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Maternal Perceptions and Concerns Immediately Preceding and During the Emergency Hospitalization of an Ill Preschool Child

by

Janet M. Jaskula

### THESIS

### Submitted in partial satisfaction of the requirements for the degree of

### MASTER OF SCIENCE

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in

Nursing

in the

# **GRADUATE DIVISION**

of the

### UNIVERSITY OF CALIFORNIA

San Francisco

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### MATERNAL PERCEPTIONS AND CONCERNS IMMEDIATELY PRECEDING AND DURING THE EMERGENCY HOSPITALIZATION OF AN ILL PRESCHOOL CHILD

### ABSTRACT

Janet M. Jaskula

When a child is hospitalized, the mother, as primary caretaker, is expected to support her child by continuing the mothering role in the hospital. Yet, neither the specific concerns nor the experiences of mothers during the transitional period from health to illness requiring a child's emergency admission have been described. An exploratory-descriptive study using role transition theory was designed to explore the unique difficulties encountered by mothers confronted with the emergency hospitalization of a preschool child. The purposes of this study were to describe mothers' perceptions and concerns immediately preceding and during an ill child's emergency hospitalization, the events mothers experience, and how mothers' perceive the effects that these factors have on the mothering role and family functioning. A convenience sample of five mothers, whose acutely i11 preschool children required emergency hospitalization, completed a family functioning survey and a one-time interview within 24 hours of the child's admission to the pediatric ward. Data were collected through administration of the Maternal Perceptions of Emergency Hospitalization Interview (MPEHI) which is a structured, open-ended interview developed specifically for this study, and the Feetham Family Functioning Survey (Feetham and Roberts, 1982). Four categories were used to group MPEHI transition, setting transition, content: illness family transition, and maternal role transition. This categorical structure was used to capture data reflecting maternal concerns during multiple role transitions. The FFFS assesses family functioning as relationships between the family and: its subsystems; broader social units; and each individual. Each of 21 indicators of family functioning is rated three times for : "what is" (a score), "what should be" (b score), and its perceived value (c score). A discrepancy score (d score) representing the degree of satisfaction with each indicator is determined by the amount of difference between the ratings of "what is" and "what should be" (a - b = d). Comparison of the mean <u>d</u> scores and various demographic characteristics of subjects in this study sample demonstrated no significant differences among mothers. Analysis of MPEHI data revealed that mothers experienced a fairly uniform progression of events from the onset of a child's illness and through the process of the child's emergency admission. Mothers also described similar concerns including difficulty accepting the need for hospitalization, uncertainty about the child's behavioral cues, fear of negative outcomes, disruption of customary mothering behaviors, ambivalence toward nurses, anxiety over the degree of perceived responsibility for the child's illness, unfamiliarity with the hospital environment and routines, and concern for welfare of self and other family members. This combination of objective events and accompanying emotional responses strongly suggest that mothers confronted with a child's emergency admission do undergo an involuntary role transition and are at risk for maternal role insufficiency. Mothers also clearly viewed nurses as authorities on mothering, were very sensitive to nurses' opinions of their mothering abilities, and concerned that nurses' considered them to be good mothers. Lastly, mothers expected nurses to help them and didn't always find the nurses to be available to do so. However, mothers reported that when nurses were available, mothers experienced a lessening of anxiety and an increased ability to participate in their children's care. Findings in this study suggest that nurses need additional information about the specific concerns of mothers during a preschool child's emergency admission. Study results also indicate that nurses neeed to directly intervene with these mothers to support and guide them through this involuntary role transition, thereby decreasing the risk of maternal role insufficiency.

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The evolution and completion of a thesis as the product of a project demands the particular research time, energies, creativity, and fortitude of an incredible number of concerned I am thankful for the bounty of caring people who individuals. have assisted me -- my thesis committee members for their patience and unflagging faith in me. Nancy Lovejoy, I thank you for your contagious, though different from mine, intellectual curiosity and your challenge that I achieve the best of which you believed I was capable. Mary Tesler, I am indebted to you not only for your vast experience and knowledge base regarding mothers and children, but more so for your ever willing ear and your belief in me. Laura Reif, I am grateful for your constant enthusiasm, optimism, and incredible skills in conducting and teaching the qualitative research process.

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In contrast to the thesis as product, the thesis as process is a solitary journey, one which, for me, was repeatedly beset by false starts and interruptions and especially plagued by my own doubts and perplexities. Nonetheless, I am profoundly blessed by the unconditional loyalty and love of my family and friends. Mary Lynch, though you got through the final gate just ahead of me, you remained by my side always ready to pull me back each time I approached "the edge". Thank you, my friend. Sir James the Sage, you may have arrived lately by comparison but you have considerably with wit, buoyed up your philosophy, me understanding, and a much needed dare to finish this journey.

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### CHAPTER I

### THE STUDY PROBLEM

### Introduction

Parents in our society, particularly mothers, are held accountable for the health and welfare of their young children. Despite shifting values and greater numbers of working mothers, the care of preschool children, especially their psychological care, remains primarily the responsibility of mothers (Slevin, 1982; Veevers, 1973; Blake, Wright & Waechter, 1970). When a preschool child must endure the stress of hospitalization, the mother by virtue of her role in the child's life is expected to act as a buffer between her child and the hospital environment and help her child adjust to the experience of illness and hospitalization (Roskies, Mongeon, Gagnon-Lefebvre, 1978). Previous research indicates, however, that hospitalization of a child for any reason is frightening and stressful for mothers and and may interfere with their ability to support and help their children adjust (Mahaffy, 1965; Skipper, Leonard, & Rhymes, 1968).

Mechanic (1964) reported that all mothers, as primary caretakers of children, experience considerable anxiety and stress when a child is hospitalized. A few studies have also suggested that there is an increase in maternal anxiety due to

the suddeness and inability to prepare when a child is hospitalized on an emergency versus an elective basis (Buckman, & Schade, 1957; Roskies, Bedard, Guilbault, & Lafortune, Gofman. 1975). In addition, the transmission of anxiety from mother to child has been noted to be one of the most significant variables affecting both the occurrence and degree of detrimental effects of hospitalization on young children (Bright, 1965; Campbell, VanderVeer, 1949). 1957: Escalona. 1953; The literature that major sources of maternal anxiety include: indicates unfamiliarity with hospital environment, routines, and procedures (Bright, 1965; Prugh, Staub, Sands, Lenihan, Kirschbaum, 1953); lack of information about diagnosis and treatments, fear and uncertainty about prognosis (Buckman, et al. 1957; Frieberg, 1972); mother-child separation, behavioral regression of the ill child. relinquishing the child's care to hospital staff. confusion about how to participate in the hospitalized child's care, and loss of confidence in mothering skills because of subordination to nurses (Bright, 1965; Irwin & Lloyd-Still, 1974; Miles, 1979). Mothers also experience guilt and fear related to feeling responsible for the child's illness and hospitalization well as helplessness and inadequacy in adjusting as and continuing the mothering role in the hospital (Bright, 1965; Hardgrove & Dawson, 1972; Miles, 1979).

While numerous variables influence a mother's anxiety in

relationship to her hospitalized child, neither the specific concerns nor the experiences of mothers during the transitional period from health to illness requiring a child's emergency admission have been described. The most significant factors influencing the young child's anxiety and adjustment, however are mother's presence during and her attitude toward а hospitalization (Prugh et al, 1953; Bright, 1965; Branstetter, Studies have also shown that mothers need assistance to 1969). cope with their own anxiety to successfully adapt and continue the mothering role in the hospital in order to help their children (Mahaffy, 1965; Skipper et al. 1968; Roskies et al. 1978: Hymovich, 1976). The presumed increase in anxiety associated with emergency hospitalization suggests that mothers confronting this event would need even more assistance in order to help their children. Yet to date, with the exception of one pilot study (Roskies, et al. 1975), no studies have been published exploring the factors that impact solely on a mother's ability to adjust to the involuntary role transition imposed by the emergency hospitalization of an ill preschool child. This deficit of knowledge seems particularly noteworthy given the responsibility mothers bear for child care.

### Significance.

The National Center for Health Statistics (1982) reports that over two million children under the age of six years are hospitalized annually. Of these admissions, approximately 60 -

70% are emergency admissions (American Hospital Association, 1984). From a pediatric nursing viewpoint which recognizes the importance of mother in a young child's life and the necessity of providing care to both mother and child, this apparent lack of interest in mothers' concerns and subsequent lack of information about them, is of concern. In order to function effectively with mothers of acutely ill preschoolers admitted on an emergency basis, nurses need a working knowledge of these mothers' concerns both before and during emergency admission of their children. Without awareness and understanding of the specific concerns of mothers experiencing this particular role transition, nurses cannot accurately assess and intervene appropriately with mothers whose ill preschool children are admitted on an emergency basis. Statement of Problem

Little is known regarding maternal concerns prior to and during the emergency hospitalization of an ill preschool child. Consequently, a distinct gap exists in current pediatric nursing knowledge and practice (Roskies, et al. 1975). In order to bridge this gap, it is essential that the unique difficulties encountered by mothers confronted with emergency hospitalization be described and a framework developed for providing appropriate and competent nursing care to this population. The first step in constructing such a framework is to describe variables that reflect a mother's concerns and needs during the process of her child's emergency hospitalization which may then influence her ability to continue performing the maternal role.

### Purpose

The objectives of this study are to:

- describe the perceptions and concerns of mothers immediately preceding and during the emergency hospitalization of an ill preschool child;
- describe the events mothers experience during this health-illness transition;
- describe mother's perceptions of their concerns and how these may affect the mothering role;
- explore mother's concerns in relationship to family functioning.

### Assumptions

Certain assumptions are inherent in any exploratory study. The assumptions known to underlie this pilot investigation are listed below.

- The mother-child relationship is a complex, interactive, evolving process.
- Mothers are expected to continue the mothering role to their hospitalized children.
- Mothers may need support and guidance to adjust and continue the maternal role.
- 4. Emergency hospitalization precludes psychological

preparation of mother and child.

- There is increased maternal stress and anxiety associated with a child's emergency hospitalization.
- Mothers faced with a child's emergency hospitalization have specific concerns and needs which they can identify.
- 7. These concerns and needs may interfere with a mother's ability to adjust and/or continue mothering her hospitalized child.

#### Definitions

Significant terms pertinent to this investigation are defined in the following list. Additional definitions specific to the conceptual framework including operational definitions of relevant concepts are presented in the discussion of the framework in Chapter II.

- <u>Acute Illness</u> A temporary sudden loss of normalcy characterized by rapid onset, severe symptoms, and usually of short duration.
- <u>Concern</u> A disquieted or uneasy state of blended interest, uncertainty, apprehension and responsibility regarding the events of a child's emergency admission.
- Emergency Hospitalization Sudden, unexpected admission through a hospital emergency room due to acute illness demanding immediate medical attention and action.

Mother - female parent residing with and responsible for the care

of a preschool child.

- <u>Perception</u> A mother's personal interpretation of observations and experiences preceding and during her child's emergency admission.
- <u>Preschool Child</u> A young person of either gender between one and four years of age who shares residence with mother or with mother and father.

<u>Limitations</u> The results of this pilot study are limited by the following factors:

- 1. A small, homogenous, voluntary sample.
- 2. Possible investigator bias or influence on subjects.
- 3. The lack of validity and reliability of tools.
- 4. Possible influence of tools on subjects' responses.
- 5. Absence of controls for type of illness, family constellation, length of time child was ill at home before emergency admission occurred, and socioeconomic status.

### CHAPTER II

### RELEVANT LITERATURE

#### AND

#### CONCEPTUAL FRAMEWORK

### Introduction

is a dearth of literature addressing There maternal responses to the emergency hospitalization of an ill preschool child. In fact, an indepth review yielded only one pilot study conducted in the past 35 years that addressed pediatric emergency hospitalization (Roskies et al., 1975). Since the purpose of this study is to describe mothers' concerns during preschool children's emergency hospitalization, literature documenting parent-child responses to elective hospitalization will be reviewed.

Generally. studies on parent-child responses to hospitalization have looked at how parent's responses influence child's psychological their hospitalized well-being and Most studies demonstrated that parents, particularly adjustment. mothers. have difficulty with parenting roles during the transitional period of a child's planned hospitalization due to their own anxiety. In presenting an overview of these studies, emphasis will be placed on highlighting studies which noted a mother's child's responses to her preschool elective

### hospitalization.

### Parent-Child Responses to Hospitalization

Nearly four decades of studies have amassed considerable evidence demonstrating that hospitalized preschool children are highly vulnerable to harmful emotional experiences, which are potentially long lasting. Psychoanalytic studies by Spitz (1945) and Freud (1951) demonstrated that institutionalized young children exhibited distorted personality development. These personality changes were believed to be caused by "object anxiety" or the lack/loss of a mother. Extensive surveys of institutional practices by Bowlby (1951) and Robertson (1953) showed that children under four years of age demonstrated an observable psychological reaction to hospitalization that was distinct from illness and often impeded recovery. The concept of "separation anxiety" was coined from these classic studies to describe this psychological phenomenon in hospitalized infants and preschoolers (Bowlby, 1951; Robertson, 1953). These same studies showed the continued presence of and care by the child's mother helped decrease these detrimental psychological effects. These studies also indicated that the mother-child affectional bond governs the child's emotional development and well-being. Acceptance of this premise spawned massive reforms in the hospital care of children and their families, including open parental visiting, rooming-in, sibling visiting, and preadmission preparation programs. These policies direct practice today, and are intended to lessen psychological distress in hospitalized children.

In 1953, Prugh and colleagues, using a quasi-experimental design, studied the immediate and long term emotional reactions of children and parents to hospitalization. The study was initiated as a result of nurses' concerns about the efficacy and benefits of reforms that had been introduced on their pediatric medical ward a year earlier. These reforms were aimed at increasing parents' participation in the care of their hospitalized children and were based on previous study findings suggesting a positive correlation between parental anxiety and a child's adjustment to hospitalization (VanderVeer, 1949; Bowlby, 1951; Robertson, 1953). The purposes of this study were to evaluate:

1. The relationship between children's immediate reactions and ajustment to hospitalization and their parents' anxieties and adjustments;

2. The nature and occurrence of long term emotional reactions of children and their parents to the experience of hospitalization; and,

3. The degree and modifiability of these emotional reactions through ward reforms actively integrating parents in their hospitalized child's care.

A convenience sample, including both control and experimental groups was selected for participation in this nonequivalent control group pretest-posttest study. Each group group was comprised of 100 ill children and their parents. All children were between 2 and 12 years of age. Most children were acutely ill and hospitalized for the first time. However, some chronically ill children who had been previously hospitalized were included in each group. Seventy percent of the admissions in each group were "unplanned".

Ward management was "rolled back" to traditional practices for the control group. Under these conditions, each parent was permitted to visit only two hours weekly and parent participation in their child's care was not facilitated. Reformed ward care was resumed for the experimental group. Parents in this second group accompanied their children through the admission process, were permitted daily visiting, and received a pamphlet to "enhance understanding of their child's needs and their own role" in their child's care (p. 76). In addition to a special play program, the children received "psychological preparation for and support during potentially emotionally traumatic diagnostic and therapeutic procedures" (p. 77).

During both the control and experimental periods, several data collection techniques were used. Data were collected by:

1. Parental interviews concerning parent's perceptions of their own and their child's anxiety; their child's reaction to illness prior to hospitalization, their child's usual behavior and methods of adjustment. These interviews were conducted by ward social workers at admission, several times during hospitalization, and after discharge;

2. Observations of the child's behavioral interactions with parents, personnel, and peers; the child's reactions to procedures and treatments; and parent's behavioral interactions

with their child, staff members and other patients and parents during visiting hours. These observations were independently recorded by the head nurse, ward psychologist, play supervisor, and other professional ward personnel; and,

3. Informal psychological appraisals to correlate the effects of changes in physical condition on the child's emotional state, intellectual functioning, and ward adjustment.

emotional reactions to hospitalization were Children's classified moderate. as severe. or minimal. These classifications were based on parental admission interview data concerning their child's adjustment level and reaction to illness prior to hospitalization compared with the data obtained by ward personnel during and after the child's hospitalization. Α child's emotional reaction was considered severe "if crippling manifestations of anxiety occurred that interfered with the child's adjustment persisting longer than three months following discharge" (p. 77). Moderate reactions were those persisting less than three months after discharge. Mild reactions were characterized by mild anxiety and transient ad justment difficulties observed primarily in the hospital.

The degree of a child's adjustment to hospitalization was based on the child's capacity to interact successfully with peers and adults, level of reality testing, and mastery of anxiety. These factors were assessed through age appropriate verbalizations and play. Adjustment levels were categorized as adequate, difficult or inadequate.

Parent adjustment to hospitalization was based on a parent's

ability to control anxiety over the child's illness and provide the child with emotional support, acceptance of the child's illness, and participation in the child's care during visiting. Parent adjustment levels were classified as adequate, difficult, or inadequate.

Chi-square analysis demonstrated that in both groups, children less than 5 years of age exhibited the most severe emotional reactions to hospitalization (p<.01). Additionally, all children in the experimental group demonstrated significantly less severe anxiety reactions compared to the control group (p <.01). The differences were not influenced by age, gender, or A direct positive correlation was noted between diagnosis. parent and child adjustments. Children who demonstrated adequate adjustment had parents, especially mothers, who also displayed adequate adjustment. This trend was more prominent in motherchild pairs in the experimental group, particularly among preschool children.

The major contribution of this study is that it is the first to directly access parents of hospitalized children to explore the influence of their responses on the child's behaviors, and to clinically demonstrate a direct correlation between parent responses and child reactions to hospitalization. Study results established that parents do manifest anxiety over a child's illness, do not automatically know how to continue the parenting role in the hospital, and have difficulty preparing and

supporting their ill child without also receiving preparation and Though nearly half of all parents in this support themselves. study had attempted to prepare their children, both parents and children were found upon admission to have fragmented and incomplete information about the hospitalization. This finding alerted hospital staff to view admission, regardless of type, as a critical time for assessment and information giving and encouraged the trend toward formalizing preadmission preparation parents and children for planned hospitalizations. of The relationship between mother-child adjustment to hospitalization noted in this study corroborated earlier surveys (Spitz, 1945; Freud, 1951; Bowlby, 1951) and provided additional clinical evidence of the psychological vulnerability of preschool children to separation from mother imposed by hospitalization. In essence, prevailing view of mother as indispensible the for her hospitalized preschool child was supported by this study. These factors became the major impetus for the continued evolution in pediatric hospital care to increase maternal participation and determine the most effective measures to reduce the incidence of emotional trauma in hospitalized children.

Findings from this study should be viewed cautiously due to a number of methodological problems. Evaluation research is subject to many sources of measurement error due to difficulty in design, complexity of study goals, and investigator bias which are

all potential threats to the internal and external validity of study results. The risk of investigator bias in this summative study is extremely high since the investigators attempted to evaluate the very ward reforms they had implemented into their This fact raises the probability of biased response practice. sets as the investigators may have communicated their own expectations to subjects. Investigator familiarity with the treatment variable (ward reforms) reduces the likelihood that the "rolled back" conditions used during data collection on the control group were truly representative of practices that had existed before the original implementation of ward reforms. The risk of investigator bias was further compounded by sequential rather than concurrent data collection which eliminated the use of blind procedures such that investigators knew whether subjects were in the control or experimental groups at the time of data collection.

Validity in this study was also threatened by the absence of controls, either procedural and/or statistical, for variables such as:

1. History - a child's type of admission whether elective or emergency, personnel turnover rate;

2. Selection - presence of underlying chronic illness in children, previous experience with hospitalization, inability to randomize subjects, use of a nonequivalent control group;

3. Maturation - normal growth and development changes in children, changes in parent-child relationships due to child development;

4. Testing - repeated administrations of parental interview;
and,
5. Mortality - a 50% subject attrition rate in each group.

Careful analysis of study findings was difficult due to the use of entirely subjective instruments to measure several dependent variables simultaneously. The minimal description of instruments precludes assessment of the accuracy with which these tools measured the dependent variables. Thus, it is not known if these instruments were reliable in reflecting changes in the variables attributable solely to dependent the treatment variables. Further threats to the internal and external validity of the study included:

Unstandardized procedures for time and place of data collection;

2. Data collection by various ward personnel;

3. Lack of observer training for data collection techniques;

4. Lack of reported interrater reliability among investigators;

5. Novelty of treatment variables and/or testing effects for investigators;

6. Instrument administration variations as investigators became accustomed to instruments; and

7. Longitudinal data collection possibly responsible for improved tool administration and interrater reliability among ward personnel.

Furthermore, this study was hampered by attempts to examine the effects of multiple independent variables (i.e. play program, unrestricted parental visiting, preprocedure preparation, information/support for mothers at admission) on several dependent variables (i.e. children's reactions, parents' responses, parent and child adjustment, and parent and child anxiety levels). Consequently, the investigators could not specify which particular aspects of the experimental treatments accounted for the obtained variance between groups. Taken together, the methodological difficulties markedly limit the generalizability of study findings. Despite these shortcomings, it is important to note context appropriately as this study is over 30 years old and represents a pivotal point in pediatric hospital care.

In an effort to determine ways in which physicians might better assist parents through the experience of hospitalizing a child. Buckman, Gofman, and Schade (1957) conducted an exploratory study to identify parents' reactions to admission for a planned hospitalization and the levels of both child and parent preparation. Hypothesizing that admission, as the first contact with the hospital, constituted a crucial point in determining the tone for subsequent interactions throughout hospitalization, the investigators interviewed 100 parents of children admitted for a variety of surgical procedures at the time of the child's admission. Using a focused, open-ended interview schedule, parents were asked to describe their feelings about hospitalizing their child and the manner in which they and their child had prepared for this event. The rationale behind this study was to facilitate modification of the admission process in order to

reduce some portion of both child and parent anxiety.

Findings from this study indicated that the majority of parents experienced overwhelming separation anxiety at the prospect of having to leave their children in both unfamiliar surroundings and in the care of strangers who might not understand, thus not provide understanding care for their child. Over one-half of these parents were so overcome with anxiety due to fears of the unknown regarding diagnosis, prognosis, and their own role in caring for their hospitalized child that they could neither prepare nor support their child. Futhermore, a majority of parents' indicated that although they desired to continue actively parenting their hospitalized child, they were uncertain about how to do so and also worried that they would be unable to care for their child following discharge.

The most disturbing finding from this study was the lack of While all parents indicated that they preadmission preparation. were informed well in advance of the need for hospitalization, the only explanation 76 parents had received from physicians was that their child needed more tests. In general, these parents felt much "left out" of verv their child's care. The remaining 24 parents and their children had received explanations from their physicians as to why the child required hospitalization, what tests and procedures to expect, and about the policies and general routines of the pediatric ward. These parents felt that they had been able to provide some preparation of their child since they themselves had received explanations. Overall, as expected, these parents reported less anxiety over seemed less fearful about their child's separation, hospitalization, and more able to actively support their child throughout hospitalization. Determining measures to improve prehospital preparation continued to be of major concern because of parent's realistic fears about hospitalizing a child and the lack of both parent and child preparation for persistent hospitalization.

The clinical evidence linking child reactions to the influence of parental attitudes strongly suggested that both parents and children should be well-informed and positively influenced by preparatory measures. Consequently, both the practices of preadmission preparation and ongoing support for parents were constituted largely by providing information and explanations to reduce parents' anxiety thereby enabling them to better prepare their children and continue their parenting roles during hospitalization.

While not disputing either the information that led to or the reported benefits from reforms in the hospital management of children and their parents engendered by these studies, Mahaffy (1965) recognized the need to clinically substantiate the inferred causal relationship between parental attitudes toward and children's responses to hospitalization upon which these

reforms were based. Mahaffy (1965) conducted the first experimental study which directly examined the effects of supportive nursing intervention for mothers on the responses of of their hospitalized children.

Drawing from clinical experience, Mahaffy (1965) determined that a "mother must be comfortable and secure in order to meet her child's needs" (pg. 12) and that it was a nursing responsibility to establish a caring relationship with a mother and intervene to help her continue caring for her hospitalized child. Based on these premises, Mahaffy (1965) hypothesized that assisting a mother in meeting her own needs would help her through the transition of adjusting her customary mothering behavior appropriately to care for her hospitalized child. In turn, the continued mothering would reduce the child's distress which could be measured by physiologic indicators such as blood pressure, pulse, ease of taking fluids and voiding.

A total sample of 43 children admitted for tonsillectomy and adenoidectomy surgery was recruited from the pediatric surgical population of a large urban hospital. All children were between two and ten years of age, had never been previously hospitalized and had no complicating health problems. All subjects were randomly selected into the study and randomized to either the control group (22 patients) or the experimental group (21 patients).

The independent variable, experimental nursing, was defined

as "creating upon admission, and carrying forth throughout the [child's] hospitalization, a sincere and warm acquaintance between the mother and nurse which permitted them to communicate freely with each other" (Mahaffy, 1965, pg. 13). This intervention was operationalized by having the experimental nurse:

1. Perform the nursing admission procedure for each child in the experimental group;

2. Interact with each mother to assess her needs;

3. Help a mother meet her needs by providing information and answering questions;

4. Encourage a mother to express her feelings and concerns;

5. Help a mother care for her child.

These interactive nursing behaviors were enacted during "critical periods" believed to be particularly stressful for mothers such as evening of admission, child's return from recovery room, and at discharge. The control group received routine nursing care.

It was predicted that a child whose mother received experimental nursing care would exhibit less post-operative distress as evidenced by: (a) lower systolic blood pressure, temperature and pulse rate; (b) fewer episodes of crying and vomiting; (c) greater ease in and larger volumes of fluid intake; and (d) shorter time to first post-operative voiding. A questionnaire mailed one week after discharge was used to evaluate a child's emotional reactions to hospitalization in the immediate post-hospital period. The questionnaire listed manifestations such as fever, vomiting. behavioral sleep disturbances, and crying which were rated by frequency of occurrence. Malingering, clinging to mother, and fear of doctors and nurses were rated on dichotomous scales. These behaviors were considered reflective of the emotional upset that could be exhibited by young children following hospitalization. It was predicted that mothers in the experimental group would report significantly fewer, if any, occurrences of these behaviors. An 86% return rate was attained on the guestionnaires. Maternal responses to hospitalization were not measured.

Tests for statistical significance were performed on each of the dependent variables in order to compare physiological responses of the two groups of children. An unpaired t-test was used to compare mean systolic blood pressure, temperature, pulse rate, and mean number of hours to first postoperative void as well as the volume differences in fluid intake between the two The Kolmogorov-Smirnov test was used to compare the groups. differences in ease of fluid intake between groups. Incidences of vomiting and crying in the two groups were examined by Chisquare analysis. Both Chi-square and Kolmogorov- Smirnov tests used to compare answers to the post-hospitalization were questionnaire.

Children in the experimental group had lower temperatures, blood pressures ( $\underline{p}$ <.0005) and pulse rates ( $\underline{p}$ <.005). These children also demonstrated a shorter time to first voiding and greater fluid intake (p< .0005). had Children in the experimental group also demonstrated greater ease in resuming fluid intake (p < .0001) and experienced fewer episodes of crying and vomiting (p < .0005) compared to children in the control group. Statistical analysis of questionnaire results showed significant differences for three post-hospital behaviors between the two More children in the control group exhibited sleep groups. disturbances and reluctance to be separated from mother (p < .05)and seemed fearful of doctors and nurses (p < .01) than did children in the experimental group.

Study results supported the developmental theory and clinical observations that young children manifest their fear, anxiety, and apprehension through a variety of both behavioral Hospital data demonstrated that and physiological responses. children in the experimental group exhibited less anxiety and stress during hospitalization. These same children displayed less behavioral upset at home resulting from anxiety in response hospitalization as indicated by questionnaire to results. These results suggest that the experimental nursing interventions to assist mothers had short and long term positive effects on children's behavior during and following hospitalization. Although the specific influences of experimental nursing on the mothers was not explored, study results tended to further

substantiate the interactive nature of mother-child emotional states (Campbell, 1957; Escalona, 1953; VanderVeer, 1949). By logical extension, it was thus concluded that mothers who received nursing care designed to help them through the transitional period of learning to mother a hospitalized child experienced reduced levels of stress and anxiety.

Skipper, Leonard, and Rhymes (1968) replicated Mahaffy's (1965) study and added checklists to obtain nurse's ratings of children's adaptation to hospitalization, and mother's stress levels and adjustment to hospitalization. Mother's stress levels were rated as: slight, moderate, or intense; and adaptation was ranked as: great, average, or little difficulty. A child's adaptation was rated as high, average, or low. Criteria against which these factors were judged were not given. In addition, the questionnaire concerning children's post-hospital mail-back behavior (Mahaffy, 1965) was expanded to include questions eliciting a mother's perceptions of her own anxiety, feelings of confidence in medical and nursing care, and helplessness. satisfaction with the experience of her child's hospitalization. Validity and reliability estimates for these tools were not reported. Blind rating procedures were utilized in completing all checklists.

A total sample of 80 children admitted for elective tonsillectomy and adenoidectomy surgery and their mothers was obtained from the pediatric surgical population of a large urban hospital. Children in the sample were between 3 and 9 years of age and had no previous hospitalizations or complicating health problems. All subjects were randomly selected into the study and randomized into control and experimental groups of 40 motherchild pairs.

The independent variable in this study, interactive nursing care, was identical to experimental nursing as defined by Mahaffy (1965) and similarly operationalized during the identified "critical periods" with one modification. These investigators that since a child's hospitalization was presumed highly stressful for mothers (Prugh et al., 1953; Buckman et al., 1958; Mahaffy, 1965), admission represented a crucial moment in which to introduce interactive nursing care. To explore this premise, the 40 mothers in the experimental group were divided into two subgroups. The first 24 mothers randomized into the experimental group, constituted experimental group I while the remaining 16 mothers formed experimental group II. Mothers in experimental group I received interactive nursing care at admission and during the "critical throughout hospitalization periods". Mothers in experimental group II received interactive nursing care only at admission. All forty mothers in the control group received routine care. For the purposes of analysis, however, this group was subdivided in the same manner into control groups I (24 mothers) and II (16 mothers).

Hypotheses tested in this study were all directional and predicted differences between control and experimental groups. No hypothesis was stated for differences among groups. The investigators predicted that children in the experimental groups would exhibit:

- 1. Easier adaptation to hospitalization;
- 2. Less distress postoperatively; and

3. Fewer negative emotional reactions post hospitalization. Identical physiologic indicators were measured on all children in the study during "critical periods". Results supported Mahaffy's (1965) original hypothesis that: children whose mothers received experimental nursing care would exhibit less post operative distress as evidenced by: (a) lower systolic blood pressure, temperature and pulse rate; (b) fewer episodes of crying and vomiting; (c) greater ease in and larger volumes of fluid intake; and, (d) shorter time to first voiding. Children in the experimental groups also adapted to hospitalization easier than did children in the control groups ( $\underline{p} < .02$ ).

The investigators hypothesized that a mother receiving interactive nursing care would:

1. Exhibit less stress;

2. Exhibit easier adjustment to her child's hospitalization;

3. Report less anxiety;

4. Report feeling more helpful to her child;

5. Actively continue mothering her hospitalized child; and,

6. Report greater satisfaction with information received and the overall experience of her child's hospitalization.

Chi-square analysis of questionnaire (92% return) and checklist results revealed statistically significant trends between control and experimental groups in the hypothesized Mothers in the experimental groups reported feeling directions. less stress and anxiety during and after the child's operation and greater ability to help their children (p<.02); more confidence in medical staff (p < .05); and, greater satisfaction with information and the overall hospital experience (p < .01). More mothers in the experimental groups reported "complete" confidence in the nursing staff (26%) compared to only 9.4% of mothers in control groups. More mothers (74%) in experimental groups were rated by nurses as having "little difficulty" adapting to hospitalization compared to mothers in the control groups (51%). Although slight differences were found between the differences were not two experimental groups of mothers, statistically significant.

Study results suggest that interactive nursing care can effectively reduce a mother's anxiety and facilitate her adaptation to her child's hospitalization. Of note, however, are the findings that neither mothers' confidence in the nursing staff nor staff nurses' ratings of mothers' adaptation were differentially affected by interactive nursing care. These two findings may be due to the methodological difficulties of unclear for assignment of ratings, lack of instrument criteria reliability, or the failure to establish interrater reliability among staff nurses completing the checklists. In addition to methodological problems, these two findings may reflect that confusion and uncertainty exist for both mothers and nurses regarding a mother's role in her hospitalized child's care (Mahaffy, 1965; Bright, 1965; Roskies, et al., 1975; Hardgrove & Kermoian, 1978). Since the interactive nursing care was provided by a special nurse who was not a member of the regular pediatric nursing staff, it is possible that mothers' confidence in the nursing staff might be significantly different if interactive care had been provided by a regular staff nurse. The study results also support the premise that admission is clearly a crucial point at which to intervene. The researchers advised that the slightly greater positive magnitude of effects from interactive nursing care received by experimental group I mothers compared to group II, "does not exclude the possibility that there is something to be gained from reinforcing it (interactive nursing) throughout hospitalization" (Skipper et al., 1968).

Wolfer and Visintainer (1975) replicated the Skipper et al., (1968) and Mahaffy (1965) studies and added a questionnaire administered shortly before discharge to obtain information about a mother's perceptions of her own anxiety, satisfaction with care, and the adequacy of information she had received during her

child's hospitalization. Using a five-point scale with one indicating no anxiety and five an extreme degree of anxiety, mothers self-rated the anxiety they had experienced during each of the identified critical periods. These ratings were then summed to obtain a mean overall anxiety rating. A mean satisfaction with care score was obtained from mothers' assessments of 20 items addressing various aspects of medical and nursing procedures and the perceived quality and effectiveness of nurse-child interactions. A four-point scale was employed for each item with ratings ranging from one = needs much improvement to four = very good. Adequacy of information was judged by mothers on 18 points such as general hospital routines, various procedures, expected length of stay, and how they could help their hospitalized children. These items were rated on dichotomous scales to indicate whether mothers considered they were adequately informed. A total possible score of 18 indicated adequate information on all 18 items. Validity and reliability estimates for this instrument were not reported.

A total sample of 80 children admitted for elective minor surgical procedures and their mothers was recruited from the pediatric surgical population of a large urban hospital. Children in the sample were between the ages of three and 14, had not been hospitalized in the past year, were English-speaking, and had no chronic or complicating health problems. All subjects were randomly selected into the study and randomized into control (35) and experimental (45) groups of mother-child pairs.

The independent variable in this study, stress-point nursing intervention, was identical to experimental nursing as defined by Mahaffy (1965) and interactive nursing care as defined by Skipper et al., (1968). As in earlier studies, stress-point nursing intervention consisted of psychologic preparation and supportive care for mother and child provided by one research nurse throughout the child's hospitalization during the identified critical periods or "stress points". The control group received routine nursing care.

All hypotheses tested in this study were directional and predicted differences between control and experimental groups. These investigators hypothesized that children in the experimental group would exhibit:

- 1. Better coping and adjustment to hospitalization;
- 2. Less upset behavior and distress postoperatively; and
- 3. Easier posthospital adjustment

Similar physiologic meansurements taken on all children at stress points corroborated with earlier study results (Mahaffy, 1965; Skipper et al. 1968). In this study, children in the experimental group demonstrated less distress as evidenced by lower pulse rates, fewer incidences of crying, greater ease in fluid intake, and shorter time to first voiding. Children in the experimental group also adapted to hospitalization easier and had

easier posthospital adjustments (p<.001).

The investigators hypothesized that mothers receiving stress point nursing intervention in contrast to mothers in the control group would:

1. report lower self-ratings of anxiety at stress points throughout hospitalization;

have greater satisfaction with medical and nursing care; and,

3. consider themselves as having received adequate information.

Mothers' mean ratings of anxiety, satisfaction with care, and information adequacy were analyzed in separate two (treatments) by two (age) by two (sex) analyses of variance which revealed statistically significant differences between control and experimental groups in the hypothesized directions. While all mothers of younger children generally had higher anxiety ratings than mothers of older children, no other significant interaction effects were reported. Mothers of 3 to 6 year old children in the experimental group had significantly lower selfratings of anxiety ( $\bar{x} = 2.89$ , df = 1, F = 9.03, p = .004) as did mothers of 7 to 14 year old children ( $\overline{x} = 2.44$ , df = 1, F = 5.78, p=.02). Mothers in the experimental group also rated information significantly higher in adequacy ( $\bar{x} = 11.68$ , df = 1, F = 84.82, p = .001) and were considerably more satisfied with care ( $\overline{x}$  = 3.26, df = 1, F = 17.99, p = .001).

The researchers postulated that stress-point nursing

intervention lessened mothers' anxiety and assisted them to more accuratelv redefine their mothering roles and activelv participate in their children's care. Although the exact causal nature of this sequence of events remains unknown. the investigators presumed that the support and information mothers received restored their sense of capability and enhanced the feeling of remaining in control over their children's care. Results in this study also supported previous findings showing that adequate mothering diminished a child's stress and promoted positive adjustment both during and after hospitalization. As in previous studies, the major limitation in this study centers on the fact that stress-point nursing intervention was provided by a single nurse researcher. This limitation raises questions as to whether the variance reported was due to the process and content of the intervention itself, the personality and manner of the nurse providing the care, or some combination of the two. Generalization of study findings is also difficult due to the restriction of all study samples to only elective surgical admissions.

Despite common limitations, the preceding series of studies strongly suggest that the quality of the nurse-mother relationship, particularly during admission, is an important predictive variable of a mother's ability to successfully manage the role transition imposed by her child's hospitalization. Findings across studies which consistently and significantly supported similar hypotheses demonstrated that supportive nursing interventions with mothers can effectively reduce both maternal and child anxiety and promote more positive adjustments for mother and child. Perhaps the primary outcome of these studies has been a paradigmatic shift in pediatric nursing care from from exclusion of mothers' needs toward a greater understanding of these needs and the vital role of mother in the child's responses to hospitalization.

# Maternal Needs and Concerns

In a narrative account drawn from clinical experience, Hymovich (1976) outlined the common needs of parents created by a child's illness. Identified parental needs included: trust in themselves and health professionals; accurate and timely information concerning the child's diagnosis, treatment, and prognosis; guidance and support in coping with their feelings about the child's illness; and both physical and financial resources to care for their child. This author further specified that these needs must be satisfied in order for parents to successfully accomplish the necessary tasks to positively manage the illness imposed stresses.

In a post-hospitalization survey, Freiberg (1972) explored mothers' perceptions of how their childrens' hospitalization had affected them. A voluntary, convenience sample of 25 mothers participated. Mothers were interviewed in their homes between

four and seven days following the child's discharge from the hospital. Although the actual interview schedule was not detailed, questions centered on mothers' reasons for experiencing anxiety during a child's hospitalization and the behavorial changes children exhibited following hospitalization.

All mothers reported experiencing some degree of fear, anxiety, or uneasiness throughout the hospitalization. Results further disclosed that the primary source of maternal anxiety was fear about treatments and procedures. Additional sources of anxiety included lack of information about procedures, treatments, diagnosis, and fear about the child's future health. While not included in the interview, nearly half of these mothers reported dissatisfaction with nursing care. The two major criticisms were that nurses did not spend enough time with the child and episodes of nurses being sarcastic to mother and/or child. Consequently, Freiberg (1972) concluded that mothers of hospitalized children need more support and information from nurses to effectively deal with their own anxiety.

As a means of helping parents with their emotional responses during hospitalization, Irwin and Lloyd-Still (1974) formed a discussion support group for parents. In designing the group, these researchers relied on earlier studies which revealed that when a professional person establishes a positive relationship with a mother, her anxiety decreases thereby changing her

perception of the hospital experience which then results in less stress for her child (Skipper et al., 1968; Mahaffy, 1965; Prugh et al., 1953). They further reasoned that the group could assist parents in working through issues related to separation and continuation of the parenting role despite hospitalization. Specific group aims included:

1. Giving parents an opportunity to express their feelings,

2. Helping parents feel less isolated,

3. Fostering supportive interactions between parents

4. Obtaining additional information about parental reactions to hospitalization (Irwin & Lloyd-Still, 1974, p. 306).

All parents of children hospitalized on the 60 bed surgical service of a large metropolitan hospital were eligible to participate in the group. For 12 consecutive weeks, group meetings convened in the parents' lounge weekly during the children's afternoon rest hour. The researchers jointly served as facilitators. Of 73 parents who were invited to attend, 39 mothers, 10 fathers, and seven other relatives participated. Of the 56 participants, 27 were parents of children seven years or older and 22 were parents of children between the ages of two and six years. No parents of neonates attended. Only six parents attended two or more of the 12 meetings.

Parents repeatedly introduced similar issues of concern for group discussion. The issue raised most consistently was parentchild separation. In particular, parents reported feeling very

leaving a child alone in unfamiliar surroundings, anxious relinquishing the child's care to hospital staff, and feeling how to participate in the child's confused about care. Additional parental concerns included: inadequate or inaccurate information, lack of objective support persons for themselves, feelings of guilt about the child's condition, isolation. about the emotional effects uncertainty, and worry of hospitalization on the child as well as other family members. The authors did not report the percentages of participants expressing these concerns.

Approaching the problem of mother-child separation somewhat differently, Roskies et al., (1978) presumed that often a mother's uncertainty about her role in caring for her hospitalized child interfered with her ability to do so. These researchers hypothesized that both the quantity and quality of a mother's participation in her child's care could be improved by offering specific suggestions about how to care for her child prior to hospitalization.

Mothers of 48 preschool children, ages one through five, scheduled for elective surgery in a large metropolitan pediatric hospital, comprised the convenience sample. All mothers were chosen from preadmission scheduling lists and assigned to control and experimental groups of equal numbers.

In a test-retest design, all mothers were seen at home during the preadmission week and again two weeks following the

child's discharge. Upon each occasion, mothers completed the Parent Participation Attitude Scale (Seidl, 1967) and а questionnaire concerning the child's customary daily routines and behaviors. In addition, mothers in the experimental group were given information about the expected course of hospitalization, typical psychological reactions of young children, and emphasis was placed on the mother's role in her child's care. "The intervention was designed to involve the mother in the process of hospitalization, to provide specific suggestions about when and how to visit, and to furnish clarification and reassurance for the specific concerns of each individual mother" (Roskies et al., 1978, p. 769). During hospitalization, the frequency, duration, and content of a mother's visits to her child were recorded. No validity or reliability estimates were reported. The Mann-Whitney U was used to test the null hypothesis: there is no difference in the visiting patterns of mothers who receive preadmission information about caring for their hospitalized children and mothers who do not receive this information.

The null hypothesis was not supported. Mothers in the experimental group visited for longer periods compared to mothers in the control group ( $\underline{p}$ <.02). Mothers in the experimental group also demonstrated more assertion in remaining with their children during highly stressful periods, such as the day of surgery, as indicated by significantly longer visits during these times

 $(\underline{p} < .05)$ . While mothers in both groups spent most of their visiting time directly with their children, a marked difference was found in the types of care mothers pursued. Mothers in the experimental group spent more time actively engaged in both routine physical care and psychological support of their children  $(\underline{p} < .05)$ . Although somewhat mixed compared to predictions, these results supported the effectiveness of the intervention in modifying mothers' visiting patterns and participation in their children's care. A serendipitous finding was the increased frequency and longer duration of visits by fathers in the experimental group.

# Emergency Hospitalization

Over half of all hospital admissions for children under six years of age occur through emergency rooms. However, the only emergency hospitalization investigation within the last 35 years is a pilot study by Roskies et al. (1975) These researchers conducted an exploratory, descriptive study "to explore the theoretical and practical feasibility of research in this area" (Roskies et al. 1975, p. 570).

The researchers presumed that a certain sequence of events characterized a typical emergency admission process that was different in comparison to an elective admission. Further, they assumed that identification of the differences between the two processes could provide information for improving the care children and parents received during admission. In order

to capture these data, they developed an observation schedule to record: a) the steps of each type of admission process, b) the number and type of people present during admission, c) the interactions that occurred, and d) the reactions manifested by In addition, a short parental parents, children, and staff. was constructed to obtain information about any interview previous hospitalizations a child had experienced, the precipitating events for this hospitalization, and parents' perceptions of the admission process. Tool validity and reliability were not established prior to the study.

Subjects in the study were followed by trained observers for at least six hours including one hour of ward observation to follow the entire admission process and complete parental interviews. In instances where parents left before the end of the observation period, interviews were conducted at the time parents departed. Content analyses of observation records and interview responses were performed to establish categories for comparative analysis. Events and interactions within categories considered to be indices of stress reactions were then quantified to permit comparisons between the two types of admission.

To control for extraneous variables and obtain sample homogeneity, stringent criteria for study inclusion were employed. Criteria required that children were: "between eight months and four years of age; accompanied by at least one parent; of French-Canadian origin; conscious; of the metropolitan area; alive during the six hours of observation; to have come directly to this hospital; admitted to a ward" (Roskies, et al., 1975, p. 572). The criterion requiring ward admission of a child posed considerable difficulty in obtaining subjects for the study primarily because the majority of children seen in the emergency room were not admitted to the hospital. Consequently, the study sample was obtained only after a total of 66 potential subjects had been observed. The final sample consisted of 16 children and 26 parents equally segregated into emergency and elective admission groups. In each group, five of the eight children were accompanied by both parents while the other three children were attended by only their mothers.

Data collected in this study revealed several differences in the events and interactions that occurred during the emergency and elective admission processes. The elective admission process was typified by four fairly uniform steps beginning with the arrival of a family in the admission office where clerical tasks such as insurance and consent forms were completed and the child received an identification band. Next, a clerk directed parents and child to the laboratory for admission blood tests then to the x-ray department if these had been ordered. Parents then accompanied their child to the pediatric ward where the nursing admission assessment was done and the child was examined by the ward pediatrician. Lastly, the child was assigned to a room and

ward orientation was provided by a member of the nursing staff. With the exception of a child's protests during lab tests, the observed interactions between parents, child, and staff were generally calm, courteous and of an informational nature.

In contrast, the events comprising the emergency admission followed no set pattern being dictated instead by the urgency of the child's condition. In many instances several events occurred simultaneously such as blood-drawing during the phycical exam or parents being sent to the admitting office while their child was taken to x-ray. Interactions observed between staff, parents, and child were limited almost entirely to the discussion required to assess the child's medical problems and needs. Often, after providing the staff with necessary information, parents were essentially ignored while the staff attended to their child.

Observational data further indicated that children in the elective least minimally prepared group were at for hospitalization whereas children in the emergency group were completely unprepared. Compared to children in the elective children in the emergency group were also sicker, group. separated from their parents sooner, and subjected to a greater number of painful procedures more rapidly (an average of eight in the first six hours as opposed to three). Further, children in the emergency group received less parental support due to their parents' anxiety and preoccupation with events.

All parents in both groups demonstrated varying degrees of helplessness, passivity, and inability to effectively anxiety, function in the hospital environment. These reactions were observed even among parents who had previously experienced a child's (N = 12) hospitalization despite their exposure to this setting. However, parents in the emergency group who had previous experience admitting a child on an emergency basis expressed relief once assured that their children (N = 6) would actually be hospitalized. Parents in the emergency group whose children (N = 2) had never been hospitalized, were extremely anxious and became more so when told their child needed to be hospitalized. These parents also expressed fear of responsibility for causing the child's illness/injury, concern about what they should have done to prevent it, and considerable regarding their child's future health. They worry also demonstrated helplessness, uncertainty, and were unable to comfort or support their children due to their own anxiety.

Based on these findings, researchers concluded that emergency hospitalization is more stressful and anxiety-producing for both parents and children. In addition, findings from this study were consistent with previous research demonstrating that parents have considerable difficulty managing the role transition imposed by a child's hospitalization and are often unable to continue parenting the ill child. A disturbing finding in the emergency group was that parents, with a history of previously admitting a child through an emergency room, actually brought their children to the hospital precisely because they <u>wanted</u> their children hospitalized. The researchers speculated that perhaps "a high level of parental incompetence and/or anxiety in the face of illness, as much as the illness of the child itself, could lead to a pattern of repeated admissions" (Roskies et al. 1975, p. 580).

Findings from this study must be viewed cautiously due to the lack of instrument reliability and validity, the absence of reported interrater reliability, and the possibility of observer influence on subjects. Generalizations are limited further due to the small, non-probability sample, absence of controls for diagnoses and reasons for emergency room utilization, and no control for a history of previous hospitalizations. In spite of these limitations, this pilot study demonstrated that it is possible to gain access to the pediatric emergency population and that characteristics and experiences of this population need to be further explored and described. Summing their own findings, the researchers strongly recommended further studies be designed to obtain more detailed knowledge of parental patterns of emergency room utilization, factors influencing parental role performance during a child's emergency admission, and factors which may interfere with staff abilities to assist parents and children during the transitional period of a child's emergency

admission.

### Nurse's Role in the Emergency Room

Based on clinical experience, Canright and Campbell (1977) offer suggestions for nurses to help a mother deal effectively when her child is admitted to the emergency room. These authors posit that by focusing on three areas of maternal concern, nurses can greatly assist a mother to maintain her role performance. First it is imperative that nurses center their attention on the child. This reassures the mother and reinforces her concern for her child. Next, nurses should discuss with the mother what they will do for her child. So doing permits the mother to not only feel included but also provides the mother an opportunity to offer helpful suggestions. Lastly, whenever possible a mother should be assisted to actually participate in her child's care.

From the authors' experience, fostering familiar aspects of the mother's role is certain to ease some of her anxiety and role conflict. Given the interaction of mother-child emotions, this should help ease her child's anxiety as well. In turn, these interventions should serve to diminish the emotional upset for all involved and aid both mother and child in adjusting to this illness experience.

#### Summary

While not exhaustive, this review of studies describes exploratory and experimental research related to hospitalized children and their parents. Research in this area consistently revealed that a mother's primary response to her child's hospitalization is anxiety (VanderVeer, 1949; Prugh, 1953; Buckman, et al., 1957; Mechanic, 1965; Bright, 1965 & Roskies et al., 1975). Furthermore, studies suggest that the level of maternal anxiety is inversely related to a mother's ability to effectively mother her hospitalized child.

Additionally, studies have demonstrated that both maternal and child anxiety are amenable to supportive nursing intervention given directly to mothers (Mahaffy, 1965; Skipper, Leonard & Rhymes, 1968; Wolfer & Visintainer, 1975; Roskies et al., 1978). These same studies also disclosed that the quantity and quality of mothering care, or preservation of the maternal role, during the transitional period of a child's illness, could be enhanced by "stress point" or "interactive" nursing interventions.

A number of studies also identified several sources of maternal anxiety including: fear of responsibility for the child's illness; fear about diagnosis, treatment and prognosis; separation; unfamiliarity with hospital atmosphere and environment; inadequate/inaccurate information; relinquishing care to hospital staff; uncertainty about how to participate in the child's care; and loss of confidence in mothering skills (Prugh, 1953; Buckman et al., 1957; Bright, 1965; Mahaffy, 1965; Skipper & Leonard, 1968; Frieberg, 1972; Irwin & Lloyd-Still, 1974; Roskies et al., 1975; and Miles, 1979). However, with the

exception of Roskies' et al., (1975) verification that an emergency engenders more intense anxiety than an elective admission, it is unknown whether these sources of anxiety represent the concerns of mothers faced with a child's emergency hospitalization. Neither is it known which supportive nursing interventions may help mothers during the role transition that accompanies the emergency admission of a child. In order for nurses to accurately assess and intervene appropriately, it is imperative that nurses have the knowledge and be aware of the specific concerns of mothers whose ill preschool children are admitted on an emergency basis.

# Conceptual\_Framework

The theoretical constructs of social role theory (Mead, 1934; Turner, 1978; Blumer, 1969) as proposed by Meleis (1975) and Allen and Van de Vliert (1982) provided the organizing framework undergirding this research. Social role theory holds that a role is a dynamic, meaningful performance which is contextually determined, and dependent upon person to person interaction. In other words, "role is a continuous, personallyevolved creation that guides a person's interactions with another person" (Allen & Van de Vliert, 1982), p. 289). Central to social role theory is this interactional component which emphasizes that any given role with its expected behaviors, meanings, and consequences can only be understood in terms of complementary roles (e.g., husband-wife, mother-child) and the social setting in which it occurs. Furthermore, it is "through interaction and role-taking processes with the other that each person's roles are discovered, created, modified, defined, and incorporated into the self-concept which is actually a conception of how one relates to major significant other roles" (Meleis, 1975, p. 265).

# Role Transition

For the most part roles are enacted in a dynamic yet steady The individuals involved in a particular role and state. counterrole understand the meaning of each other's behaviors and have learned to successfully negotiate their own behavior in response to the other's needs in order to maintain a steady state. However, situational demands or conflicting requirements of multiple roles may interfere with an individual's ability to appropriately adjust behavior or prevent adequate performance of a particular role. The inability to continue enacting a certain role leads to role strain and attempts to alleviate this strain by the involved individuals reflects role transition.

A role transition is primarily the psychological process of changing from one set of negotiated behaviors to another set of behaviors. Role transition strongly influences the behavior and social identity of all those participating in the change (Allen & Van de Vliert, 1982, p. 3). Role transitions tend to be dichotomies; they may be voluntary or involuntary, expected or unexpected, permanent or temporary, reversible or irreversible. A role transition also denotes a change in role relationships, expectations or abilities which require the role incumbent to incorporate new knowledge, alter behavior, and redefine selfconcept. In addition, "changes in one role necessitate complementary adjustments in the counterrole; changes have to be made in the behavior of one or more persons in the ego's social circle" (Meleis, 1975, p. 265).

Before enactment of a newly acquired role takes place, the meaning of the role and the expected behaviors must be understood and incorporated by the role incumbent and significant others. This transitional period of relinquishing one role and assuming another is frequently characterized by conflict, uncertainty and strained relationships due to the disruption of customary behavior patterns. These behavioral manifestations actually reflect the psychological adjustment process that occurs during a role trnasition. If, however, the individuals involved in role changes share the same goals or have supportive resources to assist them in changing, the role transition generally occurs with considerably greater ease.

Accoding to Meleis (1975), "nurses encounter numerous situations of role change, such as the transition from wellness to illness [thus] nurses are in the most opportune position to assess the clients psychosocial needs during role transitional periods and provide the necessary interventions based upon the individual's needs and deprivations created by role transitions" (p. 264). Three particular transitions of which nurses should be aware are: (a) developmental transitions, (e.g., childhood to adolescence); (b) situational transitions such as the birth or death of a family member; and (c) health-illness transitions such as the sudden role changes that result when moving from a well state to an acutely ill state (p. 266).

Although the objective situational and health-illness transitions often transpire within seconds (e.g., accident or death), the psychological adjustment process takes much longer. "The psychological and the objective beginning and ending of the transition process often do not coincide" (Allen & Van de Vliert, 1982, p. 16). While numerous role transitions are successfully managed with minimal strain, certain transitions such as those accompanying illness and hospitalization are clearly more difficult for the interactants and may predispose them to role insufficiency.

Role insufficiency is defined as the "behaviors and sentiments affiliated with the perception of disparity in fulfilling role obligations or expectations" (Meleis, 1975, p. 266). Further, she asserts that anxiety, apathy, grief, hostility, and depression manifested by patients and their family members are indicators of role insufficiency. Role insufficiency is further characterized by acute cognitive distress marked by

uncertainty, and perplexity resulting from the confusion, perceived incongruence between customary role behaviors and situational expectations. This incongruence may arise from poor role definition, disparity between the adequacy of self and role expectations of others, misinterpretation of role expectations, or impaired or absent role behavior cues from significant others. These disparities become most pronounced when the role incumbent continues to occupy the same role but "the expected behaviors associated with it change drastically" (Allen & Van de Vliert, 1982, p. 9). By understanding the causes and manifestations of role insufficiency that can occur during health-illness role transitions, nurses can accurately assess and intervene appropriately to aid clients in coping with their needs and deprivations created by involuntary role transitions.

Meleis (1975) defines role supplementation as a preventive or therapeutic nursing intervention designed to "decrease, ameliorate, or prevent role insufficiency" and promote role mastery (p. 267). Depending on the individual circumstances, nurses can assist clients toward the goal of role mastery through:

1. Role clarification or the provision of specific information and behavioral cues needed to perform a given role;

2. Role modeling or the opportunity to observe another enacting a particular role which allows a potential role incumbent to emulate the required role behaviors; and,

3. Role rehearsal which enables a role incumbent to successfully anticipate the behaviors associated with transitional and future roles.

In addition, she postulates that "the earlier preventive role supplementation is offered, the lower the probability of role insufficiency " (Meleis, 1975, p. 270).

# Maternal Role Transition

For the purpose of this study, mothers and other family members, are assumed to experience involuntary role transitions caused by the illness and subsequent emergency hospitalization of a preschool child. The specific transitions a mother must undergo are the transition at home from mothering a well child to mothering an ill child followed fairly rapidly by a second transition to mothering a hospitalized child.

The suddeness of a child's health to illness transition alters a child's usual behavior. This rapidly presents a mother with new and/or ambiguous behavioral cues which she may not understand yet which require that she adapt her customary role behaviors to meet her ill child's needs. If a mother does not understand her child's behavior she cannot continue to perform her role satisfactorily and will experience role strain. Attempts to alleviate this role strain are often stymied by her i11 child's worsening condition which presents more new behavioral cues to a mother.

The child's emergency hospitalization further compounds a mother's attempts to resolve role strain. Hospitalization of a child is very frightening for a mother and her anxiety may be increased due to the nature of an emergency which precludes

psychological preparation. A mother's customary role behavior may also be further disrupted by the expectation that she continue mothering her hospitalized child with minimal guidance in the strange hospital environment with its unfamiliar routines and procedures. These factors may further increase a mother's anxiety and her difficulty in successfully negotiating the imposed role transition. Under these circumstances, if a mother is also fatigued, uncertain, or has other conflicting role demands, the probability that she will experience role insufficiency is markedly increased.

# CHAPTER III

# METHODOLOGY

## Research Design

The purposes of this exploratory-descriptive study were to describe the perceptions and concerns of mothers immediately preceeding and during the emergency hospitalization of an ill preschool child, and the events mothers experience during this health-illness transition. Additional aims were to describe mothers' perceptions of their concerns and explore how they perceive that these concerns affect both the mothering role and family functioning.

Given the absence of studies addressing issues raised by childhood emergency hospitalization from a mother's viewpoint, a grounded theory approach was employed to begin the process of concept identification. This exploratory, inductive method is useful in nursing research for discovering relevant variables in areas where little is known (Simms, 1981; Stern, 1980). A deductive approach based on concepts derived from role transition theory was also used to guide both instrument development and data analysis in this study.

The methods of data collection included a demographic profile (see Appendix A) and the <u>Maternal Perceptions of</u>

<u>Emergency Hospitalization Interview</u> (see Appendix B) developed by the investigator. Additional data was obtained from administration of the <u>Feetham Family Functioning Survey</u> (Feetham & Roberts, 1982), (see Appendix C). Complete data were obtained from each mother within 24 hours of her child's emergency admission to the hospital. The MPEHI and FFFS are subsequently described.

# Instruments

Maternal Perceptions of Emergency Hospitalization Interview. The MPEHI was designed to elicit a mother's concerns and immediately preceding and during the emergency perceptions hospitalization of her ill preschool child. The MPEHI contained 33 questions grouped into the following four categories: illness transition, setting transition, family transition, and role The interview was structured specifically to enable transition. a mother to recount, in chronological order, the events leading to her child's emergency hospitalization. This categorical structure was used to capture discrete data reflecting the stages of multiple role transitions thought to be occurring either simultaneously or in rapid succession. The specific questions were formulated using findings from studies of parent-child responses to pediatric elective hospitalization (Buckman et al., 1957) and of mother-child affectional bonds (VanderVeer, 1949; Bowlby, 1951; Robertson, 1953) as well as the investigator's own 54

clinical experience.

More specifically the category of <u>illness transition</u> addressed the onset of the child's illness and proceeded through the events that resulted in the child's emergency admission. The manner in which a mother dealt with these events and her emotional responses to them were also explored. Questions about the <u>setting transition</u> were designed to obtain details of the actual pediatric ward admission process. Information was also sought concerning mother-staff interactions, staff competency, and mother-child separation.

The <u>family transition</u> category was developed because previous research did not consider the influences of family members on the mother's responses to hospitalization. The questions were designed to elicit mothers' perceptions of the reactions of other family members to the child's illness. Mothers' feelings about these reactions and concerns raised by them were also explored.

The questions comprising the final category of <u>role</u> <u>transition</u> pertained strictly to a mother's perceptions of the impact her child's illness had, or might have, on her maternal role performance. The focus of these questions was both behavioral and emotional aspects of the mothering role as well as the level of confidence in mothering skills and degree of comfort in continuing the mothering role in the hospital.

Prior to data collection, the MPEHI was reviewed by four

nurses with expertise in the areas of maternal child nursing and role transition theory. Each nurse independently evaluated the questions for congruency with the purposes of the study. The concensus of this group of nurses was the MPEHI demonstrated content validity.

<u>Feetham Family Functioning Survey</u>. The FFFS (Feetham & Roberts, 1982) was used in this study to obtain quantitative data about family functioning. This survey is designed to assess family functioning using three scales:

- 1. relationships between family and broader social units;
- 2. relationships between family and its subsystems;
- 3. relationships between the family and each individual

(Feetham & Roberts p. 231-32).

The survey consists of 21 indicators of family functioning. For each indicator seven-point Likert scales are provided to obtain numerical ratings. Each item is rated three times for "what is" (a score), "what should be" (b score), and the perceived value (c score), A discrepancy score (d score) representing the degree of satisfaction with each indicator is determined by the difference between the ratings assigned to "what is" and "what should be" (a-b=d). The scores closest to the greatest degree of zero indicate satisfaction with functioning and those farthest indicate that family functioning is not what it should be (Feetham & Roberts, 1982).

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Additional information can be obtained by comparing the discrepancy score (d) with the value rating or importance score (c) of a particular indicator. This comparison measures both the degree and direction of dissatisfaction with the perceived level of existing function (Feetham & Roberts, 1982). Clinically, this comparison can be useful for identifying problem areas of family functioning that require nursing intervention.

The FFFS has been administered to families with normal infants and those with infants and children who have myelodysplasia. It has also been used in a variety of both cross-sectional and longitudinal investigations with the above stated populations. The FFFS has been shown to be sensitive to changes over time in family functioning (Feetham & Roberts, 1982).

The internal consistency of ratings were estimated from responses of 103 mothers of children with myelodysplasia and shown to be .66 for a scores, .75 for b scores, .84 for c scores and .81 for d scores. An alpha coefficient of .85 for the discrepancy score (d) was obtained in a test-retest procedure 2 weeks later involving 22 of the 103 mothers originally tested. These reliability coefficients indicate that the FFFS has a fairly high degree of internal consistency (Feetham & Roberts, 1982).

Content, concurrent and construct validity were assessed for the FFFS through several methods. The content validity of indicators of family functioning were identified through a review

of family functioning literature, research involving families of children with chronic health problems and clinical observations of families of children with myelodysplasia (Feetham & Roberts, 1982). Additional content validity was provided by experts in family therapy and care of chronically ill children. Pretesting of the scale was done with parents of children with myelodysplasia who also discussed the scale with its developers and offered suggestions for improving clarity and relevance.

The Relationships Between the Family and Each Individual scale of the FFFS demonstrated concurrent validity with the Family Functioning Index (FFI Pless & Satterwhite cited in Feetham & Roberts. 1982). The FFI assesses intrafamily functioning of families with chronically ill children which is only one of the three areas included in the FFFS. Nonetheless, concurrent validity was supported by an obtained correlation coefficient of  $\underline{r} = -.54$  (p<.001) between the FFFS and the FFI (Feetham & Roberts, 1982). The concurrent validity of the FFFS scales, Relationships Between Family and Broader Social Units and Between Family and Subsystems, has not been established.

Construct validity of the FFFS was tested using Varimax rotation on the data from the 103 mothers of children with myelodysplasia. Of the 21 indicators of family functioning, 18 had eigen values greater than .43, however, the three indicators with low factor loadings (<.43) were retained for further testing. Factor loading ranges for each of the three scales are: relationship between the family and individual, .46 to .85; relationship between the family and the subsystems, .43 to .78; relationship between the family and the broader social units, .49 to .74. Results of factor analysis support the conceptualization of the instrument as a measure of family functioning in the above stated three areas of relationships (Feetham & Roberts, 1982, pp. 234).

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<u>Eligibility Criteria</u>. The target population for this study was mothers of preschool children hospitalized on an emergency basis. A convenience, nonprobability sample of 5 mothers participated in the study. The criteria used to ascertain a mother's eligibility for inclusion in the study were that she:

- have an acutely ill preschool child age 1 4 years, who had no previous hospitalizations and was admitted on a non-referral emergency basis to a general pediatric unit;
- be able to speak and read English sufficiently to complete a questionnaire;

- be interested and willing to participate in the study. As this was an exploratory study, cultural, ethnic, and socioeconomic factors were not controlled.

<u>Setting</u>. A non-profit community hospital and a large university teaching hospital were used for sample recruitment and data collection. The use of two locations was intended to maximize access to the target population. Each facility had both an emergency department and a pediatric ward. Both institutions also provided rooming-in facilities for parents.

Approval to involve humans as research subjects Human Subjects. was granted by the Committee on Human Research at the University of California. San Francisco and the Institutional Review Board of Marin General Hospital, Greenbrae, California. These approvals constituted assurance that the rights of human subjects involved in this study had been adequately addressed and explained in the consent form (see Appendix D) and were thus protected. The informed consent also described the possible benefits from and the minimal risks associated with participation in the study.

<u>Selection Process</u>. Mothers meeting eligibility criteria for inclusion in the study were identified by the investigator. Access to these mothers was mediated by the charge nurse of the pediatric unit. After the child's admission to the pediatric unit was completed and therapy initiated, the charge nurse briefly informed the mother about the study and asked permission for the investigator to contact her. If a mother agreed, the investigator met with her and explained the study. In the event a mother was willing to participate in the study, written informed consent was obtained and a time arranged for data collection. A copy of the Research Subject's Bill of Rights and the Consent form was given to each subject. Each mother was also given verbal assurance that confidentiality and anonymity would be maintained.

#### Data Collection Techniques

Complete data were obtained from each mother Procedure. within 24 hours of her child's admission to the pediatric unit. Data collection with each subject was conducted in a private conference room on the pediatric unit. Instruments were sequentially administered by the primary investigator beginning with the Demographic Profile and proceeding to the MPEHI. The interviews were tape recorded to insure accurate data collection and facilitate analysis of responses. After tape transcription was accomplished, the tapes were destroyed. Confidentiality was further protected by numerically coding all transcriptions and response sheets. An intentional pause was included halfway through each interview allowing a mother the opportunity to check her child if she desired. Lastly, each subject completed the FFFS. The data collection procedure was identical for each subject and required no more than one hour for completion. Following this, each mother was given the opportunity to discuss any additional concerns or questions she might have with the investigator. Each mother answered all questions, and no mother expressed any concerns raised by the discussion of the hospitalization experience.

Data Analysis. In keeping with the grounded theory approach, interview responses were critically examined for recurring themes using the technique of constant comparative analysis (Glaser & Strauss, 1967; Brink & Wood, 1978; Polit & Hungler, 1983). Substantive coding of themes resulted in general properties related to the study questions. These properties were further compared to the 'local concepts' (Glaser & Strauss, 1967) of role described in the study framework, for transition theory, as congruence and differences. This combination of inductive and deductive approaches in data analysis permitted verification of thematic categories regarding maternal perceptions and concerns during involuntary role transitions.

Objective data obtained from the FFFS were subjected to descriptive statistical analysis. Comparisons were made of discrepancy scores (d scores) and examined for possible MPEHI Select responses. demographic relationships to characteristics were also analyzed for relationships to family functioning scores using non-parametric tests. Results are subsequently described.

#### CHAPTER IV

#### RESULTS

The data collected in this study yielded information regarding the concerns and perceptions of mothers during the transitional period marked by the emergency hospitalization of an ill preschool child. Data was obtained by using a demographic profile, an interview guide, and a family functioning survey. These instruments were administered collectively in the above stated order to each mother within 24 hours of her preschool child's admission to the pediatric ward.

# Demographic Data

The data collection period spanned three months during which time the convenience sample of five mothers and their children was secured. Although an <u>N</u> of 10-20 mothers had been projected for this study, no subjects were obtained from the university hospital. While the number of emergency admissions during the investigation period was substantial, eligibility criteria could not be satisfied. In the majority of cases, either the admission had been a referral or the child was not of preschool age. It is possible that the teritary care level at the teaching facility responsible for the referral admissions. was Using the demographic profile, characteristics of mothers, children, and other immediate family members were obtained. The major characteristics of the five mothers and their children entered

into this study are summarized in tables 1 and 2 respectively. Demographic data were analyzed using descriptive statistics.

Mothers ranged in age from 26 to 32 years ( $\bar{x} = 29.2$ ) with educational levels ranging from 12 to 16 years ( $\bar{x} = 13.8$ ). All five mothers listed occupations besides homemaker and three were actively employed in their respective fields. At the time of the study two mothers were pregnant. The five mothers participating in this study had remained continuously with their children from admission up to the time of data collection.

The children's ages ranged from 14 to 26 months ( $\bar{x} = 18.8$ ). Of the five children, three were females and two were males: three were only children while the remaining two were the youngest child in their families. Admitting diagnoses of the children included meningitis, febrile convulsions, fever of unknown origin, and otitis media complicated by mandibular Three children had been ill less than 24 hours prior cellultis. to admission and one less than 48 hours. The fifth child had been ill at home for one week with otitis media; however, the onset of cellulitis had occurred less than 24 hours before his No child in the study had ever been previously admission. hospitalized.

All five families were intact nuclear families, with fathers gainfully employed outside the home. Three families had incomes ranging from \$20,000 to \$30,000, while one ranged \$30,000 to 64

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# Demographic Profile of Mothers

	Age	Education (years)	Occupation	Employed	Pregnant	Marital Status
1.	31	14	Radio Announcer	Yes	No	Married
2.	29	12	Jewelry Wholesaler	No	No	Married
3.	26	14	Retail Sales	Yes	No	Married
4.	32	16	English Teacher	No	Yes	Married
5.	28	13	Housewife/ bookkeeper	Yes	Yes	Married

# Table 2

# Demographic Profile of Children

(	Age months	Gender 3)	Ordinal Position	Diagnosis Len	gth of Illness Prior to Admission
1.	14	F	Youngest	Fever/unknown origin	Less than 24 hours
2.	15	F	Youngest	Febrile Convulsions	24 hours
3.	22	F	Only	Meningitis	12 hours
4.	26	М	Only	Meningitis	48 hours
5.	17	M	Only	Mandibular cellulitis bilateral otitis	1 week

\$40,000, and one greater than \$50,000. Of the two children who had older siblings, one had a 3 year old brother, the other had a 15 year old half brother and 17 year old half sister. One family was extended by the father's widowed mother who resided with them and two families had either maternal or paternal grandparents living nearby.

# Interview Themes

Mothers' responses to the <u>MPEHI</u> generated rich and complex data. The technique of comparative analysis revealed that a mother's perceptions and concerns clustered about the nature of the child's illness and the subsequent effects the illness would have upon herself, her child, other family members and nurses' views of her as a mother. The themes which emerged as most reflective of mothers's perceptions and concerns include: 1) maternal perceptions of illness and emergency admission, 2) perceptions of the effects of illness on the child, 3) effects of illness on mothering role, 4) perceptions of nurse roles, and 5) effects of illness on other family members. In all interviews, each mother addressed at least some aspect of each theme.

#### Theme One

# Maternal Perceptions of Illness and Emergency Admission

In recounting the circumstances of a child's illness and emergency admission, each mother described a fairly uniform progression of events and responses. The first phase of the general pattern which emerged from these accounts begins with the illness onset and treatment of the child at home. The second phase is characterized by ineffectiveness of treatment and increasing severity of illness leading to physician contact and emergency evaluation of the child. This was followed quickly by the third phase of emergency admission to the pediatric ward. Each of the three phases in this pattern of events stimulated similar responses in all mothers.

<u>Maternal Responses to Illness</u>. Mothers reported a child's behavioral changes as the first sign of impending illness, frequently accompanied by fever for which they administered Tylenol. During this phase, each mother observed her child closely but did not report marked concern or alarm. Most mothers indicated that they compared present symptoms with previous illness experiences of their children. One mother stated,

He was irritable, pulling at his ears a bit like when he'd had an ear infection and not wanting to eat, then seemed to sleep more than usual...

Another mother reported,

She woke up from a very short nap - which is unusual, with a temperature.

<u>Maternal Responses to Worsening Illness</u>. The second phase was characterized by increasing severity of the child's symptoms, either gradually or preciptiously, and the ineffectiveness of Tylenol to relieve fevers. These factors prompted mothers to phone their pediatricians for additional assistance. All five children were seen and examined by their individual pediatricians promptly following the phone call. Three children were seen in the doctor's office and quickly sent to the local emergency room for further tests. The remaining two mothers were instructed to take their children directly to the emergency room where they were met by the pediatrician. In the words of one mother,

I called the doctor because of his fever and he wasn't eating like he usually does. The doc told me to meet her in the ER because of the temperature.

The mother of a 17 month old reported,

He'd been a bit more fussy then had a low temp. Ι called the doctor and she saw him and said it was an ear infection so she prescribed amoxicillin. He was better for a day or two then his temp came back and he was cranky and I noticed his chin or cheek ... looked a bit puffy but I didn't think too much of it because he had fallen and banged his chin when I had my back turned for a minute...so I thought it was bruised. But the next morning there was a definite red spot along his jawline, it was puffy and not bluish at all like a bruise and his fever was 102 and he wouldn't eat and was very crabby even after Tylenol. So I called the doctor and we went right to the office and straight here to hospital - she called ahead to tell them he had ear infections and a cellulitis and he needed blood tests and antibiotics.

A third mother stated,

She was real hot one night...about 2 AM. I took her temperature - it was 102, so I gave her some Tylenol she went back to sleep, I went back to sleep - the next morning it was a little higher. I called the doctor and he said "bring her in" [to the office].

Of note during these examinations is that not one of the five mothers thought her child might be admitted to the hospital. When questioned about having suspected her child might be hospitalized, mother's responses ranged from not having considered it at all to brief thoughts of the possibility once on

the way to the emergency room. As one mother said,

I really didn't think he was that sick...but when we got to the hospital and the doctor said she wanted to do a bunch of tests, I thought she might be considering hospitalizing him.

Another responded,

Well, I can't say I had any suspicion but I started to feel afraid...

While another reported,

It never crossed my mind he would be hospitalized...

Even the mother whose child had convulsed at home stated,

I had a feeling...after she had that seizure --- that's not normal. So, I had a sense something was gonna' happen.

Upon confirmation of severe illness and recommendation that the child be admitted, mothers expressed a variety of mixed feelings including shock, fear, confusion, anger, self-doubt, guilt, and relief. As one mother stated,

I guess I was upset but on the other hand I was relieved knowing she'd be getting good care. So, I felt a heavy burden but I also felt a little more secure than when she was home.

A second mother's reply suggested guilt.

I felt terrible, I thought I had missed an important indicator that would have let me know my son was sicker sooner.

Another mother's comment revealed fear, self-doubt, and anger.

Well there's lots of feelings...like a failure as a mother. Somehow I should have been able to prevent my baby from getting sick...angry...scared...really scared

for my baby.

In addition to these emotions, mothers were also ambivalent about the recommendation for hospitalization. Each mother reported that she was not certain her child was actually sick enough to warrant admission. One mother commented,

He didn't seem all that much sicker than he has with other ear infections.

Another mom mused,

I'm not sure. At that point I don't think I thought about it. Just sort of accepted what the doctor said. We're taught to agree with what doctors tell us.

A third mother said,

No, I really didn't think he needed to be hospitalized then; I didn't really think this was so bad.

Maternal Responses to Emergency Admission. Actual admission

to the pediatric ward and initiation of treatment constituted the third phase. Here again mothers' responses, though wide ranging, were similar. In contrast to earlier doubts concerning the need for admission, once on the ward, mothers recalled feeling fear and a sense of urgency to begin treatment. In many instances, these feelings appeared to be based on a mother's interpretation of staff behaviors. According to one mother,

The nurses seemed in a rush and quickly put us in a room and said we had to be isolated.

Another mother commented,

When we first came up here, things were being done for her immediately...it wasn't being put off...afraid. I was afraid for her. Probably there were other things but the fear is what stands out. A third mother noted,

They [the nurses] asked me all sorts of questions and people came in and out to draw blood and start an IV and weigh him - it was very busy and confusing.

For some mothers the urgency was coupled with a perception of a slowed sense of time and concern that everything was "taking too long".

These feeling were summed up well by one mother,

I mostly remember them trying to find veins in her to draw blood, to give her a push on the antibiotics, give it to her immediately and that was scaring me cuz' it was taking so long...that's what I remember, sitting there...it seemed to take forever.

Finally, all mothers repeatedly expressed feeling confused, frustrated, and "in the way" during ward admission. Simultaneously, these mothers also desired to help their children but were not certain of how to do so. One mother recalled,

I just wanted to understand what was happening and what I could do, how I could help...I sort of felt like I was in the way - like it would be better if I left for awhile till things settled down some.

Another mom stated,

I wanted to make my son feel better and there didn't seem to be anything I could do to help him.

Yet another mother commented,

I was still pretty stunned...you feel a little bit lost ...it's a pretty alien environment. I really felt out of my element. I think the worst feeling I have besides feeling bad about my baby, is a little lost.

Theme Two

Maternal Perceptions of the Effects of Illness on the Child

At the time mothers were interviewed, no child's diagnosis had been positively confirmed. Each mother indicated that she had understood the rationale for and had consented to admission, diagnostic testing, and treatment for her child. However, ambivalence again characterized mothers' responses as consents seemed to be tentative in nature pending definitive diagnosis. One mother recalled.

The doctor said he needed blood tests to confirm the cellulitis...which can spread rapidly and damage lots of tissue and skin and the only way to control it certainly would be with IV's and antibiotics and that was best done in the hospital. It seemed very logical but I didn't know what to think really - it wasn't until I got to the hospital that I began to wonder if it was true or necessary - he doesn't seem that much sicker or maybe I just don't want to believe that he is - I'm just worried about him - I want him to be 0.K.

Without exception, mothers remained firmly focused on the health care team's efforts to accurately diagnose and initiate appropriate treatment so that the child would be restored to health and normalcy. One mother stated these concerns well,

I just wanted to get her to the hospital, find out what it [illness] is and get it correctly treated immediately.

The lack of a definitive diagnosis, while the focal point of concern, was also the source of considerable anxiety and uncertainty for mothers, particularly regarding outcomes. Reflected in the mother's perceptions of the effects the illness might have on her child were fears of residual deficits, especially brain damage or retardation, chronic illness, or even death. One mother clearly expressed these feelings,

The doctor told me he believed the first battery of tests - they'd find it immediately, what was causing the fever and change in temperment and enlarging of the spleen...and they could immediately start giving her something for it some medication and he preferred to do that at least initially in the hospital. I started thinking of the worst things that can happen. And I alternately went back and forth between what's worse: having this be terminal or having her be - something wrong with her for the rest of her life? They're equally bad when you're looking at them from this side. I don't know if they're equally bad when one hits them. So, a lot of different feelings - all negative.

Mothers were also frightened by the physical and behavioral changes they witnessed in their children. Furthermore, these mothers were distressed by their own inability to determine if these changes were due to the child's illness or other causes. As one mother stated.

I don't know how to tell if he's thirsty and it seems to hurt him if I hold him.

Another mother described these entangled concerns well,

She kept falling asleep and waking up and had out of focus [eyes]. It was hard for me to see what she was going through...I was afraid for her because I didn't know what was going on and what to expect and what happened or having to go through it all again.

Overall, speculating about the possible effects of illness was painful and difficult for mothers. Not knowing the source of illness nor really understanding the changes in their children provoked many feelings of anxiety and uncertainty about prognosis. These feelings were summarized quite well by the following two mothers, I'm really scared he won't be the son I've grown to know and love when this is over - and, if he's not 0.K. - I don't really know, I can't think about that yet.

And the other,

Well, I think I'm waiting for someone - I feel she's going to be fine, but I am waiting for a doctor to say she's gonna' be fine and I haven't heard that yet.

# Theme Three

# Perceptions of the Effects of Illness on the Mothering Role

Responses to questions concerning the effects of illness on the mothering role were multifaceted and revealed several specific factors that influenced a mother's ability to care for her ill child. Many mothers shared the beliefs that a child's illness was a direct reflection upon the quality of mothering skills; that a mother is responsible for her child's health and should be able to prevent illness. Mothers who hold these assumptions tend to experience role conflict or insufficiency. One mother was quite emphatic in her assessment of her role insufficiency,

Like a failure as a mother. Somehow I should have been able to prevent my baby from getting sick. Kinda' like a victim - this shouldn't have happened to me.

The uncertainty implied by the reference to feeling victimized was well-described by the mother whose son had otitis and cellulitis. She admitted feeling "confused and guilty and inadequate somehow" about her son's illness, "that I should have known better". Though no mother had previously experienced a child's illness requiring hospitalization, each mother believed she should remain with her child and wanted to do so. These beliefs reflect mothers's desires to maintain or regain role stability. All mothers indicated they were relatively comfortable in remaining with their children as well. For one mother this was enough, just to be with her daughter, "being able to be here while everything was going on".

A few mothers, while certain they wanted to continue providing care to their children, were uncertain how to do so. This uncertainty arose from unfamiliarity with the setting and the inability to accurately interpret an ill child's behavioral cues. One mother felt she was on the sidelines, watching but not participating. She recalled,

I thought she got a lot of attenion and as much as could be was being done for her. It was very hard those first couple of hours, adjusting, just being up here.

A second mother was acutely distressed,

I don't know here in the hospital what the best things for me to do are - they seem to be leaving it all up to me to figure it out though they do seem to think I should be able to comfort and calm him - when he cries they ask me what I think, if I want to hold him or if he's thirsty - I don't know how to tell for sure....

The sense of faltering in carrying out usual mothering behaviors in the hospital was beautifully summed up by this mother:

I want to hold her but I'm afraid I'll do something wrong. I've been taking care of her all this time, but suddenly I'm all thumbs. And, maybe I'll get in the way of what they're trying to do for her. Especially the I.V....an I.V. on <u>me</u> makes me afraid to move. On somebody else, especially my baby...what if I touch her wrong and make that hurt?

A conflict between maternal needs and the ill child's needs influencing the ability to continue mothering was identified by three mothers. The gist of this conflict hinged on these mothers' acute awarenesses that their own physical and emotional well-being clearly affected their mothering abilities. The two primary concerns cited by these mothers were fatigue and the need for emotional support. Reflected in these concerns was the struggle mothers had trying to balance multiple role demands to meet their own needs, those of their ill children and also other family members. One mother stated,

Here I am, obviously very pregnant, with a crabby, sick son. I'm worried and tired and uncertain of what to do...if even just one person had just let me talk a few minutes so I could begin to sort through all this. I just wanted to tell someone how it had been for me.

Another pregnant mother was quite concerned about the possibility of her unborn child contracting the same illness as her older child. This particular mother was also exhausted and very aware that her husband could be of support to her. As she indicated,

I really wanted both my husband and I to stay [in the hospital] I needed my husband and our son needed us both.

A third mother, who had an older preschool child at home, was quite graphic in the description of her emotional state and her perception of how it conflicted with her ability to meet her ill child's needs. This mother also depicted the young child's extreme dependence upon mother as the primary source for need satisfaction.

It's like I'm raw. For the past few hours, everytime she's cranked or cried or whined, there's two buttons inside me that both get pushed at the same time. One is 'Oh my God - it's because she's sick and I've got to baby her all the more', and the other is 'Dammit, just let me cope! Stop! Don't do this to me now.' That rawness - that's <u>me</u> - if you need proof, she's just as vulnerable as ever, here it is to smack you right in the face. How much she needs me. How much she <u>needs</u>, period. Not just <u>me</u>....It intensifies my awareness of how tight that bond between she and I is because I can understand her when other people can't.

Despite the severity of her child's illness and the uncertainty of prognosis, each mother reflected about her future behavior as if her child would be completely healthy and normal. Most mothers thought their own behavior would change very little. These mothers believed they would be more attentive to behavioral changes, fevers, or other signs of impending illness in their children. If these changes occurred, mothers thought they would be anxious, nervous, or afraid but that they would adjust. As one mother remarked,

I will probably be more concerned in the future when he's not eating his usual way or is listless or has a fever.

Commented a second mother,

For a while I'll be really uptight everytime she has a fever or whatever, but that'll wear off. If its something serious she's caught, I can see myself living in fear of her catching anything. I can see myself being overprotective and having to remind myself that the child has to live, has to be around people.

Considering future behavior also brought to the forefront many emotions for these mothers. Every mother was quite certain that her child's illness would influence her feelings far more than her actual behavior. One mother stated,

If he comes out of this intact, I think I'll be very nervous whenever he doesn't seem like his usual self but I don't think I'll spoil him or be overprotective maybe just more appreciative and aware of how fragile life really is -

Another mother mused,

I have lots of feelings. I should be more grateful to have basically a healthy child and an active and smart little person. Yes - grateful to have her.

# Theme Four

#### Perceptions of Nurse Roles

Throughout the interviews, mothers repeatedly mentioned nurses, particularly in relationship to maternal roles. Nurses were viewed as authorities on mothering by these mothers and mothers expected nurses to share their knowledge and expertise with them. These mothers were also sensitive to nurse's opinions of their mothering abilities and concerned that nurses saw them as good mothers. As a pregnant mother stated,

I'm worried that I've somehow jeopardized my child's health and I wonder what the nurses think - you know, they are the real experts about mothering.

#### And another mother remarked,

They [the nurses] want me to be here and help my son and I'm not really sure how to do this. No one has told me anything yet.

Another mother was concerned that the nurses weren't assisting her enough with her child. She commented,

I really wish there was someone - one of the nurses they really know an awful lot about children - maybe they could tell me what would be best but they seem to be leaving it all up to me to figure out.

While another mother's experience was quite the opposite as she recalled,

I explained to one of the nurses that she doesn't take medicine well orally and the next thing I knew they had her medicine as a suppository. Whatever they could do to make it easier, they were doing.

Generally mothers considered the nurses responsible for the technical aspects of care and expected them to be knowledgeable and competent. Mothers also relied on nurses for support and information. In addition, mothers looked to nurses for help in understanding procedures and tests, and were grateful for this help. The positive responses mothers had to assistance from nurses is reflected in the following remarks.

The night nurse was especially helpful in explaining the tests and how long we had to wait for culture results and how the antibiotics worked.

Stated a second mother,

When I asked questions of the nurse, they were explained to me to the fullest extent and I really did appreciate that...so then I didn't feel funny about asking any more questions after that. And I think, I will not be afraid to do that in the future. That was a good learning process for me.

Mothers seemed to have certain standards about nursing care and were disturbed by perceived variations in nurses' competency levels and lack of interest in their welfare. More so, mothers were particularly distressed by inconsistencies in nurses' expressions of genuine concern for both mother and child. One mother explained,

They [the nurses] are all very skillful and efficient and very nice to us but maybe a little distant - still feels rather routine or no big deal and it is a big deal to me...they explained procedures, the phones, roomingin, meals, his care, the usual stuff that goes on like temperatures, mealtimes - all that...but no one asked how I felt...

As another stated,

I wasn't real impressed with him [male nurse]. At the time, I didn't think that but after having other nurses I thought were more competent, I have to say I wasn't real impressed...what bothered me is that he wasn't trying to make my husband or I comfortable in the least. I felt like he was here just to do the basics - it just didn't feel too good. But everyone else has been very helpful and I feel very comfortable with them.

Another mother replied,

Everyone [nurses] really seems to care but there's something missing or maybe they've been quite busy...I don't want my son sick or damaged but everyone focuses on him without acknowledging me and how I feel. Maybe its just cuz' he's so very sick.

A fourth mother was very clear about her perception of the mother-

child-nurse relationship,

So it makes me feel like when they're [nurses] not paying attention to me even though they're in the room and they're not actually paying that much attention to my baby either - why are they there? Don't just come in and do the thing and split. I don't feel that's doing anything for anybody, except maybe the mechanical aspect of caring for the child. There's no warmth, no care in that, and I think warmth and care are really important [for both mother and child]. Some mothers found these inconsistencies extremely difficult during the admission period when having to interact with so many people in a short period of time. One mother clearly believed that she had been helped by having one nurse who was "genuinely interested in me". This mother stressed further,

I think the admission process being what it is and all the people I've had to see, to have that one [nurse] that I feel is so caring and so aware of me and what's going on with me as well as my baby and what's going on with her. My tendency is to say boy I'm lucky to have that one person but...I don't think it should be that way. I think the one who <u>isn't</u> that way is the one who should stand out.

# Theme Five

## Maternal Perceptions of the Effects of Illness on Family

Each mother was interviewed within 24 hours of her child's Consequently, mothers reported that except hospital admission. for their husbands, little communication with other family members about the child's illness had yet transpired. In most cases. contact had been limited to notifying grandparents about the child's hospitalization. The sole exception was one mother whose husband was out of town on business. This mother planned to call her husband when she had preliminary test results which she Similar family reactions of alarm and confusion expected soon. over the suddeness of the child's illness and hospitalization were noted by mothers. Additional responses included worry and fear but also relief that the child was being treated.

Overall, mothers expected to receive support and assistance

from their families. Some mothers reported that family members, though upset, had been quite reassuring, which they appreciated. A few mothers, however, found themselves giving support instead of receiving it, especially to grandparents. As one mother remarked,

It seemed like I was doing a lot of reassuring instead of being reassured which wasn't particularly helpful at the time.

Conversely, husbands were reported to be very supportive and grateful that their wives were good mothers. In fact, some mothers believed their husbands' opinions of them as good mothers had been positively reinforced as a result of the illness; how efficiently they had gotten care for the ill child. One mother captured these thoughts well,

He [husband] seems to think I'm a good mommy all the time. But when we have to cope with a crisis or something major, it seems I go up in his estimation. I'm a <u>better</u> mommy, instead of those things making it worse.

A few mothers expressed concern in dealing with their own mothers or their mothers-in-law due to previously experienced disagreements over child care practices. Commented one mother,

It's hard sometimes with a mother-in-law, she doesn't interfere really but sometimes I think she disapproves of how I handle things even if my husband and I are in agreement.

Although mothers were concerned about these possible encounters, most dismissed them rather quickly. One mother summed it up neatly,

I'm aware that I'm a bit edgy or on guard - that perhaps

my mother-in-law will try an 'I told you so' of some sort in a few days but I really can't think about that presently. If it comes up, I'll just have to deal with it.

# Summary of Interview Themes

The data collected by the MPEHI revealed several concerns and perceptions of mothers experiencing the emergency hospitalization of an ill preschool child. Data analysis demonstrated that mothers uniformly encountered a linear progression of events beginning with illness onset and care of the child at home and culminating with the child's emergency hospitalization. In addition to this objective pattern of events, the accompanying emotional responses described by mothers strongly suggested that mothers experienced an involuntary role transition.

Further exploration and analysis of maternal concerns and perceptions disclosed several factors which influenced a mother's responses and adjustment to this role transition. Included among these factors were: the degree of perceived responsibility for the child's illness, perceived severity of illness, uncertainty of child's behavioral cues, fear of negative outcomes, ambivalence toward nurses, disruption of customary mothering behaviors, and concern for welfare of self and other family members. The implications and limitations of these findings is further addressed in Chapter 5.

# Results of Feetham Family Functioning Survey

The FFFS is designed to measure three areas of family

functions as relationships between: the family and broader social units, the family and its subsystems, and the family and each individual. The survey contains a total of 21 indicators of family functioning such as amount of emotional support from spouse, time spent doing housework, and amount of talk with friends about concerns or problems. The multiple response format using a 7-point scale requires that the respondent rate each indicator according to: "what is" (a), "what should be" (b), and "the perceived value" (c). In addition, a discrepancy score (d) representing the degree of satisfaction with each indicator can be obtained by assessing the amount of difference between the ratings assigned to "what is" and "what should be" (a - b = d).

The only normative data presently available for comparison of FFFS scores are those of 103 mothers of children with chronic myelodysplasia (see Table 3). The means and standard deviations of scores for the 5 mothers of ill preschool children in this study are depicted in Table 4. Mothers' scores in this sample were compared with the scores of mothers of children with chronic myelodysplasia using the Mann-Whitney U-test. Data analysis revealed no significant differences between the scores of mothers of chronically ill children compared to mothers of acutely ill preschool children ( $\underline{U} = 0$ ,  $\underline{p} = .05$ ).

The Mann-Whitney U-test was also used to analyze differences in discrepancy (d) scores and various demographic characteristics of mothers of ill preschool children. Discrepancy (d) scores for each scale of family functioning as well as total  $\underline{d}$  scores were compared for pregnant versus non-pregnant mothers, working versus non-working mothers, and child's birth order (youngest versus oldest or only child). No statistical significance was demonstrated in any of these comparisons.

Scale 1			Scale 2			Scale 3	
Relationship between family and each individual member			Relationship between family and sub- systems			Relationship between family and broader social units	
Item Time with spouse	IX	Я	Item Talk with friends and relatives	١×	Я	Item Time with health wrofessionals	۲×
იი ი ი	4.51 5.70 6.19	1.56 1.07 1.18 1.46	and traditions by a by the second sec	3.97 4.85 98	1.74 1.81 2.00 1.38	риссо С С С	3.67 1.65 3.94 1.74 5.49 1.79 .75 1.02
Discuss concerns with spouse b c d	5.01 6.13 1.27	8.11.1.8	Time with neighbors a b c d	3.01 3.01 85	1.27 1.38 1.13	Problems with other children b c d	
Help from spouse a b c d	4.49 5.09 1.05	1.71 1.29 1.52 1.37	Time in leisure/ recreational b c d	3.15 4.42 4.67 1.37	1.33 1.65 1.44	Ocher children miss school a b c d	1.46 1.52 1.50 .91 5.45 2.42 .39 1.04
Time with children a b c d d	4.78 5.30 6.12 .61	1.61 1.37 1.24	Help from relatives a b c d	2.71 3.35 .88	1.91 1.74 1.31	Time your child was ill a b c d	1.74 1.16 1.35 .62 5.26 2.39 .53 .92

Table 3. Means and Standard Deviations For Each Item Subscore Comprising the FFFS 105 Mothers of Children With Myelodysplasia 87

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family and sub-systems         family and sub-systems         family and broadersystems         family and broadersystems           2.71         1.39         a $2.47$ 1.67         a $1.46$ 2.01         1.05         b $2.47$ $1.67$ a $1.46$ 2.01         1.05         c $3.18$ $2.04$ $1.67$ a $1.46$ 5.46 $1.72$ d $6.5$ $9.9$ $2.51$ $1.46$ $3.31$ $2.04$ $6.6$ $3.47$ $1.67$ $a$ $1.46$ $6.52$ $.98$ $1.22$ $d$ $.65$ $1.72$ $a$ $1.46$ $6.52$ $.98$ $1.22$ $1.60$ $1.51$ $d$ $.34$ $1.60$ $1.51$ $d$ $.29$ $1.22$ $1.23$ $0.50$ $6.52$ $.99$ $0.104$ $0.22$ $0.12$ $0.124$ $0.250$ $1.60$ $1.51$ $0.22$ $0.123$ $0.22$ $0.123$ $0.233$ $0.231$	vate 1 Relationship between			scale z Relationship between			scale 3 Relationship between		
$ \begin{array}{c ccccccccccccccccccccccccccccccccccc$	family and each individual member			family and sub- systems			family and broader social units	۲.	
2.71 1.39 a 2.47 1.67 b 2.55 1.40 c 2.55 1	Disagreements with			Help from friends			Spouse misses work		
5.42 2.01 c 3.18 2.04 c 5.01 .97 1.32 d 5.104	b b b	2.71 2.01	1.39 1.05	م ھ	2.55 2.55	1.67 1.40	م ھ	1.48 1.41	1.15 .89
Time in household tasks 6.32 .96 1.72 a 4.47 6.56 .87 c 4.94 6.56 .87 c 4.94 6.65 .87 c 4.94 7 Time miss housework 5.64 1.50 a 2.29 6.66 .80 b c 4.69 6.66 .80 b 2.26 6.66 .80 d 2.29 1.04 1.50 d 2.29 6.66 1.150 a 4.95 5.64 1.50 a 4.95 6.66 1.150 a 4.95 6.66 1.150 a 4.95 7.6 7.6 7.6	רי ט	5.42 .97	2.01	с, гр	3.18 .65	2.04 1.04	σc	5.07 .34	2.17 .87
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6.32 .96 b 6.56 .87 c 1.60 1.51 d 1.60 1.51 d 5.64 1.50 a 6.66 .80 b 6.66 .80 b 6.66 .80 c 6.66 .80 b 6.66 .80 c 6.66 .80 b 7.66 6.66 1.150 d 7.66 6.66 1.190 d 7.66 7.69 c 6.66 1.190 d 7.60 c 7.60 c	and inter-	5.46	1.72	E)	4.47	1.52			
6.56 .87 c 4.94 1.60 1.51 d c 4.98 5.64 1.50 a 2.29 6.46 .80 b c 4.69 6.63 .81 c 4.69 1.04 1.50 d 2.05 6.64 1.70 a 4.53 5.31 1.70 a 4.53 6.04 1.19 b 4.53 5.33 1.41 c 4.69 6.64 1.10 d 2.52 5.33 1.41 c 7.60 6.64 1.10 a 4.53 6.64 1.10 a 4.53 6.64 1.10 a 4.53 6.64 1.10 a 6 7.60 76 1.10 1.46 6 6 6 6 6 7 1.50 a 7.50 76 1.50 a 7.56 76 1	Ą	6.32	8.	Ð	4.35	1.33			
Time miss housework 5.64 1.50 a 2.29 6.46 .80 b 2.05 6.63 .81 c 44.69 1.04 1.50 d 2.05 8.531 1.70 a 4.53 6.04 1.19 b 4.53 5.33 1.41 c 7 4.53 6.04 1.19 b 4.53 5.62 1.41 c 7.66 1.01 1.46 d 7.56 7.67 7.67 7.67 7.67 7.67 7.67 7.67 7.67 7.67 7.67 7.67 7.67 7.67 7.67 7.67 7.67 7.67	סיט	6.56 1.60	<b>.</b> 87 1 <b>.</b> 51	ט ט	4 8 8	1.81 1.02			
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5.04       1.30       a       2.25         6.46       .80       b       2.05         6.63       .81       c       4.69         6.63       .81       c       4.69         1.04       1.50       d       2.05         5.31       1.70       a       4.53         6.04       1.19       b       4.53         5.33       1.41       c       5.62         1.01       1.46       b       4.53         5.33       1.41       c       5.62         5.03       1.41       c       5.62         76       1.01       1.46       d       76	arriage	i L	ç L		8	1 1 7			
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Support from friends 5.31 1.70 a 4.53 6.04 1.19 b 4.92 5.93 1.41 c 5.62 1.01 1.46 d 7.76	đ	1.04	1.50	q	•23	16.			
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1.01 1.46 d .76	ט ב	5.8	1.41 1.41	ں <del>د</del>	5.62	1.64			
	q	1.01	1.46	q	.76	1.28			

Table 3 - continued:

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lard Deviat	FFFS 5 Mot	
s and Stan	rising the	sy Basis.
able 4. Means and Standard Deviations For Each Item	ubscore Comprising the FFFS 5 Mothers	an Emergency

Table 4. Means and Standard Deviations For Each Item Subscore Comprising the FFFS 5 Mothers of Children on an Emergency Basis.	ndard D e FFFS (	eviations Fo 5 Mothers of	r Each Item Children					
Scale 1			Scale 2			Scale		
Relationship between family and each individual member			Relationship between family and sub- systems			Relationship between family and broader social units		
Item Time with sponse	١×	Я	Item Talk with friends	١×	ы	Item Time with health	<b>ا</b> ×	6
			and relatives			professionals		
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υ	6.8	4.	υ	5.4	1.67	U		80
đ	1.4	2.60	q	•	<b>8</b> .	q		2.60
Discuss concerns with some			Time with neighbors			Problems with other children		
69	5.4	1.14	Ø	1.8	1.30			3.04
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U	<b>6.</b> 4	1.34	U		1.30	U		20
q	1.0	1.00	q		1.30	q		1.34
Help from spouse			Time in leisure/ recreational			Other children miss school		
Ð	4.4	1.94	σ		88	σ	•4	Ъ,
Ą	5 <b>.</b> 8	ଞ	Ą	3.8	1.78	, A		5
U	5.6	1.34	U		2.19	U	2.8 3	8
q	1.6	2.50	q		2.04	q		I
Time with children			Help from relatives			Time your child was ill		
c	4.	۲ <u>.</u>	8		2.44	60		.48
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5		3	3		60 <b>•</b> T	3		ţ

Scale 1			Scale 2			Scale 3		
Relationship between family and each individual member			Relationship between family and sub- systems			Relationship between family and broader social units		
Disagreements with			Help from friends			Spouse misses work		
spouse a b	2.4 1.4	1.14 .54	م ھ		2.60 2.16	യ ഫ	2.4 3.0	2.56 2.54
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Emotional support from spouse a b c	6.6 7.0 7.0	ي <mark>ن</mark> ا ا	Time in household tasks a b c	2.8 4.0	2.48 1.51 3.00			
d Satisfaction with	<b>4</b> .	¥	d Time miss housework		1.34			
marriage a c d	6.2 7.0 .8	891189	ൽ എ ധ എ	2.4 2.4 1	2.60 2.56 1.54			
Satisfaction with sexual relations a b c d	5.6 6.6 1.0	2.07 5.47 1.34 2.23	Support from friends a b c d	2.4 2.6 2.6	2.60 2.16 1.87 2.19			

Table 4 - continued:

#### CHAPTER V

#### DISCUSSION

This exploratory-descriptive study, based on constructs of role transition theory (Meleis, 1975; Allen and VandeVliert, 1982), addressed the question:

What are the perceptions and concerns of mothers immediately preceding and during the emergency hospitalization of an ill preschool child?

Additional study aims included exploring the possible impact of these concerns and perceptions on the mothering role and family functioning.

#### Significance

During the interviews, mothers described a fairly uniform progression of events strongly suggestive of involuntary role transitions. The events circumscribing this role transition demonstrated that it has three distinct objective phases. The first phase is marked by the onset of the child's illness and care of the child at home by mother. Characterizing the second phase is a worsening of the child's illness and ineffectiveness of home treatment prompting mothers to contact the pediatrician for assistance and emergency evaluation of the child. The third and final phase of this transition is the ill preschool child's emergency admission to a pediatric ward for diagnostic testing This pattern of events is similar to that and treatment. described by Meleis (1975) as an involuntary health - illness role transition.

In addition to the objective role transition outlined, mothers also experienced similar emotional and behavioral responses to each of the three phases previously described. Study results demonstrated that mothers are very observant of their preschool children and noted behavioral changes as an early sign of impending illness to which they responded with heightened awareness but not alarm. The occurrence of fever, vomiting, or other physical changes prompted mothers to treat with over the counter drugs and even closer observation.

Worsening of the child's symptoms and/or non-responsiveness to home remedies, caused concern and led mothers to seek professional assistance. Though children in this study were pediatricians recommended acutely **i**11 and immediate hospitalization, mothers had considerable difficulty believing their children were so severely ill that hospitalization was warranted. Interview data also revealed that mothers experienced increasing uncertainty, anxiety, and fear over the need for hospital admission. The pattern of mothers' emotional responses, moving from apparent confidence in performing the mothering role home to marked emotional distress upon the child's admission, at is characteristic of the gap between the completion of objective and psychological aspects of an involuntary role transition (Allen & VandeVliert, 1982). Although results of this study are

limited by small sample size, mothers' perceptions and concerns also strongly suggest that they may be at risk for maternal role insufficiency (Meleis, 1975).

Descriptions of the actual admission process suggest that it is very confusing for mothers and generates considerable anxiety as a result. Mechanic (1964) and Buckman, et al (1957), in separate exploratory studies with parents of children electively admitted, found that mothers experience considerable anxiety over a child's admission and do not know what to do in the strange and unfamiliar hospital environment. While mothers did experience relief that the child's illness was being treated, mothers were overwhelmed by the sheer volume of people, procedures, and questions with which they had to deal very rapidly. Mothers in this study, as in an earlier pilot study (Dawson, 1984), were worried about whether they had made appropriate decisions also to insure the child's welfare, and were extremely uncertain about how to help the ill child in the hospital. Mothers also relied heavily nurses during admission quite upon to provide information, support, and guidance as to how they could adjust and help their children likewise. These findings are similar to those found by Bright (1965) and Mahaffy (1965) in exploratory and experimental studies of mothers whose children were admitted on an elective basis. These investigators independently reported that mothers are very anxious on admission and look to nurses for support and information. Mahaffy (1965) also found that the

support of a nurse during the admission process greatly reduced mothers' anxiety and facilitated the assumption of the maternal role in the hospital. In a pilot study that compared the behaviors exhibited by parents of emergency admitted children with those of electively admitted children, Roskies, et al (1975) found that although both groups of parents were anxious to the point of being unable to continue parenting their hospitalized children, this anxiety was considerably more extreme for parents the emergency group. Additional results from this study in showed that while parents in the emergency group turned to nurses for assistance, nurses were often unable to provide this due to the urgency of attention required by the children. In the present study, mothers of ill preschool children also reported that frequently the nurses were unavailable to help them but when they were available, mothers experienced a considerble decrease in anxiety and an increased ability to participate in their children's care.

Results of this study suggest that mothers confronted with the involuntary role transition imposed by the emergency admission of an ill preschool child experience some degree of maternal role insufficiency. Role insufficiency is characterized by acute cognitive distress marked by confusion, uncertainty, and perplexity resulting from the perceived incongruence between customary role behaviors and situational expectations. This incongruence may arise from poor role definition, disparity between the adequacy of self and role expectations of others, misinterpretation of role expectations, or impaired or absent role behavior cues from others. Allen and VandeVliert (1982) state that these disparities become most pronounced when an individual continues to occupy the same role but the expected behaviors associated with it change dramatically.

The mothers of preschool children in this study certainly continued to occupy the maternal role upon a child's emergency However, study findings demonstrated that these admission. mothers were no longer certain how to assess or interpret an ill child's behavioral cues, and were distressed by the disruption of customary mothering behaviors due to unfamiliar surroundings and routines. Mothers in this study were also anxious, fearful of negative illness outcomes, guilty over the degree of perceived responsibility for the child's illness, and perplexed by the sudden severity of illness. These emotional responses are quite characteristic of the indicators of role insufficiency (Meleis, Lastly, mothers were tired, concerned with their own and 1975). family welfare which produced conflicting feelings such that their abilities to adjust to a role transition were even further compromised.

Although the sample size was small and restricted to mothers confronted with an ill preschool child's emergency admission, many findings in this study were similar to previous study results of the factors influencing mothers' adjustment to a child's elective hospitalization (Prugh, et al 1953; Campbell, 1958; Mechanic, 1964; Bright, 1965; Mahaffy, 1965; Buckman, et al 1968; Roskies, et al 1975). Exploring the specific concerns and perceptions of mothers provides new and additional insights into the experiences of mothers particularly concerning maternal role function under the conditions of a preschool child's emergency admission. One unique finding is that these mothers clearly undergo an involuntary role transition. Secondly, mothers experience maternal role insufficiency. A final finding of note is the profound reliance of these mothers upon nurses to support and guide them through the role transition and the experience of role insufficiency.

Results of the FFFS (Feetham and Roberts, 1982) revealed no significant differences between the scores of mothers of children with chronic myelodysplasia and the scores of mothers in this study. There are several possible explanations for the nonsignificance of differences between the normative sample and the study sample. The FFFS has not been tested in families of children who are acutely ill, greater than 18 months of age, or who have other chronic health problems. The children in this study, although similar in age to those in the normative sample, were neither chronically ill nor could they be considered normal since they were acutely ill. Logic suggests then, that the FFFS

may not be sensitive to changes in families experiencing a child's sudden acute illness.

Comparisons of discrepancy scores with various demographic characteristics among mothers in the study sample also failed to demonstrate any significant differences. Nonsignificance in discrepancy scores could be due to the homogeneity of the study sample, the small sample size, or the timing of administration of the FFFS in this study. The brevity of elapsed time between admission and FFFS administration may mean that it was simply too soon for mothers to recognize or assess possible changes in family functioning. Finally, it is also possible that the nonsignificant differences are due to chance alone.

# Limitations

The limitations of this study are listed and described below.

1. A small, homogenous, voluntary sample limits the degree to which external validity can be achieved which then reduces the generalizability of results.

2. The absence of controls for the type of illness, length of time child was ill at home before emergency admission occurred, family constellation, and socioeconomic status. These factors limit the extent to which study results can be generalized.

3. The one-time interview with each mother precludes verification of data for either completeness or reliability.

4. Participant response sets resulting from mothers believing they were expected to think, behave, or answer in specific ways.

5. The possibility of undetected investigator bias or error having all data collected by only one person although this does provide consistency in data collection.

6. Mothers consistently offered more detailed information about their spouses and their perceptions and expectations of nurses than was required by questions on the <u>MPEHI</u> addressing these topics. This suggests that some loss of information may have occurred which can decrease confidence in results and limit generalizability. Refining questions addressing spouses/partners and nurses would increase the sensitivity of the <u>MPEHI</u> to capture more discrete data, thereby improving tool reliability and validity of results.

7. The <u>FFFS</u> did not yield useful information in this study. Though the cause for this is uncertain, it may be simply due to small sample size rather than a reflection upon reliability and internal validity of the tool.

#### Implications for Nursing

In spite of the small sample size, the results of this study strongly suggest that nurses need to be aware that the circumstances of a child's emergency admission markedly amplify a mother's stress and anxiety. This then increases a mother's need

for support and active guidance from nurses involved in her child's care. Admission is a critical period, the events and interactions of which set the tone for a11 subsequent interactions. Nurses need to establish a caring, supportive relationship with a mother during her child's admission and involved with the mother throughout activelv remain the In particular, nurses need to provide accurate hospitalization. and adequate information about the hospital setting, routines, procedures, and especially changes in the child's condition. These measures would help decrease a mother's emotional and cognitive distress, facilitate a smoother role transition, and ease the experience of role insufficiency. In turn, a mother would be more able to actively participate in her child's care which may then lessen the child's emotional upset and promote a better adjustment to the hospitalization experience for her child. The net benefit of these nursing interventions for a mother may be the restoration of confidence in her mothering abilities and perhaps, enhancement of her sense of competence as a good mother.

### Recommendations for Future Research

The findings in this study, although limited in scope, indicate important issues that warrant further investigation. Several recommendations for additional research to maximize these findings have been outlined.

1. Replicate the study using a larger sample

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- a) drawn from a broader population to include mothers of preschool children who have been admitted on an emergency basis due to trauma and exacerbations of chronic illnesses in addition to acute illnesses; and, mothers of varying cultural, ethnic, and socioeconomic backgrounds;
- b) to further explore the incidence and indicators of maternal role insufficiency mothers experience under the condition of a child's emergency admission;
- c) to ascertain specific variables that influence the incidence and degree of maternal role insufficiency.

2. Design and implement a quasi-experimental study using role supplementation as a specific nursing intervention with mothers experiencing role insufficiency under the conditions of a child's emergency admission.

3. Design and standardize a survey or questionnaire to explore nurses' perceptions of mothers' adjustment to the hospital and continuation of the mothering role in the event of a child's emergency hospitalization and administer the tool concommitently with the previously described study.

4. Administer the FFFS as a test-retest instrument at

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admission and later in the child's hospitalization to explore possible utility for obtaining baseline data, measuring changes over time, and influence of nursing interventions on perceptions of family functioning.

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Demographic Profile

# Demographic Profile

1.	Interview	number:		
2.	Date:			
3.	Diagnosis	:		
4.	How long	was child ill before	admission:	
5.	Child pre	viously hospitalized	: Yes	§
			No	
6.	Reason:	Other		
		Planned surgery		
		Illness		
		Injury		
7.	When:			
8.	Child's a	ge:		
9.	Child's s	ex:	F	
			М	
10.	Child's o	rdinal position:	youngest	
			middle	
			oldest	
			only	
11.	Mother:	Age		
		Occupation		
		Education		
		Currently working:	No	
			Yes	

		Presently	pregnant:		No	
					Yes _	
12.	Father:	Age				
		Occupation	ı			
		Education				
		<b>Currently</b>	working:		No	
					Yes	
13.	Total num	ber of sibl	ings:			
14.	Number of	siblings 1	living at	home:		
15.	Sex and a	ige of each	sibling 1	iving at	home:	
thru				F	<u>M</u>	Age
24.						
				<del></del>	<del></del>	
					<del></del>	
25.	Total num	ber of olde	er sibling	s:		
26.	Total num	ber of your	iger sibli	ngs:		

27.	Sex and age of other household/family			
Thru	members living at home (e.g. grandparents,			
32.	stepfather):	<u>F</u>	<u>M</u>	Age
			·	
33.	Total number of family members living at hom	e:		
34.	Family income:	_		
		0ver	50,000	
		40 -	50,000	
		30 -	40,000	
		20 -	30,000	
		10 -	20,000	
		Under	10,000	
35.	Race:	White		_
		Black		_
		Spani	sh	_
		Asian		_
		Other		_
36.	Shift of admission:	Day _		-
		PM		_
		Night		

37.	Day of admission:	
38.	STAFFING MATRIX:	RN
		LVN
		NA
		Other
39.	Acuity of child:	
40.	STAFF assigned to child:	

APPENDIX B

Maternal Perceptions of Emergency Hospitalization Interview

# Illness Transition

1.	How did your child's illness begin?
2.	Describe what happened that led you to contact the doctor/ER?
3.	Did you suspect your child would be hospitalized?
4.	When did you suspect this?
5.	What reason were you given for the hospitalization?
6.	How did you feel when you were told this?
7.	Did you think your child needed to be hospitalized?
8.	How sick do you think your child is - on a scale of $1 - 10$ ?
9.	Who explained to your child she/he would be hospitalized?
10.	How did you feel about the explanation?
11.	If you could do it over, is there anything you would do differently?
Sett	ing Transition
12.	What happened when you arrived on the pediatric unit?
12.	What happened when you arrived on the pediatric unit?
12 <b>.</b> 13.	What happened when you arrived on the pediatric unit? Were you separated from your child - for what reason?
12. 13. 14.	What happened when you arrived on the pediatric unit? Were you separated from your child - for what reason? What questions did you have?
12. 13. 14. 15.	What happened when you arrived on the pediatric unit? Were you separated from your child - for what reason? What questions did you have? Were these questions answered - by whom?
12. 13. 14. 15. 16.	What happened when you arrived on the pediatric unit? Were you separated from your child - for what reason? What questions did you have? Were these questions answered - by whom? Did the nurses solicit information from you about your child?
12. 13. 14. 15. 16. 17.	What happened when you arrived on the pediatric unit? Were you separated from your child - for what reason? What questions did you have? Were these questions answered - by whom? Did the nurses solicit information from you about your child? Do you think they valued what you said? How do you think the staff is handling the care of your child, on a
12. 13. 14. 15. 16. 17. 18.	<pre>What happened when you arrived on the pediatric unit? Were you separated from your child - for what reason? What questions did you have? Were these questions answered - by whom? Did the nurses solicit information from you about your child? Do you think they valued what you said? How do you think the staff is handling the care of your child, on a scale of 1 - 10?</pre>

22. What were you feeling during this time?

## Family\_Transition

- 23. Who did you notify about hospitalization?
- 24. What were their reactions?
- 25. How did they think you handled the situation?
- 26. How do you feel about their reactions?
- 27. What concerns do you have about other family members in considering their reactions?

Role Transition

- 28. In what ways has your child's illness affected your view of yourself as a mother?
- 29. In what ways do you think this illness has altered anyone else's view of you as a mother?
- 30. In what ways has this illness affected the manner in which you get along with your child?
- 31. In what ways has the illness affected your feelings toward your child?
- 32. In what ways do you think the illness will affect how you care for your child?
- 33. How comfortable are you to continue mothering your child in the hospital on a scale of 1 10?

APPENDIX C

FEETHAM FAMILY FUNCTIONING SURVEY

PLEASE CIRCLE THE NUMBER ON THE FOLLOWING SCALES WHICH REPRESENTS HOW YOU FEEL ABOUT THE QUESTIONS BEING RATED.

PLEASE TRY TO ANSWER ALL SCALES.

- The amount of talk with your friends and/ or relatives regarding your concerns and problems.
  - a. How much was there? Little 1234567 Much
  - b. How much should there have been? Little 1234567 Much
  - c. How important was this to me? Little 1234567 Much
- 2. The amount of time you spent with your
  - a. How much was there? Little 1234567 Much
  - b. How much should there have been? Little 1234567 Much
  - c. How important was this to me? Little 1234567 Much
- 3. The amount of discussion of your concerns and problems with your spouse/partner.
  - a. How much was there? Little 1234567 Much
  - b. How much should there have been? Little 1234567 Much
  - c. How important was this to me? Little 1234567 Much
- The amount of time spent with neighbors/ friends.
  - a. How much was there? Little 1234567 Much
  - b. How much should there have been? Little 1234567 Much
  - c. How important was this to me? Little 1234567 Much

- 5. The amount of time you spent in leisure/ recreational activities.
  - a. How much was there?
  - b. How much should there have been? Little 1234567 Much
  - c. How important was this to me? Little 1234567 Much
- 6. The amount of help from your spouse/partner with family tasks such as care of children, house repairs, household chores, etc.
  - a. How much was there? Little 1234567 Much
  - b. How much should there have been? Little 1234567 Much
  - c. How important was this to me? Little 1234567 Much
- 7. The amount of help from relatives (do not include your spouse) with family tasks such as care of children, house repairs, household chores, etc.
  - a. How much was there? Little 1234567 Much
  - b. How much should there have been? Little 1234567 Much
  - c. How important was this to me? Little 1234567 Much
- 8. The amount of time with health professionals (doctors, nurses, social workers, etc.) related to your child's health problems.
  - a. How much was there? Little 1234567 Much
  - b. How much should there have been? Little 1234567 Much
  - c. How important was this to me? Little 1234567 Myr<sup>1</sup>

- 9. The amount of help from your friends with family tasks such as care of children, house repairs, household chores, etc.
  - a. How much was there? Little 1234567 Much
  - b. How much should there have been? Little 1234567 Much
  - c. How important was this to me? Little 1234567 Much
- 10. If you don't have other children check here \_\_\_\_\_ and omit 11, 12, 13, and 14.
- 11. The amount of problems with your other children.
  - a. How much was there? Little 1234567 Much
  - b. How much should there have been? Little 1234567 Much
  - c. How important was this to me? Little 1234567 Much
- 12. The amount of time you spend with your children.
  - a. How much was there? Little 1234567 Much
  - b. How much should there have been? Little 1234567 Much
  - c. How important was this to me? Little 1234567 Much
- 13. If none of your children are in school, check here \_\_\_\_\_ and omit question 14.
- 14. The amount of time your other children missed school.
  - a. How much was there? Little 1234567 Much
  - b. How much should there have been? Little 1234567 Much
  - c. How important was this to me? Little 1234567 Much

- 15. The amount of disagreements with your spouse/partner.
  - a. How much was there? Little 1234567 Much
  - b. How much should there have been? Little 1234567 Much
  - c. How important was this to me? Little 1234567 Much
- 16. The amount of time your child has been ill.
  - a. How much was there? Little 1234567 Much
  - b. How much should there have been? Little 1234567 Much
  - c. How important was this to me? Little 1234567 Much
- 17. The amount of time you spend doing housework (cooking, cleaning, washing, yardwork, etc.)
  - a. How much was there? Little 1234567 Much
  - b. How much should there have been? Little 1234567 Much
  - c. How important was this to me? Little 1234567 Much
- 18. The amount of time you missed work (including housework)/
  - a. How much was there? Little 1234567 Much
  - b. How much should there have been? Little 1234567 Much
  - c. How important was this to me? Little 1234567 Much
- 19. The amount of time your spouse/partner missed work (including housework).
  - a. How much was there? Little 1234567 Much
  - b. How much should there have been? Little 1234567 Much
  - c. How important was this to me Little 1234567 Much

- 20. The amount of emotional support from friends and/or relatives.
  - a. How much was there? Little 1234567 Much
  - b. How much should there have been? Little 1234567 Much
  - c. How important was this to me? Little 1234567 Much
- 21. The amount of emotional support from your spouse/partner.
  - a. How much was there? Little 1234567 Much
  - b. How much should there have been? Little 1234567 Much
  - c. How important was this to me? Little 1234567 Much
- 22. The amount of satisfaction with your marriage/partner relationship.
  - a. How much was there? Little 1234567 Much
  - b. How much should there have been? Little 1234567 Much
  - c. How important was this to me? Little 1234567 Much
- 23. The amount of satisfaction with sexual relations with your spouse/partner.
  - a. How much was there? Little 1234567 Much
  - b. How much should there have been? Little 1234567 Much
  - c. How important was this to me? Little 1234567 Much

APPENDIX D

CONSENT TO BE A RESEARCH SUBJECT

#### CONSENT TO BE A RESEARCH SUBJECT

Janet Jaskula is a pediatric nurse who is conducting a study to find ways of making hospitalization easier for preschool children and their mothers. The study seeks to explore the concerns and experiences of mothers whose children have been hospitalized unexpectedly. Since I have a preschool child who was hospitalized for a sudden illness, I have been invited to participate in this study.

Participation in this study is voluntary. I may decline to participate or I may withdraw from the study at any time or refuse to answer any individual question without jeopardizing the services my child and I are currently receiving or may receive at this hospital.

If I agree to participate, I will answer a brief questionnaire and be interviewed by Ms. Jaskula shortly after my child is admitted to the hospital. The interview and questionnaire will take approximately one hour and I will be asked questions about what I experienced and felt when my child was hospitalized. The interview will take place in a private location on the pediatric ward. To insure accurate recording of information, a tape recorder will be used.

It is possible that some of the questions could make some mothers uncomfortable about expressing their concerns and feelings. After interviewing me, Ms. Jaskula will be present while I complete the questionnaire and remain available to discuss any concerns that may arise. Some mothers may also feel the time required to participate would be an inconvenience.

The information I give will be kept confidential. Code numbers will be assigned to subjects so my name will not appear on any information obtained from me. The names of subjects will be kept in a separate locked file so my confidentiality will be protected as much as possible under the law.

There may be no direct benefits to me or my child from participating in this study. The information I provide, however, may help other children and their mothers in the future.

I have talked with Janet Jaskula about this study and she has answered my questions. I can reach Janet at 661-7766 if I have any other questions. I have been given a copy of this consent and the experimental subject's Bill of Rights.

Signature

Date

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