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Unplanned Hospitalization of a Child: Perceptions of Stress, Family Life Events, and Coping Resources

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UNPLANNED HOSPITALIZATION OF A CHILD: PERCEPTIONS OF STRESS, FAMILY LIFE EVENTS, AND COPING RESOURCES

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ABSTRACT

UNPLANNED HOSPITALIZATION OF A CHILD: PERCEPTIONS OF STRESS, FAMILY LIFE EVENTS, AND COPING RESOURCES

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The purpose of this study was to identify the parental perceptions of family stress, family life events, and coping strategies of a family whose child is hospitalized in the pediatric unit.

A descriptive correlational design with a non-probability convenience sample consisted of 30 parents or primary caretakers of a child who was hospitalized in pediatrics. Data was obtained with three instruments; 1) demographic questionnaire assessing current perceived stress of the family, 2) Family Inventory of Life Events (FILE); and 3) Family Crisis Oriented Personal Evaluation Scales (F-COPES).

Data analysis included three correlations between (a) pile-up and perceived family stress, (b) pile-up and family's coping strategies, and (c) family's perceived level of stress and their coping strategies. The only statistically significant finding was the relationship between pile-up and the families coping strategies. As the number of other stressors in the family (pile-up) increased, the ability for the family to utilize their coping strategies decreased.

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CHAPTER 1

INTRODUCTION

The care of sick children has evolved dramatically within the last century. The transition from caring for the sick by families at home to caring for the sick by trained staff was made almost a century ago. When the care of the child moved into the hospital, the parents were alienated and often excluded from participating in care or having access to information about their child. There are documented accounts of mothers dressing up as housekeepers to sneak into the hospital ward to see their children (Page & Boeing, 1994).

In the twentieth century, specifically the 1990s, care has once again changed dramatically. More and more sick children are being managed at home in collaboration with home health care nursing agencies, outpatient labs, and physicians. The illness acuity of a hospitalized child is often much higher than it was even twenty years ago. When families experience a pediatric admission, their child is too sick to be expected to recover at home and needs medical intervention and nursing care. The decision to hospitalize may also come after the family is tired and stressed from attempting to manage the child's illness at home after several sleepless nights.

Admission of a pediatric patient is a stressful event for parents, the impact of which may precipitate a crisis in even the most adaptive family. Recognizing their child is ill and need's medical attention in the hospital produces change in the lives of each family member. Confronted with unfamiliar equipment and the complexities of their child's illness, many parents report feeling threatened, intimidated and inadequate (Farrell & Frost, 1992; Graves & Hayes, 1996; Nielsen 1990; Page & Boeing, 1994;

Tomlinson & Mitchell 1992). This situational stressor demands that the family call on existing resources to give the situation definition and meaning and somehow attempt to cope with all of the changes happening around them.

Family resources, both internal and external, are utilized to help the parents adapt and respond to the change of having a child hospitalized. Adaptation is facilitated when parents assess what their needs are related to their child's admission and find ways to facilitate meeting these needs. Several studies have suggested that parent's main needs during the pediatric hospitalization include: being with their child, being given accurate and truthful information, participating in their child's care, and being assured that their child is receiving the most optimal level of care (Farrell & Frost 1992; Graves & Hayes, 1996; Kirschbaum, 1992; Kristjándóttir, 1995).

There are many barriers within a hospital setting that have traditionally limited families' involvement, making it more difficult for them to adapt and cope. One of the main barriers to meeting parents' needs are that nurses' and parents' perceptions of participation in caring for the hospitalized child are different (Ahmann, 1994; Diehl, Moffitt, & Wade, 1991; Jacono, Hicks, Antonioni, O'Brien, & Rasi, 1990; Kawik, 1996; McNeil 1992, Scott, 1998). The introduction of family-centered care has attempted to change some of these perceptions by encouraging nurses to recognize and respect the central role of the family in the life and recovery of the child. Great strides have been made in policy changes across the country with regards to family involvement. As a result many institutions now practice twenty-four hour parental visitations, pre-hospital visits, sibling visits, and family-centered care. Family-centered care works by nurses assessing the family's needs and attempting to establish a trusting working relationship by recognizing, communicating, and incorporating the families perceived needs into each pediatric plan of care. Developing a trusting relationship that leads to role

negotiation places the family as the constant in the child's life. This has encouraged more communication between nurses and parents regarding test results pertinent to patient care, other disciplines' plans for the child, and anticipated discharge planning with the family. However, open communication and role negotiation are not consistently done and families continue to report their needs as unmet (Ahmann, 1994; Mendonca & Warren, 1998; Snowdon & Kane, 1995). When parents feel their role is being neglected or they are being denied involvement in decisions involving their child, trust is lost.

The information sharing process is the essential first step toward establishing a collaborative and trusting health care alliance (Robinson & Thorne, 1984). Establishing trust enables the parents and nurses to work as a team to evaluate the plan of care and utilize and incorporate family support in order to enable the family to cope with the admission. By including information needs in each child's plan of care, the pediatric staff can help parents toward a realistic perception of the child's status, treatment and prognosis.

Previous research has focused on a family's stress and dysfunction during a pediatric admission with a more recent shift to exploring family strengths and needs. The purpose of this study is to identify the perceptions of family stress, family life events (pile-up), and coping strategies of a family whose child is hospitalized in the pediatric unit.

Nurses play an important role in advocating for, informing, and buffering information for parents during the pediatric hospitalization. This research will attempt to identify the parental perception of stress, the pile-up of other stressful events over the past year, and coping patterns used by the family. With this information a generic intervention plan could be developed to help nurses consistently: (1) help give parents a realistic perception of the event through sharing information, (2) help parents utilize

adequate coping mechanisms, and (3) help parents find adequate situational support through family, friends, and other parents.

CHAPTER 2

CONCEPTUAL FRAMEWORK AND LITERATURE REVIEW

Conceptual Framework

Family changes and stressors, whether expected or unexpected, produce stress which may lead to a family crisis. How families negotiate their way through stress and critical transition is the focus of The Double ABCX Model of Family Stress (McCubbin & Patterson, 1983). This framework provides a description of how families adapt to stress through using their perceptions, family resources, and previous experiences as components for a coping process aimed at achieving family balance.

The ABCX model developed by Hill (1958) described the precrisis phase of adapting to a stressor. The model explores how vulnerable families are to *crisis* (i.e., incapacity in the family system) which depends on the interaction of the *stressor* (a factor) with existing *resources* (b factor) and with family *perception* of the stress or event (c factor). To illustrate these variables, one could define the initial stressor, factor (A) as a pediatric admission. Existing resources in the family, factor (B), may include, for example: (1) flexibility in changing roles, or (2) emotional support between parents to accept the hospitalization. The parents' perception of the stressor event, factor "C," could be to view the hospitalization as an opportunity for family growth though the challenge or to view the event as catastrophic, and feel overwhelmed. Without adequate resources, such as agreement on family roles, emotional support for each other, or adequate finances to cover the increased expenses, the family stability could be threatened. The first step of family functioning in the precrisis model, is to determine

the meaning to apply to the situational stressor and then to determine if the family can cope with the pediatric admission with existing resources or the family is in a crisis.

The Double ABCX model (McCubbin & Patterson, 1983) builds on Hill's precrisis theory and focuses on post crisis behavior. The Double ABCX is the framework for this research (Appendix A). This model was recreated with permission (Appendix B). Pile-up (aA) is the first major concept of the Double ABCX Model. Families seldom deal with a single stressor like a pediatric admission. Instead, multiple demands and changes are

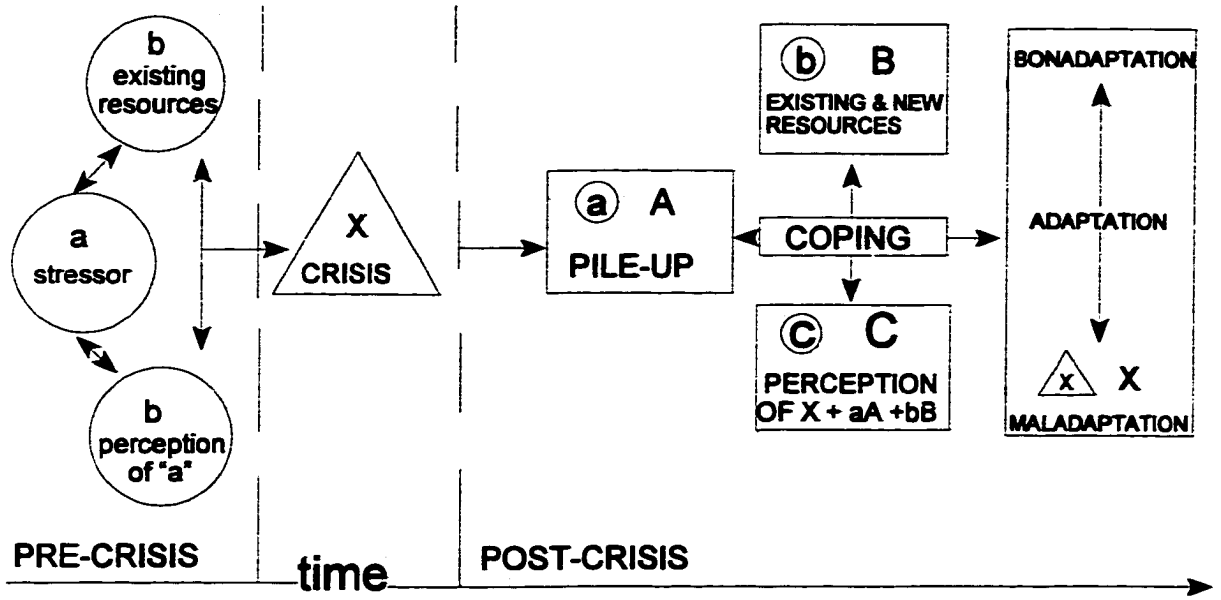

Figure 1. The Double ABCX Model

Note. From "The Family Stress Process: The Double ABCX Model of Adjustment and Adaptation," by H.I. McCubbin and J. Patterson, 1983, in H.I. McCubbin, M.B. Sussman, and J.M. Patterson (Eds.) Advances and Developments in Family Stress Theory and Research. New York:

occurring simultaneously. There are many variables that contribute to the concept of pile-up (aA). These five variables are: (a) normative changes, (b) strains and hardships, (c) prior strains, (d) consequences of family efforts to cope, and (e) intra family and social ambiguity. In the context of a family dealing with a pediatric admission there are *normative changes* the family might be experiencing like a child starting school or the

death of a grandparent. There are *strains and hardships* associated with a pediatric admission, like increased financial burdens, increased caretaking tasks, and increased marital or sibling conflict. Other variables such as *prior strains* also contribute to pile-up. Prior strains could include dealing with unresolved feelings about a prior marriage. Another source of stress and strains is from the *consequences of family efforts to cope.* Parents use behaviors and make decisions to try and cope when inevitably they create more strains upon the family unit.

The last variable contributing to the pile-up is *Intra family and social ambiguity* (McCubbin & Patterson, 1983). Families need to know who is physically and psychologically a part of the family, and whom they can count on for support. An example of intra family ambiguity may be within a divorce situation. The family experiences ambiguity about its structure; is a former spouse still a member of the family because he is the children's father? Additionally, society often places an added strain when needed social prescriptions for crisis resolution are unclear or absent. For example in a divorce, the family members also face the stigma and loss of status. Society's efforts to normalize this major transition are important in easing family strains. The pile-up of unresolved stressors and strains influences family's ability to cope and influences family's resources that may be depleted as a result of dealing with other current stressors.

The second concept of the Double ABCX Model is Resources (bB). Family demands are met with social, interpersonal, and psychological characteristic of individual family members. These include the ability to earn an income, flexibility and organization of the family unit, and access to medical services. Using existing resources within the family reduces their vulnerability to a crisis.

Finding the availability of new resources, and incorporating them into the family, influence's perception of the stressor (McCubbin & McCubbin, 1987).

The third concept of the Double ABCX Model is Family Definition and Meaning (cC). The cC factor is the family's subjective appraisal of the stressor, accompanying hardships, and effect on the family. The meaning reveals the family's values and previous skills in dealing with change and meeting crisis. Some families redefining a situation as a "challenge," or an "opportunity for growth," appear to facilitate family coping and adaptation. (McCubbin and Patterson, 1983). When families define the situation, it works to simplify the hardships, issues and tasks to make them more manageable. Giving the situation purpose decreases the intensity of the emotional burdens of the crisis and promotes members of the family unit to encourage the social and emotional development of its members.

The final variable, *Family Adaptation* (xX Factor) is the central concept in the Double ABCX Model. Achievment of family adaptation occurs when the demands of one unit are met by the capabilities of another, giving the unit balance (McCubbin & Patterson, 1987). There are three units of the family: (a) the individual family member, (b) the family unit, and (c) the community of which family members and the family unit are a part. At the first level balance is sought between individual family members and the family unit. For example if a parent begins to work more hours to compensate for the cost of a pediatric admission, the balance is upset. One parent may not be available for emotional needs and support of the other parent. The demands an individual places on the family exceed the family's capability of meeting those demands. At the second level a balance is sought between the family unit and the community of which the family is a part. Primarily the family unit may be called upon to reestablish and maintain a balance between work-community demands and family life. Illnesses and a temporary

breakdown in child-care arrangements may induce guilt and a feeling of having to be a "superparent" with equal competence to fulfill the needs at home and responsibilities at work. With a pediatric admission both parents are strained to meet the family needs and still keep up with their work obligations.

There are two levels of adaptation that the model identifies (McCubbin & McCubbin, 1987). The first level is *Maladaptation*, in which there is deterioration in family integrity. The development of both the family unity and the individual are curtailed. There is a loss of family independence and autonomy and the family is basically just surviving but has adapted poorly and is not functioning optimally. On the other extreme is *Bonadaptation* where the family integrity is strengthened. There is an enhanced member development and an enhanced family unit. The family has independence and control of the environment around them.

This research study will focus on a specific stressor, a pediatric admission, how it is perceived by the family member, the pile-up of events surrounding the pediatric admission, and the coping strategies used by the family.

Review of Literature

The focus of the literature review is concerned with perceived needs of parents during a pediatric admission, family life events and coping resources. There is a great deal of selective literature about parents' perceptions of needs during their child's hospitalization, but very little could be found that pertained to the issue of life events influencing parents' perceptions and coping.

Parents' perceptions of stress and needs

There have been several research studies that examine needs of parents with ill children and their perceptions of stress. Research has been conducted in various settings, including pediatric units, parents home, and Pediatric Intensive Care Units.

Molter (1979) conducted an exploratory, descriptive research study to identify the needs of relatives of critically ill patients, the importance of these needs to the relatives, and whether the identified needs were being met. Molter used a structured interview technique to develop the Critical Care Family Needs Inventory (CCFNI), which consists of 45 families need statements. Structured interviews were conducted with 40 family members of critically ill patients who had been admitted for at least three days and then transferred to another unit within 48 hours or less. The CCFNI interview, asked subjects to respond by rating the need statement by its importance utilizing a Likert-type scale from 1 (not important at all) to 4 (very important). The subjects were also asked to respond to questions about need fulfillment.

The five most important needs were (1) to feel there is hope, (2) to feel that hospital personnel care about the patients, (3) to have the waiting room near the patient, (4) to be called at home about changes in the condition of the patient, and (5) to know the prognosis. Review of the findings in relation to need fulfillment indicated that only four needs were not consistently met when the subject had identified the need as important. Those unmet needs were identified as (1) the need to talk to the doctor at least twice a day, (2) the need to be told about chaplain services, (3) the need to have a place to be alone while in the hospital, and (4) the need to have someone help with financial problems (Molter, 1979).

Molter's study established the foundation for further research in the identification of family members needs. Also, the Critical Care Family Needs Inventory (CCFNI) has been used in various studies since 1979. The limitations of the study were the small sample size and the introduction of a new investigational instrument.

Scott (1998) conducted a descriptive comparative study to examine needs of parents of critically ill hospitalized children as perceived by the parents and critical care

nurses, and identifing any differences between the two groups. A nonprobability convenience sample of parents or primary caregivers of critically ill children (n=21) and pediatric critical care nurses (n=17) was used. Primary caregivers and critical care nurses completed the Critical Care Family Needs Inventory modified for pediatrics and demographic questionnaires.

The survey found that information, assurance, and proximity to the critically ill child were identified as priority needs of the primary care giver's (PCGs) in the study. Significant differences on specific needs were identified between PCG/nurse matched pairs. Even though there were differences in the order of individual need statements, there was not a significant difference between the two groups in the overall perception of family needs ($t(15) = 0.77$, $p=.46$). The internal consistency reliability of the modified pediatric version of the CCFNI was .94 for the primary caregivers and .93 for the nurses. One strength of the study was the use of the Critical Care Family Needs Inventory which has been used in several needs type studies. Some limitations were the small sample size and the limited demographic representation of subjects.

Kasper & Nyamathi (1988) surveyed 41 parents to determine parental role needs and parental stress experienced during the admission of their children to the PICU. The highest ranked need category was child-related information. Specific needs included having frequent, truthful, complete information about the child's illness, condition, treatment, and prognosis; not to receive conflicting information; and to have hope or receive encouragement about the child's condition. The other five subcategories of parental needs included visiting or staying with the child, sleep or rest, the child's care giver's emotional support, and participating in the child's care. These parental needs' results are fairly consistent with other studies examining parental needs in PICU. The limitations of a small sample size, a newly developed interview guide and a limited

representation of demographic and sociological characteristics of the parents suggest the need for further research.

Using crisis theory as a conceptual framework, Kirschbaum (1992) studied the needs of parents of critically ill children to identify the needs of parents before discharge and explore the relative importance of those needs to parents. Forty-one participated in a qualitative research design by answering a questionnaire adapted from Molter's list of 45 need statements. An additional eight needs' statements were added to the original tool to make it more suitable for the pediatric population. The 41 parents surveyed identified "knowing my child is being treated medically, feeling there is hope, and being assured that the best care possible is being given" as the three most important needs. Informational needs such as knowing my child's prognosis, knowing what is being done for my child and having questions answered honestly were also listed as very important. One of the strengths of the study was the extensive discussion of findings and implications for nursing. The specific nursing strategies included giving a realistic perception of the event: information, adequate coping mechanisms, hope, and adequate situational supports such as family, friends, and other parents. The majority of the discussion was derived strictly based on the research conducted. Other limitations included the modification of a tool without testing for reliability and validity, and the unclear explanation of results with regards to measurement.

Additional research conducted by Farrell and Frost (1992) studied the most important needs of parents of critically ill children. The instrument used consisted of a total of 55 questions, six open-ended questions, 17 closed, and 32 need statements. The qualitative portion of the study interviewed 30 parents with their verbal consent. The major needs expressed by the parents included the need for information; what is happening, why, and the likely course of events? , to be with the child, and being

assured that their child was receiving the best and most appropriate care. The strengths of the study were that the parents were interviewed and asked some open ended questions. Limitations included the small sample size, potential for misinterpreting the open-ended questions, the instrument used for this study was a newly developed instrument, and the validity and reliability of the instrument were not provided.

Kristjánsdóttir (1995) conducted a descriptive exploratory study in Iceland with the purpose of identifying the importance of the various needs of parents of hospitalized children in Iceland. A sample of 34 parents, 12 fathers and 22 mothers, of hospitalized two to six year olds responded to 43 statements of possible needs during their child's hospitalization. Subjects responded to the statements on a Likert-type scale. There instrument contained six subscales, (1) parents' need to be able to trust doctors and nurses, (2) parents' need for information, (3) parents' needs related to other family members, (4) parents' need to feel that they are trusted, (5) parents' needs related to human and physical resources, and (6) parents' need for support and guidance. Study results indicated that parent's perception of importance was significantly and positively correlated with their perception of how their needs were being met and with their request for help from the hospital to fulfill them (r=0.37, p=<0.02). Consistently rated as very important was the parents' need to trust nurses and doctors. Items related to the need for information and needs of other family members were consistently rated as lying between important and very important. A strength of this research were limiting the age of the children between 2 and six years of age. One major limitation of this study was the use of a newly developed instrument. However, the Cronbach's Alpha for the scale was 0.91 indicating a sufficient reliability. This study sample conducted in Iceland, was somewhat homogenous, without a broad representation of cultural or economic

variances. Additionally, the instrument did not include questions regarding physical resources such as the need for financial assistance.

Within all of these studies there are several needs that are consistent for parents of ill children. These needs included the need for trust, the need for information, physical needs, and the need for support and guidance. Through this research the main needs of parents has been established. What we still have not determined is how nurse's can assist in the parental need for support and guidance? With the stress of life in addition to a pediatric admission, what coping strategies do families most often utilize?

Perceived Stress and Coping Resources

A study by Nolan et al. (1992) explored and described perceived stress and coping strategies among families of candidates for a cardiac transplant during the organ waiting period. This descriptive study utilized the T-Double ABCX Model of Family Adjustment and Adaptation (McCubbin & Thompson, 1987). Thirty-eight family members of patients on the active list for cardiac transplantation, included 35 women and three men. They were given three questionnaires to complete: (1) Family Inventory of Life Events and Changes (FILE), (2) Family Crisis Oriented personal Scale (F-COPES), and (3) Family Perception of the Transplant Experience Scale (FPTES). Coping strategies most utilized included: knowing our family has the strength to solve our problems, facing problems' head-on, and seeking support from friends. The three statements that the subjects most strongly agreed upon included, "heart illness has changed roles of family members," "a family member will survive the transplant operation," and "this is an experience that could bring out the family's strengths." One strength of the study was that all family members interviewed currently had a family member on the waiting list. Limitations include the small sample size; stress, coping

and appraisals were assessed only once; and 68% of the subjects in this study were wives of transplant candidates. In order to fully assess and understand the stressful effects of this period on the entire family other members should be questioned. This study was included in the literature review because the nature of the study examined perceived stress and coping and used the instruments FILE and F-COPES.

Pile-up

Two additional studies were included in the literature review because of their application to the Pile-Up (aA Factor). The first study by Snowdon and Kane (1995) examined parental needs following the discharge of a hospitalized child. An exploratory descriptive study of 16 families examined parents' needs following their child's discharge and parents' perceptions of the effectiveness of a discharge follow-up program. The families who had agreed to be in the study were visited in their homes 24 hours after discharge by nursing students in a community health nursing rotation. The home visits provided families with the opportunity to express their individual health and learning needs. Students charted the visits using standardized community health nursing charts from the Public Health Department. Care plans to describe the natures of parents' needs and interventions to be used for the duration of the semester were documented. Two weeks after the completion of the students' clinical rotation the instructors conducted telephone interviews to determine the parents' perceptions of the discharge program. Open-ended questionnaires were completed during the telephone interview. Examples of questions include: "How have you and your child been managing at home since the hospitalization?" Can you describe your home visit with the student nurse? Families described needs in two areas (1) the need for detailed information about their child, and (2) the need for support regarding multiple stresses that their families were facing. Limitations included the small sample size and interviewer's interpretation of the

parents interview. The main reason for inclusion of this study within pile-up is the finding that families need support regarding multiple stresses.

An additional study by Tomlinson and Mitchell (1992) also supported the pile-up factor aA. The purpose of this study was to examine the nature of family social support during an unexpected critical illness of a child. The study was designed to explore a number of questions: (a) how was support perceived during an acute health crisis? , (b) how was support mobilized during a critical health event?, (c) were there gender-related aspects of perceived support?, and (d) were spouses able to give mutual support when their child was acutely ill?

A convenience sample of 10 families was obtained from the PICU. Families participated in a tape-recorded interview in the hospital 2 to 13 days after admission to the PICU using the Family Crisis Support Qualitative Analysis, a research tool that was designed for this study. One result of the study illuminates the effect of simultaneous crisis between families and their support structure, confirming McCubbin and McCubbin's (1987) "stress pile-up" hypothesis. The pile-up of unrelated stress limited access to key support persons and if contacting the support people was left to the parents, bringing in family and social support was slower, and parents were more isolated initially. Access was limited by parents who were concerned about adding to the burden of already stressed family and friends who had been supporting them. Mobilizing the social network was much faster if the family had a maternal grandmother or other relative that took over and was the "gatekeeper" for the family. The role of the gatekeeper was sharing of information and limiting visitors. This relieved the parents and enabled them to spend more time with their child. This article reinforces that family's resources which include their support network has a strong relationship in mobilizing their coping strategies. This could be relevant for PICU staffs who

experience a family in the isolation of the critical care environment and who may not be aware of the full context in which families operate. These findings can only have limited application due to the small sample size, development of a new tool, and the limited representation of different cultural, demographic, and geographical variables.

Summary and Implications for Study

In summary, the literature review yielded no studies examining perceived stress of parents with the variables of family life events and coping resources during the pediatric hospitalization. The majority of research conducted in the pediatric setting has traditionally looked at parental needs during the PICU hospitalization. Very few studies have been conducted in the general pediatric unit. Variables of interest have generally been perceived needs with a few studies examining coping. There are very few studies that address perceived stress of parents during a unplanned pediatric hospitalization. Studies reviewed recommend that more research be conducted examining how families cope with pediatric hospitalization.

This study is implicated because it contributes to the body of knowledge about families' coping in general and benefits pediatric nurses by increasing the knowledge regarding family stress and general family coping strategies. It has implications for health care workers because of the emphasis of a thorough family assessment. In addition, it contributes to the knowledge about the usefulness of family-centered care, including the consistent finding of how parents value honest, consistent information and support during their child's hospitalization.

Research Questions

This research was conducted to answer the following questions:

1. What is the relationship between the pile-up of stressful family life events over the past year and the family's perceived level of stress?

2. What is the relationship between the pile-up of stressful family life events over the past year and the family's coping strategies?
3. What is the relationship between the family's perceived level of stress and their coping strategies?

Definition of Terms

Children - newborn through 18 years of age, admitted to the pediatric unit for at least 24 hours.

Illness - an acute onset of an illness, exacerbation of a chronic illness, or a surgical procedure that requires monitoring, observation and nursing care in a pediatric unit.

Parent(s) - a specific role in the family structure that focuses on the care of the children in the family unit (Thomas, Bernard, & Summer, 1993). For the purpose of this study the primary caretaker is the person the family defines as the primary caretaker of the child.

Family - the basic structural and functional unit of society; a social system with organized boundaries, roles and positions, that provides the primary social environment for individual members (King, 1981). For the purpose of this study, a family may be a dyad, consisting of the child and the primary caretaker.

Stress - the organism's physiological and psychological response to stressors, particularly when there is a perceived imbalance between environmental demands (life changes) and the individual's capability to meet these demands (Holmes & Rahe, 1967). For the purpose of this study stress is measured using a visual analogue scale, stress scores may range from 0- (no stress) to 100- (stress as bad as it could be).

Coping Resources - include the family's use of social support networks, such as extended family members, friends, and neighbors. The family's approach to problem solving (Hill's B factor, 1958). This will be measured using Family Crisis Oriented

Personal Evaluation Scales (F-COPES).

Perception - each human being's representation of reality. It is an awareness of persons, objects, and events. It gives meaning to one's experiences and represents one's image of reality and influence's one's behavior (King, 1981).

Pile-up - the cumulative normative and non-normative stressors and Intra family strains (McCubbin & Patterson, 1983). For the purpose of this study Pile-up will be measured using the Family Inventory of Life Events (FILE).

CHAPTER 3

METHODS

Design

A descriptive correlational research design was utilized for this study to identify the perceptions of family stress, family life events, and coping strategies of family's whose children were hospitalized in a pediatric unit.

Several potential problems with descriptive research were identified and efforts were taken to minimize or avoid them. One of the variables of the study was perception of stress. Perceptions may change with time. Parents who have had a couple days to adapt and adjust to the admission and utilize coping resources may not have a true reflection of their feelings immediately following the admission. To minimize this problem, the sample was selected from parents whose child had been admitted within the last 48 hours. However, three of the subjects have number of hours of admission listed as greater than 48 hours because the parents were approached within 48 hours, but were unable to complete the full questionnaire within that time.

Another weakness of this design was the use of self-reported data. Participants may have been hesitant to respond in a truthful manner. To reduce this risk, participants were informed that all responses were confidential, therefore reducing hesitancy of the participant to be truthful.

An additional weakness is that this research studied families. The tools that were used in the study FILE and F-COPES are preferably completed by couples separately and both scores are used to determine the level of family stress and coping (McCubbin, Thompson, & McCubbin, 1996). Unfortunately, due to time constraints only

one family member completed the questionnaires. The family member who was determined by the couple to be the primary caregiver for the child was the designated respondent. If the mother and father both shared in the caretaking responsibilities, the family elected a representative to answer the questionnaires.

One advantage of the study setting was that the researcher had access to the place of data collection twenty-four hours a day. This increased the availability of subjects and presented sampling bias, due to lost subjects that may have resulted from restricted research availability.

Population and Sample

A non-probability convenience sample was utilized for this study, consisting of 30 parents or primary caretakers of children. The sample consisted of a parent or primary care giver who self-identified as being primarily responsible for the majority of physical, emotional and mental needs of the pediatric patient.

Parents were selected from a metropolitan Midwestern hospital in which their child (newborn through eighteen years) was hospitalized for at least 12 hours in the pediatric unit. The parent(s) were 18 years of age or older. All parents spoke and understood the English language. Parents were not selected for inclusion in this study if the nurse and/or researcher determined that inclusion would compromise a parent's emotional well-being.

Characteristics of the Subjects

Parents/primary caretaker sample. Thirty parents or primary care takers participated in this study. Twenty-nine of the respondents were parents (97.0%) of a child in the pediatric unit. One of the respondents was a grandparent (3.0%). The majority of the respondents were female (83.3%). The age of the respondents ranged from 20 to 53 with a mean of 31.5 years (S.D. = 8.6).

Approximately 73.3% of the respondents had attended or completed high school education. Nineteen of the respondents had attended college (63.3%), with five of the respondents successfully completing a college degree (16.6%). Three of the respondents had participated in graduate studies.

The employment status of the majority of the respondents was full-time (66.6%). Two of the respondents worked part-time, five were homemakers, and the remaining 3 were homemakers and worked part-time. Twenty-six (86.6%) of the respondents had at least one other child at home. Nine of the respondents had one child (30.0%) at home, while another nine had two other children at home (30%)

The majority of respondents were married (66%), Caucasian, and with an above average income. Eighteen of the respondents (60%) had an income ranging from 0-$59,999. Four of the respondents (13.3%) had an annual income exceeding $100,000. Twenty-three of the respondents were Caucasian (76.6%). Six of the respondents were Hispanic (20.0%).

The parents or primary caretakers of 30 children participated in the study. Data collection occurred between 12 and 75 hours of admission to the pediatric unit with a mean data collection time of 24.3 hours. The ages of the children ranged from 1 day to 15.8 years with a mean age of 5.7 years (S.D. = 5.2 years). Nine (30.3%) of the children were admitted for respiratory illnesses. Examples of these diagnoses include: asthma, R.S.V., croup, pneumonia, and bronchiolitis. Table 1 depicts the number of children admitted for each diagnosis and their ages.

Table 1

Pediatric Admission Diagnoses

Diagnoses	Ages	Total Number of Cases
Respiratory Illness	29 days to 10 years	9
Infection	7 days to 15 years	4
Dehydration/Flu/Stomatitis/	13 months to 9 years	3
Broken Leg	12 months to 13 years	3
Fever	4 days to 20 months	3
Trauma/Surgery	8 years to 16 years	3
Appendicitis	10 years old & 14.5 years	2
Closed Head Injury	8 years old	1
Jaundice	4 days old	1
Hemorrhagic Cyst	14 years old	1

The parents or primary caretakers were asked to indicate what they perceived their family's stress level to be at the time of the completion of the questionnaires. A linear scale of 0 to 100 was used with 0 denoting no stress, to 100 denoting stress as bad as it could be. The perceived level of stress ranged between 6 to 100 with a mean of 53.8 (S.D. = 26.0) and a median of 59.5.

Instruments

The three instruments that were utilized in this study included (1) a demographic data questionnaire for parents (Appendix C); (2) Family Inventory of Life Events and Changes (Appendix D); and (3) Family Crisis Oriented Personal Evaluation Scales (Appendix E).

Permission for use of FILE and F-COPES was obtained from the author (Appendix F). The demographic tool was designed to collect general demographic data and perceived level of family stress.

Visual Analogue Scale within the Demographic Questionnaire

Within the demographic questionnaire a visual analogue scale (VAS) was created. The participant was asked to place an (x) on the line depicting what he or she perceived the family's current stress level. A straight line was used for the VAS, with right angle end anchors labeling the extreme boundaries of stress, no stress=0, and stress as bad as it could be=100. A horizontal 100mm VAS was used, due to the fact that a horizontal VAS has been shown to produce a more uniform distribution of scores as opposed to a vertical VAS. Additionally, lines shorter than 100mm tend to produce a greater error variance (Revil, Robinson, Rosen, & Hogg, 1976 in Wewers & Lowe, 1990). Right angle stops have also been placed at the ends of the VAS to contain the scores and limit marks beyond the ends of the line as recommended by Huskisson, 1983 in Weweers & Lowe, 1990. The descriptive anchors are placed beyond the right angle stops, not underneath or above the stop (Huskisson, 1983 in Wewers & Lowe, 1990). The VAS was scored by measuring the distance, in millimeters, from the 0 points of the scale to the 100 points of the scale (Guiffre, 1983 in Weweres & Lowe, 1990). The test-retest approach is not recommended for this VAS measurement. Stress is a variable that changes quickly, the test-retest approach is not suitable for measuring stress. However, normal experimental subjects tended to estimate accurately with an average error of +/- 2mm (Wewers & Lowe, 1990). For the most part, investigators have deemed the VAS to be a valid and reliable measurement tool (Wewers & Lowe, 1990).

Family Stress Instrument

The Family Inventory of Life Events and Changes (FILE), was designed by McCubbin and Patterson (1983) to assess the pile-up or accumulation of family stressors. It has 71 items, grouped into nine subscales: (1) intra family strains or difficulties in family relationships, such as strains between parents and children or between ex-spouses; (2) marital strains; (3) pregnancy and childbearing strain; (4) financial and business strain; (5) work-family transitions and strains; (6) illness and family "care" systems; (7) losses (deaths in nuclear and extended family); (8) transitions "in and out" (children being launched or returning home after leaving); (9) family legal violations. The FILE questionnaire has been validated in many research studies. Families with a higher accumulation of life events (i.e., higher scores on the FILE) have been found to have lower family functioning and poorer health of family members (McCubbin & Patterson, 1992). The development of items for the instrument was guided by research by Coddington (1972) and by Holmes and Rahe (1967) and modified with data from a sample of 322 families who have a chronically ill child (myelomeningocele or cerebral palsy). The FILE total score ranges from 0-3307. These family stress scores are based on a methodology developed by Holmes and Rahe (1967) in which each life event and strain is assigned a standard weight that indicates the relative magnitude and intensity of the event or strain (McCubbin, Thompson, and McCubbin, 1996). Scores for each subscale were computed by summing the weighted items in the subscale. For the purpose of this study subscales were not used.

Previous studies have computed the Cronbach's alpha (n=2740) as .81. The Reliability coefficients for this study were computed at .77 (n=21). There were only 21 complete cases for this study, 8 subjects did not fully complete the questionnaire,

therefore their data could not be included. Because of the increased stability of the total score the subscales scores were not calculated (McCubbin, Thompson and McCubbin 1996).

Family Coping Instrument

The Family Crisis Oriented Personal Evaluation Scales (F-COPES), developed by Hamilton McCubbin, David Olson, and Andrea Larsen (1981), was created to identify problem solving and behavioral strategies utilized by families in difficult and problematic situations (McCubbin, Thompson and McCubbin, 1996). F-COPES draws upon the coping dimensions of the Resiliency Model of Family Adjustment and Adaptation in which the following factors are integrated: pile-up, family resources, and meaning/perceptions.

The instrument features 30 coping behavior items which focus on the two levels of interaction outlined in the resiliency model: 1) individual to family system, or the ways a family internally handles problems between its members; and 2) family to social environment, or the ways the family handles external demands that effect the whole family. There are five factors of coping that the instrument measures. (1) Acquiring social support, (2) Reframing, (3) Seeking spiritual support, (4) Mobilizing family to acquire and accept help, and (5) Passive appraisals.

Each item is rated on a five point Likert scale. A total score was obtained by summing the total numbers circled by the family member (0=Strongly Disagree; 5=Strongly Agree) to identify the coping resources most often used by the family. The subscale scores were not calculated for this study. There are four select items (12,17,26 and 28), the scores must be reversed. These select items are, 1) watching television, 2) knowing luck plays a big part in how we are able to solve our family problems, 3) feeling that no matter what we do to prepare, we will have difficulty

handling problems, and 4) believing if we wait long enough, the problem will go away. These four items are considered passive appraisal coping which is not the healthiest of coping strategies. The range of scores for F-COPES is 0-150. The top four coping strategies utilized on the F-COPES scale for this study: 1) having faith in God, 2) believing if we wait long enough the problem will go away, 3)attending church services, and 4) accepting stressful events as a fact of life. It is interesting to note that the second highest coping strategy utilized by these families was believing if we wait long enough the problem will go away. Previous studies using F-COPES have reported a reliability coefficient using Cronbach's alpha computed as .81 (n=2740). The reliability coefficient for this study was computed at .89 (n=25). There were 5 subjects who had incomplete F-COPES questionnaires.

Procedure

Permission was obtained from Grand Valley State University Human Subjects Committee (Appendix G) and the Nursing Research Committee at the metropolitan midwestern hospital (Appendix H). Following approval, the director of pediatrics at the midwestern metropolitan hospital was contacted. A copy of the hospital approved proposal was given to the director. The researcher requested a memo be sent to all of the staff on pediatric unit describing the study, criteria for inclusion of subjects, number of subjects needed, and nursing implications for this research.

The researcher phoned or physically visited the unit almost everyday to inquire about new pediatric admissions. If there was a new admission, the nurse caring for that patient was approached by the research and asked about inclusion criteria for that patient. For instance, did they speak english? Was the family extremly stressed by the admission and diagnosis? If the nurse felt the parents would be open to the study, the family was approached after being admitted for at least 12 hours.

A script for recruiting subjects was read to each potential participant, identifying the researcher as a graduate nursing student from Grand Valley State University (Appendix J). Questions about the study were answered, and if the subject declined the parent was thanked for their time and the researcher left. All participants were told that the purpose of the study was to identify perceived family stress, the stressful events that have occurred in the family within the last year, and how the family generally copes with stress. All participants were informed that participation was voluntary and that confidentiality, as well as anonymity would be maintained. Risks and benefits were explained to the subject. All participants were informed of the fact that they could discontinue participation at any time without consequences to themselves or their child and of the amount of time involved answering the questionnaires. Any and all questions were answered prior to obtaining consent for participation in the study.

The subjects that agreed to participate were given a manilla envelope marked CONFIDENTIAL. The forms within the packet included the family consent form, demographic questionnaire, FILE, and F-COPES. The consent was assigned a code number as well as the other forms within the packet. Participants then signed the consent form and the researcher either made a copy of the original consent form, or an additional consent was signed and left with the subject.

The most appropriate time for the researcher to pick-up the questionnaire was negotiated. At times if the family was going to fill the questionnaire out immediately, the researcher left the room and returned at an agreed upon time, usually 30 minutes later. However, for many parents they were busy with other tasks that needed to be completed for their family members and child. They would delegate the time for the researcher to retrieve the form, which ranged from an hour to tomorrow morning. There were times when the patient would be discharged before the packet was retrieved. If

this happened the researcher and parent agreed to seal the manilla packet and leave it with their nurse to be picked up later. The parent was given the option if they did not feel comfortable leaving the packet with someone they could simply discard of it or take it with them, deciding not to participate based on these circumstances. There were two cases where the researcher returned for the completed packet at the agreed upon time and the questionnaires were not completed. When this happened the researcher asked, "Are you planning on completing the forms at a later time, or would you rather not participate?" When the parent declined the researcher thanked them for their time, wished their family and child well, and left the room.

Benefits and Risks to Subjects

It was determined that the participants in this study would not receive any direct benefit from their participation. However, this study may assist health care practitioners to develop a better understanding of the needs of parents of hospitalized children, as well as the services that could provide assistance to parents. Results of this study were made available to the participants if requested.

Participants in the study had a minimal number of risks. The parents were given the option to not complete the forms. If they became emotionally upset during completion or if they were too physically exhausted to fill out the paperwork they were not included in this study. There were three participants who were unable to complete the questionnaires after giving consent. The rights to refusal of these parents was respected and no further questions were asked regarding why they chose not to participate. Confidentiality and anonymity of all participants were maintained. All of the data sheets were encoded for each individual subjects.

CHAPTER 4

RESULTS

The purpose of this research was to (a) identify the perceived family stress level, (b) identify stressful events that occurred within the family in the past year, and (c) identify family coping strategies among families with a hospitalized child. Data analysis was completed utilizing the Statistical Package for Social Sciences (SPSS for Windows) software. Significance was set at $p < .05$ for all tests.

Techniques

Perceived family stress levels were obtained using a visual analogue scale located on the demographic questionnaire. Possible scores ranged from 0 indicating no stress, through 100 indicating stress as bad as it could be. All 30 subjects responded to the perceived family stress scale. The perceived stress scores ranged from 6-100 with a mean of 53.80 (S.D. = 26.0). The majority of subjects had a moderate level of perceived stress.

The Family Inventory of Life Events and Changes (FILE) was used to determine the pile-up of stressful events that had happened within the family during the past 12 months. Of the 30 subjects asked to complete FILE, 9 (30%) had missing data. If the subject had less than 20% of the data missing, the weighted score was taken and the statistical mean was obtained for that individual question. This technique was recommended by the author (McCubbin, 1999) as well as Polit & Hungler, (1995). Subjects with more than 20% data missing were excluded.

A weighted score was obtained for the questions in which the subject responded yes. The possible weight for each individual question was 0-100. These weighted

scores were added together for a total pile-up score. The range of total possible pile-up scores is 0-3307. The tables below indicates the response rates for the top ten stressful events on the FILE instrument (See Table 2), response rates for ten lowest possible scores on the instrument or least stressful (See Table 3), number of valid cases, and the percent of families who answered yes to the individual stressor.

Table 2

Response Rate for Top Ten Stressful Events (FILE)

Item	Weighted Score	Valid Cases	Frequency (%)	
1. A child member died.	99	30	1	(3.3%)
2. A parent/spouse died.	98	30	0	(0.0%)
3. Spouse/parent was separated or divorced.	79	28	4	(13.3%)
4. A member became physically disabled or chronically ill.	73	29	5	(16.7%)
5. Spouse/parent had an "affair."	68	28	1	(3.3%)
6. A member went to jail or juvenile detention.	68	30	2	(6.7%)
7. A member appears to depend on alcohol or drugs.	66	29	1	(3.3%)
8. A unmarried member became pregnant.	65	28	5	(16.7%)
9. A member ran away from home.	61	30	0	(0.0%)
10. Married son or daughter was separated or divorced.	58	30	0	(0.0%)

Table 3

Response Rate for Ten Lowest Stressful Events (FILE)

Item		Weighted Score	Valid Cases	% of Respondents	
1.	A member purchased a car or other major item.	19	30	12	(40.0%)
2.	Increased strain on family "money" for food, clothing, energy, home care.	21	30	13	(43.3%)
3.	Increased strain on family "money" for children's education.	22	29	2	(6.7%)
4.	Increased strain on family "money" for medical/dental expenses.	23	30	9	(30.0%)
5.	A child/adolescent member changed to a new school.	24	30	1	(3.3%)
6.	Increase in the amount of "outside activities" which the children are involved in.	25	30	10	(33.3%)
7.	Young adult member began college (or post high school training).	28	30	1	(3.3%)
8.	Took out a loan or refinanced a loan to cover increased expenses.	29	30	5	(16.7%)
9.	Increased financial debts due to over-use of credit cards.	31	30	7	(23.3%)
10.	A member had increased difficulty with people at work.	32	30	9	(30.0%)

The FILE scores for this study ranged from 0 to 1338. The mean score for FILE was 467.94 (S.D. = 260.9; n=30). The table below lists the stress level ranges for the subjects. Cut off scores for moderate stress levels were determined by the mean and one standard deviation above and below; low stress levels were those more than one standard deviation below the mean; and high stress levels were those more than one standard deviation above the mean. Cut off scores were rounded off to even numbers.

Table 4

Family Pile-up stress scores [a]

	Pile-Up		
Mean	Low	Moderate	High
468	0-207 (13.2%)	208-728 (76.6%)	729+ (10%)

[a] n=29

The majority of subjects had a moderate stress level, indicating a moderate amount of other family stressful events that the family may have been dealing with simultaneously with the pediatric admission.

The Family Crisis Oriented Personal Evaluation Scales (F-COPES) was used to identify problem solving and behavioral strategies used by families in difficult or problematic situations. The instrument features 30 coping behavior items, which focus on the two levels of interaction: (1) Individual to family system, or the ways a family internally handles difficulties and problems between its members; (2) Family to social environment, or the ways in which the family externally handles problems or demands that emerge outside its boundaries, but affect the family unit and its members (McCubbin, Thompson, & McCubbin, 1996). The meaning a family attaches to the stressful situation, or the family's appraisal, may contribute to the family's overall coping behavior. F-COPES were designed to integrate family resources and the meaning perception factors identified in family stress theory (Burr, 1973; Hansen & Hill, 1964; H.I. McCubbin & Patterson, 1982, 1983).

Each respondent completed a questionnaire, rating 30 items on a five-point Likert scale. Of the 30 subjects asked to complete F-COPES there was 29 (96.6%) valid cases. A total Coping score was obtained by summing the numbers circled by the respondents. The possible coping scores ranged from 0-150. The actual coping scores ranged from 60-137 with a mean of 108.79 (S.D.=16.43; n=29).

The table below lists the coping ranges for the subjects. Cut off scores for moderate coping levels were determined by the mean and one standard deviation above and below; low coping levels were those more than one standard deviation below the mean; and high coping levels were those more than one standard deviation above the mean. Cut off scores were rounded off to even numbers.

Table 5

Family Coping scores [a]

	Coping Level		
Mean	Low	Moderate	High
109	0-92 (10%)	93-125 (70%)	125+ (16.6%)

[a] n=30

Research Questions

This research was conducted to answer the following questions:

1. What is the relationship between the pile-up of stressful family life events over the past year and the family's perceived level of stress?
2. What is the relationship between the pile-up of stressful family life events over the past year and the family's coping strategies?
3. What is the relationship between the family's perceived level of stress and their coping strategies?

Data analysis included a comparison of the perceived family stress level according to the parent/primary caretakers and the pile-up of stressful life events within the last year. The perceived family stress level recorded by the parent/primary caretaker was based on the family's current level of stress. The perceived family stress measurement had a mean of 53.8 (S.D.=26.0). The pile-up was measured by the FILE

instrument using a nominal level of measurement. The range of the total FILE scores for this study ranged from 0 to 1338 with the mean score being 467.94. A Correlation coefficient using Pearson r was calculated for the variables of perceived stress and pile-up of stressful life events. No statistical significance was found between these two variables in this study (r=0.25; p=.18).

The second research question addressed the relationship between Pile-up of family life events and the family's coping. The question wanted to discover if there is a relationship between the amount of stress or different stressors that some family faces and that family's ability to cope. The pile-up score for this study was 0-1338 with a mean of 53.8 and the coping score ranging from 69 to 137, ordinal level of measurement with a mean score of 108.79, mean of 107.00 (S.D. = 16.43). A Pearsons r correlation was obtained showing r = -.47 with a moderate correlation. There was a statistically significant relationship (p=.009). For this study as the number of other stressors the family had experienced in the past year (pile-up) increased, the family's coping strategies decreased. This is a significant finding when it comes to beginning to understand the dynamics of families experiencing a pediatric admission.

The final Pearson r correlation was obtained for the variables of perceived family stress and family coping. The perceived family stress scores ranged from 6-100 with a mean of 53.8 (S.D.=26.01). The family coping scores ranged from 69 - 137 with a mean score of 108.79, (S.D.=16.43). Pearson r correlation reveals r= -.1230 with a very weak relationship. There is no statistically significant relationship (p=.525) between the variables of perceived family stress and family coping for this study. The average perceived stress score was fairly moderate at 53.8 as well as a fairly moderate coping score of 108.79. Perhaps with a larger sample size and a broader representation of subjects the parent wouldn't have had average perceived stress and average coping

and a different relationship would have been found between the variables of perceived family stress and family coping.

CHAPTER 5

DISCUSSION AND IMPLICATIONS

Findings in Relation to Conceptual Framework

The Double ABCX Model builds upon the previous ABCX Model to signify a more complete picture of how families react to life events, particularly a stressful event such as a pediatric hospitilization. The Double ABCX Model focuses on post-crisis behaviors. Using hospitilizaiton as the trigger event the Double ABCX Model provided the structure for this study. Pile-up (aA) is the first major concept of the Double ABCX Model. This variable incorporates the initial stressor and its hardships as well as demands that are placed on the family over time such as, normative growth and development, birth and development of children, changes in society (i.e., increased number of divorces, changing roles of women, the scare of Y2K). The variable (aA) pile-up was measured two ways 1) visual analogue scale that asked, "What do you think your family's stress level is right now?", this visual analogue scale measures perception, and 2) Family Inventory of Life Events and Changes (FILE), which assessed cumulative stressful events or changes that may have occurred to any family member within the past year.

Subjcets were approached for inclusion in the study between 12 and 75 hours of admission to the pediatric unit with a mean data collection time of 24.3 hours. The majority of subjects (67%) within this study perceived their current stress level to be moderate with a mean of 53.8 (S.D.=26; n=30). This moderate perception of stress may indicate that some families defined the pediatric admission in relation to current stressors as manageable, a challenge, or and opportunity for growth. While others

(13.3%) had a high stress perception, which could indicate either a higher overall pile-up of current stressors or a decrease in the coping strategies within their family.

For pile-up (aA) measured by FILE, the mean score was 467.9 (S.D.=260.9; n=30) with a range of scores from 0-1338. Of 30 subjects only 10% had a high pile-up score (>729). The majority of subjects (76.6%) had a moderate pile-up score. The findings for this research study found that, the variables of perceived stress and pile-up had no relationship. With a moderate perception of stress and a moderate amount of other stressful events the family was dealing with, they may have found the pediatric hospital admission to be manageable and not a crisis. A larger sample size may yield different results. This supports the Double ABCX Model, there is no direct relationship between (cC) perception of the crisis and (aA) pile-up. For the model, pile-up is incorporated within (cC) perception of the crisis.

The second variable (bB) existing and new resources are part of the family's capabilities for meeting demands and needs which emerge in the context of a crisis (McCubbin & Patterson, 1983). Existing and new resources are compiled of personal resources, family system resources, family cohesion, and social support. For this study existing and new resources was not specifically measured. However, questions on the demographic questionnaire assessed the number of years of education and annual family income. Education may contribute to cognitive ability that promotes realistic stress perception and problem solving skills. Family income was assessed but economic well-being and financial stability were not measured. Education and financial stability are considered family system resources. Resources were not a variable measured for this study. Therefore, the relationship of coping strategies and resources is unknown.

Coping influences all aspects of the Model, including resolution of the situation, both positive and negative. The instrument F-COPES was used to measure the coping strategies, attitudes, and behaviors used by the family. The total coping strategies utilized ranged from 69-137 with a mean of 53.8 (S.D.=26.01; n=29). The majority of subjects (70%) had a moderate coping strategies score, with 16.6% having a high score greater than 125.

The relationship between pile-up and coping was statistically significant (p=.009; r= -.47). This supports the Double ABCX Model, suggesting that the coping strategies used by the families influence's perceptions of pile-up. For this study a higher number of coping strategies utilized had an inverse relationship with pile-up of stressful life events. This may indicate that for these families they had a higher amount of stressful life events to deal with, fewer coping strategies, or both.

The data suggests a weak relationship between the variables coping and perception of stress. Perceived family stress was measured by a visual analogue scale with a possible range of 0-100. Subjects perceived level of stress ranged between 6 to 100 with a mean of 53.8. The possible scores for coping strategies ranged from 0-150 with actual coping scores ranging from 60-137, mean of 108.79. Pearson r correlation reveals r= -.1230 with a very weak relationship. There is no statistically significant relationship (p=.525) between the variables of perceived family stress and family coping for this study. Perhaps for this study if the data collection time had been less than 24 hours the perceptions of stress would have been different. Data collection was performed an average of 24 hours after the pediatric admission. Perceptions are constantly changing and are variable. The more time that passes the more coping strategies are being utilized.

This Double ABCX Model was specifically chosen for the relationship between coping strategies, stress perception and pile-up of stressful family life events and these findings support the Double ABCX Model. The families new and existing resources (bB) were not specifically measured, nor were the levels of adaptation.

Findings in Relation to Previous Research

The majority of studies within the review of literature focused on perceived needs of parents. There were no studies that utilized the variables perceived stress, pile-up and coping strategies. Although there are many articles that exist that have looked at coping, coping strategies was only one variable being evaluated within this research study.

Previous research by Tomlinson and Mitchell (1992) focused on social support during an unexpected critical illness of a child. Although the Double ABCX Model was not used for this study, Tomlinson related their findings to the "stress pile-up" hypothesis (McCubbin and McCubbin, 1987). The pile-up of unrelated stress limited access to key support persons and if contacting the support people was left to the parents, bringing in family and social support was slower, and parents were more isolated initially.

The findings of this study correlated the relationship between the pile-up of family life events and the family's coping strategies within the context of a pediatric admission. This study found there was a statistically significant relationship between these two variables. As the family had an increased number of other stressors there coping strategies decreased. This study supports the findings of Tomlinson and Mitchell (1992), there is a relationship between pile-up of other stressors and utilizing and having access to coping strategies. This has many implications for nursing education and practice.

Implications for Nursing

Over the past several decades, pediatric care practices have adapted in an effort to meet the changing emotional and developmental needs of children and their families. Some of these changes have included pre-hospital visits, pre-surgical preparation, 24-hour parental visitation, and sibling visitation policies (Ahmann, 1994). Regardless of the policy changes to improve support for children who are ill, the hospitalization of a child remains a stressful event for the family.

Previous research has focused on the stress of a pediatric admission for the family and parental needs during the pediatric hospitalization. Recent research indicates that perceived needs of parents' and family needs as perceived by nurses are not congruent (Ahmann, 1994; Diehl, Moffitt, & Wade, 1991; Jacono, Hicks, Antonioni, O'Brien, & Rasi, 1990; Kawik, 1996; McNeil 1992, Scott, 1998). In recent years many hospitals have attempted to change the way care is provided for children and families by incorporating family-centered care. This type of care is based on the philosophy that the family is the center in a child's life and should be central in the child's pediatric admission and hospitalization. Family-centered care encourages partnerships between parents and professionals, supporting parents as the central caring role in the child's life.

Family-centered care supports nursing actions that promote the family's role as primary caregiver for their child. In order to promote the family's role it is important for nurses to accept and expect that families may need to cope with stress in a variety of ways. Some families withdraw from the admission and hospitalization, others may appear to be demanding, questioning, and difficult to please. During the initial phases of the pediatric hospitalization nurses can facilitate the family's recognition of their own strengths and coping strategies.

Nurses can also support family-centered care by reassuring parents of their essential role in the care of their child. With nurses having more knowledge and expertise of the child's condition, they may be tempted to lose sight of the fact that the family is the expertise on the individual child. The family is intimately familiar with the strengths, abilities, and needs of the child. By the nurses "taking over" parents may feel left out and inadequate in caring for their child. A study by Page & Boeing, (1994) found that disruption of the parent-child relationship was more stressfulfor parents than other aspects of the admission. Preserving the parents-child relationship may be an important intervention in reducing parental stress. Nurses need to facilitate family involvement and give active encouragement for the parents or caregivers to participate in the care of the hospitalized child. Some examples to facilitate parental participation may be regularly calling the family who visits their hospitalized child only infrequently, teaching parents specialized care giving skills, or acknowledging that a parent's solution to a feeding problem may work as well as the suggestions of professionals (Ahmann, 1994).

Nurses in practice may also be a support to families by assessing their overall stress level and helping to facilitate their coping strategies. This study indicated that there is a relationship between coping strategies and pile-up of stressful family life events. There are two specific areas in which nursing may be able to incorporate this information into practice. First, it may be useful to incorporate a question such as "What other significant life stressors have you been dealing with lately?", or "On a scale of 0-10 how stressful would you rate your family's stress level to be right now?" Secondly, it is essential to assess the families coping strategies as soon as possible to facilitate support and the coping process. This could be accomplished by asking the parent, "Who do you usually turn to when your family experiences a stressful event such as this?", or "What

types of coping strategies do you and your family usually use?", "Is there anyone I may contact for you to have here now?"

Nursing staff education development programs and orientation programs particularly for pediatric units should focus attention on the abundant psychosocial needs of parents of ill children. This would enable nurses to better serve the families of the hospitalized children. It is also important for nurses to know and involve the hospital resources that are available such as a chaplain or social worker. Also, having an understanding that the hospitalization of the child may not be the only stressful event happening within the family. Assisting the family in contacting and enabling their social support system as quickly as possible is vital to the coping of the family.

Nurse administrators in support of family-centered care should be cognizant of the parents' increased psychosocial needs on the pediatric unit. Provisions of funds for additional staff, available chaplains and social workers should be made for the pediatric unit. Other needs include the need for specific psychosocial training for nurses and other staff members with regards to family-centered care, and the development of policies that make it easier for families to have access to their support network.

Hospital administrators that encourage pediatric directors to embrace family-centered care would help to ensure that nursing staff are attempting to allow parents to participate in care. Through advertising the hospital could promote a family-centered care hospital, with good staff, nurses, and physicians. Perhaps a packet of information could be distributed at the beginning of the pediatric admission that explains family-centered care and a survey that inquires on the overall satisfaction of the care their child received. Were they able to be with their child, were they given accurate and truthful information, how did they participate in care, were they encouraged or made to feel

included in their child's care, how do they feel about the overall quality of care that they received from the hospital, nurses, and physicans?

During nursing educational programs a large emphasis is placed on technical skills. Psychosical skills and communications skills that are learned during nursing education are just as important as the mastery of technical skills. Due to the dynamic dimensions of the family it is important during the nursing students pediatric rotation that they are exposed to different types of families and family-centered care. Nursing students should be encouraged to embrace diversity in family structures, cultural backgrounds, choices, strengths and needs. The assignment of care plans for the pediatric unit should be nursing student and family-centered care plans with specific examples of how the familes desires, needs, and choices were incorporated into the plan of care for their child.

The challenge for pediatric nurses, administrators and educators is to recognize that even developmentally sensitive, psychosocially oriented pediatric care is not enough for children and families. The family has the central role in the life of the child whether admitted to the pediatric unit or not. By incoporating the principles of family-centered care into the areas of nursing practice, administration, and education we will ensure that the needs of families are more throughly met. Thus enabling and freeing up the parents to provide the emotional, development, and physical care that their child needs from them. Through consistently providing assessment of families overall stress, coping strategies, and support structure nurses facilitate family-centered care, potentially aiding in a quicker recovery of the pediatric patient.

Limitations

There are several limitations that affect the strength of the findings in this study. A small, non random sample (n = 30) was selected for this study, therefore the findings

cannot be generalized beyond the present sample. Generalizability would be facilitated by using a much larger sample of parents. Additionally, the time interval for data collection may influence the parents perceived stress level. The greater the amount of time between data collection the family may have had more time to implement coping by contacting family and other support people. This may present a false representation of how stressful the pediatric admission is perceived. The parent may have been given more medical information from doctors and nurses and have a clearer understanding of the severity of their childs' condition negating a pediatric admission. The parents could have previously had this child or other children within their family admitted to the hospital. They may have experience and previous coping strategies that helped them cope with a pediatric admission. The severity of the child's illness at home was also not assessed. Perhaps the care for the child was exhausting and overwhelming at home. The pediatric admission could possibly be a relief for the parents. The support network of friends, relatives, and church members may have already been involved and contaced, therefore decreasing the families perceived stress.

An additional limitation was the way in which the instrument FILE was administered. The instrument FILE was administered to one parent who acted as the representative for the family. This is not the recommended procedure for completion to receive an accurate perception of what the "family" has experienced with stressful life events. The authors (McCubbin, Thompson & McCubbin, 1996) recommend that preferably, the FILE instrument be completed separately and both scores used to determine the level of family stress. Although the instrument was designed to be adminstered to either one or both adult members of the family, the authors prefer having both parents complete the questionnaire.

A further limitation of this study was the limited representation of male subjects. The majority of respondents in this study were female. The perception of fathers or male providers may have perceived the stressor, family life events, and coping strategies of the family much differently than the mother or female provider.

Suggestions for further research

Further research in the area of families with pediatric hospitalizations is needed. Research that explores the family stage, resiliency, and adaptation over time would be interesting. Families function before, during, and after their child is admitted to pediatrics. Research that investigates how nurses' can make the biggest impact to facilitate family functioning would contribute to improving family-centered care.

Additional research is needed that explores how nurses' and the healthcare delivery team influences and meets the coping needs of parents during a pediatric hospitalization. This would enable hospitals and pediatric providers around the country to change the way they approach the admission process. During the pediatric admission critical changes are happening within the family. Nurses need to be aware of the families needs, how the family is coping, and what they need to optimize their coping strategies. Parents or primary care-takers that are coping at their optimum level are more readily available to provide for the emotional and physical needs of their childs' recovery process.

Parents have basic needs during an admission and pediatric hospitalizaiton. They need information, they need hope, and they need to be assured that their child is receiving the best care possible. The variables that change with each individual family are how they perceive the stress of the admission, the other stressful life events occurring simultaneously, and the coping strategies they utilize. Researchers need to evaluate what influences the perception of the stress and more specifically, can nurses

influence the perception of stress during a pediatric admission? How can we as nurses' make an impact on families coping utilization? Are nurses' somehow able to help families begin their coping process during a pediatric hospitalization?

It is important to note that the focus of this study was to identify perceived family stress, pile-up of life events, and coping strategies identified by the family member. It was not the objective of this study to identify whether nurses influenced the perceived family stress or coping strategies utilized by the family. Continued research in this area will contribute to the existing body of nursing knowledge with regards to families and the children they love.

Appendices

APPENDIX A

The Double ABCX Model

Appendix A

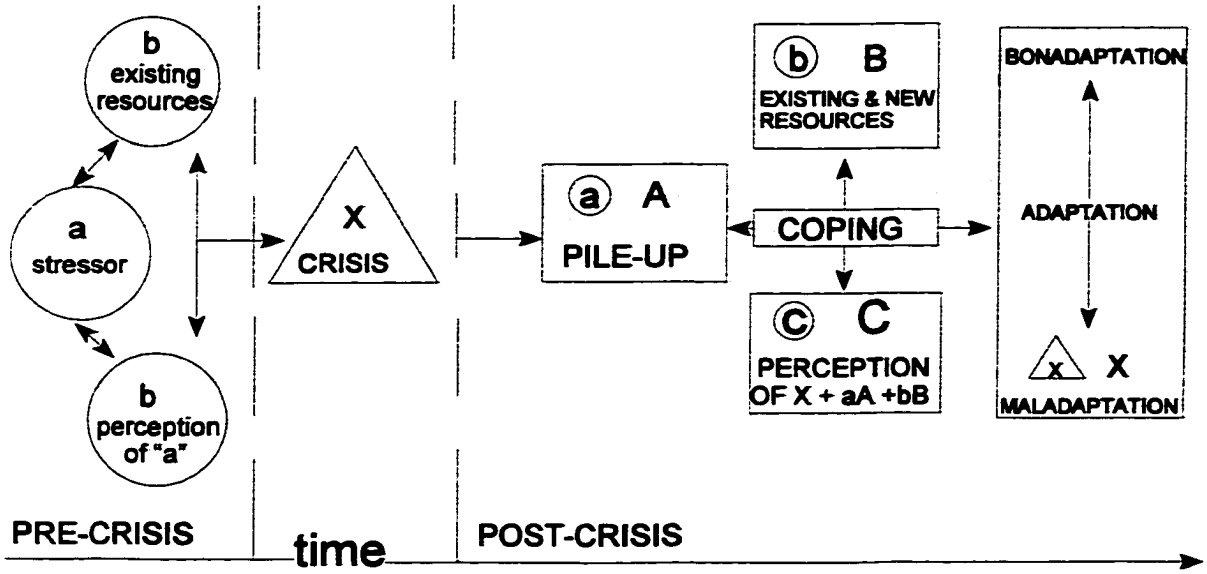

Figure 1. The Double ABCX Model

Note McCubbin, H.I. and J. Patterson (1983). "The Family Stress Process: The Double ABCX Model of Adjustment." In H.I. McCubbin, M.B. Sussman, and J.M. Patterson (Eds.) Advances and Developments in Family Stress Theory and Research. New York: Haworth Press.

APPENDIX B

Permission To Use The Double ABCX Model

SCHOOL OF HUMAN ECOLOGY

October 11, 1999

Jennifer Moes
1389 Woodfield Lane
Zeeland, MI 49464

Dear Ms. Moes,

I am pleased to give you my permission to use the Double ABCX Model in your work.

When using the Double ABCX model the correct reference is McCubbin, H.I. and J. Patterson (1983). "The Family Stress Process: The Double ABCX Model of Adjustment and Adaptation." In H. I. McCubbin , M.B. Sussman, and J.M. Patterson (Eds.) **Advances and Developments in Family Stress Theory and Research. New York: Haworth Press.**

If I could be of any further assistance to you, please let me know.

Sincerely,

[redacted]

Hamilton I. McCubbin
Director
Family Stress, Coping and Health Project
University of Wisconsin-Madison
1300 Linden Drive
Madison, WI 53706

APPENDIX C

Demographic Questionnaire

Appendix C

Demographic Questionnaire

Code#_____

Date and Time:_____

Please provide the following information:

1. Admission Date_____ Admission Time_____

2. Patients age_____

3. Your age_____

4. Are you Male or Female? (Please circle one)

5. Child's Diagnosis_____

6. How many years of school have you completed? _____(in years)

7. Your employment status

___Full time ___Part time ___Homemaker
___Retired _____Other (please specify)

8. What is your marital status?
___Married ___Single ___ Separated ___Divorced
___Widowed _____Other (please specify)

9. Please check the culture/race(s) that apply best to you:

___American Indian or Alaskan Native ___Hispanic or Latino
___Native Hawaiian or other Pacific Islander ___Black or African American
___White ___Asian

10. What was the range of your family's gross annual income last year?
___0--$19,999 ___$20,000-$39,999 ___$40,000-$59,999
___$60,000-$79,999 ___$80,000-$99,999 ___>$100,000

11. Your relationship to the Child:
___Mother ___Father ___Step-Mother ___Step-Father
___Grandmother ___Grandfather ___Aunt
___Uncle _____ Other (please list)

12. Number of other children in your family_____

13. What do you think your families stress level is right now?
Please mark an X on the line:

No stress 0 |_____| 100 Stress as bad as it could be

APPENDIX D

Family Inventory of Life Events and Changes

Family Stress, Coping and Health Project
School of Human Ecology
1300 Linden Drive
University of Wisconsin-Madison
Madison, WI 53706

FILE

FAMILY INVENTORY OF LIFE EVENTS AND CHANGES

Hamilton I. McCubbin Joan M. Patterson Lance R. Wilson

Purpose:

Over their life cycle, all families experience many changes as a result of normal growth and development of members and due to external circumstances. The following list of family life changes can happen in a family at any time. Because family members are connected to each other in some way, a life change for any one member affects all the other persons in the family to some degree.

"FAMILY" means a group of two or more persons living together who are related by blood, marriage or adoption. This includes persons who live with you and to whom you have a long term commitment.

Directions:

"Did the change happen in your family?"

Please read each family life change and decide whether it happened to any member of your family — **including you** — during the past 12 months and check **Yes** or **No**.

Did the change happen in your family:	During the last 12 months **Yes**	**No**	**Score**
I. Intrafamily Strains			
1. Increase of husband/father's time away from family	☐	☐	46
2. Increase of wife/mother's time away from family	☐	☐	51
3. A member appears to have emotional problems	☐	☐	58
4. A member appears to depend on alcohol or drugs	☐	☐	66
5. Increase in conflict between husband and wife	☐	☐	53
6. Increase in arguments between parent(s) and child(ren)	☐	☐	45
7. Increase in conflict among children in the family	☐	☐	48
8. Increased difficulty in managing teenage child(ren)	☐	☐	55
9. Increased difficulty in managing school age child(ren) (6–12 yrs)	☐	☐	39
10. Increased difficulty in managing preschool age child(ren) (2.5–6 yrs)	☐	☐	36

Please continue on next page ⟶

Did the change happen in your family:	During the last 12 months Yes	No	Score
11. Increased difficulty in managing toddler(s) (1–2.5 yrs.)	☐	☐	36
12. Increased difficulty in managing infant(s) (0–1 yr.)	☐	☐	35
13. Increase in the amount of "outside activities" which the children are involved in	☐	☐	25
14. Increased disagreement about a member's friends or activities	☐	☐	35
15. Increase in the number of problems or issues which don't get resolved	☐	☐	45
16. Increase in the number of tasks or chores which don't get done	☐	☐	35
17. Increased conflict with in-laws or relatives	☐	☐	40
II. Marital Strains			
18. Spouse/parent was separated or divorced	☐	☐	79
19. Spouse/parent had an "affair"	☐	☐	68
20. Increased difficulty in resolving issues with a "former" or separated spouse	☐	☐	47
21. Increased difficulty with sexual relationship between husband and wife	☐	☐	58
III. Pregnancy and Childbearing Strains			
22. Spouse had unwanted or difficult pregnancy	☐	☐	45
23. An unmarried member became pregnant	☐	☐	65
24. A member had an abortion	☐	☐	50
25. A member gave birth to or adopted a child	☐	☐	50
IV. Finance and Business Strains			
26. Took out a loan or refinanced a loan to cover increased expenses	☐	☐	29
27. Went on welfare	☐	☐	55
28. Change in conditions (economic, political, weather) which hurts the family investments	☐	☐	41
29. Change in agriculture market, stock market, or land values which hurts family investments and/or income	☐	☐	43
30. A member started a new business	☐	☐	50
31. Purchased or built a home	☐	☐	41
32. A member purchased a car or other major item	☐	☐	19
33. Increased financial debts due to over-use of credit cards	☐	☐	31

Please continue on next page ⟶

Did the change happen in your family:	During the last 12 months Yes	No	Score
34. Increased strain on family "money" for medical/dental expenses	☐	☐	23
35. Increased strain on family "money" for food, clothing, energy, home care	☐	☐	21
36. Increased strain on family "money" for child(ren)'s education	☐	☐	22
37. Delay in receiving child support or alimony payments	☐	☐	41
V. Work-Family Transitions and Strains			
38. A member changed to a new job/career	☐	☐	40
39. A member lost or quit a job	☐	☐	55
40. A member retired from work	☐	☐	48
41. A member started or returned to work	☐	☐	41
42. A member stopped working for extended period (e.g., laid off, leave of absence, strike)	☐	☐	51
43. Decrease in satisfaction with job/career	☐	☐	45
44. A member had increased difficulty with people at work	☐	☐	32
45. A member was promoted at work or given more responsibilities	☐	☐	40
46. Family moved to a new home/apartment	☐	☐	43
47. A child/adolescent member changed to a new school	☐	☐	24
VI. Illness and Family "Care" Strains			
48. Parent/spouse became seriously ill or injured	☐	☐	44
49. Child became seriously ill or injured	☐	☐	35
50. Close relative or friend of the family became seriously ill	☐	☐	44
51. A member became physically disabled or chronically ill	☐	☐	73
52. Increased difficulty in managing a chronically ill or disabled member	☐	☐	58
53. Member or close relative was committed to an institution or nursing home	☐	☐	44
54. Increased responsibility to provide direct care or financial help to husband's and/or wife's parents	☐	☐	47
55. Experienced difficulty in arranging for satisfactory child care	☐	☐	40

Please continue on next page ⟶

Did the change happen in your family:	During the last 12 months Yes	No	Score
VII. Losses			
56. A parent/spouse died	_	_	98
57. A child member died	_	_	99
58. Death of husband's or wife's parent or close relative	_	_	48
59. Close friend of the family died	_	_	47
60. Married son or daughter was separated or divorced	_	_	58
61. A member "broke up" a relationship with a close friend	_	_	35
VIII. Transitions "In and Out"			
62. A member was married	_	_	42
63. Young adult member left home	_	_	43
64. Young adult member began college (or post high school training)	_	_	28
65. A member moved back home or a new person moved into the household	_	_	42
66. A parent/spouse started school (or training program) after being away from school for a long time	_	_	38
IX. Family Legal Violations			
67. A member went to jail or juvenile detention	_	_	68
68. A member was picked up by police or arrested	_	_	57
69. Physical or sexual abuse or violence in the home	_	_	75
70. A member ran away from home	_	_	61
71. A member dropped out of school or was suspended from school	_	_	38

APPENDIX E

Family Crisis Oriented Personal Scales

Appendix E

Family Stress, Coping and Health Project
School of Human Ecology
1300 Linden Drive
University of Wisconsin-Madison
Madison, WI 53706

F-COPES

FAMILY CRISIS ORIENTED PERSONAL SCALES

Hamilton I. McCubbin David H. Olson Andrea S. Larsen

Purpose

The Family Crisis Oriented Personal Evaluation Scales is designed to record problem-solving attitudes and behaviors which families develop to respond to problems or difficulties.

Directions

First, read the list of "Response Choices" one at a time.
Second, decide how well each statement describes your attitudes and behavior in response to problems or difficulties. If the statement describes your response very well, then circle the number 5 indicating that you strongly agree; if the statement does not describe your response at all, then circle the number 1 indicating that you strongly disagree; if the statement describes your response to some degree, then select a number 2, 3, or 4 to indicate how much you agree or disagree with the statement about your response.

Please circle a number (1, 2, 3, 4, or 5) to match your response to each statement. Thank you.

When we face problems or difficulties in our family, we respond by:	Strongly Disagree	Moderately Disagree	Neither Agree Nor Disagree	Moderately Agree	Strongly Agree
1. Sharing our difficulties with relatives	1	2	3	4	5
2. Seeking encouragement and support from friends	1	2	3	4	5
3. Knowing we have the power to solve major problems	1	2	3	4	5
4. Seeking information and advice from persons in other families who have faced the same or similar problems	1	2	3	4	5
5. Seeking advice from relatives (grandparents, etc.)	1	2	3	4	5
6. Seeking assistance from community agencies and programs designed to help families in our situation	1	2	3	4	5
7. Knowing that we have the strength within our own family to solve our problems	1	2	3	4	5
8. Receiving gifts and favors from neighbors (e.g., food, taking in mail, etc.)	1	2	3	4	5

Please continue on other side →

When we face problems or difficulties in our family, we respond by:	Strongly Disagree	Moderately Disagree	Neither Agree Nor Disagree	Moderately Agree	Strongly Agree
9. Seeking information and advice from the family doctor	1	2	3	4	5
10. Asking neighbors for favors and assistance	1	2	3	4	5
11. Facing the problems "head-on" and trying to get solution right away	1	2	3	4	5
12. Watching television	1	2	3	4	5
13. Showing that we are strong	1	2	3	4	5
14. Attending church services	1	2	3	4	5
15. Accepting stressful events as a fact of life	1	2	3	4	5
16. Sharing concerns with close friends	1	2	3	4	5
17. Knowing luck plays a big part in how well we are able to solve family problems	1	2	3	4	5
18. Exercising with friends to stay fit and reduce tension	1	2	3	4	5
19. Accepting that difficulties occur unexpectedly	1	2	3	4	5
20. Doing things with relatives (get-togethers, dinners, etc.)	1	2	3	4	5
21. Seeking professional counseling and help for family difficulties	1	2	3	4	5
22. Believing we can handle our own problems	1	2	3	4	5
23. Participating in church activities	1	2	3	4	5
24. Defining the family problem in a more positive way so that we do not become too discouraged	1	2	3	4	5
25. Asking relatives how they feel about problems we face	1	2	3	4	5
26. Feeling that no matter what we do to prepare, we will have difficulty handling problems	1	2	3	4	5
27. Seeking advice from a minister	1	2	3	4	5
28. Believing if we wait long enough, the problem will go away	1	2	3	4	5
29. Sharing problems with neighbors	1	2	3	4	5
30. Having faith in God	1	2	3	4	5

APPENDIX F

Permission Letter to Use Questionnaires

Appendix F

April 7, 1999

Jennifer L. Brower
1389 Woodfield Lane
Zeeland, MI 49464
Manual ID# 000621

Dear Ms. Brower,

This letter is to confirm that you are a registered user of the FILE: Family Inventory of Life Events and Changes, and the F-COPES: Family-Crisis Oriented Personal Evaluation Scales instruments. As a registered user, you have permission to make photocopies of the instruments, administer them, and present a copy in your final publication, such as a thesis, dissertation or journal article. This permission does not extend to revenue generating publications such as books. If you require this type of permission, please contact the project office. Permission is granted to you as an individual and is not transferable to a colleague or student.

If permission is required at a later date for additional instruments or for the same instruments but for a different project, please photocopy and send another abstract form, and this written permission will be sent at no additional charge as well.

If we could be of any further assistance to you, please let us know.

Sincerely,

Hamilton I. McCubbin
Director

Anne I. Thompson
Associate Director

Family Stress, Coping and Health Project

Kelly Elver
Research Program Manager

Family Stress Coping & Health Project
University of Wisconsin-Madison
1300 Linden Drive
Madison, WI 53706
Phone (608) 829-0297
FAX (608) 265-4969
e-mail kelver@facstaff.wisc.edu http://sohe.wisc.edu/CfFS/CfFS_main.html

APPENDIX G

Grand Valley State University Permission Letter

Appendix G

GRAND VALLEY
STATE UNIVERSITY

1 CAMPUS DRIVE • ALLENDALE MICHIGAN 49401-9403 • 616/895-6611

June 9, 1999

Jennifer Brower
1389 Woodfield Lane
Zeeland, MI 49464

Dear Jennifer:

Your proposed project entitled ***Unplanned Hospitalization of a Child: Perceptions of Stress, Family Life Events, and Coping Resources*** has been reviewed. It has been approved as a study which is exempt from the regulations by section 46.101 of the Federal Register 46(16):8336, January 26, 1981.

Sincerely,

[redacted]

Paul Huizenga, Chair
Human Research Review Committee

APPENDIX H

Holland Community Hospital Permission Letter

Appendix H

June 22, 1999

Jennifer Brower
1389 Woodfield Lane
Zeeland, MI 49464

Dear Jennifer:

I am pleased to inform you that on June 15, 1999, on the recommendation of the Institutional Review Committee (IRC), the Hospital Board of Directors gave approval for you to conduct your research project: "A Thesis: Unplanned hospitalization of a child: Perceptions of stress, family life events, and coping resources." It was noted that your approval letter would include note of the cautions and concerns discussed by the IRC regarding the sample size, relationship to the number of variables and whether any real information of value will be able to be derived from the study because of the degree of variables and the small sample size.

As you know you will be asked to attend an Institutional Review Committee meeting to report on your research project and supply a copy of your final thesis report. This can be anytime following completion of your study, but no later than July 2000. In addition, any changes in the study tool must be addressed immediately to me.

I wish you much success in conducting your study and look forward to receiving the results.

Sincerely,

Catherine (Reezie) DeVet
Corporate Vice President, Clinical Integration & CNO.

APPENDIX I

Family Consent Form

Appendix I

Family Representative Consent Form ID#_____

Title of Project: Unplanned Hospitalization of a Child: Perceptions of Stress, Family Life Events, and Coping Resources.

PURPOSE OF THE STUDY (RESEARCH)
I understand that I am being asked to participate in a study about how parents (care givers) of children deal with their child's unplanned hospitalization, how stressful (upsetting) this experience has been for me, and what other changes or events have happened in my family in the past year. I understand that I am being asked because my child's hospitalization was unexpected.

PROCEDURES
I understand that I will be asked to answer printed questionnaires for approximately 30 minutes. Some of the questions are very personal. This information is used to describe the families who participate in the study.

RISKS AND DISCOMFORTS
I understand there are no risks for participating in this study. My child's care will not be affected by my participation in the study. My child's physician is not involved in this study.

BENEFITS
I understand there is no direct benefit for me participating in this study. The results from the study may help nurses and other health care professionals learn more about how to help families when a child has an unplanned hospitalization. There is no payment for participating in this study.

CONFIDENTIALITY
I understand that the information from this study will be stored in the investigator's research file and identified only by a code number. No names will be ever be used, even if the information and results of this study are used for publication in the nursing, medical, or other health related literature.

If there are any questions concerning my rights as a research participant I may contact the chairperson of the Grand Valley State University Human Research Review Committee, Professor Paul Huizenga at (616) 895-2472.

REQUEST FOR MORE INFORMATION
I understand that I may ask more questions about the study at any time. The investigator, Ms. Brower, R.N., may be reached at 772-2642. I will receive a copy of this consent form.

REFUSAL OR WITHDRAWAL OF PARTICIPATION
I understand that my participation is voluntary and that I may refuse to participate or may withdraw my consent and discontinue participation in the study at any time without prejudice to my child's present or future care.

I have read and I understand the consent form. Therefore, I agree to give my consent to participate as a subject in this research project.

_____ _____
Participant Date

_____ _____
Investigator Date

APPENDIX J

Script for Approaching Family Participants

Appendix J

Script for Approaching Family Participants

Hello. My name is Jennifer Brower. I am a registered nurse and a graduate student at Grand Valley State University. I have practiced in nursing caring for children for five years and I am interested in your families perceived stress, family life events over the past year, and family coping resources related to the child you care for being admitted to the pediatric unit.

I am hoping to find 30 parents or primary caretakers who would be willing to respond to questionnaire's about their families perceived stress, family life events over the past year, and family coping resources. The questionnaire's will take approximately 30 minutes to complete. The decision to participate is entirely up to you. All your responses to the questionnaire's will remain confidential. Your decision to participate or not to participate, will in no way affect the care or services your child will receive.

Do you have any questions about this study?

Would you be willing to participate in this study?

Would you like some time to think about participating in this study?

When might I speak to you again?

List of References

List of References

Ahmann, E. (1994). Family-centered care: Shifting orientation. Pediatric Nursing, 20, 113-117.

Burr, W. (1973). Theory construction and the sociology of the family. New York: John Wiley & Sons.

Coddington, R.D. (1972). The significance of life events as an etiologic factor in the diseases of children, II: A study of te normal populations. Journal of Psychosomatic Research, 16, 205-213.

Diehl, S. E., Moffitt, K. A., & Wade, S. M. (1991). Focus group interview with parents of children with medically complex needs: An intimate look at their perceptions and feelings. Children's Health Care, 20, 170-178.

Farrell, M., & Frost, C. (1992). The most important needs of parents of critically ill children: parents' perceptions. Intensive and Critical Care Nursing, 8, 130-139.

Graves, C., & Hayes, V. E. (1996). Do nurses and parents of children with chronic conditions agree on parental needs? Journal of Pediatric Nursing, 11, 288-299.

Guiffre, M. (1983). Validation of a visual analogue scale for pain measurement in childbirth. Unpublished doctoral dissertation. University of Rochester, New York.

Hansen, D., & Hill, R. (1964). Families under stress. In Christensen (Ed.), Handbook of Marriage and the Family. Chicago: Rand McNally.

Hill, R. (1958). Generic features of families under stress. Social Casework, 49, 139-150.

Holmes, T. H., & Rahe, R. (1967). The social readjustment rating scale. Journal of Psychosomatic Research, 11, 213-218.

Huskisson, E. C. (1983). Visual analogue scales. In R. Melzack (Ed.), Pain measurement and assesssment (pp. 33-40). New York: Raven Press.

Jacono, J., Hicks, G., Antonioni, C., O'Brien, K., & Rasi, M. (1990). Comparison of perceived needs of family members between registered nurses and family members of critically ill patients in intensive care and neonatal intensive care units. Heart & Lung, 19, 72-78.

Kasper, N. Y., & Nyamathi, A. M. (1988). Parents of children in the pediatric intensive care unit: what are their needs? Heart and Lung: Journal of Critical Care, 17, 574-587.

Kawik, L. (1996). Nurses' and parents' perceptions of participation and partnership in caring for a hospitalized child. British Journal of Nursing, 5, 430-434.

King, I. M. (1981). A theory for nursing: System, concepts, process. New York: Delmar.

Kirschbaum, M. S. (1992). Needs of parents of critically ill children. Dimensions of Cricial Care Nursing, 9, 344-352.

Kristjánsdóttir, G. (1995). Perceived importance of needs expressed by parents of hospitalized two- to six-year olds. Scandinavian Journal of Caring Science, 9, 95-103.

McNeil, D. (1992). Uncertainly, waiting, and possibilities: experiences of becoming a mother with an infant in Neonatal Intensive Care Unit. Neonatal Network: Journal of Neonatal Nursing, 11, 78.

McCubbin, H. I., Olson, D.H., & Larsen, A. S. F-COPES: Family crises oriented personal evaluation scales. In H.I. McCubbin & A. T. Thompson (Eds). Family assessment inventories for research and practice (p. 193-207). Madison, WI: University of Wisconsin.

McCubbin, H.I., & Patterson, J. M. (1982). Family adaptation to crisis. In H.I. McCubbin, A. Cauble, & J. Patterson (Eds.), Family stress, coping and social support. Pp 26-47. Springfield, Illinois: Charles C. Thomas.

McCubbin, H.I., & Patterson, J. (1983). Family transitions: Adaptation to stress. In H.I. McCubbin & C.R. Figley (Eds.). Stress and the family: Vol. 1. Coping with Normative Transitions (p. 5-25). New York: Brunner/Maxel.

McCubbin, M.A., & McCubbin, H.I. (1987). Family stress theory and assessment: The t-double ABCX model of family adjustment and adaptation. In H.I. McCubbin & A.I. Thompson (Eds). Family Assessment Inventories for Research and Practice (pp. 3-32). Madison, WI: University of Wisconsin.

McCubbin, H.I., & Patterson, J.M. (1992). Family adaptation to crisis. In H.I. McCubbin, E. Cauble, & J. M. Patterson (Eds.), Family stress, coping and social support (pp. 26-47). Springfield, IL: Charles C. Thomas.

McCubbin, H. I., Thomspon, A.I., & McCubbin, M. A. (1996). Family Assessment: Resiliency, Coping, and Adaptation. Madison: University of Wisconsin.

Mendonca, D., & Warren, N. A. (1998). Perceived and unmet needs of critical care family members. Critical Care Nursing, 21, 58-67.

Molter, N. C. (1979). Needs of relatives of critically ill patients: A descriptive study. Heart and Lung, 8, 332-339.

Nielsen, R. (1990). With a little help from. . . American Journal of Nursing, 90, 136.

Nolan, M. T., Cupples, S. A., Brown, M. M., Pierce, L., Lepley, D., & Ohler, L. (1992). Heart & Lung, 21, 540-547.

Page, N. E., & Boeing, N. M. (1994). Visitation in the pediatric intensive care unit: controversy and compromise. AACN: Critical Nurses, 5, 289-294.

Polit D. F., & Hungler, B. P. (1995). Nursing research (5th ed.). Philadelphia: Lippincott.

Revill, S.I., Robinson, J. O., Rosen, M., & Hogg, M. I. J. (1976). The reliability of a linear analogue for evaluating pain. Anesthesia, 31, 1191-1198.

Robinson, C. A. & Thorne, S. (1984). Strengthening family 'interference'. Journal of Advanced Nursing, 9, 597-602.

Scott, L. D. (1998). Perceived needs of parents of critically ill children. Journal of the Society of Pediatric Nurses, 3, 4-12.

Snowdon, A. W., & Kane, D. J. (1995). Parental needs following the discharge of a hospitalized child. Pediatric Nursing, 21, 425-428.

Tomlinson, P. S., & Mitchell, K. E. (1992). On the nature of social support for families of critically ill children. Journal of Pediatric Nursing, 7, 386-394.

Wewers, M. E., & Lowe, N. K. (1990). A critical review of visual analogue scales in the measurement of clinical phenomena. Research in Nursing and Health, 13, 227-236.