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CHILDHOOD CHRONIC ILLNESS: HEALTHY SIBLING'S PERCEPTION OF FAMILY COPING

By

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ABSTRACT

CHILDHOOD CHRONIC ILLNESS: HEALTHY SIBLING'S PERCEPTION OF FAMILY COPING

By

Sherry Nelson

Chronic illness affects approximately 10 million children under the age of 18 in the United States. An exploratory descriptive research design was used to gain insight into the healthy siblings' perception of family coping strategies in families with a chronically ill child. A comparison group of children without a chronically ill sibling was employed to increase the validity of the findings. Family coping strategies were measured by use of the Family Crisis Oriented Personal Evaluation Scales (F-COPES) instrument (McCubbin, Olson & Larsen, 1981).

Statistical significance was reached on one of the F-COPES sub-scales; Seeking Spiritual Support ($p \leq .05$). This finding is consistent with anecdotal evidence that families of children with chronic illness frequently seek deeper meaning from the experience. The remainder of the sub-scales and the total scale values did not reach significance. This would support the conclusion that there are minimal differences in the overall coping strategies of families regardless of the presence of a child with a chronic illness.

This thesis is dedicated to my son Daniel Nelson.

The true N=1 experimental subject.

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I would like to thank my family first of all for their patience, cooperation, and understanding. Without their assistance this could not have happened. I would also like to thank all of the members of my committee for their help. This is especially true of my chairperson, Dr. Linda Spence. Thanks to each of you for believing in me.

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INTRODUCTION

Chronic illness affects approximately 10 million children or nearly 10% of the United States population under the age of eighteen. The growth of this population has been attributed to advances in technology which have made it possible for an increased number of children to survive previous life-threatening illnesses and premature births (Sharkey, 1995). Each member of the family is impacted in some way by the initial diagnosis and on-going management of the chronic illness. Unique demands are placed on the family as a unit that are not found in families whose children do not have chronic illnesses. Child care concerns, complex treatment schedules, frequent visits to health care providers, worry and uncertainty about the future outcome of the chronically ill child are but a few of the demands experienced by the family as a whole.

Individual family members also have increased demands as a consequence of the chronic illness. Working parents may be required to rearrange work schedules, utilize family leave or maintain an undesirable position in order to keep health care benefits. Treatments, medications, or special health care services for the chronically ill child place increased costs on an already stretched budget. Families with one working parent may feel compelled to have the unemployed parent return to or begin employment to meet the added expenses. These financial demands may limit the family members' ability to enjoy leisure or recreational activities. Vacations, when taken, may need to be modified in order to meet the unique needs of the ill child.

Healthy siblings also experience heightened demands in a family with a chronically ill child as there may be an increase in the number or type of responsibilities placed upon or assumed by the well children. Furthermore, some families may experience disruptions in parent-child communication, scapegoating, overprotection of the ill child, formation of family coalitions, increased intrafamily tensions, or hostility. In addition, some children experience stigma from peers or others in the community (Gallo, Breitmayer, Knafl & Zoeller, 1991).

In most families, siblings share a common cultural background as well as their parents' affection, time, interest, and love. Within the sibling relationship, children can practice a wide range of nurturing behaviors with one another: mentor, protector, supporter, comforter, socializer and educator (Siemon, 1984). These roles are often countered with feelings of rivalry, jealousy, cruelty, deceit, betrayal and hatred (Walker, 1990). Sibling interactions provide important affectional needs, assist in the process of socialization, aid in identity formation, and act as an intermediary between the parents and the other siblings (Gallo, 1988). Siblings use their intense interactions to resolve conflicts, to learn socialization skills, and to compare and define themselves (Gallo, 1988).

Play and conflict between siblings increase mutual understanding and provide an important context for learning social roles and rules (Dunn, 1985).

For a number of years, researchers have examined the impact of childhood chronic illness on the family. Research in the late 1950s into the early 1970s focused on either the ill child or the ill child's mother. Early studies that included sibling response to chronic illness were frequently concerned with a specific crisis point associated with the illness such as the initial diagnosis, or death of the chronically ill sibling. Many early studies approached the topic from the perspective that the chronic illness leads to negative psychological or behavioral consequences for the well siblings (Lavigne & Ryan, 1979; Menke, 1987). In contrast, later studies found that many siblings seemed to derive prosocial benefits such as increased empathy and maturity in families with a chronically ill child (Lobato, 1988). Other research studies (Tew & Laurence, 1973) suggested that specific characteristics such as age, gender, or family constellation might be predictive of vulnerability or resiliency in some siblings. Nurse researchers Trahd (1986) and Walker (1990), have recently begun to explore the influence of childhood chronic illness on healthy siblings and are adding important information to the current body of knowledge regarding this complex phenomena. However, at this time, the effects of childhood chronic illness on siblings are inconclusive.

The issues regarding the effects of growing up with a chronically ill sibling have a number of implications for the Advanced Practice Nurse (APN) in the primary care setting. First, the APN can identify and assess problems that the sibling is experiencing in the family or in the community (Ross-Alaolmolki, Heinzer, Howard & Marszal, 1995). Following a thorough evaluation, the APN can develop a care plan to assist the siblings in coping with the increased family demands (Ross-Alaolmolki et al., 1995).

Problem Statement

Siblings are involved in the lives of their brothers and/or sisters over the course of their lifetime. The process of acquiring coping strategies begins during childhood. It appears that little is known about siblings' perception of family coping strategies. Therefore, the purpose of this study is to compare the perception of family coping strategies in children with a chronically ill sibling to a comparison group of children with a healthy sibling.

Research Question

The following research question will be asked: Are there any significant differences in family coping strategies reported by children with a chronically ill sibling as compared to the children without a chronically ill sibling?

Study Relevance

The results of this study have the potential to add significantly to the current body of scientific knowledge.

First, information from this study could expand theoretical knowledge of the types of family coping strategies recognized by children, and specifically family coping strategies recognized by children whose siblings have chronic illness. The APN can also devise methods to educate parents about typical sibling needs, fears and concerns. Lastly, the APN can educate parents regarding the influence of family coping strategies on the development of individual coping strategies in children. Development of specific nursing interventions will be based on what the findings reveal regarding the family coping strategies identified by children with a chronically ill sibling as compared to those with healthy siblings. In the future, these interventions can be evaluated through the research process to determine their effectiveness.

Definition of the Study Variables

The independent variable in this study is the health status of the chronically ill child. Specifically, this study is concerned with the siblings that currently reside with a target child who has an identified chronic illness. Medical diagnoses included in this study are: asthma, diabetes mellitus, cystic fibrosis, and congenital heart defects. Each of these diagnoses requires management through a pediatric sub-specialty clinic.

Chronic illness during childhood is defined by Stein and Jessop (1994) as "a condition that lasted or was certain to last at least 3 months or had necessitated a period of hospitalization of 1 month or more in the past year". Stein and Jessop (1982) found that children with chronic illnesses and their families have many similarities in life experiences that are different than those in families without a chronically ill child. For the purpose of this study, healthy siblings are defined as those who have not been identified to have a chronic illness or developmental disability.

Family coping strategies identified by healthy children with and without a chronically ill sibling is also a variable in this study. For the purpose of this study, family coping strategies are defined as the psychological and/or behavioral actions in response to the available resources, demands, and definitions given to the pile-up of demands (McCubbin, Olson & Larson, 1981). In this study, the following types of coping strategies to be measured are: Acquiring Social Support; Reframing; Passive Appraisal; Mobilizing Family to Acquire and Accept Help; and Seeking Spiritual Support.

Theoretical Framework

The theoretical framework chosen to guide this study is the Roy Adaptation Model (RAM)(Roy, 1970). She posits that families attempt to attain or maintain adaptation in response to stimuli from the internal and external environment. Roy derived many of her concepts from earlier work by Helson in the field of physiological psychology (Roy, 1991). Helson's work laid the foundation for the concept of the adaptation level zone, which determines whether a stimulus will elicit a positive or negative response (Roy, 1991). In accordance with Helson's theory, adaptation is a process of responding positively to environmental changes (Marriner, 1986). Coping mechanisms encompass both the innate and acquired processes that an individual uses to regulate or process the incoming stimuli from the environment. Since the RAM was built upon systems and adaptation theories, it is an appropriate model to study the adaptation of children to life in a family with a chronically ill sibling. Families of children with chronic illnesses are faced with numerous focal, contextual, and residual stimuli that are not experienced by the families of children who do not have chronic illnesses. The RAM provides a comprehensive framework for nursing assessment of healthy siblings within the family system.

Description of the Roy Adaptation Model

Roy describes a person as an adaptive system which both affects and is affected by his or her environment (Roy, 1991). The recipient of nursing care may be an individual, a family, a group, a community, or a society (Galbreath, 1985). Each is considered as an adaptive system. The environment is made up of the internal and external stimuli that give input to the individual. Thus, the family is ever changing as it attempts to adapt to a constant barrage of in-coming stimuli (Roy, 1991). There are three classes of stimuli that encompass a family's environment. The focal stimulus is the primary focus of the family's attention and can come from either the external or internal environment (Roy, 1991). In families with a chronically ill child, the focal stimuli would often be the ill child's health status.

Other stimuli present in the family's environment that contribute to the effect of the focal stimuli are considered contextual stimuli. Examples of contextual stimuli which confront the healthy sibling of a child with a chronic illness would be the age, developmental level, gender, and birth order of the healthy child in relationship to the ill child. Other contextual stimuli would be the family constellation and size, communication patterns, material resources, and the amount and type of social support. The family's coping strategies are also a contextual stimulus for the healthy siblings in a family with a chronically ill child. These stimuli are in the background of the family's attention. However, contextual stimuli influence the manner in which the individual or family perceives and processes the focal stimuli (Roy, 1991).

Residual stimuli are the internal and external environmental factors whose effects are uncertain (Roy, 1991). These stimuli are often hidden deeply in the subconscious and have an indirect effect on the persons' perception of the focal stimulus. Temperament is a residual stimulus that may influence healthy sibling's choice of coping strategies. The sum effect of the focal, contextual, and residual stimuli together comprise the individual or family's adaptation level (Roy, 1991).

Coping strategies are used by the individual and family as a control process to mediate stimuli (Figure 1).

ENVIRONMENT	CONTROL PROCESSING	ADAPTATION LEVEL
Focal Stimuli	**Cognator Subsystem Coping**	Adaptive Response
Contextual Stimuli		
Residual Stimuli	Regulator Subsystem Coping	Maladaptive Response
Nursing Interventions	Feedback	

Figure 1. Overview of Coping Response Outcomes within the Roy Adaptation Model

After processing the input through control mechanisms, the person makes a response (Roy, 1991). These responses are termed behaviors. Behaviors can either lead to effective adaptation or ineffective adaptation (Roy, 1991). These responses then feedback into the system in the form of environmental stimuli (Roy, 1991). Within the RAM coping mechanisms are classified into two subsystems: the regulator subsystem and the cognator subsystem. The regulator subsystem responds to stimuli automatically through innate biological processes such as neural, chemical, and hormonal fluctuation (Roy, 1991). The cognator subsystem responds to stimuli or sensory inputs through four cognitive-emotive channels: perceptual or information processing, learning, judgment, and emotion (Roy, 1991). The coping strategies in the cognator subsystem are developed over an individuals lifetime, they are learned, practiced and reinforced by use in a variety of situations (Roy, 1991).

Behavioral responses are a result of modification by the regulator or the cognator subsystems and can be either adaptive or ineffective. Adaptive responses serve to maintain or improve the person's integrity (Roy, 1991). On the other hand, ineffective responses disrupt integrity and can lead to maladaption (Roy, 1991).

Coping Strategies within the Roy Adaptation Model

According to Roy's theory, the sibling as an adaptive system receives input from the environment in the form of stimuli (Figure 2).

ENVIRONMENT
Focal Stimuli:
Ill Child's Health Status
Contextual Stimuli:
Family Coping Strategies,
Family Communication,
Social Support,
Material Resources
Residual Stimuli:
Temperament

COGNATOR PROCESSING
Coping Strategies:
Acquiring Social Support;
Reframing;
Passive Appraisal;
Mobilizing Family to Acquire and Accept Help; and,
Seeking Spiritual Support

Figure 2. Coping Strategies within the Roy Adaptation Model

The focal stimulus is the health status of the chronically ill child. Roy defines the focal stimulus as the object or event that captures the family's attention (Roy, 1991). Contextual stimuli consist of all other stimuli that contribute to the effect of the focal stimuli (Roy, 1991). Residual stimuli are the internal or external environmental factors whose impact are uncertain and unmeasurable (Roy, 1991).

Once stimuli have been received, they are processed through the regulator and cognator subsystems (Roy, 1991). The family then chooses one or more coping strategies in an attempt to mediate the effects of the stimuli. Then, the family receives feedback which allows the members to decide whether to increase or decrease efforts to cope with the stimuli. This study will focus on the coping strategies used by the family as a result of processing through the cognator subsystem (Figure 2). The cognator subsystem acts to process information in order to assist the family to maintain adaptation, thus promoting the integrity of the family unit (Roy, 1991). Coping strategies that are regulated through the regulator subsystem are not the subject of this study as measurement would require monitoring levels of stress hormones and neurotransmitters which exceed the boundaries of this study.

In this study, family coping strategies identified by healthy siblings were measured by use of the Family Crisis Oriented Personal Evaluation Scales (F-COPES), (McCubbin, Olsen, & Larsen, 1987). This instrument allowed assessment of the child's perception of the coping strategies used by his or her family as a result of cognator processing. As previously described, these family coping strategies are developed over time through learning and reinforcement. Specifically, the coping strategies to be evaluated in this study are as follows: 1) Acquiring Social Support; 2) Reframing; 3) Passive Appraisal; 4) Mobilizing Family to Acquire and Accept Help; and 5) Seeking Spiritual Support.

The goal of nursing within the RAM is to promote adaptive responses through manipulation of the focal, contextual, or residual stimuli that are impinging on the client (Roy, 1991). However, the nurse is unable to manipulate the focal stimuli for the healthy siblings which is the chronically ill child's health status. Nor can the nurse manipulate the residual stimuli which is the healthy sibling's Temperament. The nurse may be able to impact some of the contextual stimuli such as family communication, social support, material resources, and use of effective family coping strategies. Other contextual stimuli including family constellation and size, age, developmental level, gender of sibling, and birth order are also not amenable to nursing interventions. Therefore, the focus of interventions for the family with a chronically ill child will be on the modifiable contextual stimuli of family communication patterns, social support networks, material resources, and family coping strategies. Thus, it can be seen that the RAM will guide not only assessment for this study, but also help to identify appropriate interventions to enhance family adaptation.

Review of the Literature

This literature review focuses on seven areas. The first area is the development of coping strategies in healthy children. The second area describes the impact of family communication patterns on the well sibling in a family with a chronically ill child. The third area examines the effect of social support on the healthy sibling. The fourth area explores the influence of material resources on the adaptation of the healthy sibling. The fifth area examines the impact of sibling chronic illness on the well child based on the focal stimulus of the ill child's health status. The sixth area explores the influence of the contextual stimuli of healthy child characteristics of age, gender, and birth order in relation to the chronically ill sibling. The final area of review focuses on the impact of the residual stimuli of the well child's temperament on his or her selection and use of coping strategies.

Development of Childhood Coping Strategies

Children learn and model the coping strategies that they observe their parents using. In a qualitative study by Whyte (1991), denial was an adaptive coping strategy for parents as it allowed them to block out future fears and instead concentrate on day-to-day life. Parental coping strategies identified by Ray & Ritchie (1993) which were most helpful were those which strengthened family relationships, and assisted in the maintenance of a hopeful and optimistic outlook. Finding meaning in the experience of having a child with a chronic illness was also noted by Whyte (1991).

The coping strategies used by healthy children to mediate daily stressors are being explored by several nurse researchers at this time. Sorenson (1990) examined 32 healthy 8 to 11 year old children with the use of sentence completion lists of hypothetical stressors, and a daily journal which the children maintained over a 6 week time period. Analysis of the sentence completion lists found that the number of coping strategies employed per subject ranged from 9 to 17 with a mean of 12.38. In contrast, the analysis of the daily journals found that the total number of coping strategies used ranged from 1 to 9, with a mean of 4.0. Sorenson reported that the discrepancy between the scores between the two data collection methods might be attributed to the short time span recorded in which the children did not experience the range of stressors that were found in the hypothetical sentence completion lists. She found that children's coping strategies fell into 4 general themes: 1) cognitive-intrapsychic; 2) cognitive-behavioral; 3) behavioral, and; 4) interpersonal. The coping strategy most frequently reported by the children was that of submission or endurance under the theme of cognitive-behavioral. This finding appears to validate the work of Ryan-Wenger (1992) which proposed that a large number of childrens' stressors are perceived as being beyond their capability to change.

In a study by Sorenson (1994) that compared stress and coping between rural and suburban children via the use of daily journals, she found that suburban boys were more likely to employ submission as a coping strategy than were rural boys (19.3% versus 4.51%). The rural boys used organized activities more often as a coping resource than the suburban boys (22.95% versus 8.48%). The rural (8.11%) and suburban (8.38%) girls utilized problem solving strategies more frequently than the rural (1.64%) or suburban (4.10%) boys. Sorenson also found that all of the children sought social support from peers outside the family and sought their mother for social support within the family.

In a qualitative study by Walker (1988) to investigate coping strategies, she interviewed both the healthy siblings of children with cancer and their parents. She then compared the parents' perception of the siblings coping strategies to the siblings' own report. The two groups completely agreed on coping strategies used 22% of the time, partially agreed 33% of the time, and disagreed 44% of the time. This would seem to indicate that what is deemed coping by the siblings is not always viewed the same by parents. One possibility for the difference in perception between parent and child is that the perception is altered due to cognitive or developmental maturity. Another possible reason for the discrepancy might be attributed to the parents' interpretation of external behavior as opposed to the internal responses of the siblings.

Family Communication

Effective communication is a crucial component of healthy family functioning in all families. The addition of a child with chronic illness poses additional demands for clear communication (Patterson, 1991). Family members often need to utilize more problem-solving communication in order to make treatment decisions. The family members also need to be able to express feelings related to the diagnosis and on-going care of the child with a chronic illness. Family members with chronically ill children often repress negative feelings such as grief and loss. Burton (1975) reported that 53% of mothers either did not discuss the chronic illness with the siblings or gave only superficial explanations. When questioned by well siblings, both mothers and fathers reported that they evaded answering questions completely or accurately. Daniels et al. (1987) used mothers reports on the Health and Daily Living Form on a sample of 72 siblings of children with rheumatoid arthritis. They found the highest level of sibling adjustment problems occurred in families with lower levels of cohesion and expressiveness. Similar findings were noted in a study by Dyson, Edgar & Crnic (1989), that compared behavior problems and social competence in well siblings of children with developmental disabilities. In a study by Taylor (1980), siblings were found to have an inadequate knowledge of why their ill brother or sister looked and behaved as they did.

There are many barriers to effective parent-child communication in a family with a chronically ill child. Parents are burdened with a multitude of stressors which may tax their own coping abilities. In some families, one parent may become overly involved in the care of the chronically ill child to the exclusion of the other parent. Furthermore, "the presence of added demands associated with meeting illness-related needs calls for more problem-solving communication" (Patterson, 1991). Denial may be one coping strategy that is effective for the parents at the same time that well siblings are striving to gain information. The intrusion of well sibling questions may increase the parents feelings of loss, grief, and despair. Many well siblings sense these feelings and are reluctant to ask parents for information.

Social Support

Another important variable which impacts sibling coping strategies is the amount of available social support. Social support can help mediate the effects of increased demands on the family, including the well siblings of a chronically ill child. Specifically, social support has been identified as a mediator of the negative impact of stress on health (Tomlinson & Mitchell, 1992, p. 386). Social support can assist in the expression of affect, clarification of feelings, development of new problem solving and coping strategies as well as the provision of tangible help (Tomlinson & Mitchell, 1992). However, the chronic illness can also create barriers to attaining and maintaining adequate social support. For example, in a study by Gallo et al. (1991), they found that well siblings overall were selective in sharing the diagnosis of the chronic illness with others. The authors attribute this finding to their attempt at minimizing the stigma attached to the chronic illness. Another factor that can limit well sibling's ability to maintain social support is decreased leisure time which may be due to care demands of the chronically ill child.

Material Resources

Material resources available to the family members are variables which can influence the coping strategies of all family members including well siblings. Level of family income can either enable or impede the families of children with chronic illness to procure resources which can facilitate adaptation to the demands placed upon them (Thompson, Curtner & O'Rear, 1994). Most communities have very limited respite care resources available at an affordable cost. Thompson et al. (1994) found that family income was significantly correlated with well sibling functioning. In this study, well siblings from lower income levels were found to be more socially withdrawn and have more peer conflicts than those with higher income levels.

Ill Child's Health Status

Investigators have proposed that some characteristics of the chronic illness such as etiology, prognosis, and visibility have important ramifications for the well sibling. Genetic transmission of a chronic illness such as cystic fibrosis may lead to extreme levels of parental guilt and shame (Loboto, Faust & Spirito, 1988). These feelings may in turn affect the way the parents interact with both the ill child and the healthy siblings. Effective sibling adaptation has been found to occur most frequently when the parents demonstrate a positive attitude toward the ill child (Lynn, 1989). The perception of the illness can vary from the extremes of irreparable loss to elevated value with different families (Brett, 1988). These perceptions are formed based on cultural background, personality characteristics of the family members, understanding of the disease, religious up-bringing as well as many other complex and interactive variables. Families that are able to either reduce their perception of chronic illness demands or increase the perception of positive contributions gained from the child's illness are more likely to maintain adaptive functioning (Patterson, 1991). The meaning that is attributed to the illness is especially important to assess in young children due to their use of magical thinking and self-blame (Brett, 1988). In addition, the meaning attached to the illness also influences the type of coping strategies utilized by the family.

Disease prognosis has been speculated by many authors (Drotar & Crawford, 1985; Lavigne & Ryan, 1979; Taylor, 1980) to have an increased negative impact on siblings. However, none of these studies were able to demonstrate statistical significance based on disease severity alone. Moreover, Tritt & Esses (1988) found that well sibling (n=27) concerns were stable across several diagnostic categories including diabetes mellitus, juvenile rheumatoid arthritis, and gastrointestinal disorders. This study used three measures to assess the siblings; the Behavior Problem Checklist for behavioral adjustment, the Self-Appraisal Inventory for subjective feelings, and the What I Think and Feel Questionnaire to measure anxiety level. The authors also employed a matched control group of children with well siblings. They found no statistical differences in self-concept scores between the two groups. Significant findings of this study were that parents of ill children perceived the siblings had more behavioral adjustment problems than did parents of healthy children.

Several researchers have proposed that visibility of the chronic illness can impact the well siblings (Gallo, Breitmayer, Knafl & Zoeller, 1991; Lavigne & Ryan, 1979; McCubbin, Nevin, Cauble, Larsen, Comeau & Patterson, 1982). Gallo et al. (1991) investigated the effect of "courtesy stigma" on the siblings of children with chronic illness and found that siblings younger than 10 years of age were reluctant to discuss their sibling's illness with others. The authors thought this was related to the younger children's inability to understand the cause of the illness. Lavigne & Ryan (1979) investigated four groups of children whose siblings were diagnosed with congenital heart disease, craniofacial abnormalities, or cancer, and a control group of children without any identifiable chronic conditions. Statistically significant differences included an increase in irritability and social withdrawal in the healthy siblings of children with the more visible illnesses.

In contrast, a study by Sargent et al. (1995), found that well siblings reported they had become more caring and compassionate as a result of having a brother or sister with cancer. This was noted to be especially true if the sibling was older than the affected child. However, the younger siblings reported that nothing good had come from the experience of having an ill sibling. Older siblings felt that their family had an increased level of cohesion while the younger siblings reported no change or could not answer.

Several authors have reported statistically significant differences between mothers' rating of sibling adaptation and the responses of the siblings themselves (Tritt & Esses, 1988; Walker, 1988). Each of these studies found that mothers reported more psychological and behavioral difficulties than did the siblings. A multisite collaborative study by Sahler et al. (1994), used parental, sibling and teacher report data on a large number of standardized instruments to assess sibling (n=254) adjustment using a modification of the family systems theory developed by McCubbin and colleagues. Matched controls were obtained from various sections of national health interview surveys. This study found that the frequency of a sibling having an emotional or behavioral problem lasting three or more months was 16.9% compared to 6.3% of the control group subjects. In addition, 22.4% of the children with a chronically ill sibling had received mental health care in the past as compared to only 5.1% in the control group. These findings were statistically significant. The study then examined the prevalence of sibling distress based on whether the emotional or behavior problem manifested before (7.7%) or after (9.2%) the diagnosis of the chronic illness. The baseline prevalence of children with behavioral or emotional problems was not statistically different from that of the control group. However, after diagnosis an additional 9.2% of the siblings developed problems as perceived by their parents. The most statistically significant effect was found in the siblings who were experiencing problems before the diagnosis. Of this group of children, 40% were reported to have behavioral or emotional problems of such magnitude as to be perceived as needing mental health intervention. This compared to only 2% of the siblings who developed problems following the diagnosis.

Healthy Sibling Characteristics

This section discusses the findings of studies which have examined the effect of age, gender, and birth order on the adaptation of the healthy sibling. Gallo et al. (1992) examined 28 healthy siblings of children with diabetes, chronic renal failure, juvenile rheumatoid arthritis, asthma, systemic lupus, scleroderma, and Crohn's disease. They used the Child Behavior Checklist (CBCL) at two data collection sessions conducted with the parents 12 months apart. They found that mothers of the younger siblings reported an increased risk of behavior problems. And, both mothers and fathers reported an increase in maladjustment in social competence of the well siblings. Tew and Laurence (1973) concluded that in relationship to the chronically ill child, older sisters and younger brothers had a higher rate of behavior problems as reported by their mothers and teachers. The Sahler et al. (1994) group found that younger boys had the most intense behavioral distress.

Temperament

Hymovich (1992) defines temperament as the relatively stable and consistent tendency of an individual to respond to stimuli in a particular manner. In the healthy child with a chronically ill sibling, the residual stimuli has an effect on his or her coping strategies which is indeterminable. Longitudinal studies which have evaluated infant temperaments have found that temperament is consistent over time into the school-age population (Ryan, 1988). It is believed by many researchers that temperament may influence not only the types of coping strategies utilized by the child, but also their perception of the specific events as being stressful or not (Ryan, 1988). However, temperament is so broad that it is poorly predictive of behavioral coping strategies in any given circumstance (Hymovich & Hagopian, 1992).

Rationale for Proposed Study

The literature review section focused on several focal, contextual, and residual stimuli variables which affect well siblings of children with chronic illness. Many of the studies cited in the literature review are not recent, used small samples, case studies and anecdotal reports, and relied on maternal ratings as the only data source. Additionally, most of the studies did not utilize a comparison group. In the limited number of studies which did employ a comparison group, there was a lower reported incidence of emotional or behavioral problems. Many early studies were designed to quantify maladaptation in the well siblings and did not investigate the possibility of enhanced coping strategies which could be derived by growing up with a chronically ill brother or sister. These methodological issues limit the applicability of the results to well siblings today. In addition, there are few if any studies which describe well siblings' perception of family coping strategies within the five domains identified by McCubbin et al.

Methods

This research project is a secondary analysis of data collected by Professors Carla Barnes, Linda Spence, and Patty Peek, in the College of Nursing at Michigan State University. The data were collected from 48 families, 28 with, and 19 without a chronically ill child. The original quantitative study was designed to examine the entire family's adaptation to the experience of living with childhood chronic illness.

Research Design

An exploratory descriptive design was used in this study in order to gain as much insight as possible into the siblings' perception of family coping strategies in children with a chronically ill brother or sister. This approach is appropriate to the purpose of this study since there is very limited and conflictual information about the healthy sibling experience (Brink & Wood, 1988). The comparison group of children with a sibling who did not have a chronic illness was utilized to enhance the internal validity of this study.

Sample

The target subjects in this study were siblings of school age (8-12 year old) children with chronic illness. The comparison group consisted of children whose siblings did not have a chronic illness. There were 39 families, 26 families with a child who had been diagnosed with a chronic illness for at least one year and 13 comparison families with healthy children. School-aged children are able to define and describe their perception of their family's coping strategies (Faux, 1991). The data on both of these groups of children were collected as part of a larger study of families of children with chronic illness. There were 7 families of children with asthma, 5 families of children with congenital heart disease, 8 families of children with cystic fibrosis, and 6 families of children with insulin-dependent diabetes mellitus. School-aged healthy siblings were chosen to provide the information on their perception of family coping strategies in order to validate both the internal and external components of their coping strategies. The families having a child with a chronic illness were recruited for the study during treatment in pediatric sub-specialty clinics in the Department of Pediatrics and Human Development at Michigan State University. The comparison families were recruited through university, neighborhood, and community agency announcement (Spence, 1992, p.68). Each comparison family was matched to a selected chronic illness family based on: age, sex, and birth order of the chronically ill child: number of parents in the home: approximate family size: and income level (Spence, 1992, p.69). The sample is a non-probability sample and this limitation is recognized. See original dissertation for a copy of the original sample selection criteria and procedure for recruitment.

Instrument

The Family Crisis Oriented Personal Evaluation Scales (F-COPES) (McCubbin, Olson & Larsen, 1981) was the instrument used to measure family coping strategies in this study (Appendix B). F-COPES was designed to measure the coping dimensions of the Double ABCX Model in which the factors of pile-up, family resources, and perceptions are integrated. The instrument contains 30 items scored on a 5-point Likert-type scale with answers ranging from (1) strongly disagree to (5) strongly agree. These questions were developed to identify problem-solving and behavioral strategies utilized by families who are undergoing challenging life circumstances (McCubbin, Olson & Larsen, 1981). The measure has five sub-scales: Acquiring Social Support; Reframing; Passive Appraisal; Mobilizing Family to Acquire and Accept Help; and, Seeking Spiritual Support. The Acquiring Social Support sub-scale consists of 9 questions that measures the family's ability to obtain and utilize social support from relatives, friends and neighbors. The Reframing sub-scale is comprised of 8 questions which measures the family's ability to redefine problematic situations to make them less stressful. The Passive Appraisal sub-scale has 4 questions that are used to measure the family's ability to accept a difficult situation by minimizing their reaction. The Mobilizing Family to Acquire and Accept Help sub-scale contains 4 questions that measures the family's ability to seek out and use community resources. Lastly, the Seeking Spiritual Support sub-scale has 4 questions used to measure the family's ability to acquire spiritual support (McCubbin, Olson & Larsen, 1981). Each of the sub-scales can be scored by adding the number circled by the respondent for each of the items. However, scores must be reversed (5=1, 4=2, etc.) on items 17, 26, and 28. Reversal of these scores ensures that all items are weighted in a positive direction for analysis and interpretation of the results. A total F-COPES score ranges from a low score of 30 to a high score of 150. Effective coping in response to challenges is indicated by a higher overall F-COPES score (McCubbin, Olson & Larsen, 1981).

Validity and Reliability

A number of reliability and validity studies on the use of the F-COPES instrument have established the scale as an effective tool to assess family coping behaviors (McCubbin, Olson & Larsen, 1981). Initially, coping strategies were identified from the family coping literature to establish content validity (McCubbin, Olson & Larsen, 1981). Use of a large sample (n=2740) was employed to replicate reliability and validity checks. A test-retest reliability study was conducted using a sample of 150 participants. Time lapse between the first and second test administration was 4-5 weeks. The alpha reliability of the total scale is .71 (McCubbin, Olson & Larsen, 1981). Cronbach's Alpha for the each of the factors are as follows: Acquiring Social Support, .84; Reframing, .82; Seeking Spiritual Support,

.79; Mobilizing Family to Acquire and Accept Help, .71; and Passive Appraisal, .64.

Data Analysis

The data analysis for this study involved descriptive analysis of information obtained during the family interviews. Demographic information regarding the age of the siblings was included in order to examine differences in coping strategies based on the child's cognitive and developmental level.

For this study's purpose, the plan was to determine whether there were significant differences between perception of family coping strategies identified by siblings of healthy children and siblings of chronically ill children. Therefore, the use of ANOVA analysis was employed to measure differences on each of the 5 sub-scales of the F-COPES instrument.

Limitations

Due to the nature of this secondary analysis study, several assumptions must be made. First, the researcher assumes that the procedures for recruiting subjects were followed. Secondly, the researcher must assume that the children responded truthfully to the questions on the F-COPES scale. Additionally, the researcher recognizes that the F-COPES scale was developed, designed, and tested on an adult population which may influence the results derived from the identified sample of children.

Protection of Human Rights

Several methods were used to ensure the protection of human subjects in this study. The proposal was presented to the University Committee on Research Involving Human Subjects, Michigan State University for review and approved (Appendix A). Secondly, the rights of human subjects were initially protected by the University Committee on Research Involving Human Subjects for the original study of family adaptation to childhood chronic illness. Additionally, as a secondary analysis study, the data for analysis has already been translated into numeric form which will be provided to this researcher on computer disk without any identifying information.

Results/Findings

Data were analyzed on the 26 target siblings of chronically ill children and compared to 13 children without a chronically ill sibling. The chronically ill children ranged in age from 8-12 years. Target siblings ranged in age from 8-18 years. Eighteen of the target siblings were older than the chronically ill child and 8 of the target siblings were younger than the chronically ill child. Chi square analysis of the chronic illness and comparison families detected no statistical differences based on the characteristics of the chronically ill child (age, sex, and birth order), or family characteristics (number of parents, number of children, and income) (Spence, 1992, p.69).

F-COPES raw scores were computed for the target siblings and the comparison group and compared to each other and standardized norms for adolescents (Table 1). The sub-scale Mobilizing Family to Acquire and Accept Help scores were very similar between the 2 groups. Scores were also similar on the 2 sub-scales of Passive Appraisal, and Seeking Spiritual Support. The total instrument raw scores were again similar with a range of 55 to 117 for the target siblings and 61 to 115 for the comparison siblings. The sub-scale of Acquiring Social Support had a range of 17 to 38 in the target siblings and 10 to 38 in the comparison siblings. The Reframing sub-scale had a narrower range with higher raw score values in the comparison group with values from 23 to 38 as compared to the target siblings scores of 14 to 39.

Mean values and standard deviations were calculated for each of the F-COPES sub-scales and for the total F-COPES instrument. Results of means and standard deviations are found in Table 2. Means and standard deviations for each of the sub-scales were similar with the exception of the Seeking Spiritual Support sub-scale. Seeking Spiritual Support had the highest mean value (3.34, S.D. .97) of the sub-scales for the target siblings. Reframing was the next highest mean value for the target siblings (3.33, S.D. .79). The lowest mean value (2.50, SD .85) was found on the sub-

Table 1.

Raw Score Values and Norms for F-COPES Instrument

Sub-scale	Target Siblings				Comparison Siblings			
	Range	Mean	SD	Norm	Range	Mean	SD	Norm
Acquiring social support	17-38	27.88	6.44	27.28	10-38	24.58	6.93	27.28
Reframing	14-39	26.65	6.32	29.19	23-38	30.62	4.03	29.19
Seeking spiritual support	4-19	13.35	3.89	15.00	4-20	10.69	4.35	15.00
Mobilizing family to acquire and accept help	5-17	10.00	3.39	10.43	5-17	9.69	3.75	10.43
Passive appraisal	8-18	13.46	2.53	9.72	9-18	13.15	2.85	9.72
Total score	55-117	89.21	15.44	94.48	61-115	87.75	13.88	94.48

Table 2.

Frequency Analysis of F-COPES Sub-scales Values

Sub-scale	Target Siblings (n=26)				Comparison Siblings (n=13)			
	N	Mean	Range	SD	N	Mean	Range	SD
Acquiring social support	25	2.99	(1.89-4.22)	.72	12	2.73	(1.11-4.22)	.77
Reframing	26	3.33	(1.75-4.88)	.79	13	3.83	(2.88-4.75)	.50
Passive app	26	2.69	(2.00-4.50)	.87	13	2.37	(2.25-4.50)	.47
Mobilizing family to acquire and accept help	26	2.50	(1.25-4.25)	.85	13	2.42	(1.25-4.25)	.94
Seeking spiritual support	26	3.34	(1.00-4.75)	.97	13	2.67	(1.00-5.00)	1.09
Total F-COPES	24	2.97	(2.10-3.97)	.51	12	2.93	(2.17-3.97)	.46

scale of Mobilizing the Family to Acquire and Accept Help for both groups of children.

Following assessment of the mean values and standard deviations, analysis of variance (ANOVA) procedures were performed. ANOVA values are listed in Table 3. The results of ANOVA were consistent with the descriptive analysis. Statistical significance was reached on the Seeking Spiritual Support sub-scale ($p \leq .05$). ANOVA procedures also revealed findings that approached statistical significance on the Reframing sub-scale ($p \leq .07$). Total coping scores between the target and comparison groups did not reach statistical significance. Therefore, the null hypothesis cannot be rejected. Numerous explanations could account for this finding. First, the null hypothesis may indeed be true and there is no significant differences in how siblings interpret family coping strategies in families with a chronically ill child. Another explanation for the mixed results is that the F-COPES sub-scales were not able to accurately measure different constructs of coping. Cronbach's Alpha values for the factors in this study are as follows: Acquiring Social Support .87, Mobilizing Family to Acquire and Accept Help .74, Reframing .68, Seeking Spiritual Support .57, and, Passive Appraisal .48. The Alpha value for the total scale was .71. The total scale Alpha may indicate that the sub-scales are too interrelated to be adequately predictive of the separate constructs of coping that they attempted to measure.

Table 3.

Analysis of Variance F-COPES Instrument

Source	DF	Sum of Squares	Mean Squares	F Ratio	F Prob.
Acquiring Social Support		**Analysis of Variance**			
Between groups	6	2.4692	.4115	.7308	.6285
Within groups	30	16.8929	.5631		
Total	36	19.3620			
Reframing		**Analysis of Variance**			
Between groups	6	5.9895	.9982	2.1619	.0731
Within groups	32	14.7758	.4617		
Total	38	20.7652			
Passive Appraisal		**Analysis of Variance**			
Between groups	6	4.0130	.6688	1.7582	.1396
Within groups	32	12.1729	.3804		
Total	38	16.1859			
Mobilizing Family		**Analysis of Variance**			
Between groups	6	3.3158	.5526	.6994	.6520
Within groups	32	25.2835	.7901		
Total	38	28.5994			
Seeking Spiritual Support		**Analysis of Variance**			
Between groups	6	13.0903	2.1817	2.4483	.0462*
Within groups	32	28.5155	.8911	.8911	
Total	38	41.6058			
Total Instrument		**Analysis of Variance**			
Between groups	6	1.0071	.1679	.7968	.5802
Within groups	29	6.1094	.2107		
Total	35	7.1165			

*$p \leq .05$

Discussion

The findings of this study suggest that there are only limited differences in family coping strategies in a family with a chronically ill child than of those in a family that does not have a chronically ill child. Significance was reached on the Seeking Spiritual Support sub-scale. This finding corresponds with anecdotal evidence that families with chronically ill children often ask questions that seek a purpose or meaning for the event. Family members ask, "Why did this happen to us?" Siblings also perceived that their families relied upon the coping strategy of reframing as was evidenced by the near significance value ($p \leq .07$) on the Reframing sub-scale. Anecdotally, many families report that they have come to appreciate life and enjoy simple pleasures more fully since the diagnosis of their child's chronic illness. Often times, the chronic illness is viewed as a turning point in the life of the family and that following the diagnosis their lives have been enriched. In contrast, the lowest sub-scale value was found in the Mobilizing Family to Acquire and Accept Help. Two different conclusions could be derived from this finding. First, the low value on the scale may mean that families have difficulty utilizing this form of coping. Numerous explanations could account for this including lack of access to resources, lack of appropriate resources, limited material resources, and/or lack of knowledge regarding the services which are available. On the other hand, the low value on the sub-scale could indicate that siblings do not perceive that this is an important coping strategy in their family. Total coping was not found to be statistically significant. The review of literature is congruent with this finding as the existing literature has very conflicting conclusions about the coping strategies and abilities of siblings in a family with a chronically ill child.

Implications

The results of this study suggest a number of strategies for the APN to utilize while working with the families of children with a chronic illness. The lack of significance between the two groups in total coping is an important finding because it can assist the primary care APN to normalize perceived problems in these families. Parents of chronically ill children frequently worry about the impact of the chronic illness on all the members of the family. The APN can accurately inform and educate concerned parents that siblings of chronically ill children have not been found to have more psychological problems than their peers without a chronically ill sibling. Additionally, the siblings of chronically ill children have been found to be resilient to many of the stressors that accompany childhood chronic illnesses. Nursing interventions for the family with a chronically ill child needs to focus on the modifiable contextual stimuli of family communication patterns, social support networks, and material resources. This is consistent with the RAM, the theoretical framework that served as a guide for this study. Community resources that assist parents to improve their parenting and communication skills include educational workshops such as Systematic Training for Effective Parenting (STEP), Family Support Services division of the local intermediate school district, and Child and Family Services of the local health department. These same services can also assist parents to develop a stronger social support network. Other community resources for families which may serve to enhance social support networks are the support groups for various chronic illnesses such as the Wheezers Club for children with asthma, camps for children with diabetes, asthma, and cystic fibrosis. Material resources for families of children with a chronic illness can be facilitated by the local health department, specifically the Michigan Services for Children with Special Health Care Needs program. Families need to be made aware of the service and encouraged to participate. In the managed care arena, services may be denied for pre-existing conditions. This makes it critical that the family be protected from devastating financial losses due to inadequate health care insurance. There are other community resources that are also available to the family of a child with chronic illness. The Cystic Fibrosis Foundation, Juvenile Diabetes Foundation, American Lung Association each have local chapters that provide educational and financial resources to these families.

Nursing Education

Paradigm shifts in the health care field necessitates changes in the education of nurses both at the undergraduate and graduate level. First, undergraduate nurses need to be prepared to care for an increased population of children with chronic illnesses outside the tertiary care setting.

Children with chronic illnesses are managed more and more in the primary care setting making it necessary to develop a reciprocal working relationship with the child's family. Developing realistic care plans which take into account the demands on the family as a whole as well as the chronically ill child is one part of this interaction. Discussion with the family to establish routines that are integrated into the family's schedule will help to enhance the life of the entire family. Theoretical frameworks such as the Double ABCX Model that can graphically illustrate the dynamics at work in a family with a chronically ill child need to be included in the undergraduate curriculum. Use of such a model makes the assessment of family strengths as well as concerns an important component of the care planning process. Graduate nursing education must also be sensitive to the changes in the health care field. The role of the APN as a case manager for chronically ill children in the home care as well as primary care settings are developing in many areas of the country. The APN in this role coordinates health care, social services care, physical therapy, occupational therapy, speech therapy, as well as interfaces with the school system as necessary. Graduate education needs to include objectives that facilitate the development of critical thinking and advanced judgment skills necessary to assume this type of role.

Future Research

Implications drawn from this study for future research include changes in the instrument used to measure coping, changes in the sample, and changes in the research design. The sub-scales on the F-COPES instrument may be inadequate to accurately measure the critical attributes of coping that it describes. The sample size of 26 target and 13 control siblings make it difficult to generalize the findings to the larger population of children with chronically ill siblings. In the future, research studies could be designed that utilized an instrument that has been finely tuned to discern the separate constructs of coping. A larger sample size would also enhance future studies by making the findings more generalizable to the population as a whole. Larger sample size would also allow the researcher to evaluate the influence of other variables on the coping perceptions of siblings such as the gender of the sibling and birth order.

Alterations in the research design to include an experimental group of siblings that undergo an intervention is one possible approach to advancing the existing body of knowledge on the experience of childhood chronic illness. One type of intervention that may make a difference in the lives of children with chronically ill siblings would be a type of support group aimed at addressing some of their social support needs. The opportunity for children to interact with peers that are faced with similar circumstances may be found to enhance their feelings of self-esteem. Other potential experimental interventions would include a teaching group for siblings, one on one educational sessions with siblings, and parental education which included information regarding sibling coping strategies. Finally, the use of a longitudinal research design would also be useful in improving the understanding of how siblings perceive family coping strategies over time. One of the most significant strengths of this study was the use of a comparison group of siblings. There is a paucity of existing literature on childhood chronic illness that has utilized this method of investigation.

This study does help to advance the Roy Adaptation Model (RAM) theoretical framework. Roy's concepts of focal, contextual, and residual stimuli were key elements in this study. The target siblings in this study perceived that their family relied more heavily on the Seeking Spiritual Support domain than the comparison group. The siblings have learned an effective method of coping with the demands placed on them by virtue of living with a brother or sister with a chronic illness. Unfortunately, based on the limitations of this study, there is no way to know if the learned coping strategies will continue to be effective for the siblings as they mature.

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APPENDIX A

MICHIGAN STATE
UNIVERSITY

March 3, 1997

TO: Linda Spence
A230 Life Sciences

RE:
IRB#: 97-048
TITLE: CHILDHOOD CHRONIC ILLNESS: HEALTHY SIBLING PERCEPTION OF FAMILY COPING STRATEGIES
REVISION REQUESTED: N/A
CATEGORY: 1-E
APPROVAL DATE: 03/03/97

The University Committee on Research Involving Human Subjects'(UCRIHS) review of this project is complete. I am pleased to advise that the rights and welfare of the human subjects appear to be adequately protected and methods to obtain informed consent are appropriate. Therefore, the UCRIHS approved this project and any revisions listed above.

RENEWAL: UCRIHS approval is valid for one calendar year, beginning with the approval date shown above. Investigators planning to continue a project beyond one year must use the green renewal form (enclosed with the original approval letter or when a project is renewed) to seek updated certification. There is a maximum of four such expedited renewals possible. Investigators wishing to continue a project beyond that time need to submit it again for complete review.

REVISIONS: UCRIHS must review any changes in procedures involving human subjects, prior to initiation of the change. If this is done at the time of renewal, please use the green renewal form. To revise an approved protocol at any other time during the year, send your written request to the UCRIHS Chair, requesting revised approval and referencing the project's IRB # and title. Include in your request a description of the change and any revised instruments, consent forms or advertisements that are applicable.

PROBLEMS/ CHANGES: Should either of the following arise during the course of the work, investigators must notify UCRIHS promptly: (1) problems (unexpected side effects, complaints, etc.) involving human subjects or (2) changes in the research environment or new information indicating greater risk to the human subjects than existed when the protocol was previously reviewed and approved.

If we can be of any future help, please do not hesitate to contact us at (517)355-2180 or FAX (517)432-1171.

Sincerely,

David E. Wright, Ph.D.
UCRIHS Chair

DEW:bed

cc: Sherry Nelson

OFFICE OF
RESEARCH
AND
GRADUATE
STUDIES

University Committee on
Research Involving
Human Subjects
(UCRIHS)

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APPENDIX B

SUBJECT #______
DATE__________

F-COPES-C

DIRECTIONS

Listed below are several sentences that describe how families respond to problems or difficulties. We want to know how well each of these sentences describes how your family handles problems or difficulties.

Please read each sentence. Decide how true the statement is of your family. Put an X in the correct box.

WHEN WE FACE PROBLEMS OR DIFFICULTIES IN OUR FAMILY, WE RESPOND BY:	VERY UNTRUE	SORT OF UNTRUE	NOT TRUE OR UNTRUE	SORT OF TRUE	VERY TRUE
1. Sharing our problems with relatives (grandparents, aunts, uncles).					
2. Seeking encouragement and comfort from friends.					
3. Knowing we have the power to solve major problems.					
4. Seeking information and advice from persons in other families who have faced the same problems.					
5. Seeking advice from relatives (grandparents, aunts, uncles).					
6. Seeking help from community agencies and programs designed to help families (church,school) school).					
7. Knowing that we have the strength within our own family to solve our problems.					

F-COPES-C

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WHEN WE FACE PROBLEMS OR DIFFICULTIES IN OUR FAMILY, WE RESPOND BY:	VERY UNTRUE	SORT OF UNTRUE	NOT TRUE OR UNTRUE	SORT OF TRUE	VERY TRUE
8. Receiving gifts and favors from neighbors (food, taking in the in mail).					
9. Seeking information and advice from the family doctor.					
10. Asking neighbors for favors and help.					
11. Facing problems directly and trying to get solutions right away.					
12. Watching television.					
13. Showing that we are strong.					
14. Attending church services.					
15. Accepting stressful events as a fact of life.					
16. Sharing worries with close friends.					
17. Knowing luck plays a big part in how well we are able to solve family problems.					
18. Exercising with friends to stay fit and reduce stress.					
19. Accepting that difficulties occur without warning.					

F-COPES-C

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WHEN WE FACE PROBLEMS OR DIFFICULTIES IN OUR FAMILY, WE RESPOND BY:	VERY UNTRUE	SORT OF UNTRUE	NOT TRUE OR UNTRUE	SORT OF TRUE	VERY TRUE
20. Doing things with relatives (dinners, get-togethers).					
21. Seeking professional counseling and help for family problems.					
22. Believing we can handle our own problems.					
23. Participating in church activities.					
24. Defining the family problem in a more positive way so that we do not become too discouraged.					
25. Asking relatives how they feel about problems we face.					
26. Feeling that no matter what we do to get ready, we will have trouble handling problems.					
27. Seeking advice from a minister.					
28. Believing if we wait long enough the problem will go away.					
29. Sharing problems with neighbors.					
30. Having faith in God.					