THE EFFECT OF INTRODUCING PARENTS OF HOSPITALIZED CHILDREN TO THE NURSING MUTUAL PARTICIPATION MODEL OF CARE: A RANDOMIZED CONTROLLED TRIAL

by

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THE EFFECT OF INTRODUCING PARENTS OF HOSPITALIZED CHILDREN TO THE NURSING MUTUAL PARTICIPATION MODEL OF CARE: A RANDOMIZED CONTROLLED TRIAL

Objective: *Primary*: To determine if introducing the Nursing Mutual Participation Model of Care (NMPMC) to nurses and parents, compared to only nurses, will reduce parent anxiety at the time of their child's discharge following hospitalization. *Secondary*: To measure NMPMC's effect on mutual participation (MP) between parents and nurses; to determine if a relationship exists between parent anxiety and MP.

Methods: Parents of children 3 months to 12 years of age were randomized within 16 hours of admission to the hospital for an acute medical or surgical episode to receive usual hospital information (control) or usual information plus NMPMC information (treatment). Prior to randomization, all nurses on the unit were introduced to the NMPMC through videos, workshops, and written material. Nurses completed questionnaires on mutual participation at the beginning and end of the trial. Parents completed the Spielberger Trait and State Inventory at 1-16 hours after admission, the State Inventory at 16-24 hours, and the State Inventory and a MP questionnaire at discharge.

Results: Trait and state anxiety scores at admission and at 16-24 hours were similar in the 46 treatment and 45 control parents. At discharge, anxiety was significantly lower in treatment parents (M=29.0; sd=8.8) compared to controls (M=33.0; sd=8.9). Treatment parents reported significantly higher comfort levels in MP activities. However, anxiety scores were not correlated with MP scores at 16-24 hours or at discharge. Although nurses reported a moderate amount of change in their practice, no significant change in MP was found between their time 1 and time 2 measures. Nurses rated themselves significantly higher in the consistency MP subscale than did the control group of parents.

Conclusions: If nurses are introduced to the NMPMC and if parents are given the NMPMC information, parents will experience less anxiety at discharge, and have a higher level of comfort in MP activities compared to parents given usual hospital information. Further, parent anxiety and mutual participation, as measured in this study, are not related; nurses themselves rate themselves at a higher level of performance in MP behavior compared to parents who have not been introduced to the NMPMC.

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DEDICATION

To my husband Merrill for his enduring patience and generous gift of time and to my son, Jason whose presence in my life is the source of my energy. Thank you for making this *our* journey.

"Occasionally in life there are those moments of unutterable fulfillment which cannot be completely explained by those symbols called words. Their meanings can only be articulated by the inaudible language of the heart.
Dr. Martin Luther King, Jr.

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CHAPTER 1

INTRODUCTION

The evolution in health care practices related to the care of children in hospitals has resulted in unparalleled benefits to children. It is now inconceivable that at one time parents were expected to leave a child in the hospital and not return until the day of their child's discharge. The role of parents since the mid-20th century has evolved from not being allowed to stay with their children to open visiting for families, a place to sleep at the bedside of their hospitalized children each night, and extensive participation of family members in their child's care.

The changes in attitude and practice that continue to evolve are gradual, but not without difficult role transitions for families and professional caregivers. The current need is to turn our attention to strategies that facilitate the formation of alliances between parents and professionals with the goal to mutually benefit children, parents, and professionals.

1.1 STATEMENT OF THE PROBLEM

The role taken on by parents during their child's hospitalization varies across families and according to the nature of their child's illness. Regardless of the circumstances, the hospitalization of a sick child creates a context in which parents suffer because of their child's distress. Research has consistently reported that hospitalization of a child is an experience of uncertainty and anxiety for parents (Knafl, Cavallari & Dixon, 1988; Kristensson-Hallström & Elander, 1997; Mishel, 1983). Parents report that they worry about their child's condition and outcome and that they themselves experience emotional and physical exhaustion in their efforts to be available for their sick child (Hunsberger, McGrath, Palin, Austin, Clause, & Bowman, 1999). In spite of the enormous stress experienced by parents, they unrelentingly extend themselves to their children during this critical time. The phenomenon of parent presence in hospitals is now widely accepted practice, yet the needs and worries of parents are not well recognized nor understood by professionals in the context of a rapidly changing health care environment.

The stress of parents is of particular interest to those who care for children because of the potential for parent stress to be transferred to children. This transfer, first described by Skipper and Leonard (1968) as the "emotional contagion hypothesis" (p. 278), has been further endorsed by Hatfield, Cacioppo and Rapson's (1994) premise that children "catch their parents' emotions" (p. 83). The importance of studying the experience of parents during their child's hospitalization is based on the belief that infants and children can be "exquisitely sensitive to the emotions and moods of their parents" and that nursing care to facilitate parent functioning will, theoretically, decrease the stress of children as well as that of their parents (Curley & Wallace, 1992, p. 50). Nurses are in a key position to reduce parent stress because they are present twenty-four hours daily with direct responsibility for the nursing care of children in hospitals. Nurses are also resources to parents in the overall co-ordination and integration of services for families.

As the role of parents is expanding, the demands on professionals are not reduced, but rather changed in ways that require new models of care to maximize the benefits for children. Nurses are challenged to adapt their practice to include parents and establish a working relationship with them. The dynamics of nurse-parent relationships in the care of children during hospitalization has been the focus of numerous research studies but remain unclear (Brown & Ritchie, 1989; Gill, 1987; 1993; Jay, 1977; Seidl, 1969).

The involvement of parents is recognized as a comfort to children but the strain that this places on families requires the attention of clinicians and researchers alike. The stress of parents related to the hospitalization of their child has been addressed with a variety of supportive and educational strategies. Preparing children and parents for procedures, as well as for hospitalization and surgery has been demonstrated to have positive effects (Melamed & Siegel, 1975; Peterson & Shigetomi, 1981). Furthermore, the importance of play to normalize a child's life and to prepare them for medical procedures has long been recognized to reduce the stress of children (Bolig, Fernie, & Klein, 1986; Crocker, 1978; Petrillo & Sanger,1980; Plank, 1971; Wilson, 1985). In spite of these interventions for parents and children, the stressful experience of parents during their child's hospitalization is an enduring problem (Curley & Wallace, 1992; Hunsberger et. al., 1999; Melynk, 1994). The concern for parents has been reflected in the numerous studies that target the role of parents and nursing interventions to reduce their stress (Burke, Handley-Derry, Costello, Kaufmann & Dillon, 1997; Curley, 1988; Curley & Wallace, 1992; Keatinge & Gilmore, 1996; Melnyk, 1994; Melnyk, Alpert-Gillis, Hensel, Cable-Beiling, & Rubenstein, 1997; Visintainer & Wolfer, 1975). Approaches are needed to facilitate parents in their efforts to help their children with the least amount of stress induced for parents.

While nurses who care for children have increasingly recognized the importance of the family, it is a challenge for nurses to care for the parents as well as the child. As the acuity level of hospitalized children and the complexity of care escalates, parents and nurses face ever-increasing challenges. Parents need to be made to feel important and allowed to participate in a way that is comfortable for them and should be encouraged to take a reprieve when needed. Interventions are required that help parents and nurses establish relationships that achieve these goals. The challenge is to keep parents involved but to reduce their stress.

1.2 STATEMENT OF PURPOSE

The purpose of this study was to test a model of nursing care that has the potential to reduce parent stress while simultaneously encouraging their participation. The Nursing Mutual Participation Model of Care (NMPMC) is a model that provides a framework for individualized care encouraging mutual involvement of parents and nurses. It promotes a nurse-parent relationship that exemplifies respect with mutual sharing of expertise and active parent participation; a primary goal is to foster the confidence of parents in performing their vital role while their child is sick. It has been demonstrated that implementation of this model by nurses in a Pediatric Intensive Care Unit (PICU) can reduce the stress experienced by parents (Curley, 1988; Curley & Wallace, 1992). Using sequential sampling the model was tested by comparing usual care to implementation of the model by the researcher (Curley, 1988). In a second study Curley and Wallace (1992) contrasted usual care to care by nurses who had been taught to use the model. Since parents in general pediatric settings also experience a high level of stress it was hypothesized that this model could have similar effects in these settings. In contrast to the previous studies, the purpose of this study was to extend its use to a general pediatric setting and to introduce the model to parents as well as to nurses.

In this study the NMPMC was introduced to nurses and parents in an acute care pediatric setting. Since the model is based on an interactive process that affects the parent and nurse participants, it was reasonable to expect that greater benefits could be achieved if the model was introduced to parents as well as to nurses. By introducing the model to parents the specific intention was to enhance the nurse-parent relationship in a way that would make parents feel comfortable in their role with nurses and increase their ability to negotiate for their child within the hospital setting. The uniqueness of the current study, in comparison to previous studies using the NMPMC, is the use of an experimental design in which *parents* were randomized to treatment and non-treatment groups. Nurses could not be randomized on this ward because all nurses care for all patients on the ward, therefore, all nurses were introduced to the NMPMC. With this design, all parents were exposed to similarly-educated nurses.

CHAPTER 2

REVIEW OF THE LITERATURE

A ward in a children's hospital today has few similarities to the time when visitation by parents was restricted and even forbidden. The sounds of crying children and their anxious looks of distrust, however, remain. In spite of the dramatic signs of progress as mirrored in the child-appropriate decor, play areas with child-appropriate equipment, parental rooming-in, humane approaches to pain management, and systematic preparation for surgery and procedures, it is agreed by researchers and clinicians that stress and anxiety associated with a child's hospitalization persist for children and their families (Brown & Ritchie, 1990; Burke et al., 1997; Hunsberger et al., 1999; Melnyk et al., 1997; Ogilvie, 1990; Tiedeman, 1997; Visintainer & Wolfer, 1975; Vulcan & Nikulich-Barrett, 1988; Wolfer & Visintainer, 1975; 1979). The magnitude of stress and anxiety experienced by parents, in the face of increasing acuity of hospitalized children, is a pediatric practice issue that requires innovative interventions by the health care team.

The following review of the literature pertains to: 1) the evolution of attitudes toward parent presence; 2) the transition from having no parents present in hospitals to an expanded parental role; 3) stress and anxiety associated with the hospital experience for parents; and, 4) interventions that have been tested to reduce parent anxiety.

2.1 THE EVOLUTION OF ATTITUDES TOWARD PARENTS IN HOSPITALS

Historically, it was common to separate children from parents during hospitalization either by total absence or through very restricted visiting hours. As studies began to identify the adverse effects of early deprivation of maternal care (Bowlby, 1951; Robertson, 1958; Spitz, 1945), liberalization of visiting policies in hospitals followed. Of major influence was the seminal work by Prugh, Staub, Sands, Kirschbaum, and Lenihan (1953) who demonstrated that the emotional distress of hospitalized children could be reduced if parents were allowed to visit. Over time, researchers were able to demonstrate that children's regressive behaviors, aggression, self-oriented activities, and fears related to hospitalization were reduced if parents were allowed to visit their children during hospitalization (Fagin, 1964; Prugh et al., 1953; Schulman, Foley, Vernon, & Allen, 1967).

An area of interest that emerged was whether the presence of a substitute care giver would bring about similar results. Branstetter (1969) suggested that much of the "upset" noted among children who were separated from their parents resulted from the absence of the consistent attention, or "mothering care" that is associated with attachment figures. To test this hypothesis, three groups of children described as mother-present, mother-substitute, and mother-absent were observed. Children in the mother-present and mother-substitute groups both demonstrated less disturbed behaviour than in the mother-absent group; however, there were certain differences between the mother-present and mother-substitute groups: more dependency behaviour, withdrawal, and self-orientation were observed in the mother-substitute group (Branstetter, 1969).

Philosophies of care related to children in hospitals have evolved over time and reflect the integration of a large body of research. It is now common for parents to be present when children are hospitalized. Hospital policies permit open visiting and overnight stay by parents and offer preparation programs for children and parents. Parents have become increasingly involved in their child's care; it has become common practice in many institutions for parents to accompany their children to the operating room for induction and to the recovery room following surgery. Parents are also invited to be present during painful procedures and participate in medically complex technical aspects of care in the hospital and at home. The need for children to be nurtured during hospitalization is reflected in programs that substitute for parents when they cannot be present such as volunteer cuddlers (volunteers who come to the hospital to hold children who need extra nurturing due to parent absence).

2.2 THE TRANSITION FROM NO VISITATION TO PARENT INVOLVEMENT

The transition from no visitation, to restricted visiting, to full involvement of parents in acute care hospitals has been gradual and not without some misgivings on the part of professionals. This expanded family involvement is presenting new challenges in the roles of and relationships between health care professionals and families. When parents visited only a few hours at a time the roles of parents and nurses were clear: nurses cared for the children while parents visited within designated restricted visiting hours.

The challenge of relating to families with their increased caregiving role has produced multiple reports of difficulty in role negotiation for healthcare professionals (Ahmann, 1994; Brown & Ritchie, 1989; 1990; Burke, Kaufmann, Costello, & Dillon, 1991; Callery & Smith, 1991; Gill, 1993; Hayes & Knox, 1984). In a study by Brown and Ritchie (1990), twenty-five nurses were interviewed and asked to describe their perceptions of parent and nurse roles in caring for hospitalized children. Nurses' descriptions indicated that their role in the emotional care of parents "was limited, and that, in certain situations, parents and nurses experienced interpersonal conflict" (Brown & Ritchie, 1990, p. 30). One of the descriptors with respect to types of roles identified by the researchers, based on nurse reports, was that nurses acted as "gatekeeper by exerting control over parents and children" (p. 30). Nurses indicated that they felt responsible and accountable for the care and well-being of children and that for this reason they had legitimate reasons for being vigilant of parents and the care they provided. The difficulty in sharing the caregiving roles with families was thought by the researchers to be due to the long-standing orientation of nurses working within the traditional medical model, a model in which nurses have been oriented to function in a helping role, one in which the professional is in control with little input from the family. This philosophy of helping is based on the premise that families are not seen in a role of responsibility for the solution (Brown & Ritchie, 1990).

While researchers have described the hesitance of nurses to include parents, it is apparent that there is a discrepancy between what nurses do and what nurses say they believe (Ahmann, 1994; Johnson, 1990). For example, even though nurses agree with the elements in family-centered care, nurses report that their day-to-day care is less family-centered than they feel is desirable (Bruce & Ritchie, 1997). A contributing factor to these discrepancies in clinical care is the ongoing debate by professionals as to what constitutes 'family nursing' (Ahmann, 1994; Allen & Petr, 1998). Furthermore there is a need for expanded knowledge in understanding family processes during the acute illness of children (Rennick, 1995).

There is also considerable evidence in the literature that nurses are ambivalent about the role of parents. While nurses have reservations about parents participating in the care of their hospitalized child (Gill, 1987; Roskies, Mongeon, & Gagnon-Lefebvre, 1978), they also report that parent participation is valuable (Gill, 1987; Goodell, 1979; Sainsbury, Gray, Cleary, Davies, & Rowlandson, 1986). Explanations given for these discrepancies are that the knowledge and skill of nurses related to the practice of family-centered care are limited, that there is inadequate support of nurses by hospitals to practice family-centered care, and that nurses have varied perceptions about their role in caring for families (Bruce & Ritchie, 1997). It has been suggested that nurses could benefit from more education in communication skills, conflict management skills, and the principles of family-centered care (Brown & Ritchie, 1989; 1990).

The preferences and experiences of parents related to their role in the care of a hospitalized child have also been reported. Earlier studies reported that parents wanted to provide more care than the nurses thought they should (McDonald, 1969; Merrow & Johnson, 1968), and that parents wished to carry out more technical tasks (Algren, 1985; Jackson, Bradham, & Burwell, 1978; Knafl & Dixon, 1984). The wishes of parents vary according to individual circumstances of parents and are not clearly understood by professionals. To further understand this aspect of care, efforts have been made to construct a profile of mothers who prefer to have control over their child's care. In a study of 384 mothers of hospitalized children aged 1 month to 18 years, it was reported that the child's age was the strongest correlate of preference for control, indicating mothers of younger children preferred to have more control over their care. Other correlates identified in decreasing order of significance were younger mothers, mothers who spent more time with their child in the hospital, and mothers with fewer children (Schepp, 1992).

There seems to be no consensus about "what form parental participation should take and how far that participation should extend" (Coyne, 1995, p. 719). The abilities and willingness of parents to participate varies enormously with the continuum of participation ranging from complete involvement to a complete relinquishing of their parental role. Areas of difficulty for parents in their role with hospitalized children include lack of information, non-negotiation of roles, inadequate facilities, and feelings of anxiety and loneliness (Coyne, 1995). In a recent survey of 51 parents of hospitalized children ages 2 months to 14 years, parents were asked specific questions about participation and sources of stress. In this study there was clear evidence that parents wanted to participate in their child's care. When asked whether they were expected to be involved too much in their child's care 47 (92.2%) answered "no". On the other hand, 16 (31.4%) said they did not know what was expected of them, 11 (22%) said they were expected to give care even though they were exhausted, and 20 (39%) indicated that they were unable to leave the bedside to replenish their energy (Hunsberger et al., 1999). These data indicate that parents continue to want to be involved but there is also evidence of a trend toward parent exhaustion with too great an expectation of parents by institutions and a sense of being 'trapped' in their child's room.

2.3 PARENT STRESS AND ANXIETY WHEN CHILDREN ARE HOSPITALIZED

Children hospitalized in acute care hospitals are admitted for a broad range of clinical problems. Some children are repeatedly hospitalized while others are experiencing hospitalization for the first time. This variation in circumstances results in diverse populations of parents and children on the same ward requiring professionals to respond to a range of parent needs. The following sections examine the literature on parent stress and needs associated with the hospitalization of children with acute and chronic conditions.

2.3.1 Children with Acute Illness

Parents in PICU have been the focus of many of the studies on parent stress related to a child's hospitalization. One study found that the greatest needs of parents were to be with their child and to be kept informed of their child's condition (Kasper & Nyamathi, 1988). Similarly findings by Fisher (1994) indicated that the most important needs for parents of children hospitalized in a PICU were knowing about their child's prognosis, receiving explanations about things being done for their child, feeling there was hope, and knowing their child's pain was being relieved.

The needs of parents of hospitalized 2- to 6- year-old children in a general pediatric setting were studied by Kristjansdottir (1991) through interviews with parents and pediatric health care providers. The data from these interviews were analyzed by content. From these data and a review of the literature, six groups of needs were reported. The needs reported included: 1) to be able to trust doctors and nurses; 2) to receive information; 3) support for other family members; 4) to feel that they are trusted; 5) for human and physical resources; and, 6) support and guidance. Other researchers have focused on the actual stressors and have described the major sources of stress (Carnevale, 1990; Carter, Miles, Buford & Hassanein, 1985; Fisher, 1994; Heuer, 1993; LaMontagne & Pawlak, 1990; Seideman et al., 1997; Youngblut & Jay, 1991). Miles and Carter (1982) identified 79 items describing sources of stress for parents of a child in PICU. These were then categorized into eight dimensions including sights and sounds, child's appearance, child's behavior, child's emotions, procedures, staff communication, staff behavior, and parental role alteration.

The most important stressors named by parents are similar across studies. Carter et al. (1985) found that the alteration in parental role was the greatest stressor. Miles, Carter, Riddle, Hennessey and Eberly (1989) reported that the dimensions of child behavior and emotions and parental role alteration were the most stressful aspects of the PICU experience. The five categories identified by Carnevale (1990) were parental role changes, concern for their child, the PICU environment, lack of support from friends, and concern for their child's siblings. In a study conducted by Hunsberger et al. (1999) the top five ranking stressors reported by parents were: 1) parent loss of sleep; 2) not being able to be with children at home; 3) seeing their child in pain; 4) seeing their child's distress related to procedures; and, 5) seeing their child's general distress about being in the hospital.

The change in parental anxiety over a period of time has been studied by Tiedeman (1997) in a probability sample of 52 parents of hospitalized children aged 5- to 11-years of age. Parental anxiety was measured using the State Anxiety Inventory (STAI) (Spielberger, 1983). Parents were measured at three points in time: within 24 hours of admission, during the 24 hour period before discharge, and 7 to 14 days after discharge. A change in anxiety over time was reported with a significant reduction in anxiety from admission to discharge but not from discharge to post-hospitalization.

In summary, studies about parent stress and anxiety associated with a child's hospitalization for acute illness indicate that there are multiple factors that contribute to their experience. Many of the parental issues identified by these various studies are related to needing information, re-establishing their parental role, relating to staff, and having sufficient resources to maintain their own level of energy. As well, their child's pain and general distress related to being in the hospital are recurring themes that parents identify as sources of stress during their child's hospitalization in acute care settings.

2.3.2 Children with Chronic Illness

Children with chronic illnesses are more likely to be hospitalized frequently. These families become familiar with the health care system and are often well known to hospital staff upon their admission. The nature of stress for families when chronically ill children are hospitalized has been studied by Burke, Costello and Handley-Derry (1989) and Burke et al. (1991). Parents of chronically ill children who are repeatedly hospitalized have not been found to experience decreasing stress as one might expect with increased experience in hospitals (Burke et al., 1989). It has been suggested that parental stress related to hospitalizations of a chronically ill child is a subset of the stresses these parents cope with throughout the life of their child. The events leading up to and following hospitalization thus contribute to the nature of their experience during hospitalization (Burke et al., 1991).

The stress experienced by parents of hospitalized chronically ill children has been well documented. Stress for these parent clusters around the uniqueness of procedures and routines, the complexity of daily activities, communication with multiple health care professionals, and the maintenance of the families' routines in the face of repeated, extended hospitalization (Burke et al., 1989). An added stress that has been reported is that numerous health professionals who care for chronically ill children in the hospital do not recognize and respect the expertise of parents as care givers (Cole, 1990; Knafl, Breitmayer, Gallo, & Zoeller, 1992; Thomas, 1990).

A specific phenomenon that has been studied by Burke et al. (1991) is the reluctance of parents to take charge. In this study, reluctance was found to be associated with parents not being able to access enough information and encountering barriers when they try to obtain information. Parents fear being viewed as troublemakers if they are too forceful about seeking information and taking charge. For this reason parents are cautious in their interactions and through a gradual process take charge. The process of "taking charge" is defined as regaining control; even though it is gradual, it puts a parent at risk for mounting exhaustion.

One of the ways of taking charge is through constant vigilance. Vigilance for these parents means "being there just in case". When the strategies of "vigilance, negotiating or information seeking are no longer effective in reducing parental stress, a point of exhaustion is reached" (Burke et al., 1991, p. 43). Chronically ill children may be dependent on various forms of technology making constant vigilance even more likely to occur. The theme of exhaustion in parents of chronically ill children is consistent with findings in parents of acutely ill hospitalized children.

2.4 INTERVENTION STUDIES RELATED TO PARENT STRESS

There is a growing body of literature about parent stressors related to the hospitalization of acutely ill children. However, there is a paucity of literature that has followed up these studies with interventions. Studies of children undergoing surgery have documented the positive effects of psychological preparation prior to surgery (Lynch, 1994; Melamed & Siegel, 1975), although there is some indication that age of child and timing of preparation require further research (Kain, Mayes, & Caramico, 1996). The effect of interventions at selected times during hospitalization is reported by Wolfer and Visintainer (1975). Recent intervention research focuses on information-giving interventions (Melnyk, 1994; Melnyk et al., 1997) stress-point interventions for repeatedly hospitalized children with chronic illness (Burke et al., 1997), and a specific model of care emphasizing mutual participation in the nurse-parent relationship (Curley & Wallace, 1992).

2.4.1 Psychological Preparation and Supportive Care

The effects of psychological preparation and supportive care have had a major impact on the care of children in hospitals. The response of children aged 3-14 years has been studied by introducing stress-point nursing interventions at selected times throughout hospitalization (Visintainer & Wolfer, 1975; Wolfer & Visintainer, 1975). In these studies parents were taught stress management techniques to use at stressful times with their children. Nursing intervention included information giving and orientation to hospital sequence of events, specific support during procedures, as well as information about professional roles and encouragement of parents to take an active role. Children in the experimental groups demonstrated more cooperation during intrusive procedures and less upset behavior during the entire experience than children in the control groups. Emphasizing the role of parents in assisting their children in coping with hospitalization during minor elective surgeries has also been shown to result in positive outcomes for both parents and children (Peterson & Shigetomi, 1981; Roskies et al., 1978). These and many other studies have changed the face of pediatric practice so that today many institutions have surgical preparation programs for parents and children and a range of specialized in-patient services to support children.

2.4.2 Information-Giving Interventions

The role of information-giving as an intervention to reduce parental stress has been studied by Vulcan and Nickulich-Barrett (1988) and Melnyk (1994). In the first study, a convenience sample of forty mothers of hospitalized children between the ages of 1 and 5 formed two 20-member groups. Demographic characteristics including age of mother, age of children, gender of child, marital status of mother, and average number of children in the home were not significantly different in the control and experimental groups. Mothers in the experimental groups viewed a 14-minute videotape which focused on the range of behaviors that toddlers and preschool children display during hospitalization. The videotape also provided suggestions for parents to help their children cope with the hospital experience. Mothers in the control group received only the routine information that nurses usually share with parents during admission. The State-Trait Anxiety Inventory (STAI) was completed by both groups at the time of admission and the State Anxiety scale (SAI) was repeated at 24-36 hours after admission. In this study it was demonstrated that when tested at 24-36 hours, mothers in the experimental group had a significantly lower level of anxiety compared to those in the control group. Number of children in the home (i.e. 0 children at home compared to 2 additional children at home) was also found to have a significant positive relationship to anxiety. No difference was found in state anxiety scores with the combinations of 0 and 1 child, nor between 1 and 2 children in the home (Vulcan & Nikulich-Barrett, 1988).

The Vulcan and Nikulich-Barrett (1988) study was expanded to include more extensive parent role information. In a study with 108 parents of children 2-5 years of age admitted for unplanned hospitalizations, parents were randomized into 3 intervention groups and a control group (Melnyk et al., 1994). The intervention groups received: 1) information on child behavior; 2) information on parenting roles; and, 3) both sets of information. Parents in either information group and in the combined group experienced significantly less anxiety during hospitalization and 2 weeks post-hospitalization compared to the control group as measured by the STAI. The effect of behavioral information and the parental role information were measured by instruments developed by Melnyk for this study including an Index of Parent Participation and an Index of Parental Support During Intrusive Procedures. The information given had significant effects on parental support and participation in their children's care during hospitalization; positive main effects were also shown for child behavior information on children's negative behaviors post-hospitalizaton.

These studies were enlarged to include a parent-child activity in addition to child behavior and parent role information. In a pilot study a randomized trial was conducted to test the effects of an intervention program on the coping outcomes in mothers and their critically ill children 2 to 6 years of age (Melnyk et al., 1997). The intervention program, COPE (Creating Opportunities for Parent Empowerment) consisted of providing information for parents and therapeutic activities that they could do with their children. The convenience sample in this study comprised 30 mothers (16 in the experimental group and 14 in the control group). The instrument used to measure mother's state anxiety was the STAI (Spielberger, 1983). In this study, the mothers who received the COPE intervention reported less parental anxiety, provided more support to their children during intrusive procedures, provided more overall emotional support to their children, had fewer post-traumatic stress symptoms, and less parental role change four weeks following hospitalization. In this pilot study, the small sample size did not allow for sufficient power to detect significance at the .05 level. There were no significant differences in mother's reports of State anxiety following hospitalization; however, a large effect size (.80) for the COPE program on mother's State anxiety levels following hospitalization was reported. The study provides support for interventions that provide information to parents to assist them in their role of parenting their critically ill child.

In the studies by Vulcan and Nikulich-Barrett (1988), Melnyk (1994) and Melnyk et al. (1997) staff nurses were not apprised of the content of the research. They were kept blind to the specific content of the study, and therefore did not reinforce information and activities provided for parents. In the proposed study, the intervention was designed to foster mutuality in nurse-parent relationships. For this reason, the study intentionally involves nurses and parents.

2.4.3 Stress-Point Intervention

Stress-point intervention is an approach that focuses on nursing support given at the family's critical stress points. The earlier research using this method focused on stressors associated with a child's hospitalization for minor surgery as discussed in section 2.4.1.

Stress-point intervention has more recently been tailored to children with chronic illness who are repeatedly hospitalized (Burke et al., 1997; Kaufman, Burke, Harrison & Wong, 1998). In these studies Stress-Point Intervention by Nurses (SPIN) involved parent-nurse contact before admission, during hospitalization, and after discharge. SPIN is a process whereby the family's critical stress points are identified through nurse-parent communication and coping strategies are developed from the family's perspective. The Burke Stressors and Tasks Checklist (Burke, Kauffmann, Harrison & Wiskin, 1999) is used to guide this process. Specific steps are taken to maintain contact throughout the process beginning about 2 weeks before admission with phone calls and visits during hospitalization and contact at about 2 weeks following discharge.

The SPIN approach was tested in a two-group, pretest-posttest design in which fifty parents were randomly assigned to intervention or usual care control group. Randomization was stratified based on diagnostic categories and age > 10 years and younger children. Outcome variables including developmental delay, behavior problems after discharge, parental anxiety, family function, and family coping were measured about 2 weeks before hospitalization. 2 weeks after discharge and 3 months after discharge.

Findings from this study demonstrated that those in the intervention group experienced increased coping and family functioning and reduced parental stress and child developmental delays after a planned hospital admission. There were no differences in child behavior between the groups after hospitalization. It is interesting that in this study parental anxiety as measured by the Spielberger State-Trait Anxiety Inventory was higher in the intervention group than the control group at 2 weeks ($p < 0.01$) but lower at 3 months $p < 0.05$) post-hospitalization.

2.4.4 Parent-Nurse Relationship

Clinical approaches that focus on relationships between nurses and parents have been introduced as philosophies of care but have been only minimally tested. Many institutions espouse the adoption of family-centered care as their philosophy of practice. One of the dimensions of family-centered care is the belief that there should be a partnership between professionals and families. One model of care that focuses on this partnership between nurses and parents is the Nursing Mutual Participation Model of Care (NMPMC). This model has been tested as an intervention to reduce parent stress in PICU's (Curley, 1988; Curley & Wallace, 1992). Using a quasi-experimental design, Curley (1988) tested the NMPMC in a study of 33 parents. Through sequential sampling the first 17 subjects were placed in the control group and the next 16 subjects in the experimental group. The intervention was daily bedside contact by the researcher during which the NMPMC was implemented. Using the NMPMC, the researcher helped the parent to recognize something that was still the same about his/her child, role-modelled interactions with the child, gave explanations about the equipment, provided anticipatory guidance, and helped the parents with nurturing activities and socialization to the PICU and hospital system (Curley, 1988). Control parents received the usual nursing care. The researcher's contact with the control group involved only the collection of demographic and descriptive data and giving instructions on how to complete the measurement tool.

Parental stress in both groups was measured within 24-48 hours after their child's admission to the PICU, every 48 hours thereafter, and at 24 hours after discharge from the PICU using the Parental Stressor Scale: Pediatric Intensive Care Unit (PSS: PICU) developed by Miles and Carter (1982). This scale has 36 items using a Likert-type scale to measure stressors categorized along seven dimensions of the PICU environment: 1) the child's appearance; 2) sights and sounds in the unit; 3) procedures done to the child; 4) patient-nursing staff communications; 5) the child's behavior and emotional reactions; 6) nursing staff behaviour; and, 7) parental role revision. Parents in the experimental group were reported to perceive significantly less stress in the dimensions of: 1) the child's behavior and emotions; 2) parental role alteration; 3) the child's procedures; and, 4) nursing behaviour. A limitation of this study is the small sample size, the possibility of intervening variables, and the potential for the Hawthorne effect due to the nurse researcher's extra time spent with the experimental group compared to the control group.

To expand on previous work, Curley and Wallace (1992) studied the effect of the NMPMC when implemented by PICU staff nurses. By sequential sampling the first 31 subjects in the study were placed into the control group and the next 25 subjects in the experimental group. Parents in the control group received the usual primary nursing care from the PICU staff. After data collection for the control group was complete, all PICU nursing staff were introduced to the model through an educational session. After 89% of the full and part time PICU nursing staff participated in the sessions, data were collected from the experimental group using the PSS: PICU. Parents in both groups completed the PSS: PICU questionnaire within 24 to 48 hours after their child's admission, and every 48 hours thereafter, ending 24 hours after PICU discharge. The only contact the researcher had with both the control and experimental subjects in this study was to collect demographic data and to give instructions about the PSS: PICU instrument. The perceived level of stress among parents between the groups was significantly lower in the intervention group along the dimensions of parental role (p = .042) and the computed PSS:PICU total (p = .026).

A limitation of this study is that staff nurse implementation of the model was not measured. While staff nurses said they would implement the model there is no measure of how well this was done by nurses. The design of sequential sampling is also a limitation in that it did not control for other factors that may have intervened to affect the control and experimental groups.

2.5 SUMMARY

Parent stress persists as a problem in general pediatric acute care settings. There are research data to indicate that parent anxiety and stress can be reduced with specifically-designed interventions. The interventions that have been found to reduce parent stress are information-giving as tested by Vulcan and Nikulich-Barnett (1988); Melynk (1994); and Melnyk et al. (1997), stress point nursing by Wolfer and Visintainer (1979), SPIN by Burke et al. (1997), and implementation of the NMPMC by Curley (1988) and Curley and Wallace (1992). In the Vulcan and Melnyk studies parents were given information, but nurses were not apprised of the intervention. Stress point nursing by Wolfer and Visintainer (1979), and the SPIN study utilize approaches that focus on parent-nurse relationship building which have some common elements with the Curley studies. In the Curley studies, nurses were taught to implement a model of care with instructions regarding mutual participation, but without giving parents specific information about the model. It is hypothesized that since the model reduced parent stress when it was used by nurses, an experiment that teaches the model to nurses and parents could also significantly reduce parent stress. Prior to this study, the NMPMC had not been tested in a general acute care hospital setting and had been taught to nurses only. It was hypothesized that introduction of this model to nurses and parents simultaneously would guide nurses and parents in the same philosophical direction with the potential to achieve mutuality in the relationship and reduce parent anxiety.

CHAPTER 3

THEORETICAL FRAMEWORK AND STUDY HYPOTHESES

The theoretical concepts guiding this study are drawn from the psychological and nursing literature and include: 1) The Transactional Model of Stress and Coping; and, 2) The Nursing Mutual Participation Model of Care.

3.1 TRANSACTIONAL MODEL OF STRESS AND COPING

The transactional model of stress and coping (Lazarus, 1991; 1993) is the theoretical framework used to explain the inter-relationships of the concepts relevant to this study. Historically, theories of stress have been of three types: stimulus-oriented, response-oriented and interactional, or transactional (Lazarus, 1966). Stimulus-oriented theories view stress as "a potential residing within the stimulus provided by the organism's environment" (Derogatis & Coons, 1993 p. 201). An engineering analogy using the concepts of load and strain has often been used to describe the stimulus in the environment and its effect on the person. According to the stimulus-oriented theories, components of the environment that increase demands upon an individual are sources of stress. Response-oriented theories of stress define stress in terms of response variables; the response of the individual to the events of the environment defines the presence of stress. These responses according to response-oriented theories can be precursors to the development of psychological or physical disease processes (Derogatis & Coons, 1993).

In contrast to these theories, interactional theories emphasize the individual characteristics of the person as important variables that operate between the stimulus and the responses they invoke within the person. In transactional theory the importance of individual variability is taken one step further; not only does the individual mediate the impact of the environmental stimulus upon the person's responses, but the perceptual, cognitive and physiological characteristics of the individual affect and inform the perception of the environment (Lazarus & Launier, 1978; Lazarus, 1991) and the person responds to the environment as perceived. The concept of transaction is key to this relationship. Transaction is differentiated from interaction in that "transaction implies a newly created level of abstraction in which the separate person and environmental elements are joined together to form a new relational meaning" (Lazarus & Folkman, 1984, p. 294), whereas in interactions the interacting variables retain their separate identities. According to the transactional model of stress and coping the person-environment encounter is a "dynamic, mutually reciprocal, bi-directional relationship" (p. 293).

Relationships according to Lazarus (1991) have emotional significance. Emotions are about person-environment relationships and cannot be understood from the standpoint of environmental demands or intrapsychic needs alone. Mammals are constantly engaged in "evaluation (appraisal) of their changing relationships with the environment with respect to the significance of these relationships for well-being" (Lazarus, 1991, p. 213). With each appraisal pattern a person-environment relationship develops and a specific emotion follows: the differences in how people appraise their person-environment relationships is an individual variable that is influenced strongly by what is learned in the course of development and from sociocultural influences.

Emotions that arise as the person-environment relationship is appraised are interactive with coping. Lazarus (1993) explains that the way coping influences the emotions is through a change in appraisal. Coping according to Lazarus (1991) is a mediator of emotions. The behavioral flow is summarized in Figure 1.

Coping describes an individual's efforts to "master demands (conditions of harm, threat, or challenge) that are appraised (or perceived) as exceeding or taxing his or her resources" (Monat & Lazarus, 1991, p. 5). Pathways through which coping alters the person-environment relationship require further research. Three possible mechanisms offered are: 1) cognitive activity diverts attention away from the source of distress (avoidant strategies) or by directing attention to it (vigilant strategies); 2) cognitive activity alters the significance of the encounter for well-being including denial, to distancing or emphasizing the positive aspects of a situation; and, 3) actual terms of the person-environment relationship is altered through problem-focused and emotion-focused processes (Folkman & Lazarus, 1991). The Nursing Mutual Participation Model of Care (NMPMC) is an intervention that was hypothesized to be instrumental in assisting parents in their coping efforts. The processes involved in parent-nurse mutual participation were expected to reduce the stress and anxiety through the new relational meaning that would develop. Reappraisal of the event was hypothesized to result in a modified level of emotion and a new person-environment-encounter.

3.2 THE NURSING MUTUAL PARTICIPATION MODEL OF CARE (NMPMC).

The NMPMC is based on the work of Szasz and Hollender (1956) who described three models of physician practice including activity-passivity, guidance-cooperation and mutual participation. The historical model of activity-passivity is one in which the physician does

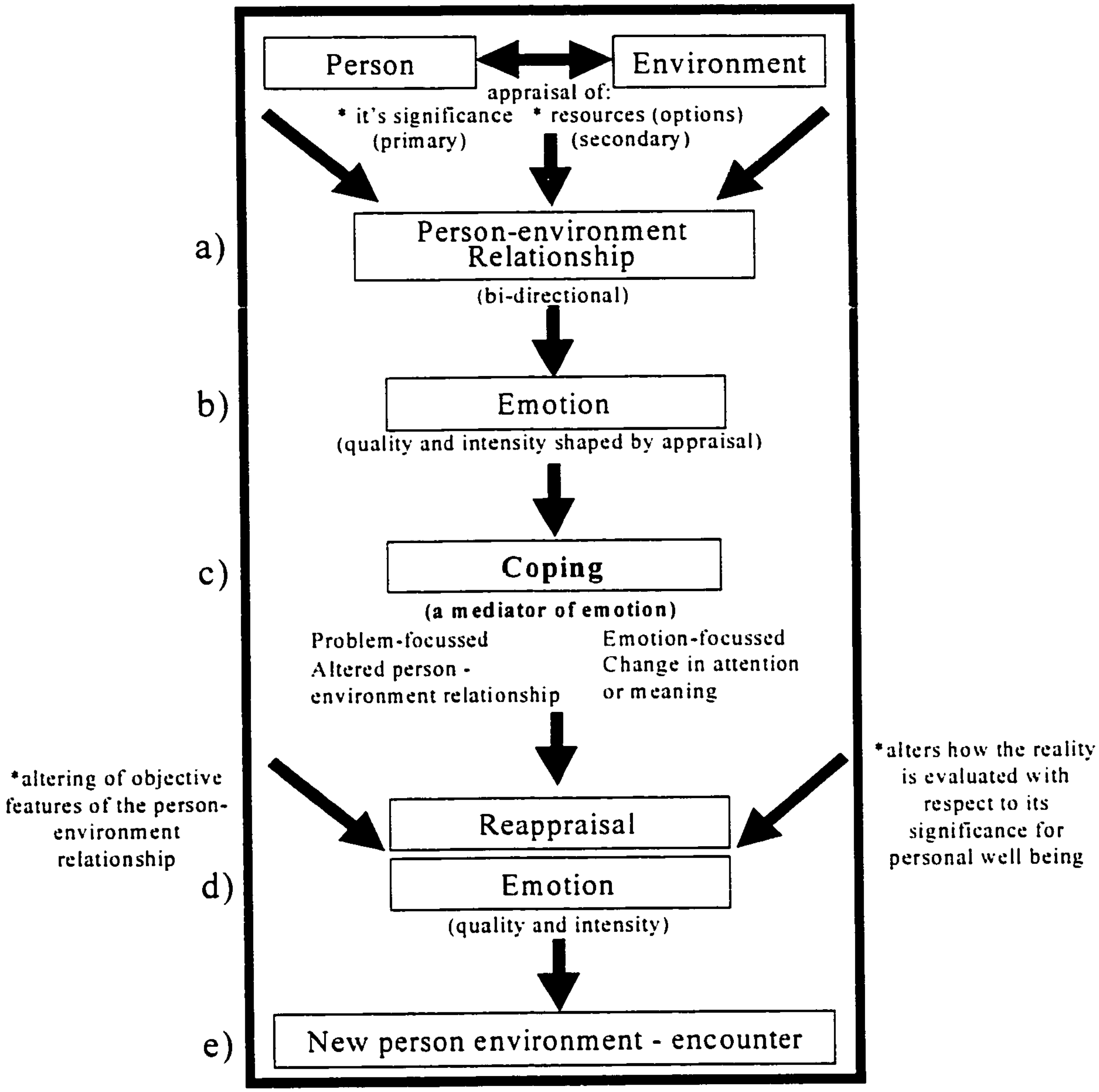


Figure 1: Transactional Model of Stress and Coping: Coping as a Mediator of Emotion

An appraisal of a person-environment encounter results in a) a person-environment relationship with b) associated emotions that require c) coping efforts (problem and emotion-focused) which work to d) reappraise the situation and influence the quality and intensity of emotion resulting in e) a new person environment encounter.

(Adapted from Folkman, S. & Lazarus, R. S. (1991). Stress and coping - some current issues and controversies. In A. Monat,& R. S. Lazarus (Eds.), Stress and coping: An anthology (pp.12). N.Y.: Columbia University Press.)

something to the patient and the patient's role is to be the recipient. In the guidance-cooperation model the physician tells the patient what to do and the patient obeys or is the cooperator. In contrast, in the mutual participation model the physician's role is to help patients to help themselves and the patient's role is to participate in a partnership. The model of mutual participation described by Szasz and Hollender (1956) is based on the premise that equality among human beings is desirable. Mutuality is described as involving "complex processes of identification -- which facilitate conceiving others in terms of oneself -- together with maintaining and tolerating the discrete individuality of the observer and the observed" (p. 587). Crucial to this type of interaction is "that the participants have approximately equal power, are mutually interdependent, and that the activity will be in some ways satisfying to both" (Szasz & Hollender, 1956, p. 587).

The NMPMC is based on these principles of mutual participation in a physician-client relationship and is applied to the nurse-parent relationship, emphasizing an individualized approach to nursing interventions. Mutuality sets up a context in which both parties access essential information without a concern that either party will be threatened by the expertise of the other. Mutuality in a relationship makes the nurse's job easier in knowing that parents are comfortable in asking for information instead of assuming that they will be told everything they should know (Curley & Wallace, 1992). The underlying principle that becomes evident when mutuality is achieved is that each party in the relationship refrains from expecting the same of all parents or the same of all nurses. The principle that is not negotiable is that both work towards a common goal -- the best care for the child. Mutuality in nurse-parent relationships is based on the premise that nurses have something of value to offer parents and that parents have something of value to contribute to the caregiving process of their hospitalized child (Curley & Meyer, 1996). Parents provide expertise related to their child's particular circumstances and illness and more broadly about the nature of the child and the child's needs. Nurses provide expertise about the child's condition and care of the child based on their professional knowledge. Identification of the child's problem in this context of equally-respected expertise leads to the sharing of common goals of care in the best interests of the child. For parents, there is comfort in knowing that the professional expertise of the nurse will be freely shared and that the nurse is interested in accessing the parent's expertise about their child's individual needs.

The model focuses on two specific phases of caring including admission and daily bedside contact as summarized in Table 1. This table presents a guideline for nurse-parent interactions. Following is a discussion of the NMPMC related to these phases of nurse-parent interaction.

3.2.1 Admission

According to the NMPMC admission is known to be a particularly stressful period for parents during which specific actions should be taken to make parents feel less anxious. The interventions at this time are designed to extend nursing care to include parents. The loss of control that parents sense at this time can be modified if the parents are made to feel that they have an irreplaceable role with their child. According to Curley and Meyer (1996) the important role of parents should be communicated to them deliberately at the outset by making statements that acknowledge their importance and explain that nurses want to work with parents to help them find ways to continue feeling important to their child. Parents also need

Table 1

Nursing Mutual Participation Model of Care

ADMISSION
Extend our care to include parents
Acknowledge their importance
DAILY BEDSIDE CONTACT
Enabling strategies that provide parents with system savvy
1. Information – teach & clarify.
2. Anticipatory guidance - illness trajectory
3. Provide instrumental resources

Facilitate transition to "parent-to-a-critically-ill-child"
1. Enhance parent-child unique connectedness
2. Role model interactions
3. Invite participation in nurturant activity
4. Provide options during procedures

Communication pattern
1. Establish a caring relationship with the parent. *How are you doing today?*
2. Assess parental perception of the child's illness. *How does s/he look to you today?*
3. Determine parental goals, objectives, and expectations. *What troubles you most?*
4. Seek informed suggestions and preferences, and invite participation in care. *How can I help you today!*

Note. Data from Curley, M. A. Q. (1988). Effects of the nursing mutual participation model of care and parental stress in the pediatric intensive care unit. Heart and Lung, 17(6,1), 682-688; Curley, M. A. Q. & Wallace J. (1992). Effects of the nursing mutual participation model of care on parental stress in the pediatric intensive care unit: A replication. Journal of Pediatric Nursing, 7(6), 377-385.
Reprinted with permission from Curley, M. A. Q. & Meyer, E. C. (1996). The impact of the critical care experience on the family. In M. A. Q. Curley, J. B. Smith, & P. A. Moloney-Harmon (Eds.), Critical care nursing of infants and children (pp. 56). Philadephia: W. B. Saunders.

information about their child's illness as soon as it is available. Information may need to be repeated because of the high level of anxiety during this period (Curley & Meyer, 1996).

The most apparent stressors upon admission are those related to the threatening environment, unfamiliar equipment, and the nature of the child's illness. Brief explanations are provided with opportunity to ask questions and to express any concerns they may have as a strategy to make them feel less anxious. According to the NMPMC it is also important to acknowledge the anxiety that parents may feel related to the loss of control and powerlessness in their parenting role. There is variability in the level of participation and the amount of information that parents desire. The philosophy of mutual participation dictates that parents should be encouraged to make their preferences known and that these should be honored in providing individualized nursing care.

3.2.2 Daily Bedside Contact

This section will discuss the NMPMC framework focusing on three aspects of daily bedside contact including: 1) system savvy; 2) facilitation of the parenting role; and, 3) communication patterns (Curley & Meyer, 1996).

3.2.2.1 Enabling Strategies That Provide Parents with System Savvy

Information. Parents need information and opportunities to discuss changes in their child's appearance, behavioral and emotional reactions, as well as information on how parents can participate. Parents are oriented to the environment and ward routines and coached on how to function within the system. The parental role is discussed with parents with a sharing of information about the perceived alterations in parental role and responsibility.

Having access to information about the organization and whom to contact for information about their child is fundamental to parents functioning within the system. Information reduces their feelings of helplessness and enhances their sense of control. However, when an illness is uncontrollable, parents may feel out of control regardless of how well they are oriented to the system. Therefore, when treatment does not bring immediate results, it is particularly important for parents to have access to information to learn about the illness, about the system and how to get the resources they need.

Anticipatory Guidance. It is difficult for parents to know what is expected and what is not expected with respect to the progress of their child. It is important for parents to receive information that will help them distinguish that which is expected from unexpected events (Curley & Meyer, 1996). Unnecessary anxieties are introduced for parents when changes occur that are difficult for them to understand and they mistakenly interpret a change to represent a worsening condition. Receiving anticipatory guidance about what to expect before it occurs has the potential to tremendously reduce the overall anxiety experienced by parents (Curley & Meyer, 1996).

Instrumental resources. The support that parents can give to their hospitalized child cannot be replaced by professionals. For this reason it is important that nursing care provides for the comfort needs of parents. Instrumental resources such as sleep facilities, showers, telephones, nutritious food, transportation and parking for parents are effective approaches to increase the potential for parents to be physically and emotionally available for their children (Fisher, 1994). Concern from professionals about the comfort of parents gives parents permission to express their unmet needs.

3.2.2.2 Facilitate Transition to Parenting an Ill Child

The NMPMC identifies alterations in parental role and subsequent disruption in the parent-child relationship that are stressful for parents. The model emphasizes the importance of assisting parents in a successful transition to parenting their ill child. The areas addressed in the model include: 1) enhancing the unique connectedness of parents and children; 2) role modelling interactions with children by nurses; 3) inviting parent participation in nurturing activities; and

4) providing options to parents during procedures (Curley & Meyer, 1996).

Enhancing parent-child unique connectedness. Illness and hospitalization can result in changes in the appearance of children and in their behavior. Appearance may be altered because of intravenous therapy, feeding tubes, dressings, or various forms of equipment attached to their child. These external changes as well as the child's emotional state can interfere with a child's usual responses. Parents may feel disconnected because the usual forms of interaction and personal exchanges have been altered. These changes are anxiety-producing for parents and can result in a distance that is difficult for them to bridge. The NMPMC suggests that the unique parent-child connectedness can be re-established if nurses ask parents to focus on characteristics of their child that have not changed. Also, bringing in familiar articles from home such as a child's favourite blanket, toy and family pictures can help to re-establish feelings of familiarity for the parent and child. All of these nonverbal cues are important reminders of life at home and help the parents to focus on things that have not changed.

Role modelling of interactions by nurses. Parents become familiar with the care their child requires by observing and imitating nurses. Role modelling occurs whenever nurses are providing care even if there is no verbal communication. Jay (1977) reported that parents notice and sort activities according to what is familiar and what is not familiar to them. By watching nurses, the initial fears of parents are lessened and they gradually take on roles as they feel comfortable.

Participation in nurturant activity. The unfamiliar care that is required is a source of anxiety for parents. Parents usually know what to do for their children at home, whereas in a hospital setting even the basic tasks of bathing and feeding can be made complicated by tubes and confinement to a bed. Parents feel anxious when there is no way for them to be instrumental in their child's recovery. Unfamiliarity with their child's care acts as a barrier to their participation. Encouraging parents to do things that they normally do for their children is a recommended starting point. However, it needs to be acknowledged that familiar tasks that were once performed at home may be overwhelming for parents in the hospital environment and may require help. During this process when parents are learning how to participate, it is essential for parents and nurses to communicate clearly and to establish mutual trust.

Provide options during procedures. There is great variability across institutions in practices concerning the presence of parents during procedures. Additionally, there is often inconsistency in approaches among staff within the same institution, a phenomenon that can be anxiety-provoking for parents as well as children. The approach espoused by the NMPMC is that behavior such as crying and resisting may occur even when parents are present during a procedure. The distress responses of children are highly variable and not necessarily related to whether parents are absent or present. However, it is proposed that "parental presence can potentially support the child's coping efforts and provide the child with a familiar source of comfort" (Curley & Meyer, 1996, p. 59). If parents choose to stay with their child, parents can be supported by helping them identify effective comforting strategies to use during the procedure.

According to the NMPMC it is recommended that parents be given a choice regarding their presence or participation and then supported in the decision they make. The reasons that parents may choose not to stay are variable and some parents may need help to articulate their fears about staying and may need help to understand the sources of their own ambivalence.

Parent stress associated with a child's procedures can potentially be reduced if parents have the opportunity to share feelings and anxieties, receive support through the decision-making process, and are accepted by professionals regardless of the parent's presence during a procedure.

3.2.2.3 Communication Pattern

Communication is clearly outlined by the NMPMC as a four-step process: 1) establishing a caring relationship with parents; 2) assessing parental perception of the child's illness; 3) determining parental goals, objectives and expectations; and, 4) seeking suggestions and preferences from parents and inviting their participation in care. Following is an analysis of how this communication pattern can reduce parent anxiety.

Caring relationship with the parent. To develop a caring relationship with the parent, specific communication strategies are used. Verbally focussing on how the parents are and asking them specific questions about themselves communicates to them their importance in the care of their child. It is also important to communicate that parents are understood. Parental affect or behaviors in a stressful environment can be easily misinterpreted. Parents who are not understood become increasingly anxious as their behaviors receive inappropriate responses from nurses. For example, fear can be misinterpreted as anger, yet "interventions for angry parents versus scared parents are quite different" (Curley & Meyer, 1996, p. 60). Appropriate responses to behavioral cues are critical to the development of caring relationships.

The nurse assesses parental perceptions of the child's illness by specifically asking how the parent thinks the child is doing and how serious they think the child's condition is. The goal is to combine the expertise of nurses and parents to make the most accurate assessments possible. Parents are able to notice a child's subtle behavioral and communicative cues that contribute to individualization of care because of their familiarity with their child. It is the working together of nurses and parents that leads to the best understanding of an individual child's needs and increases a parent's sense of involvement and control (Curley & Meyer, 1996).

Determining parental goals, objectives and expectations. The expression of feelings and concerns of parents is encouraged with specific questions that promote parent communication. Parent anxiety is reduced by encouraging parents to talk about what troubles them and what questions they need answered. Their suggestions or preferences are sought concerning their child's care. Encouraging expression of the parents' perspective about their goals, objectives and expectations sanctions the expression of feelings that parents might otherwise harbour. The blending of parent and nurse goals through open communication has the potential to diminish a parent's sense of losing control over their child's destiny (Curley & Meyer, 1996).

Seeking suggestions and preferences and inviting participation in care. Parents are invited to participate in decisions about how nursing care is provided. Specific questions are directed at the parent to develop ways of working together with a focus on parent-specific issues. It is important to follow through with a parent's agenda, especially after it has been elicited. It has been suggested that if parent concerns are elicited and then not addressed an increase in stress and parental dissatisfaction may result (Curley & Meyer, 1996).

3.3 CONCEPTUAL FRAMEWORK: NMPMC & THE TRANSACTIONAL MODEL

Mutual participation described by Curley and Wallace (1992) and Curley (1997) is consistent with the Transactional Model of Stress and Coping (Lazarus & Folkman, 1984).

The relationship that parents develop with nurses follows a person-environment encounter. The event in this study is the encounter with the hospital context and the experience of a child's illness. Hospitalization of a child is a stressful experience that introduces a family to unfamiliar experiences and in many cases evokes uncertainty and worry that may involve feelings of threat concerning the child's health and life. Such an emotional response, typically consists of fear and/or anxiety and is associated with physical symptoms, resulting from: 1) the appraisal of an object, situation, outcome, idea , as threatening to one's physical or psychological well-being or self-esteem; 2) the implicit belief that action needs to be taken to deal with the threat thus producing conflict; and, 3) uncertainty regarding one's ability to successfully identify and carry out the requisite action (Lock & Taylor, 1991). The event of hospitalization thus for parents represents an experience where the stakes are high and has the potential to evoke a variety of emotions. The relationship of the NMPMC and Transactional Model of Stress and Coping is shown in Figure 2.

Mutual participation between parents and nurses is a dynamic bi-directional relationship resulting in a new relational meaning. Curley (1997) defined mutuality as a relationship in which participants "develop greater self-awareness and self-understanding which contributes to personal becoming" (p. 210). This relationship is affected by the processes of appraisal and resultant emotions as defined by the Transactional Model of Stress and Coping. As parents and nurses develop a relationship there is a continuous appraisal of the

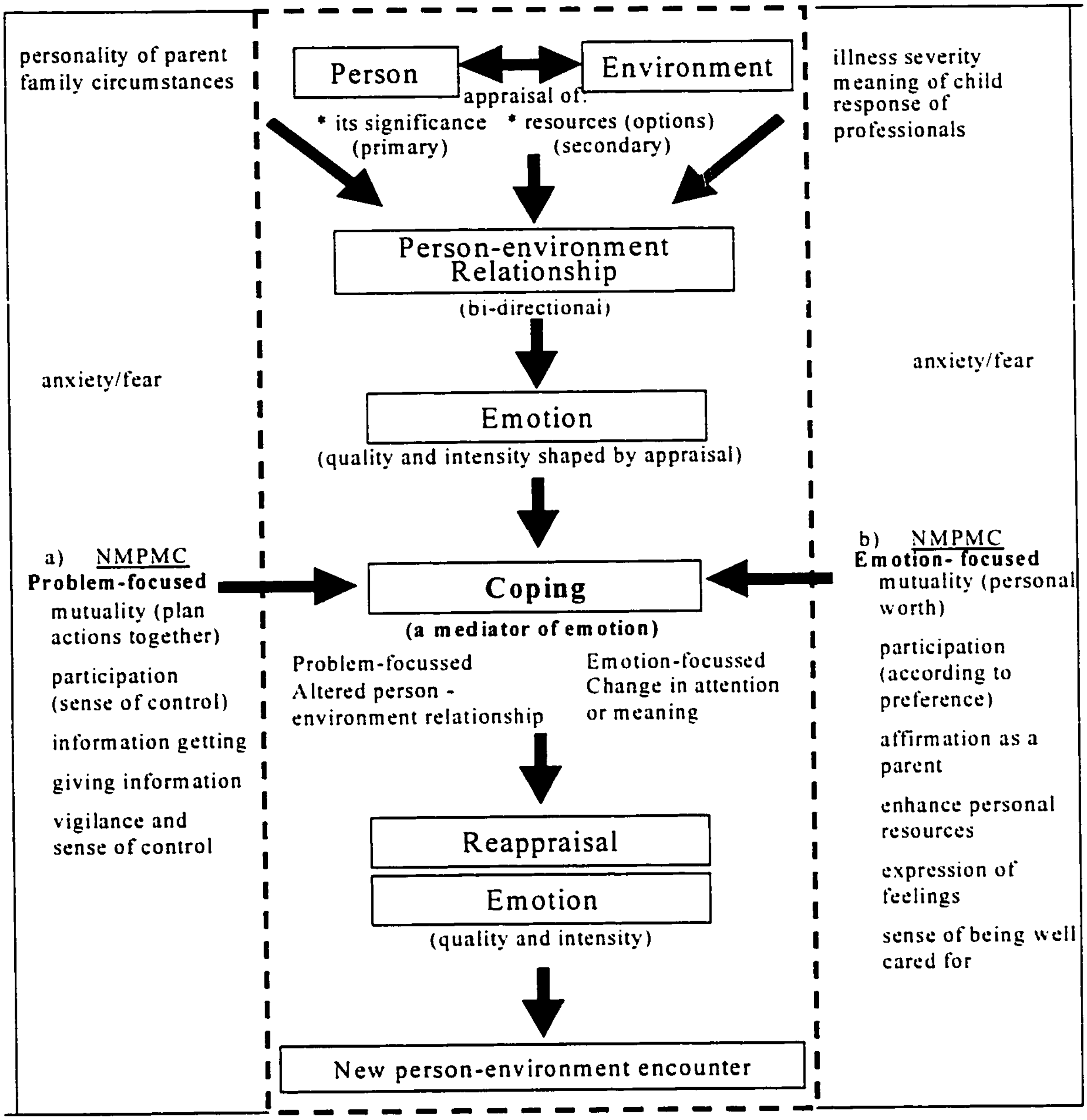


Figure 2: Relationship of NMPMC and Transactional Model

The NMPMC is characterized by a) problem focused and b) emotion focused coping which reduce emotions such as anxiety and fear, through the process of reappraisal resulting in a new person-environment encounter

Based on Folkman, S. & Lazarus, R.S. (1991). Stress and coping - some current issues and controversies. In A. Monat & R. S. Lazarus (Eds.), Stress and coping: An anthology (pp.12). N.Y.: Columbia University Press; Curley, M. A. Q. & Meyer, E. C. (1996). The impact of the critical care experience on the family. In M. A. Q. Curley, J. B. Smith, & P. A. Moloney-Harmon (Eds.), Critical care nursing of infants and children (pp.47-67). Philadephia: W. B. Saunders.

components of the relationship and this in turn results in a variety of emotions.

It is potentially stressful for parents when they cannot manage the situation and when the factors that contribute to their feelings are out of their control. According to Carver and Scheier (1982), a loss or change of role can produce a discrepancy between a current state and a preexisting standard or goal. Parents in the situation of having a child hospitalized may sense a loss of their role as parent; they attempt to decrease this discrepancy but the hospital environment and illness of their child may act as barriers to its successful resolution due to their own reduced confidence and the need for information and support. Parent-nurse relationships based on the model of mutual participation provide an opportunity for the feelings of loss of control to be modified as nurses model and teach parents how to care for their sick child and parents in turn share their own expertise with nurses. In this way parents are restored to their parenting role and the care nurses provide is modified through new insights from the parents about their child. The objective features of the environment are in this way modified in that nurses, a component of the hospital context, are perceived to share their experience. The new relational meaning that characterizes the parent-nurse relationship affects the quality and intensity of their emotional responses. Furthermore, in relationships governed by mutuality, parents can feel free to negotiate and re-negotiate their role which further reduces their anxiety in a context where parents are assured that nurses will recognize and respect their preferences to do more or less of the care as they are able.

It was hypothesized that mutual participation would have the effect of reducing parent anxiety because it promotes an environment of respect and equality; open communication gives parents permission to seek help and support from professionals. The respect for one another and the recognition of expertise and equity in the relationship enable parents to express their needs openly so that nurses can in turn be effective in meeting them. With respect and equality in a relationship, parents are free to discuss what they think is causing their stress. This assists them in problem-solving coping as well as emotion-focused coping processes.

In this study, the interaction with nurses was viewed as both problem-focused and emotion-focused coping (See Figure 2). The NMPMC suggests that nurses and parents engage in a relationship that is based on mutual participation. In mutual participation, parents are affirmed as equal partners and facilitated in their search for information and involvement according to their preference. The person-environment relationship is thus mediated through a process of coping that gives parents a "sense of being well cared for" (Curley & Wallace, 1992). An important component of the appraisal process is the interaction with professionals who actively engage with parents in the process of appraising both the event and their coping options. The processes involved in mutual participation were expected to reduce the anxiety that parents experience as a result of their child's hospitalization.

3.4 RESEARCH QUESTIONS/HYPOTHESES

The purpose of this study was to compare the effect of introducing the NMPMC to nurses only versus the effect of introducing the model to both nurses and parents. The research questions this study attempted to answer are as follows:

3.4.1 Primary Research Question

Does introducing the NMPMC to nurses and parents on a general pediatric ward result in a lower level of parent anxiety at discharge compared to introducing the model to nurses only?

3.4.2 Secondary Research Questions

i) Does introducing the NMPMC to nurses and parents on a general pediatric ward have the effect of increasing the degree of mutual participation experienced by parents compared to introducing the model to nurses only?

ii) Does introducing the NMPMC to nurses on a general pediatric ward have the effect of increasing the degree of mutual participation nurses experience?

iii) Is there a relationship between the parent's degree of mutual participation experienced and their level of anxiety reported at discharge?

iv) Is there a relationship between the degree of mutual participation experienced by nurses and parents?

3.4.3 Primary Hypothesis

Parents in the nurse and parent intervention (treatment) group will report a lower level of anxiety at discharge than parents in the nurse intervention only (control) comparison group;

3.4.4 Secondary Hypotheses

i) Parents in the treatment group will report an increase in the degree of mutual participation experienced compared to the parents in the control group;

ii) Nurses on a general pediatric ward will report an increase in the degree of mutual participation experienced after being introduced to the NMPMC compared to prior to its introduction to nurses;

iii) A parent's degree of mutual participation experienced will be inversely correlated with their level of anxiety reported at discharge;

iv) Difference reported by nurses, parent (treatment), and parent (control) groups for each subscale will be as follows:

a) level of importance of nurse mutual participation activities will be similar in the nurse, parent treatment, and parent control groups;

b) consistency of nurse performance will be rated at a higher level by nurses themselves compared to parents in both the treatment and control groups; and

c) parent participation will be rated at a lower level by nurses compared to parents themselves in both the treatment and control groups.

CHAPTER 4

METHODOLOGY

4.1 RESEARCH DESIGN

A randomized controlled trial was conducted to study the effects of introducing the NMPMC to nurses and parents. The study design is depicted in Figure 3. Parents were randomized to receive usual hospital information (control group) or NMPMC information (treatment group) upon admission of their child to the hospital. Parents in both the control and treatment groups were cared for by nurses who had been introduced to the NMPMC.

4.2 STUDY SETTING, SAMPLE, AND SAMPLE SIZE

4.2.1 Study Setting

The setting of the study was a 24-bed acute care pediatric unit at Children's Hospital. Hamilton Health Sciences Corporation (McMaster), a 392-bed medical center in southwestern Ontario. Approximately one third of the 24-bed ward is occupied by oncology patients and the remainder is occupied by medical patients and overflow surgical patients from another pediatric ward within the same hospital. The age range of children admitted to the selected study site is from newborn to 18 years of age. The average length of stay of children who are admitted for reasons other than oncology is 4.5 days. Parents are permitted to room-in; one single size pull-out chair converting into a bed is available at each bedside. Only one parent is allowed to stay overnight but families have 24-hour visiting privileges.

On this ward the direct patient care is primarily provided by registered nurses. A mix of

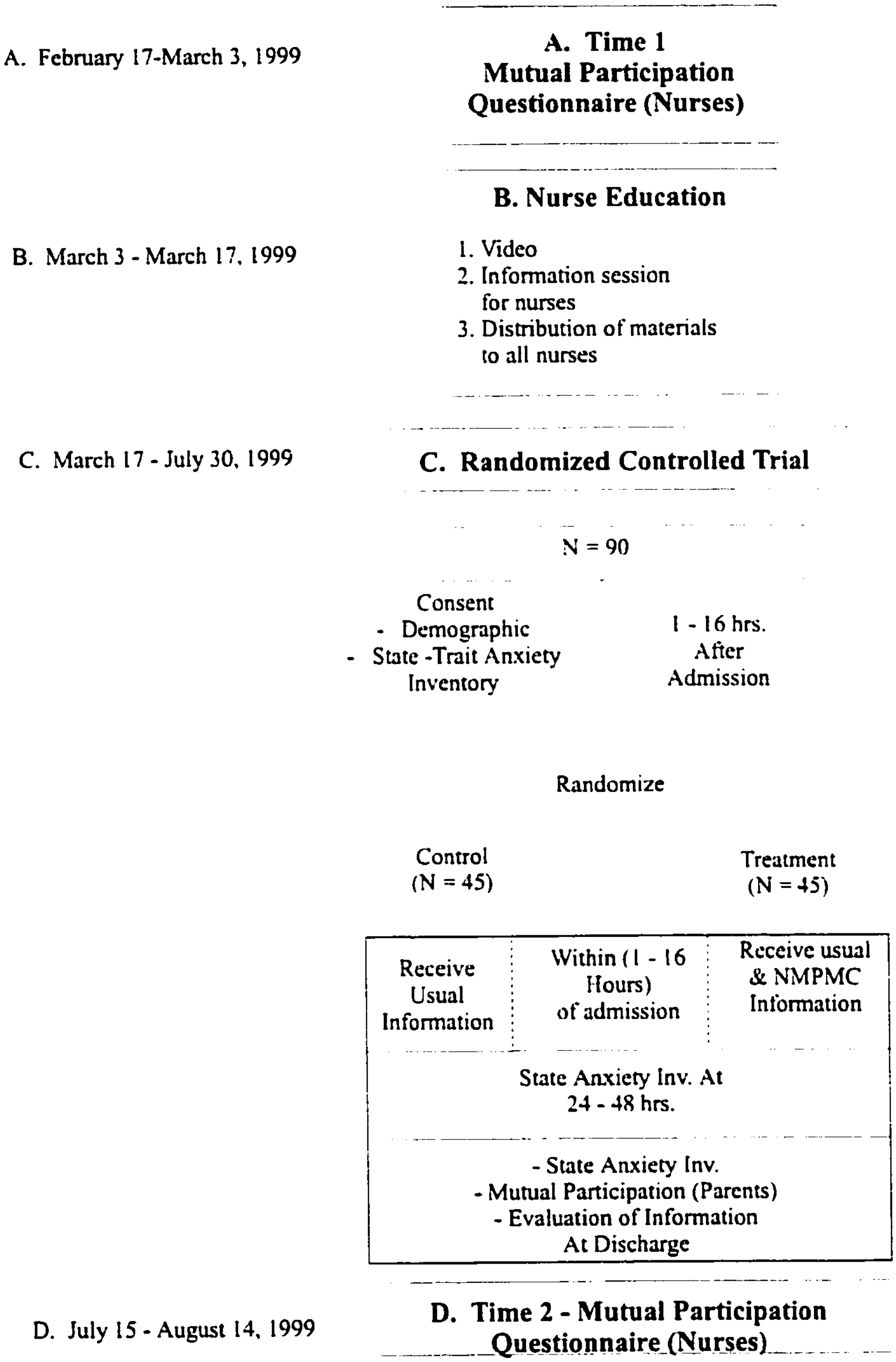


Figure 3: The Design and Timeline.
A Depiction of the Intervention Components of the Design.

support staff assist with organization of the unit, transporting of patients, and maintaining equipment.

4.2.2 Sample (Nurses)

All nurses employed on the ward were eligible to participate in the study with the exception of those who were on extended leave at the time of the study. There is not a division of nursing staff between the oncology and non-oncology patients; all nurses care for children with cancer and those who do not have cancer. Therefore, all nurses working on the ward at the time of the study were recruited to participate.

4.2.3 Sample (Parents)

The parents of children aged 3 months to 12 years of age admitted to the selected ward were invited to participate in the study. The upper and lower limits of age for this study were determined by numerous factors including child and family developmental issues, ages of hospitalized children in previous parent intervention studies, and the feasibility of obtaining the sample in a reasonable length of time.

Child and family developmental issues are related to both the lower and upper age limits selected. Birth of an infant is a potentially stress-producing event for parents. Because anxiety prior to 3 months of age could be associated with this experience, the lower limit of age was selected as 3 months. Because the study was focused on the role of parents in their child's care, the upper limit was selected to reflect an age when parents continue to participate to some degree in the care of their child during hospitalization.

Although a child's age has not been consistently found to be predictive for parent anxiety during the experience of hospitalization (Berenbaum & Hatcher, 1992; Tiedeman, 1997), the intention was to select an age range consistent with previous studies. Previous intervention studies to reduce the stress of parents during their child's acute illness and hospitalization have been conducted on parents of children ranging in age from 1-6 years (Melynk,1994; Melynk et al., 1997) and 4 - 10 years (Curley, 1988; Curley & Wallace, 1992). In this study the age range was increased compared to previous studies to facilitate collecting data from the required number of parents within a reasonable time period. The lower limit was 3 months and the upper limit was 12 years of age.

Selection was based on the following inclusion and exclusion criteria:

Inclusion Criteria:

1. Parent can speak and read English
2. Parent is cognitively capable of understanding questions
3. Parent is at the hospital 1-16 hours after admission for recruitment

Exclusion Criteria:

1. Parents of children who have been diagnosed with any form of cancer
2. Parents in crisis associated with their child's impending death
3. Parents in crisis related to accidents where either a sibling or parent was killed
4. Cases of known and suspected child abuse
5. Parents of children admitted for attempted suicide
6. When it was known upon admission a child would be discharged within 24 hours.
7. Parents of children who upon admission were predicted to stay longer than 1 month.

The first three exclusions have been identified as extraordinary circumstances that would interfere with the ability of parents to focus and respond to the questions on the instruments. Exclusions 4 and 5 are situations in which asking for information through questionnaires could be viewed with suspicion by parents; they could feel that the questionnaires are a way of gathering evidence that might be used against them. It was felt that it would be unethical to include these parents and that the validity of their responses could be affected by their suspicions. The sixth exclusion was necessary because it would be inappropriate to lead parents to think they will be included in the study when their exit from the unit before the first 24 hours would make them unavailable to complete the questionnaires at the required times. The percentage of lost subjects to the study would therefore be reduced. The last criterion would exclude those few subjects whose experience is dramatically different and would delay completion of the study.

4.2.4 Sample Size

Since parent anxiety is the primary outcome measure, sample size was based on previous work using the Spielberger et al. (1983) state anxiety inventory. From Melnyk's (1994) intervention study, means on Spielberger measures of parent anxiety in the control group versus three treatment groups were 46.6 (sd = 11.6), 40.7 (sd = 9.9), 39.1 (sd = 11.2) and 38.3 (sd = 7.7) respectively, during hospitalization. Two weeks post hospitalization, means for control and the three treatment groups were 39.8 (sd = 12.8), 29.8 (sd = 9.1), 30.4 (sd = 9.3) and 33.0 (sd = 8.7) respectively. It was expected that parent anxiety scores in a general pediatric unit would be lower than in a pediatric intensive care unit. The following results were hypothesized: parent anxiety during hospitalization would be 45 in the control group and 37 in the treatment group. At discharge, these means would be 37 and 29, respectively. Further, the variance in anxiety among parents in this general pediatric setting may be larger than that in a PICU. Thus, the standard deviation was set conservatively at 11; Melnyk's average standard deviation was 10. Given these hypothesized means and standard deviation, a sample size of 41 per group is required at alpha = .05 and power = .90. A further 10% was added to account for loss of subjects to follow-up, giving a final sample size of 45 per group.

4.3 DESCRIPTION OF THE INTERVENTION

The intervention comprised two components: 1) introduction of the NMPMC to nurses; and, 2) introduction of the NMPMC to parents. The NMPMC was taught to 3 research assistants by the researcher. Training sessions were held at the beginning of the project and each research assistant was oriented to the project by observing the researcher recruit one control and one treatment subject.

4.3.1 Introduction of NMPMC to Nurses:

Nurses were introduced to the NMPMC through a video, information sessions, and printed materials prior to beginning the randomization of parents. A few weeks prior to commencing the study an e-mail was sent to all nurses (N = 35) working on the selected study unit at the time to advise the nurses that the study was being conducted and that they would be receiving e-mails and notices in their hospital mail to keep them informed about the study.

Prior to any educational intervention that introduced the NMPMC, nurses were asked to complete a questionnaire measuring mutual participation in their own practice. The questionnaire was mailed to all nurses on the unit with a flyer explaining the sequence of the project and a cover letter that explained the nature and purpose of the project. The letter gave information about the questionnaire, the video, the information sessions for nurses, and the package of reading material that would be mailed to them.

After 85.7 % of the questionnaires were returned (within a 2 week period of time), the video was made available to the nurses and the content of the NMPMC was introduced to all the nurses on the selected unit through a second mailing. This mailing included a copy of information about the model for nurses (Appendix A), a diagram depicting the design of the research, an announcement about the incentives to promote their participation, and a copy of the NMPMC information that would be used for the parent intervention. These packages were attractively assembled and placed in their mail box on the study site ward of the hospital.

There was insufficient free time for nurses to view the 30 minute video during their work time. Therefore, multiple copies were made available for nurses to sign out and take home. The video was produced by Dr. Martha Curley and demonstrated the nurse's role in interacting with families according to the NMPMC. The video was duplicated with permission from Dr. Curley (personal communication November, 1998). Enclosed in the package for nurses to take home was an outline of content for note-taking and an evaluation form developed by the researcher.

Subsequent to the mailing of the NMPMC package, four information sessions were conducted for nurses by the researcher to further explain the study and the model and to gain staff nurse support and interest. While nurses were encouraged to attend these sessions, attendance was voluntary. These sessions were approximately one-half hour in length and were held at various times of the day over a period of two weeks to increase the availability of the sessions to nurses working various shifts. Content of these sessions was a reinforcement of the information they received in the mail and was drawn from a description of the model as presented in this paper in Chapter 3, section 3.2. The research design was explained and nurses were requested not to ask parents which information the parent received. During the study 3 new nurses were employed on the unit. The videos and written materials were made available and the researcher explained the project and materials to 2 of the 3 nurses. The one nurse was not available until the project had ended.

4.3.2 Introduction of NMPMC to Parents

Parents in the control group received a package containing information about the ward that was considered to be usual information (Appendix B). Parents in the treatment group received the usual information plus the additional materials about the NMPMC (Appendix C). The NMPMC materials included photographs of nurses on the unit engaging in nursing care activities with children and parents. This technique was used to draw the parents into reading the material because they would see familiar nurses in the photographs. The content, including photographs, was spread across three double-sided pages and presented in color.

The parents in both the control and treatment groups were given binders that looked identical. The researcher/research assistant gave the binder to the parent and turned to the section which contained the information. Parents were asked to review the information at their earliest convenience and were provided an evaluation form to complete after they felt they had reviewed the information sufficiently to evaluate it. Parents in the treatment group received two sets of information (usual information plus information about NMPMC) and two evaluation forms (one for each set of information).

Between 16-24 hours after admission both control and treatment groups were again approached and asked whether they had reviewed the information. A form was kept in the binder to document when the researcher had reviewed the information with the parent and to monitor whether the parent had read the material. Each subject in both the control and treatment groups was approached at least once daily thereafter to determine whether they understood the material and whether they had any questions about the information. These interactions were no longer than five minutes; these daily contact times were also used to check how soon they might be discharged and to remind them to complete the package of forms at discharge.

4.4 MEASURES

Measurement included parent and child demographic data including characteristics of the child's hospitalization, the Spielberger State/Trait Anxiety Inventory (STAI), measurement of mutual participation by parents and nurses, and evaluation of the intervention materials.

4.4.1 Demographic Data and Characteristics of Hospitalization

A form was developed by the researcher to collect demographic information considered relevant to this study. The form was self-administered by the parent and reviewed by the researcher; it included age of child and age of parent respondent, number of children in the family at home, gender of child and parent respondent, reason for admission, number of previous hospitalizations, education and employment of parent respondent and spouse/partner of respondent, marital status, and place of residence. (See Appendix D).

4.4.2 The State-Trait Anxiety Inventory (STAI)

The STAI (Spielberger, 1983) has two separate 20-item self-report scales: the State Anxiety Inventory (SAI) and the Trait Anxiety Inventory (TAI) (Appendix E and F). The SAI assesses feelings of apprehension, tension, and worry that vary in intensity over time. Feelings of anxiety (SAI) at specific points in time are measured by asking subjects to indicate how they feel about each of the 20 items on a 4-point Likert scale that ranges from 'not at all' (1) to 'very much so' (4). The second 20 item scale (TAI), indicates an individual's anxiety proneness with responses ranging from 'almost never' to 'almost always'. The range for each scale is 20 to 80, with higher scores representing greater anxiety. The scale has been used in a variety of pediatric settings (Melnyk, 1994; Berenbaum & Hatcher, 1992; Keatinge & Gilmore, 1996; Tiedeman, 1997) including pediatric emergency, pediatric intensive care, and a general pediatric hospital ward. High test-retest reliability (range of .73 to .86) is reported for trait anxiety (Spielberger, 1983). The validity of the STAI is supported by reports that demonstrate its ability to differentiate between normal and stressful conditions (Spielberger, 1983). The instrument has demonstrated high concurrent validity (.52 to .80) with other related measures (Spielberger, 1983).

4.4.3 Mutual Participation Questionnaire

The degree of parent-nurse mutual participation experienced by parents was evaluated with a questionnaire developed for this study by the author. In previous studies mutual participation was not measured. For this study a scale was developed from the literature describing the concept. Thirty items were drawn from the NMPMC as described in the publications of Curley and Wallace (1992) and Curley (1997) reflecting key concepts of mutual participation as summarized in Chapter 3 above. Two versions were developed: one for parents and one for nurses.

For the nurse questionnaire face validity was established by a team of 9 experts. It was reviewed by Dr. Curley, 2 clinical nurses specialists at the study site, 2 clinical nurse educators, 2 staff nurses in pediatric settings other than the study site, and 2 nursing students, one from the study site and one from the other pediatric ward in the same institution. The version for parents was reviewed by Dr. Curley, 2 staff nurses, 2 nurse educators, and 4 parents. After both of the versions were revised the instruments were again reviewed by Dr. Curley for final revisions prior to piloting the instrument.

Items were identical in the nurse and parent questionnaire, but the questions were re-worded to be applicable to parents or to nurses. The questionnaire has 30 items, scaled 1 to 5 ['not at all' (1) to 'very much' (5)]. There are two subsections of the questionnaire one of which focuses on what nurses do (18 items) and one that focuses on what parents do (12 items). Internal consistency and test-retest reliability, tested prior to use of the instrument during a pilot phase, are reported below.

4.4.3.1 Mutual Participation Questionnaire (Parent Respondent).

In the first section (Items 1-18) the questionnaire asked parents to indicate: 1) the importance of each item ("Importance" scale), and 2) how consistently nurses performed each item during the child's hospital stay ("Consistency" scale). In the second section (Items 19-30) parents were asked to indicate: 1) the degree to which they themselves performed each item ("Parent Behaviour" scale), and 2) how comfortable they were in performing each item ("Comfort" scale). The Mutual Participation Questionnaire for Parents can be found in Appendix G.

In pretesting, the instrument had high parent acceptability and feedback from 21 parents indicating that it was easily understood and answered. Some questions were slightly modified based on the results of the pretest. The four subscales were tested for internal consistency. Internal consistency was high for each : importance: $\alpha = .85$, consistency: $\alpha = .93$, parent behavior: $\alpha = .92$, comfort: $\alpha = .90$. Test-retest reliability was not assessed for this instrument; the same parents were not available at a later date.

4.4.3.2 Mutual Participation Questionnaire (Nurse Respondent)

The questionnaire administered to nurses at the beginning of the study had only 3 subscales. It had two sections in the nurse component (items 1-18) asking nurses to indicate: 1) the importance of each item, and 2) how well the nurses performed each item. In the parent component (items 19-30) there was only one section in which nurses were asked how much they felt parents performed each item. The Mutual Participation Questionnaire for Nurses - Pre-Intervention can be found in Appendix H.

The questionnaire used at the end of the study was identical to the one used at the beginning of the study with the exception that the nurse section (items 1-18) had 3 columns in which nurses were asked to indicate: 1) the importance of each item, 2) how well the nurse performed each item, and 3) how much the project information changed their practice from the time the project started. The Mutual Participation Questionnaire for Nurses- Intervention can be found in Appendix I.

The instrument developed for nurses to complete at the beginning of the study was piloted on another pediatric ward in the same institution as the study site. Eight nurses participated in a test-retest reliability phase of the project. They each completed the questionnaire twice, approximately three weeks apart. Test-retest reliabilities were calculated for three components of the scale. The intraclass correlation coefficients (ICC) for these three components were as follows: importance = 0.82, consistency = 0.92, and parent behavior = 0.79. These correlation coefficients were considered to be sufficiently high to use as an instrument to measure mutual participation in the main study. The least reliable component was the parent behavior subscale; it is possible that specific experiences that nurses had just prior to completing the questionnaire affected their answers in this section accounting for the slightly lower correlation between the test and retest scores.

The psychometric properties of these instruments established during the randomized trial are reported in the results section under section 5.4.3.

4.4.4 Evaluation of the Intervention

Parents in the treatment and control groups were asked to complete an evaluation of the material they received with respect to its relevance and usefulness. Two forms were developed by the researcher: 1) to evaluate the usual hospital information (See Appendix J), and 2) to evaluate the NMPMC information (See Appendix K). There were five questions concerning usual hospital information which asked parents to indicate how much the information helped them to understand the ward and to feel welcome and comfortable on the ward; they were asked to respond on a scale of 1-5 ['very little' (1) to 'a lot' (5)]. They were also asked to indicate whether all parents should receive the information and were invited to write other comments about information they would have liked to receive.

Additionally, parents in the treatment group were asked to complete an evaluation of the NMPMC information included in their binder. There were nine questions concerning the NMPMC asking parents to indicate how much the information helped them to participate in the way that was outlined in the model. These questions dealt with how much the parents asked nurses things, told them things, participated in various aspects of care, and how comfortable parents felt on the ward and in their parent role. Parents were asked to respond on a scale 1-5 ['very little' (1) to 'a lot' (5)]. On this form parents were also asked to indicate whether all parents should receive the information, what other information they would have liked to receive, and they were asked to indicate whether the amount of information was appropriate. For this last question they were asked to respond on a scale of 1-5 ['too little' (1) - 'just right' (3) and 'too much' (5)].

Nurses were not asked to complete a separate form about the usefulness of the information. They were only asked to indicate how much the project affected their practice when they completed the third column (questions 1-18) on the mutual participation questionnaire at the end of the study.

4.5 DATA COLLECTION PROCEDURE

4.5.1 Recruitment and Consent

Parents of children 3 months to 12 years of age were recruited 1-16 hours after admission. Eligible parents were approached by the researcher/research assistant and were given an information letter (Appendix L). Parents were given time to read the letter after which the researcher returned to review the information and answer questions. After questions were answered, and if parents verbally agreed to participate in the study, the consent form was explained and reviewed with the participating parent(s) and then they were asked to sign the consent (see Appendix M). Parents were given the choice as to which parent participated in the study. They were encouraged to select the parent that would be most often available to complete the questionnaires.

4.5.2 Randomization

Consenting parents were randomized to a treatment or control group. Allocation was blocked after every 8 cases to keep the number of treatment and control subjects entered at any point of time nearly the same. A list of 100 1's and 2's was randomly generated by computer. Each block of eight numbers was then examined and if there were unequal 1's and 2's in a block of 8 the group was manually adjusted to contain 4 number 1's and 4 number 2's. A set of sealed envelops was developed and numbered consecutively using the generated list with the 1's representing the control group and the 2's representing the treatment group. The assigned group was indicated on the inside of the sealed envelop.

4.5.3 Timing of Measurement

Demographic data, the Spielberger SAI and the Spielberger TAI were collected at 1-16 hours after admission. Measurement instruments and timing of measurement is summarized in Table 2. A minimum time of 1 hour prior to approaching parents was selected to allow the parents a settling-in time. The time range of up to 16 hours was used to make it feasible for the researcher/research assistant to be available within the designated time span in circumstances when subjects were admitted during the night. Availability of the researcher/research assistant from approximately 8:00 am to 6:00 pm made it possible to contact parents whose children were admitted during the night within the 16 hour time limit. At 16-24 hours post admission parents were asked to complete the State Anxiety Inventory. However, this second state anxiety measure was at no time completed until at least 8 hours had elapsed since the first measure of state anxiety. After parents had read the informational materials given to them and indicated they understood the information they were asked to complete an evaluation form.

Table 2
Timing of Measurement

I. Instruments Completed by Parents				
		Time of Administration		
Instrument	Constructs	1 - 16 hours post admission	16-24 hrs	Discharge
A. Demographic Questionnaire (Questions developed and tested in pilot)	• Sociodemographic characteristics of parent age, martial status, number of children, education etc.	✓		
	• Sociodemographic characteristics of child: age, number of previous hospitalizations etc.	✓		
	• Characteristics of family (no. of children, distance from hospital)	✓		
	• Circumstance of admission, diagnosis, where child admitted from	✓		
B. Anxiety Measures Spielberger Trait Anxiety	• trait anxiety	✓		
Spielberger State Anxiety	• state anxiety	✓	✓	✓
C. Mutual Participation Questionnaire (Parents) (Questions developed and tested in pilot)	• mutual participation			✓
D. Evaluation of Mutual Participation Materials (Questions developed and tested in pilot)	• evaluation of materials	when read and understand		
Evaluation of Hospital Information (Questions developed and tested in pilot)	•evaluation of materials	when read and understand		
II. Instruments completed by Nurses				
A. Mutual Participation (Nurses) Pre-intervention (Questions developed and pretested during pilot)	• mutual participation	Just prior to education of nurses: re mutual participation (time 1).		
B. Mutual Participation (Nurses) Intervention	• mutual participation	At the completion of the randomized controlled trial (time 2).		

At discharge parents were asked to complete the Mutual Participation Questionnaire for Parents and a State Anxiety Inventory.

Nurses completed a Mutual Participation questionnaire two weeks prior to the introduction of information about the model to nurses (Time 1). After the last patient in the randomized trial was discharged nurses were asked to complete a second Mutual Participation questionnaire (Time 2).

4.6 DATA ANALYSIS

The child, parent and nurse sample was described. Statistical testing was carried out to determine if: 1) the sample was representative of the eligible ward population; 2) the treatment and control groups were comparable at the beginning of the study; 3) significant differences existed between the groups in anxiety measures at 24 hours and at discharge; 4) significant differences existed between the groups in the degree of mutual participation experienced; 5) there was a significant relationship between anxiety and mutual participation; and, 6) there was a relationship between nurse and parent mutual participation scores.

4.6.1 Representativeness of Sample

Data for eligible children were used to compare parents who consented to participate in the study to those who did not. Differences in age were compared using a t-test. Reason for admission was categorized; diagnosis categories and gender were compared using chi-square analysis. Representativeness of the nurse sample was assessed using t-tests and chi square analysis of demographic characteristics.

4.6.2 Comparability of the Groups at Baseline

Groups were compared on demographic characteristics, previous experience with hospitalization, characteristics of current admission, and state and trait anxiety scores. Chi square analysis was used for categorical data, and t-tests for continuous data.

4.6.3 Anxiety Measures at 24 hours and at Discharge

Parent anxiety at 16-24 hours during hospitalization and at discharge was tested for differences between the control and treatment groups with a t-test in an intention to treat analysis. Differences in anxiety measures between the treatment and control groups represented the effect of the combined nurse-parent intervention compared to the nurse only intervention.

4.6.4. Degree of Mutual Participation Experienced

Degree of mutual participation experienced by parents in the control and treatment groups was compared using a t-test for each of the four subscales (importance, consistency, parent behavior, and parent comfort).

4.6.5 Effect of NMPMC on Anxiety

Mutual participation scores were correlated with anxiety scores at 16-24 hours and at discharge to determine if anxiety was significantly related to the degree to which parents experienced mutual participation during the hospital experience. A regression analysis using the four subscales to predict anxiety was carried out.

4.6.6. Relationship Between Nurse and Parent Mutual Participation Scores

Mutual participation was tested for differences among the treatment, control and time 2 nurse groups using an ANOVA. Pairwise differences were tested with Tukey's HSD.

CHAPTER 5

RESULTS

The findings of the study are presented in five sections: 1) description of the sample including the children, parents, and nurses; 2) the major findings; 3) the secondary findings; 4) findings other than those related to the hypotheses and research questions; and, 5) a summary of key findings.

5.1 DESCRIPTION OF SAMPLE

5.1.1 Representativeness of the Nurse Sample

The derivation of the nurse sample for this study is shown in Figure 4. Of 40 nurses employed on the ward, 5 were on extended leave including sick leave, educational leave, or pregnancy leave. Of the remaining 35, 30 (85.7%) completed the first questionnaire and 24 of those (80%) completed the second questionnaire. Overall, 68.6% of nurses on active duty for the whole study provided complete data. Demographic data were available for only two of the five who did not complete the first questionnaire. In the comparison of those who completed both questionnaires with those who did not, no significant differences were found in any of the variables measured. Representativeness of the nurse sample are reported in Tables 3 (demographic) and Table 4 (employment).

5.1.2 Representativeness of the Child and Parent Sample

Accrual of the sample of parent participants is shown in Figure 5. A total of 618 children were admitted to the ward during the study period. Of these, 206 were admitted for cancer or a cancer-related diagnosis and 412 were admitted with a diagnosis other than oncology.

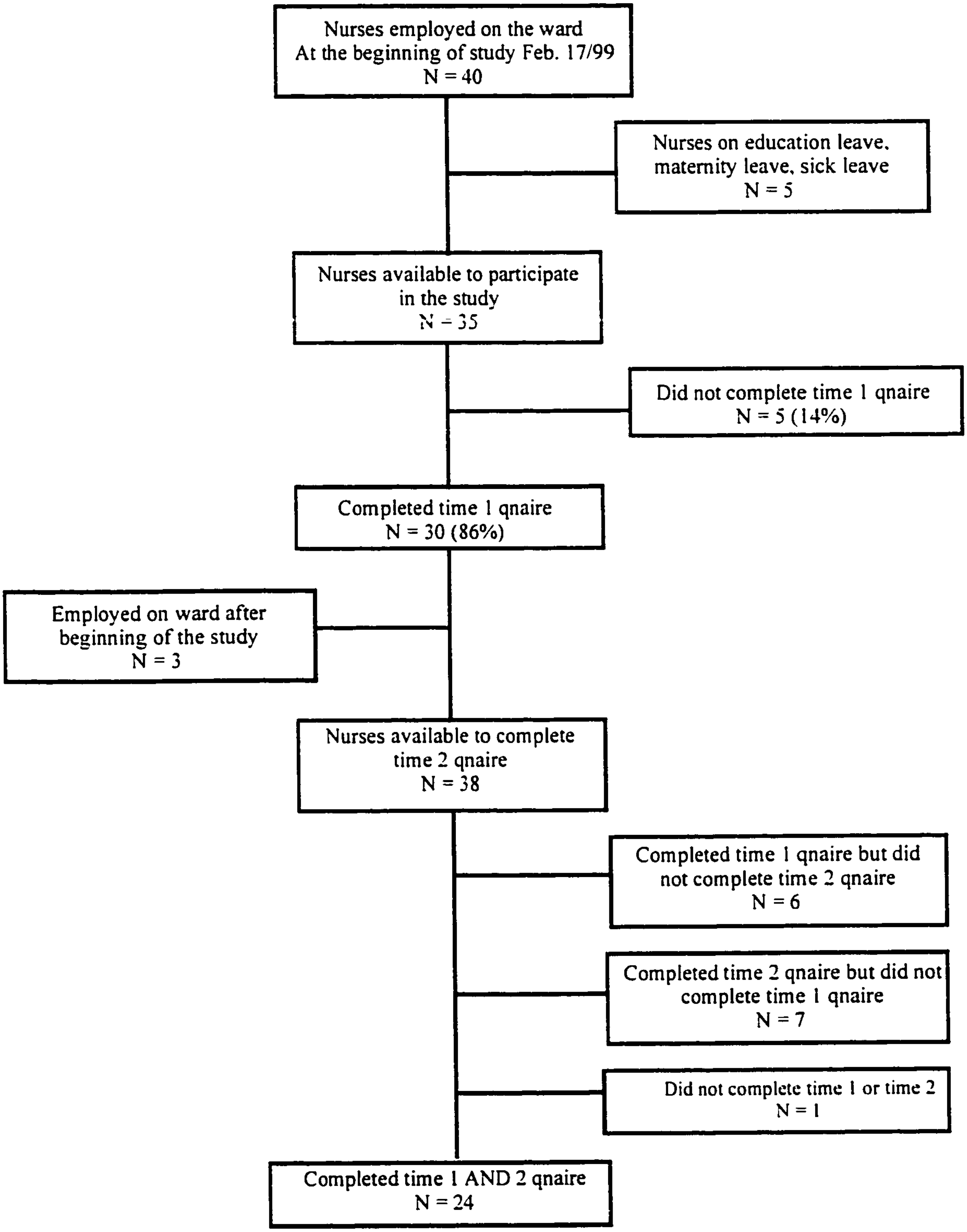


Figure 4 - Derivation of the Nurse Sample

Table 3

Representativeness of Nurse Sample (Demographic)

Demographic Characteristics	Did not complete t2		Did complete t2	
	N	%	N	%
Education				
RN	6	75.0	21	87.5
Baccalaureate	2	25.0	3	12.5
Total	8	100.0	24	100.0
Employment status				
Full time	4	50.0	12	50.0
Part time	3	37.5	9	37.5
Casual	1	12.5	3	12.5
Total	8	100.0	24	100.0
Age category				
50+			3	12.5
40-49	1	12.5	5	20.8
30-39	3	37.5	11	45.8
20-29	4	50.0	5	20.8
Total	8	100.0	24	100.0

Table 4

Representativeness of the Nurse Sample (Employment)

Employment Status	Questionnaire completion	
	Did not complete t2	Completed t2
Years working as a nurse		
Mean	9.9	14.6
sd	7.4	8.9
Min	1.0	.7
Max	19.0	36.0
N	6	24
Years working at this hospital		
Mean	8.5	10.4
sd	6.6	6.2
Min	1.0	.3
Max	17.0	18.0
N	6	24
Years working on this ward		
Mean	8.5	9.3
sd	6.6	6.9
Min	1.0	.1
Max	17.0	18.0
N	6	24

Of these, there were 260 children whose parents were not eligible to participate according to the study criteria, leaving 152 parents eligible to participate.

Of the parents eligible to participate in the study, 4 were not approached due to unavailability of the parent because of large numbers of constant visitors or being on the phone for long periods. Of the remaining 148 parents who were approached, 16 parents refused for reasons reported in the accrual diagram. Of the 132 parents who consented to participate, 21 were discharged prior to 24 hours and therefore could not complete the required questionnaires.

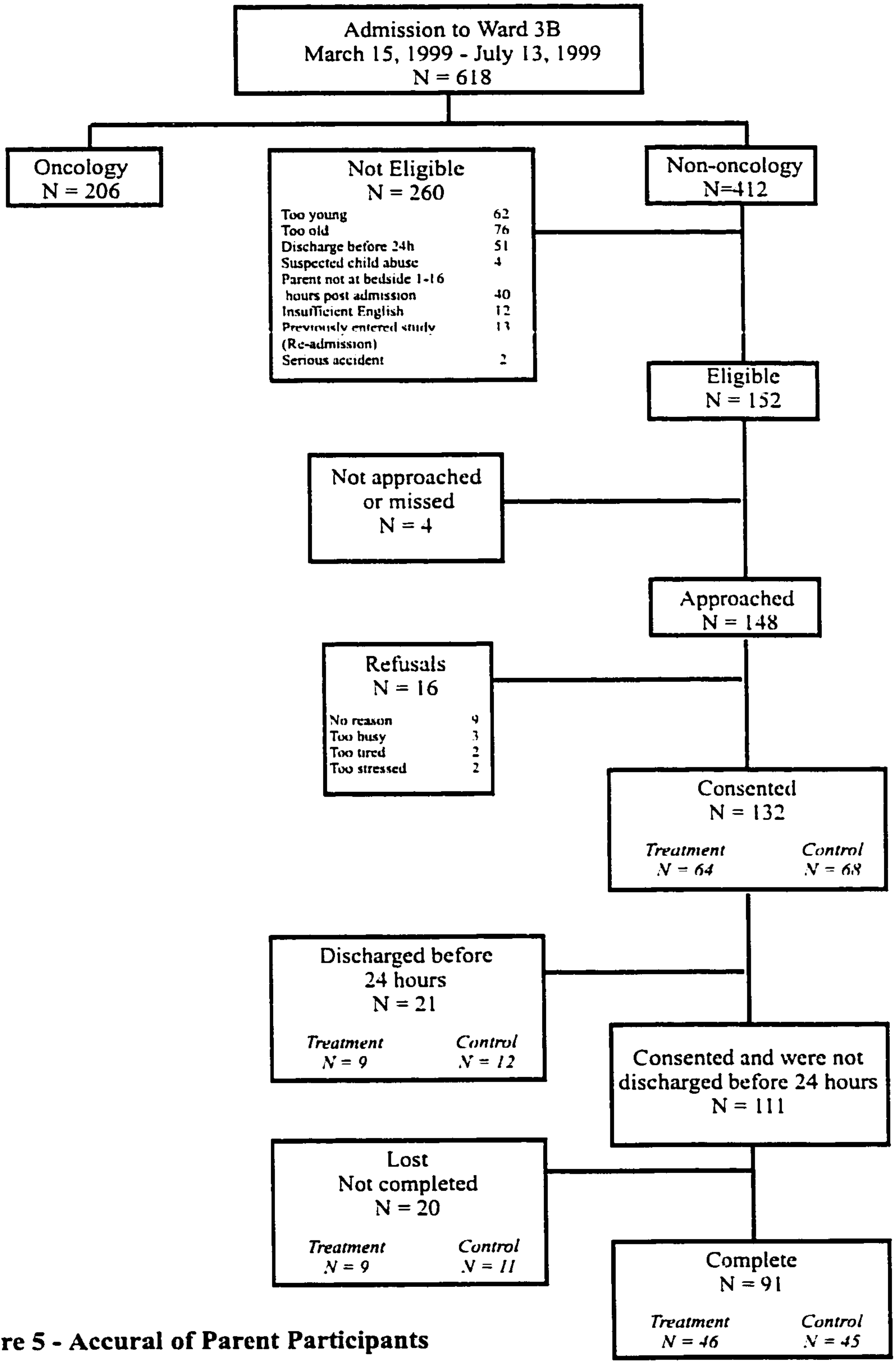


Figure 5 - Accural of Parent Participants

Of the 111 parents who consented to participate and who were not discharged before 24 hours, an additional 20 parents did not complete the discharge forms. No reasons were given for these dropouts; they usually left at a time when a researcher was not on the ward. The total number that completed the primary outcome measure (state anxiety at discharge) was 91, and the mutual participation questionnaire 90.

Participants who were eligible but refused to participate and those who dropped out during the study are described in Table 5 (gender and diagnosis) and Table 6 (age). No significant differences were found on these variables.

Table 5

Representativeness of the Child Sample (Gender and Diagnosis)

Gender and Diagnosis	Parents participated n=91		Did not participate n=57	
	N	%	N	%
Gender of child				
Male	43	47.3	30	52.6
Female	48	52.7	27	47.4
Reason for admission				
Gastro/fever/vomiting/flu	24	26.4	15	26.3
Surgical	13	14.3	3	5.3
Respiratory	14	15.4	15	26.3
Neurological	10	11.0	9	15.8
Skin	10	11.0	2	3.5
Endocrine	7	7.7	3	5.3
Other	13	14.3	10	17.5

Table 6

Representativeness of the Child Sample, Age

	Parents participated	Did not participate
Age of child		
Mean	4.1	3.2
sd	3.4	2.9
N	91	57

5.1.3 Demographics of Children, Parents, and Nurses

The parents of 91 children aged 3 months to 12 years participated in the randomized controlled trial. Characteristics of the child sample by group are displayed in Table 7. Of the 91 children, 43 (47.3%) were male. Most children (56/91, 61.5%) were admitted from the emergency room. For 35 (38.5 %) of the children this was their first hospitalization. Of the 91 children, 78 (85.7%) were admitted for medical reasons. Diagnoses of the children whose parents participated are summarized in Table 7. Age of child and average length of stay in the hospital, are summarized in Table 8.

Table 7

Comparability of children in the treatment and control groups

Characteristics	Treatment		Control		Total	
	N	%	N	%	N	%
Gender of child						
Male	24	52.2	19	42.2	43	47.3
Female	22	47.8	26	57.8	48	52.7
Admitted from						
Home						
Emergency room	9	19.6	4	8.9	13	14.3
Ward 3C	26	56.5	30	66.7	56	61.5
Surgery	3	6.5	1	2.2	4	4.4
Other	4	8.7	1	2.2	5	5.5
	4	8.7	9	20.0	13	14.3
Child in for surgery						
Yes	8	17.4	5	11.8	13	14.3
No	38	82.6	40	88.9	79	86.7
Total # of previous admissions						
None	18	39.1	17	37.8	35	38.5
1	15	32.6	10	22.2	25	27.5
2	3	6.5	7	15.6	10	11.0
3	2	4.3	5	11.1	7	7.7
4+	8	17.4	6	20.0	2	2.2
Reason for admission						
gastro/fever/vomiting/flu	11	23.9	13	28.9	24	26.4
surgical	8	17.4	5	11.1	13	14.3
respiratory	7	15.2	7	15.6	14	15.4
neurological	6	13.0	4	8.9	10	11.0
skin	4	8.7	6	13.3	10	11.0
endocrine	3	6.5	4	8.9	7	7.7
other	7	15.2	6	13.3	13	14.3

Table 8

Comparability of Children in Treatment and Control Groups (Age and Length of Stay)

Age and Length of Stay	Treatment	Control	Total
Age of child*			
Mean	3.0	5.2	4.1
sd	2.5	3.6	3.3
N	46	45	91
Length of stay (days)			
Mean	4.3	4.3	4.3
sd	2.8	3.0	3.0
N	46	45	91

*t= -3.39, df=89, p=.001

Characteristics of parents in the sample are shown in Tables 9 and 10 . Of parent respondents, 79 (86.8%) were mothers and 12 (13.2%) fathers. Most parents (75/91, 82.4%) had other children at home. The majority of families (58/91, 63.7%) lived within 20 miles of the hospital. Seventy-seven (84.5%) respondents were either married or living with a partner. Fifty-one (56.0%) had completed college/university; 48 (52.7%) of the spouses/partners of the respondents had completed college/university. Forty (43.9%) of the respondents were employed full-time, 26 (29.2%) were home-makers, and 23 (25.2%) were employed part-time or in other forms of partial employment. Sixty-eight (74.7%) of the spouses of the respondents were employed full-time.

To give a more complete picture of the nurses who cared for families in this study, Table 11 and 12 shows the characteristics of all nurses completing the demographic section of the time 1 or time 2 Mutual Participation questionnaire, including those who joined the ward after the beginning of the study; data were available for 35 of the 38 nurses who worked on the

Table 9

Comparability of Parents in Treatment and Control Group

Characteristics	Treatment		Control		Total	
	N	%	N	%	N	%
Person responding						
Mother	42	91.3	37	82.2	79	86.8
Father	4	8.7	8	17.8	12	13.2
Number of other children at home						
0	11	23.9	5	11.1	16	17.6
1	16	34.8	22	48.9	38	41.8
2	10	21.7	13	28.9	23	25.3
3+	9	9.9	5	5.5	14	15.3
Within 20 miles of the hospital						
Yes	27	58.7	31	68.9	58	63.7
No	19	41.3	14	31.1	33	36.3
Marital status, collapsed						
Married	37	82.2	40	90.9	77	86.5
Single/separated/divorced	8	17.8	4	9.1	12	13.5
Education, collapsed						
< Completed college/university	21	45.7	19	42.2	40	44.0
Completed college/university	25	54.3	26	57.8	51	56.0
Education, spouse, collapsed						
< Completed college/university	18	41.9	19	45.2	37	43.5
Completed college/university	25	58.1	23	54.8	48	56.5
Employment, collapsed						
Full time	21	46.7	19	43.2	40	44.9
Home maker	12	26.7	14	31.8	26	29.2
Other	12	26.7	11	25.0	23	25.8
Employment, spouse, collapsed						
Full time	35	81.4	33	82.5	68	81.9
Other	8	18.6	7	17.5	15	18.1

Table 10

Comparability of Parents in Treatment and Control Groups (Age of Parent)

	Treatment	Control	Total
Age of parent			
Mean	31.8	34.1	32.9
sd	8.0	5.6	7.0
N	44	41	85*

*6 missing birth date

Table 11

Demographic Characteristics of the Nurse Sample

Characteristics	N	%
Education		
RN	30	85.7
Baccalaureate	5	14.3
Total	35	100.0
Employment status		
Full time	16	45.7
Part time	12	34.3
Casual	7	20.0
Total	35	100.0
Age category		
50+	3	8.6
40-49	7	20.0
30-39	15	42.9
20-29	10	28.6
Total	35	100.0

Table 12

Demographic Characteristics of the Nurses Sample (Employment)

Employment	Mean	sd	Minimum	Maximum	N
Years working as nurse	12.2	9.0	.3	36.0	35
Years working at this hospital	8.8	6.5	.3	18.0	35
Years working on this ward	8.0	6.8	.1	18.0	35

ward during the study period. Most (85.7%) nurses were prepared at the Diploma in Nursing level; 45.7% were working full time. Mean number of years working as a nurse was 12.2 (sd 9.0), years working at the hospital was 8.8 (sd 6.5) and years working on the ward was 8.0 (sd 6.8).

5.1.4 Comparability of Groups

Tables 7 and 8 present the demographic characteristics of the children by group. Age of the child was significantly different between groups; the mean age of treatment children was 3.0 years (sd 2.5) versus 5.2 years (sd 3.6) in controls. No other significant differences were found.

Tables 9 and 10 present the characteristics of the parents by group. No significant differences were found on demographic characteristics. Trait and state anxiety scores at admission were similar in both groups (see Table 13).

Table 13

Comparability of Parents in Treatment and Control Groups (Anxiety at Admission)

Anxiety	Treatment	Control	Total
Trait anxiety at admission 20-80(worst)			
mean	33.8	35.5	34.7
sd	7.8	7.4	7.6
median	34.0	34.0	34.0
min	24.0	23.0	23.0
max	60.0	51.0	60.0
N	46	45	91
State anxiety at admission 20-80(worst)			
mean	44.2	42.6	43.4
sd	12.9	13.1	12.9
median	42.5	39.0	42.0
min	23.0	20.0	20.0
max	75.0	76.0	76.0
N	46	45	91

5.2 MAJOR FINDINGS

No significant difference was found between the control and treatment groups for parent anxiety at 16-24 hours during hospitalization. At discharge, parent state anxiety was significantly lower in the treatment group (M = 29.0; sd = 8.8) compared to the control group (M = 33.0; sd = 8.9) (see Table 14).

Of all anxiety measures, only state anxiety scores at admission were significantly correlated with the age of the child r = -.2634, p = .012, N = 91); however, tests for all anxiety measures were adjusted for age, since this was significantly different in the two groups.

Table 14

State Anxiety at 24 Hours and at Discharge

State Anxiety	Treatment	Control	Total
State anxiety at 24 hours			
20-80(worst)			
mean	36.2	37.9	37.0
sd	11.6	10.8	11.2
median	32.5	36.0	35.0
min	20.0	20.0	20.0
max	66.0	60.0	66.0
N	46	45	91
State anxiety at discharge			
20-80(worst)*			
mean	29.0	33.0	31.0
sd	8.8	8.9	9.0
median	26.0	32.0	29.0
min	20.0	20.0	20.0
max	53.0	55.0	55.0
N	46	45	91

*ANOVA adjusting for age of child:
F(group)=4.463, df=1,88, p=.037
Age had no significant effect on State anxiety score at discharge
F(overall)=2.357, df= 1,88,p=.101

5.3 SECONDARY FINDINGS

5.3.1 Degree of Mutual Participation Experienced by Parents

A comparison of the four subscales by t-test resulted in no significant difference between the treatment and control groups in the importance subscale (the importance of the item as assessed by parents) or the parent behaviour subcale (the degree to which parents performed each item). Significant differences were found in the consistency subscale (the consistency with which nurses performed the items as assessed by parents) and the comfort subscale (the comfort with which parents said they performed each item) between the treatment and control groups. The difference at p = .039 for the consistency scale was no longer significant when corrected for age (See Table 15).

Table 15

Means on Parent Mutual Participation Scales by Group

	Treatment	Control	Total
Importance of nurse MP activities 18-90(best)			
Mean	83.3	83.0	83.1
sd	7.4	9.0	8.2
Median	86.0	86.0	86.0
N	46	44	90
Consistency with which nurses performed MP activities 18-90(best)*			
Mean	70.9	64.4	67.7
sd	13.7	16.1	15.2
Median	73.0	68.0	72.0
N	46	44	90
Degree to which parents performed MP activities 12-60(best)			
Mean	46.1	44.2	45.2
sd	7.7	8.9	8.3
Median	45.5	43.0	44.0
N	46	44	90
Comfort with which parents performed MP activities 12-60(best) †			
Mean	51.4	46.3	48.9
sd	8.4	10.6	9.8
Median	53.0	48.5	52.3
N	46	44	90
MP Nurses			
Mean	154.2	147.3	150.8
sd	16.6	17.9	17.5
Median	158.0	148.0	154.0
N	46	44	90
MP Parents			
Mean	97.5	90.5	94.1
sd	14.4	18.0	16.5
Median	97.5	89.5	96.0
N	46	44	90

* F(age)=2.45, df=1,87, p=.121; F(group)=2.71, df=1,87, p=.103; F(overall)=2.58, df=2,87,p=.081

† F(age)=1.00, df=1,87, p=.319; F(group)=5.33, df=1,87, p=.023; F(overall)=3.17, df=2,87,p=.047

5.3.2 Nurse Responses on Mutual Participation Questionnaire

Descriptive statistics for the 24 nurse questionnaires completed at time 1 and time 2 are reported in Table 16. A paired t-test on the three subscales of Importance, Consistency, and Parent Behaviour did not reveal any significant differences between time 1 and time 2 measures. Mean score for the subscale reflecting how the intervention had changed nurses' practice was 48.2 (sd 18.2) on a scale of 18-90.

Table 16

Means on Nurse Mutual Participation Scales, by Time, (For those Completing a Time 1and Time 2 questionnaire)

Scales and Totals	Time 1	Time 2	Change
Importance of nurse MP activities 18-90(best)			
Mean	84.7	83.1	-1.6
sd	5.0	5.5	5.1
Median	85.00	82.5	-1.0
N	24	24	24
Consistency with which nurses performed MP activities 18-90 (Best)			
Mean	76.5	75.7	-.8
sd	7.0	6.1	5.7
Median	75.00	77.0	-.88
N	24	24	24
Degree to which parents performed MP activities 12-60(best)			
Mean	45.4	44.7	-.6
sd	6.2	6.5	6.1
Median	45.00	45.0	-2.0
N	24	24	24
MP total Parents (identical to Parent Behavior)			
Mean	45.4	44.7	-.6
sd	6.2	6.5	6.1
Median	45.00	45.0	-2.0
N	24	24	24
MP total Nurses			
Mean	161.1	158.8	-2.3
sd	10.3	10.3	9.0
Median	159.00	160.0	-2.0
N	24	24	24
How much project changed practice 18-90 (t2 only)			
Mean		48.2	
sd	-	18.2	-
Median		49.0	
N		24	

5.3.3 Relationship Between Anxiety and Mutual Participation

Parent state anxiety scores at 16-24 hours and at discharge were not significantly correlated with any of the four subscales in the mutual participation measure for parents (see Table 17). In a regression analysis, the four subscales altogether explained a total of only 5.7% of the variance in parent state anxiety at discharge.

Table 17

Correlation of the Parent Mutual Participation Scale Scores with Anxiety Scores

	r	p	N
Importance	.2018	.056	90
Consistency	-.1155	.278	90
Parent behaviour	.0235	.826	90
Comfort	-.0866	.417	90
MP Nurse total	-.0058	.957	90
MP Parent total	-.0396	.711	90

5.3.4 Relationship of Nurse and Parent Responses

No significant differences were found among the treatment, control, and nurse groups for the subscale of importance (nurse mutual participation activities). In the consistency scale there was a significant difference between the rating by nurses (M = 70.9; sd 13.7) and the control group (parents) (M = 64.4; sd 90) with nurses rating themselves higher than they were rated by the parents in the control group. (See Table 18). In the parent behaviour subscale (degree to which parents performed mutual participation activities) no significant difference was found among the three groups.

Table 18

Mean Scores for Parent and Nurse Time 2 Mutual Participation Scales

Scales	Treatment parents	Control parents	Nurses	Total
Importance of nurse MP activities 18-90(best)				
Mean	83.3	83.0	83.9	83.3
sd	7.4	9.0	5.6	7.6
Median	86.0	86.0	85.0	86.0
N	46	44	31	121
Consistency with which nurses performed MP activities 18-90(best) *				
Mean	70.9	64.4	76.4	69.9
sd	13.7	16.1	6.8	14.0
Median	73.0	68.0	77.0	73.0
N	46	44	31	121
Degree to which parents performed MP activities 12-60(best)				
Mean	46.1	44.2	44.8	45.1
sd	7.7	8.9	6.7	7.9
Median	45.5	43.0	45.0	45.0
N	46	44	31	121

* F(overall)=7.6813, df=2,118, p=.0007
Significantly different groups are control parents vs nurses

5.4 OTHER FINDINGS

Findings other than those related to the hypotheses and research questions include; 1) evaluation of materials by parents; and 2) psychometrics of the mutual participation instrument developed for parents and nurses.

5.4.1 Evaluation of Materials by Parents

Forty-two of the 46 parents in the treatment group completed the evaluation questionnaire related to usual hospital information and 39 of the 45 parents in the control group completed it. Responses of parents were not significantly different between the two groups (Table 19). Most parents indicated that all parents should receive the usual hospital information. In the open ended question, an area that was repeatedly identified by parents in both the control and treatment groups was the need to receive information about parking, cafeteria hours, and more information about what other services are available in the hospital (not shown).

Parents in the treatment group responded positively to the value of the NMPMC material; mean scores on the nine questions ranged from 3.7 (sd 1.1) to 4.5 (sd .8) (See Table 20). Most parents indicated that all parents should receive the mutual participation material and they indicated that the amount of material was just right (mean 3.1, sd 0.8) with 3 being the midpoint from 1-5 indicating just right.

Table 19

Parent Evaluation of Usual Hospital Materials by Group

How much did the information help you to:	Treatment	Control	Total
1 Become familiar with the ward routines			
Mean	4.1	4.1	4.1
sd	1.1	1.1	1.1
N	42	39	81
2 Understand what is available for you			
Mean	4.2	4.3	4.3
sd	1.1	.7	.9
N	42	38	80
3 Understand what is available for your child			
Mean	4.2	4.2	4.2
sd	1.1	.8	1.0
N	41	38	79
4 Feel comfortable asking for the things you need			
Mean	4.0	3.8	3.9
sd	1.2	1.0	1.1
N	42	38	80
5 Feel welcome on the ward			
Mean	4.0	4.2	4.1
sd	1.2	1.0	1.1
N	42	38	80

	N	%	N	%	N	%
6 Should all parents receive this information?						
Yes		97.6	36	94.7	77	96.3
No	41	0	1	2.6	1	1.3
Maybe	0	2.4	1	2.6	2	2.5
	1					

Table 20

Treatment Group Parent Evaluation of Mutual Participation Materials

How much did the information help you to:		Treatment
1 Become familiar with the ward routines		
Mean		3.7
sd		1.1
N		39
2 Understand what is available for you		
Mean		3.9
sd		1.0
N		39
3 Feel comfortable asking for the things you need		
Mean		4.4
sd		.8
N		39
4 Take the initiative to tell nurses things about your child		
Mean		4.5
sd		.8
N		39
5 Ask nurses things about your child		
Mean		4.5
sd		.8
N		39
6 Bring your concerns to the nurses		
Mean		4.4
sd		.9
N		39
7 Participate in giving care to your child in a way that was comfortable for you		
Mean		4.2
sd		1.2
N		39
8 Participate in decisions about your child's care in a way that was comfortable		
Mean		4.0
sd		1.1
N		39
9 Feel welcome on the ward		
Mean		4.3
sd		.8
N		39
10 The amount of information to read was (1=too little 3 = just right 5 = too much)		
Mean		3.1
sd		.8
N		40
11 Should all parents receive this information	N	%
Yes	37	92.5
Maybe	3	7.5

5.4.2 Psychometrics of Mutual Participation Questionnaire for Parents and Nurses

5.4.2.1 Mutual Participation, Parent Questionnaire

A factor analysis was done on the four subscales, forcing items into one factor in each of the four components designed to measure importance, consistency, parent behaviour, and parent comfort. Four items loaded below .5 in the importance subscale and three items below .5 in the parent behavior subscale. Factor loading in the four subscales of the Mutual Participation-Parent Questionnaire are presented in Table 21.

The parent questionnaire was tested for internal consistency. Internal consistency was high for each of the four subscales; importance: $\alpha = .88$ ($N = 82$); consistency: $\alpha = .92$ ($N = 82$); parent behaviour: $\alpha = .80$ ($N = 86$); Comfort: $\alpha = .91$ ($N = 76$).

5.4.2.2 Mutual Participation, Nurse Questionnaire

A factor analysis was done on the subscales by forcing the items into one factor in each of the subscales. The loadings for the nurse scale were not as high as for the parent questionnaire for the subscales of importance, consistency, and parent behaviour; factor loading for the change in practice scale was high ranging from .60 to .87. Factor loadings of the mutual participation questionnaire completed by nurses are presented in Table 22. The Mutual Participation Questionnaire for Nurses was tested for internal consistency by taking all cases together at time 1 and time 2. Internal consistency was high for each of the 3 subscales (time 1 and time 2) and the one subscale (change in practice; time 2 only): importance: $\alpha = .85$; consistency: $\alpha = .83$; change in practice: $\alpha = .96$; parent behaviour: $\alpha = .85$.

Table 21

Parent Mutual Participation Scales, (Factor Loadings)

Scale and item	Loading
IMPORTANCE	
Q1A Made me feel welcome	.54509
Q2A Made me feel important	.53531
Q3A Tell them things about child	.27522
Q4A Explain purpose of equipment	.60756
Q5A Ask how I want to participate	.47236
Q6A Figure out how I can be most helpful	.72058
Q7A Helped me to feel self confident	.57530
Q8A Working together	.46823
Q9A Valued team member	.76322
Q10A Explanations re nursing care	.78880
Q11A Explained changes to expect	.53981
Q12A How to respond to behaviour	.56572
Q13A Ideas on how to respond	.61954
Q14A Ask me how child is doing	.69410
Q15A Tell me they value my opinion	.76127
Q16A Used my suggestions in care	.75104
Q17A Encouraged to take break	.39061
Q18A Encouraged to express any anxious feelings	.72736
CONSISTENCY	
Q1B Made me feel welcome	.54431
Q2B Made me feel important	.70347
Q3B Tell them things about child	.65571
Q4B Explain purpose of equipment	.69066
Q5B Ask how I want to participate	.69167
Q6B Figure out how I can be most helpful	.70944
Q7B Helped me to feel self confident	.65881
Q8B Working together	.86678
Q9B Valued team member	.76103
Q10B Explanations re nursing care	.67020
Q11B Explained changes to expect	.61934
Q12B How to respond to behaviour	.64955
Q13B Ideas on how to respond	.75795
Q14B Ask me how child is doing	.61260
Q15B Tell me they value my opinion	.77367
Q16B Used my suggestions in care	.55022
Q17B Encouraged to take break	.51692
Q18B Encouraged to express any anxious feelings	.59787

Table 21 (cont'd)

Parent Mutual Participation Scales, (Factor Loadings)

Scale and item	Loading
PARENT BEHAVIOR	
Q19A I told things about child	.62034
Q20A I told how I will participate	.53847
Q21A I asked about being most helpful	.62217
Q22A I asked about nursing care	.53299
Q23A I asked re changes in child's condition	.56838
Q24A I asked how best to respond	.66264
Q25A I suggested how best to respond	.61603
Q26A I told how my child is doing	.49349
Q27A I expressed anxieties	.70440
Q28A I could take breaks	.43118
Q29A I participated in decisions	.46061
Q30A I gave care	.56401
COMFORT	
Q19B I told things about child	.76115
Q20B I told how I will participate	.71585
Q21B I asked about being most helpful	.79321
Q22B I asked about nursing care	.73970
Q23B I asked re changes in child's condition	.81251
Q24B I asked how best to respond	.71376
Q25B I suggested how best to respond	.69654
Q26B I told how my child is doing	.68758
Q27B I expressed anxieties	.73684
Q28B I could take breaks	.64114
Q29B I participated in decisions	.74280
Q30B I gave care	.54445

Table 22

Nurse Mutual Participation Scales, (Factor Loadings)

Scale and item	Loading
IMPORTANCE	
Q1A Make parent feel welcome	.22783
Q2A Make parent feel important	.25162
Q3A Tell them things about child	.49632
Q4A Explain purpose of equipment	.54813
Q5A Ask how they want to participate	.46936
Q6A How they can be most helpful	.51473
Q7A Help them to feel self confident	.71338
Q8A Working together	.63411
Q9A Valued team member	.77937
Q10A Explanations re nursing care	.45287
Q11A Explained changes to expect	.43016
Q12A How to respond to behavior	.61635
Q13A Ideas on how to respond	.67865
Q14A Ask them how child is doing	.64084
Q15A Tell them I value their opinion	.51519
Q16A Use their suggestions in care	.57079
Q17A Encourage parents to take break	.35679
Q18A Encourage to express any anxious feelings	.43806
CONSISTENCY	
Q1B Make parent feel welcome	.42483
Q2B Make parent feel important	.63160
Q3B Tell them things about child	.35886
Q4B Explain purpose of equipment	.54724
Q5B Ask how they want to participate	.45389
Q6B How they can be most helpful	.77876
Q7B Help them feel self confident	.70392
Q8B Working together	.58226
Q9B Valued team member	.67936
Q10B Explanations re nursing care	.51716
Q11B Explained changes to expect	.57559
Q12B How to respond to behavior	.67816
Q13B Ideas on how to respond	.48925
Q14B Ask them how child is doing	.37018
Q15B Tell them I value their opinion	.25299
Q16B Use their suggestions in care	.33438
Q17B Encourage parents to take break	.39029
Q18B Encourage to express any anxious feelings	.52863

Table 22 (cont'd)

Nurse Mutual Participation Scales, (Factor loadings)

Scale and item	Loading
CHANGE IN PRACTICE	
Q1C Make parents feel welcome	.60449
Q2C Make parents feel important	.75297
Q3C Tell them things about child	.86904
Q4C Explain purpose of equipment	.73853
Q5C Ask how they want to participate	.77102
Q6C How they can be most helpful	.67471
Q7C Help them to feel self confident	.72427
Q8C Working together	.65878
Q9C Valued team member	.79235
Q10C Explanations re nursing care	.80967
Q11C Explained changes to expect	.79870
Q12C How to respond to behavior	.75785
Q13C Ideas on how to respond	.76102
Q14C Ask them how child is doing	.79096
Q15C Tell them I value their opinion	.88941
Q16C Use their suggestions in care	.87586
Q17C Encouraged to take break	.82990
Q18C Encourage to express any anxious feelings.	.86112
PARENT BEHAVIOR	
Q19 Parent told things about child	.65483
Q20 Parent told how they will participate	.60589
Q21 Parent asked about being most helpful	.71545
Q22 Parent asked about nursing care	.71871
Q23 Parent asked re changes in child's condition	.66707
Q24 Parent asked how best to respond	.67540
Q25 Parent suggested how best to respond	.71705
Q26 Parent told how their child is doing	.70070
Q27 Parent expressed anxieties	.45734
Q28 Parent could take breaks	.48761
Q29 Parent participated in decisions	.48302
Q30 Parent gave care	.46636

5.5 COMPLIANCE

The information in the binders of the control and treatment groups was reviewed with all parents by the researcher or research assistant. Parents were then asked to read it again on their own. Parents were asked on the second day whether they had reviewed the material. All parents participating in the study reported reviewing the material at least once. Some read it more than once.

Of the 35 nurses on the ward at the time of the introduction of the NMPMC, self-reported compliance data were complete for 26. Of these, 25 (96.2%) reported having read the material, 23 (88.5%) had viewed the video and 13 (50%) had attended sessions.

5.6 SUMMARY OF FINDINGS

The major hypothesis was supported. Parents in the treatment group reported a lower level of anxiety at discharge than parents in the control group. The secondary hypothesis -- parents in the nurse and parent intervention group will experience a greater degree of mutual participation than parents in the nurse intervention only group -- was supported in one of the four components of the parent mutual participation scale. Parents in the treatment group reported higher levels of mutual participation in the subscale of how comfortable parents feel in mutual participation activities. On the secondary hypothesis, introducing nurses to NMPMC on a general pediatric ward will have the effect of increasing the degree of mutual participation nurses experience, conflicting results were found. There was no significant difference in reported level of mutual participation by nurses before and after the intervention. However, when nurses were asked whether the NMPMC educational sessions and materials changed their practice, nurses reported that the information had a moderate impact on their practice. The secondary hypothesis: a parent's degree of mutual participation experienced will be inversely correlated with their level of anxiety reported at discharge was not supported. There was no significant correlation between anxiety and mutual participation; all mutual participation subscales explained little of the variance in anxiety at discharge.

In the analysis of nurse and parent responses on the mutual participation questionnaires, a significant difference was found between the control group (parents) and the time 2 nurse group in the consistency subscale.

CHAPTER 6

DISCUSSION AND IMPLICATIONS

The discussion of the study findings is presented in five sections. The sections include: 1) a discussion of the study findings in relation to the literature; 2) a discussion of the study findings in relation to the conceptual framework; 3) limitations of the study; 4) conclusions from the study; and 5) implications for practice, education, and research.

6.1 FINDINGS IN RELATION TO THE LITERATURE

6.1.1 Major Hypothesis: State Anxiety at Discharge

A comparison of state anxiety scores reported in studies using the Spielberger instrument contributes to the interpretation of the current study results. State anxiety scores around the time of admission in the current study are slightly lower than in some studies (Melynk, 1994; Vulcan and Nikulich-Barrett, 1988) and higher than in others (Tiedeman, 1997). The mean state anxiety scores in this study at admission were 44.2 (sd 12.8) for the treatment group and 42.6 (sd 13.1) for the control group. The mean state anxiety scores at admission reported in the literature range from 39.2 (sd 12.3) to 49.0 (sd 9.2); those in the current study are within this range. A summary of state anxiety means and standard deviations is presented in Table 23. The differences in these admission scores could be real differences in the samples, i.e. the people measured were different or the people had the same amount of anxiety but reported it differently. Or, there may have been error variance from the measurement instrument since any instrument will have some error associated with it.

Mean anxiety scores during hospitalization in the current study were very similar in the treatment and control groups; those reported in other studies show a difference of 5 to 9 points

Table 23

Comparison of State Anxiety Means and Standard Deviations (Sd)

	Admission (before intervention)		During hospitalization		At discharge		Post-discharge	
	Treatment	Control	Treatment	Control	Treatment	Control	Treatment	Control
Hunsberger	44.2 (12.8)	42.6 (13.1)	36.2 (11.6)	37.9 (10.8)	29.0 (8.8)	33.0 (8.8)		
Vulcan (1988)	49.0 (9.2)	46.7 (12.0)	34.1 (8.2)	39.2 (10.1)				
Melnyk (1994)	Not reported		38.3* (7.7)	46.6 (11.6)			33.0 * (8.7)	39.8 (12.8)
			40.7** (9.9)				29.8 ** (9.1)	
			39.1*** (11.2)				30.4 *** (9.3)	
Tiedeman (1997)	M = 39.7 (12.3)				M = 32.9 (8.7)		M = 30.7 (9.1)	

* Combined Information
** Parental Role Information
*** Child Behavior Information

between treatment and control groups. The similarity between the treatment and control groups in the current study may have occurred due to the later introduction (up to 16 hours after admission) of the intervention compared to immediately upon admission (Vulcan & Nikulich-Barrett, 1988) and within 12 hours of admission (Melnyk, 1994). The scores during hospitalization that are most similar to those reported in the literature are the treatment group in the current study (36.2) and the treatment group that received the combined information (38.3) in the Melnyk (1994) study. The greatest discrepancy in means during hospitalization was between the control group (46.6 sd 11.6) in the Melnyk (1994) study and the control group

(37.9 sd 10.8) in the current study. The anxiety scores reported by Vulcan and Nikulich-Barrett (1988) for the treatment group and those in the current study treatment group are similar; the scores reported for the control groups by Vulcan and in the current study are also similar. The mean scores during hospitalization may show less consistency across studies because of the variations in timing of interventions.

The discharge state anxiety scores in the current study are consistent with reports in the literature. Tiedeman (1997) reported a mean state anxiety score of 32.9 (sd 8.7) within 24 hours prior to discharge from the hospital. This serves as a comparison for the mean discharge score of 33.0 (sd 8.8) in the control group of the current study because both scores are for subjects who were not exposed to an intervention. The discharge mean state anxiety score of 29.0 (sd 8.8) for the treatment group of the current study is considerably lower than in the normative population of working adults, however, it is consistent with other reported scores as described above, and is also consistent with the mean of 29.6 (sd 6.9) reported by Spielberger (1983) for females tested in a relaxed condition. Because of the consistently lower scores compared to the population norms reported across the hospitalization studies, it could be interpreted that when parents complete a state anxiety scale at a point after the hospitalization experience, their response is affected by what they have just come through--they respond with a point of comparison in mind, that is the experience of hospitalization. It is, therefore, reasonable to expect a rating that is consistent with the emotion of relief and that it might be similar to a relaxed situation; this is in contrast to a score that might characterize a point in time that reflects the usual anxieties in life.

Overall, the state anxiety scores in this study are similar to those reported in the literature considering the variability in sample and methodology among studies. The subjects in the Vulcan and Nikulich-Barrett (1988) and Melnyk (1994) studies were parents of younger children (1-5 and 2-5 years of age), whereas Tiedeman (1997) studied parents of children aged 5-11 years. Although age of child has not consistently been found to be related to parent anxiety (Tiedeman 1997), in the current study age was found to be a factor that affected state anxiety at admission. The children in this study were aged 3 months to 12 years. Melnyk (1994) entered subjects into the study within 12 hours after admission and the intervention was done immediately following completion of the initial forms. This procedure is similar to that in the current study, except that the intervention was begun somewhat later; subjects were entered up to 16 hours after admission followed by the intervention.

There was also a difference in delivery of the information across studies. Melnyk (1994) used tape recordings which parents were asked to listen to in a private room. This technique was not used because of the hesitancy parents showed when asked to leave their child's room when doing parent interviews for a previous study (Hunsberger et al., 1999) in the same setting. In the current study the intervention was limited to written information and verbal explanations introducing parents to the intervention (NMPMC) information.

The mean scores of the normative population of working adults have been reported by Spielberger (1983) as 35.2 (sd 10.6) and 35.72 (sd 10.4) for men and women, respectively. State anxiety mean scores at admission reported in the literature range from 39.7 (sd 12.3) to 49.0 (sd 9.2) which are higher than these population norms. According to the current study and other similar studies (Vulcan & Nikulich-Barrett, 1988; Melnyk, 1994), these comparisons suggest that having a child admitted to the hospital is an anxiety-producing experience for parents.

Curley (1988) and Curley and Wallace (1992) used the NMPMC as an intervention and measured outcome with the PSS: PICU instead of the SAI (Spielberger, 1983). This instrument measures specific dimensions of the parent's experience during hospitalization, whereas, the SAI measures a more general anxiety state. Curley (1988) found a significant difference in the level of stress experienced by the experimental group in the dimensions of the child's behavior and emotions, parental role alteration, children's procedures, nursing behavior and in the computed PSS: PICU total, with the experimental group experiencing reduced stress. Similarly, Curley and Wallace (1992) found a significant difference between the control and experimental group in the dimensions of parental role and the computed PSS: PICU total, with the experimental group experiencing less stress. These findings of reducing parent stress when the NMPMC was introduced to nurses lend support to the current results in which the NMPMC reduced anxiety when introduced to both nurses and parents.

It is interesting that the child's age did not significantly affect discharge state anxiety of parents even though it significantly affected state anxiety at admission. It is possible that the universal effect of feeling relieved to go home resulted in age no longer making a difference, while at admission the dependency of a young child on parents could have the effect of increasing parent anxiety compared to the experience with older children.

The results of being able to affect the anxiety level of parents with an information-giving intervention is an important finding. Although the difference of 4 points on a 20-80 point scale represents only a 6.7% difference, it is important to note that the intervention is inexpensive in terms of nursing and parent time and effort, as well as in terms of the cost of materials. It should also be recognized that with more intensive education for nurses and with open discussion between the nurse and parent about the model, there is a potential to have a greater effect on anxiety.

6.1.2 Secondary Hypotheses

6.1.2.1 Degree of Mutual Participation Experienced

The finding that the intervention significantly increased parent comfort is important. With respect to the importance scale the findings are consistent with what was expected. It was expected that there would be no difference between the treatment and control groups in how the parents rated the importance of each item of the nurses' activities. The way a parent judges the importance of each nurse activity is a value and belief that parents hold about the profession of nursing and is not likely affected by a one-time intervention such as information giving about the NMPMC. The subscale of consistency, however, could be affected by an intervention that encourages parents to engage nurses and interact with them. The intervention of introducing the NMPMC to parents could have the effect of increasing parent expectations of nurses resulting in lower ratings of nurses by parents. On the other hand, it is possible that the intervention could help parents to understand the intent of nurses and thus view what nurses do in a more positive way resulting in a higher rating of nurses on the consistency scale even though nurses may not have actually behaved differently. The results prior to correction for age indicated that parents in the treatment group did rate nurses higher on the consistency scale; after the scores were corrected for age there was no significant difference between the two groups. This indicates that parents of younger children may expect more of nurses or have a greater need for more parent–nurse mutual participation.

The expectation that parents in the treatment group would show more initiation of interaction with nurses and more evidence of working with nurses was not demonstrated. Melynk (1994) found an increased amount of participation in her treatment groups when information about parent role was provided. It is possible that the mutual participation information did not affect the way parents sought to work with nurses or that the instrument did not effectively measure this construct. Parents in both groups indicated that they participated with nurses in the care of their child.

The reason for finding no difference in what parents did may be because there in fact was no difference in the behavior of the parents in the treatment and control groups, the mutual participation instrument was not sensitive enough to pick up the difference, or parents did not report their activities accurately. Parent behavior scores indicated that all parents were very involved in their child's care. One could interpret this as a social desirability effect, that is, that all parents would feel they should report high involvement in caring for their child.

The NMPMC information was found to have the effect of making parents feel more comfortable in the interactive process of caring for their child in partnership with nurses; parents in the treatment group had a significantly higher score on the comfort scale. The higher score on the comfort scale indicates that parents introduced to the NMPMC developed a comfortable interactive relationship in which they could ask questions, tell nurses their own observations and participate according to their own abilities. This is an important goal to achieve in nursing practice and is an important finding. While the instrument needs further testing it is of clinical importance to have found this difference between the control and treatment groups.

6.1.2.2 Relationship Between Anxiety and Mutual Participation

It was expected that these two constructs would be inversely correlated: as mutual participation increased it was expected that anxiety would decrease. The inability to find this correlation could be because: 1) the two constructs are not in fact related; 2) the instrument did not measure mutual participation properly; or 3) there was not sufficient variability in the mutual participation scale. This measure is subject to the numerous biases of self-report scales and requires further refining to reduce these biases.

The measuring of mutual participation remains problematic within this study. It is particularly difficult to understand why the comfort scale of parents did not correlate with parent anxiety. This finding indicates that the mechanism by which the intervention with parents reduced parent anxiety is not understood and requires further study.

6.1.3 Other Findings

6.1.3.1 Evaluation of Materials by Parents

It was expected that parents would evaluate the usual hospital information similarly in the treatment and control groups. The material was viewed as worthwhile, with both groups indicating that it should be given to all parents. Information in written form received at the time of admission was viewed by parents in a very positive way. This is of particular interest at a time when personnel shortages and patient overload reduce the amount of time that nurses have to verbally explain the hospital facilities and routines.

Parents in the treatment group rated the helpfulness of the NMPMC information highly: mean scores on all of the items ranged from 3.7 (sd 1.1) to 4.5 (sd 0.8) on a range of 1-5. For example, the questions about whether parents: 1) take initiative to tell nurses things; and 2) ask nurses things about your child were scored high by parents with a mean of 4.5 (sd .8) for each item. The additional comments that parents offered related to instrumental resources have been previously reported in the literature (Curley & Meyer, 1996; Fisher, 1994, Hunsberger et al., 1999). These issues may not be conducive to change in the current hospital environments but it adds information to take into consideration as nurses plan their care for parents.

6.1.3.2 Nurses' Responses to Mutual Participation Questionnaire

Nurses rated the items on the importance scale consistently high with a mean of 84.7 (sd 5) on a scale of 18-90 at time 1. This would indicate that nurses believed before the intervention that the mutual participation items were important; the high scores at the beginning meant there was no room for improvement in the importance score. These high scores indicate that the items selected for this subscale are behaviors deemed important for nurses to practice in their relationship with parents.

It was expected that the educational intervention of teaching nurses about the NMPMC would increase their score on the consistency scale between time 1 (before the intervention) and time 2 (after the intervention at the end of the randomized controlled trial with parents). There is insufficient data in this study to support the premise that educating nurses about the NMPMC significantly affects their practice. While they reported an effect on their practice, the data collected at time 1 and time 2 indicated no change in practice. There are no comparative data in the literature to evaluate the effect on nurses of introducing the NMPMC to nurses. Curley and Wallace (1992) asked nurses whether they would implement the model. Out of a possible range of 3-15 points the nurses' scores ranged from 9-15 which was interpreted as an indication that they would implement the model "in at least most situations" (Curley & Wallace, 1992, p. 382). However, the actual actions of the nurses with respect to mutual participation were not measured.

In the current study, the inability to find a significant difference in any of the subscales between time 1 and time 2 nurse scores may be related to numerous factors. The finding of no significant difference between time 1 and time 2 could be because: 1) there was no actual difference; 2) the instrument did not measure mutual participation; 3) the instrument measured mutual participation, but in a way that was not sensitive to change; or 4) the nurses were not reporting accurately. The reasons no actual difference might exist could be because: 1) the nurses were already engaging in mutual participation activities; 2) the nurses did not "learn" the mutual participation material; or 3) they learned it (cognitively) but did not implement/practice it. Reasons for not learning the material could be that they did not have the time to study the material. These are only speculations in that the only evidence we have from the data is the nurse's report that the intervention made a difference in their practice -- yet this data is not supported by the responses that show no difference in mutual participation before and after the intervention. The conflicting data cannot be explained but support the need to continue the testing and development of the mutual participation scale. The data on how much the intervention changed their practice could be the result of a social desirability response even though they were completing questionnaires anonymously.

6.1.3.3 Psychometrics of Mutual Participation Questionnaire for Parents and Nurses

This study contributes a beginning data set toward the development of an instrument to measure mutual participation. Curley and Wallace (1992) recommended that in future studies outcome measures should include parental perceptions of mutual participation to increase our understanding of the NMPMC. The current study contributes an instrument that can be further tested for use with parents and nurses. While internal consistency and test-retest reliability were high, further testing is required. Of interest is the finding that the mutual participation scores did not correlate with parent anxiety, yet from a theoretical viewpoint it would seem that there should be some correlation. Also, some of the questions did not load well into the one factor of mutual participation. Additional analysis of this data set and other data sets will need to be done to be confident that the instrument is valid, reliable and sensitive to change. This instrument is currently being used by an associate of Dr. Curley to collect additional data; this will serve to further validate this instrument and make revisions as indicated.

6.1.4 Relationship of Nurse and Parent Responses on the Mutual Participation Scale

It is important to recognize that nurses who answered this questionnaire responded with respect to their overall experience with parents rather than at a specific point in time or with a particular group of parents. Nurses could not be asked to respond to their experience specifically with the parents in the study because many times they did not know which parents were participating. The answers of nurses, therefore, are affected by the attitudes they hold about parent performance in general. Interpretations of the findings in this study need to be made with this limitation in mind.

The finding of no difference in the subscale of importance among the treatment. control. and nurse groups was an expected result. This indicates that there is agreement between nurses and parents with respect to important activities that nurses should perform. This finding has relevance for the planning of care on children's units in that it provides a standard of care with respect to parent-nurse relationships -- one that is agreed upon by nurses and parents. This information is instructive for planning educational programs for nurses in practice, for those entering the profession, and for students in nursing.

The significant difference between the control group and the nurses on the consistency scale indicates that nurses perceive their performance in these important areas of practice to be at a higher level than is perceived by parents who were not introduced to the NMPMC. This may be because nurses are responding to self-perceptions of the usual care rather than the care they delivered at the time this particular group of parents was on the ward. Because of the bias that self-report can introduce it is also possible that nurses responded with answers that reflect what they would like to do, rather than what they actually do. While the mean score in the consistency subscale of the parents in the treatment group was also lower than that of the nurses, the results indicate that the treatment group perceptions of nurse performance are not significantly different from the rating by nurses themselves. These results can be interpreted to mean that when parents are made to feel important and are introduced to a model that emphasizes their mutual contribution, it may affect how they view the performance of nurses. The process at work may be that parents recognize the approaches and efforts of nurses in the context of mutual participation and are then able to label what nurses do.

The importance of understanding the perceptions of both nurses and parents is that these perceptions are likely to affect the nature of the nurse-parent relationship. The difference between the parent control and nurse group is an important finding and indicates that introduction of the NMPMC may have the secondary effect of altering parent perceptions of how nurses perform these important mutual participation activities. These ideas need to be subjected to further testing with parent-nurse dyad responses on the performance of mutual participation activities by nurses.

With respect to parent behaviors, the similar ratings by the treatment, control, and nurse groups indicate that parents and nurses agree in their perception of parent behavior. Again, it is important to recognize that nurses were responding to this questionnaire with respect to their experience with parents they encounter on the ward over time. As they answered these questions they would have also included in their reporting parents who do not stay with their children in the hospital. The agreement between nurses and parents in this scale indicates that nurses view the parents as very involved in decisions, planning, and giving care. This does not, however, clarify whether nurses are satisfied with the role of parents. It does not give information as to whether they feel parents are too involved or too demanding.

6.2 FINDINGS IN RELATION TO THE CONCEPTUAL FRAMEWORK

The lower level of anxiety in the group that was introduced to the NMPMC supports the theoretical assumptions of the transactional model of stress and coping. The experimental group was introduced to information about the NMPMC which is characterized by "a high degree of empathy, equal partnership, and a reciprocal sharing of expert advice" (Curley & Wallace, 1992, p. 384). The reciprocal recognition of one another's point of view is exemplary of the "mutually reciprocal bi-directional relationship" (Lazarus & Folkman, 1984, p. 293) that comprises the transactional model of stress and coping. The new relational meaning flowing from a bi-directional process affects the appraisal of the significance of the situation and of the resources or options that parents have. If parents in the experimental group did establish such a new relational meaning then it would follow that their appraisal of the situation of hospitalization would be affected in a way that could reduce their anxiety. When relational meaning is established, nurses value the contributions of parents and parents are encouraged to "identify a role that they each will find individually helpful" (Curley & Wallace, 1992, p. 384). It follows that parents in the treatment group who were taught about mutual participation would experience a lower level of anxiety because of their appraisal of the situation i.e. the equality of the relationship and sense of their own resourcefulness. The parents who felt assured that nurses were there to work with them and that they themselves were being valued would feel less threatened and anxious about the event.

The NMPMC comprises both problem-focused and emotion-focused coping elements; it encouraged parents to get physical help from nurses to care for their child but also to express concerns and worries about their child. These processes, according to the transactional model of care, would alter the appraisal of the situation with resultant alterations in emotions. These processes, therefore, could explain the lower level of anxiety in parents who were introduced to the NMPMC.

The higher scores for parents in the experimental group in the mutual participation questionnaire in the comfort scale is further evidence to support the transactional model of stress and coping. The results indicate that the NMPMC intervention affected this important component of mutual participation. However, according to the theoretical framework of the transactional model of stress and coping, if mutual participation is experienced to a greater degree with respect to parent comfort, it would be expected that those same parents would experience a lower level of anxiety. The intervention did result in a lower anxiety level and in a higher level of mutual participation in the comfort scale by parents, but the two were not significantly correlated. This calls into question the mechanism of action. Since the source of anxiety can be much broader than only how parents relate to nurses, these results seem to indicate that anxiety may have been reduced by mechanisms not measured by the mutual participation scale. Variables thought to be related to anxiety (demographic characteristics, number of hospital admissions, surgery, diagnosis etc) were tested. The treatment and control groups were not significantly different at admission on any of these. The one exception was age of child, and statistical testing of all anxiety scores adjusted for age of child. While some other mechanism may have been at work, it was not any of the variables that were measured.

6.3 LIMITATIONS OF THE STUDY

Controlling the experiment in a naturalistic setting was difficult. Each parent was advised not to discuss the contents of their binder with other parents or with nurses. The researcher and research assistant did ask parents whether they shared any of the information and according to their self report none of the participants shared their information with other parents or with nurses. At least two nurses were asked twice a week by the researcher whether they knew which information the parents had received. Nurses all responded that they were aware parents had a binder but they did not know which information each parent had received. An attempt was also made to keep the parents blind as to which information they received. Because both groups received information and because the binders and information packages were identical in appearance from the outside, parents were not aware whether they received the experimental or the control information. All parents were told that two kinds of information were being tested but they were not told what the two kinds of information were. It was interesting that none of the parents asked which information they received. While every attempt was made to keep nurses and parents blind, and there was no indication that they were not kept blind, one cannot be entirely sure about this aspect of the procedure.

Another limitation of this study is that because the model promotes a sharing of information it is probable that the model could have a greater effect if each nurse and parent dyad could discuss the elements of the NMPMC and talk about how it will be implemented. However, to evaluate its effect it was necessary to make every effort to keep the parents and the nurses blind. Parents did not ask which information they had and nurses did not ask which information parents had; parents and nurses accepted these restrictions because they knew it was a research project. With open communication between parents and nurses it is expected a greater effect of treatment could be demonstrated. Also, if nurses could have been randomized to treatment and control groups using a four-group design, a greater effect may have been demonstrated. In such a design the lowest anxiety scores would be expected in the group of treatment nurses with treatment parents; however, on this ward this design was not feasible.

The stresses within the unit for nurses at the time of the study made it difficult to operationalize a comprehensive educational program for nurses. It also made it difficult to ask nurses to complete evaluation forms for each segment of the program because of the strain on their time. A specific limitation of the study is that the nurses did not formally evaluate the program format. They did indicate whether it changed their practice but their feedback would have been helpful in the design of future research and educational programs.

The sensitive nature of the study limited the extent of testing that could prudently be carried out with nurses. It would have been useful to collect data from specific nurse-parent dyads, that is, to ask a specific parent to evaluate their level of mutual participation with a specific nurse and ask the nurse in turn to evaluate the degree of mutual participation with that same parent. Collection of this type of data would have required a separate subset of consent forms and data collection processes. The researcher also sensed that this type of information would be sensitive to collect at this particular time because of the strain on nurses which made them feel they could not do the kind of job they wanted to do. The sense of being specifically evaluated in this way by parents would have added an extra stress to their working situation. For this particular study it was felt that the more general use of the mutual participation questionnaire was appropriate until the psychometric properties of mutual participation instrument are further established.

The need to exclude parents who could not speak and read English is a limitation in this study because it resulted in a sample of primarily white, middle class parents. Using different forms of presenting the information could have expanded the sample. For example, a video or tape recorded information that parents could listen to would reduce the necessity of reading ability. In this study having parents watch a video or listen to a tape was financially prohibitive due to cost of having sufficient tape-recorders available. The need for parents to learn how to use the machine would add an additional time factor for the researcher to monitor and it would have been more difficult to keep nurses from knowing group assignment of parents. Also the monitoring of equipment to ensure it would not be lost or stolen would have required additional personnel time on the ward.

The long waits in the emergency room and the rapid discharge from the ward were two phenomena that worked together to reduce the length of time that the model could have an impact on the participants. Parents and children often spent many hours in the emergency room waiting for a bed on the ward. During the waiting period, lab work was done and treatment was begun, so that often by the time they reached the ward the child was already improving. For this reason, a considerable number of subjects were lost because they were discharged within 24 hours from the time they were admitted to the ward. The broad range of 1-16 hours made it possible to enter more parents because admissions overnight were not lost; however, the parameter of 16 hours reduced the number of hours that some of the subjects were actually exposed to the information. For example, parents of children who were admitted during the night may have been introduced to the information at around 16 hours after admission and discharged from the unit within another 16 hours. This may have reduced the impact of the intervention in the experimental group.

A broad age range of children was necessary to facilitate data collection within a reasonable time period; however, it is possible that the intervention would be more suited to parents with children within a smaller age range and restricted to younger children. The sample size was too small to make any judgments about the effect of age range from the data in this study. The significant difference in age in the control and experimental group is a limitation in this study because there may be other intervening variables related to age that have not been tested for in this study. It is probable that had the sample size been larger, the two groups would have been more similar in age range.

6.4 CONCLUSIONS FROM THE STUDY

From this study it can be concluded that if nurses on the ward have been introduced to the NMPMC and if parents who are on the hospital ward more than 24 hours are introduced to the NMPMC, they will experience less anxiety at the time of discharge compared to those parents who have not been introduced to the model. It can also be concluded that these parents as a group will experience an increased level comfort as measured by the mutual participation instrument. It can be further concluded that a lower anxiety level is not related to mutual participation as measured in this study. Finally, based on the results of this study, nurses rate their own consistency of performing mutual participation activities as measured in this study at a higher level than do parents. Those parents who have not been introduced to the NMPMC rate the consistency of performance at a significantly lower level than nurses themselves. Parents who have been introduced to the NMPMC also rate the consistency of performance of nurses at a lower level than nurses themselves, but the differences in scores are not significantly different.

These conclusions are dependent on the model being introduced in a way that is similar to the procedure that was followed in this study and in a similar setting. The findings in this study are dependent on not only giving the information but taking five minutes to discuss the information and being given the opportunity on a daily basis to further discuss their experience. These findings are generalizable only to children's units with a similar mix of ages, diagnoses, and length of stay as well as children whose parents have a similar educational level and who stay at the bedside to make the educational program possible.

The conclusions concerning the degree of mutual participation experienced by parents are limited because the instrument used to measure mutual participation requires further testing. Although the instrument was piloted and there is some evidence of reliability and validity, the lack of correlation between anxiety and mutual participation as measured calls into question the validity of the instrument or the validity of the hypothesis that the concepts of anxiety and mutual participation are in fact related. The STAI by Spielberger (1983) is a well-established instrument and the results in this study are comparable to those in other studies. However, it might have strengthened the study to have an instrument that more specifically measures the stress experiences of hospitalization. Such an instrument was not available; the PSS:PICU instrument used in PICU settings was not appropriate for the setting selected in this study, which was a nonintensive care setting.

6.5 IMPLICATIONS FOR PRACTICE, EDUCATION, AND RESEARCH

6.5.1 Implications for Practice

This study provides new data for pediatric wards in acute care settings. Prior to this study the NMPMC was introduced only in pediatric intensive care settings. Furthermore, this study presents information about the impact of introducing the NMPMC to parents in addition to nurses. Because this study used a randomized controlled trial design the results of this study are of particular interest compared to previous studies which were conducted using less rigorous designs. This study demonstrates that a simple intervention of giving parents written information about the NMPMC, ensuring that they read it, using approximately 5 minutes to review the major points of the model, and reinforcing the information will result in a lower anxiety level at the time of discharge than if parents are given only the usual hospital information. It also suggests that parents experience a higher level of mutual participation in that they feel more comfortable in their relationship with nurses regarding the care of their child. Based on this study, when a child is admitted to an acute care pediatric setting the materials parents receive about the ward should be supplemented with specific information about the NMPMC in an attractive, easily readable form. Nurses should reinforce the information by asking whether they read it and respond to any questions they have. If parents can be affected by only giving written material and having minimal contact with the parents, there is good potential for this model to have an even greater impact if nurses who care for parents consistently reinforce the mutuality of the nurse-parent relationship and deliver their care according to this model. This data, along with previous studies, provides information for institutions to begin to consider the adoption of the NMPMC as a philosophy of care in acute care pediatric settings.

6.5.2 Implications for Education

This study has implications for nursing and parent education. The results regarding the usefulness of education for nurses are mixed. However, in this study the mutual participation model was introduced to parents in the context of nurses also having received the information; therefore, education of nurses should supplement parent education if the same results were to be obtained. Furthermore, the discrepancy in how nurses view themselves and how parents in the control group viewed nurses indicates that more education is required for nurses and parents to understand each other's needs. As this perception gap is closed there is a potential for nurse-parent relationships to evolve into higher levels of relational meaning.

This study has implications for the education of student nurses working with parents in an acute care setting. Nurses learning how to care for parents should be introduced to the NMPMC so that they can effectively intervene in a way that has been demonstrated to reduce the stress of parents and to make parents feel comfortable in working with nurses to care for children.

While the results from this study do not indicate that education of nurses affects nurse performance, there is indication that more education is needed for nurses to judge their own delivery of nursing care practices with respect to mutual participation with parents. Because parents benefit from this model, new staff nurses who have not yet developed their own practice patterns should be taught this model as a framework for developing nurse-parent relationships as they embark on their professional careers. Because nurses and parents agree on the items that are important in a nurse-parent relationship, these items can be used as practice guidelines toward achieving best practice for nurses.

6.5.3 Implications for Research

The results of this study demonstrate that further knowledge is required to understand the experience of parents and nurses working together in pediatric acute care settings when a child is hospitalized. Because the data did not support that there is a relationship between anxiety and mutual participation, the mechanism of anxiety reduction needs to be further explored. This finding leads one to believe there is a need for further testing and modification of the instrument developed to measure mutual participation for this study. There is a need to learn more about the constructs that comprise mutual participation and how they affect the experience of parents and nurses. Further research issues include whether parent anxiety can be reduced by teaching parents alone the NMPMC or whether nurses also need to be exposed to information sessions as part of their orientation to a specific ward. The conflicting findings regarding change in nurse practice demonstrates the need for a greater understanding of how to measure mutual participation as practiced by nurses. There is no clear understanding of how teaching nurses about the model affects their perceptions of their practice or the way they actually practice. Developing an acceptable way to test the level of mutual participation experienced in selected dyads of nurses and parents would be an effective strategy to develop a better understanding of how mutual participation is viewed by nurses and parents. Future studies should be designed to include a manipulation check with respect to nurses, that is, to determine whether they carried out the various phases of the mutual participation model. A setting in which nurses could be randomized to treatment and control groups would also be an effective design to further measure the effects of teaching nurses mutual participation. Testing in ways other than self report to determine the effect of teaching nurses about the mutual participation model on actual nursing practice is also recommended.

This study should be repeated but the sample should be selected in a way that controls for age. Consideration should be given to stratifiying for age in which case a larger sample would be required. Another approach could be to restrict the age range to avoid the confounding of age between control and treatment groups. The study should also be designed to focus on parents of younger children, a time when the intervention is most likely to have an impact. Since a child's age is correlated with a parent's anxiety at admission, and Curley and Wallace (1992) reported that the model has a greater effect on parents of younger children, the model should be tested in populations limited to younger children; the age when parents are most directly involved in their child's care, with the upper limit being around the age of 10.

6.6 SUMMARY

This study has supports findings in previous studies, presents new findings, and identifies areas for changes in practice and education as well as research directions. The result of a reduced level of anxiety is an important finding and should be further tested. The potential for the NMPMC to influence nurse-parent relationships, according to the transactional model of coping and stress should be further tested. The effect of the NMPMC on the experience of parents and nurses requires further attention from clinicians, educators, and researchers as the future hospital environments are characterized by advanced technology and increased levels of acuity of hospitalized children. A specific contribution that this study has made is the development of an instrument that has the potential to accurately measure the effects of mutual participation with further testing and revision. With the current emphasis on consumer involvement in health care, the findings in this study contribute to this larger body of health care system research.

APPENDIX A

Mutual Participation Information for Nurses

NURSING MUTUAL PARTICIPATION MODEL OF CARE*

INFORMATION FOR NURSES

The Nursing Mutual Participation Model of Care (NMPMC) emphasizes that parents are important to their hospitalized child and that nurses help parents find ways to continue to be important to their sick child. It is based on the premise that nurses and parents work together to an understanding about the individual needs of parents and their children. Parents are invited to actively participate and partner in the care of their child to the degree that is individually comfortable for them.

Central to the model is the belief that nurses value and deliberately encourage parents to express their individual ideas, concerns, and needs. Nurses and parents remain **flexible** to achieve mutual goals. Information and suggestions about care are equally shared between parents and professionals to achieve the best care for each child. The combination of practices emphasized in this model have been introduced and studied in various settings in the U.S. The NMPMC is the focus of the current Parent Comfort study being conducted on 3B. This model defines an approach that is consistent with the goals of practice at Children's Hospital. The attached is a summary of the model.

***This model was developed by Martha A. Q. Curley, RN, PhD, CCRN, Children's Hospital, Boston, MA.**

NURSING MUTUAL PARTICIPATION MODEL OF CARE INFORMATION FOR NURSES ... cont'd

To Nurses: ***The following information outlines the components of the Nursing Mutual Participation Model of Care.***

A. HELP PARENTS TO FEEL WELCOME AND ABLE TO FUNCTION WITHIN THE HOSPITAL SYSTEM

The model emphasizes that it is important to make each parent feel welcome and comfortable in the hospital environment as soon as is possible after admission. The process of admission can set the milieu for the entire hospitalization. Encourage parents to ask for clarification of anything they do not understand.

Equipment in a child's room is overwhelming for parents. Offer explanations about equipment and ask parents if they have any other questions. Include the child as appropriate for age in these explanations.

Parents can feel overwhelmed by the many people involved in their child's care. Let parents know who the various people are on the team. If you are unable to answer a parent's questions direct them to the appropriate person on the team.

This model stresses the importance of helping parents be as comfortable as possible. Explain reasons for any restrictions and encourage parents to voice their concerns about anything that interferes with their ability to support their child. Make individual adaptations to meet their needs as possible.

B. HELPING PARENTS TO GET AND SHARE INFORMATION ABOUT THEIR CHILD'S ILLNESS

The model emphasizes mutual sharing of information. Parents know their child the best and make excellent observations about their child and child's illness. Encourage parents to share their observations and explain your observations. At the same time, explain as much as you can about the child's condition and care. Help educate parents about their child's illness, illness trajectory and what to expect. If parents need further explanations than what you are able to provide, refer them to the appropriate team member to have their questions answered.

The model also encourages nurses to note whether parents seem to be feeling anxious about any aspect of their child's care. Explore their feelings with them and help them with their concerns; if you feel you cannot adequately relieve their anxieties refer them to the appropriate team member.

The exchange of information between nurses and parents is central to this model. Parents may notice changes in their child's appearance and behaviour related to his/her illness or hospitalization. Make a deliberate effort to get parents to share their observations and understanding of what they observe. Discuss these with parents and help them understand changes in their child's illness and behaviour. Clarify any misinterpretations.

C. FACILITATING A PARENT'S TRANSITION TO PARENTING AN ILL CHILD

In this model there is a strong emphasis on the importance of helping parents in their role of parenting an ill child. Parents of an ill, hospitalized child may feel different than they usually do in their parenting role. They may feel separated from their child by equipment or changes in behaviour and appearance. A primary goal in this model is to help parents be the best parent they can during their child's hospitalization. Parents often know what helps them and what does not help them so it is important for you to encourage parents to talk about how you can be the most helpful to them.

Parents recognize that you will have some suggestions about how they can better cope with the experience of hospitalization. It is important to share your ideas with parents. Focusing on things that are still the same about their child, such as their child's eyes, smile, or any special things their child does that is unique, may help parents to feel more comfortable in their parenting role during their child's illness and hospitalization. It may also be helpful to try to keep the environment as familiar as possible by encouraging parents to bring in some things from home such as a favorite toy, book, pictures, a blanket, music, etc.

According to this model nurses have an important role in helping parents to relate to their ill child. Parents may feel strained and uncomfortable because of their child's unusual responses. Explain to parents that children respond to hospitalization in a variety of ways; some may become quiet while others become demanding or irritable. Get parents to express how they are feeling about their interactions with their child. Parents have some ideas about how to parent an ill child but may lack confidence because their child seems so different. Combine parent ideas with your own ideas about relating to an ill child and role model some behaviours that parents can use. Offer some explanations for their child's behaviour related to illness and hospitalization.

D. HELPING PARENTS TO PARTICIPATE IN THEIR CHILD'S CARE

According to this model nurses play an important role in helping parents to participate in their child's care. Parents often need some time to become familiar with their child's care. Encourage parents to share their ideas about how to care for their child and also ask them to watch what you are doing and let them know that not all nurses do things the same.

Provide options to parents in how they might care for their child. Let parents know that care is flexible depending upon the individual needs of parents and children. As they feel comfortable, ask parents to indicate their preferences with respect to their involvement. The level of participation desired varies across individuals and circumstances. The goal is to encourage parents to participate at a level that is comfortable during hospitalization and to give them every opportunity to achieve a feeling of competence as they prepare to care for their child at home.

Parents are important and know their children the best. Ask them for hints about things that might work in caring for their child i.e. how to get their child to co-operate in the care he/she needs. Encourage them to share with you what works best for them so that you can help them to feel successful in caring for their child. It is the successful combining of your expertise as a nurse and that of the parent in a partnership that achieves the best care for each child.

Parents usually feel comfortable in caring for their child at home. Now that their child is ill, parents may feel overwhelmed with even the most basic aspects of care. Offer assistance with all aspects of care until parents make the adjustment of caring for their ill child to the degree that they feel they can. Encourage parents to identify areas in which they need more assistance or things they do not understand.

E. HELPING PARENTS WHEN THEIR CHILD NEEDS TO HAVE A PROCEDURE

Nurses and parents work together to support a child through a procedure. Parents who choose to stay with their child should be given assistance with the process of comforting their child. Parents often have excellent ideas about how to support their child. Encourage parents to express their ideas and offer additional ideas for the parent to choose from.

Assess how anxious parents are feeling about staying with their child during a procedure. Give parents the option of not staying with their child. Assure them that someone will attend to the comfort needs of their child. Let parents know that it is okay to wait somewhere until the procedure is completed.

Some parents may feel ambivalent because they themselves get upset when they stay with their child yet they feel obligated because they feel their child wants them to stay. Encourage parents to discuss their feelings and assist them to select an option of staying or not staying. Assure them their child will receive care and comfort either way.

NURSING MUTUAL PARTICIPATION MODEL OF CARE INFORMATION FOR NURSES...cont'd

F. HINTS ABOUT COMMUNICATION

Establish a Caring Relationship

Parents are important to a child's recovery. Verbalize to parents that you are here to care for them and their child and that they should feel free to express their concerns and voice their own needs. Deliberately seek to understand them by asking specific questions, for example, "How are you doing today?".

Parental Perception

Parents are very perceptive about their child's progress. Encourage parents to express their own observations about how they think their child is doing by specifically asking, "How do you think you child looks today?". Set a tone of working together so that you can elicit the help of parents in order to reach the best understanding of their child's needs. Specifically ask them questions such as, "Do you have any concerns you want to discuss with me?".

Parental Goals

Parents have their own set of goals, objectives and expectations. Encourage parents to make these known to the team. Encourage parents to express any feelings and concerns they have about their child's care. Encourage them to talk about what troubles them and to ask any questions they want answered. Especially try to elicit their greatest concerns by deliberately asking questions such as, "What concerns you the most about your child?".

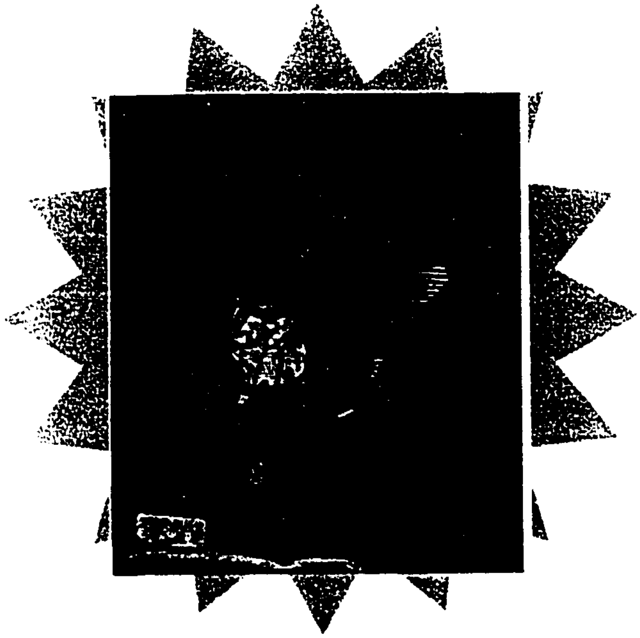
Invite Participation

Parents often want to be involved in decisions about their child's care. Encourage parents to bring any specific issues they want addressed to the nurse or any other professional that is involved in their care. Ask them questions which encourage working together such as, "How can we do this together?" or "How can I help you the most?".

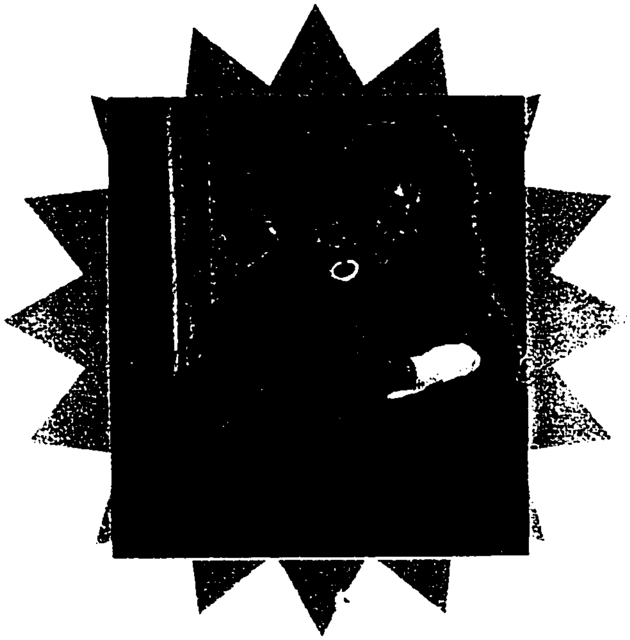
APPENDIX B

Usual Hospital Information

WELCOME
to the
Children's Hospital



PARENT COMFORT STUDY



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Note to Parents:

If you have received a blue pamphlet upon admission you will note this is the same information as in that pamphlet

A Guide for Children/Youth and Families

This guide is to help you learn about Ward 3B. We hope to make your child's stay here as comfortable as possible. A brochure with general information about the Hospital is available in your child's room. If you have any questions or concerns, please ask your child's nurse or health professional.

If you have further concerns, you may ask for the Clinical Manager, Alida Bowman (ext. 6346).

Visiting

Parents are welcome at any time to be with their child. We ask other family members or friends to visit between:

- 8:30 a.m. and 12:30 p.m.
- 2:00 p.m. and 8:30 p.m.

Quiet Time

Quiet time is between 12:30 p.m. and 2:00 p.m. This lights are often dimmed. During this time, children should be in their rooms resting or doing quiet activities.

Rooming In

A parent or designate may sleep in their child's room. A brother or sister may room in if they are 16 years of age or older. If you room in please fold up your cot at 8:00 a.m. so the nurse can begin morning care for your child. There may be rooms in the hospital that can be rented to families for a small cost or at Ronald MacDonald House. Ronald MacDonald House is available for some families next to the hospital. Please ask your child's nurse for further information.

Bed Time

Unless they are with a parent, children should b on the ward after 7:00 p.m. We ask that children be in their rooms by 9:00 p.m. with lights out by 10:00 p.m. to ensure rest and relaxation.

Telephone Calls

We ask that only parents call to see how their child is doing. Parents can then pass that information on to friends and relatives.

You can call directly into your child's room once you have the extension. Please try to call between 9:00 a.m. and 8:oo p.m.

Hospital Number - 521-2100
Pediatric Unit 3B - Ext. 5040

Call Bells

There are special call bells in each room to call for nursing help. Please ask your child's nurse how to use them. The call bells in the bathrooms are for emergencies.

Food

Hospital food is supplied through the kitchen for the patients only. Parents may bring in food for themselves and their children and keep it in the white refrigerator locked in the kitchen area. Please label your food containers and date them so they will not be thrown out.

Television

Please fill in a card near the front desk to rent a TV. We also have VCRs, movies and Nintendo games which can be used between 8:30 a.m. and 10:00 p.m. There are limited numbers of machines available. Directions for use are with the equipment.

Isolation

Occasionally children must be placed in isolation to prevent the spread of infection. Ask you nurse for details prior to entering isolation. Handwashing is very important. Family members should not visit if they have a cold or flu.

People That May Be Involved in Your Child's Care

- ➢ Nurse
- ➢ Physician
- ➢ Resident (a doctor in training to be a specialist.)
- ➢ Occupational Therapist
- ➢ Physiotherapist
- ➢ Speech Therapist
- ➢ Child Life Specialist
- ➢ Health Care Aide
- ➢ Learners
- ➢ Other Staff, depending on your child's needs

We will introduce ourselves to you and your children. Please let us know if you do not understand our role.

General Information

We encourage you to bring in personal items for your child and/or family such as:

- ➢ His or her favorite toy
- ➢ Blanket
- ➢ Toothbrush and toothpaste
- ➢ Shampoo and hygienic items
- ➢ Diapers
- ➢ Kleenex
- ➢ And any other personal hygiene needs

Please write your child's name on any personal items. We recommend that you keep valuable items at home. You are responsible for your child's belongings in the room.

For safety, please do not bring electrical appliances. Battery-operated appliances are okay. The supply room is for the staff only. Please ask your child's nurse for help. Washrooms in the patient's room are for patients only. There are washrooms and showers for parents near the family room. Visitors may use the public washrooms across from the red elevators.

Thank you so much.

We wish to provide a comfortable and caring environment for children and families. There are suggestion boxes on each of the wards and outside the wards. We wish to hear your ideas.

APPENDIX C

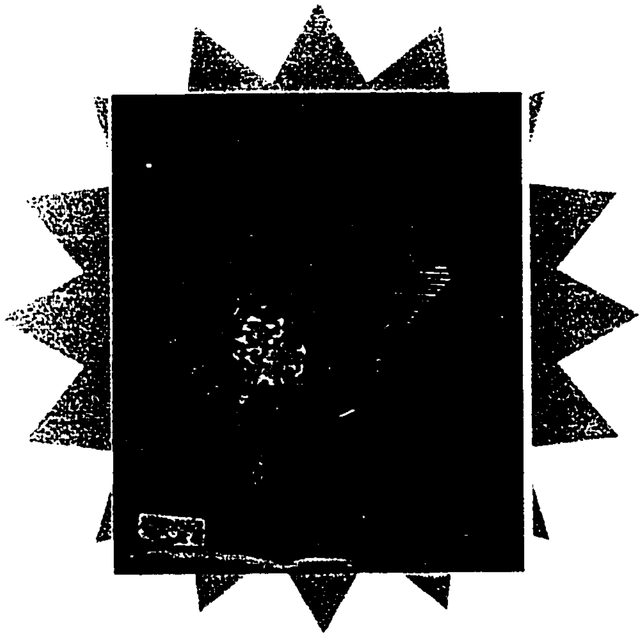
NMPMC Information for Parents (treatment)

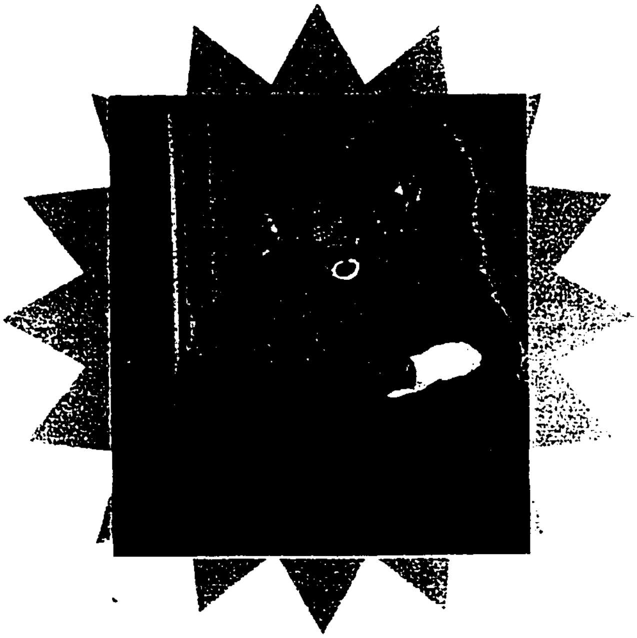
WELCOME
to the
Children's Hospital

PARENT

COMFORT

STUDY





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To Parents:

The following information outlines the main ideas about mutual participation and how you can work with nurses.

Instructions:

1. ***Nurses know that some parents are receiving this information, but they do not know whether you have it.***
2. ***Please do not share this information with other parents.***
3. ***Please read all the material.***
4. ***Re-read the material periodically until you are very familiar with it.***
5. ***Try to do the things that are suggested to help you during your child's hospitalization - your feedback at discharge will be helpful.***

Thank you for your help in this project.

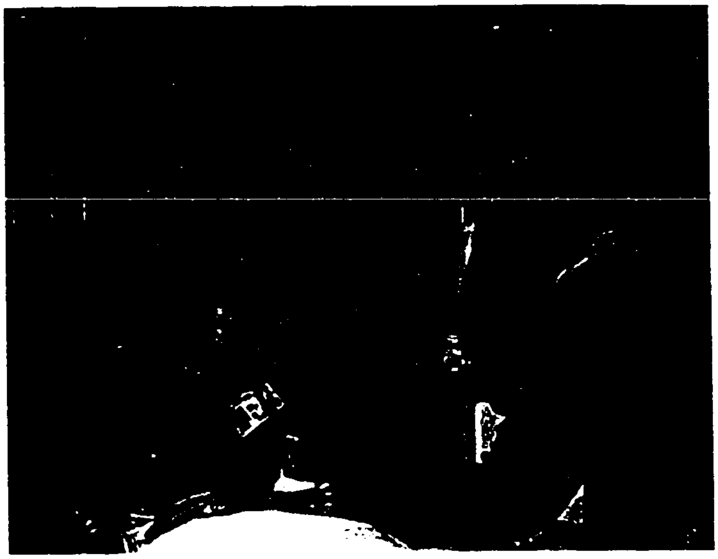
This information has been compiled by Mabel Hunsberger, Principal Investigator, Parent Comfort Study, Copyright, 1999.

If you have any questions about this study, please do not hesitate to contact Mabel Hunsberger, Associate Professor, School of Nursing, McMaster University at (905) 525-9140, ext. 22404.

NURSING MUTUAL PARTICIPATION MODEL OF CARE* INFORMATION FOR PARENTS

Here at Children's Hospital we believe that children benefit when parents and nurses work together to care for hospitalized children. You are encouraged to participate in the care of your child to the degree that is comfortable for you. Mutual participation means that:

information and suggestions about care are "equally shared "



Mutual participation is sharing information and working together

Mutual participation also involves a sense of mutual respect for one another...an acceptance of each other's viewpoint.

Your ideas are valued:

Your ideas and suggestions about the care of your child are valued and your questions, concerns, and worries should be brought to the attention of your nurse. The intent is that you will receive the information and the support you need to be involved in the care of your child, in a way that is comfortable for you. The enclosed information for parents is about a specific nursing approach called the **Nursing Mutual Participation Model of Care**.

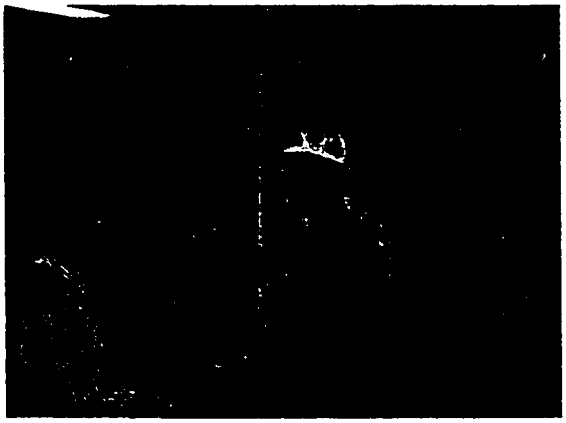
*** This model was developed by Martha A. Q. Curley, RN, PhD, CCRN Children's Hospital, Boston, MA**

To Parents: The main ideas about mutual participation are outlined in these pages. Please read and review several times. You will be given an opportunity to evaluate whether it has helped you to feel more at ease during your child's hospitalization.

FEELING WELCOME AND LEARNING ABOUT THE HOSPITAL

You are welcome here....

We want to make you feel welcome, show you where things are on the ward, and to explain the ward routines as soon as possible after admission. Admission is a busy time but our goal is to orient you to your surroundings as soon as possible.



Ask about the kitchen if you have not been shown around

If you are uncertain about things related to the ward and hospital, ask your nurse to help you. Things to ask about are showers and washrooms for parents, the kitchen area, a place to keep food, rooming-in, T-V's and the phone. If you need more information to make you feel comfortable, express this to your nurse. There are also Health Care Aides who work on this unit who can help to show you around.

Nurses cannot always know what the individual needs of parents are. It is helpful if you ask about the things for which you need some explanations. For example, you may see unfamiliar equipment in your child's room or have questions about how something works or where to find something.

There are many people involved in the care of your child. If you have questions about who does what, check with your nurse first. The team has many different professionals available to support you and your child. If you need something and don't know who to ask, check with your nurse first.

GETTING AND SHARING INFORMATION ABOUT YOUR CHILD'S ILLNESS

Nurses recognize that parents make excellent observations about their child's illness. You can help by telling your nurse what you observe about your child and give any suggestions you have about what your child needs. If you don't know what certain changes mean with respect to your child's progress, ask your nurse to explain. If you have questions that your nurse is unable to answer, she/he can help you to figure out who the best person is to help you get the information you need.

Children respond to hospitalization in a variety of ways...nurses understand this and will help to comfort your child

PARENTING MY ILL CHILD WHILE HOSPITALIZED

The hospital situation can be overwhelming and you may feel distanced from your child by equipment or treatment restrictions. Also, it is not uncommon for children to behave differently when they are sick and especially when they are hospitalized. Children respond to hospitalization in a variety of ways; some may become quiet while others may become more dependent, demanding, or irritable.

Nurses recognize that you have good ideas about what helps and what does not help your child, so it is important for you to share this with us. Nurses have a lot of experience in caring for sick children and are willing to also share their ideas with you. You may get some ideas by watching nurses or asking them to help you when your child is upset.

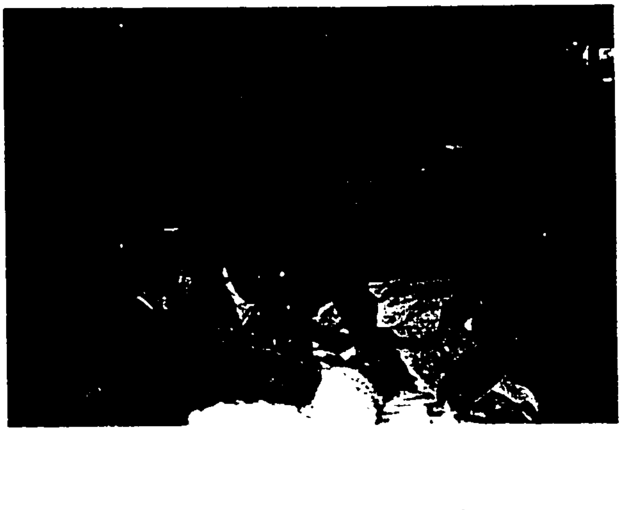
As well, there is a team of child life specialists and other professionals that can help children adjust to the hospital and get through difficulties. Ask your nurse about these services if you think you and your child could benefit from this support. It may also be helpful to bring in familiar things from home such as a favorite toy, pictures, a blanket, etc. to help your child feel less anxious.

Nurses can help you to understand things about your child's care. It is our intent to help you if you are feeling anxious or have any concerns about any aspect of your child's care. Talk to your child's nurses about your feelings and concerns. We are here to support you but cannot be certain about your concerns unless you tell us what they are.

HELPING MY CHILD DURING PROCEDURES

Many young children prefer to have a parent present during a procedure. Parents provide a familiar source of comfort and security to their child and often have good ideas about how to comfort their child during procedures. You can also ask the nurses/child life specialists for their ideas to help you. Again, it is by combining what you know about your child and what nurses know from their experience that the best approach can be taken.

Some parents are too anxious themselves to stay in the room. If you prefer to wait somewhere, someone will attend to your child's needs for support and comfort and let you know when the procedure is over.



Parents and nurses work together to support children during procedures...distraction may help your child at such times.

If you are uncertain about what you want to do, discuss your feelings with your nurse or the person doing the procedure. If you feel torn between staying and not staying, express this so that someone can help you to feel comfortable about your choice. Your child will receive care and comfort either way.

HELPING MY CHILD TO BE COMFORTABLE

You can participate by telling us whether you think your child has pain or needs something for pain. You know your child's usual responses. Your observations are important for professionals to hear.

Participating in discussions about how to keep your child comfortable will help you and the nurses to plan together to choose the best way to handle your child's discomfort.

Medication can be given for pain if it is ordered. Pain medication is ordered to be given at certain times and in certain ways to keep your child comfortable. You can ask your nurse to explain what medications are available for your child.

WORKING TOGETHER TO CARE FOR MY CHILD

Some of the care that your child requires may be unfamiliar to you. You can tell your nurse how you wish to be involved in your child's care and gradually do things that are comfortable for you. We want you to feel comfortable in assisting with your child's care; you are encouraged to ask for more explanations as you need them and you should feel equally comfortable to tell the nurses what you want them to know about caring for your child.

You may find it easiest to start doing those things that you normally do at home such as bathing and feeding. However, even these familiar tasks may be difficult because of your child's illness, treatment, or equipment. It is not uncommon to need assistance with these familiar tasks when your child is ill or is attached to an I.V. or other machines; ask your nurse for the assistance you need. There are different ways of doing things so don't be surprised if all nurses do not do everything exactly the same.

We want you to feel successful in assisting with the care of your child so you should share with nurses what works best for you.

You know your child the best.

In some instances parents may be very familiar with their child's care and have a great deal to offer to the nurses. It is our intention to use any hints from you about what kinds of things work with your child. Offer your suggestions to nurses who are caring for your child i.e. how to get your child to co-operate in the care he/she needs, how to give special treatments, or how to get your child to eat or take a medication.

Nurses will help you to gradually learn how to care for your child...let your nurse know if you need some assistance.

We believe that working together as partners is the way to provide the best care for your child.

HINTS ABOUT COMMUNICATION

Caring for parents involves open communication with nurses.......

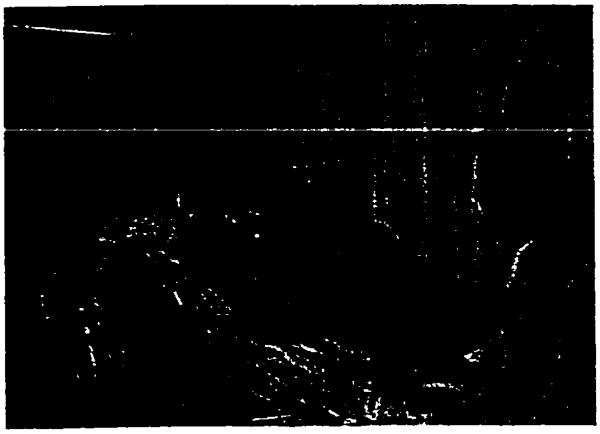
Our intention is to show a caring attitude to parents. Nurses show this by expressing concern for how you are and by letting you know how important you are in the care of your child. If you have concerns that are not being heard, express your feelings to your nurse.

Tell us what your concerns are

Your ideas and observations are important...

Your ideas about how your child is doing are important. We encourage you to express your observations about how your child is doing. Our intention is to work with you to reach the best understanding of your child's needs.

Parents have their own set of ideas and expectations about their child's illness and progress. You should feel free to express concerns about your child's care. You can talk to a professional about what troubles you. It may help you to feel more able to cope with the circumstances that you are facing.



You can talk to your nurse about any concerns you have... they care about you and your child.

Tell us "what troubles you the most"

Our intention is to involve you in decisions about how nursing care is provided. Any specific issues you would like to address can be brought to the nurses or other professionals.

You are important in helping us to care for your child - it is through sharing what "you and we" know that your child will receive the best care.

Thank you for reading this information.

TIP SHEET FOR PARENTS:
HOW PARENTS AND NURSES CAN WORK TOGETHER

Feeling Welcomed and Comfortable on the Ward

- Your child's nurse is the person to ask about the Children's Unit and your child.
- A kitchen, bathrooms, showers, and a family lounge are near the ward.
- TV's, VCR's, movies and Nintendo's are available (number of VCR's are limited).

Getting and Sharing Information about My Child's Illness and Progress

- Tell nurses special things you want them to know about your child.
- Nurses are willing to explain things to you about your child's care - just ask.
- Nurses may not always be able to fully explain the medical aspects of your child's care, but will help you figure out who to ask.

Understanding How My Child's Illness Affects Me as A Parent

- Your child may act differently than at home - nurses understand this.
- A child's upset behaviour in hospital is usually temporary.
- Familiar things from home can help your child feel more comfortable (e.g. toy, blanket, books, etc.).
- Child life specialists and social workers are also available to help you.
- Remember, you are not alone in trying to figure out how to help your child - ask professionals to help you.

Helping My Child

- You are welcome to assist with the care of your child as you feel comfortable.
- Nurses will show you how to care for your child - if you aren't sure ask your nurse.
- You are welcome to stay with your child during procedures.
- If you feel too anxious to stay with your child for a procedure, a professional will provide support to your child. Discuss it with your nurse.
- Let the nurses know if you think your child needs something for pain.

The Importance of Communicating

- Nurses are here to care for **you** as well as your child
- If you feel worried or troubled about anything, bring it to your nurse's attention.

It is putting together "what you know and what we know" that will help your child the most.

APPENDIX D

Demographic Instrument

☐☐☐
ID NUMBER

Date of Completion ☐☐ ☐☐ ☐☐
month day year

Time: __________

PARENT COMFORT STUDY

A. Child Data

1. Child's Gender *(Circle choice)*: 1 Male 2 Female

2. Child's date of birth: ☐☐ ☐☐ ☐☐
month day year

3. Child's date of admission to hospital: ☐☐ ☐☐ ☐☐
month day year

4. Child's date of admission to this unit, if different than above: ☐☐ ☐☐ ☐☐
month day year

4a. Time of admission to this unit, __________

5. My child was admitted to this Unit from:
1 home
2 emergency room
3 Ward 3C
4 surgery
5 other: __________

6. Child's date of surgery (if applicable): ☐☐ ☐☐ ☐☐
month day year

7. Reason for child's hospitalization: ______________________________

B. Parent Data

8. Person filling in questionnaire: 1 mother 2 father 3 other: __________

9. Your date of birth: ☐☐ ☐☐ ☐☐
month day year

10. How many other children do you have living at home: __________

11. Name of town or city where you live: ____________________
(state nearest town if in country)

12. Indicate your present marital status.

1	Never married	3	Divorced	5	Widowed
2	Married or living with a partner	4	Separated		

13. What is the highest level of education that **you** have completed?

1	No formal education	5	Completed High School
2	Some grade school	6	Some college or university
3	Completed grade school	7	Completed college or university
4	Some High School	8	Post-graduate

14. What is the highest level of education that **your spouse (partner)** has completed?

1	No formal education	5	Completed High School
2	Some grade school	6	Some college or university
3	Completed grade school	7	Completed college or university
4	Some High School	8	Post-graduate

15. What is your employment status at present? *(Please check all that apply.)*

1	Employed full time (at least 30 hrs/wk)	3	Homemaker	5	Other (please specify): ____________________
2	Employed part time	4	Retired		

16. What is the employment status of your spouse/partner? *(Please check all that apply.)*

1	Employed full time (at least 30 hrs/wk)	3	Homemaker	5	Other (please specify): ____________________
2	Employed part time	4	Retired		

C. Hospitalization

17. Approximately how many times has your child been previously hospitalized:

1 In this hospital? _____ time(s) 2 In other hospitals? _____ time(s)

Thank you for completing this questionnaire.

Please place completed questionnaire in the front pocket of the binder. The form will be picked up by a Research Team Member. If you have any questions that have not been answered, please do not hesitate to contact Mabel Hunsberger at (905) 525-9140, ext. 22404.

APPENDIX E

Stait Anxiety Inventory

SELF-EVALUATION QUESTIONNAIRE (STAI)

EXAMPLE:

- The **S-Anxiety scale** consists of twenty statements that evaluate how respondents feel *"right now, at this moment."*

  1= NOT AT ALL **2** = SOMEWHAT **3** = MODERATELY SO **4** = VERY MUCH SO

  A. I feel at ease 1 2 3 4

  B. I feel upset 1 2 3 4

APPENDIX F

Trait Anxiety Inventory

SELF-EVALUATION QUESTIONNAIRE (TRAI)

EXAMPLE:

- The **T-Anxiety scale** consists of twenty statements that evaluate how respondents feel *"generally."*

  1= ALMOST NEVER **2** = SOMETIMES **3** = OFTEN **4** = ALMOST ALWAYS

  A. I am a steady person 1 2 3 4

  B. I lack self-confidence 1 2 3 4

APPENDIX G

Mutual Participation Questionnaire - Parents

☐☐☐
ID NUMBER

Date of Completion ☐☐ ☐☐ ☐☐
month day year

PARENT COMFORT STUDY

MUTUAL PARTICIPATION SCALE
Parent Scale

Mutual participation in this study describes a situation in which parents are helped to feel involved with the health care team in the care of their hospitalized child. Parents and professionals share their expertise and work together to achieve the best care for children. This questionnaire is designed to measure the degree of mutual participation that occurs in your relationship with ***nurses****. It is recognized that relationships vary, however, this questionnaire asks for your* *overall* *experience with nurses.*

Think about your experience on this unit and indicate which best describes your relationship with nurses.

If you have any questions, please do not hesitate to contact Mabel Hunsberger at (905) 525-9140, ext. 22404. Please place completed questionnaire in sealed envelope and put envelope back into the binder provided.

PARENT COMFORT STUDY
MUTUAL PARTICIPATION SCALE
Parent Scale ... cont'd

I. STATEMENTS ABOUT NURSES:

Please circle the number which best describes: A) how important you think it is for nurses to do each item; and B) how consistently nurses did each item?

	Section A: How important is it for nurses to do this?					Section B: How consistently did nurses do this?				
STATEMENTS ABOUT NURSES	Not at all important				Very important	Not at all consistent				Very consistent
1. Nurses made me feel welcome at all times	1	2	3	4	5	1	2	3	4	5
2. Nurses made me feel important in my child's care	1	2	3	4	5	1	2	3	4	5
3. Nurses asked me to tell them things about my child that they should know	1	2	3	4	5	1	2	3	4	5
4. Nurses explained the purpose of the equipment in my child's room ..	1	2	3	4	5	1	2	3	4	5
5. Nurses asked me how I wanted to participate in my child's care	1	2	3	4	5	1	2	3	4	5
6. Nurses helped me to figure out how I can be most helpful to my child	1	2	3	4	5	1	2	3	4	5
7. Nurses helped me to feel self-confident in caring for my sick child ...	1	2	3	4	5	1	2	3	4	5
8. Nurses told me that working together results in the best care for my child	1	2	3	4	5	1	2	3	4	5
9. Nurses treated me as a valued team member when planning my child's nursing care	1	2	3	4	5	1	2	3	4	5
10. Nurses gave explanations about the nursing care they provided	1	2	3	4	5	1	2	3	4	5
11. Nurses explained about changes I could expect in my child's condition	1	2	3	4	5	1	2	3	4	5
12. Nurses explained how to respond to my child's behaviour and emotional reactions related to illness and hospitalization	1	2	3	4	5	1	2	3	4	5
13. Nurses asked me for my ideas on how to respond to my child's behaviour and emotional reactions related to illness and hospitalization	1	2	3	4	5	1	2	3	4	5
14. Nurses asked me how I think my child is doing	1	2	3	4	5	1	2	3	4	5
15. Nurses told me they value my opinion	1	2	3	4	5	1	2	3	4	5
16. Nurses used my suggestions about how to care for my child	1	2	3	4	5	1	2	3	4	5
17. Nurses encouraged me to take a break from my child's room	1	2	3	4	5	1	2	3	4	5
18. Nurses encouraged me to express any anxious feelings or concerns I might have	1	2	3	4	5	1	2	3	4	5

PARENT COMFORT STUDY
MUTUAL PARTICIPATION SCALE
Parent Scale ... cont'd

II. STATEMENTS ABOUT PARENTS:

Please circle the number which best describes: A) how much did you do this; and B) how comfortable were you doing this?

STATEMENTS ABOUT PARENTS	Section A: How much did you do this?					Section B: How comfortable did you feel doing this?				
	Not at all				A lot	Not at all				A lot
19. I told nurses things about my child that were important for them to know	1	2	3	4	5	1	2	3	4	5
20. I told nurses how I wanted to participate in my child's care	1	2	3	4	5	1	2	3	4	5
21. I asked nurses how I could be most helpful to my child	1	2	3	4	5	1	2	3	4	5
22. I asked nurses for explanations about the nursing care they provided	1	2	3	4	5	1	2	3	4	5
23. I asked nurses about changes I could expect in my child's condition	1	2	3	4	5	1	2	3	4	5
24. I asked nurses how to best respond to my child's behaviour and emotional reactions	1	2	3	4	5	1	2	3	4	5
25. I suggested ways to best respond to my child's behaviour and emotional reactions	1	2	3	4	5	1	2	3	4	5
26. I told nurses how I thought my child was doing	1	2	3	4	5	1	2	3	4	5
27. I expressed to nurses any anxieties and concerns about the care of my child	1	2	3	4	5	1	2	3	4	5
28. I planned with nurses so that I could feel comfortable leaving my child's room for breaks	1	2	3	4	5	1	2	3	4	5
29. I participated in the decisions made about my child's nursing care	1	2	3	4	5	1	2	3	4	5
30. I participated by giving care required by my child	1	2	3	4	5	1	2	3	4	5

Thank you for completing this questionnaire.

(mp parent scale jan 4)

APPENDIX H

Mutual Participation Questionnaire for Nurses - Pre-intervention

☐☐☐
ID NUMBER

Date of Completion ☐☐ ☐☐ ☐☐
month day year

PARENT COMFORT STUDY

MUTUAL PARTICIPATION SCALE

Nurse Scale - Pre-Intervention Phase

Mutual participation in this study describes a situation in which parents are helped to feel involved with the health care team in the care of their hospitalized child. Parents and professionals share their expertise and work together to achieve the best care for children. This questionnaire is designed to measure the degree of mutual participation that occurs in your relationship with ***parents****. It is recognized that relationships vary, however, this questionnaire asks for your* overall *experience with parents.*

Think about your experience on this unit and indicate which best describes your overall experience.

If you have any questions, please do not hesitate to contact Mabel Hunsberger at (905) 525-9140, ext. 22404. Please return the completed questionnaire to Janie Lappan.

PARENT COMFORT STUDY
MUTUAL PARTICIPATION SCALE
Nurse Scale - Pre-Intervention Phase ... cont'd

I. STATEMENTS ABOUT NURSES:

Please circle the number which best describes: A) how important each item is to your nursing practice; and B) how consistently do you do each item?

STATEMENT ABOUT NURSES	Section A: How important is this to your practice? Not at all important … Very important	Section B: How consistently do you do this? Not at all consistent … Very consistent
1. I make parents feel welcome at all times	1 2 3 4 5	1 2 3 4 5
2. I make parents feel important to their child's care	1 2 3 4 5	1 2 3 4 5
3. I ask parents to tell me things about their child that I should know	1 2 3 4 5	1 2 3 4 5
4. I explain the purpose of the equipment in the child's room to parents	1 2 3 4 5	1 2 3 4 5
5. I ask parents how they want to participate in their child's care	1 2 3 4 5	1 2 3 4 5
6. I help parents to figure out how they can be most helpful to their child	1 2 3 4 5	1 2 3 4 5
7. I help parents to feel self-confident in caring for their sick child	1 2 3 4 5	1 2 3 4 5
8. I tell parents that working together results in the best care for their child	1 2 3 4 5	1 2 3 4 5
9. I treat parents as valued team members when planning their child's nursing care	1 2 3 4 5	1 2 3 4 5
10. I give parents explanations about the nursing care I provide	1 2 3 4 5	1 2 3 4 5
11. I explain to parents about changes they can expect in their child's condition	1 2 3 4 5	1 2 3 4 5
12. I explain to parents how to respond to their child's behaviour and emotional reactions related to illness and hospitalization	1 2 3 4 5	1 2 3 4 5
13. I ask parents for their ideas on how to respond to their child's behaviour and emotional reactions related to illness and hospitalization	1 2 3 4 5	1 2 3 4 5
14. I ask parents how they think their child is doing	1 2 3 4 5	1 2 3 4 5
15. I tell parents I value their opinion	1 2 3 4 5	1 2 3 4 5
16. I use the suggestions of parents about how to care for their child	1 2 3 4 5	1 2 3 4 5
17. I encourage parents to take a break from their child's room	1 2 3 4 5	1 2 3 4 5
18. I encourage parents to express any anxious feelings or concerns they might have	1 2 3 4 5	1 2 3 4 5

PARENT COMFORT STUDY
MUTUAL PARTICIPATION SCALE
Nurse Scale - Pre-Intervention Phase ... cont'd

II. STATEMENTS ABOUT PARENTS:

Please circle the number which best describes how much parents do each item?

STATEMENTS ABOUT PARENTS	How much parents do this? Not at all				A lot
19. Parents tell me things about their child that are important for me to know	1	2	3	4	5
20. Parents tell me how they want to participate in their child's care	1	2	3	4	5
21. Parents ask me how they can be most helpful to their child	1	2	3	4	5
22. Parents ask me to explain about the nursing care I provide	1	2	3	4	5
23. Parents ask me about changes they can expect in their child's condition	1	2	3	4	5
24. Parents ask me how to best respond to their child's behaviour and emotional reactions	1	2	3	4	5
25. Parents suggest ways to respond to their child's behaviour and emotional reactions	1	2	3	4	5
26. Parents tell me how they think their child is doing	1	2	3	4	5
27. Parents discuss with me their anxieties and concerns about the care of their child	1	2	3	4	5
28. Parents plan with me so that they can feel comfortable leaving their child's room for breaks	1	2	3	4	5
29. Parents participate in the decisions about their child's nursing care	1	2	3	4	5
30. Parents participate by giving care required by their child	1	2	3	4	5

Thank you for completing this questionnaire.

(mp nurse preint jan 4)

APPENDIX I

Mutual Participation Questionnaire for Nurses - Intervention

☐☐☐
ID NUMBER

Date of Completion ☐☐ ☐☐ ☐☐
month day year

PARENT COMFORT STUDY

MUTUAL PARTICIPATION SCALE

Nurse Scale - Intervention Phase

Mutual participation in this study describes a situation in which parents are helped to feel involved with the health care team in the care of their hospitalized child. Parents and professionals share their expertise and work together to achieve the best care for children. This questionnaire is designed to measure the degree of mutual participation that occurs in your relationship with ***parents****. It is recognized that relationships vary, however, this questionnaire asks for your overall experience with parents.*

Think about your experience on this unit and indicate which best describes your overall experience.

If you have any questions, please do not hesitate to contact Mabel Hunsberger at (905) 525-9140, ext. 22404. Please return the completed questionnaire to Janie Lappan.

PARENT COMFORT STUDY
MUTUAL PARTICIPATION SCALE
Nurse Scale - Intervention Phase ... cont'd

I. STATEMENTS ABOUT NURSES:

Please circle the number which best describes: A) how important each item is to your nursing practice; B) how consistently do you do each item; and C) how much the project information has changed your practice related to each item?

STATEMENTS ABOUT NURSES	Section A: How important is this to your practice?					Section B: How consistently do you do this?					Section C: How much has the project information changed your practice?				
	Not at all important				Very important	Not at all consistent				Very consistent	Not at all				A lot
1. I make parents feel welcome at all times	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
2. I make parents feel important in their child's care ...	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
3. I ask parents to tell me things about their child that I should know	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
4. I explain the purpose of the equipment in the child's room to parents	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
5. I ask parents how they want to participate in their child's care	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
6. I help parents to figure out how they can be most helpful to their child	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
7. I help parents to feel self-confident in caring for their sick child	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
8. I tell parents that working together results in the best care for their child	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
9. I treat parents as valued team members when planning their nursing care	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
10. I give parents explanations about the nursing care I provide	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
11. I explain to parents about changes they can expect in their child's condition	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
12. I explain to parents how to respond to their child's behaviour and emotional reactions related to illness and hospitalization	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
13. I ask parents for their ideas on how to respond to their child's behaviour and emotional reactions related to illness and hospitalization	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
14. I ask parents how they think their child is doing	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
15. I tell parents I value their opinion	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5

PARENT COMFORT STUDY
MUTUAL PARTICIPATION SCALE
Nurse Scale - Intervention Phase ... cont'd

STATEMENTS ABOUT NURSES	Section A: How important is this to your practice? Not at all important … Very important	Section B: How consistently do you do this? Not at all consistent … Very consistent	Section C: How much has the project information changed your practice? Not at all … A lot
16. I use the suggestions of parents about how to care for their child	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
17. I encourage parents to take a break from their child's room	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
18. I encourage parents to express any anxious feelings or concerns they might have	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5

II. STATEMENTS ABOUT PARENTS:

Please circle the number which best describe how much parents do each item?

STATEMENTS ABOUT PARENTS	How much parents do this? Not at all … A lot
19. Parents tell me things about their child that are important for me to know	1 2 3 4 5
20. Parents tell me how they want to participate in their child's care	1 2 3 4 5
21. Parents ask me how they can be most helpful to their child	1 2 3 4 5
22. Parents ask me to explain about the nursing care I provide	1 2 3 4 5
23. Parents ask me about changes they can expect in their child's condition	1 2 3 4 5
24. Parents ask me how to best respond to their child's behaviour and emotional reactions	1 2 3 4 5
25. Parents suggest ways to best respond to their child's behaviour and emotional reactions	1 2 3 4 5
26. Parents tell me how they think their child is doing	1 2 3 4 5
27. Parents discuss with me their anxieties and concerns about the care of their child ...	1 2 3 4 5
28. Parents plan with me so that they can feel comfortable leaving their child's room for breaks	1 2 3 4 5
29. Parents participate in the decisions about their child's nursing care	1 2 3 4 5
30. Parents participate by giving care required by their child	1 2 3 4 5

Thank you for completing this questionnaire. (mp nurse int jan 4)

APPENDIX J

Evaluation of Usual Hospital Information

☐☐☐
ID NUMBER

Date of Completion: ☐☐ ☐☐ ☐☐
month day year

PARENT COMFORT STUDY: FEEDBACK ON INFORMATION RECEIVED

Please let us know whether the information was helpful and what other information you would have liked to have.

How much did the information help you to:	Very little A lot
1. Become familiar with the ward routines?	1 2 3 4 5
2. Understand what is available for you?	1 2 3 4 5
3. Understand what is available for your child?	1 2 3 4 5
4. Feel comfortable asking for things you needed?	1 2 3 4 5
5. Feel welcome on the ward?	1 2 3 4 5

6. Should all parents receive this information?

☐ Yes ☐ No ☐ Maybe, Please specify: ________________

7. What other information would you have liked to receive?

Thank you for completing this questionnaire.

Please fold and place in plastic pocket provided in binder. If you have any questions, please do not hesitate to contact Mabel Hunsberger at (905) 525-9140, ext. 22404.

APPENDIX K

Evaluation of NMPMC Information

☐☐☐
ID NUMBER

Date of Completion: ☐☐ ☐☐ ☐☐
month day year

PARENT COMFORT STUDY: FEEDBACK ON INFORMATION RECEIVED

Please let us know whether the information was helpful and what other information you would have liked to have.

How much did the information help you to:	Very little A lot
1. Become familiar with the ward routines?	1 2 3 4 5
2. Understand what is available for you?	1 2 3 4 5
3. Feel comfortable asking for things you needed?	1 2 3 4 5
4. Take the initiative to tell nurses things about your child?	1 2 3 4 5
5. Ask nurses things about your child?	1 2 3 4 5
6. Bring your concerns to the nurses?	1 2 3 4 5
7. Participate in giving care to your child in a way that was comfortable for you?	1 2 3 4 5
8. Participate in decisions about your child's nursing care in a way that was comfortable for you?	1 2 3 4 5
9. Feel welcome on the ward?	1 2 3 4 5

Please tell us about reading the information:	Too little Just right Too much
10. The amount of information to read was	1 2 3 4 5

11. Should all parents receive this information?

☐ Yes ☐ No ☐ Maybe, please specify: ____________________

12. What other information would you have liked to receive?

Thank you for completing this questionnaire.

Please fold and place in plastic pocket provided in binder. If you have any questions, please do not hesitate to contact Mabel Hunsberger at (905) 525-9140, ext. 22404.

APPENDIX L

Information Letter

INFORMATION ON THE PARENT COMFORT STUDY
(Intervention)

This is an invitation to participate in a research project about the experience of parents whose children are in hospital. It is common for parents to experience some stress during this experience. The purpose of this phase of the project is to examine: 1) how parents feel during their child's hospitalization; 2) whether giving specific information to parents can reduce their anxiety; and 3) how parents and nurses work together to care for children. If you participate, one parent will be asked to respond to the questionnaires; in two-parent families you would be asked to choose the parent who is most available to participate.

Procedure: If you agree to participate in this study, you would be asked to do the following:

1. *Soon after admission*:
   a) complete a form that requests some information such as marital status, age, and education;
   b) complete a 2-page questionnaire about how anxious you feel; and
   c) read some information that is given to you.
   (Note: You will receive one of two information packages by random assignment.)

2. *A few days after admission*:
   a) complete a 1-page questionnaire about how anxious you feel.

3. *At the time of discharge you will be asked to complete:*
   a) a 1 page questionnaire about how anxious you feel;
   b) a questionnaire about how nurses and parents work together; and
   c) a 1-page evaluation of the materials you received.

Participation: Your participation is entirely voluntary and you may withdraw from the study at any time. Any decisions you make about the study will not affect the current or future care of you or your child in this hospital. Information will be kept confidential and no reports of the study will identify you or your child. The total time required to participate in the study is about one hour.

Risks and Benefits: There are no known risks related to your participation in this project. While all nurses on the unit are aware of the information in the study packages, not all nurses will respond in the same manner to your questions. While there is no known immediate benefit to you, your participation has the potential to affect how nurses and parents work together in the future with the potential to increase the level of comfort experienced by parents during their child's hospitalization.

This study is being conducted by Mabel Hunsberger, who is an Associate Professor in the School of Nursing, at McMaster University and a Ph.D. student at the University of Waterloo and Alida Bowman, who is the Clinical Manager of Pediatrics at Children's Hospital, Hamilton Health Sciences Corporation. Ethics clearance has been obtained from the McMaster University/Hamilton Health Sciences Corporation Research Ethics Board and from the Human Research Ethics Committee at University of Waterloo. You will be given the phone number(s) of the researcher in case you have further questions about the study.

APPENDIX M

Consent Form

CONSENT FORM
PARENT COMFORT STUDY
(Intervention)

In signing this document, you are giving consent to participate in a research project about the comfort of parents and how nurses and parents work together to care for hospitalized children. The purpose of this phase of the project is to examine: 1) how parents feel during their child's hospitalization; 2) whether giving specific information to parents can reduce their anxiety; and 3) how parents and nurses work together to care for children.

By signing below, I understand the following:

1. **My participation in this study is entirely voluntary.**
2. **I understand that there are two different information packages and that I will be given one of these by random assignment.**
3. **I may choose not to answer certain questions and may withdraw my consent to participate at any time by contacting the researchers Mabel Hunsberger and Alida Bowman at the numbers listed on this form.**
4. **Any decisions I make about participating in this study will not affect the current or future care of me or my child in this facility.**
5. **Any information I give will be kept confidential and no reports of this study will identify me or my child in any way.**
6. **I will not receive any payment for being in this study.**
7. **I will be asked to complete questionnaires as outlined in the Information Letter.**
8. **I can ask questions at any time about the study.**
9. **The following information will be copied from my child's chart: age, gender, diagnosis, and admission date.**
10. **Signing this form means I will be given a signed copy of this consent.**
11. **If I have any concerns about my rights in this study, I may call a patient-relations specialist at 905-527-4322, ext. 6449 (Hamilton Health Sciences Corporation, Medical Affairs).**

This study is being conducted by Mabel Hunsberger, who is a faculty member at McMaster University, School of Nursing and a Ph.D. student at University of Waterloo in the Health Studies program in the Faculty of Applied Health Sciences and Alida Bowman, Clinical Manager of Pediatrics, Children's Hospital, Hamilton Health Sciences Corporation. Alida Bowman can be contacted at (905) 521-2100 ext. 6346. Mabel Hunsberger can be contacted at (905) 525-9140, ext. 22404.

I CONSENT TO PARTICIPATE:

Name (please print)	Signature	Date
Research Team Member (please print)	Signature	Date

PARENT COMFORT STUDY
INFORMATION FOR FOLLOW-UP

If you would like a summary of the study results, please fill in the following information.

MAILING ADDRESS:

Name: ______________________________, ______________________________
Surname (print) Given Name (print)

Address: ____
Number & Street (print)

____________________, ____________________, ____________________
City (print) Province (print) Postal Code (print)

Telephone No: ____
Area Code + Number (print)

Thank you for participating in this study.

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