for the caretakers. Indeed, previous research has documented increased somatic complaints and health problems in parents of chronically ill or handicapped children (Burden, 1979; Meyerowitz & Kaplan, 1967; Petersen, 1984; Shapiro, 1983). This strain on the mothers' personal health may reflect diminished personal resources (bB factor of the Double ABCX model) available to meet the current hospitalization stressor.

Consistent with previous studies was the widespread report of stress associated with the spousal relationship. An extensive review of family adjustment to chronic childhood illness determined that marital distress was consistently present, even though marital dissolution was not increased above the general population (Sabbeth & Leventhal, 1984). Marital distress was the third most common source of stress for mothers in one study (Mardiros, 1982). In another study, the only family variable

significantly associated with stress in families of handicapped infants was the marital status of mothers, with single mothers reporting more stress than mothers in intact relationships (Gallagher, Beckman & Cross, 1983). The effect of caring for a chronically ill and hospitalized child on the marital relationship was quite evident in this sample, since marital distress ranked second amongst the maternal functioning stresses.

Mothers were also quite distressed over their sense of competency in the parent role. This worry over parental competency supports previous assertions suggesting that the parents' self-concept is a particularly vulnerable area (Murphy, 1982), with the maternal role being very difficult and worrisome (Holaday, 1978). Lack of confidence in the maternal role (Tavormina et al., 1981) may relate to the lack of societal guidelines in how to care for a chronically ill child (Mardiros, 1982). Mothers' doubts about their ability to parent their chronically ill, hospitalized children affected their stress in all other areas related to the mother role, as well as their acceptance of their demanding child.

Social isolation was problematic for the mothers with hospitalized, chronically ill children. Nearly one quarter (23%) of the mothers reported extremely high stress in this area. This supports findings from previous research which found that mothers had decreased interaction with their neighbors when they had a child with a chronic illness as compared to mothers with healthy

children (Cummings, Bayley & Rie, 1966). Other parents have reported feeling socially isolated by both their extended family and the larger community (Meyerowitz & Kaplan, 1967). Families may view themselves in a we-they relationship with the outside world (Shapiro, 1983). Decreased interaction with others in the community may be a result of family adaptation where personal and family resources are conserved or mobilized toward the care of the ill child, and become less available for the broader community (Double ABCX model). Thus, the adaptive response of protecting energy and resources for the family unit may ultimately limit the availability of outside social support.

Given the multiple stresses for mothers with hospitalized, chronically ill children, it was not surprising to find that a substantial number of the mothers (23%) were significantly depressed. Certainly, depression in mothers with chronically ill or handicapped children has been widely explored, and reported in mothers whose children were not hospitalized (Burden, 1979; Cummings, Bayley & Rie, 1966; Gayton, et al., 1977; Shapiro, 1983). Hospitalization of the child may increase depression in mothers through the vivid reminder of their child's long-term illness.

Attachment to the ill child was the one area where there was the greatest variance in the stress levels of mothers. Although 23% of the sample had severely high stress with attachment to their child, there was another 20% of the sample who had

abnormally low attachment stress. Abnormally low scores may represent mothers with little emotional investment in their children, and a tenuous maternal-child bond. Exploration of altered attachment in handicapped children has previously focused on children with mental deficiencies or severe sensory deficits (Blacher & Meyers, 1983) and has shown that the attachment formation seems to be delayed, distorted, or even absent between mothers and disabled children. Nearly one half (43%) of the sample mothers in this study had child attachment stress outside the normal range. This raises the concern that chronic illness in children may affect the attachment process, which continues to develop over the first four to five years of life (Blacher & Meyers, 1983). Since this study limited its investigation of mothers' stress with children between 18 months and five and one half years, the diagnosis of a chronic illness did occur during the stage of attachment formation. This study cannot yet confirm problems in attachment formation with chronically ill children, but it does point to the need for further investigation in this area.

The last area of stress explored in this study was the sense of restrictions imposed by the parental role. This was the area of least concern for this sample population, with the greatest majority of mothers (80%) reporting stress within the normal range. However, a few mothers (13%) did have extraordinary stress in this area, and other researchers have reported a lack of

freedom for personal development related to caring for a handicapped child (Holroyd, 1974).

The findings of this study were fairly consistent with previous research concerning parenting stresses of mothers with chronically ill children at home. Mothers of children with spina bifida (Kazak & Marvin, 1984) reported their children as being poorly adaptable to changes in their environment, more demanding, and less adequately fulfilling the mothers' own expectations for their children. Additionally, mothers were more depressed, and felt less competent compared to a control group.

Parenting Stresses and Family Demographics

Certain family demographic characteristics did account for differential degrees of parenting-related stress. The variables to be discussed which led to significant differences amongst the mothers of these hospitalized children related to their ages, their marital status, their socioeconomic status including employment, and factors related to the child. Particularly relevant was the child's age at diagnosis, and the length of elapsed time since diagnosis. Also, the length of time that mothers spent with the hospitalized child may be pertinent to the stress around functioning in the maternal role.

Stresses seemed more acute for mothers based on their ages. Young mothers, between 18 and 21 years, tended to have the highest parenting-related stress, followed by mothers over the age of 31 years. Certainly, young mothers have less life experience and

maturation to guide them in the increasingly difficult task of caring for a chronically ill and hospitalized child. Young mothers, as well as older mothers, were more distressed by their competence in caring for a chronically ill, hospitalized child.

The mothers' marital status influenced their stress. Mothers who lived with a man who had a stepfather role to the hospitalized child were consistently more stressed than either the single mothers, or the mothers in intact relationships. Mothers who shared the parenting tasks with the child's biological father had consistently lower parenting-related stress. Women living with the child's stepfather saw their child as incredibly demanding, poorly adaptable, had less acceptance of their ill child, and rated their child as quite moody. Further, mothers living with the child's non-biological father had extraordinary fears about their competency as parents, reported significant social isolation, had increased physical health problems, and had a stressful interpersonal relationship with the child's stepfather. In short, women seemed the least stressed if they were in an intact relationship with the child's father, had somewhat higher stresses if they were alone, but had unexpectedly high stresses by living with a man who was not the father of the chronically ill child's father. Perhaps when a mother's attention is divided between her child, and a non-father male, she has greater conflict trying to meet both her child's needs, while at the same time

balancing her needs of an interpersonal relationship with someone of the opposite sex.

The socioeconomic status of the family has been considered a critical demographic variable when examining stress (Gallagher, Beckman & Cross, 1983). However, there was very little difference in the stress scores for mothers related to income. It was interesting to note that women with a higher annual income (more than \$30,000 a year) considered their children excessively demanding when compared to mothers of lower income. Children of mothers with a higher annual income may also be seen as less adaptable and slightly moodier. Attachment of the child was most stressful for the higher income mothers, although the mothers were less depressed. These findings may suggest that although adequate finances may be a mediator in reducing the effects of some types of stress (Petersen, 1984; Shapiro, 1983), other factors interplay in the parenting-stress for women of higher financial means.

Annual family income is affected by the working status of the mother. The majority of the sample (70%) did not work outside the home. This may reflect a shift of previously employed women who returned to the role of full-time mother after diagnosis of the chronically ill child. In a study by Meyerowitz and Kaplan (1967) the home management requirements of the ill child led to one half of previously employed mothers to quit their jobs in order to provide care to their child with cystic fibrosis. McCubbin (1988) too, found that almost two thirds of the mothers were not employed

outside of the home due to the home care demands. Unfortunately, change of employment status related to the child's diagnosis was not explored in this study, and perhaps many mothers changed their employment status. Mothers who remained employed may have had conflicts between their professional life or their need to contribute to the family income, and the needs of caring for their young chronically ill child.

Working women did see their children as more demanding, and professionally employed women had the highest difficulty accepting their child. Professionally employed women felt less positive reinforcement for their parent role by their child, and they had severe stress related to attachment with their child. Thus, although the clinical tendency is to assume that middle class mothers, or those with higher financial resources, may do better with the stresses of caring for a chronically ill child, perhaps their stresses are compounded by the requirements of both home and work. Women of higher socioeconomic status may have higher expectations of themselves and their children. When the child fails that hoped-for ideal, there may be greater difficulty for the higher income mother.

The age of the child at diagnosis may alter how the child is perceived by both the parent and the extended family. Mothers of children with cystic fibrosis (Meyerowitz & Kaplan, 1967) reported that the relatives were more understanding and helpful when the child was diagnosed in early infancy, compared to mothers of

children diagnosed beyond one year of age. Children of mothers in this study were either diagnosed at birth or early infancy (mean of 6 weeks), around a year of age (mean of 11 1/2 months), or as a toddler (mean of 3 years). The children diagnosed around a year of age were seen as extremely demanding, much more distractible, and somewhat moodier compared to the other two groups. Mothers of children diagnosed about one year of age also had much higher stress around attachment to their child when compared to children diagnosed around three years of age. Those mothers with children diagnosed close to birth had extremely low stress with attachment to their child. This suggests that the attachment process may be altered depending on the child's age when diagnosed with a long-term chronic illness.

The length of elapsed time from the child's diagnosis to the present hospitalization merits some comment. It is well established that the diagnosis of a "defect" or persistent condition or illness in a child throws the family into crisis and resolution may lead to a state of "chronic sorrow" (Drotar, 1975; Olshansky, 1962; Solnit & Stark, 1961). Mothers of children who had been diagnosed for less than one year prior to this hospitalization had significantly higher stresses in many areas when compared to mothers of children diagnosed longer than one or two years ago. The mothers of the more recently diagnosed children had increased difficulty accepting their child, and they were generally more distressed with their child. Not

surprisingly, the mothers were more depressed, felt socially isolated, and they questioned their competency as parents. These findings suggest that aspects of the crisis surrounding a child's diagnosis lasts for at least a year.

One last consideration which accounted for some within-group stress differences related to the number of hours spent by mothers at their child's bedside. The majority of the sample (60%) chose to "room-in" with their child, while another third (30%) reported they spent between 12 to 16 hours per day with their hospitalized child. Only a few mothers (10%) reported less time, with an average of nine bedside hours per day. The mothers who spent the least time with their children saw them as incredibly demanding, less adaptable, and they tended to have less acceptance of the child. Personal health problems were particularly high for this group of mothers, and they tended to doubt their competency as parents. Since this subgroup of mothers was quite small (10%), it is difficult to speculate exactly what contributed to their increased stress. However, these findings suggest attention should be paid to the number of hours reportedly spent by mothers with their hospitalized young child.

There were many family demographic variables which did not account for differences in the levels of mothers stress. The sex of the affected child, the mothers' ethnic group, or the number of previous hospitalizations did not contribute to stress differences. Also the child's medical diagnosis, or diagnostic

group had no significant effect on the level of the mothers' stress.

The multi-faceted areas related to parenting a chronically ill, hospitalized child result in varying levels of stress for mothers. McCubbin's Double ABCX model allows us to understand why stress differed amongst mothers. The pile-up of ongoing stresses affect the mother's perception of herself and her child. The child, too, experiences a pile-up of stresses which affects the child's interaction with the mother. The resources within the child, the mother, the family and the environment all affect the mother's perception of the stressful situation of having a hospitalized child, and the resultant adaptive responses of each family member.

Mother's Coping Behaviors

Having explored the parenting-related stresses of mothers, as well as certain contributing variables, attention will be directed towards the coping responses of mothers. The diagnosis of a chronic long-term illness in a child results in family disruption and disorganization (Shapiro, 1983). Coping patterns emerge to resolve the crisis and manage the stresses of the situation (McCubbin, 1987). Coping strategies may be problem focused and attempt to alter the stress, or may be emotion focused and decrease the negative feelings engendered by the perception of the stresses (Lazarus & Folkman, 1984).

Coping was measured using the CHIP, which specifies behaviors

relevant to three separate coping patterns. The CHIP is designed to ascertain which behaviors help parents cope with the stresses of caring for a chronically ill child. Parents under high stress are expected to mobilize their repertoire of coping strategies, and use a higher frequency of coping behaviors to manage their stresses (McCubbin et al, 1981).

The coping pattern most helpful to mothers in this study was Coping Pattern III, "understanding the medical situation through communication with other parents and consultation with the medical staff". Parents used behaviors such as "talking with the doctor about my concerns about my child with the medical condition". The majority of mothers (60%) had higher scores on this pattern compared to the reference mean. The greater use of this coping pattern over others implies that mothers of children with illness exacerbation or those requiring hospital-based intervention are focused on aspects of their child's illness and treatment program, and direct their coping efforts towards understanding. Information-seeking behaviors help individuals cope by dealing directly with the problem (Lazarus, 1981). This coping pattern supports previous assertions that helpful coping strategies for parents was to look to the physician or nurse for information about their child (Hymovich, 1985).

The coping pattern which was second most helpful for mothers was Coping Pattern I "family integration, cooperation, and an optimistic definition of the situation". The mothers' mean score

on this pattern closely approximated the reference norm, and over half (57%) of the mothers scored above the reference mean. Specific behaviors such as "doing things together as a family (involving all members of the family)", "getting other members of the family to help with chores and tasks at home", and "doing things with my children" are consistent with a previous study (Venters, 1981) which found an effective coping strategy for parents consisted of sharing the burdens of care with the family. Many of the behaviors in the family integration coping pattern relate to the marital relationship. Positive coping has been associated with open communication and good marital and familial relationships (Athreya & McCormick, 1987; Friedrich, 1979; Shapiro, 1983).

The only coping pattern where the mothers as a group scored below the reference mean was Coping Pattern II, "maintaining social support, self-esteem, and psychological stability". Over half (53%) of this sample had scores lower than the normal mean, suggesting mothers in the hospital setting with chronically ill children may be more vulnerable to feelings of poor self-esteem, have less social support, and may be at increased psychological risk from the stresses of parenting their ill child away from their familiar home environment. Previous studies using the CHIP (Gibson, 1986; McCubbin, 1984) reported higher support, esteem and stability coping scores with parents of chronically ill children treated as outpatients.

The finding that the pattern which includes social support was the least helpful group of coping behaviors for this sample was most concerning. Social support may be the critical variable determining how well an individual copes with stress (Cobb, 1976). Yet, there may be threats to mothers in obtaining this much needed social support. Evidence suggests families and friends withdraw from parents who have a chronically ill child (Cummings, Bayley & Rie, 1966; Meyerowitz & Kaplan, 1967), and mothers' social relationships may suffer when there are delays in the children's functional developmental status and self-help ability (Schlomann, 1988). Yet, in families with a chronically ill child, the presence of a good support system and religious faith was associated with positive coping (Athreya & McCormick, 1987). An effective social support system has been shown to lessen the negative effects of high stress, resulting in fewer problems for mothers with chronically ill or handicapped children (Petersen, 1984). Further, McCubbin (1988) found that extended family social support was associated with fewer health problems in the children with cystic fibrosis.

Social support may be more useful to parents when caring for their children at home. However, perhaps the hospitalization of a child decreases the availability of social support to mothers. The diminishment of social support during hospitalization may be a "red flag" in determining which families are at risk for negative effects as a result of their stress and the hospitalization of the

child.

Individual coping behaviors

In addition to examining the coping patterns most helpful for this sample, individual coping behaviors of the group were analyzed. Ten specific coping behaviors were identified by over half of the sample as being extremely helpful to them in coping with their hospitalized child. Interestingly, although the medical communication and consultation pattern was the most helpful, only two of the ten specific behaviors came from that pattern: "talking with the doctor about my concerns about my child with the medical condition" and "talking with the medical staff (nurses, social worker, etc) when we visit the medical center". The other eight behaviors all were associated with the coping pattern of family integration, cooperation, and optimism. Four extremely helpful behaviors for over 73% of the mothers were positive affirmations and beliefs such as "belief that the child was getting the best medical care possible", "belief that the child will get better", "belief that the medical center has the family's best interest in mind", and "belief in God".

Prayer and religion has been shown to help parents adjust to caring for a handicapped or chronically ill child (Barsch, 1968). Families who used prayer actually had fewer somatic manifestations of stress compared to the level of physical complaints in family members who did not pray (Meyerowitz & Kaplan, 1967). The belief in God may also represent a form of social support available

through religious institutions, but untapped by this present study in mothers' coping with their hospitalized children. The sources and availability of social support to mothers with hospitalized, chronically ill children should be further explored.

There were three coping behaviors which were the least helpful for this sample of mothers. The behavior identified the least frequently as being helpful by 72% of the mothers was "working, outside employment". Almost half (48%) of the sample mothers stated they chose not to work. Another 20% stated it was not possible, and one mother indicated working was not helpful in helping her cope. Many of these mothers may have foregone employment in order to stay home and care for their ill child. Unfortunately, the previous employment status of the mothers was not ascertained in this study. The second least helpful coping behavior may be also related to the mothers' finances, since nearly half of the mothers (48%) indicated that "purchasing gifts for self/family" was not helpful, not possible or was chosen not to. Considering that adequate financial resources has been identified as reducing the negative effects of stress (Shapiro, 1983), this forced unemployment and subsequently decreased income may impact on the ultimate adequacy of coping for mothers.

The last coping behavior which negatively affected a large percentage of this sample was "getting other members of the family to help with chores and tasks at home". Although very helpful to many of the mothers, 41% of the sample mothers had difficulty

getting any help at home. Perhaps this underscores the decreased social support available to many mothers during the hospitalization of their ill child.

Thus, the coping behaviors most helpful for these hospitalized mothers were first directed towards increasing their understanding of their children's medical condition and treatment. Secondly, positive affirmations about themselves and their child seemed very useful, and are consistent with Lazarus' (1981) discussion of emotion-regulation behaviors designed to lessen the negative emotional effects of stress. However, self esteem appeared to falter and social support seemed inadequate in helping the mothers cope with the stresses of their hospitalized children.

Coping and Family Demographics

Only a few demographic variables seemed to make a real impact on the coping patterns of mothers. There were some differences depending on the sex of the child, the mothers marital status and her socioeconomic status. Also, the length of time the child had been diagnosed with the chronic illness affected the coping strategies of mothers. There were no differences in coping related to the child's medical diagnosis, or to issues related to the number of hospitalizations.

The only measured aspect of this entire study that pertained to the sex of the affected child was related to mothers' social support, self esteem and emotional stability. When the sick child was a boy, mothers seemed more vulnerable and found Coping Pattern

II related to self esteem, social support and emotional stability much less helpful. A previous study (Gayton et al., 1977) suggested parents were more stressed when a male child had cystic fibrosis compared to a female child. Perhaps this relates to the value society places on the future productive status of boys over girls, and mothers of sick boy children are influenced by this.

The marital status of the mother impacted the degree of helpfulness of Coping Pattern I relating to family integration, cooperation, and optimism. Single mothers used this pattern much less than women in couple relationships. However, this was not surprising since many items in this pattern relate to the marital relationship. It was interesting to note that women who lived with the child's stepfather tended to rely on the medical communication and consultation pattern more than either the single mothers, or the women who lived with the child's father.

There was evidence that the small group of women who were professionally employed had higher social support, self esteem and emotional stability. Women employed in semi-skilled positions and the full-time housewives had much lower support and self esteem, and although there was little difference in their scores, the semi-skilled employed women had the lowest coping scores. Again, adequate financial resources emerges as an asset to positive coping.

The mothers of children who had been diagnosed less than one year prior to this study (mean of 5.3 months) used all three

coping patterns less frequently compared to the other mothers. This reinforces the concept that families are thrown into crisis upon diagnosis of a chronic illness in their child, and considerable time is needed to re-organize their life and adjust to the changes. Their coping was less related to participating in the medical treatments of their child, and problems with the relationship with the child's father was particularly evident. Talking with other parents was not helpful, and the mothers were not yet sure that the medical center had the family's best interest in mind. These findings suggest this would not be the time to encourage mothers involvement in a parent-support group, but rather some family counseling and communication skills would be a better intervention.

Correlations of Stress and Coping

There were few clear statistical relationships between the parenting-stress measure and the mother's coping patterns. However, one of the stress subscales concerning the mother's perception of her child, and two of the stress subscales related to her parent role function which correlated with one coping pattern will be discussed. Also, the apparent clinical usefulness of the two measures together will be considered.

The acceptability subscale, which measures how the perceived child matches the mother's expectations for her child was inversely related to Coping Pattern I of family integration, cooperation and optimism. This suggests that the higher the mother's stress with

accepting her child, the less she was able to use the coping behaviors found in Coping Pattern I. High stress in the acceptability subscale may represent poor attachment with the child, or actual rejection of the child by the mother (Abidin, 1986). Mothers who had difficulty accepting their child had difficulty having a positive outlook on life and in their family relationships.

The subscale of maternal depression was also inversely related to Coping Pattern I, meaning the higher the mothers' depression, the lower the availability of coping behaviors related to family integration, cooperation and optimism. This correlation of depression with decreased helpfulness of behaviors related to a positive outlook lends credence to the ability of these measures to independently and accurately assess the mental state of individuals.

The last stress subscale which was related to coping behaviors was related to the mothers' sense of competence in the maternal role. Role competency was also inversely related to Coping Pattern I, suggesting that when mothers' doubted their own ability or effectiveness to parent the chronically ill, hospitalized child, they were less able to find comfort by working together as a family. It may be that when mothers had decreased confidence in their maternal role, their relationship with the child's father suffered, since many of the behaviors in Coping Pattern I pertain to her relationship with her spouse.

The use of the Parenting Stress Index together with the Coping Health Inventory for Parents has the potential to identify parents who may be quite vulnerable. Mothers under fairly high stress, but with the ability to actively cope with their stress may be of less concern. Coping behaviors measured by the CHIP have been higher in high-conflict families under greater stress (McCubbin, et al, 1983). Therefore, mothers demonstrating high stress should have had coping scores higher than the reference norm. Yet unexpectedly, mothers with higher stress scores generally had lower coping scores compared to mothers under lower stress.

The mothers with severely high stress related to their child and themselves actually had the lowest coping scores for Pattern I, family integration, cooperation, and optimism and for Pattern II, social support, self esteem and emotional stability. These high stressed mothers with diminished coping resources may be at risk for either a dysfunctional relationship with their ill child, or for increased personal problems. Petersen (1984) found mothers of children with physical or mental handicaps with high stress and low resources had more problems than mothers with high stress but high resources. These findings suggest that mothers under higher stress would benefit from an intervention program designed to lessen their stress and bolster their coping efforts. The use of the stress measure coupled with the coping measure allows for a greater understanding of who may be at risk, and in most need of effective intervention.

Conclusion

Mothers of chronically ill, hospitalized children face a very challenging parenting situation. However, the presence of such acute stresses does not mean that maladaptation inevitably occurs. The conflicting findings between studies which show that many families do quite well, while other families have difficulty (Masters, Cerreto & Mendlowitz, 1983) have been related to the adequacy of family coping strengths and resources. This study demonstrated that despite the innumerable parenting-related stresses, mothers had a wide range of coping behaviors which they found helpful in coping with their hospitalized young chronically ill toddler or preschool children.

Mothers of children with several medical problems were included in this study, including childhood cancer and leukemia, heart or lung problems, and disorders of the musculoskeletal or gastrointestinal systems. No differences were found in either the parenting stresses or coping patterns of mothers attributed to the child's medical diagnosis. This suggests that approaching issues of stress and coping from a concept of chronic illness (Stein & Jessop, 1982), rather than an illness-specific approach may be appropriate.

The Double ABCX model (McCubbin & Patterson, 1981) and Lazarus' coping theory (1984) contribute to our understanding of the stresses and coping responses of mothers with hospitalized, chronically ill children. The interaction between the mothers and

children within the hospital environment affects how the mothers perceive their children and their current situation (Lazarus & Folkman, 1984). The appraised degree of their stress is related to the pile-up of concurrent stressors for each mother, as well as the availability of resources to manage their stress. Coping resources must be mobilized as mothers readjust to the onset of new stress (McCubbin & Patterson, 1981).

This study shed light on some specific areas of difficulty for mothers when caring for chronically ill young children in the hospital. The child's excessive demandingness and the associated areas of stressful child characteristics presents us with a vivid picture of why it is so difficult to care for these children. Perhaps the well published tendency of parents to overprotect and overindulge the chronically ill child is a response to finding the child demanding, poorly adaptable and moody or depressed. It may represent a parent's attempt to compensate for the child's pain and limitations associated with the chronic condition. Further, it is of little wonder that the mothers have high concerns with their own personal health, when their health problems relate to feelings of depression, social isolation, and lack of support from the child's father. When mothers are coping with the stresses of ill and hospitalized children, along with doubts about their competency as parents, mothers may have little energy left to attend to the needs of their spouse. Thus, problematic relationships with the husband can arise and serve to reinforce

the mothers' stress.

However, along with the stresses encountered by mothers, this study demonstrated numerous coping strategies used by mothers. Mothers relied upon the health care team to provide care and information, consistent with Lazarus' (1981) problem focused, information-seeking coping. Mothers also relied on personal positive affirmations in helping them cope, both related to themselves, and their child. Mothers who can emphasize their own personal strengths may reduce their vulnerability to stress (Stullenbarger et al., 1987). One set of coping strategies which deserves further attention is the issue of social support. Since these mothers scored lower on the pattern of social support and self esteem compared to the reference norm, hospitalization may threaten and diminish social support.

It seems that the two measures used in this study yield rich information regarding both the parenting stresses and coping patterns of mothers with hospitalized, chronically ill children. Most beneficial, may be the identification of mothers under severe stress but with limited coping resources. Future intervention plans can be formulated based on specific target areas identified by the PSI and the CHIP.

Implications for Nursing

The results of this study emphasize the need for pediatric nurses to become aware of the significant stress placed on a mother when caring for a chronically ill, hospitalized young child. The psychosocial and emotional aspects of care may be the most important variables in helping children and families adapt to their illness-related demands and limitations (Stein & Jessop, 1982). The nursing responsibility of appropriate parental education is dependent upon the nurse having proper information regarding the stresses and concerns of parents who care for a chronically ill child.

It is evident that the mother-child relationship may be strained with the child's ongoing illness and subsequent hospitalization. How the nurse perceives and approaches the mother-child dyad may affect the mother's parenting role with her child. Since stress is affected by the perception of the situation, the nurse can assist mothers to realize that negative feelings about their child's characteristics, or concerns over their ability to parent that child, is normal for parents with chronically ill children, thus lessening their worries regarding their perception of their ill child.

Nurses have an opportunity to "become outstanding sources of personal support for parents" by listening to parental concerns, giving badly needed information, and assisting parents in coping

with the medical service system (Gallagher, Beckman & Cross, 1983, p. 16). A recent study that explored parents' feelings about raising a child with a chronic illness (Canam, 1987) found over half of the study parents did not talk about their feelings with anyone because they felt no one wanted to listen to their concerns. The group of parents who did communicate their feelings found other parents and the nurse as the most helpful source of support for talking about their feelings and concerns. Indeed, one investigator (Burden, 1980) reduced the negative effects of stress through the provision of social support to mothers by health care professionals.

In another study using the CHIP in an outpatient setting (Gibson, 1986), several of the coping behaviors rated as extremely helpful were precisely the same behaviors identified by mothers in this study. Four of the behaviors related to the parent's relationship with the health care setting and personnel. This dual finding emphasizes the importance that the health care team, specifically nurses, has as a source of support in the coping process of parents.

Nurses are in a unique position of being able to help meet both the emotional and educational needs of parents with hospitalized, chronically ill children. Nurses can offer parents anticipatory guidance about what to expect with their ill child, discuss common parenting worries and concerns the mother might be reluctant to initiate on her own, and provide a compassionate

listening ear.

The Parenting Stress Index and the Coping Health Inventory for Parents are effective measures which can be used clinically to determine which mothers are under excessive stress, and less able to mobilize their coping resources. Future interventions tailored to address the mothers' specific stresses and augment their coping resources could not only improve the mothers' ability to cope, but would then indirectly influence how the children cope with the stress of hospitalization.

Suggestions for Future Research

The findings in this study support previous research and suggest that further investigation is warranted. Replication of this study with a larger sample would advance our understanding of the complex interactions in families under stress. It would also allow us to understand why some families are resilient, while others seem more vulnerable.

Since social support seems so crucial to coping with chronic illness, the use of a social support measure could better tap this important dimension of coping. Although the CHIP measures aspects of social support, it seems to give incomplete data about this critical area, and vital information may be missed.

Another critical area untouched by this study is the concept of uncertainty. Dealing with chronic childhood illness evokes uncertainty at every turn. There is uncertainty related to the cause of the disorder, ultimate survival and the effects of the

illness and treatment regimen on the child's development (Cohen & Martinson, 1988). Uncertainty may play a significant role in parenting stress and subsequent coping efforts.

Insights about within-group differences need to be replicated and cross validated with other samples. Certain demographic variables need to be further explored. Since it appeared that mothers remain in crisis for the first year after diagnosis of the chronic illness, having equal groups of mothers with children recently diagnosed contrasted to mothers with children diagnosed for over a year could lead to greater comparison of the stresses and coping behaviors, both in the early and later phase of chronic illness. Future study could also determine if there was a change in employment or living status related to the child's diagnosis with a chronic illness.

Including fathers in the study of stress and coping with hospitalized, chronically ill children is crucial. Multiple studies have suggested there is also a significant negative impact on fathers of chronically ill children (Cummings, 1976; Gayton et al, 1977).

Finally, the issue of attachment between the mother and a chronically ill child needs to be further explored. Alterations in attachment seemed to be a recurrent finding, and little is understood about the effects of chronic childhood illness on this aspect of the maternal-child relationship.

Study Limitations

The greatest limitation of this study was the small sample size, thus making generalizations to the population of other mothers with hospitalized, young chronically ill children difficult. In addition, this convenience sample was drawn from a single multi-specialty referral center with a high percentage of chronically ill children. Further, nearly all of the chronically ill children received some episodic care from the University-based ambulatory services of the subspecialists. Many services use a multi-disciplinary team approach consisting of physician, nurse specialist and social worker to provide patient care and education. Hence, the stresses and coping strategies of this population of mothers may be different and/or modified by receiving such care compared to mothers receiving care by a single, private physician. However, smaller community hospitals may not have hospitalized ill children with the complexity of problems found in the population of chronically ill children hospitalized at a tertiary care University teaching hospital.

No control or comparison group of mothers was used since this study represents the first time either of the two quantitative measures have been used on a population of mothers with hospitalized, chronically ill children. However, the inclusion of fathers in the sample population would have added considerably to the findings of this study.

The premise that parenting stress and maternal coping is more

related to the chronicity of caring for a child with an ongoing chronic illness, rather than a specific medical diagnosis, guided the sample selection criteria for this study. Since no differences emerged for mothers based on their child's diagnosis, the non-categorical approach seemed supported. However, there were only a few children with the same condition, and they were grouped into one of three categories to examine if differences existed amongst the mothers of children with varying illnesses. Perhaps the groupings of children with heart or lung problems, and children with musculoskeletal or gastrointestinal problems obscured some differences. However, nearly one third of the sample mothers had children with leukemia or cancer, and they did not have any differences in their stress or coping scores compared to the other groups of mothers. Thus, although the non-diagnostic approach can not be confirmed with this study, the findings tend to lend support to the chronic illness approach.

Despite the limitations of this study, there were many areas which confirmed and supported previous work. It remains for future research to confirm or reject some of the insights suggested by this inquiry.

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APPENDIX A
FAMILY DATA SHEET

ID # _____

DATE OF STUDY _____

HOSPITAL ADMISSION DATE _____

CHILD INFORMATION

1. Child's first name _____ 2. Sex _____

3. Date of Birth _____ 4. Age _____

4. Medical conditions or diagnosis:

(Rank the most severe first)

5. Age at diagnosis:

a. _____ a. _____

b. _____ b. _____

c. _____ c. _____

d. _____ d. _____

6a. Has this child been previously hospitalized? _____

6b. If yes, complete the following:

NUMBER OF TIMES? _____ GIVE DATES _____

REASON FOR HOSP? _____

LENGTH OF STAY? _____ PLACE? _____

FAMILY INFORMATION

8. Please list FIRST names and ages of all living in your
household: (parent, grandparent, sisters, brothers, etc)

<u>Name</u>	<u>Relationship to ill child</u>	<u>Age</u>	<u>Occupation</u>
a. _____	_____	_____	_____
b. _____	_____	_____	_____
c. _____	_____	_____	_____
d. _____	_____	_____	_____
e. _____	_____	_____	_____

9. Marital status_____
10. Ethnic background (circle one): Asian, Black,
Caucasian, Hispanic, Other (please specify)_____
11. Do you have, or have you had, any other children with
ongoing medical conditions or illnesses?_____
-
12. How many miles do you live from this hospital?_____
13. About what hours do you spend with your child in the hospital
daytime_____
- afternoon_____
- evening_____
14. Are you rooming-in with your child?_____
-
15. Mark the box that best describes your family's
annual income;
- a. _____ \$0 - \$6,000 year
- b. _____ \$6,000 - \$10,000 year
- c. _____ \$10,000 - \$20,000 year
- d. _____ \$20,000 - \$30,000 year
- e. _____ \$30,000 - \$40,000 year
- f. _____ over \$40,000 year

PARENTING STRESS INDEX (PSI)

Administration Booklet

Richard R. Abidin
Institute of Clinical Psychology
University of Virginia

Directions:

In answering the following questions, please think about the child you are most concerned about.

The questions on the following pages ask you to mark an answer which best describes your feelings. While you may not find an answer which exactly states your feelings, please mark the answer which comes closest to describing how you feel. **YOUR FIRST REACTION TO EACH QUESTION SHOULD BE YOUR ANSWER.**

Please mark the degree to which you agree or disagree with the following statements by filling in the number which best matches how you feel. If you are not sure, please fill in #3.

1
Strongly
Agree

2
Agree

3
Not
Sure

4
Disagree

5
Strongly
Disagree

Example: 1 (2) 3 4 5

I enjoy going to the movies. (If you sometimes enjoy going to the movies, you would fill in #2.)

1
Strongly
Agree

2
Agree

3
Not
Sure

4
Disagree

5
Strongly
Disagree

1. When my child wants something, my child usually keeps trying to get it.
2. My child is so active that it exhausts me.
3. My child appears disorganized and is easily distracted.
4. Compared to most, my child has more difficulty concentrating and paying attention.
5. My child will often stay occupied with a toy for more than 10 minutes.
6. My child wanders away much more than I expected.
7. My child is much more active than I expected.
8. My child squirms and kicks a great deal when being dressed or bathed.
9. My child can be easily distracted from wanting something.
10. My child rarely does things for me that make me feel good.
11. Most times I feel that my child likes me and wants to be close to me.
12. Sometimes I feel my child doesn't like me and doesn't want to be close to me.
13. My child smiles at me much less than I expected.
14. When I do things for my child I get the feeling that my efforts are not appreciated very much.
15. Which statement best describes your child?
 1. almost always likes to play with me,
 2. sometimes likes to play with me,
 4. usually doesn't like to play with me,
 5. almost never likes to play with me.
16. My child cries and fusses:
 1. much less than I had expected,
 2. less than I expected,
 3. about as much as I expected,
 4. much more than I expected,
 5. it seems almost constant.
17. My child seems to cry or fuss more often than most children.
18. When playing, my child doesn't often giggle or laugh.
19. My child generally wakes up in a bad mood.
20. I feel that my child is very moody and easily upset.
21. My child looks a little different than I expected and it bothers me at times.
22. In some areas my child seems to have forgotten past learnings and has gone back to doing things characteristic of younger children.

1
Strongly
Agree

2
Agree

3
Not
Sure

4
Disagree

5
Strongly
Disagree 190

23. My child doesn't seem to learn as quickly as most children.
24. My child doesn't seem to smile as much as most children.
25. My child does a few things which bother me a great deal.
26. My child is not able to do as much as I expected.
27. My child does not like to be cuddled or touched very much.
28. When my child came home from the hospital, I had doubtful feelings about my ability to handle being a parent.
29. Being a parent is harder than I thought it would be.
30. I feel capable and on top of things when I am caring for my child.
31. Compared to the average child, my child has a great deal of difficulty in getting used to changes in schedules or changes around the house.
32. My child reacts very strongly when something happens that my child doesn't like.
33. Leaving my child with a babysitter is usually a problem.
34. My child gets upset easily over the smallest thing.
35. My child easily notices and overreacts to loud sounds and bright lights.
36. My child's sleeping or eating schedule was much harder to establish than I expected.
37. My child usually avoids a new toy for a while before beginning to play with it.
38. It takes a long time and it is very hard for my child to get used to new things.
39. My child doesn't seem comfortable when meeting strangers.
40. When upset, my child is:
 1. easy to calm down,
 2. harder to calm down than I expected,
 4. very difficult to calm down,
 5. nothing I do helps to calm my child.
41. I have found that getting my child to do something or stop doing something is:
 1. much harder than I expected,
 2. somewhat harder than I expected,
 3. about as hard as I expected,
 4. somewhat easier than I expected,
 5. much easier than I expected.

1
Strongly
Agree

2
Agree

3
Not
Sure

4
Disagree

5
Strongly
Disagree

191

42. Think carefully and count the number of things which your child does that bothers you. For example: dawdles, refuses to listen, overactive, cries, interrupts, fights, whines, etc. Please fill in the number which includes the number of things you counted.
1. 1-3
 2. 4-5
 3. 6-7
 4. 8-9
 5. 10+
43. When my child cries it usually lasts:
1. less than 2 minutes,
 2. 2-5 minutes,
 3. 5-10 minutes,
 4. 10-15 minutes,
 5. more than 15 minutes.
44. There are some things my child does that really bother me a lot.
45. My child has had more health problems than I expected.
46. As my child has grown older and become more independent, I find myself more worried that my child will get hurt or into trouble.
47. My child turned out to be more of a problem than I had expected.
48. My child seems to be much harder to care for than most.
49. My child is always hanging on me.
50. My child makes more demands on me than most children.
51. I can't make decisions without help.
52. I have had many more problems raising children than I expected.
53. I enjoy being a parent.
54. I feel that I am successful most of the time when I try to get my child to do or not do something.
55. Since I brought my last child home from the hospital, I find that I am not able to take care of this child as well as I thought I could. I need help.
56. I often have the feeling that I cannot handle things very well.
57. When I think about myself as a parent I believe:
1. I can handle anything that happens,
 2. I can handle most things pretty well,
 3. sometimes I have doubts, but find that I handle most things without any problems,
 4. I have some doubts about being able to handle things,
 5. I don't think I handle things very well at all.

1
Strongly
Agree

2
Agree

3
Not
Sure

4
Disagree

5
Strongly
Disagree

192

58. I feel that I am:

- 1. a very good parent,**
- 2. a better than average parent,**
- 3. an average parent,**
- 4. a person who has some trouble being a parent,**
- 5. not very good at being a parent.**

59. What were the highest levels in school or college you and the child's father/mother have completed?
Mother:

- 1. 1-8th grade**
- 2. 9-12th grade**
- 3. Vocational or some college**
- 4. College graduate**
- 5. Graduate or professional school**

60. Father:

- 1. 1-8th grade**
- 2. 9-12th grade**
- 3. Vocational or some college**
- 4. College graduate**
- 5. Graduate or professional school**

61. How easy is it for you to understand what your child wants or needs?

- 1. very easy,**
- 2. easy,**
- 3. somewhat difficult,**
- 4. it is very hard,**
- 5. I usually can't figure out what the problem is.**

62. It takes a long time for parents to develop close, warm feelings for their children.

63. I expected to have closer and warmer feelings for my child than I do and this bothers me.

64. Sometimes my child does things that bother me just to be mean.

65. When I was young, I never felt comfortable holding or taking care of children.

66. My child knows I am his or her parent and wants me more than other people.

67. The number of children that I have now is too many.

68. Most of my life is spent doing things for my child.

69. I find myself giving up more of my life to meet my children's needs than I ever expected.

70. I feel trapped by my responsibilities as a parent.

71. I often feel that my child's needs control my life.

72. Since having this child I have been unable to do new and different things.

73. Since having a child I feel that I am almost never able to do things that I like to do.
74. It is hard to find a place in our home where I can go to be by myself.
75. When I think about the kind of parent I am, I often feel guilty or bad about myself.
76. I am unhappy with the last purchase of clothing I made for myself.
77. When my child misbehaves or fusses too much I feel responsible, as if I didn't do something right.
78. I feel everytime my child does something wrong it is really my fault.
79. I often feel guilty about the way I feel towards my child.
80. There are quite a few things that bother me about my life.
81. I felt sadder and more depressed than I expected after leaving the hospital with my baby.
82. I wind up feeling guilty when I get angry at my child and this bothers me.
83. After my child had been home from the hospital for about a month, I noticed that I was feeling more sad and depressed than I had expected.
84. Since having my child, my spouse (male/female friend) has not given me as much help and support as I expected.
85. Having a child has caused more problems than I expected in my relationship with my spouse (male/female friend).
86. Since having a child my spouse (or male/female friend) and I don't do as many things together.
87. Since having my child, my spouse (or male/female friend) and I don't spend as much time together as a family as I had expected.
88. Since having my last child, I have had less interest in sex.
89. Having a child seems to have increased the number of problems we have with in-laws and relatives.
90. Having children has been much more expensive than I had expected.
91. I feel alone and without friends.
92. When I go to a party I usually expect not to enjoy myself.
93. I am not as interested in people as I used to be.
94. I often have the feeling that other people my own age don't particularly like my company.
95. When I run into a problem taking care of my children I have a lot of people to whom I can talk to get help or advice.

1
Strongly
Agree

2
Agree

3
Not
Sure

4
Disagree

5
Strongly
Disagree

194

96. Since having children I have a lot fewer chances to see my friends and to make new friends.
97. During the past six months I have been sicker than usual or have had more aches and pains than I normally do.
98. Physically, I feel good most of the time.
99. Having a child has caused changes in the way I sleep.
100. I don't enjoy things as I used to.
101. Since I've had my child:
1. I have been sick a great deal,
 2. I haven't felt as good,
 4. I haven't noticed any change in my health,
 5. I have been healthier.

STOP HERE — unless asked to do items below

During the last 12 months, have any of the following events occurred in your immediate family? Please check on the answer sheet any that have happened.

102. Divorce
103. Marital reconciliation
104. Marriage
105. Separation
106. Pregnancy
107. Other relative moved into household
108. Income increased substantially (20% or more)
109. Went deeply into debt
110. Moved to new location
111. Promotion at work
112. Income decreased substantially
113. Alcohol or drug problem
114. Death of close family friend
115. Began new job
116. Entered new school
117. Trouble with superiors at work
118. Trouble with teachers at school
119. Legal problems
120. Death of immediate family member



FAMILY STRESS COPING AND HEALTH PROJECT
1300 Linden Drive
University of Wisconsin-Madison
Madison, WI 53706

CHIP

FORM D
1983
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COPING-HEALTH INVENTORY FOR PARENTS

Family Health Program

Hamilton I. McCubbin Marilyn A. McCubbin Robert S. Nevin Elizabeth Cauble

PURPOSE

CHIP – The Coping-Health Inventory for Parents was developed to record what parents find helpful or not helpful to them in the management of family life when one or more of its members is ill for a brief period or has a medical condition which call for continued medical care. Coping is defined as personal or collective (with other individuals, programs) efforts to manage the hardships associated with health problems in the family.

DIRECTIONS

- To complete this inventory you are asked to read the list of "Coping behaviors" below, one at a time.
- For each coping behavior you used, please record how helpful it was.

HOW HELPFUL was this COPING BEHAVIOR to you and/or your family: Circle ONE number

- 3 = *Extremely* Helpful
- 2 = *Moderately* Helpful
- 1 = *Minimally* Helpful
- 0 = *Not* Helpful

- For each Coping Behavior you did *Not* use please record your "Reason."

Please *RECORD* this by *Checking* ☐ one of the reasons:

Chose not to use it Not Possible

☐ or ☐

PLEASE BEGIN: Please read and record your decision for EACH and EVERY Coping Behavior listed below.

COMPUTER CODES: IID ☐☐☐☐ GID ☐☐☐ FAMID ☐☐☐☐

COPING BEHAVIORS

	Extremely Helpful	Moderately Helpful	Minimally Helpful	Not Helpful	I do not cope this way because:		For Computer Use Only		
					Chose Not To	Not Possible	F	S	M
1 Trying to maintain family stability	3	2	1	0	☐	☐	☐		☐
2 Engaging in relationships and friendships which help me to feel important and appreciated	3	2	1	0	☐	☐	☐	☐	
3 Trusting my spouse (or former spouse) to help support me and my child(ren)	3	2	1	0	☐	☐	☐	☐	
4 Sleeping	3	2	1	0	☐	☐		☐	☐
5 Talking with the medical staff (nurses, social worker, etc.) when we visit the medical center	3	2	1	0	☐	☐		☐	☐
6 Believing that my child(ren) will get better *	3	2	1	0	☐	☐	☐	☐	
7 Working, outside employment	3	2	1	0	☐	☐	☐	☐	
8 Showing that I am strong	3	2	1	0	☐	☐	☐		☐
9 Purchasing gifts for myself and/or other family members	3	2	1	0	☐	☐	☐	☐	
10 Talking with other individuals/parents in my same situation	3	2	1	0	☐	☐		☐	☐
11 Taking good care of all the medical equipment at home	3	2	1	0	☐	☐	☐		☐
12 Eating	3	2	1	0	☐	☐		☐	☐
13 Getting other members of the family to help with chores and tasks at home	3	2	1	0	☐	☐	☐	☐	
14 Getting away by myself	3	2	1	0	☐	☐	☐	☐	
15 Talking with the Doctor about my concerns about my child(ren) with the medical condition *	3	2	1	0	☐	☐	☐		☐
16 Believing that the medical center/hospital has my family's best interest in mind	3	2	1	0	☐	☐	☐	☐	
17 Building close relationships with people	3	2	1	0	☐	☐	☐	☐	
18 Believing in God	3	2	1	0	☐	☐	☐		☐
19 Develop myself as a person	3	2	1	0	☐	☐	☐	☐	
20 Talking with other parents in the same type of situation and learning about their experiences	3	2	1	0	☐	☐		☐	☐
21 Doing things together as a family (involving all members of the family)	3	2	1	0	☐	☐	☐	☐	
22 Investing time and energy in my job	3	2	1	0	☐	☐		☐	☐
23 Believing that my child is getting the best medical care possible *	3	2	1	0	☐	☐	☐		☐
24 Entertaining friends in our home	3	2	1	0	☐	☐	☐	☐	
25 Reading about how other persons in my situation handle things	3	2	1	0	☐	☐	☐	☐	☐
26 Doing things with family relatives	3	2	1	0	☐	☐	☐	☐	
27 Becoming more self reliant and independent	3	2	1	0	☐	☐	☐	☐	☐
28 Telling myself that I have many things I should be thankful for	3	2	1	0	☐	☐	☐	☐	
29 Concentrating on hobbies (art, music, jogging, etc.)	3	2	1	0	☐	☐	☐	☐	☐
30 Explaining our family situation to friends and neighbors so they will understand us	3	2	1	0	☐	☐	☐	☐	☐
31 Encouraging child(ren) with medical condition to be more independent *	3	2	1	0	☐	☐	☐	☐	
32 Keeping myself in shape and well groomed	3	2	1	0	☐	☐	☐	☐	☐
33 Involvement in social activities (parties, etc.) with friends	3	2	1	0	☐	☐	☐	☐	
34 Going out with my spouse on a regular basis	3	2	1	0	☐	☐	☐	☐	
35 Being sure prescribed medical treatments for child(ren) are carried out at home on a daily basis	3	2	1	0	☐	☐		☐	☐
36 Building a closer relationship with my spouse	3	2	1	0	☐	☐	☐	☐	
37 Allowing myself to get angry	3	2	1	0	☐	☐	☐	☐	☐
38 Investing myself in my child(ren)	3	2	1	0	☐	☐	☐		☐
39 Talking to someone (not professional counselor/doctor) about how I feel	3	2	1	0	☐	☐	☐	☐	☐
40 Reading more about the medical problem which concerns me	3	2	1	0	☐	☐	☐	☐	☐
41 Talking over personal feelings and concerns with spouse	3	2	1	0	☐	☐	☐	☐	
42 Being able to get away from the home care tasks and responsibilities for some relief	3	2	1	0	☐	☐		☐	☐
43 Having my child with the medical condition seen at the clinic/hospital on a regular basis *	3	2	1	0	☐	☐	☐	☐	
44 Believing that things will always work out	3	2	1	0	☐	☐	☐	☐	
45 Doing things with my children	3	2	1	0	☐	☐	☐		☐

FAM ☐ 58

SUP ☐ 60

PLEASE Check all 45 items to be sure you have either circled a number or checked a box for each one. This is important.

APPENDIX D

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO
DEPARTMENT OF FAMILY HEALTH CARE NURSING

Consent to Be a Research Subject

A study is being done by Celia Buckley, R.N., a graduate student in nursing at the University of California, San Francisco, to learn more about mothers stress and coping during hospitalization of young children with ongoing health problems. When a young child has a condition that requires fairly frequent medical attention, and occasional hospitalizations, the mother must respond and cope with many demands associated with the child, the illness, and the family. I have been asked to take part in this study in order to help nurses and doctors to understand what areas are most stressful for mothers and how mothers cope when they have a young child with ongoing health problems who is hospitalized.

PROCEDURES: If I agree to be in this study, I will be asked to fill out a family data sheet and two questionnaires. I may answer the questionnaires either in my child's hospital room, or a nearby parent conference room. One questionnaire asks questions about possible areas of stress regarding the child and mother. The second questionnaire lists coping behaviors and asks whether mothers use those coping behaviors, and how helpful they might be. Answering both questionnaires will take approximately 30 to 40 minutes of my time. When I have finished, Ms. Buckley will ask for my comments about the questionnaire and any other information I wish to give her.

RISKS/DISCOMFORTS: There are few, if any, risks to me as a result of participating in this study. There is a possible loss of my privacy. However, the data sheets and questionnaires will not have my name on them, but be coded, and the codes kept locked away from the responses. My responses do not go into my child's records. My confidentiality will be protected as much as is possible within the law. There also is a slight possibility that some questions may make me feel uncomfortable or stressful. I have the right to refuse to answer any questions at any time.

BENEFITS: There will be no direct benefit to me or my child as a result of being in this study. However, the information may help future mothers and children by providing more information and understanding to nurses. This may help nurses and health care professionals improve their care and support to mothers and young children with ongoing health problems.

REIMBURSEMENT: There will be no reimbursement to me or my child for taking part in this study.

QUESTIONS: I have talked with Celia Buckley, R.N., and have had all of my questions answered. If I have any further questions, I may contact her at (916) 453-3456.

CONSENT: I have been given a copy of this form and the Experimental Subject's Bill of Rights to keep.

PARTICIPATION IN THE STUDY IS VOLUNTARY: I have the right to refuse to participate or withdraw from the study at any time without any effect on the care my child receives.

Date

Subject's signature

Investigator's signature

UNIVERSITY OF CALIFORNIA, DAVIS

EXPERIMENTAL SUBJECT'S

BILL OF RIGHTS

The rights below are the rights of every person who is asked to be in a medical research study. As an experimental subject, you have the following rights:

- 1) To be told what the study is trying to find out;
- 2) To be told what will happen to you and whether any of the procedures, drugs, or devices is different from what would be used in standard practice;
- 3) To be told about the frequent and/or important risks, side effects or discomforts of the things that will happen to you for research purposes;
- 4) To be told if you can expect any benefit from participating and, if so, what the benefit might be;
- 5) To be told other choices you have and how they may be better or worse than being in the study;
- 6) To be allowed to ask any questions concerning the study, both before agreeing to be involved and during the course of the study;
- 7) To be told what sort of medical treatment is available if any complications arise;
- 8) To refuse to participate at all or to change your mind about participating after the study is started. This decision will not affect your right to receive the care you would receive if you were not in the study;
- 9) To receive a copy of the signed and dated consent form;
- 10) To be free of pressure when considering whether you wish to agree to be in the study.

If you have other questions, please ask the researcher or research assistant. In addition, you may contact the Human Subjects Review Committee, which are concerned with protecting volunteers in research projects. You may reach the committee office by calling (916) 752-2075, from 8:00 am to 5:00 pm, Monday through Friday, or by writing to the Human Subjects Review Committee, Office of Research, 275 Mrak Hall, University of California, Davis, California 95616.

FOR REFERENCE

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