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## Parental Coping With a Chronically Ill Child

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**Parental Coping With A Chronically Ill Child**

**by**

**Shari Jo Allore Bertolone**

**A THESIS**

**Submitted to  
Grand Valley State University  
In partial fulfillment of the requirements for the  
degree of**

**MASTERS OF SCIENCE IN NURSING  
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## ABSTRACT

### PARENTAL COPING WITH A CHRONICALLY ILL CHILD

By

Shari Jo Allore Bertolone

The purpose of this study was to determine what coping mechanisms families of chronically ill children indicated they utilized to cope on a daily basis. This study utilized the Coping Health Inventory for Parents (CHIP) to collect data. The CHIP is designed to assess parents perceptions of behaviors they are currently using to manage family life. There are three main coping patterns focused on and it is hypothesized that a balance of these three patterns is essential for a positive outcome. This study found there are certain mothers and fathers who are at risk for not using a balance of coping patterns. The mothers found at risk were younger mothers with less formal education. Fathers with lower incomes were also found to be at risk. Parents whose child needed frequent hospitalizations and physician attention also were found to be at risk for an imbalance of coping patterns. By determining which coping patterns are employed by parents, nurses can support current coping styles and facilitate the use of additional methods.

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CHAPTER 1  
INTRODUCTION

The impact of chronic illness on the family and the coping patterns families employ have been popular issues for behavioral and family scientists over the past decade. Prevalent research questions focus on the impact of the illness on the family, changes in family dynamics, and how these changes affect the ill member. Families with chronically ill children are subject to similar concerns. A chronic illness is defined by Mattson (1972, p. 801) as "a disorder with a protracted course which can be progressive and fatal, or associated with a relatively normal life-span, despite impaired mental and physical functioning." Chronic illness, which is an umbrella term for diseases such as cystic fibrosis, cerebral palsy, diabetes and asthma, comprises 15% of all childhood illnesses (Sabbeth & Leventhal, 1984). Although each disease has its own symptoms, treatment protocols and prognosis, similarities exist in terms of impact on the family and family coping. Chronic diseases are characterized by intensive medical care at home and frequent hospitalizations for acute exacerbations.

Medical technology is continually addressing the issues surrounding chronic illnesses. Medical treatments that expand the life expectancy of chronically ill children are being developed. Because of the increasing possibilities for cures of many chronic illnesses, it is paramount for children and parents to be optimistic about their future. Along with this positive viewpoint, families must be realistic about the demands of the long term medical condition. Some of the hardships that face families who have a chronically ill child are increased financial strains, changes in prior routines and increased time constraints. These and many more factors can precipitate stress for the family.

Lazarus (1966) conceptualizes stress as demands that exceed the capabilities of the involved persons based on their stress perception. Stress is a generic term that encompasses many physiological and psychological phenomena. These phenomenon include a precipitating event, a reaction to this event and an interaction between the two. A chronic illness in a family member can pose as a stressor according to Lazarus's definition because it places both physical and emotional demands on the family. Often the families of the chronically ill

are forced to be knowledgeable and skillful in areas previously the domain of professionals. Routines and treatment protocols must be worked into patterns of daily living, leaving little personal time to pursue career and leisure activities. Because these illnesses are chronic, most of the care takes place in the home. This includes providing special diets, using technical equipment and providing therapy and medication. The scarcity of child home health care providers and the increasing trend towards home care, compounds the problem and the lack of support to the family.

It is at this time that it is imperative to maximize positive coping resources in order to maintain some stability and effective family functioning. Lazarus (1966) describes coping as efforts to maintain control under conditions of harm, threat or challenge when a routine response is not available. Coping includes any and all actions towards diminishing the demands and maximizing all resources. Coping is also linked closely with adaptation. McCubbin, Sussman and Patterson (1983) conceptualize adaptation as "the process that families use to achieve stability in the face of stressful life events and transitions." The stressors already identified threaten the solidity of

these families. Frequently, prior to the illness, families have a general sense of stability. This balance is threatened by the uncertainty of the illness, the care of the child and any prior stressors that may be potentiated at this point. These families need to be aware of and call upon all internal and external supports.

#### **Problem Statement**

This research will explore the question of what coping strategies parents report using when caring for a chronically ill child on a daily basis.

#### **Purpose**

The purpose of this study is to identify coping patterns that mothers and fathers use to manage the care of a chronically ill child. By identifying coping methods, positive coping can be encouraged and negative coping redirected.

## CHAPTER 2

### LITERATURE REVIEW AND CONCEPTUAL FRAMEWORK

#### Selected Review of Literature

The stress of caring for a chronically ill child at home impacts each family member differently. Studies such as Lawler (1966), Solnit and Stark (1961), and Burke, Costello & Derry(1988), focus more on mothers and their relationship with the chronically ill child. It has been hypothesized that the birth of an imperfect child is more distressing to the mother than the father (Sabbeth, 1983). Mothers may experience stages of grief. Initially they mourn the loss of their anticipated perfect child. Denial may also be evident as well as pretending the illness doesn't exist and fantasizing that the baby is perfect. When the reality of the care needed to maintain the child sets in, many mothers become angry. Frequent responses are "Why me", and "What have I done to deserve this"? Some mothers feel as if it is their fault, or that God is punishing them (Sabbeth, 1984).

Studies support the idea that fathers are affected differently by the illness. Gayton (1977) found that 32% of fathers with a chronically ill child obtained

scores suggesting emotional disturbances on the Minnesota Multiphasic Personality Inventory (MMPI). Apley (1967) found that 42% of fathers had unsatisfactory relations with their children. Fathers of chronically ill children have been described as spending long hours at work and not directly involving themselves with the care of the child (Sabbeth, 1984). McCullom and Gibson (1970) found 47% of fathers stated that they participated in therapy rarely or never. Financial demands may keep fathers physically absent and removed from the situation.

The family unit as a whole can also be affected by the illness. Gayton (1977), studied 43 families using the Family Concept Q-sort scale and supported the hypothesis that the primary effect of chronic illness on the family is decreased family satisfaction and family adjustment. The family may also go through many strains on its relationships. McCubbin et al. (1983) identified altered relationships with friends because of friends inability to deal with the illness and some families experienced rejection by their peers. Intrafamily strains were also apparent such as coalitions between the ill child and primary caretaker leaving other members out, blaming a family member for the illness,

sibling competition for parental time and overall escalating family tension and conflict. Financial responsibilities and medical concerns add to intrafamily strain. These stressors can wear down even the strongest of families.

There are many published studies on chronic illness and its ramifications. In order to maintain a holistic viewpoint, it is necessary to understand the impact the illness has on the family. The findings of the studies reviewed support the premise that chronic illness has the potential to precipitate stress for the family. In Turk's (1964) study of 25 children with cystic fibrosis (CF) the parents reported lack of flexible leisure time less quality time with spouses and decreased sexual activity. These factors lead to resentment or negative feelings may develop towards the ill child. In a study of 111 families with a CF member, Meyerowitz and Kaplan (1967) reported patients feeling their family life, routines and family roles were disrupted. Families perceived negative attitudes from the community which added to the isolation they felt (Hymovich,1983). McLean, Schragger and Stoeffers (1968) studied asthmatic children and found a multitude of financial burdens placed on the family. Transportation,

equipment, specialists and medications all added to the financial hardship. Epidemiological studies showed that 20 to 30 % of chronically ill children had behavioral problems. This is twice the rate of healthy children (Burns and Lavigne, 1981). This poses as one more threat to the family. These studies exemplify chronic illness as a stressor.

There are also several empirical studies published supporting the need for positive coping and revealing coping patterns that parents of ill children utilize. McCullom and Gibson, (1970) conducted a study of 56 families of children with cystic fibrosis. Four stages of coping were named and explained. The prediagnosis stage is characterized by wondering what is wrong with the child, and problems with bonding. When a definite diagnosis is arrived at families move into the confrontation stage, where grief and associated feelings are seen. The third stage is termed the adaptive stage. Family relationships and stability are maintained, and there is an underlying hope that a cure will be found and the child will live. The final stage, appropriately named the terminal stage is marked by the death of the child. The authors did not explore this stage any further. These stages of coping are plausible, but

whether these stages are unidirectional or repeated during various stages of the child's illness is uncertain. The methodology for this study was primitive, no validity studies were conducted on the tools and the sample size was small and predominantly white leading to poor generalizability.

Gibson (1988) conducted a study on 56 families with a child with CF. The author discovered three main coping resources utilized by these families. The first resource was social support, including support from friends, family, spouse and the health care system. A second resource was problem solving skills. These skills involved the ability to maintain a positive outlook on the situations, remain optimistic and avoid a disease focus. The third resource was a belief system. This incorporated a feeling of mastery over the demands and threats of the illness. Friedman, Chedof, Masan and Hamburg (1963) found similar results in their study of families with leukemic children. Gibson (1988) used Lazarus's theory on stress and coping for a strong theoretical framework, but her study lacked a valid tool for data collection. The sample size was small with unclear demographics limiting generalizability.

Two studies have utilized a common tool, the Coping Health Inventory for Parents (CHIP) (McCubbin, McCubbin, Nevin and Cauble, 1979), as the data gathering instrument.

McCubbin, Patterson, Cauble, Wilson, and Warwick, (1983) utilized the CHIP to study 100 families of children with cystic fibrosis. The purpose of the study was to correlate positive coping with improved health status of the children, stressing the importance of positive coping. Results of the study supported the idea that positive coping such as maintaining family integration and maintenance of social support was related to statistically significant increases in the child's health as measured by health indices such as pulmonary function, height and weight percentiles. The tool used has established validity and reliability. The methodology used in this study was sound, but extraneous variables that have direct bearing on the child's health were not addressed (e.g., course of the disease, number of hospitalizations, number of children in the family).

Austin and McDermott (1988) used the CHIP to study 27 families of epileptic children. The purpose of this study was to link positive parental attitudes with adaptive coping responses. The Fishbein Expectancy

Value Model of Attitude (Fishbein and Azen, 1975) was used to evaluate the families. Parents were asked questions about beliefs and using a Likert format. Each belief could be rated as a positive, a negative or a neutral. Coping strategies of maintaining family integration and maintaining social support were correlated with positive attitudes toward the children. The sample size for the study was 27 giving it little generalizability. Extraneous variables affecting parents attitudes were not addressed. The only coping patterns studied were adaptive patterns, with no attention given to negative coping and if this was affected by parental attitudes. These results were supported in a study by Copelli, McGrath, MacDonald, Boland, Fried, and Katsanis. (1988). They studied 38 families with a child with cystic fibrosis. They utilized different tools, but found similar results. They proposed that families who were adjusted to and accepting of the chronic illness, had children with positive views of themselves and their illness.

The literature reviewed demonstrates that most studies on coping with a chronically ill child are non-experimental, descriptive and retrospective. Although there are some empirical studies, pure experimental

research on the topic is scarce. The studies that have been done do reveal some common findings but also have many common flaws. The core findings of research on the impact upon the family of a chronically ill child are that chronic illness is a stressor and produces changes in family functioning. Research on coping with these changes has common themes such as the need for the family to mobilize resources such as family support, health care workers and the belief that they have the ability to handle the illness and its ramifications. Another common link seen in the research is that over time, with support, there is a gradual adjustment to the illness.

#### **Conceptual Framework**

McCubbin, Sussman and Pattersons (1983) Double ABCX Model of family stress will be used as the conceptual framework for this study. This framework provides a way of viewing family adaptation efforts over time in dealing with chronic illness.

The ABCX theory was initially developed by Reubin Hill in 1949 and updated in 1958. Hill developed four main pre-crisis variables, while McCubbin expanded the model to include post-crisis variables. There are four main pre-crisis variables. A-the stressor event, B-

family resources, C-the family's perception of the stressor and X-the crisis. Hill feels there are two distinct types of stressors (A factors): normative and catastrophic. Normative stressors are the events that cause change by adding or losing a member, or some loss of family unity. Catastrophic stressors are those that are unexpected and unplanned. The birth of a chronically ill child is a catastrophic stressor. The impact on the family of a single stressor event cannot be understood completely without exploring other normative life changes.

The B factor helps determine the family's ability to prevent the stressor from disrupting family dynamics (Hill, 1949). Some examples of these crisis resisting resources are a strong marriage, financial support, extended family and community support.

The C factor is how the family perceives the stressor as affecting the family. Some families may be threatened by or resentful of the illness. As demonstrated previously, many families feel that giving the illness a positive meaning helps to cope positively.

The X factor is the crisis itself. Hill (1949) describes this as the degree of disruptiveness and disorganization of the family. The crisis may be

prevented, but is inevitable if there is a demand capabilities imbalance. Many families see the constant demands of caring for an ill child as far outweighing their abilities.

There are four post-crisis variables to be evaluated: aA-pile up, bB-resources, cC-family interpretation of the illness, and xX-family adaptation. McCubbin utilizes this framework to assess the family's coping and adjustment to chronic illness.

Pile up (aA) of stressors has a large influence on family adaptation. The family has not only the initial stressor, the illness, but all normative stressors to deal with. Pile up for the family of a chronically ill child is a very real problem. As indicated there are family concerns, financial concerns, and the ambiguity of the illness. All additional problems only compound the crisis potential.

Family adaptive resources (bB) are the family's abilities to meet the challenges and needs that occur in a crisis situation. There are three kinds of resources: family's personal resources, family resources and community resources. These include the existing resources and any support systems that have developed

since the crisis (ie. medical personnel and specific support groups).

The cC factor is the family's perception of the situation as a whole. This interpretation includes the definition the family makes of the crisis, the meaning attributed to it and the family's attempt to put the situation in perspective and redefine it. This perception plays a critical part in family functioning and coping.

The xX factor is family adaptation or the reduction of disruption to the family. McCubbin et al. (1983) states that adaptation is a continuum with maladaptation and bonadaptation being the two points. Bonadaptation results in strengthened family structure, control over environment and family development. Maladaptation is an imbalance at one or more levels of functioning, or a balance, but at great compromise to the family unit.

This theory suggests a framework for assessing families with chronically ill children. In looking at the outlined factors, one can better determine family's perspectives and needs and try to intervene where possible.

The literature reviewed certainly substantiates the concept that chronic illness of a family member is a

likely precipitator of stress. The double ABCX framework gives a method of looking at how the family adapts to such stressors. While looking at the illness, the family resources, and the family interpretation of the illness, one can determine if the illness is going to be seen as a crisis by the family. If the illness does present a crisis to the family, the post-crisis variables can be assessed. One key concept for these families can be the pile up of both normative and situational stressors. This pile up includes emotional, physical and financial concerns surrounding the care of an ill child. Supports systems such as friends, relatives, church and the health care workers can participate in lessening the degree of crisis to which the family is subject. When looking at these very individual factors for each family, their ability to cope with the illness can be addressed. Because of the increased longevity of children with various chronic illnesses, the coping efforts on the part of parents are going to be more long term and persist through various developmental stages. When coping styles are identified, interventions can be made to support and facilitate positive coping means and to avoid ineffective coping styles.

### Research Question

What methods do parents indicate they utilize to cope with a chronically ill child on a daily basis?

### Definition of Terms

Chronic illness- A disorder with a protracted course which can be progressive and fatal, or associated with a relatively normal life-span, despite impaired mental and physical function (Mattson, 1972).

Family stress- A state that arises from actual or perceived imbalance in demands and capabilities in the family.

Coping behaviors- Activities the family utilizes to deal with stressor events and associated conflicts in an effort to prevent the stressor from disrupting the family unit.

Perception of stressors- The seriousness of the experienced stressor as defined by the family. The impact the stressor has on the family.

Crisis- The family's inability to restore stability. Any change that leaves old coping methods inadequate.

Pile Up- The accumulation of demands from situational and normative stressors.

Resources- All capabilities for resisting crisis.

Adaptation- Descriptive term determining the outcome of

family adjustment. There are two levels of adaptation:  
bonadaptation-homeostasis and maladaptation- an  
imbalance at some level of family functioning.

## Chapter 3

### Methodology

#### Introduction

The purpose of this study was to examine how parents with chronically ill children report that they cope with various aspects of their children's care. This chapter describes the methodology for the study, the research design, sample selection, data producing instrument, procedure and protection of human rights.

#### Research Design

The research design was a multivariate descriptive design to identify how parents of chronically ill children indicate they handle the stressors they encounter as the result of the illness.

#### Setting

The study was conducted at Butterworth Hospital, a 500 bed acute care hospital. This hospital also is affiliated with an outpatient clinic for the pediatric population. These outpatient clinics include specialties such as pulmonary, cystic fibrosis, hematology-oncology and developmental assessment. Both the outpatient clinic and the inpatient population were be utilized to gather families to participate in the study.

### **Sample**

The sequential sample consisted of forty-seven parents with one chronically ill child. To reduce variability the illnesses included were limited to cystic fibrosis, cancer and cerebral palsy. The mother and father (if applicable) were asked to fill out the questionnaire separately. These participants were able to speak, read and write in English at the sixth grade level at a minimum. Subjects were excluded from the sample under the following conditions: If there was more than one chronically ill child in the family, if the child had more than one illness and if the child was over fourteen years old.

### **Data Producing Instrument**

The instrument utilized in this study was the Coping Health Inventory for Parents (CHIP) (McCubbin, McCubbin, Nevin & Cauble, 1979) (Appendix A). This tool was developed to record what coping methods parents report that they use in the management of family life when one family member is ill. This inventory has been used in many studies with various illnesses. The CHIP was developed including behaviors that families stated they used in previous studies of families in response to stress. The initial tool consisted of 80 items.

McCubbin, McCubbin, Patterson, Cauble, Wilson and Warwick, (1983) conducted a study of 185 parents of children with cystic fibrosis. Thirty of the eighty items were listed as not applicable. Five other variables were eliminated as the result of showing little variance. The 45 items that were left were analyzed using SPSS principle factoring. The scree test was applied to determine the final number of factors. The three factors resulting were designated as coping patterns and represented 71% of the variance. Cronbachs alpha computed for each item of each pattern indicated the reliability of .79, .79, and .71 respectively.

The mean and standard deviation from a sample of 308 parents with an ill child were produced for each coping pattern (McCubbin and Thompson, 1987). The results were published as an index of data for comparison with other samples of parents with other types of illnesses.

Validity checks were provided using the items from the CHIP and from a discriminant analysis between low conflict and high conflict families with children with cerebral palsy. The findings suggested that families in high conflict utilized all three coping patterns.

Another validity assessment of the CHIP was done using the Family Environmental Scale (Moos, 1979). It was hypothesized that the three coping patterns would be associated with dimensions of the family environment. Coping patterns I and II were correlated with family cohesiveness. Coping pattern I was inversely associated with family conflict. Coping pattern II was associated with family expressiveness.

The first coping pattern is associated with 19 behaviors that focus on family support, relationships and parents view of life with a chronically ill child. Coping Pattern I is called Maintaining Family Integration, Cooperation, and An Optimistic Definition of the Situation.

Coping pattern II consists of 18 items involving parents efforts to pursue relationships with others and to get involved in events that put emphasis on their self concept and individualism. This pattern is called Maintaining Social Support, Self Esteem and Psychological Stability.

Coping pattern III contains 8 behaviors directed at effective utilization of the health care system and the support of families in similar situations. Coping pattern III is called Understanding the Medical

Situation Through Communication with Other Parents and Consultation with Medical Staff.

The CHIP is a self report questionnaire. Parents are asked to record how helpful each behavior is in their particular situation. If the behavior is not utilized, they are asked to qualify why it isn't used in terms of "we choose not to" or "it is impossible." Two levels of behaviors are defined by this tool, the coping behaviors listed and the three main coping patterns they make up.

There are 20 studies which have utilized the CHIP for data collection. Of this group 77% of subjects were parents of chronically ill children and 20% were caretakers of these children (McCubbin and Thompson, 1987). The CHIP has established itself as a reliable and valid tool for data collection, especially for this particular population.

#### **Protection of Human Subjects**

Before collecting data, the proposal was submitted to the research committee and the internal review committee to assure protection of the rights and welfare of human subjects. A standard introduction to families was utilized (Appendix B). Risk to the family was minimal because participation was voluntary. The

subject matter of the questionnaire and the design of collecting data ensured confidentiality and anonymity of all subjects.

### Procedure

The parents were recruited through the pediatric outpatient clinic and inpatient census at Butterworth hospital. The nurses in these facilities were given an inservice on the purpose and the aim of the study and the criteria that parents must meet to participate in the study. Parents meeting the listed criteria were recommended by nurses in this setting. As parents were referred, each parent was approached in the setting individually and informed of the purpose of the study (see Appendix B). They were assured that their anonymity would be maintained. The participants were assured that their spouse would not be informed of their response by the data collector. The parents were assured that the institution would not be privy to any responses on an individual basis. The participants then filled out a consent form (Appendix C). In addition to the CHIP, a demographic data sheet (Appendix D), collecting information such as age, educational level and family income was completed by each parent.

## CHAPTER 4

### RESULTS

Data were analyzed using SPSS (version 4.0). The significance level was established at .05. The sample included 47 parents of chronically ill children. There were 11 families in which both mother and father filled out the questionnaire. These parents were looked at separately and as part of the whole. The return rate for these questionnaires was 75%. Responses of parents were looked at using descriptive statistics. Parent pairs were analyzed using paired t tests to discover any significant difference between mother's and father's responses. Correlations between demographic data and the three coping patterns were looked at using Pearson's r.

#### Characteristics of the sample

The sample contained 29 mothers and 18 fathers. The average age of the mothers was 33.8 (range 23-47) and the average age of the fathers was 35.6 (range 25-43). The family income ranged from less than \$10,000 annually to \$90,000 annually (see Table 1).

Table 1  
Family Income

Income	Fathers		Mothers	
	f	%	f	%
<10,000	1	5.6	2	6.9
10,000-				
19,900	1	5.6	2	6.9
20,000-				
29,900	8	44.4	7	24.1
30,000-				
39,900	1	5.6	2	6.9
40,000-				
49,000			5	17.2
50,000-				
59,900	5	27.8	4	13.8
60,000-				
69,900	1	5.6	3	10.3
70,000-				
79,900			1	3.4
80,000-				
89,900	1	5.6	3	10.3

Fifty-five percent of the families had an annual income of over \$20,000 and 48% more than \$40,000.

Family size ranged from 1 to 5 children.

(see Table 2).

Table 2

Family Size

Children	Fathers		Mothers	
	f	%	f	%
1	5	27.8	10	34.5
2	3	16.7	6	20.7
3	7	38.9	9	31.0
4	3	16.7	3	10.3
5			1	3.4

The sample was a well educated group in which all of the parents had high school diplomas, 59% had college degrees and 9% had graduate degrees.

Forty of the parents were married, 3 parents were divorced, 3 parents were single and one classified herself as other.

The sample was very homogeneous, but reflective of the community, with 83% being white. Blacks and Hispanics completed the ethnic makeup of this group (see Table 3).

Table 3

Ethnic Makeup

Ethnic Group	Fathers		Mothers	
	f	%	f	%
Hispanic	1	5.6	2	6.9
Black	1	5.6	4	13.8
White	16	88.9	23	79.3

The length of time since diagnosis of the illness ranged from 1 month to thirteen years with the mean being 2.95 years (see Table 4).  
Table 4

Years Since Diagnosis

Year(s)	f	%
< 1	21	45
1-2	9	19
2-4	10	21
6-9	4	9
12-13	3	6

The sampling included parents of hospitalized and non-hospitalized children. Eight percent of the children whose parents participated in the study were hospitalized at the time their parent(s) completed the survey.

The parents had children with a variety of ages. The youngest child was 6 months old and the oldest child was fourteen years old. The mean age of the children in this sample was 7.2 years old.

The sex of the children is shown in Table 5.

Table 5

Sex of the Chronically Ill Child

Sex of child	f	%
Male	23	48
Female	24	51

Children whose parents comprised the sample had three main chronic illnesses. These diagnoses are seen in Table 6.

Table 6

Diagnoses of the Children

Diagnosis	Fathers		Mothers	
	f	%	f	%
Cerebral Palsy	1	5.6	4	13.8
Cancer	9	50.0	18	62.1
Cystic Fibrosis	8	44.4	7	24.1

The parents were eligible for inclusion in the sample if they had any of the following relationships to the child: mother, father, step parent or adoptive parent. The frequency of these relationships are in Table 7.

Table 7

Relationship to Chronically Ill Child

	f	%
Mother	25	53.2
Father	15	32
Step Parent	2	4.2
Adoptive parent	5	10.6

**Research question**

The research question evaluated was what coping methods do parents with a chronically ill

child state they use to cope on a daily basis.

The means of the scores for both mothers and fathers for each of the three coping patterns are given in Table 8.

Table 8  
Mean Scores of Coping Patterns

Coping patterns		I	II	III
		Integration Cooperation & Optimism	Support Esteem & Stability	Health Care Consultation Communication
Fathers	mean	37.05	23.33	12.33
	SD	9.37	8.93	5.97
	range	16-56	9-41	4-19
Mothers	mean	43.48	26.20	17.38
	SD	8.24	8.93	4.66
	range	25-55	16-40	8-22

The mean scores and the standard deviations are based on the sample. The normal ranges are published by the authors of the tool. There are no published mean scores. Based on the published information, mothers' range scores tend to be higher than the fathers' range scores. All of this samples mean scores fell within the published range. The fathers' mean scores for all three coping patterns fell below the mothers' mean scores.

The reliability of each of the three main coping patterns was analyzed using alpha coefficients which were calculated separately for mothers and for fathers. These coefficients are listed in Table 9.

Table 9

<u>Alpha Coefficients for Coping Patterns</u>	<u>Fathers</u>	<u>Mothers</u>
Coping Pattern I	.8686	.8398
Coping Pattern II	.8708	.8121
Coping Pattern III	.8526	.8499

The correlation between selected demographic data and the three coping patterns for both mothers and fathers was assessed. These values are listed in Table 10.

Table 10

Correlation Between Demographics and Coping Patterns

	Coping pattern I	Coping pattern II	Coping pattern III
<u>Mothers</u>			
Age	.3692*	.3309*	.2552
Income	-.1014	.2676	-.1646
@Years	.0495	.1001	.0754
@Hospital	-.2784	-.3680*	.0585
@Doctor	-.1211	-.4149*	.0589
@Care	-.1968	.0034	-.2641
@Education	-.0994	.3696*	-.2428

	Coping pattern I	Coping pattern II	Coping pattern III
<u>Fathers</u>			
Age	.1221	.2543	-.0556
Income	.1529	.4660 *	-.0742
Years	-.0076	.4902 *	-.2511
Hospital	.0924	-.1871	.0122
Doctor	-.3056	-.3901 *	-.2841
Care	.2584	.2604	.1207
Education	.2323	.2596	-.0914

@ Years-Years known of child's diagnosis  
 @ Hospital-# of hospitalizations in a year  
 @ Doctor-# of visits to the doctor in a year  
 @ Care-Percentage of care done by the parent  
 @ Education-Highest level of education  
 \*significant to .05

A significant relationship was found between Coping Pattern I and age of mother:  $\underline{r}=.3692$ ,  $\underline{p}<.05$  and Coping Pattern II and the age of mother:  $\underline{r}=.3309$ ,  $\underline{p}<.05$ . This indicates that as the age of the mother increased, the use of Coping Pattern I and Coping Pattern II increased. Two significant negative correlations were found between Coping Pattern II and the number of hospitalizations of the child  $\underline{r}= -.3680$ ,  $\underline{p}<.05$ , and the number of visits to the doctor  $\underline{r}=-.4149$ ,  $\underline{p}<.05$ . This indicates that as the number of hospitalizations and the number of visits to the doctor increased, the utilization of Coping Pattern II by mothers decreased. There was also a correlation between Coping pattern II and the mother's education  $\underline{r}=.3696$ ,  $\underline{p}<.05$ . This indicates that the higher the level of education, the more these mothers reported utilizing Coping Pattern II.

For the fathers, a relationship was noted between Coping pattern II and level of income  $\underline{r}=.4660$ ,  $\underline{p}<.05$ , indicating that the higher the total family income, the more Coping Pattern II was used by the father. There was a negative significant correlation between Coping pattern II

and visits to the doctor  $r = -.3901$ ,  $p < .05$ , again indicating that the more frequently the child visited the doctor, the less the father utilized Coping Pattern II. The association between Coping pattern II and years the family has known of the illness was also significant  $r = .4902$ ,  $p < .05$ . This indicates that the longer period of time that the fathers were aware of the child's diagnosis, the more they utilized Coping Pattern II.

The eleven parent pairs were analyzed separately to determine the differences in their responses. These were evaluated using the t test for dependent samples. The results are summarized in Table 11. The only significant difference was seen in Coping pattern III. This indicates that the parents of these children differ the most in their utilization of Coping Pattern III.

Table 11

T test of Parent Pairs

	Mean	SD	Value	df	Prob
Coping Pattern I	2.45	6.5	1.25	10	.239
Coping Pattern II	.4545	8.5	.18	10	.864
Coping Pattern III	4.27	6.3	2.25	10	.048*

\*  $p < .05$

## Chapter 5

### Discussion

The purpose of this descriptive-correlational study was to describe the methods parents indicate they use to cope with a chronically ill child.

The means for all the coping patterns fell within the norms published by McCubbin and Thompson (1987) (see Appendix E). This indicates that these parents report the same coping methods found in previous studies of parents of chronically ill children. The mother's means were higher for each of the three patterns.

This study found a significant relationship between certain coping patterns and socio-demographic data. A correlation between Coping Pattern I, which centers around family dynamics and the parent's outlook on life with a chronically ill child, and maternal age was found. This relationship is supported by Gibson's (1988) findings that spouse and family are most often listed as the primary support to older mothers. Coping Pattern I also involves an optimistic definition of the situation. Over time parents may become more knowledgeable about the child's

prognosis and have had more time to deal with and gain increased control of stressors. Often younger mothers feel they need to be more independent and may not employ the support that their family offers.

Coping Pattern II was correlated with several demographic measures. This pattern focuses on developing relationships that make the parent feel important and includes activities which increase feeling of self worth and decreased psychological stress. This study identified a relationship between maternal age and this coping pattern. This does not support the findings of McCubbin et al. (1983) which found a negative correlation, although insignificant, between age and Pattern II. McCubbin et al. (1983) felt that as mothers became older, they utilized these self fulfilling methods less often. However, there is supporting evidence in the literature that older mothers seek out social support more than younger mothers (Schilling, 1986).

Another significant relationship was found between Coping Pattern II and maternal education. Although no clear support is seen in the literature

for this finding, Mattson (1972) feels that "effective coping uses intellectual processes to master distressing emotions caused by illness." In addition, mothers who are better educated may have knowledge of and access to more community resources. They may also be more aware of the benefit of enlisting social activities and relationships to effect a positive method of coping.

Three significant negative relationships were found. The number of visits of the ill child to the hospital in a year was negatively correlated with Coping Pattern II for mothers, and number of visits to the doctors in a year was negatively correlated with Coping Pattern II for the mothers and fathers. These hospitalizations and visits to the doctor are relative indications of the severity of the child's illness. Of all the Coping Patterns, pattern II necessitates the most time away from the ill child. If a child needs substantial medical attention (hospitalizations and office visits) the time allowed for parents to pursue personal interests and relationships is decreased. Burke, Costello and Derry (1990) concluded that stress is

increased with successive hospitalizations which gives mothers less time and emotional energy to invest in themselves. Financially, the burden of frequent visits to the doctor falls on the fathers. Gayton, Standford and Friedman (1977) reported that fathers, as the primary economic provider, are most often responsible for financial concerns. This burden and possible lack of financial resources leaves fathers less than motivated to pursue self-focused activities and relationships. Another correlation was seen between fathers level of income and the use of Coping Pattern II. Both Meyerwitz and Kaplan (1967) and Turk(1964) illustrate financial demands as very draining to families and as an added stressor. Because our culture considers the fathers responsible for financial demands, being able to effectively manage the family budget may contribute to a positive self image and may afford these fathers more time and monetary resources to pursue outside activities.

The last correlation was seen between the years the father has known of the illness and utilization of Coping Pattern II. Many coping theories suggest that adaptation to a chronically

ill child is a progressive phenomenon (McCullom & Gibson, 1970). Initial stages of diagnosis and care of the child are depicted as difficult with many accumulative stressors. Some researchers feel that over time the situation may become more manageable. Also, initially many parents are totally involved in the care of the child. As time progresses, fathers may be able to focus on themselves more and their own self esteem and interests. Some researchers feel the opposite is true. Austin and McDermot (1988) propose that parents, over time, become less able to focus away from the child and less functional in their coping resources. A significant relationship between years known of the child's illness and the use of Coping Pattern II did not emerge for the mothers in this study.

When looking at the eleven parent pairs, the only significant difference was seen in their use of Coping Pattern III. This pattern focuses on the parent's relationship to the health care team. This difference supports McKeever's (1981) study of fathers with chronically ill children. He found that most fathers were dissatisfied with the

information they received from the health care institution. Other literature depicts fathers as spending more time working and away from the child making contact with the health care team less frequent. McCubbin et al. (1983) found that the mother's relationship with the medical center was paramount to her functioning. Sabbeth (1984) also supports this theory. She found mothers more involved in the day to day care, more affected by the illness and needing to be more knowledgeable of the disease process. They seek this knowledge from their health care provider. Thus improving their relationships with the health care team. It is interesting to note that coping pattern III found no significant relationships with the variables studied. The significant correlations were seen predominantly in coping pattern II, which the t test shows as being most alike in responses for these parent pairs. Possibly, the variables that were studied were not those that elicited significant relationships. Perhaps if variables such as religiosity and each individual coping pattern were studied, more significant relationships with coping patterns I and III would

have been seen.

### **Limitations**

The major limitation of this study is the homogeneity of the sample. This confines the ability to generalize to a larger population. This sample was especially homogeneous in respect to ethnicity. There may be cultural variations and coping may be experienced differently by ethnic minorities. Another limitation is the sampling method. A non-random convenience sample was utilized to increase the sample size. This sample size was also relatively small. Both of these factors affect generalizability. Another limitation was that coping methods were assessed by a self-report instrument which may or may not reflect actual coping. Lastly, not all extraneous variables that may impact coping have been examined. There are many other factors such as other stressors that may impact coping but were not evaluated in this study.

### **Indications for nurses**

Based on the theoretical framework of this study, a balance of all three coping patterns is vital to effective coping. Because coping with a

chronically ill child involves a complex phenomenon of responses, nurses need to be able to assess these. By using a tool such as the CHIP, parental coping resources can be evaluated. The coping patterns that parents are utilizing can be encouraged and supported. Also, other possible coping strategies can be suggested, trying to achieve a balance of all three. Based on this study, there are risk factors for poor utilization of certain coping patterns. Younger mothers and mothers with less education did not utilize coping pattern II. Nurses can apply this information and target this population. The importance of pursuing relationships and activities that increased their self worth should be pointed out to these mothers. Also, the barriers to using these coping methods can be assessed. Respite and foster care are possibilities, to allow mothers time away from the ill child and to focus on themselves. There are many support groups that are formally and informally set up for families with chronically ill children. Targeting these mothers that are at risk and getting them involved in community resources can be a very important intervention for these

mothers and the ill child. Another population that were at risk for not utilizing coping pattern II was low income fathers. Nurses can get involved here and see what financial resources are available. If hospital and doctors bills are becoming overwhelming, nurses can suggest a minimal monthly payment plan that most hospitals have adopted, but many families are unaware of. There are also many community resources that can assist with financial concerns that these fathers may not be aware of. Doing a thorough assessment of high risk parents, the resources they are utilizing and the barriers to utilization of all the coping patterns may open up a variety of coping resources for these parents.

Nurses can look at these patterns for both parents and focus on the whole family. If parents are using one or two of the patterns, but not all, suggestions and referrals can be made to help them utilize all three. Because both mothers and fathers scored at or above the published means for Coping Pattern III, the use of the health care team as a coping mechanism is supported. Nurses can be the first line of the health care team and initiate

assessment and intervention for these families.

This can help motivate other nurses to learn more about families with chronically ill children.

#### Implications for research

Considerable research needs to be done in the area of parental coping with a chronically ill child. It is necessary to support and strengthen this ever-growing population. This study could be repeated with a larger sample size. Continued assessment of coping methods and their effect on specific outcomes is indicated. Studies looking at coping methods utilized in non-Caucasian, single parent and reconstituted families would be beneficial. The sub sample of non-caucasian parents in this study was too small to do data manipulation (17% non-Caucasian). Also, the effects of both parents' coping behaviors on family stability and child well being is another area open for research. This research could uncover interactional, organizational and cognitive factors which affect family coping. Clues to causal relationships among key variables can be discovered. All of this will stimulate more research so that a more integrated theory of coping

with a chronically ill child can be developed.

## APPENDICES

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## LIST OF REFERENCES

## List of References

- Apley, J., & Barbour, R.F. (1967). Impact of congenital disease on the family. British Medical Journal, 7, 103-105.
- Austin, J., & McDermott, N. (1988). Parental attitudes and coping behaviors in families of children with epilepsy. Journal of Neuroscience Nursing, 20, 174-179.
- Azen, I., & Fishbein, M. (1977). Attitude-behavior relations: A theoretical analysis and review of empirical research. Psychological Bulletin, 84, 888-918.
- Burke, S., Costello, E., & Derry, M. (1989). Maternal stress and repeated hospitalizations of children who are disabled. CHC, 18(2), 82-89.
- Copelli, M., McGrath, P., MacDonald, N., Boland, M., Fried, P., & Katsanis, J. (1988). Parents, family and disease factors as predictors of psychosocial functioning in children with cystic fibrosis. Journal of Behavioral Science, 20 (4), 413-423.
- Friedman, S.B., Chedoff, P., Masan, J.W., & Hamburg, D. (1963). Behavioral observations on parents anticipating death of a child. Pediatrics, 32, 610-625.
- Gayton, W., Friedman, S., Tavormina, J., & Tucker, F. (1977). Children with cystic fibrosis. Pediatrics, 56, 888-894.
- Gibson, C. (1988). Perspective in parental coping with a chronically ill child: The case of cystic fibrosis. Issues in Comprehensive Pediatric Nursing, 11, 33-41.
- Hill, R. (1949). Families under stress. Westport, CT: Greenwood Press.
- Hymovich, D. (1983). The chronicity impact and coping instrument. Nursing Research, 32, 275-281.
- Lavigne, J., & Burns, W. (1981). Pediatric psychology. New York: Grune and Stratton.

- Lawler, R., Nakiely, W., & Wright, N.A. (1966). Psychological indications of cystic fibrosis. Canadian Medical Association Journal , 94 , 1043-1046.
- Lazarus, R. (1966). Psychological stress and the coping process. New York: McGraw-Hill.
- Mattson, A. (1972). Long term physical illness in childhood: A challenge to psychosocial adjustment. Pediatrics , 50 , 801-811.
- McCubbin, H., McCubbin, M., Nevin, R., and Cauble, A. (1979). CHIP-Coping Health Inventory for Parents. (Research Instrument). St. Paul, MN: University of Minnesota
- McCubbin, H., McCubbin, M., Patterson, J., Cauble, A.E., Wilson, L. & Warwick, P. (1983). Coping health inventory for parents: An assessment of coping patterns in the care of the chronically ill. Journal of Marriage and the Family , 45 , 359-370.
- McCubbin, H., & Patterson, J. (1983). The family stress process: The double ABCX model of family adjustment and adaptation. In H. McCubbin, M. Sussman & J. Patterson (Eds.), Advances and developments in family stress theory and research (pp. 7-37). New York: Hayworth Press.
- McCubbin, H. & Thompson, A. (Eds) (1987). Family assessment inventories for research and practice. Madison: University of Wisconsin.
- McCubbin, M. (1984). Nursing assessment of parental coping with cystic fibrosis. Western Journal of Nursing Research, 6(4), 406-417.
- McCollum, A.T., & Gibson, C. (1970). Family adaptation to the child with cystic fibrosis. The Journal of Pediatrics, 77(4), 571-578.
- McKeever, P.T. (1981). Fathering the chronically ill child. MCN, 6 , 124-128.
- McLean, J., Schragger, J., & Stoeffler, V.R. (1968). Severe asthma in children. Michigan Medicine, 67 , 1219-1226.

- Meyerwitz, J.H., & Kaplan, H.B.(1967). Familial response to stress. Social Science & Medicine, 1 , 249-266.
- Moos, R. (1977). Coping with physical illness.  
New York: Plenum Press.
- Sabbeth, B. (1984). Understanding the impact of chronic illness on the family. Pediatric Clinics of North America, 31 , 47-55.
- Sabbeth, B. & Levethal, J. (1984). Marital adjustment to chronic illness. Pediatrics, 65 , 948-956.
- Solnit, A., & Stark, M. (1961). Mourning the birth of a defective child. Psychoanalytical Study of the Child, 16 , 523-537.
- Turk, I. (1964). Impact of chronic illness on family functioning. Pediatrics, 34 , 67-71.