# CONGRUENCY BETWEEN PARENTS' ACTUAL AND DESIRED PARTICIPATION IN THE CARE OF THEIR HOSPITALIZED CHILD

By

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# ABSTRACT

Parents' participation in the care of their hospitalized child is an integral part of pediatric nursing practice and is considered to be beneficial for children and parents. However, parents may not discuss their participation with nurses and instead base their activities on their perceptions of nurses' assumptions and expectations regarding parents' participation in care. Nurses may assume a gate keeping role regarding parents' participation, deciding what parents will do and then monitoring these activities. Nurses' heavy workloads may preclude the teaching necessary for parents to participate in certain aspects of care. As a result, parents' actual participation in care may be more or less than their desired level of participation. Measuring actual participation alone may thus give an incomplete picture of a family's situation.

To date, no attempt has been made to measure the difference between parents' actual and desired participation in care. A cross-sectional, descriptive design was used to measure parents' actual level of participation in care and their desired level of participation in care, and to describe the congruency between them. Parents of children admitted to medical and surgical units in a tertiary care children's hospital (N = 191) completed two instruments measuring desired and actual participation in care as well as providing demographic data. Study results indicate a difference between parents' actual and desired participation, with the majority of parents expressing a desire to increase their participation. Parents' care activities included providing comfort, assisting with activities of daily living, assisting with mechanical care and advocating for the hospitalized child. Recommendations are made for nursing practice at the bedside, for nursing administration and for future research. Measuring congruency between actual and desired levels of participation can contribute to our understanding of parents' experiences of their child's hospitalization and may provide a unique perspective on parental participation in care.

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# CHAPTER 1: Introduction

In the early part of the 20th century, hospitalization of a child necessitated extended separation from parents. By the 1950s, recognition of the importance of a child's attachment to his/her parents and the detrimental effects of separation from parents led to changes in pediatric hospital practice: where parents had once been kept out of hospital, they were now encouraged to stay (Alsop-Shields & Mohay, 2001). Over many years, it has become clear that parents want to be with their hospitalized children and that children benefit from their parents' presence. It has also become clear that the decision to welcome parents into children's hospitals marked the beginning of important changes in the way children's hospitals function and, in particular, in the way pediatric nurses provide care (Alsop-Shields & Mohay, 2001). One of these changes, parental participation in the care of the hospitalized child, has posed challenges that can affect the experiences of children, parents and nurses in the pediatric inpatient setting. Research over many years indicates that these challenges persist, and further study is needed to address them.

## Background

As parents began to spend time in hospital with their children, it became evident that this change involved more than simply having parents present. Being a parent inherently involves providing care to one's child, but, faced with unfamiliar surroundings and activities, parents in hospital felt unsure about what they could or should do for their children (Hill, 1978; Roy, 1967). They often found themselves ready to take on more responsibility than nurses were willing to give them (MacDonald, 1969; Merrow & Johnson, 1968). Early research was aimed at determining which activities parents wanted to participate in (Hill, 1978, MacDonald, 1969; Merrow & Johnson, 1968) and at identifying nursing interventions to support participation (Roy, 1967).

Even with these initial challenges, the practice of parents staying with their hospitalized child and providing care became firmly entrenched. In the majority of pediatric health care settings today, the principles of family-centred care are presented as a guide for nursing practice with children and families. Family-centered care is a philosophy that recognizes the importance of the family in the child's life. This philosophy promotes parent-professional collaboration based on the unique needs of each child and family, encouraging professionals to take into consideration families' diverse backgrounds, strengths and coping strategies (Ahmann, 1994). Supporting parents' participation in their hospitalized child's care is one aspect of family-centered care (Ahmann, 1994; Newton, 2000). Parental participation in care is seen as a way to support the child through the hospital experience (Ahmann, 1994; Forsner, Jansson, & Sørlie, 2005; Jones, 1994; Melnyk & Feinstein, 2001; Newton, 2000), while also assisting the parent to cope with the stresses associated with the altered parental role engendered by hospitalization (Curley, 1988; Curley & Wallace, 1992; Hayes & Knox, 1983; Hayes & Knox, 1984; Hopia, Tomlinson, Pavvilainen, & Astedt-Kurki, 2005; Knox & Hayes, 1983).

Despite perceived benefits, implementation of parent participation has posed challenges. Early research indicated that parents were often limited in their participation due to insufficient information about how they could care for their child in the hospital setting (Algren, 1985; Hill, 1978; Jackson, Bradham, & Burwell, 1978; MacDonald, 1969; Merrow & Johnson, 1968; Roy, 1967). More recently, parents reported that they rarely discussed the extent of their participation with their child's nurses (Balling & McCubbin, 2001; Coyne, 1995; Darbyshire, 1994; Espezel & Canam, 2003; Kawik, 1996; Kristensson-Hallstrom & Elander, 1997; Neill, 1996; Roden, 2005; Ygge & Arnetz, 2004). Parents in these studies also indicated that they often based their care activities on their perceptions of nurses' assumptions and expectations regarding parents' participation in care. Studies that focused on nurses indicated that they often assumed a gate keeping role regarding child care activities undertaken by parents, deciding whether the parent or nurse will perform the activity and monitoring the care parents provided (Brown & Ritchie, 1990; McKiel, 2002; O'Haire & Blackford, 2005; Paliadelis, Cruickshank, Wainohu, Winskill, & Stevens, 2005; Roden, 2005). Studies also indicate that nurses had set expectations regarding parental participation in care, in particular, they assumed that parents would provide care related to activities of daily living (Darbyshire, 1994; O'Haire & Blackford, 2005).

Research indicates that different parents desire different levels of participation in their hospitalized child's care. Kristensson-Hallström and Elander

(1997) reported that some parents expressed a desire to increase their participation in their children's care, but needed nurses' support and guidance in order to do so. Parents in Darbyshire's (1994) study expressed appreciation for the opportunity to choose the extent of their participation in care "without feeling that they were being pressured" (p.191). Coyne and Cowley (2007) reported that, while parents felt that being with their child was integral to their role as a parent, their decision to stay was also related to a fear that the nurse might not be available when the child needed attention. They also found that parents felt obliged to provide care to the child. There is growing evidence to indicate "that parents are feeling imposed upon by nurses who take their participation for granted" (Shields, Pratt, & Hunter, 2006). If parents' actual participation in care differs from their desired level of participation, this can negatively affect their hospitalization experience (Savage & Callery, 2000).

## Statement of the Problem

Studies to date have examined the extent of parents' participation in care. However, it may be incomplete to measure the extent of parents' participation in care if there is a discrepancy between parents' desired and actual levels of participation. Research has also explored the kinds of care activities parents feel able to participate in and parents' desires for control of their child's care. No study to date has specifically measured parents' desired level of participation and their actual participation to allow for a comparison between them. Documenting the extent of congruency between parents' desired and actual levels of participation can contribute to the overall understanding of parent participation within the context of family centered care. Measuring congruency could also be an important first step for future research examining the factors that influence parents' participation in care and the outcomes of parental participation in care, as knowledge of these areas is limited.

## Statement of Purpose

The purpose of this study was to describe the congruency between parents' actual level of participation in care and their desired level of participation in care. This research makes a unique contribution to knowledge about parent participation by measuring parents' actual participation and desired participation, and then comparing these scores, which describes the extent to which parents' participation in care reflects their desires. Furthermore, a comparison of parents' actual and desired participation in specific care activities increases the knowledge of the nature of parents' participation, indicating current strengths and potential areas for development in pediatric nursing practice.

### Overview of Thesis

The next chapter of this thesis presents the review of the literature about parent participation, culminating in the presentation of a conceptual framework for the study, the research question and the study hypothesis. The research methodology is described in Chapter 3. Subsequently, the results are presented to describe the sample, address the hypothesis and illustrate the nature of parent participation. The concluding chapters examine the study results in relation to the literature and conceptual framework, address strengths and limitations of the study and present implications for research and nursing practice.

## CHAPTER 2: Review of the Literature

Knowledge of parent participation in care is based on studies of parent participation specifically, as well as studies that report more broadly the experiences of parents and nurses caring for hospitalized children. For ease of discussion, in this literature review the current knowledge of parental participation in care will be examined within four categories. These categories are: 1. Benefits of Participation (for children and for parents); 2. Nurses' support for parent participation; 3. Parents' Care Activities (from parents' perspectives and nurses' perspectives); and 4. Deciding the Extent of Parent Participation (parents' decisions and nurses' decisions). Literature addressing neonatal intensive care units (NICU) was excluded, as parents in the NICU are establishing a role with their infant as opposed to maintaining a developed role, which may influence their ability to participate in care (Wong & Hockenberry, 2003).

### Benefits of Participation

Parent participation can be beneficial for children as well as for parents. Details of the articles included in this section of the literature review can be found in Appendix A Table A1.

**Benefits for children.** A review of the literature indicates that outcomes for children related to their parents' participation in their care have rarely been examined. In qualitative studies, Forsner, Jansson and Sørlie (2005), and Coyne (2006) interviewed children between the ages of 7 – 14 years, who reported that their parents' presence during their hospitalization was important to them.

However, these studies involved children's hospital experiences in general and did not examine their perspectives on their parents' participation in care specifically. One quantitative study was identified that specifically examined parent participation in relation to the child. Jones (1994) observed hospitalized children's behaviour in relation to the extent of their mothers' participation. Mothers' participation was categorized according to their responses on a checklist of care activities adapted from a tool developed by Deatrick, Stull, Dixon, Puczynski and Jackson (1986). Jones found that the more actively and consistently a mother was involved in her child's care, the better the child's response. Specifically, she found that the child was more cooperative, less upset during painful procedures and was generally more active during the admission. However, the small sample size (n=13) and the fact that all the children in the sample were admitted with the same diagnosis and received identical treatment makes it difficult to generalize these findings.

In another study, the implementation of an intervention aimed at increasing parental participation in care was assessed by evaluating children's adjustment post-discharge (Melnyk & Feinstein, 2001). Parental participation was measured using the Index of Parent Participation/Hospitalized Child (IPP/HC) (Melnyk, 1994). Melnyk and Feinstein hypothesized that mothers' participation in care would mediate the effects of this intervention on children's adjustment after discharge. In comparison with a control group whose parents did not receive the intervention, the children whose parents received the intervention and thus participated more in their care, were found to have fewer difficulties in adjustment after discharge. The limitations of the study include the use of a small convenience sample, and mothers' self-report of their participation and child's post-discharge behaviours (Melnyk & Feinstein, 2001). The use of the IPP/HC can be considered a strength of this study, as the tool has been used previously, and both face validity and reliability have been reported.

**Benefits for parents.** There has been little research documenting the outcomes for parents who participate in their hospitalized child's day-to-day care. Studies evaluating practices that have changed on pediatric nursing units provide some information about possible benefits of participation. Keatinge and Gilmore (1996) described the implementation of a Shared Care program on an acute care pediatric unit. They measured parental anxiety before and after this program was introduced, and found that parents who participated in the Shared Care program reported less anxiety at discharge than the parents whose children were hospitalized before the program was initiated. As this study represents the evaluation of a practice change as opposed to a specifically designed study, issues such as sample selection, sample size and the possibility of intervening variables affecting the pre- and post- implementation groups were not addressed. These limitations affect interpretation of the results.

Supporting parental participation in care has been included as part of an intervention undertaken to minimize parental stress during hospitalization. The Nursing Mutual Participation Model of Care (NMPMC) (Curley, 1988; Curley &

Wallace, 1992) aims to support the establishment of a therapeutic nurse-parent relationship and, in turn, reduce the stress experienced by parents whose children have been admitted to a pediatric intensive care unit (PICU). In implementing this model, nurses ask parents for their perspective on their child's status and needs, and show them how they can contribute to their child's care. Using a quasi-experimental research design, the authors demonstrated that parents receiving the intervention experienced less stress overall and less stress related to parental role alteration than did parents in the control group (Curley, 1988; Curley & Wallace, 1992). Hunsberger (2000) implemented the NMPMC on an acute-care pediatric unit, introducing both parents and nurses to the model. Two variables were considered: anxiety and mutual participation. Mutual participation referred to the parent's interactions with the nurses regarding the child's care, and was measured with the Mutual Participation Questionnaire, developed from Curley's earlier work. Using a randomized controlled trial to study the effects of this implementation, Hunsberger found that parents who received the intervention were significantly less anxious at discharge and were more comfortable with participating in mutual participation activities. In these three studies using the NMPMC, parents were encouraged to participate in their child's care but the extent of their participation was not measured. Thus, the specific relationship between participation in care and reduction of stress cannot be determined.

In summary, research indicates that parental participation in care is beneficial for children and parents. However, much of this research has been completed in the context of supportive interventions for parents, and parent participation has rarely been the focus of study. Further research is warranted to document parental participation specifically and to link it to possible outcomes.

**Nurses' Support of Parental Participation**

Details of the articles examined in the following section can be found in Appendix A Table A2. Nurses' attitudes toward parental participation were first studied by Seidl (1969), who found that nurses were generally accepting of parental participation, but this acceptance varied according to several factors. One of these factors was the nurse's level of education, which Seidl used as an indicator of the nurse's position in the hospital hierarchy. He found that nurses prepared at the baccalaureate level or higher demonstrated the most accepting attitudes toward parent participation. Seidl and Pilliteri developed the Parent Participation Attitude Scale (PPAS) for this study (1967). The PPAS has since been used in several other studies, all of which also found that nurses and other health care professionals were generally accepting of parental participation but that there were variations related to level of education and job title (Daneman, Macaluso, & Guzzetta, 2003; Gill, 1987; Gill, 1993; Johnson & Lindschau, 1996). Participants with a higher level of education were more supportive (Daneman et al., 2003; Gill, 1987; Gill, 1993), as were nursing supervisors (Gill, 1987), educators (Gill, 1993) and registered nurses (Johnson & Lindschau, 1996). Seidl and Pilitteri reported a modest internal consistency for the PPAS of 0.37, obtained with the split-half method using the Pearson product-moment correlation with the

Spearman formula for correction. Subsequent studies reported internal consistency for the PPAS with a Cronbach's alpha coefficient of 0.75 (Daneman et al., 2003; Gill, 1987).

Pidgeon and Sander (1982) completed a cross-sectional descriptive study to examine how pediatric nurses perceive various aspects of their work. They asked pediatric nurses to rate 43 pediatric nursing functions using a nine-point scale developed for this study. These functions were categorized into seven components. Encouraging parents' participation in care was considered a psychosocial component, and Pidgeon and Sander reported that it was the third-highest rated psychosocial function (score = 8.57 out of nine). However, encouraging parents' participation was not included among the five highest rated activities overall (scores ranging from 8.81 to 8.69). Content and face validity of the tool were determined, but reliability data were not provided. The authors recognized that the large proportion of master's and doctorally prepared nurses in their sample may have affected the study findings. Although a convenience sample was used, it included participants from a wide variety of geographical locations, which may strengthen the generalizability of the findings.

To summarize, nurses and other health care professionals are generally supportive of parental participation in hospitalized children's care. The extent of support can vary according to the individual's role in the institution and their level of education, as those with more senior positions and/or higher levels of education tend to be more supportive. Registered nurses tend to be more supportive than other health care professionals. Overall, nurses consider encouraging parental participation an important part of their practice.

## Parents' Care Activities

The following discussion addresses research undertaken to determine specific activities that parents participate in when their child is in hospital, looking at the perspective of parents as well as that of nurses. Details of the studies discussed below can be found in Appendix A, Table A3.

**Parents' perspectives on their care activities.** Several researchers have used checklists of child care activities to identify activities parents participate in or in which they would like to participate (Algren, 1985; Blower, & Morgan, 2000; Hill, 1978; Jackson, Bradham, & Burwell, 1978; Kristensson-Hallström, & Elander, 1994; Merrow, & Johnson, 1968; Webb, Hull, & Madeley, 1985). Parents most frequently reported that their child care activities in the hospital focused on activities of daily living (ADL), and include consoling/comforting, entertaining, meeting hygiene and nutritional needs, and advocating for their child when he/she was in pain. Blower and Morgan (2000) and Hill (1978) also noted that even with basic care activities related to hygiene and nutrition, parents may want support from the nurse while providing this care when a child is acutely ill or when medical equipment (e.g. an IV) complicates the activity. Parents' interest in participating in technical aspects of care varied. For example, with regard to dressing changes, Kristensson-Hallstrom and Elander (1994) reported that 15% of parents did this procedure while 62% felt they could have done it. Webb et al.(1985) found that 43% of parents either did or felt they could do a dressing change, while Hill identified that 38% of mothers wanted to do this care. The proportion of parents who were willing to give oral medication ranged from 60% in Algren's (1985)study to 89% in Hill's study. Kristensson-Hallström and Elander, and Webb et al. reported that overall, parents believed that they could have provided more care than they actually did provide.

Generalizations from these studies are limited by small sample sizes and the tools used to collect data. Sample sizes ranged from 20 to 80, with no reports of procedures for determining the adequacy of these samples. Each of the studies used a different tool, although some were similar. Merrow and Johnson (1968) developed a checklist of 30 care items, based on a literature review, lists of activities identified by pediatric nursing students and the authors' own clinical experiences. They used a pilot study to determine face validity. Jackson, Bradham and Burwell (1978) reported choosing the 11 items on their checklist according to the items in which Merrow (1964, as cited in Jackson, Bradham & Burwell 1978) found parents most willing to participate. Algren (1985) adapted her tool from Merrow and Johnson's list, but did not specify the nature of the adaptations or why she felt they were necessary. Webb et al. (1985) used a list of 31 nursing procedures that they stated was compiled by the General Nursing Council, but no information about this council or how they developed the list was provided. Kristensson-Hallström and Elander (1994) used a revised version of Webb et al.'s list, preparing a checklist of 37 items. Reliability was not reported for any of the tools discussed above. Blower and Morgan (2000) did not specify the source for the 15 items on their checklist. They stated that their questionnaire was pre-tested in a pilot study, but did not report whether or not any changes to the questionnaire were made based on this pilot. Hill (1978) stated she asked mothers about 37 care activities, but did not indicate how she came to choose these activities for inclusion in her interview.

MacDonald (1969) administered a questionnaire to parents to determine their perspective on care activities. As in other studies, she found that the majority of parents were willing to participate in comfort care and ADL care activities, and were varied in their readiness to participate in technical aspects of care. A limitation of this study is that the basis for development of the questionnaire is not specified, and it is not clear whether it was administered via interview or self-report.

Qualitative research supports the findings of the studies discussed above. Parents were most willing to participate in ADL and comfort care, while their desire to participate in technical care varied (Coyne, 1995; Darbyshire, 1994; Niell, 1996b). Coyne (1995) reported that all of the parents in her study fully expected to participate in ADL and comfort care. She stated that parents of children who required more complex care on a day-to-day basis (e.g. colostomy care) prior to admission were willing to continue providing that care in hospital, as they saw it as part of their daily child care activities. When complex care needs arose during the admission, parents in Coyne's study recognized the need to learn this care and practice it by providing it in hospital, as this was part of their child's long-term care plan and was a prerequisite for discharge. However, they were less open to providing complex care that was considered short term and would not be required after discharge.

**Nurses' perspectives on parents' care activities.** Studies of nurses indicate that they are generally supportive of parents' participation in ADL-related care, but have reservations about parents' participation in more technical aspects of care (Brown, & Ritchie, 1990; Paliadelis et al., 2005). In a qualitative study, Paliadelis et al.(2005) found that nurses were less comfortable with parents giving oral medications and changing dressings than they were with participation in ADL care. Brown and Ritchie (1990) conducted a descriptive study using the same checklist employed in previous studies of parents (Algren, 1985; Merrow & Johnson, 1968). They asked nurses to identify activities in which they felt a parent could participate. Of 25 nurses surveyed, at least 23 agreed that parents could feed, bathe, comfort and entertain the child. When it came to more technical care activities, nurses were less supportive – nine were comfortable with parents giving oral medication and eight felt parents could change dressings. The results of this study are limited by the lack of reliability and validity data for the checklist tool used, despite its implementation in previous studies. Additionally, while the study report indicated that the sample consisted of volunteers, it did not describe the recruitment process for obtaining these participants nor did it describe those who chose not to participate. This, together with the small sample size and use of only one setting, limits the generalizability of the study.

Some studies included both parents and nurses, and compared their responses, finding that parents are generally prepared to take on more than nurses believe they should (Kristensson-Hallstrom & Elander, 1994; MacDonald, 1969; Merrow & Johnson, 1968). Through interviews with parents and nurses, and observations of unit activities, MacDonald (1969) recognized that while many parents were eager to participate in technical care such as giving oral medications and changing dressings, nurses were reluctant to have them take on these activities. Kristensson-Halström and Elander (1994) asked groups of parents and nurses to specify their comfort with parents' performance of specific child care activities. As in previous studies, these authors noted that parents and nurses were comfortable with parental involvement in ADL care and less comfortable with involvement in technical care. However, this study also demonstrated significant differences ($p \leq 0.01$) between parents and nurses regarding which technical care parents could provide. For example, nurses were more comfortable with parents administering enemas, while parents were more comfortable with assessing a child's pain and giving analgesics. Parents and nurses in Blower and Morgan's (2000) study agreed that when learning technical care was a requirement for the child's discharge, parents should learn the care and provide it in hospital.

In summary, while parents generally choose to participate in care related to ADL, their interest in participating in technical aspects of care varies. In some circumstances parents may need support from the nurse while providing ADL care. These studies also indicate that while parents and nurses agree that parents can provide ADL care to their hospitalized child, they differ in their beliefs regarding technical care. As a result, nurses may not be comfortable with the level of technical care some parents would like to provide for their child. Parents and nurses differ in their beliefs about which activities are appropriate for parents to perform.

## Deciding the Extent of Parent Participation

The following discussion addresses the factors that influence parents' and nurses' decisions regarding parental participation in care. Appendix A, Table A4 presents the details of these studies.

**Understanding parents' decisions regarding their participation.** Parents choose to stay in hospital with their children because they feel it is best for their child (Coyne, 1995; Dearmun, 1992; Lam, Chang, & Morrissey, 2006; Romaniuk, 1993). Being present with the child in hospital is seen as a way of providing emotional support to the child during a difficult time and is considered an integral part of parenthood (Coyne, 1995; Dearmun, 1992; Lam et al., 2006; Romaniuk, 1993). Coyne and Cowley (2007) found that "parents' primary motive for being there was to provide emotional support....rather than to be involved in giving physical care" (p.896). Parents in Coyne and Cowley's study expressed concern that nurses were focused on technical and administrative duties and thus may not be available to provide emotional support to the child whenever he/she needed it.

However, parents do participate in their children's physical care, and they give various reasons for doing so. Participation in care is seen as a way to provide further emotional support for the child (Coyne, 1995). Coyne (1995) also reported that some parents considered themselves to be the "expert" on their child and thus the best person to provide care. Research indicates that parents' participation in care is also related to a sense of uncertainty about nurses' ability to fulfill all of the child's care needs. Lam et al. (2006) reported that parents' participation allowed them to individualize their child's care and to provide more consistent monitoring.

With the exception of Dearmun's (1992) work, the studies described above were completed using qualitative approaches. Coyne and Cowley (2007) and Romaniuk (1993) used a grounded theory approach in their work, and their reports are strengthened by the inclusion of clear descriptions of procedures for data analysis and maintenance of rigour. Lam et al. (2006) also clearly described procedures for data analysis and maintenance of rigour, but this study would be strengthened by the specification of a qualitative research approach. Coyne (1995) used a phenomenological approach in her study, but the report does not identify the data analysis procedures used nor does it identify how rigour was maintained. As a result, it is difficult to evaluate the use of the phenomenological perspective in this study. Coyne (1995), Coyne and Cowley (2007), Lam et al.

(2006), and Romaniuk (1993) all provide rich descriptions and include quotations from participants in conveying their results, and this strengthens the reports. Coyne and Cowley (2007) clearly describe their data analysis procedures and their procedures for maintaining rigour of the study. Dearmun's (1992) quantitative study was completed at one site, thus limiting generalizability, and further limitations include a small sample size and the lack of reliability data for the tool used. However, her study did benefit from efforts to minimize the Hawthorne effect and from face-to-face administration of the questionnaire.

The extent of participation may reflect parents' perceptions of the assumptions and expectations of nurses (Avis & Reardon, 2008; Coyne & Cowley, 2007; Neill, 1996b; Ygge & Arnetz, 2004). Frequently, parents sensed an expectation that they would participate in care because the nurses were so busy. Parents would take on certain activities to allay their worries and ensure their child received necessary care in a timely manner (Balling & McCubbin, 2001; Coyne, 1995; Espezel & Canam, 2003; Lam et al., 2006; Romaniuk, 1993; Ygge & Arnetz, 2004). Coyne and Cowley (2007) described how parents would provide care that they were not entirely comfortable with if they sensed it was the nurses' expectation. They did so out of fear that the care would not otherwise be done. Sensing such expectations could lead parents to feel that they must be at the bedside at all times, turning the choice to remain with the child into a requirement (Avis & Reardon, 2008; Coyne & Cowley, 2007; Ygge & Arnetz, 2004).

Avis and Reardon (2008), Espezel and Canam (2003), Neill (1996a) and Ygge and Arnetz (2004) completed qualitative studies using unspecified methodologies, but their work is strengthened by the inclusion of descriptions of data analysis procedures and efforts to ensure rigour. One exception to this is Neill's work, which did not include a description of data analysis procedures. Balling and McCubbin's (2001) work, the one quantitative study reported above, benefited from the availability of Cronbach's alpha scores for the tools used. However, the sample in this study was recruited from the membership of a parental support network, raising the possibility of sampling bias, as parents who join such a group may be more supportive of parental participation in care than non-members. Balling and McCubbin's use of a convenience sample also limits generalizability of the results.

It is important to note that parents' understanding of nurses' expectations often arose from their perceptions as opposed to any clear statement on the part of nurses. As a result, parents could experience a sense of uncertainty about what care they were expected to participate in and what care they should not attempt. This role uncertainty has been identified as a significant stressor for parents of hospitalized children (Hayes, & Knox, 1984; Knox, & Hayes, 1983). Parents reported that it was not always made clear to them what they could and could not do for their child, as discussions about parent participation rarely occurred between parents and nurses (Algren, 1985; Blower & Morgan, 2000; Darbyshire, 1994; Kristensson-Hallström & Elander, 1997). Darbyshire (1994) described how parents learned limits through trial and error, a chastening experience for them. Darbyshire's report of his phenomenological study includes a rich description that illustrates the development of themes, but the report is limited by the absence of descriptions of the data analysis and procedures to maintain rigour. Coyne and Cowley (2007) reported that parents feared displeasing the nurse by not doing a task they were expected to do, or by providing care that the nurse saw as part of "professional territory" (p.898) . Some parents, who labeled certain tasks as part of the nursing role, would not take on those activities (Blower & Morgan, 2000; Coyne, 1995; Roden, 2005; Romaniuk, 1993).

Parents who wanted to increase their participation were not always able to do so. A perception that the nurses were too busy or a sense of being less powerful than the nurses could interfere with parents' ability to develop their own role. Despite their interest in learning a particular care activity, some parents were reluctant to disturb the nurses with questions and, thus, did not expand their role (Blower & Morgan, 2000; Neill, 1996b).

Kristensson-Halström and Elander (1997) reported a grounded theory study aimed at understanding parents' experiences when their child is hospitalized. In their findings, they described variations in parents' level of participation, role perception and interactions with nurses, and linked these to parents' strategies for feeling secure. They divided parents' strategies into three categories: "1) Security through leaving the care to the staff; 2) Security through obtaining a measure of control over the care; and 3) Security through depending on knowing one's child best" (p. 343). Parents in the first category participated minimally in care and believed their role was to support the child. They were generally trusting of the nurses. Parents in the second category participated actively in their child's care and believed they could have done even more with some guidance from the staff. They saw their role as one of monitoring their child's overall care and providing the child with security. This group of parents was more likely to question or criticize the nurses. Parents in the third category were also active participants in their child's care and would have liked to do more. They described their role as one focused on the natural closeness between parent and child. They were reticent in their interactions with nurses, seldom telling nurses of problems for fear of disturbing them. In a subsequent study, Kristensson-Halström (1999) tested these categories using questionnaires that asked parents to identify their desired level of participation and what gave them security during their child's hospitalization. Their analysis supported the descriptions of categories developed in the original study, finding that parents who gained security from having control or by knowing their child best (categories 2 and 3) wanted more active participation in their child's care. While generalizations from the first study may be limited because all the children involved had been hospitalized for the same procedure, this limitation is mitigated somewhat by the wider variety of diagnoses in the children whose parents participated in the second study. However, the tools used in the second study were developed specifically for that study, and no reliability and validity information was reported.

**Understanding nurses' decisions regarding parents' participation.** Research indicates that parental participation is controlled largely by nurses, who play the role of gate keeper by determining what parents can and cannot do for their hospitalized child (Brown, & Ritchie, 1990; Kawik, 1996; Paliadelis et al., 2005; Rowe, 1996). These decisions are often based on the nurse's perspective of the situation, without considering the parents' viewpoint. Brown and Ritchie (1990) noted that the gate keeper role could interfere with nurses' ability to provide supportive emotional care to parents. There is a general expectation that parents will attend to ADL care needs while they are with their child (Brown, & Ritchie, 1990; Darbyshire, 1994; Kawik, 1996). Kawik (1996) reported that 60% of nurses surveyed did not believe that nurses should be responsible for ADL care when parents were present. However, Kawik does not describe the sample of nurse participants nor how they were recruited, making it difficult to judge the representativeness of this sample. Darbyshire (1994) identified that nurses assessed a parent's readiness, willingness and ability to participate, and encouraged participation accordingly. This assessment was largely intuitive, and the encouragement subtle. Darbyshire observed that nurses gave parents what they perceived to be necessary information (e.g., where diapers were stored) and expected that parents would then participate. They also encouraged parents to behave as if they were at home, and do all the care they would normally do. This expectation could place parents in an awkward situation: often the care they would normally do, such as bathing, was complicated by dressings or intravenous (IV) lines and, thus, they could not do this care as they would have done at home. At the same time, this suggestion to the parents that they should take on the care they would do at home implied that the other activities were in the nurses' domain. Coyne and Cowley (2007) reported that the nurses in their study assumed that "parents…experienced a role deficit with the hospitalization of their child because they were no longer responsible for the care for their child" (p.900). However, this assumption was not supported by data from the parents in their study.

Interviews with nurses provide insight into their motivation for maintaining control of parental participation in care. One of these motivating factors can be lack of time – nurses are busy. Using qualitative approaches, McKiel (2002) and Paliadelis et al. (2005) examined nurses' perceptions of the role they play in supporting parental participation in care and what influences this role. Both of these studies utilized a qualitative methodology and specified their procedures for maintaining rigour, however Paliadelis et al.'s work would have benefited from the identification of a specific methodology, and the inclusion of a description of data analysis procedures would strengthen McKiel's report. In both studies nurses noted that the "busyness" of their work environment had a negative impact on their ability to support parental participation, as it impeded their ability to teach parents what they needed to know to increase their involvement in care.

This finding reflects the results of the studies discussed previously, in which parents commented that they would have done more care if someone had taught them how. However, neither McKiel nor Paliadelis et al. addressed the possibility that parents did more care because of nurses' "busyness", a concern expressed by some parents. The nurses in Dearmun's (1992) study did recognize this issue, with statements such as, "On a busy ward it is taken for granted that mum will do it" (p.7). The effect of heavy workloads was also clearly expressed by nurses in Coyne and Cowley's (2007) study, who explicitly referred to needing the parents' presence and participation in care to ensure that all work was completed. In another study, nurses noted that when they were busy they were less able to provide emotional support for children whose parents were unable to stay, but they gave no indication that this "busyness" could lead parents to take on increased care responsibilities (Roden, 2005). Roden's (2005) grounded theory study was limited by the minimal participation of nurses in their focus groups.

Another motivating factor for controlling parental participation is the nurses' sense of responsibility. One aspect of this responsibility is the need to protect parents from perceived stressors, in particular the stress of seeing their child in pain (Brown & Ritchie, 1990; Paliadelis et al., 2005). As a result, nurses were often the ones to decide whether or not a parent would stay with the child during a painful procedure. A second aspect is legal accountability. Nurses were motivated to control parents' involvement in care because they understood that they, as registered nurses, were ultimately responsible for the child's well-being in hospital. This belief was demonstrated in various ways. This belief justified nurses' decisions to limit parental involvement in technical care activities (Blower & Morgan, 2000; Paliadelis et al., 2005). It also justified nurses' monitoring of all parental care activities, implying that parents could not be trusted to provide safe and adequate care to their child (Brown & Ritchie, 1990).

O'Haire and Blackford (2005) identified moral agency as the central concept in their grounded theory study of nurses' approaches to parental participation in care. Nurses demonstrated this moral agency by providing care they believed was in the child's best interest. Included in these beliefs about care were expectations of how the parent should be involved in the child's care. When parents did not meet these expectations, for example, by resisting the medical or nursing plan of care, nurses experienced moral distress. This distress led them to feel angry, frustrated and powerless, and resulted in ineffective coping strategies, such as negatively labeling the parents and limiting interaction with them. O'Haire and Blackford completed their grounded theory study on a unit that specialized in the care of children with cardiac and renal illnesses, thus application of the results to other settings must be made with caution. Coyne (2007) also found that nurses negatively labeled parents who did not meet their expectations regarding parental presence in hospital and parental provision of care.

In summary, research to date indicates the ways in which parents may determine their participation in care and how nurses influence their participation.

Parents' feelings of uncertainty about the care they could or should provide, and their perceptions of nurses' expectations and assumptions can influence parental participation. Parents may limit their involvement if they perceive certain activities as being within the nurses' domain. They may also be reluctant to ask the nurse for assistance in learning care skills if they perceive the nurse to be too busy or too powerful. Parents' participation may also be affected by their need to feel secure and how they meet this need.

The studies discussed above indicate that set expectations and assumptions about parental participation in care do exist among nurses. Nurses may not clearly express these expectations and assumptions to parents but nonetheless expect parents to behave accordingly. Parents who do not meet nurses' expectations may be labeled as 'difficult'. Nurses' expectations regarding parent participation may be related to their busy work life, which can also decrease their ability to interact with parents and teach them about their child's care. Nurses tend to assume a gate keeping role with regard to parental participation in care. They monitor parents' care and may limit parents' involvement in certain activities, which can have a negative impact on the parent-nurse relationship. Gate keeping may be related to heavy workloads, as well as to nurses' accountability and sense of moral agency regarding the care provided to the hospitalized child. Moral distress can occur when parents and nurses disagree about the plan of care, and this may lead to ineffective parent-nurse interactions.

**Summary of Literature Review**

This review of the literature indicates that parent participation has benefits for children and parents, and that it is supported as an important part of pediatric care by nurses and other health care professionals. It also demonstrates that parents are generally willing to participate in child care activities related to ADL, and that nurses are supportive of parents doing so. However, parents may need assistance with ADL care under certain circumstances. Parents' desire to participate in technical aspects of care is variable, and nurses may be less comfortable with parents participating in this care. Parents' decisions regarding participation in care are based in their belief of what is best for their child, and these decisions can be influenced by parents' perceptions of nurses' expectations and assumptions. Nurses' may have set expectations and assumptions regarding parental participation, and their decisions regarding parents' participation can be influenced by how busy their work environment is, as well as their professional sense of responsibility for the child. Communication between parents and nurses about parents' participation in their child's care is not always explicit.

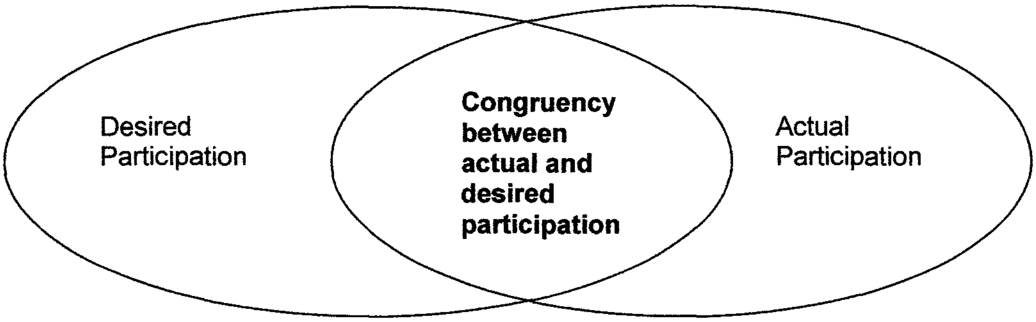
Parents may have different preferences for participation, but if nurses expect similar levels of participation from all parents these preferences may not be taken into consideration. Parents whose actual participation is more or less than desired may not experience full benefits from participation. Research to date alludes to discrepancies between parents' actual and desired participation, however no attempt has been made to measure discrepancies between actual and desired participation. The current study begins to address this gap, by specifically examining possible differences between parents' actual and desired participation.

## Conceptual Framework

To date, researchers examining parental participation in care using quantitative methodology have rarely stipulated conceptual frameworks for their studies. Many qualitative studies have been completed, each presenting their results in the form of themes or categories, which share enough similarity across studies to indicate some commonality of experience among parents. However, the variability in how these themes and categories are structured makes it difficult to link one study to another in a way that would support the development of a conceptual framework that could be used for future research.

The primary concept in the current study is parent participation in the care of the hospitalized child, which is an integral part of family-centered care (Ahmann, 1994; Newton, 2000). Parent participation is manifested in different ways, according to parents' preferences and perceptions. However, due to a variety of influences on the parent, the level of participation observed may not accurately reflect the level of participation desired. Thus, this study is based on the premise that to fully understand parental participation, both the actual participation and the desired participation must be considered. Describing the overlap, or congruency, between parents' desired and actual participation (Figure 1), is an important step in developing an understanding of parental participation.

Figure 1 Conceptual Framework: Congruency



## Research Question and Hypothesis

The question to be addressed in this study is: "What is the congruency between parents' desired and actual levels of participation in their child's care?" The hypothesis is that parents' actual level of participation will differ from their desired level of participation.

## Summary

In this chapter, the review of the literature was organized under the following categories: 1. Benefits of Participation (for children and for parents); 2. Nurses' support for parent participation; 3. Parents' Care Activities (from parents' perspectives and nurses' perspectives); and 4. Deciding the Extent of Parent Participation (parents' decisions and nurses' decisions). Significant findings and gaps in the literature were identified. The conceptual framework for the study was presented. The chapter concluded with statements of the research question and the hypothesis.

# CHAPTER 3: Methodology

This chapter describes the research methods used for data collection and data analysis for this study. It begins with a presentation of the research design selected, followed by a description of the study setting. Procedures used to select the sample are explained, including a discussion of the determination of sample size. This chapter also includes the process of selecting an instrument to measure parent participation, followed by a discussion of the variables selected for inclusion in the demographic questionnaire. Data collection procedures are presented, including recruitment and consent. A description of data analysis includes preparation of data, statistical procedures and qualitative processes for content analysis. This chapter concludes with a discussion of the ethical considerations for this study.

## Design

The phenomenon in question in this study is the extent to which parents' actual participation in their hospitalized child's care reflects their desired level of participation in such care. Thus, the variable of interest is the congruency between actual and desired participation. To study this variable, two other variables were measured: actual participation and desired participation. Measuring the difference between these two variables provided a measurement of congruency between them and allowed for the description of the phenomenon at a specific point in time. A cross-sectional, descriptive design was used, as this was the most suitable and economical approach for describing the variable of congruency with a one-time measurement (Polit & Beck, 2004; Wood & Ross-Kerr, 2006).

## Setting

The study was conducted on two of the in-patient pediatric units (units 3B and 3C) at McMaster Children's Hospital, a tertiary care facility in southern Ontario. The two units have a total of 51 beds, and serve a population of children aged newborn to 18 years with illnesses that include both medical and surgical diagnoses. The population on unit 3B (19 beds) is largely patients with cancer or eating disorders, while the population on 3C (32 beds) includes children who have undergone a variety of surgical procedures, as well as those with medical conditions such as cystic fibrosis and diabetes. The average length of stay on the units is 4.2 days; however, some patients stay for several weeks. Both units provide family-centered care that focuses on communicating, collaborating and responding to families' needs and preferences. Nurses on the units are all registered nurses prepared at the diploma or baccalaureate level, and patient assignments range from three to four patients per nurse, depending on patient acuity (A. Bowman, Program Manager, McMaster Children's Hospital, personal communication, June 13, 2007).

## Sample

A convenience sample of all parents who agreed to participate in the study was used. In this study, "parent" was defined as a caregiver who regularly remained with the hospitalized child for an extended period of time and participated in his/her care. This broad definition was used to include mothers and fathers as well as other significant people in the child's life. Inclusion and exclusion criteria for the sample are outlined in Table 1. Eligibility based on these criteria was determined by the charge nurse on the unit. The sample was collected consecutively, that is, as children were admitted to the units their parents were asked whether or not they were interested in participating in the study.

Table 1: Study Inclusion and Exclusion criteria

| Inclusion Criteria | Rationale |
|---|---|
| ▪ Parents of children aged 12 years and under | o Adolescents may be assuming more responsibility for their own care |
| ▪ Parents read and speak English | o Ensures understanding of written questionnaires |
| • Child admitted to unit 1 or more days prior to data collection date | o To give parents time to become familiar with the unit and their own participation in care |
| Exclusion Criteria | Rationale |
| ▪ Parents of children who are receiving palliative care | o Ethical consideration of child and family |
| ▪ Parents of children admitted due to suspicions of child abuse | o Parents may fear being judged by their responses to the questionnaire |
| ▪ Parents of children admitted for treatment related to psychiatric illness, including eating disorders. | o Conceptual basis of this study formed from review of research that did not include psychiatric illness |
| ▪ Parents of children involved in accidents where another family member was killed or was hospitalized with life-threatening injuries | o Ethical consideration of child and family |
| ▪ Parents of children newly | o Ethical consideration of child and family |

| | |
|---|---|
| diagnosed with a life-threatening illness | |

**Sample Size**

A power analysis was undertaken to determine the sample size of 199 for this study. Specifically, Cohen's (1988) approach for determining sample size as a function of alpha, effect size and power was applied. The conventionally-accepted standards for alpha ($\alpha = .05$) and power ($1-\beta = .80$) were used (Polit & Beck, 2004). The effect size represents the extent to which a phenomenon is evident within the population (Cohen, 1988). Ideally, effect size is calculated based on the results of previous studies, but when such studies are not available effect size can be estimated as small (.20), medium (.50) or large (.80) using available information (Cohen, 1988; Polit & Beck, 2004; Polit & Sherman, 1990). The effect size estimated for this study was .25, and its determination is outlined below.

The effect size of .25 was estimated based on guidelines recommended in the literature, prior research and clinical experience. Polit and Beck (2004) suggest that effect sizes between .20 and .40 are most common in nursing studies. Polit and Sherman (1990), based on their analysis of 62 nursing research articles, recommend using a small effect size or one no higher than midway between small and medium. Cohen (1988) indicates that in new areas of study (such as the current study) a small effect size should be anticipated. He also states that unless an effect is strong enough to be identified without formal research procedures (i.e., the effect is readily visible to an observer), a small effect size should be estimated. The effect size in the current study will indicate the extent of differences between parents' desired level of participation and their actual participation. It is unlikely that this difference would be readily identifiable to an observer, as desired level of participation cannot be observed unless parents verbalize their preferences.

The only reported effect sizes for the instrument used in this study, the Index of Parent Participation, are in relation to the implementation of an intervention to support mothers coping with a critically ill child (Melnyk et al., 2004; Melnyk et al., 1997). In a pilot study and in the main study that followed, parent participation was reported as an outcome measure to evaluate the effect of the intervention. The effect size in the pilot study (N = 30) was .07 (Melnyk et al., 1997), while the effect size in the full-scale study (N = 174) was .25 (Melnyk et al., 2004). These results indicate a small effect size (Cohen, 1988). Thus, taking into account Melnyk's research, as well as the guidelines suggested by Cohen and other authors, the effect size selected for this study was .25, and the required sample size was 199.

### Instruments

Participants were asked to complete three tools: a demographic questionnaire and two instruments to measure participation. The demographic questionnaire (Appendix B) was designed by the researcher to collect information about the participant (relationship to child, age, gender, level of education, employment status, marital status, location of residence, size of family) and the hospitalized child (age, gender). These demographic data from the parent were supplemented with a review of the chart by the researcher/research assistant to determine the following information about the child: date of admission, admitting diagnosis (used to categorize the illness as acute or chronic) and whether the admission was planned or an emergency. The variables examined via the demographic questionnaire and chart review were selected to enable a description of study participants that would be reflective of previous studies in this area.

Two measurement instruments were completed by the participants in this study. Both of these instruments were adapted from the Index of Parent Participation /Hospitalized Child (IPP/HC) (Melnyk, 1994; Melnyk, 1995; Melnyk et al., 2004; Melnyk, & Feinstein, 2001) with permission from its author (Appendix C). The IPP/HC was selected for this study after a detailed review of the literature. This review revealed that few instruments measuring parental participation in care were available. The majority of studies used a variation of one of three checklists for which limited or no reliability data were available. None of these tools was accessible by the researcher for further examination. The IPP/HC had been used in several studies, and as a result, validity and reliability data were available for this tool. The IPP/HC included communication-related aspects of parents' participation, which were absent in other tools. As well, this tool was easily accessed by the researcher and so could be reviewed to determine its suitability. To date, the IPP/HC has been used with mothers of children aged 1 to 7 years. The decision to use this tool in the current study of children up to age 12 years was based on the perceived advantage of using a tool with existing reliability and validity. Development of a new tool was beyond the scope of this project.

Melnyk (1994) reported that development of the IPP/HC began with a systematic review of the literature to identify a list of parent care items. This list was reviewed for content validity by eight pediatric clinical nurse specialists. The revised list was then reviewed for face validity and pilot tested with a group of 15 mothers. As a result, further revisions were made, resulting in a 36-item questionnaire. Internal consistency of the IPP/HC is supported by several studies reporting Cronbach's alpha coefficients of 0.77 (Melnyk, 1994), 0.82 (Melnyk et al., 1997), 0.80 (Melnyk & Feinstein, 2001) and 0.85 (Melnyk et al., 2004). In preparation for this study, the scale was reviewed by two pediatric nurses familiar with the study setting, and one advanced practice nurse in a similar pediatric setting. The scale was adapted for this study in two ways. First, the word "shot" was changed to "needle", to better reflect Canadian language usage. Second, as the original version of the scale was designed to measure actual participation, the wording and tense were changed to reflect responses about parents' desired level of participation. The three instruments were pilot-tested by three parents, all of whom completed the set of questionnaires within 10 minutes.

The actual level of participation was measured with the Index of Parent Participation/Hospitalized Child - Actual Activity (IPP/HC - A), while desired participation was measured using the Index of Parent Participation/Hospitalized Child – Desired Activity (IPP/HC - D). Both the IPP/HC – A (Appendix D) and the IPP/HC - D (Appendix E) are comprised of checklists of activities a parent might perform while caring for their child in hospital. In the IPP/HC - A, parents were asked to check the activities they participated in during the last 24 hours, while the IPP/HC - D asked parents to check the activities they wanted to participate in during the same time period. Both tools provided space at the end for parents to identify activities they did or wanted to do but that were not included in the checklist. The score for each checklist was determined by counting the number of activities checked – the higher the number, the higher the parental participation score, with possible scores ranging from 0 to 36 (Melnyk et al., 2004).

### Procedure

The data collection process began with the charge nurse providing eligible parents with a flyer explaining the study (Appendix F) and telling them that someone would come to ask them if they were interested in participating. Flyer distribution took place after the charge nurse was approached by the researcher/research assistant on each day that data collection took place. In some instances, this process was initiated by the charge nurse, if he/she had become familiar with the study. Parents were approached by the researcher or a research assistant as soon as possible after the flyer had been received, usually within a day or two of receiving the flyer. At this initial contact, parents were asked if they were interested in hearing more about the study. Parents who expressed interest in learning more about the study received a detailed verbal explanation of the study and, if they chose to participate, were given the written information/consent form (Appendix G) to sign. Parents who chose to participate were offered the opportunity to receive a summary of the study results upon its completion; those who accepted were asked to provide their mailing address, and were assured that this identifying information would not be linked to their questionnaires (Appendix H). Further description of ethical considerations for this study is provided later in this chapter.

After the study was explained and informed consent was obtained, participants were given the stamped, self-addressed envelope with the questionnaires. They were instructed to complete the questionnaires, place them back in the envelope and give them to unit staff at the nursing station. The envelopes were subsequently returned to the researcher by mail. Parents who received the questionnaire had already been on the unit a minimum of 24 hours. They were encouraged to complete the questionnaires as soon as possible after receiving them.

General instructions for completing the questionnaires were included in the envelope (Appendix I). These instructions asked that the form be completed by the person most involved in the child's care that day. Participants were asked to date each questionnaire. The envelope and each questionnaire in it were coded to facilitate linkage between the two versions of the IPP and the demographic questionnaire, as well as with data obtained from the child's chart. No other identifying information was noted on the questionnaires.

After obtaining informed consent, the researcher/research assistant reviewed the chart to determine the child's date of admission, whether the admission was planned or an emergency, and the admitting diagnosis. This information was recorded on a specific form (Appendix J), to be used to describe the sample.

## Data Analysis

Data were analyzed using SPSS computer software (version 15.0) to address the study question: "What is the congruency between parents' desired and actual levels of participation in their child's care?" Statistical inference was used to test the hypothesis that parents' actual level of participation would differ from their desired level of participation. Reliability for the IPP/HC-A and IPP/HC-D was determined using Cronbach's alpha. Descriptive statistics were used to describe the study sample. The nature of parents' participation in their children's care was described using frequencies of items selected on the IPP/HC-A and IPP/HC-D, as well as content analysis of parents' written comments.

**Preparation of data.** With large data sets, Burns and Grove (2005) recommend a random check of data for accuracy. Data were cross-checked by comparing the printed spreadsheet with the originally completed questionnaires. Coding errors were identified and corrected.

**Demographic data.** The demographic data were analyzed using descriptive statistics. The mean and range of ages of participants' children, and the mean and range of the number of children in each participating family were determined. All other demographic data were categorized and reported as frequencies.

**Data from IPP/A and IPP/D.** Data collected with the IPP/HC-A and the IPP/HC-D were analyzed using both descriptive and inferential statistics. For each participant, the scores on both the IPP/HC-A and the IPP/HC-D were determined, and the difference between the two scores was calculated. This difference is referred to as the congruency score (IPP/HC-A score minus IPP/HC-D score equals the congruency score). A positive congruency score indicates that the parent's actual participation was greater than his/her desired participation. A negative congruency score indicates that the parent's actual participation was less than his/her desired participation. A neutral score indicates that the parent selected the same number of items on both the Actual and Desired scales. The frequencies of positive and negative congruency scores were determined. The mean, range and standard deviation were calculated for the group of scores on each of the scales as well as for the congruency scores. The IPP/HC-A score and IPP/HC-D score were compared, and the hypothesis tested, using a paired t-test.

Responses to individual test items were examined to describe the nature of parents' participation. The frequencies of items checked off on each scale were determined. In addition, each participant's responses to the individual test items were coded for one of the following categories: 1. Item checked on both Actual and Desired scales; 2. Item checked on Actual scale only; 3. Item checked on Desired scale only; 4. Item not checked on either scale. The frequencies of these categories for each item were calculated.

**Analysis of written comments.** Parent participation activities identified by parents in the open-ended questions at the end of the tool were examined using content analysis. An inductive approach was used, beginning with open coding of data and generation of sub-categories, and culminating in the organization of activities into categories (Elo & Kyngäs, 2008).

### Ethical Considerations

Ethical approval for this study was obtained from the Research Ethics Boards (REB) of McMaster University/Hamilton Health Sciences and Ryerson University. As stipulated by the McMaster University/Hamilton Health Sciences REB, the study was introduced to potential participants by a person within the participant's circle of care, who in this case was the charge nurse. The researcher did not have contact with potential participants prior to the charge nurse's introduction of the study.

At the initial meeting with the researcher or research assistant, the study was explained and potential participants were assured that their decision whether or not to participate in the study would not influence the care that their child received. They were also told that they could refuse to answer any questions or withdraw from the study at any point in time. Parents were encouraged to ask questions at any point during this introductory meeting. Those who chose to participate in the study were given a written information/consent form (Appendix G). Any further questions were addressed by the researcher/ research assistant, and the form was signed by the participant and the researcher/research assistant; one copy of the signed consent was placed in the chart and one was given to the participant, while the original was filed by the researcher.

There were no identified risks associated with participation in this study. While participants may not have benefited directly from their participation, they may have gained some satisfaction in knowing that they were making a contribution to the improvement of the care of children and families in hospital. Some parents may have found that the reflection required to complete the questionnaires helped them to learn from their experience.

Confidentiality was maintained by identifying all questionnaires and data collected from the chart by a code. Names and provincial insurance plan numbers were not recorded. Completed questionnaires and consents were kept in a locked office.

### Summary

A cross-sectional descriptive design was used to examine the phenomenon of congruency between parents' desired and actual participation in their child's care. A convenience sample was recruited and participants completed three questionnaires (one demographic questionnaire and two tools measuring parents' actual and desired participation in their child's care). Inferential and descriptive statistics, and content analysis were used to test the study hypothesis, and to describe participants and their participation in their hospitalized child's care. Ethical considerations for participants were maintained in conducting this research.

# CHAPTER 4: Results

This chapter presents the results of the study, beginning with a discussion of the response rate and sample, followed by a demographic description of the participants, their children and the children of non-completers. Reliability data are then presented for each tool. Hypothesis-testing using a paired t-test, and participants' congruency scores are presented. The nature of parental participation in this study is described next, drawing on scale scores and results of content analysis of written comments.

## Description of the Sample

A total of 230 questionnaires were distributed to eligible caregivers who consented to participate in the study. Of these, 191 were completed and returned to the researcher, resulting in a completion rate of 83%. The number of eligible caregivers who were not approached to participate in the study and the total number of flyers distributed were not recorded. No information was recorded about parents who chose not to participate in the study. Data about the children of those who accepted the questionnaire but did not return it (referred to as "non-completers") were collected from the chart and were used to describe this group of parents.

**Characteristics of participants.** Detailed demographic data about the sample can be found in Table 1. One hundred sixty one participants in the study were mothers (84.3%), while 24 (12.6%) were fathers. The five participants in the "Other" category included a grandfather and a foster parent (not specified if male or female), as well as three cases in which the parents completed the questionnaire together and identified themselves as "both parents". One hundred forty four participants (75.4%) were between the ages of 21 and 40 years, and 165 (86.4%) were married or living in a common-law relationship. Sixty-four participants (33.5%) were working full-time, while 63 (33.0%) identified themselves as stay-at-home parents. Of the 36 (18.8%) individuals who marked the "Other" category for employment status, 28 were on leave from their jobs, most often due to maternity leave or unspecified leave, but in one case the parent identified being on disability leave due to their child's illness. Also included in the "Other" category were five self-employed individuals and one student. While 72 (37.7%) participants reported their level of education as a high school diploma or less, 113 (59.2%) reported completion of post-secondary education. Travel time between home and hospital was an hour or less for 155 families (81.2%).

Table 1
Characteristics of Participants (N=191)

| **Variable** | **f** | **%** |
|---|---|---|
| Relationship to Child | | |
| Mother | 161 | 84.3 |
| Father | 24 | 12.6 |
| Other | 5 | 2.6 |
| No response | 1 | 0.5 |
| Age of Caregiver | | |
| 20 yrs or less | 9 | 4.7 |
| 21-30 years | 44 | 23.0 |
| 31-40 years | 100 | 52.4 |
| 41-50 years | 36 | 18.8 |
| 51 yrs or more | 1 | 0.5 |
| No response | 1 | 0.5 |
| Marital Status (condensed) | | |
| Single (never Married) | 15 | 7.9 |
| Married | 137 | 71.7 |
| Common-law | 28 | 14.7 |
| Divorced/Separated | 8 | 4.2 |
| Widowed | 2 | 1.0 |
| No response | 1 | 0.5 |
| Employment Status | | |
| Full-time | 64 | 33.5 |
| Part-time | 24 | 12.6 |
| Stay-at-home parent | 63 | 33.0 |
| Looking for work | 3 | 1.6 |
| Other | 36 | 18.8 |
| No response | 1 | 0.5 |
| Level of Education | | |
| Less than High School | 16 | 8.4 |
| High School Diploma | 56 | 29.3 |
| College Diploma | 56 | 29.3 |
| University undergraduate degree | 28 | 14.7 |
| University graduate degree | 29 | 15.2 |
| Other | 5 | 2.6 |
| No response | 1 | 0.5 |

Table 1
Characteristics of Participants (N=191) (continued)

| Variable | f | % |
|---|---|---|
| Travel Time to Hospital | | |
| < 30 minutes | 76 | 39.8 |
| 30-60 minutes | 79 | 41.4 |
| > 60 minutes | 34 | 17.8 |
| No response | 2 | 1.0 |

**Characteristics of children of participants.** Children of the study participants are described in Table 2. These children ranged in age from 1 week to 12 years, with a mean age of 3 years, 8 months. The largest proportion of children was 1 year of age or less (37.7%). Approximately one-third (32.5%) of the participants' children were only children, with the remainder having one to six siblings. Over half of the children (58.6%) had been hospitalized at least once prior to the current admission. Their length of stay at the time of questionnaire completion averaged 7.2 days, ranging from 1 to 126 days. Length of stay could not be determined for 7.3% of children because participants did not date the questionnaire. Approximately two-thirds (67.5%) of the children were admitted to the hospital on an emergency basis. These children were identified based on the presence of an emergency department (ED) record sheet on their chart, or a note indicating transfer to the unit from another hospital's ED.

The admitting diagnosis, as written in the chart, was used to determine the reason for hospitalization. The most common admitting diagnosis in this group of children was "investigation of symptoms". This category included admitting diagnoses that were based on symptoms, rather than identifying a specific illness or procedure. Of the 34 (17.8%) children admitted for investigation of symptoms, 10 (29.4%) had gastrointestinal symptoms with or without fever, 7 (20.6%) were admitted for failure to thrive and 3 (8.8%) for investigation of fever not yet diagnosed. The next most common diagnosis category was gastrointestinal illness, with 28 (14.7%) children, followed by neurological disorders, with 23 (12.0%) children. Seven children (3.7%) were placed in the "other" category because their admitting diagnosis did not provide enough information to accurately categorize their condition.

Table 2
Characteristics of Children of Participants (N=191)

| Variable | f | % |
|---|---|---|
| Age of Child (years) | | |
| ≤1 | 72 | 37.7 |
| >1 - <3 | 30 | 15.7 |
| 3 - <6 | 37 | 19.4 |
| 6-8 | 20 | 10.5 |
| 9-12 | 31 | 16.2 |
| Missing data | 1 | 0.5 |
| Length of Stay at Time of Questionnaire Completion (days) | | |
| 1-3 | 104 | 54.5 |
| 4-7 | 44 | 23.0 |
| 8-14 | 20 | 10.5 |
| ≥15 | 9 | 4.7 |
| Missing data | 14 | 7.3 |
| Child's Gender | | |
| Female | 82 | 43.0 |
| Male | 107 | 56.0 |
| Missing data | 2 | 1.0 |

Table 2
Characteristics of Children of Participants (continued)

| | | |
|---|---|---|
| Number of Previous Hospitalizations | | |
| 0 | 76 | 39.8 |
| 1 | 49 | 25.7 |
| 2 | 19 | 9.9 |
| ≥3 | 44 | 23.0 |
| Missing data | 3 | 1.6 |
| Number of Children in Family | | |
| 1 | 62 | 32.5 |
| 2-3 | 103 | 53.9 |
| ≥4 | 25 | 13.1 |
| Missing data | 1 | 0.5 |
| Chronic vs. Acute Illness | | |
| Chronic | 82 | 43.0 |
| Acute | 107 | 56.0 |
| Missing data | 2 | 1.0 |
| Planned vs. Emergency Admission | | |
| Planned | 61 | 32.0 |
| Emergency | 129 | 67.5 |
| Missing data | 1 | 0.5 |
| Diagnosis | | |
| Investigation of Symptoms | 34 | 17.8 |
| Gastrointestinal | 28 | 14.7 |
| Neurological | 23 | 12.0 |
| Respiratory | 19 | 10.0 |
| Musculoskeletal | 16 | 8.4 |
| Genitourinary | 14 | 7.3 |
| Cancer | 10 | 5.2 |
| Head & Neck | 9 | 4.7 |
| Injury | 9 | 4.7 |
| Miscellaneous Infection | 8 | 4.2 |
| Other | 7 | 3.7 |
| Cardiac | 6 | 3.1 |
| Skin | 3 | 1.6 |
| Procedure | 3 | 1.6 |
| Endocrine | 2 | 1.0 |

Admitting diagnosis was also used to identify which children were admitted with health problems related to a chronic condition and which had an acute condition not related to an ongoing illness. More children (56%) were admitted with acute illness than chronic illness (43%). Of the children identified as having a chronic illness, 50% had been hospitalized two or more times, while only 19.7% of the children identified with acute illness had had two or more hospitalizations (see Table 3).

Table 3
Number of Hospitalizations: Comparison of Children with Chronic vs. Acute Illness (N=189)[a]

| Number of Hospitalizations | Children with Chronic Illness (n=82) | | Children with Acute Illness (n=107) | |
|---|---|---|---|---|
| | f | % | f | % |
| 0 | 23 | 28.0 | 52 | 48.6 |
| 1 | 17 | 20.7 | 32 | 29.9 |
| 2 | 14 | 17.1 | 5 | 4.7 |
| ≥3 | 27 | 32.9 | 16 | 15.0 |
| Missing data | 1 | 1.2 | 2 | 1.9 |

[a] Information regarding type of illness (acute or chronic) not available for two participants

**Characteristics of children of non-completers.** Caregivers who agreed to complete the questionnaire signed the consent form giving permission for the researcher to gather data from their child's chart, thus the group of non-completers (n=39) can be described using this information. As with the participants' children, the most frequent diagnosis categories were investigation of symptoms (23.1%), gastrointestinal disorders (10.3%) and neurological disorders (10.3%). Of the nine children categorized as "investigation of symptoms", four were diagnosed with fever NYD. The remaining five children each had a different admitting diagnosis. Similar to the participants' children, the non-participant group was almost evenly divided between chronic (46.2%) and acute (53.8%) illness, and the majority (71.8%) experienced emergency admissions to hospital. However, the rate of emergency admissions in the non-completer group was slightly higher than that in the participant group (71.8% vs. 67.5% respectively). Fisher's Exact Test indicated that there was no significant difference between participants' children and non-completers' children on the variables of acute vs. chronic illness ($p = 0.806$) and planned vs. emergency admission ($p = 0.708$). Characteristics of non-completers' children are listed in Table 4.

Table 4
Description of Children of Non-Completers (N=39)

| Variable | f | % |
|---|---|---|
| Chronic vs. Acute Illness | | |
| Chronic | 18 | 46.2 |
| Acute | 21 | 53.8 |
| Missing data | 0 | 0.0 |
| Planned vs. Emergency Admission | | |
| Planned | 11 | 28.2 |
| Emergency | 28 | 71.8 |
| Missing data | 0 | 0.0 |
| Diagnosis | | |
| Investigation of Symptoms | 9 | 23.1 |
| Gastrointestinal | 4 | 10.3 |
| Neurological | 4 | 10.3 |
| Respiratory | 3 | 7.7 |
| Cancer | 3 | 7.7 |
| Head and Neck | 3 | 7.7 |
| Miscellaneous Infection | 3 | 7.7 |
| Injury | 2 | 5.1 |
| Musculoskeletal | 2 | 5.1 |
| Cardiac | 2 | 5.1 |
| Skin | 2 | 5.1 |
| Genitourinary | 1 | 2.6 |
| Hematology | 1 | 2.6 |
| Procedure | 0 | 0.0 |
| Endocrine | 0 | 0.0 |
| Other | 0 | 0.0 |

## Study Results

**Reliability testing.** Internal consistency was determined for the IPP/Actual and the IPP/Desired using Cronbach's alpha. For the IPP/Actual, the alpha coefficient was 0.90, while for the IPP/Desired, it was 0.91.

**Testing of the hypothesis.** The research question addressed in this study was: "What is the congruency between parents' desired and actual levels of participation in their child's care?" and the hypothesis was that parents' actual level of participation will differ from their desired level of participation. This hypothesis was tested using a paired samples t-test, which revealed a significant difference between participants' actual and desired levels of participation (t = -9.382, df = 190, p < 0.0001). The mean on the IPP Actual scale was 22.3 (SD = 7.6) while the mean on the IPP Desired scale was 27.1 (SD = 7.3).

Congruency scores, the calculation of the difference between actual and desired participation, were determined for each participant. The congruency score was determined by subtracting the IPP/HC-D score from the IPP/HC-A score. Congruency scores ranged from -30 to 22, with a mean of -4.8 (SD = 7.1). The majority of participants (74.9%) had a negative congruency score, indicating a desire to perform more care activities than they actually performed. Nineteen participants (9.9%) received a neutral congruency score, in which their score on the IPP Actual equaled that on the IPP desired. Further details about the congruency scores are found in Table 5.

Table 5
Scale Scores and Congruency Scores (N=191)

| Score | Frequency (%) | Mean | SD | Range | Minimum | Maximum |
|---|---|---|---|---|---|---|
| IPP Actual | | 22.3 | 7.6 | 36 | 0 | 36 |
| IPP Desired | | 27.1 | 7.3 | 36 | 0 | 36 |
| Congruency Score | - | - 4.8 | 7.1 | 52 | -30 | 22 |
| Negative Score | 143 (74.9) | -7.4 | 5.7 | 29 | -30 | -1 |
| Positive Score | 29 (15.2) | 4.7 | 5.6 | 21 | 1 | 22 |
| Neutral Score | 19 (9.9) | 0 | 0 | 0 | 0 | 0 |

**Description of the nature of parental participation.** The following discussion describes the nature of parents' participation in this study, illustrating parents' actual and desired participation using the frequencies of items checked on each scale and then content analysis of written comments. These data provide a way of comparing parents' participation in the current study with other studies. It should be noted that these data provide a snapshot of each participant's activity for a 24-hour period only, and reflect their child's condition and care needs on the day that the questionnaire was completed.

***Data from IPP/A and IPP/D.*** Table 6 lists frequencies for each item selected on each scale, as selected by all participants on each scale individually, while Table 7 lists frequencies for items selected as Desired Only. Frequencies for item selection were also determined according to the following categories: 1. Items checked on both Actual and Desired scales (i.e. selected by one participant on both scales); 2. Items checked on Actual scale only; 3. Items not checked on either scale. The frequencies for these categories can be found in Appendix K.

On the Actual scale (see Table 6), the items most often selected were: "Spent quiet time interacting with child" (92.1%), "Stroked child/rubbed back" (90.6%), "Comforted child when upset (not related to a painful procedure" (90.1%), "Helped with elimination" (90.1%), and "Told nurse about something your child needed" (87.4%). These five items were also among the six most frequent responses on the Desired scale. Two items were identified as least frequent on both the Actual scale and the Desired scales respectively: "Played with child for the purpose of getting him/her to talk about or show feelings by use of puppets, dolls or stuffed animals or used role play" (18.3%, 30.9%), and "Talked with another parent or person (besides a nurse or doctor) to gain more information about some part of the hospital experience or your child's illness or injury" (29.8%, 49.7%).

Table 6
Item Frequencies for IPP/HC-A and IPP/HC-D (N = 191)
*(In descending order of frequency on Actual Scale)*

| Item | Actual | | Desired | |
|---|---|---|---|---|
| | f | % | f | % |
| Spent quiet time interacting with child | 176 | 92.1 | 183 | 95.8 |
| Stroked child/rubbed back | 173 | 90.6 | 169 | 88.5 |
| Comforted child when upset (does not include comforting during a painful procedure) | 172 | 90.1 | 181 | 94.8 |
| Helped with elimination | 172 | 90.1 | 176 | 92.1 |
| Told nurse about something your child needed | 167 | 87.4 | 175 | 91.6 |
| Settled for sleep or nap | 167 | 87.4 | 175 | 91.6 |
| Fed child or set up his/her food tray | 166 | 86.9 | 169 | 88.5 |
| Changed clothes or pajamas | 163 | 85.3 | 176 | 92.1 |

Table 6
Item Frequencies for IPP/HC-A and IPP/HC-D (N = 191) (Continued)
*(In descending order of frequency on Actual Scale)*

| Item | Actual | | Desired | |
|---|---|---|---|---|
| | f | % | f | % |
| Held or rocked child | 151 | 79.1 | 169 | 88.5 |
| Asked nurse for information about child's condition | 146 | 76.4 | 157 | 82.2 |
| Asked physician for information about child's condition | 144 | 75.4 | 172 | 90.1 |
| Asked nurse for information about child's care | 141 | 73.8 | 163 | 85.3 |
| Kept track of how much child ate or drank and told nurse or recorded the amount on an intake and output sheet | 138 | 72.3 | 142 | 74.3 |
| Kept track of how much or how often child urinated and told nurse or recorded it on an intake and output sheet | 138 | 72.3 | 138 | 72.3 |
| Comforted child during a painful procedure | 133 | 69.6 | 170 | 89.0 |
| Kept track of when child had a bowel movement and told nurse or recorded it on an intake and output sheet | 128 | 67.0 | 143 | 74.9 |
| Encouraged fluids | 124 | 64.9 | 146 | 76.4 |
| Helped nurse give medication (would include getting child to cooperate) | 121 | 63.4 | 144 | 75.4 |
| Bathed child/sponged with a washcloth | 119 | 62.3 | 156 | 81.7 |
| Actively played with child in room (games, blocks, etc) | 115 | 60.2 | 133 | 69.6 |
| Asked the nurse or doctor to explain something that you did not understand | 113 | 59.2 | 155 | 81.2 |
| Took child for a walk, if allowed | 109 | 57.1 | 164 | 85.9 |
| Made a decision regarding your child's care | 108 | 56.5 | 155 | 81.2 |
| Told physician about something your child needed | 89 | 46.6 | 139 | 72.8 |
| Combed/brushed hair | 89 | 46.6 | 123 | 64.4 |

Table 6
Item Frequencies for IPP/HC-A and IPP/HC-D (N = 191) (Continued)
*(In descending order of frequency on Actual Scale)*

| Item | Actual | | Desired | |
|---|---|---|---|---|
| | f | % | f | % |
| Talked with child about why he/she is in the hospital | 86 | 45.0 | 104 | 54.5 |
| Talked with child about why he/she needs a test or treatment | 83 | 43.5 | 101 | 52.9 |
| Brushed teeth/performed mouth care | 83 | 43.5 | 127 | 66.5 |
| Took child to playroom if allowed | 82 | 42.9 | 144 | 75.4 |
| Told nurse about child's daily routines or his/her likes or dislikes without being asked to do so | 81 | 42.4 | 129 | 67.5 |
| Let child know what to expect about a treatment or test | 79 | 41.4 | 95 | 49.7 |
| Suggested to a nurse or doctor a different way or time of doing something that you thought would be better for your child | 78 | 40.8 | 120 | 62.8 |
| Asked a nurse or physician about how your child was during the time you were not with him/her | 77 | 40.3 | 118 | 61.8 |
| Asked a nurse or doctor to describe a certain test or procedure so that you could tell your child about it | 66 | 34.6 | 102 | 53.4 |
| Talked with another parent or person (besides a nurse or doctor) to gain more information about some part of the hospital experience or your child's illness or injury | 57 | 29.8 | 95 | 49.7 |
| Played with child for the purpose of getting him/her to talk about or show feelings by use of puppets, dolls or stuffed animals or used role play. | 35 | 18.3 | 59 | 30.9 |

The items most often indicated as a Desired activity but not actually done (see Table 7) were "Take child to playroom if allowed" (35.6%), "Told physician about something your child needed" (31.4%) , "Took child for a walk if allowed" (30.4%), "Told nurse about child's routines, likes and dislikes without being asked to do so" (29.8%) and "Suggested to nurse or doctor a different way or time of doing something that you thought would be better for your child" (27.2%). Six activities related to parent-professional communication were checked as Desired but not actually done by 24% or more of participants.

Table 7
Comparison of Item Frequencies: Selected on Desired Scale Only (N = 191)
*(In descending order of frequency)*

| Item | Desired Only | |
|---|---|---|
| | f | % |
| Took child to playroom if allowed | 68 | 35.6 |
| Told physician about something your child needed | 60 | 31.4 |
| Took child for a walk, if allowed | 58 | 30.4 |
| Told nurse about child's daily routines or his/her likes or dislikes without being asked to do so | 57 | 29.8 |
| Suggested to a nurse or doctor a different way or time of doing something that you thought would be better for your child | 52 | 27.2 |
| Asked a nurse or physician about how your child was during the time you were not with him/her | 51 | 26.7 |
| Made a decision regarding your child's care | 51 | 26.7 |
| Asked the nurse or doctor to explain something that you did not understand | 50 | 26.2 |
| Brushed teeth/performed mouth care | 48 | 25.1 |
| Talked with another parent or person ... to gain more information about some part of the hospital experience or your child's illness or injury | 47 | 24.6 |

Table 7
Comparison of Item Frequencies: Selected on Desired Scale Only (N = 191) (Continued)
*(In descending order of frequency)*

| Item | Desired Only | |
|---|---|---|
| | f | % |
| Asked a nurse or doctor to describe a certain test or procedure so that you could tell your child about it | 46 | 24.1 |
| Bathed child/sponged with a washcloth | 41 | 21.5 |
| Comforted child during a painful procedure | 41 | 21.5 |
| Kept track of when child had a bowel movement and told nurse or recorded it on an intake and output sheet | 38 | 19.9 |
| Combed/brushed hair | 36 | 18.8 |
| Asked physician for information about child's condition | 35 | 18.3 |
| Asked nurse for information about child's care | 31 | 16.2 |
| Played with child for the purpose of getting him/her to talk about or show feelings by use of puppets, dolls or stuffed animals or used role play | 30 | 15.7 |
| Helped nurse give medication (would include getting child to cooperate) | 30 | 15.7 |
| Encouraged fluids | 28 | 14.7 |
| Actively played with child in room (games, blocks, etc) | 27 | 14.1 |
| Let child know what to expect about a treatment or test | 27 | 14.1 |
| Talked with child about why he/she needs a test or treatment | 27 | 14.1 |

Table 7
Comparison of Item Frequencies: Selected on Desired Scale Only (N = 191) (Continued)
*(In descending order of frequency)*

| Item | Desired Only | |
|---|---|---|
| | f | % |
| Talked with child about why he/she is in the hospital | 27 | 14.1 |
| Asked nurse for information about child's condition | 26 | 13.6 |
| Held or rocked child | 24 | 12.6 |
| Kept track of how much or how often child urinated and told nurse or recorded it on an intake and output sheet | 22 | 11.5 |
| Kept track of how much child ate or drank and told nurse or recorded the amount on an intake and output sheet | 22 | 11.5 |
| Changed clothes or pajamas | 21 | 11.0 |
| Told nurse about something your child needed. | 15 | 7.9 |
| Comforted child when upset (does not include comforting during a painful procedure) | 14 | 7.3 |
| Helped with elimination | 13 | 6.8 |
| Spent quiet time interacting with child | 12 | 6.3 |
| Settled for sleep or nap | 12 | 6.3 |
| Fed child or set up his/her food tray | 10 | 5.2 |
| Stroked child/rubbed back | 5 | 2.6 |

Participants expressed a desire to comfort their children when upset (94.8%) and during painful procedures (89%) (see Table 6) While 90.1% reported “Comforted child when upset (does not include comforting during a painful procedure)” as an Actual activity, only 69.6% reported “Comforted child during a painful procedure” as an Actual activity. Close to one quarter of participants (21.5%) identified “Bathed child/sponged with a washcloth” as a Desired activity that they did not actually perform (see Table 7). Less than half of the participants (43.5%) reported “Brushed teeth/performed mouth care” as an Actual activity, while 66.5% indicated this as a Desired activity (see Table 6). Parents who wanted to help the nurse give their child’s medication but did not do so outnumbered those who did help with medication administration but did not indicate it as a Desired activity (15.7% vs. 3.7%); 59.7% of parents wanted to help give medications and did so (see Appendix K).

Infrequently indicated on the Actual Scale overall was “Suggested to nurse or doctor a different way or time of doing something that you thought would be better for your child”, with 40.8% checking this as an Actual activity (see Table 6). However, this item was one of the five most likely to be identified as Desired only, with 27.2% of participants indicating that they wanted to do this activity, but did not actually perform it (see Table 7).

***Content analysis of written comments.*** Content analysis was completed on written comments provided by 38 participants. These comments were in response to the question “Were there any other activities that you performed/wanted to perform for your child that are not on this list? If yes, what were they?" The intention here was to elicit specific care activities not included on the list. Parents listed 34 specific activities that they actually did, and 10 specific activities that they desired to do. Participants also identified some needs of their own that could influence their ability to care for their child, adding 17 statements describing these needs. Three main categories of activities were identified: "Participation in Physical Care Activities", "Psychosocial Care of Child" and "Meeting Parental Needs". These categories and their sub-categories are listed in Table 8 and specific examples of each category are provided in Appendix L. Each category will be discussed below.

Table 8
Results of Content Analysis

| Category | Sub-categories |
|---|---|
| Participation in Physical Care Activities | Activities of Daily Living (ADL)<br>Complex ADL<br>Technical care |
| Psychosocial Care of Child | Support child<br>Entertain child<br>Maintain child's connections |
| Meeting Parental Needs | Need for assistance<br>Need for information<br>Need for security<br>Need for control |

The category "Participation in Physical Care Activities" includes "Activities of Daily Living (ADL)", "Complex ADL" and "Technical care". The most frequently identified ADL activity was making the bed and/or changing bed sheets. Complex ADL included preparing and administering feedings via pump or syringe, and preparing a special bath. In these two sub-categories, activities were listed on the Actual scale only. In the Technical care sub-category, one participant specified provision of gastrointestinal tube site care, tracheotomy care and giving non-intravenous medications on both the Actual and Desired scales, indicating that he/she was providing care that he/she wanted to provide. Another participant accompanied his/her child to physiotherapy and noted this on both the Actual and Desired scales. Two participants identified a desire to learn some aspects of looking after their child's intravenous infusion. Several participants listed various activities on the Actual scale, but did not list them on the Desired scale.

Three categories are included in "Psychosocial Care of the Child". The first, "Support Child", includes activities undertaken to provide the child with emotional support. The importance of this activity was clearly stated by one parent, who wrote, "the most important activity of all, loving and keeping my child happy". One participant listed developing and implementing a reward system for his/her child (to help him/her through tests and procedures) as both an Actual and Desired activity. Identified on the Desired scale only was one participant's wish to accompany his/her child to the operating room for induction of anesthesia. In the second sub-category, "Entertain Child", participants included riding a bike in the playground and water play in a basin, but also listed activities that were already included on the instruments, such as reading with the child and taking him/her for a walk. Participants who listed these activities also checked them off on the scales. Taking the child for a walk was listed by two participants as both Actual and Desired. The final sub-category, "Maintain Child's Connections" included facilitation of phone conversations with family and friends (included as Actual and Desired by two participants) and bringing family to visit.

The third category, "Meeting Parental Needs" identifies four needs expressed by participants: (1) Assistance; (2) Information; (3) Security; and (4) Control. The need for Assistance ranged from very specific (e.g., assistance with showering child, support for providing mouth care) to more global requests for assistance. For example, one parent with physical disabilities wrote that there were no accommodations for her disabilities and that she was not "offered any type of "help" for me to help [my child]". The need for Information consisted mostly of actual activities required for learning about the hospital environment, but one participant expressed a desire for more information about isolation procedures. The need for Security focused on parents' comfort with leaving their child alone. One participant, who identified herself as a single parent, listed staying long hours to ensure her child received the necessary care and support as an Actual activity, and expressed a desire to be assured that these needs would be met in her absence. The need to Control referred to efforts to maintain the child's usual schedule and routines. One participant, who coordinated treatment and care for her child with a rare disorder, identified this activity as both Actual and Desired.

## Summary

A sample of 191 participants, consisting mostly of mothers, completed the study questionnaires. The group of participants, their children and the children of non-completers were described. Reliability testing using Cronbach's alpha was reported, with $\alpha = 0.90$ for the IPP/Actual Scale and . $\alpha = 0.91$ for the IPP/Desired Scale. The hypothesis "Parents' actual level of participation will differ from their desired level of participation" was accepted based on the statistically significant t-test result. Congruency scores were presented. The majority of parents (74.9%) had negative congruency scores, indicating that their actual participation was less than their desired participation. Examination of frequencies of responses to each item on each scale, together with the content analysis of written responses to the questionnaires, were used to describe the nature of parents' participation. Parent participation in the current study consisted largely of providing comfort care, providing ADL care, and advocating for the child, with some participation in technical care activities.

# CHAPTER 5: Discussion and Limitations

In this chapter, results of the study are discussed in comparison to relevant literature and within the context of the conceptual framework. The sample used in this research is compared with those used in earlier studies. Congruency scores are examined, linking positive and negative scores with parental experiences described in previous studies. The nature of parent participation, as indicated by frequencies of items selected on the scales and parents' written comments, is described and compared with the literature. Strengths and limitations of the study are presented.

## Discussion of Findings

**Findings related to the sample.** The sample used in this study is similar to samples used in previous research. One similarity is the high proportion of mothers responding to the questionnaire. In the current study, 84.3% of participants were mothers and 12.6% were fathers. In the literature reviewed, most studies reported a proportion of mothers between 80% and 90% (Coyne & Cowley, 2007; Coyne, 1995; Darbyshire, 1994; Espezel & Canam, 2003; Hill, 1978; Kristensson-Hallström, 1999; Lam et al., 2006; Neill, 1996b). Only two studies used samples in which less than 80% of participants were mothers: Kristensson-Hallström and Elander (1997) reported 60% and Roden (2005) reported 69%.

The continuing preponderance of mothers taking part in studies of parent participation likely reflects the reality of child hospitalization, in that it is more often the mother who stays with the child. Knafl and Dixon (1984) reported that 76% of fathers in their study of parents were with their child in hospital for less than 50% of the child's waking hours, with 8% staying with their child for 75%-100% of their waking hours. While it is possible that fathers' participation has changed in the 25 years since Knafl and Dixon completed their work, no studies have looked specifically at fathers' participation since that time. Research examining fathers' experiences with their child's hospitalization in general and with participation in care specifically is warranted, as their perspectives may differ from that of mothers.

The age of children of participants in this study, ranging from 0.02-12.0 years, reflects the ages reported in other studies (Coyne & Cowley, 2007; Espezel & Canam, 2003; Kristensson-Hallström, 1999; Kristensson-Hallström & Elander, 1994; Kristensson-Hallström & Elander, 1997; Lam et al., 2006; MacDonald, 1969). In these studies, the lower limit for age varies from 1 week (Kristensson-Hallström, & Elander, 1994) to 7 years (Coyne & Cowley, 2007), while the upper limit extends from 5 years (Kristensson-Hallström & Elander, 1994) to 16 years (Kristensson-Hallström, 1999). The shortest length of stay (LOS) reported in previous studies was 12 hours (Kristensson-Hallström, 1999); upper limits for LOS were not always specified, but have been described in terms of months (Darbyshire, 1994; Kristensson-Hallström 1999; Lam et al., 2006). Thus, the LOS reported in the literature reviewed are comparable with the 1-126 days spent in hospital by the children of the current study's participants. The number of hospitalizations experienced by children of participants is not reported consistently in the literature, but available data indicate that the current study's finding that participants' children had experienced zero to three or more hospitalizations is similar to samples used in other studies. Balling and McCubbin (2001) reported that children of participants in their study had been hospitalized from 2 to over 50 times, while Neill (1996b) reported hospitalizations ranging from 0 to 10 times. Other authors indicate that participants' children had been hospitalized more than once but do not specify the number (Espezel & Canam, 2003; Kristensson-Hallstrom & Elander, 1994; Lam et al., 2006). The current sample included children with chronic illness (43%) and acute illness (56%); samples specifying inclusion of children with both chronically and acutely ill children have been used previously (Coyne & Cowley, 2007; Darbyshire, 1994; Kristensson-Hallstrom & Elander, 1994; Lam et al., 2006; Neill, 1996b). However, none of these reports provides statistics regarding the proportion of chronic versus acute illness amongst their participants, making a more detailed comparison with the current study difficult.

Data indicate that the current study is comparable to others with regard to parents' age (Balling & McCubbin, 2001; Coyne & Cowley, 2007; Coyne, 1995; Kristensson-Hallström & Elander, 1997). The upper age limit in these studies ranges from 42 to 60 years, while the lower limit ranges from 22 to 30 years. In the current study there were 37 parents aged 41 or higher; this sample also included some younger parents, with 9 who were 20 years old or less.

Participants' marital status was similar to other studies, with the majority (over 80%) in married or common-law relationships (Balling & McCubbin, 2001; Coyne, 1995; Kristensson-Hallström, 1999; Kristensson-Hallström & Elander, 1997; Lam et al., 2006). Another similarity includes employment status, with the majority of parents working full- or part-time (Balling & McCubbin, 2001; Kristensson-Hallström & Elander, 1997; Lam et al., 2006), Comparisons with education are difficult to specify, as other authors report education in years (Balling & McCubbin, 2001; Kristensson-Hallström, 1999) or through qualitative descriptions (Kristensson-Hallström, & Elander, 1997). Family size in the current study ranged from one to six children, comparable to other studies reporting from one to nine children in a family (Kristensson-Hallström, 1999; Kristensson-Hallström & Elander, 1997). Travel distance between home and hospital was reported only by Coyne (1995), using kilometers. In the current study this was reported as time required to travel between hospital and home, thus limiting comparisons. While the demographic data discussed above have been reported previously, these data have been used mainly for descriptive purposes. Some connections have been reported between parent participation and age of the child (Balling & McCubbin, 2001), as well as parent participation, and length and frequency of hospitalization (Kristensson-Hallstrom, & Elander 1994). Efforts to link characteristics of children, parents and families with their experiences of parent participation may provide a better understanding of factors influencing their participation.

**Findings related to hypothesis.** The results of the current study support the hypothesis that there is a difference between parents' actual participation and their desired participation, as reflected in the congruency score for each participant. The discrepancy between parents' Actual and Desired participation indicates that role uncertainty persists among parents of hospitalized children, where the direction of the score indicates that parents wanted to expand their participation (negative score) or decrease their participation (positive score).

The majority of participants (74.9%) had negative congruency scores, indicating that their desired participation was higher than their actual participation. The desire to increase involvement in care has been reported previously. Kristensson-Halstrom and Elander (1997) reported that parents wanted to take on more care responsibilities but were not able to do so because they did not receive the support and guidance from the nurses that they required. Neill (1996b) also reported that parents did not always participate in care as desired. In particular, parents in her study wanted a more active role in assessing their child's needs and participating in care planning. The description of the nature of parent participation later in this chapter will discuss certain activities in which parents wanted to increase their participation. In considering factors affecting parents' desire to increase their participation, one influence might be the child's age. Balling and McCubbin (2001) examined parents' desire for control over their child's care, using a scale that took into consideration parents' participation in physical care activities. They found that parents of younger children wanted more control over their child's care. This need for control may have influenced participants in the current study, as three-quarters of participants had negative congruency scores and 52.7% had children younger than 3 years of age.

Parents whose congruency scores were positive, indicating that their actual participation was greater than their desired participation, made up 15.2% of the sample. In earlier studies, parents have reported providing more care than they desired due to their perception that it was expected of them by the nursing staff (Coyne & Cowley, 2007; Espezel & Canam, 2003; Roden, 2005; Ygge & Arnetz, 2004). Espezel and Canam (2003), and Coyne and Cowley (2007), identified that such experiences were difficult for parents. Coyne and Cowley stated that parents participated in care even when they would have preferred not to for two reasons: parents wanted to ensure that their child's care needs were not neglected, and they believed that doing so would contribute to a good relationship with the nurse, which in turn would help to ensure good care for their child. In the current study, a single parent's written comments reflect the fear of neglect: "[I] stayed all night and all day for feeling that if I don't stay my child would not get all these tasks performed…Sometimes the single parent [sic] needs to be home and I want to know he will be getting the quality of care he deserves when I am not there".

Neutral congruency scores, where the number of items checked on the Actual scale equaled the number of items checked on the Desired scale, accounted for 9.9% of the sample. While a neutral score indicates that the same number of items was checked on each scale, it does not mean that identical items were checked on both scales. Examination of these neutral scores indicated that while 11 participants selected identical items on both scales, 8 had differences on between 2 and 10 items. Thus, while a neutral score indicates balance between the number of Actual and Desired activities, it also includes parents who may have wanted to participate in activities that they did not actually do, and *vice versa.*

The measurement of a difference between actual and desired participation indicates that there may be a need for greater dialogue between parents and nurses about participation in care activities. While the current study was not designed to determine the reasons for differences in Actual and Desired participation, earlier research does provide some information regarding factors that may influence parent participation. Further research comparing congruency scores to measurement of influencing factors may provide knowledge that can enhance nurses' ability to facilitate parents' desired participation.

**Findings related to the nature of parents' participation.** Frequencies of Actual and Desired participation in specific activities and data from participants' written comments provide a description of parent's participation in caring for their hospitalized children. In the following discussion, parents' participation will be described within four areas: 1) Providing comfort; 2) Providing ADL care; 3) Providing technical care; and 4) Advocating for the child.

***Providing comfort.*** Activities that provide comfort to the hospitalized child were the most frequently reported activities in this study. Examination of parents' responses on the IPP/HC-A indicated that the most frequently reported activities in which parents actually participated were "Spent quiet time interacting with child" (92.1%), "Stroked child/rubbed back" (90.6%), and "Comforted child when upset (does not include comforting during a painful procedure)" (90.1%). This distribution is also reflected in the IPP/HC-D, as "Spending quiet time interacting with the child" and "Comforting the child when upset" were also the most frequently reported Desired activities by parents (95.8% and 94.8% respectively). Earlier research has indicated that providing comfort is a priority for parents of hospitalized children (Algren, 1985; Dearmun, 1992; Hill, 1978; Jackson, Bradham, & Burwell, 1978; Kristensson-Hallström,& Elander, 1994; MacDonald, 1969; Merrow & Johnson, 1968; Coyne, 1995; Webb et al., 1985). One way that parents provide comfort is by simply being in the hospital with their child. Romaniuk and Kristjanson (1995) identified "Just Being There" (p.86) as the component of parents' care that encompasses all other activities, while Coyne and Cowley (2007) identified that parents' priority was to comfort their child by "being there and being with" (p.896) them. Parents in Roden's (2005) study felt that they were with their child to provide support rather than physical care. One parent in the current study listed as an additional Actual activity "The most important activity of all, loving and keeping my child happy", reflecting the findings of previous research.

The biggest differences between Actual and Desired scores were for "Took child to playroom, if allowed" (Actual 42.9%, Desired 75.4%), and "Took child for a walk, if allowed" (Actual 57.1%, Desired 85.9%). Providing opportunities for play has been identified previously as a priority by parents of hospitalized children, as this is seen to be an important means of bringing some normalcy into the child's life and is considered integral to the child's recovery (Coyne & Cowley, 2007; Darbyshire, 1994; Romaniuk, 1993). If parents are not able to provide play opportunities as desired, it is worthwhile to consider possible reasons. It is possible that activities such as waiting to go for tests or waiting to speak with physicians limited opportunities to leave the room. It is also possible that parents' desire for their child to feel well enough to do these activities is reflected in these scores.

While 89.0% of parents expressed a desire to provide comfort to their child during a painful procedure, only 69.9% reported doing so. Given the priority parents place on providing comfort, this difference raises concern. Similar discrepancies have been reported in previous research. Ygge and Arnetz (2004) reported that parents in their study were often not asked about preferences for participation in their children's painful procedure. Some participants felt that they were expected to restrain their child, whereas they would have preferred to provide only emotional support during the procedure. Lam et al. (2006) described the experiences of some parents who had been forced to wait outside the room during their child's painful procedure, and other parents who insisted that they be allowed to stay with their child despite health care professionals' requests that they leave the room. Nurses may ask parents to wait outside the room during painful procedures, believing that they need to protect parents from the stress of seeing their child in pain. (Brown & Ritchie, 1990; Paliadelis et. al.2005).

Research indicates that parents may be reluctant to approach nurses for help or information for fear of inconveniencing them (Kawik, 1996; Kristensson-Hallstrom & Elander, 1997; Neill, 1996b; Ygge & Arnetz, 2004), thus they may be uncomfortable asserting their preferences when their child undergoes a painful procedure. Parents may also be unsure of how they can support their child during painful procedures. A descriptive study of parents' perceptions of their child's acute pain experience reported that 70% of the parents participating were not given instructions on how they could be helpful during their child's painful procedure (Watt-Watson, Evernden, & Lawson, 1990). Regardless of their desire to be with their child, parents may step back out of concern that they may hinder rather than help with the completion of the procedure. Research with parents of children who had undergone a surgical procedure found that lack of information, insufficient emotional support and unclear roles regarding relieving their child's pain influenced parents' experiences with participation in post-operative pain care (Pölkki, Pietelä, Vehviläinen, Julkunen, Laukkala & Ryhänen, 2002). In a study of children's experiences with pain during hospitalization, Pölkki, Pietelä and Rissanen (1999) reported that children found their parents' presence during a painful procedure to be comforting, and that it helped them feel more secure. If parental presence is important to both children and parents, it is important that nurses identify parents' preferences regarding participation in painful procedures and support parents to make these preferences a reality.

***Providing ADL care.*** Parents in the current study were active participants in care related to their child's ADL. This finding supports results of previous studies which identified parents' active participation in their children's ADL care (Algren, 1985; Balling, & McCubbin, 2001; Hill, 1978; Jackson et al., 1978; Kristensson-Hallström & Elander, 1994; MacDonald, 1969; Merrow & Johnson, 1968; Neill, 1996a; Webb et al., 1985). Four ADL activities were rated highly on both the Actual and Desired scales respectively: Helped with elimination (90.1% and 92.1%); Settled for sleep or nap (87.4% and 91.6%); Fed child or set up his food tray (86.9% and 92.1%); and Changed clothes or pajamas (85.3% and 92.1%). In contrast, fewer parents reported bathing their child, despite wanting to do so (Actual 62.3%, Desired 81.7%). Previous studies have identified bathing as an activity that parents may need assistance with, especially in the presence of intravenous (IV) infusions or other equipment (Algren, 1985; Blower & Morgan, 2000; Hill, 1978; Kristensson-Hallström & Elander, 1994; Lam et al., 2006). However, Brown and Ritchie (1990) reported that 23 of 25 nurses in their study identified bathing a child with an IV as something that parents could do. In the current study, parents' written comments indicate that this was a concern for them as well. If parents are left to "get on with it", as has been described in the literature (Coyne & Cowley, 2007; Darbyshire, 1994; Neill, 1996b), they may find themselves in the position of having to ask for assistance. When that help is not readily available, parents may not be able to provide the care. Another reason that bathing may not occur could be related to routine. Activities such as meals and bedtimes are supported by cues in the hospital environment, such as the arrival of meals at about the same time each day and dimming of lights when it is time to sleep. Such cues may not exist for bath times. Families' usual routines around bath times may be difficult to maintain due to the child's physical condition, other activities and limited availability of facilities. If the unit does not have a routine regarding bathing, parents may have difficulty establishing their own routines.

One ADL activity important to well-being received lower scores on both the Actual and Desired scales. "Brushed teeth/performed mouth care" was reported as an Actual activity by 43.5% of participants and as a Desired activity by 66.5%. A partial explanation for these results may be that with 37% of the participants' children under 1 year of age, oral hygiene routines might not have been well established yet in these families. However, with older children, who do have established routines for brushing teeth, it may have been difficult to maintain oral hygiene routines in the hospital. Brushing teeth requires a toothbrush, paste, water and a sink or kidney basin. In her written comments, one parent noted that as their daughter's admission had been unexpected, they did not bring a toothbrush with them and so would have appreciated receiving one on the unit. This parent also noted that it would have been helpful for the nursing staff to reinforce the need to brush, as their daughter did not like to brush her teeth and was particularly reluctant to do so in hospital. Parents may be reluctant to approach staff for assistance with oral hygiene, thus it can be helpful for staff to offer assistance and/or supplies.

***Providing technical care.*** The examination of technical care activities within the IPP/HC is limited to administration of medication, and monitoring of intake and output. It was expected that those parents who participated in other technical care activities or wanted to do so would write these down at the end of the questionnaire. Previous research indicates that parents are less likely to participate in technical care activities than in ADL activities (Algren, 1985; Hill, 1978; Kristensson-Hallström & Elander, 1994; Webb et al., 1985). In the current study, differences between actual and desired scores for participation in activities related to maintaining input and output records were small. Previous research has demonstrated that while parents would often like to take an active role in giving their child's medications, nurses may be reluctant to allow them to do so (Blower & Morgan, 2000; Brown & Ritchie, 1990; MacDonald, 1969). In the current study, 75.4% of parents desired to assist with medication administration while 63.4% actually did so. This rate is comparable to previous research reporting rates of between 60% and 89% (Algren, 1985; Hill, 1978; Webb et al., 1985). Actual technical care activities listed in the written comments included gastrointestinal tube site care, tracheotomy care and suctioning (unspecified). Previous literature states that parents are more likely to participate in technical care activities that they also carry out at home (Coyne, 1995), and the three activities listed above likely reflect that reality. One parent listed the exact same technical care activities as both Actual and Desired, suggesting that she is providing technical care that she wants to provide. Troubleshooting IV issues and changing a central venous line dressing were identified as Desired activities.

Overall, while differences between Actual and Desired participation in technical care activities exist in this sample they are not prominent differences, which is consistent with previous research indicating that not all parents are interested in taking on technical care tasks. Kristensson-Halström and Elander (1994) found that parents whose children had a length of stay longer than 5 days or had previous hospitalizations were more likely to participate in certain activities, suggesting that experience may influence parents' involvement with technical care. In the current study, 65.5% of participants' children experienced their first or second hospitalization and 54.5% had a length of stay (at time of administration of the questionnaire) of 1 to 3 days. Thus, parents in this study may not have had enough experience to develop the confidence to take on technical aspects of care. As noted previously, parents of children requiring technical care at home are more likely to take on that care in hospital (Coyne, 1995). With 56% of participants' children experiencing acute illness, it is less likely that complex care would have been required post-discharge.

***Advocating for their child.*** Parents' responses also indicate that advocating for their child is an important parental activity in hospital. One of the most frequently reported Actual activities was "Told nurse about something your child needed" (87.4%). Among the top five activities that parents expressed a desire to perform but did not actually do were three advocacy-related activities: "Told physician about something your child needed" (31.4%), "Told nurse about child's daily routines or his/her likes or dislikes without being asked to do so" (29.8%) and "Suggested to a nurse or a doctor a different way or time of doing something that you thought would be better for your child" (27.2%). These findings support previous research which indicated that parents consider being a mediator between their child and hospital staff an important part of their role in hospital (Coyne,& Cowley, 2007; Kristensson-Hallström & Elander, 1997; Lam et al., 2006). In the case of "Told nurse about child's daily routines or his/her likes or dislikes without being asked to do so", it is possible that parents did not feel a need to do this because the nurses were asking these questions of their own initiative. However, considering that several communication-related items also received high ratings as "Desired only" it is possible that the current study's findings indicate that parents may not be completely comfortable bringing all of their concerns to the attention of health care professionals.

As noted previously, parents may be hesitant to disturb nurses with questions or comments (Kawik, 1996; Kristensson-Hallstrom & Elander, 1997; Neill, 1996b; Ygge & Arnetz, 2004). Knafl, Cavallari and Dixon (1988) distinguished between two types of parents in terms of their comfort in communicating with health care professionals. Level I parents were characterized by trust in the nurses and a strong reluctance to make requests, while Level II parents were less trusting of the nurses but more comfortable asking for modifications to care. It was beyond the scope of the current study to link characteristics of parents with the activities they did or desired to do, but it is recommended that future studies identify characteristics of parents who are less comfortable raising concerns with health care professionals. It would then be possible to implement specific communication strategies to support these individuals in meeting their need to advocate for their child.

**Unanticipated findings from written comments.** While the written comments section of the questionnaire was intended to elicit additional activities that parents did or wanted to do, it also provided some insight into parents' needs while in hospital. The need for assistance with bathing and oral hygiene has been discussed previously in this chapter. Needs for information, security and control were also identified. One situation not addressed in the literature about parent participation is that of the physically disabled parent. Comments by a disabled parent in the current study reflect the challenges she faced in trying to help her daughter with ADL activities when she was "never offered any type of "help" for me to help her". Prilleltensky (2003) found that mothers with physical disabilities face significant challenges in day-to-day care of their infants and children, and require various forms of support to meet these challenges. Disabled parents do not have to be singled out to determine what assistance they need to care for their child in hospital. Asking parents what assistance they may need to care for their child in hospital should be a routine part of nursing practice with all parents of hospitalized children. Addressing parents' needs can support their ability to participate in their child's care.

**Findings in Relation to Conceptual Framework.** The conceptual framework for this study depicts congruency as the overlap between parents' Actual and Desired participation. The results of the current study indicate that the amount of this overlap and its direction vary among parents. These variations are shown in Figure 1. For the majority of parents, their Desired participation exceeded their Actual participation (negative congruency score). Taking into account the extent and direction of this overlap may contribute to successful facilitation of parent participation as a part of family-centred care.

Figure 1 Variations in Congruency Scores

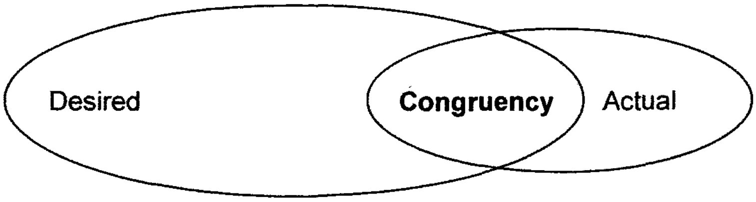


Diagram A

A. Negative Congruency Score: indicates Desired participation score greater than Actual participation score

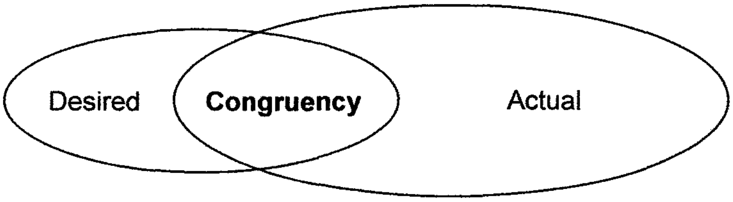


Diagram B

B. Positive Congruency Score: indicates Actual participation score greater than Desired participation score

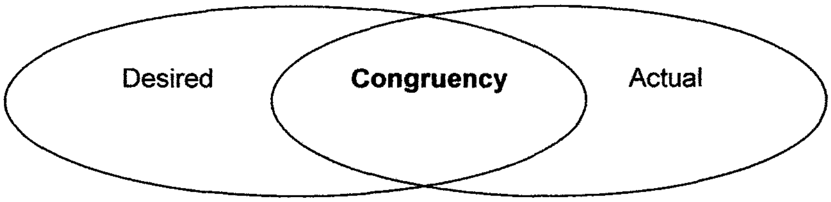


Diagram C

C. Neutral Congruency Score: indicates Actual participation score equal to Desired participation score with different items selected on each scale.

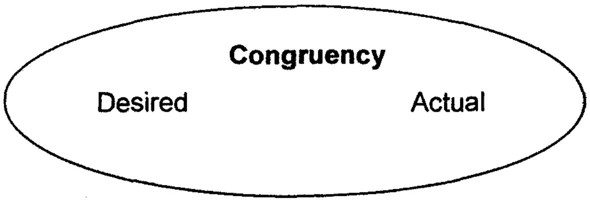


Diagram D

D. Neutral Congruency Score: indicates Actual participation identical to Desired participation

## Strengths of the Study

An important strength of this study is the size of the sample. Using power analysis, the required sample size for this research was 199 participants. The final sample, after 1 year of data collection, was 191. While this sample is slightly smaller than projected, it was sufficient to prevent a Type II error, as the difference between actual and desired participation was statistically significant (Polit & Beck, 2004). Another strength of the study in relation to the sample is the heterogeneity of the children of the participants, who represent a wide variety of ages and diagnoses. This variety allows for wider generalizability of the results.

A further strength is the use of the IPP/HC to measure parental participation. This tool has established reliability and validity, and it includes activities related to the physical and psychosocial care of children as well as activities related to communication between parents and health care professionals. As the first study to use a tool to measure the congruency between parents' actual participation in care and their desired participation in care, an additional strength of this research is the unique perspective it contributes to knowledge in this area.

## Limitations of the study

Limitations related to the sample include sampling method, limited description of those who chose not to take part in the study, and aspects of demographic data collection that could affect the description of participants. The current study used convenience sampling to recruit participants, increasing the possibility of bias within the sample (Burns & Grove, 2005). In particular, the large proportion of mothers responding to the questionnaire (84.3%) limits generalizability to other caregivers.

A further limitation related to the sample involves incomplete information regarding parents who chose not to participate in the study. It is not known how many flyers were distributed on the units, nor is it known how many parents were approached to participate. Accordingly, characteristics of those individuals who refused to participate are not known, limiting opportunities for comparison with the participants and contributing to the potential for non-response bias. The resulting possibility of sampling bias and non-response bias could limit the external validity of the findings (Polit & Beck, 2004). Information about non-completers' children, collected from their charts, allows for some comparison with the children of participants, and indicates that the two groups are similar.

The description of the study participants was limited by two aspects of demographic data collection. First, the child's admitting diagnosis as written in the chart was used to categorize the child's illness and to determine if the illness was chronic or acute. These categorization decisions proved difficult, as many of the admitting diagnoses were imprecise. Inclusion of emergency room documentation on the chart was also used as an indicator for categorization as "acute", unless the admitting diagnosis clearly indicated otherwise (e.g., fever and neutropenia associated with chemotherapy). However, it is possible that some children with chronic illness were categorized as acute due to their admission through the emergency department. Analysis of demographic data indicated that the children categorized as having chronic illness were more likely to have been admitted to hospital more than once, providing some support for categorization decisions. However, overall, the description of children of participants is limited by the charting related to diagnosis. Secondly, information about the participants' country of origin or ethnic background was not collected, limiting comparison of the sample with other studies as well as generalizability of results.

There are three potential limitations to the study related to the data collected using the IPP-HC. First, there is the potential for social desirability response bias, which is defined as the misrepresentation of responses to ensure they reflect perceived societal values (Polit & Beck, 2004). If participants believed that "good" parents should participate in their child's care and should want to do so, they may have responded with answers to reflect those values. Second, the IPP-HC was designed to measure actual participation, and in this study it was modified to measure desired participation as well. In the current study, Cronbach's alpha coefficient for the Actual scale was 0.90, which is higher than the coefficients of 0.77 to 0.85 reported in previous studies (Melnyk, 1994; Melnyk et al., 1997; Melnyk & Feinstein, 2001; Melnyk et al., 2004). The Cronbach's alpha coefficient for the Desired scale was 0.91. Streiner and Norman (2003) state that alpha coefficients greater than 0.90 may indicate item redundancy. Finally, with the use of a one-time data collection it was not possible to determine if parents' actual and desired participation changed over time.

Recruiting participants on busy in-patient units presented certain challenges. In this study, cooperation from the charge nurses was essential for the success of the study. To ensure that eligibility criteria were applied consistently in indentifying potential participants, it was necessary for the researcher/research assistant to review the patients with the charge nurse. The charge nurses were also involved in providing potential participants with initial information about the study in the form of a flyer, as the hospital's REB required that this information be provided to potential participants by someone within their "circle of care". The researcher/assistant could not approach potential participants until they received this flyer from the charge nurse.

Reviewing the patients to determine potential participants and distribution of flyers required a time investment on the part of the charge nurses, and the willingness and ability to take this time varied with the busyness of the unit as well as with the individual's experience in the charge nurse role and his/her commitment to supporting this research. As a result, access to potential participants was difficult at times, which contributed to the length of time needed to recruit the sample. In addition, it meant that on days when the charge nurse was unable to take the time to assist with recruitment, eligible potential participants would not be identified and thus not approached for recruitment. This limitation has implications for the generalizability of results, as previous research demonstrates that nurses' "busyness" might influence parental participation and parents who were on the unit at some of the busiest times would not have had the opportunity to participate in the study.

### Summary

The sample used in this study is similar to samples used in previous research, most notably in its high proportion of mothers compared to fathers. Negative, positive and neutral congruency scores were discussed in comparison with earlier studies. The nature of parent participation was described and compared with findings from previous research. Parents' participation in this study consisted of providing comfort care, ADL care and some technical care, as well as advocating for their children. The conceptual framework was developed to illustrate different types of congruency scores. Strengths and limitations of the study were presented. Study strengths include adequate sample size and use of a tool with established reliability and validity. Limitations of the study include use of convenience sampling and the potential for social desirability response bias. The challenges of collecting data on busy in-patient units were discussed, and the potential limitations resulting from these challenges were identified.

# CHAPTER 6: Implications and Conclusion

This chapter presents the implications of the study. Implications for practice are identified for nurses at the bedside as well as for nurses in administrative positions. Implications for future research are discussed, addressing areas for further study as well as methodological suggestions for future research. These sections are followed by the study conclusion.

## Implications for Practice

The findings of the current study serve as a reminder to pediatric nurses that parent participation is a dynamic concept, which is manifested differently by different parents. It is unrealistic for nurses to hold one expectation about participation that is applied to all parents. Pediatric nurses need to develop and maintain self-awareness about their own expectations and assumptions regarding parent participation, ensuring that these expectations do not lead to situations in which parents feel pressured to provide more care than they are comfortable with or less care than they would like to and could safely provide. The current study measured parents' participation for one 24-hour period, so it cannot be assumed that the results reflect parents feelings for of all days within an admission. Nurses should, therefore, be prepared for the possibility of changes in parent's participation from one day to the next.

The nature of parents' participation as described in the current study indicates that nurses should be aware of the specific activities in which parents may need extra support and encouragement to successfully participate. Nurses need to be mindful of the high priority parents place on comforting their child. Determining parents' preference for participating, or not participating, in an activity that can cause their child pain or stress is essential. Parents may need support or education in order to fulfill their supportive role during painful procedures to the best of their ability. Parents may not be comfortable asking for assistance with ADL care and, thus, it is important that nurses take the initiative in this regard. Asking parents about their preferences for meeting their child's hygiene needs gives parents the opportunity to voice their need for assistance and may support development of routines for this type of care.

The results of the current study also indicate that parents consider advocating for their child an important part of their role in hospital. Aside from asking parents directly for their suggestions, pediatric health care professionals need to cultivate an atmosphere in which parents feel comfortable expressing their suggestions for their child's care. Nurses need to ensure that parents' preferences for participation in their child's care are accepted non-judgmentally.

A supportive atmosphere for parental participation becomes especially important when parents have special needs due to disability, or life circumstances such as single parenthood. Such an atmosphere can help parents feel more comfortable to express their specific needs and work with the nurse to achieve them. Nurses may need to take extra time to assess parents' needs in these special circumstances.

The results indicate that nurse administrators should not determine staffing levels based on the assumption that parents will provide an expected amount of care. Staffing levels should ensure that nurses have sufficient time to meet the care needs of their patients and families. Staffing plans should also consider the time that nurses need to teach parents skills necessary for certain aspects of their child's care and/or for providing support to parents' participation in care. Administrators also need to consider how their nursing staff can support parents with disabilities and single parents, ensuring that nurses are aware of the resources available to assist individuals in these circumstances.

## Implications for Research

Much of the existing knowledge about parent participation comes from qualitative studies that have provided a consistent description of parents' and nurses' experiences about participation specifically, and about family-centred care in general. However, knowledge of the effects of family-centered care on children and families is sparse (Shields, Pratt, Davis, & Hunter, 2007), as is knowledge of factors that influence successful implementation of family-centered care. Previous authors have acknowledged the need for quantitative research to develop this knowledge base (Coyne & Cowley, 2007; Shields et al., 2007). Further research involving congruency may contribute to filling these gaps.

As the current study was the first to examine and measure congruency between parents' actual and desired participation, further research is warranted to refine the concept of the congruency score and its measurement. In particular, there is a need to better understand the meaning of neutral scores, as neutral scores do not necessarily indicate perfect congruence between actual and desired participation. The written comments added by parents in the current study indicate some activities that could be added to the instrument. Collecting data in-person rather than through self-report would allow participants to ask questions as needed while they complete the questionnaires. Such feedback could prove useful in refining the tool and its administration, as it could provide information about parents' understanding of checklist items and the suitability of these items for the study setting. Understanding of congruency and refinement of the tool could also be enhanced by combining quantitative measurement with qualitative examination, which could provide additional information about discrepancies between Actual and Desired scores. Such information could enhance understanding of the role uncertainty that may be experienced by parents when caring for their hospitalized child. Combining methods could also contribute toward an understanding of what parents need in order to participate in their child's care as they desire. A better understanding of congruency and how it changes through the course of hospitalization could be developed through longitudinal studies, where parents complete the tool more than once during their child's admission.

Linking congruency with other variables will also contribute to a better understanding of parent participation. Examining congruency in relation to demographic and other variables could provide valuable information that would contribute to improving nurses' ability to anticipate family needs and identify possible interventions. Previous studies indicate that parent participation varies with the length of admission and frequency of hospitalization (Kristensson-Hallström & Elander, 1994), the child's age (Balling & McCubbin, 2001; Kristensson-Hallström, 1999), parent's employment status (Balling & McCubbin, 2001), acute versus planned admission and which parent remained with the child (Kristensson-Hallström, 1999). Type of illness (acute or chronic), family size, and the distance between home and hospital may influence parent participation and therefore these variables should be examined as well. Circumstances on the nursing unit, such as staffing patterns and patient acuity, may also affect participation (McKiel, 2002). A study combining measurement of congruency scores with qualitative methods could examine parents' perceptions of nurses' expectations and parents' responses to those perceptions, thereby contributing to the understanding of how parents' perceptions of nurses' expectations affect congruency scores. Including nurses in such qualitative studies could contribute to understanding nurses' experience with parent participation, and in particular may help to develop knowledge of the extent to which parents' perceptions accurately reflect nurses' expectations. In addition, examination of congruency in more homogeneous populations, for example, parents of children admitted for elective surgery, would also be valuable.

The results of this study indicate that examination of parent participation within the context of painful procedures is warranted. Qualitative research could be valuable in understanding parents' experiences in this regard, as well as determining what can be done to assist them in participating as they desire. Qualitative research could also contribute to a better understanding of nurses' experiences and beliefs regarding parental involvement in painful procedures, leading to strategies for supporting nurses in their work with parents.

There have been some groups consistently neglected within the parent participation literature, and research examining these groups in greater depth is needed. Adolescents were excluded from this study, but parents of adolescents do stay in the hospital with their children, and research with this population would contribute to developing a better understanding of how these parents participate in care and what influences their choices in this regard. Also excluded from the study were children with psychiatric diagnoses; parents of these children may have a unique experience with parent participation that deserves further exploration. The current study revealed that disabled parents may be in particular need of assistance to participate in their hospitalized children's care; therefore, exploratory research to better understand this group's experience is recommended. Also, examination of the perspective of fathers remains a priority, as the extent of their participation as well as their perspectives on participation have not been well documented.

## Conclusion

The current study has examined and compared parents' Actual and Desired participation in their hospitalized children's care, and the results demonstrated that there is a significant difference between them. Parents' scores on both scales varied, but overall, most parents desired to be involved in more care activities. Examination of responses to specific items on the Actual scale indicated that parents were most active in providing comfort measures and care related to activities of daily living. They demonstrated a desire to increase their participation in activities related to advocating for their child. Data from written comments indicated that parents with a disability and single parents may require more support to participate successfully in their child's care.

Strengths of the study included an adequate sample size and use of a tool with established reliability and validity. Limitations of the study included incomplete information about those who chose not to participate in the study, the potential for social desirability bias and limitations arising from the challenges of collecting data on a busy clinical unit.

Recommendations were made for practice and research. Nurses in pediatric practice need to maintain awareness of parents' varied preferences for participation and support them to participate accordingly. Further research is necessary to refine the concept of congruency and its measurement. Examination of variables that might be associated with congruency is also warranted.

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# APPENDICES

# APPENDIX A

Table A1: Benefits of participation

| Author, Year, Title | Study Purpose | Study Design, Data Collection Methods | Description of Sample, Setting | Data Analysis | Strengths, Limitations |
|---|---|---|---|---|---|
| Coyne, I. (2006)<br>Children's experience of hospitalization | To understand children's experiences with hospitalization | Grounded theory design<br>Tape-recorded semi-structured interviews conducted during admission to hospital | N = 11 children experiencing chronic (n = 8) or acute (n=3) conditions<br>***Setting:*** 4 pediatric wards in 2 hospitals in southern England | Constant comparative method of data analysis | **Strengths**<br>▪ Data collection and analysis procedures clearly described<br>**Limitations**<br>▪ Procedures for maintaining rigour of data not identified |
| Curley, M. (1988)<br>Effects of the nursing mutual participation model of care on parental stress in | To examine the effect of the nursing mutual participation model of care (NMPMC) on stress experienced | Quasi-experimental design<br>Parental stress measured with the Parental Stressor | N = 33 parents (17 in control group, 16 in experimental group)<br>***Setting:*** 9-bed PICU in a large | Two-way repeated measures analysis of variance; parental stress was compared between groups to assess effect of | **Strengths**<br>▪ Use of quasi-experimental design using two groups is preferable to one-group |

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|---|---|---|---|---|---|
| the pediatric intensive care unit (PICU) | by parents of children admitted to the PICU. | Scale: PICU (PSS:PICU) within 24-48 hours after admission, then every 48 hours while in PICU and finally 24 hours after discharge from PICU.<br>Parents in the experimental group received usual nursing care and also care by the investigator based on the NMPMC; control group received usual nursing care | acute-care, university affiliated hospital | intervention, and within group to assess effect of time | design<br>▪ Validity & reliability of PSS:PICU supported by previous research<br>**Limitations**<br>▪ Adequacy of sample size not confirmed<br>▪ use of one setting limits generalizability<br>▪ potential for Hawthorne effect due to additional care from investigator |

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| **Author, Year, Title** | **Study Purpose** | **Study Design, Data Collection Methods** | **Description of Sample, Setting** | **Data Analysis** | **Strengths, Limitations** |
|---|---|---|---|---|---|
| | | | | | who implemented the NMPMC |
| Curley, M. & Wallace, J. (1992)<br>Effects of the nursing mutual participation model of care on parental stress in the pediatric intensive care unit – a replication | To examine how stress experienced by parents of children admitted to the PICU as affected by implementation of the nursing mutual participation model of care (NMPMC) by staff nurses. | Quasi-experimental design<br>Parental stress measured with the Parental Stressor Scale: PICU (PSS:PICU) within 24-48 hours after admission, then every 48 hours while in PICU and finally 24 hours after discharge from PICU. | N = 56 parents (31 in control group, 25 in experimental group)<br>***Setting:*** 18-bed PICU in a large pediatric teaching hospital | Two-way ANOVA with repeated measures; parental stress was compared between groups to assess effect of intervention, and within group to assess effect of time | **Strengths**<br>▪ Use of quasi-experimental design using two groups is preferable to one-group design<br>▪ Validity & reliability of PSS:PICU supported by previous research<br>▪ Implementation by staff nurses |

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|---|---|---|---|---|---|
| | | Parents in the experimental group received nursing care based on the NMPMC; control group received usual nursing care | | | may limit possibility of Hawthorne effect compared to original study<br>**Limitations**<br>▪ Adequacy of sample size not confirmed<br>▪ use of one setting limits generalizability<br>▪ unable to fully assess nurses' ability to implement NMPMC |

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| Author, Year, Title | Study Purpose | Study Design, Data Collection Methods | Description of Sample, Setting | Data Analysis | Strengths, Limitations |
|---|---|---|---|---|---|
| Forsner, M, Jansson, L & Sørlie, V. (2005)<br>The experience of being ill as narrated by hospitalized children aged 7-10 years with a short-term illness | To understand the lived experience of children 7-10 years of age hospitalized with a short-term illness. | Qualitative approach (unspecified)<br>Tape-recorded semi-structured, open-ended interviews conducted within 6 months of discharge | N = 7 (3 girls, 4 boys) experiencing acute illness or injury<br>***Setting:*** Pediatric ward in a hospital in northern Sweden | Thematic qualitative content analysis | **Strengths**<br>Data collection and analysis procedures clearly described<br>***Procedures to maintain rigour:***<br>▪ Discussion of analysis with other experienced researchers<br>**Limitations**<br>▪ Potential risk of inadvertently influencing children's narratives |

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Table A1: Benefits of participation

| Author, Year, Title | Study Purpose | Study Design, Data Collection Methods | Description of Sample, Setting | Data Analysis | Strengths, Limitations |
|---|---|---|---|---|---|
| Hunsberger, M. (2000).<br>The effect of introducing parents of hospitalized children to the nursing mutual participation model of care: a randomized control trial | To test the nursing mutual participation model of care (NMPMC) in a general pediatric inpatient setting, where the model is introduced to parents as well as to nurses. | Randomized control trial<br>State-Trait Anxiety Inventory (STAI) completed by parents 1-16 hours after admission, SAI completed at least 8 hours later (16-24 hours after admission) and again at discharge.<br>Parents completed the Mutual Participation Questionnaire at discharge | N = 91 parents (45 in control group, 46 in treatment group) with children age 3 months to 12 years<br>***Setting:*** a 24-bed acute care pediatric unit in a university-affiliated tertiary care centre in Canada | Differences in anxiety and mutual participation scores between treatment and control scores measured using t-tests.<br>Regression analysis used to correlate mutual participation scores with anxiety scores.<br>ANOVA used to evaluate the relationship between nurses' and parents' | **Strengths**<br>▪ Use of randomization limits bias within the sample<br>**Limitations**<br>▪ Not possible to ensure that all parents and nurses were kept blind regarding who was in the control group and who was in the treatment group<br>▪ Differences in age of children |

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| Author, Year, Title | Study Purpose | Study Design, Data Collection Methods | Description of Sample, Setting | Data Analysis | Strengths, Limitations |
|---|---|---|---|---|---|
| | | Parents in the treatment group received usual unit admission information and information about the NMPMC; control group received usual unit admission information<br>Nurses completed the Mutual Participation Questionnaire prior to NMPMC information session and again | | mutual participation scores | in the control group and treatment group may have influenced the results |

APPENDIX A

Table A1: Benefits of participation

| Author, Year, Title | Study Purpose | Study Design, Data Collection Methods | Description of Sample, Setting | Data Analysis | Strengths, Limitations |
|---|---|---|---|---|---|
| | | once last patient in trial had been discharged | | | |
| Jones, D.C. (1994) Effect of parental participation on hospitalized child behaviour | To determine the relationship between the parent's level of participation and the hospitalized child's behaviour. | Short-term, longitudinal descriptive study<br>Mother-child dyads evaluated during each of 3 consecutive admissions; evaluations took place on day 2 of each admission. | N = 13 mother-child dyads; children 2-5yrs old, diagnosed with leukemia, admitted for scheduled chemotherapy<br>***Setting:*** pediatric unit in a university - affiliated hospital; 24-hr | Individual variables described using frequencies and means; relationships between variable assessed using correlation coefficients | **Strengths**<br>▪ Inter-rater reliability reported for instruments measuring cooperation , upset and parent participation<br>**Limitations**<br>▪ Development of instrument |

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| Author, Year, Title | Study Purpose | Study Design, Data Collection Methods | Description of Sample, Setting | Data Analysis | Strengths, Limitations |
|---|---|---|---|---|---|
| | | Separate instruments used to measure each of the following variables: child's cooperation with a procedure; child's emotional state (upset) during a procedure; child's activity level during previous 24 hrs; parent participation | visiting permitted but unit did not have an explicit family-centered care philosophy. | | measuring child's activity level not described and reliability data not reported.<br>▪ Adequacy of sample size not confirmed<br>▪ use of one setting limits generalizability |
| Keatinge, D. & Gilmore, V. (1996).<br>Shared care: a | To evaluate the implementation of shared care on a pediatric in-patient unit. | Pre-test/post-test design with 2 groups: nurse and parents. | **Pre-test:**<br>$N_{nurses}$ = 20<br>$N_{parents}$ (at admission only) = 39 | Results of nurses' questionnaires reported as frequencies | **Strengths**<br>▪ Well-developed tool used to measure |

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| **Author, Year, Title** | **Study Purpose** | **Study Design, Data Collection Methods** | **Description of Sample, Setting** | **Data Analysis** | **Strengths, Limitations** |
|---|---|---|---|---|---|
| partnership between parents and nurses | | Testing occurred before and after shared care was implemented on the unit.<br>Nurses: learning needs and attitudes to shared care examined<br>Parents: anxiety was examined at admission and at discharge using the STAI | $N_{parents}$ (at discharge only) = 30<br>**Post-test:**<br>$N_{nurses}$ = 13<br>$N_{parents}$ (at admission & discharge) = 35<br>***Setting:*** Pediatric in-patient unit in an Australian hospital | Parents' STAI scores reported as means, differences tested using t-test. | parents' anxiety (STAI)<br>**Limitations:**<br>▪ Convenience sampling increases potential for response bias<br>▪ Reliability data for instruments not reported.<br>▪ Adequacy of sample size not confirmed<br>▪ use of one setting limits generalizability |
| Melnyk, B. M. & Feinstein, N. F. (2001). | "…to determine whether mothers' anxiety and | Quasi-experimental study, 2 X 2 | N = 49 mothers of children (age 2 – 5 ½ years) | Regression analysis was used to determine | **Strengths:**<br>▪ Cronbach's alpha reported |

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| Author, Year, Title | Study Purpose | Study Design, Data Collection Methods | Description of Sample, Setting | Data Analysis | Strengths, Limitations |
|---|---|---|---|---|---|
| Mediating functions of maternal anxiety and participation in care on young children's posthospital adjustment | participation in their children's care mediated the effects of a mother-targeted informational intervention on the children's posthospital adjustment." (p.19) | factorial design<br>Intervention (within 12 hrs after admission): audiotaped information about children's responses to hospitalization (control group listed to audiotape about hospital services & policies)<br>Separate instruments used to measure each of the following | hospitalized with acute illness.<br>***Setting:*** pediatric units in two acute-care hospitals | relationships among variables | for all measures.<br>▪ Sufficient power, as demonstrated by significant findings<br>**Limitations:**<br>▪ Small convenience sample, limiting generalizability<br>▪ Potential bias in mothers' self-report of participation and their observations of child behaviour |

## APPENDIX A

Table A1: Benefits of participation

| Author, Year, Title | Study Purpose | Study Design, Data Collection Methods | Description of Sample, Setting | Data Analysis | Strengths, Limitations |
|---|---|---|---|---|---|
| | | variables: maternal anxiety, parent participation, child behaviour<br>Anxiety measured before & after intervention; parent participation measure 48 - 72 hours after admission; child behaviour measured 10-14 days after discharge. | | | |

# APPENDIX A

Table A2 – Nurses' support for Parent Participation

| Author, Year, Title | Study Purpose | Study Design, Data Collection Methods | Description of Sample, Setting | Data Analysis | Strengths, Limitations |
|---|---|---|---|---|---|
| Daneman, S., Macaluso, J. & Guzzetta, C.E. (2003).<br>Healthcare providers' attitudes toward parent participation in the care of the hospitalized child | To compare "healthcare providers' attitudes toward parent participation in the care of their hospitalized child among a variety of health care disciplines and to identify differences in these attitudes based on selected demographic characteristics of the respondents." | Descriptive, comparative study<br>Attitudes measured using Parent Participation Attitude Scale (PPAS); demographic survey completed also | N = 256 healthcare personnel (51.2% were nurses)<br>***Setting:*** tertiary hospital care hospital in the USA | Mean attitude scores derived for each participant and for total group<br>Comparisons of attitude scores according to age & experience completed using Pearson's *r*<br>Comparisons of attitude scores according to gender, marital status, parental | **Strengths**<br>▪ Reliability data for the PPAS reported for this study and for previous studies using this tool<br>**Limitations**<br>▪ Convenience sampling increases potential for response bias |

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Table A2 – Nurses' support for Parent Participation

| Author, Year, Title | Study Purpose | Study Design, Data Collection Methods | Description of Sample, Setting | Data Analysis | Strengths, Limitations |
|---|---|---|---|---|---|
| | (p.91). | | | status, job title, level of education, area of practice completed using ANOVA or student's t-test.<br>Comparison of significant ANOVAs done using Newman-Keuls test | |
| Gill, K.M. (1987).<br>Nurses' attitudes toward parent participation: personal and | To explore "several personal and professional characteristics of nurses and their correlation with | Descriptive design<br>Attitudes measured using PPAS; personal-professional data | N = 273 nurses<br>***Setting:*** four children's hospitals in one American state | For examination of individual nurse characteristics: ANOVA<br>For examination of | **Strengths**<br>▪ Reliability data reported for the PPAS; Gill also confirmed construct |

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Table A2 – Nurses' support for Parent Participation

| Author, Year, Title | Study Purpose | Study Design, Data Collection Methods | Description of Sample, Setting | Data Analysis | Strengths, Limitations |
|---|---|---|---|---|---|
| professional characteristics | the respective nurses' attitude toward parent participation" (p.149) | questionnaire completed also | | relationships between characteristics: two-way ANOVA. | validity using factor analysis.<br>**Limitations**<br>▪ Sample recruitment procedures not described thus difficult to judge representativeness of sample |
| Gill, K.M. (1993).<br>Health professionals' attitudes toward parent participation in | To examine health professionals' attitudes towards parent participation in relation to personal and professional | Descriptive study<br>Mailed questionnaire to randomly selected members of the Association for the | N = 651 health professionals recruited through ACCH.<br>Sample included Americans | Analysis of attitude differences relevant to personal & professional characteristics completed using | **Strengths:**<br>▪ Established reliability and construct validity of the PPAS<br>▪ Quota |

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Table A2 – Nurses' support for Parent Participation

| Author, Year, Title | Study Purpose | Study Design, Data Collection Methods | Description of Sample, Setting | Data Analysis | Strengths, Limitations |
|---|---|---|---|---|---|
| hospitalized children's care characteristics | characteristics | Care of Children's Health (ACCH)<br>Attitudes measured using PPAS; personal-professional data questionnaire completed also | (90.9%), Canadians (8.2%) and other nationalities (0.9%) | multiple linear regression. Tests included: t-tests, Spearman rho correlations, Wilcoxin/Kruskal-Wallis | sampling used to recruit members in different professions within ACCH<br>**Limitations:**<br>▪ ACCH members may not reflect attitudes of all health care professionals working with children.<br>▪ Results generalizable only to those groups who |

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Table A2 – Nurses' support for Parent Participation

| Author, Year, Title | Study Purpose | Study Design, Data Collection Methods | Description of Sample, Setting | Data Analysis | Strengths, Limitations |
|---|---|---|---|---|---|
| | | | | | were well-represented in the sample (nurses, child life specialists, Americans) |
| Johnson, A. & Lindschau, A. (1996).<br>Staff attitudes toward parent participation in the care of children who are hospitalized" | "The aim of this study was to identify staff attitudes toward parent participation in their hospitalized child's care and to assess personal and professional characteristics that could influence | Descriptive study<br>Attitudes measured using the PPAS (with minor language modifications for Australian participants) and personal-professional data questionnaire | N = 62 staff members<br>***Setting:*** four pediatric wards in an Australian women's and children's hospital | Descriptive statistics (M, SD, Range) reported.<br>No report of inferential statistics. | **Strengths:**<br>▪ Established reliability and construct validity of the PPAS<br>**Limitations**<br>▪ Convenience sample increases potential for sampling bias |

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Table A2 – Nurses' support for Parent Participation

| Author, Year, Title | Study Purpose | Study Design, Data Collection Methods | Description of Sample, Setting | Data Analysis | Strengths, Limitations |
|---|---|---|---|---|---|
| | these attitudes." (p.100). | | | | ▪ Small convenience sample, limiting generalizability |
| Pidgeon, V. & Sander, C. (1982). Nurses' perceptions of pediatric nursing functions | To examine how nurses perceive the importance of various pediatric nursing functions and to find out if how perceptions vary among nurses in different positions. | Descriptive study<br>Questionnaire rating 43 pediatric nursing functions on a 9-point scale distributed to nurses meeting study criteria by members of ACCH in various regions of the USA and Canada. | N = 125 nurses in clinical, managerial and teaching positions in a variety of settings | For each function, mean ratings were determined by group and compared using one-way ANOVA | **Strengths:**<br>▪ Use of several setting may enhance generalizability of results<br>**Limitations:**<br>▪ Tool used was newly-developed and reliability data was not reported |

APPENDIX A

Table A2 – Nurses' support for Parent Participation

| Author, Year, Title | Study Purpose | Study Design, Data Collection Methods | Description of Sample, Setting | Data Analysis | Strengths, Limitations |
|---|---|---|---|---|---|
| | | | | | ▪ ACCH members may not reflect attitudes of all nurses working with children.<br>▪ Large proportion of respondents with graduate degrees limits generalizability |
| Seidl, F.W. (1969)<br><br>Pediatric nursing personnel and parent participation: a | To determine nurses' attitudes towards parent participation and identify factors that may influence | Descriptive study<br><br>Attitudes measured using PPAS; personal-professional data | N = 231 nursing personnel<br><br>***Setting:*** Children's hospital in the USA | Mean attitude scores of nurses with different characteristics compared using t-tests. | **Strengths**<br>▪ Reliability data available for the PPAS<br>**Limitations**<br>▪ Convenience |

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Table A2 – Nurses' support for Parent Participation

| **Author, Year, Title** | **Study Purpose** | **Study Design, Data Collection Methods** | **Description of Sample, Setting** | **Data Analysis** | **Strengths, Limitations** |
|---|---|---|---|---|---|
| study in attitudes | attitude. | questionnaire completed also | | Relationship between head nurse scores and staff nurses' mean scores analyzed using Spearman *r* | sampling increases potential for response bias |

## APPENDIX A

Table A3: Parents' Care Activities

| Author, Year, Title | Study Purpose | Study Design, Data Collection Methods | Description of Sample, Setting | Data Analysis | Strengths, Limitations |
|---|---|---|---|---|---|
| Algren, C.L. (1985)<br>Role perception of mothers who have hospitalized children | "To explore the concept of role perception in mothers who have a hospitalized child" (p.6) | Cross-sectional, descriptive design<br>One-time administration of questionnaire to mothers via individual interview<br>Questionnaire included a list of 30 activities parents might participate in (based on Merrow & Johnson's work) and 3 Likert-type | N= 20 (18 mothers, 1 father, 1 mother and father)<br>Children under 10 yrs and not critically ill<br>***Setting:*** medical-surgical unit in a tertiary care children's hospital in the USA | Frequencies reported for care activities on list | **Strengths**<br>▪ Used tool developed for previous studies<br>**Limitations**<br>▪ Limited description of tool development<br>▪ reliability and validity data for tool not provided<br>▪ Adequacy of sample size not confirmed |

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Table A3: Parents' Care Activities

| **Author, Year, Title** | **Study Purpose** | **Study Design, Data Collection Methods** | **Description of Sample, Setting** | **Data Analysis** | **Strengths, Limitations** |
|---|---|---|---|---|---|
| | | questions about parental role | | | ▪ use of one setting limits generalizability |
| Brown, J. & Ritchie, J.A. (1990)<br>Nurses' perceptions of parent and nurse roles in caring for hospitalized children | "to describe nurses' perceptions of …nursing and parental roles and the factors that modify them" (p.28) | Cross-sectional, exploratory study<br>**Quantitative component**: Administration of a questionnaire consisting of a list of 31 care activities (based on work of Merrow & Johnson and Algren)<br>**Qualitative component**: Audiotaped semi- | N=25 pediatric nurses<br>***Setting:*** tertiary care children's hospital in Canada | Frequencies reported for care activities on list<br>Content analysis used to analyze interview data | **Strengths**<br>▪ Inter- and intrarater reliability reported for content analysis data<br>▪ Used tool developed for previous studies<br>**Limitations**<br>▪ Limited description of tool development |

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Table A3: Parents' Care Activities

| Author, Year, Title | Study Purpose | Study Design, Data Collection Methods | Description of Sample, Setting | Data Analysis | Strengths, Limitations |
|---|---|---|---|---|---|
| | | structured interviews | | | ▪ reliability and validity data for tool not provided |
| Blower, K. & Morgan, E. (2000)<br>Great expectations? Parental participation in care | "To compare parents' and nurses' expectations of parental participation in care" (p.60) | Cross-sectional, exploratory study<br>One-time administration of self-report questionnaire to parents and nurses<br>Questionnaire included a list of 15 activities in which parents might participate | $N_{nurses} = 40$<br>$N_{parents} = 40$<br>Parents had children 0-5 yrs, all short-stay admissions<br>***Setting:*** regional children's hospital in the UK | Chi-square used to compare responses of nurses and parents<br>Content analysis used for written component of questionnaire | **Strengths**<br>▪ efforts made to minimize 'halo effect' in respondents<br>▪ tool development described<br>**Limitations**<br>▪ reliability and validity data for tool not provided<br>▪ adequacy of |

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Table A3: Parents' Care Activities

| Author, Year, Title | Study Purpose | Study Design, Data Collection Methods | Description of Sample, Setting | Data Analysis | Strengths, Limitations |
|---|---|---|---|---|---|
| | | and included space for written comments | | | sample size not determined<br>▪ use of one setting limits generalizability |
| Coyne, I. (1995)<br>Partnership in care: parents' views of participation in their hospitalized child's care | To identify why parents chose to participate in their child's care and factors influencing participation | Phenomenological approach<br>Semi-structured interview schedule<br>Interview location not specified.<br>Timing of interview in relation to hospitalization not | 18 parents (16 mothers, 2 fathers; all Caucasian); children's ages and illnesses not specified<br>Recruitment procedures not described<br>***Setting:*** General surgical pediatric | | **Strengths:**<br>▪ direct quotations from participants used to illustrate categories<br>**Limitations:**<br>▪ Data analysis procedures not described.<br>▪ Procedures for |

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Table A3: Parents' Care Activities

| Author, Year, Title | Study Purpose | Study Design, Data Collection Methods | Description of Sample, Setting | Data Analysis | Strengths, Limitations |
|---|---|---|---|---|---|
| | | specified | ward in a tertiary care hospital in the UK | | maintaining rigour of data not identified |
| Darbyshire, P. (1994)<br>Parenting in public: Parental participation and involvement in the care of their hospitalized child | To examine the lived experience of parents who remained in hospital with their child | Phenomenological study<br>Data collected during 9 months of fieldwork on hospital units<br>Informal discussions, interviews and focus group sessions | 30 parents (26 mother, 4 fathers)<br>27 nurses<br>Children's ages and illnesses not specified<br>Recruitment procedures not described<br>***Setting:*** A general medical ward and a burn unit in a | Author describes how he began his research using grounded theory but over time found hermeneutic phenomenology to be more appropriate and thus changed his approach | **Strengths:**<br>▪ Rich description with quotations from participants enhance presentation of themes<br>**Limitations:**<br>▪ Specific data analysis procedures not described.<br>▪ Procedures for maintaining |

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Table A3: Parents' Care Activities

| Author, Year, Title | Study Purpose | Study Design, Data Collection Methods | Description of Sample, Setting | Data Analysis | Strengths, Limitations |
|---|---|---|---|---|---|
| | | | pediatric hospital in the UK | | rigour of data not identified |
| Hill, C.J.S. (1978)<br>The mother on the pediatric ward: insider or outlawed? | To determine mothers' preferences for participation | Cross-sectional, descriptive design<br>One-time administration of questionnaire to mothers via individual interview<br>Questionnaire consisted of list of 37 activities; mothers asked if they preferred to do activity alone, with help or not at | N=18 mothers of children aged 1-4yrs not experiencing serious illness and without permanent disability<br>***Setting:*** University teaching hospital in the USA | Frequencies reported for each care activity | **Strengths**<br>▪ administration of questionnaire via interview may help to ensure parental understanding of questions<br>**Limitations**<br>▪ description of tool development not provided<br>▪ reliability and validity data for tool not |

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Table A3: Parents' Care Activities

| Author, Year, Title | Study Purpose | Study Design, Data Collection Methods | Description of Sample, Setting | Data Analysis | Strengths, Limitations |
|---|---|---|---|---|---|
| | | all. | | | provided<br>- small sample size and use of one setting limit generalizability |
| Jackson, P.B., Bradham, R.F. & Burwell, H.J. (1978)<br>Child care in the hospital - a parent/staff partnership | Evaluation of an admission questionnaire to determine parents' preferences re: participation | Longitudinal, descriptive design (evaluation of clinical practice change)<br>Questionnaire consisting of a checklist of 11 items (based on Merrow's work) administered at | N= 31 parents Of children under 10yrs and not critically ill<br>***Setting:***<br>10-bed pediatric ward in the USA (hospital not described) | Statistical methods not reported and analysis not described | **Strengths**<br>- administration of questionnaire via interview may help to ensure parental understanding of questions<br>**Limitations**<br>- Limited description of |

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Table A3: Parents' Care Activities

| Author, Year, Title | Study Purpose | Study Design, Data Collection Methods | Description of Sample, Setting | Data Analysis | Strengths, Limitations |
|---|---|---|---|---|---|
| | | admission to determine preferences<br>Parents' responses incorporated into care plan, and questionnaire re-administered at Day 3 to determine consistency between preferences and care | | | tool development<br>▪ reliability and validity data for tool not provided<br>▪ use of one setting limit generalizability |
| Kawik, L. (1996)<br>Nurses' and parents' | To find out if parents of hospitalized children | Phase 1: Quantitative<br>• Survey mailed to all staff | Phase 1: Nurses N=55 (response rate 84.6%) | Across method triangulation<br>Phase 1: | **Strengths:**<br>▪ Data analysis procedures described |

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Table A3: Parents' Care Activities

| Author, Year, Title | Study Purpose | Study Design, Data Collection Methods | Description of Sample, Setting | Data Analysis | Strengths, Limitations |
|---|---|---|---|---|---|
| perceptions of participation and partnership in caring for a hospitalized child | participated in care and worked as partners with nurse | nurses on units.<br>Phase 2: Qualitative (unspecified methodology)<br>• In-depth interviews with parents after child's discharge from hospital<br>Interviews done at parent's home<br>Timing of interview in | Phase 2: Parents 12 interviews completed (not known if 12 parents were interviewed or if some individuals gave more than one interview; number of mothers vs. fathers also not known)<br>Children's ages and illnesses not specified<br>Recruitment procedures not | Quantitative Data analysis using descriptive statistics<br>Phase 2: Qualitative Data analysis using content analysis | **Limitations:**<br>▪ Procedures for maintaining rigour of data not identified specifically |

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Table A3: Parents' Care Activities

| Author, Year, Title | Study Purpose | Study Design, Data Collection Methods | Description of Sample, Setting | Data Analysis | Strengths, Limitations |
|---|---|---|---|---|---|
| | | relation to hospitalization not specified | described<br>***Setting:*** Three pediatric wards in a hospital in the UK | | |
| Kristensson-Hallström, I. & Elander, G. (1994)<br>Parental participation in the care of hospitalized children | To determine parents' current care activities, potential care activities and compare opinions of parents and staff | Cross-sectional, descriptive design<br>One-time administration of self-report questionnaire to parents and hospital staff<br>Two similar questionnaires | $N_{parents} = 40$ $N_{staff} = 44$<br>Parents had children aged 1wk to 5 yrs; all were admitted for elective surgery<br>Staff included nurses (86%) and doctors (14%) | t-test for unpaired samples used for data analysis | **Strengths**<br>▪ Tool development described<br>**Limitations**<br>▪ reliability and validity data for tool not provided<br>▪ Adequacy of sample size not confirmed |

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Table A3: Parents' Care Activities

| **Author, Year, Title** | **Study Purpose** | **Study Design, Data Collection Methods** | **Description of Sample, Setting** | **Data Analysis** | **Strengths, Limitations** |
|---|---|---|---|---|---|
| | | (one for parents, one for staff) consisting of 37 care activities based on a list published by the British General Nursing Council | ***Setting:***<br>Pediatric surgical unit of a university hospital in Sweden | | ▪ use of one setting limits generalizability |
| MacDonald, E.M. (1969)<br>Parents participate in the care of the hospitalized child | To determine parents' and nurses' perspectives on how parents could participate in the care of their hospitalized children. | Descriptive study<br>Administration of questionnaire to parents and nurses regarding care activities<br>Observation of care and nurse- | $N_{parents}$=76 (62 mother, 2 fathers, 12 father and mother pairs)<br>$N_{nurses}$ = 71<br>Parents of children from infancy to adolescence | Frequencies reported for selected questions<br>Data analysis not described | **Strengths**<br>▪ combination of questionnaire and observation strengthens results<br>▪ Inclusion of several hospital units may |

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Table A3: Parents' Care Activities

| Author, Year, Title | Study Purpose | Study Design, Data Collection Methods | Description of Sample, Setting | Data Analysis | Strengths, Limitations |
|---|---|---|---|---|---|
| | | parent interaction at the bedside | (specific age range not provided)<br>***Setting:*** General and specialty surgical units (number not specified) in a tertiary care children's hospital in Canada | | improve generalizability<br>**Limitations**<br>▪ Limited description of tool development<br>▪ reliability and validity data for tool not provided |
| Merrow, D.L. & Johnson, B.S. (1968)<br>Perceptions of the mother's role with her hospitalized | To determine if there are differences between nurses' and mothers' perceptions of the mother's role with | Cross-sectional, descriptive design<br>One-time administration of questionnaire to mothers via | $N_{mothers} = 50$<br>$N_{nurses} = 50$<br>No description of sample provided<br>***Setting:*** Pediatric | Chi-square used for data analysis | **Strengths**<br>▪ pilot study used to determine face validity of instrument, questionnaire |

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Table A3: Parents' Care Activities

| Author, Year, Title | Study Purpose | Study Design, Data Collection Methods | Description of Sample, Setting | Data Analysis | Strengths, Limitations |
|---|---|---|---|---|---|
| child | her hospitalized child | individual interview and to nurses via individual or group interview<br>Questionnaire consisted of list of 30 activities developed by authors, based on literature review, authors' experience and lists of activities identified by pediatric nursing students | wards of 4 general hospitals in the USA (nurses recruited from all 4 sites, mothers recruited from 2 sites) | | changed accordingly<br>▪ administration of questionnaire via interview may help to ensure parental understanding of questions<br>**Limitations**<br>▪ reliability not reported<br>▪ restricted population (i.e. mothers recruited from only 2 sites, nurses from 4) |

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Table A3: Parents' Care Activities

| Author, Year, Title | Study Purpose | Study Design, Data Collection Methods | Description of Sample, Setting | Data Analysis | Strengths, Limitations |
|---|---|---|---|---|---|
| | | | | | limited statistical comparison between mothers and nurses<br>▪ Adequacy of sample size not confirmed |
| Neill, S.J. (1996a & 1996b)<br>Parent participation 1: literature review and methodology<br>*and* | To describe parents' experiences in participating in care for their hospitalized child | Qualitative approach (unspecified)<br>Semi-structured interviews<br>Interviews done at parent's home or | 16 parents (14 mothers, 2 fathers)<br>Children with acute and chronic conditions aged 2-5 years<br>Parents invited to | Content analysis to identify themes | **Strengths:**<br>***Procedures for maintaining rigour:***<br>• Parents sent copies of transcripts and feedback requested; no |

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Table A3: Parents' Care Activities

| Author, Year, Title | Study Purpose | Study Design, Data Collection Methods | Description of Sample, Setting | Data Analysis | Strengths, Limitations |
|---|---|---|---|---|---|
| Parent participation 2: findings and implications for practice | | work<br>Interviews completed 1-8 weeks post-discharge | participate via letter; follow-up phone call gave opportunity to accept or decline invitation to participate<br>***Setting:*** Acute pediatric ward in a district general hospital in the UK | | respondents provided feedback<br>• Interviews conducted after discharge to minimize halo effect.<br>• Analysis checked by experienced researchers<br>**Limitations:**<br>• Data analysis procedures not described |
| Paliadelis, P., Cruikshank, M., | "to explore how paediatric nursing | Qualitative approach | N=14 nurses | Data were analyzed using | **Strengths:**<br>Data analysis |

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Table A3: Parents' Care Activities

| **Author, Year, Title** | **Study Purpose** | **Study Design, Data Collection Methods** | **Description of Sample, Setting** | **Data Analysis** | **Strengths, Limitations** |
|---|---|---|---|---|---|
| Wainohu, D. Winskill, R. & Sevens, H. (2005)<br>Implementing family-centered care: an exploration of the beliefs and practices of paediatric nurses" | staff included and involved family members in the care of the hospitalised [sic] child" (p.32) | (unspecified)<br>Unstructured, audio taped interviews | Purposive sampling used to obtain participants<br>***Setting:*** Pediatric wards of 2 hospitals in Australia | thematic coding | procedures described<br>***Procedures for maintaining rigour:***<br>▪ Transcripts analyzed and re-analyzed by members of research team to ensure consistency in developing themes<br>▪ Findings shared with participants, requested to provide |

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Table A3: Parents' Care Activities

| Author, Year, Title | Study Purpose | Study Design, Data Collection Methods | Description of Sample, Setting | Data Analysis | Strengths, Limitations |
|---|---|---|---|---|---|
| | | | | | feedback; feedback received from participants not described in article<br>**Limitations:**<br>▪ Use of a specified methodology would strengthen findings |
| Webb, N., Hull, D. & Madeley, R. (1985)<br>Care by parents in | To determine parents' current care activities, potential care activities and staff | Cross-sectional, descriptive design<br>One-time administration of | $N_{parents} = 80$<br>$N_{staff} = 54$<br>***Setting:*** acute medical ward in a | Frequencies reported for each care activity<br>Statistical analysis | **Strengths**<br>▪ administration of questionnaire via interview |

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Table A3: Parents' Care Activities

| Author, Year, Title | Study Purpose | Study Design, Data Collection Methods | Description of Sample, Setting | Data Analysis | Strengths, Limitations |
|---|---|---|---|---|---|
| hospital | perspective on potential care activities | questionnaire to mothers and staff<br>Questionnaire consisting of a list of 31 care activities published by the British General Nursing Council | university hospital in the UK | not described | may help to ensure parental understanding of questions<br>**Limitations**<br>▪ limited description of tool development<br>▪ reliability and validity data for tool not provided<br>▪ Adequacy of sample size not confirmed<br>▪ use of one setting limits generalizability |

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Table A3: Parents' Care Activities

| **Author, Year, Title** | **Study Purpose** | **Study Design, Data Collection Methods** | **Description of Sample, Setting** | **Data Analysis** | **Strengths, Limitations** |
|---|---|---|---|---|---|
| | | | | | ▪ limited discussion of study procedures |

## APPENDIX A

Table A4: Deciding the Extent of Parent Participation

| Author, Year, Title | Study Purpose | Study Design, Data Collection Methods | Description of Sample, Setting | Data Analysis | Strengths, Limitations |
|---|---|---|---|---|---|
| Algren, C.L. (1985)<br>Role perception of mothers who have hospitalized children | "To explore the concept of role perception in mothers who have a hospitalized child" (p.6) | Cross-sectional, descriptive design<br>One-time administration of questionnaire to mothers via individual interview<br>Questionnaire included a list of 30 activities; parents were asked if they wanted to provide that care or if they wanted the nurse to | N= 20 (18 mothers, 1 father, 1 mother and father)<br>Children under 10 yrs and not critically ill<br>***Setting:*** medical-surgical unit in a tertiary care children's hospital in the USA | Frequencies reported for care activities on list | **Strengths**<br>▪ Used tool developed for previous studies<br>**Limitations**<br>▪ Limited description of tool development<br>▪ reliability and validity data for tool not provided<br>▪ Adequacy of sample size not confirmed<br>▪ use of one setting limits generalizability |

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Table A4: Deciding the Extent of Parent Participation

| Author, Year, Title | Study Purpose | Study Design, Data Collection Methods | Description of Sample, Setting | Data Analysis | Strengths, Limitations |
|---|---|---|---|---|---|
| | | provide it (based on Merrow & Johnson's work) and 3 Likert-type questions about parental role | | | |
| Avis, M. & Reardon, R. (2008)<br>Understanding the views of parents of children with special needs about the nursing care their child receives when in | To explore parents' perspectives of the nursing care their child with special needs received while hospitalized | Qualitative methodology (unspecified)<br>Semi-structured interviews, consisting of 7 open questions with possible prompts | 12 interviews were conducted; not specified if each interview was with an individual parent or with a mother/father pair.<br>Purposive sampling used to | Pragmatic thematic analysis of data | **Strengths:**<br>▪ Data analysis procedures clearly described.<br>***Procedures for maintaining rigour:***<br>▪ Reflexivity: consideration of potential influence on data analysis of researcher's |

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Table A4: Deciding the Extent of Parent Participation

| Author, Year, Title | Study Purpose | Study Design, Data Collection Methods | Description of Sample, Setting | Data Analysis | Strengths, Limitations |
|---|---|---|---|---|---|
| hospital: a qualitative study | | | recruit parents of children who had been hospitalized within the previous year; sampling frame used to ensure inclusion of specific family characteristics (e.g., family size, age of child)<br>***Setting:*** Participants recruited through a Children's Centre in the UK | | knowledge, subjective perspective and interactions with participants, achieved through maintenance of detailed notes<br>**Limitations:**<br>▪ Richer description of themes could enhance transferability of results |

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Table A4: Deciding the Extent of Parent Participation

| Author, Year, Title | Study Purpose | Study Design, Data Collection Methods | Description of Sample, Setting | Data Analysis | Strengths, Limitations |
|---|---|---|---|---|---|
| | | | that provides respite to families of children with special needs | | |
| Balling, K. & McCubbin, M. (2001)<br>Hospitalized children with chronic illness: Parental care giving needs and valuing parental expertise | To describe the extent to which parents want to participate in their hospitalized child's care and to what extent they believe their expertise is valued by health care professionals | Retrospective, cross-sectional, descriptive correlational design<br>Family Profile Inventory (Demographic data)<br>Parental Control Preference Scale (PCPS) (included one open-ended | N= 50 (41.3% response rate)<br>Participants: Primary caregivers to children with chronic illness<br>Recruited via mailed questionnaires with follow-up phone call using membership list | Descriptive statistics (Demographic data, PCPS subscales, VOPE individual items)<br>Correlation (among demographic and illness data, PCPS, VOPE)<br>$P < .05$<br>Content Analysis | **Strengths**<br>▪ Cronbach's alpha coefficient reported for both scales<br>▪ Data from open-ended question reviewed and discussed by 3 nurse-experts, two with PhD<br>**Limitations**<br>▪ Test-re-test reliability not reported for either |

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Table A4: Deciding the Extent of Parent Participation

| Author, Year, Title | Study Purpose | Study Design, Data Collection Methods | Description of Sample, Setting | Data Analysis | Strengths, Limitations |
|---|---|---|---|---|---|
| | | question)<br>Cronbach's alpha coefficient = 0.85 - 0 .95 (for 4 subscales)<br>Valuing of Parental Expertise Scale (VOPE) Cronbach's alpha coefficient= 0.69 | of parental support organization<br>Convenience sample<br>Children's age range 1.25-21.3 years | (open-ended question on PCPS) | scale<br>▪ Adequacy of sample size not confirmed<br>▪ PCPS designed for use with parents of acutely ill children, not chronically ill children<br>▪ Representativeness of sample not reported<br>▪ No information available about non-responders |
| Brown, J. & Ritchie, J.A. (1990) | "to describe nurses' perceptions of | Cross-sectional, exploratory study | N=25 pediatric nurses | Frequencies reported for care activities on list | **Strengths**<br>▪ Inter- and intra-rater reliability |

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Table A4: Deciding the Extent of Parent Participation

| Author, Year, Title | Study Purpose | Study Design, Data Collection Methods | Description of Sample, Setting | Data Analysis | Strengths, Limitations |
|---|---|---|---|---|---|
| Nurses' perceptions of parent and nurse roles in caring for hospitalized children | …nursing and parental roles and the factors that modify them" (p.28) | **Quantitative component**: Administration of a questionnaire consisting of a list of 31 care activities (based on work of Merrow & Johnson and Algren)<br>**Qualitative component**: Audiotaped, semi-structured interviews | ***Setting:*** tertiary care children's hospital in Canada | Content analysis used to analyze interview data | reported for content analysis data<br>▪ Used tool developed for previous studies<br>**Limitations**<br>▪ Limited description of tool development<br>▪ reliability and validity data for tool not provided |
| Blower, K. & Morgan, E. (2000) | "To compare parents' and nurses' | Cross-sectional, exploratory study | $N_{nurses} = 40$<br>$N_{parents} = 40$ | Chi-square used to compare responses of | **Strengths**<br>▪ efforts made to minimize 'halo |

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Table A4: Deciding the Extent of Parent Participation

| **Author, Year, Title** | **Study Purpose** | **Study Design, Data Collection Methods** | **Description of Sample, Setting** | **Data Analysis** | **Strengths, Limitations** |
|---|---|---|---|---|---|
| Great expectations? Parental participation in care | expectations of parental participation in care" (p.60) | One-time administration of self-report questionnaire to parents and nurses<br>Questionnaire included a list of 15 activities in which parents might participate and included space for written comments | Parents of children age 0-5 yrs, all short-stay admissions<br>***Setting:*** regional children's hospital in the UK | nurses and parents<br>Content analysis used for written component of questionnaire | effect' in respondents<br>▪ tool development described<br>**Limitations**<br>▪ reliability and validity data for tool not provided<br>▪ adequacy of sample size not determined<br>▪ use of one setting limits generalizability |
| Coyne, I. (1995)<br>Partnership in care: parents' | To identify why parents chose to participate in their child's care and | Phenomenological approach<br>Semi-structured | 18 parents (16 mothers, 2 fathers; all Caucasian) | | **Strengths:**<br>▪ direct quotations from participants used to illustrate |

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Table A4: Deciding the Extent of Parent Participation

| **Author, Year, Title** | **Study Purpose** | **Study Design, Data Collection Methods** | **Description of Sample, Setting** | **Data Analysis** | **Strengths, Limitations** |
|---|---|---|---|---|---|
| views of participation in their hospitalized child's care | factors influencing participation | interview schedule<br>Interview location not specified<br>Timing of interview in relation to hospitalization not specified | Children's ages and illnesses not specified<br>Recruitment procedures not described<br>***Setting:*** General surgical pediatric ward in a tertiary referral hospital in the UK | | categories<br>**Limitations:**<br>▪ Data analysis procedures not described<br>▪ Procedures for maintaining rigour of data not identified |
| Coyne, I. & Cowley, S.(2007 ) Challenging the philosophy of partnership with | To describe parents, nurses and children's perspectives on parent | Grounded theory method<br>Observation of daily activities on | 10 parents (8 mothers, 2 fathers)<br>12 nurses (4 staff | Constant comparative method of data analysis used | **Strengths:**<br>Data analysis procedures clearly described<br>***Procedures for*** |

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Table A4: Deciding the Extent of Parent Participation

| **Author, Year, Title** | **Study Purpose** | **Study Design, Data Collection Methods** | **Description of Sample, Setting** | **Data Analysis** | **Strengths, Limitations** |
|---|---|---|---|---|---|
| parents: a grounded theory study<br>Coyne, I. (2007) Disruption of parent participation: nurses' strategies to manage parents on children's wards<br>(two reports of the same study) | participation in care | the unit and in-hospital interviews with parents, nurses, children<br>Interviews focusing on reason for hospitalization and parents, nurses' and children's' participation<br>Field notes recorded after each observation period | nurses, 8 charge nurses)<br>11 children 7-14 yrs old with various acute and chronic illnesses)<br>Purposeful sampling used to obtain participants.<br>***Setting:*** 4 medical/surgical units in 2 hospitals in the UK (1 specialized children's | | ***maintaining rigour:***<br>▪ Strict adherence to tenets of constant comparative method;<br>▪ Reflexivity: consideration of potential influence on data analysis of researcher's knowledge, subjective perspective and interactions with participants, achieved through maintenance of detailed notes;<br>▪ Resulting |

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Table A4: Deciding the Extent of Parent Participation

| Author, Year, Title | Study Purpose | Study Design, Data Collection Methods | Description of Sample, Setting | Data Analysis | Strengths, Limitations |
|---|---|---|---|---|---|
| | | | hospital, 1 general hospital) | | theoretical framework validated with "several children's nurses" (Coyne, 2007); not specified whether this group included nurse participants<br>**Limitations:**<br>▪ Unable to validate theory with parent participants as children had been discharged by the time the framework was developed |

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Table A4: Deciding the Extent of Parent Participation

| Author, Year, Title | Study Purpose | Study Design, Data Collection Methods | Description of Sample, Setting | Data Analysis | Strengths, Limitations |
|---|---|---|---|---|---|
| | | | | | ▪ Results may not reflect the experiences of parents with children younger than 7 years. |
| Darbyshire, P. (1994)<br>Parenting in public: Parental participation and involvement in the care of their hospitalized child | To examine the lived experience of parents who remained in hospital with their child | Phenomenological study<br>Data collected during 9 months of fieldwork on hospital units<br>Informal discussions, interviews and focus group | 30 parents (26 mother, 4 fathers)<br>27 nurses<br>Children's ages and illnesses not specified<br>Recruitment procedures not described | Author describes how he began his research using grounded theory but over time found hermeneutic phenomenology to be more appropriate and thus changed his approach | **Strengths:**<br>▪ Rich description with quotations from participants enhance presentation of themes<br>**Limitations:**<br>▪ Specific data analysis procedures not described. |

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Table A4: Deciding the Extent of Parent Participation

| Author, Year, Title | Study Purpose | Study Design, Data Collection Methods | Description of Sample, Setting | Data Analysis | Strengths, Limitations |
|---|---|---|---|---|---|
| | | sessions | ***Setting:*** A general medical ward and a burn unit in a pediatric hospital in the UK | | ▪ Procedures for maintaining rigour of data not identified |
| Dearmun, A. (1992)<br>Perceptions of parental participation | To explore the differences and similarities between parents' and nurses' perceptions of care provided by parents for their hospitalized children | Cross-sectional, descriptive design<br>Data collection included:<br>▪ interview using a semi-structured schedule;<br>▪ non-participant observation using a | Interviews:<br>14 mothers and 21 nurses (experience ranging from 1-10 years)<br>Observations: 7 children and their families<br>Volunteer sample | Frequencies reported for responses to questionnaire | **Strengths**<br>▪ Tool development described<br>▪ administration of questionnaire via interview may help to ensure parental understanding of questions<br>▪ researcher tried to minimize |

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Table A4: Deciding the Extent of Parent Participation

| Author, Year, Title | Study Purpose | Study Design, Data Collection Methods | Description of Sample, Setting | Data Analysis | Strengths, Limitations |
|---|---|---|---|---|---|
| | | structured format for recording observations with 5-minute sampling plan<br>Development of both tools described in article | ***Setting:*** Pediatric ward in UK (no description given) | | Hawthorne Effect by wearing lay clothing to blend in with visitors on unit.<br>**Limitations**<br>▪ reliability and validity data for tool not provided<br>▪ small sample size and use of one setting limit generalizability<br>▪ Author notes that parents were reluctant to criticize nurses and thus speculates whether |

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Table A4: Deciding the Extent of Parent Participation

| **Author, Year, Title** | **Study Purpose** | **Study Design, Data Collection Methods** | **Description of Sample, Setting** | **Data Analysis** | **Strengths, Limitations** |
|---|---|---|---|---|---|
| | | | | | interview after discharge may have strengthened credibility of data |
| Espezel, H.J.E. & Canam,C.J. (2003)<br>Parent-nurse interactions: care of hospitalized children | To examine parents' experiences in interacting with nurses when their child was hospitalized. | Qualitative methodology (unspecified)<br>Interview using open-ended questions<br>Field notes<br>Interviews done at parent's home or work. | 8 parents (7 mothers, 1 father)<br>Children with chronic illness greater than 18 months of age<br>Recruitment procedures: Eligible parents contacted by ambulatory clinic nurse, interested | Thematic analysis | **Strengths:**<br>▪ Data analysis procedures described<br>***Procedures for maintaining rigour:***<br>• Auditability: explicit decision trail<br>• Confirmability: use of reflective journal to identify biases, ethical considerations that |

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Table A4: Deciding the Extent of Parent Participation

| Author, Year, Title | Study Purpose | Study Design, Data Collection Methods | Description of Sample, Setting | Data Analysis | Strengths, Limitations |
|---|---|---|---|---|---|
| | | Timing of interview in relation to hospitalization not specified | parents contacted researcher<br>***Setting:*** Large urban children's hospital in Canada | | could enhance rapport and sharing<br>• Credibility: rich description in research report<br>**Limitations:**<br>• Use of a specified methodology would strengthen findings |
| Kawik, L. (1996)<br>Nurses' and parents' perceptions of participation and | To find out if parents of hospitalized children participated in care and worked | Phase 1: Quantitative<br>• Survey mailed to all staff nurses on units | ***Phase 1:*** Nurses N=55 (response rate 84.6%)<br>***Phase 2:*** Parents 12 interviews completed | Across method triangulation<br>Phase 1: Quantitative Data analysis | **Strengths:**<br>▪ Data analysis procedures described<br>**Limitations:**<br>▪ Procedures for |

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Table A4: Deciding the Extent of Parent Participation

| Author, Year, Title | Study Purpose | Study Design, Data Collection Methods | Description of Sample, Setting | Data Analysis | Strengths, Limitations |
|---|---|---|---|---|---|
| partnership in caring for a hospitalized child | as partners with nurses | Phase 2: Qualitative (unspecified methodology)<br>• In-depth interviews with parents after child's discharge from hospital<br>Interviews done at parent's home<br>Timing of interview in relation to hospitalization not | (not known if 12 parents were interviewed or if some individuals gave more than one interview; number of mothers vs. fathers also not known)<br>Children's ages and illnesses not specified<br>Recruitment procedures not described | using descriptive statistics<br>Phase 2: Qualitative Data analysis using content analysis | maintaining rigour of data not identified specifically<br>▪ Use of a specified methodology would strengthen findings |

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Table A4: Deciding the Extent of Parent Participation

| Author, Year, Title | Study Purpose | Study Design, Data Collection Methods | Description of Sample, Setting | Data Analysis | Strengths, Limitations |
|---|---|---|---|---|---|
| | | specified | ***Setting:*** Three pediatric wards in a hospital in the UK | | |
| Kristensson-Hallstrom, I. & Elander, G.(1997)<br>Parents' experience of hospitalization; different strategies for feeling secure | To understand parents' experiences during their child's hospitalization | Grounded theory approach<br>Interviews following a flexible guide identifying areas to be covered in interview<br>Each parent interviewed twice (after admission and prior to | 20 Parents (12 mothers, 8 fathers; included one set of foster parents)<br>Children with hypospadias repair, ages 2-14 years<br>Recruitment procedures not described | Data collection influenced by grounded theory, data analysis used hermeneutic view | **Strengths:**<br>• Data analysis procedures described<br>• Details given re: ethical considerations that could enhance rapport and sharing<br>**Limitations:**<br>• Procedures for maintaining rigour of data not |

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Table A4: Deciding the Extent of Parent Participation

| **Author, Year, Title** | **Study Purpose** | **Study Design, Data Collection Methods** | **Description of Sample, Setting** | **Data Analysis** | **Strengths, Limitations** |
|---|---|---|---|---|---|
| | | discharge), in hospital.<br>Parents kept record of staff encountered during hospitalization<br>Data collection continued until saturation reached. | ***Setting:*** Pediatric surgical floor in a university hospital in Sweden | | identified specifically<br>• Reason for mixing qualitative approaches unclear |
| Kristensson-Hallström, I. (1999)<br>Strategies for feeling secure | To test two hypotheses:<br>1. "parents of hospitalized children have | Cross-sectional, descriptive design<br>One-time administration of self-report | N = 224 parents (majority were mothers) of children aged <1yr – 16 yrs, majority | Student's t-test for unpaired samples used to compare two groups, ANOVA or Kruskall- | **Strengths**<br>▪ Tool development described<br>▪ Large sample size and use of multiple settings |

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Table A4: Deciding the Extent of Parent Participation

| **Author, Year, Title** | **Study Purpose** | **Study Design, Data Collection Methods** | **Description of Sample, Setting** | **Data Analysis** | **Strengths, Limitations** |
|---|---|---|---|---|---|
| influence parents' participation in care | different ways of reaching security and thus participate in the care of their hospitalized child to different degrees;"<br>2. "degree of parental participation influences child's pain and sleep during hospitalization | questionnaire to parents<br>Questionnaire based on results of previous qualitative research<br>Questionnaire included:<br>- Demographic variables;<br>- Two 10cm visual analog scales to measure parents assessment of | undergoing surgery<br>***Setting:*** 3 pediatric units (2 surgical, 1 medical-surgical) at 2 university hospitals in Sweden | Wallis used for more than two groups (groups not specified in report)<br>Statistical significance set at $p < 0.05$ | may improve generalizability<br>**Limitations**<br>- reliability and validity data for tool not provided |

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Table A4: Deciding the Extent of Parent Participation

| Author, Year, Title | Study Purpose | Study Design, Data Collection Methods | Description of Sample, Setting | Data Analysis | Strengths, Limitations |
|---|---|---|---|---|---|
| | ”<br>(p.587) | child's sleep and pain;<br>▪ Description of participation – parents chose 1 of 4 statements to describe their participation<br>▪ Description of feeling secure - parents chose 1of 4 statements to describe their feelings of security | | | |

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Table A4: Deciding the Extent of Parent Participation

| Author, Year, Title | Study Purpose | Study Design, Data Collection Methods | Description of Sample, Setting | Data Analysis | Strengths, Limitations |
|---|---|---|---|---|---|
| | | | | | |
| Lam, L.W., Chang, A.M. & Morrissey, J. (2006)<br>Parents' experiences of participation in the care of hospitalized children: a qualitative study | To explore the experiences and perceptions of Chinese parents of hospitalized children in Hong Kong | Qualitative approach (unspecified)<br>Semi-structured interviews completed in hospital (in child's room or alternate space, as preferred by parent) | 19 parents (16 mothers, 3 fathers) of children aged 6 months to 11years<br>Children had various diagnoses and length of admission ranged from 3 days to more than 1 week<br>Convenience sampling<br>***Setting:*** 4 pediatric wards in | Content analysis | **Strengths:**<br>▪ Data analysis procedures clearly described.<br>***Procedures for maintaining rigour:***<br>• Initial coding completed by 2 researchers independently, then compared and agreements reached<br>• Final themes confirmed by full research team<br>**Limitations:**<br>• Use of a specified |

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Table A4: Deciding the Extent of Parent Participation

| Author, Year, Title | Study Purpose | Study Design, Data Collection Methods | Description of Sample, Setting | Data Analysis | Strengths, Limitations |
|---|---|---|---|---|---|
| | | | a regional acute-care general hospital in Hong Kong | | methodology would strengthen findings |
| McKiel, E. (2002)<br>Impact of organizational restructuring on nurses' facilitation of parental participatory care | To understand how nurses perceive their role in facilitating parents' participation in care and to identify factors influencing their role | Narrative inquiry<br>Interviews, field notes<br>Data collection continued until saturation reached<br>Interview location not specified | 8 RNs<br>Children's ages and illnesses not specified<br>All nurses in practice setting offered opportunity to participate, interested nurses contacted researcher | Narrative analyses to identify themes | **Strengths:**<br>Procedures for maintaining rigour:<br>• Narratives reviewed by participants, changes made based on feedback received<br>• Review of narratives by faculty colleagues<br>• Prior assumptions recorded as memos, checked |

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Table A4: Deciding the Extent of Parent Participation

| Author, Year, Title | Study Purpose | Study Design, Data Collection Methods | Description of Sample, Setting | Data Analysis | Strengths, Limitations |
|---|---|---|---|---|---|
| | | | ***Setting:*** Acute care pediatric hospital in Canada | | during analysis to ensure no influence on interpretation<br>**Limitations:**<br>• Data analysis procedures not clearly described |
| Neill, S.J. (1996a & 1996b)<br>Parent participation 1: literature review and methodology<br>*and* | To describe parents' experiences in participating in care for their hospitalized child | Qualitative approach (unspecified)<br>Semi-structured interviews<br>Interviews done at parent's home or work | 16 parents (14 mothers, 2 fathers)<br>Children with acute and chronic conditions aged 2-5 years<br>Parents invited to | Content analysis to identify themes | **Strengths:**<br>***Procedures for maintaining rigour:***<br>• Parents sent copies of transcripts and feedback requested; no respondents provided feedback<br>• Interviews |

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Table A4: Deciding the Extent of Parent Participation

| Author, Year, Title | Study Purpose | Study Design, Data Collection Methods | Description of Sample, Setting | Data Analysis | Strengths, Limitations |
|---|---|---|---|---|---|
| Parent participation 2: findings and implications for practice | | Interviews completed 1-8 weeks post-discharge | participate via letter; follow-up phone call gave opportunity to accept or decline invitation to participate<br>***Setting:*** Acute pediatric ward in a district general hospital in the UK | | conducted after discharge to minimize halo effect.<br>• Analysis checked by experienced researchers<br>**Limitations:**<br>• Data analysis procedures not described |
| O'Haire, S.E. & Blackford, J.C. (2005)<br>Nurses' moral agency in negotiating | To explore and understand, from nurses' perspectives, parental participation in care, how it is | Grounded theory approach<br>Semi-structured, audio taped interviews | 9 nurses (3 nurses, 3 clinical nurse specialists, 3 nurse managers) with experience ranging from 1-15 years | Constant comparative method | **Strengths:**<br>• General description of coding and categorization process provided<br>***Procedures for*** |

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Table A4: Deciding the Extent of Parent Participation

| **Author, Year, Title** | **Study Purpose** | **Study Design, Data Collection Methods** | **Description of Sample, Setting** | **Data Analysis** | **Strengths, Limitations** |
|---|---|---|---|---|---|
| parental participation in care | negotiated and facilitated, and barriers to parents' participation | | Theoretical sampling used to select participants<br>***Setting:*** Pediatric cardiac/renal unit in Australia | | ***maintaining rigour:***<br>▪ Participants took part in a focus group interview to discuss categories after preliminary analysis of data, confirming preliminary findings<br>**Limitations:**<br>▪ Minimal description provided of theoretical sampling procedures |

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Table A4: Deciding the Extent of Parent Participation

| Author, Year, Title | Study Purpose | Study Design, Data Collection Methods | Description of Sample, Setting | Data Analysis | Strengths, Limitations |
|---|---|---|---|---|---|
| Paliadelis, P., Cruikshank, M., Wainohu, D. Winskill, R. & Sevens, H. (2005)<br>Implementing family-centered care: an exploration of the beliefs and practices of paediatric nurses | "to explore how paediatric nursing staff included and involved family members in the care of the hospitalised [sic] child" (p.32) | Qualitative approach (unspecified)<br>Unstructured, audio taped interviews | N=14 nurses<br>Purposive sampling used to obtain participants.<br>***Setting:***<br>Pediatric wards of 2 hospitals in Australia | Data were analyzed using thematic coding | **Strengths:**<br>• Data analysis procedures described<br>***Procedures for maintaining rigour:***<br>▪ Transcripts analyzed and re-analyzed by members of research team to ensure consistency in developing themes<br>▪ Findings shared with participants, requested to provide feedback; feedback received |

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Table A4: Deciding the Extent of Parent Participation

| Author, Year, Title | Study Purpose | Study Design, Data Collection Methods | Description of Sample, Setting | Data Analysis | Strengths, Limitations |
|---|---|---|---|---|---|
| | | | | | from participants not described in article<br>**Limitations:**<br>▪ Use of a specified methodology would strengthen findings |
| Roden, J. (2005)<br><br>The involvement of parents and nurses in the care of acutely-ill children in a non-specialist paediatric setting | To understand parents' and nurses' perceptions of parental participation and factors influencing this participation | Grounded theory approach<br><br>Parents recruited via distribution of research information sheets Interviews with parents took place on the ward | 16 parents (2 couples, 9 mothers, 1 father, 2 female caregivers)<br><br>***Setting:*** Pediatric ward at a community hospital in Australia | Content analysis | **Strengths:**<br>• Data analysis procedures clearly described<br>***Procedures for maintaining rigour:***<br>• One parent couple who participated in the study gave feedback on the resulting themes |

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Table A4: Deciding the Extent of Parent Participation

| Author, Year, Title | Study Purpose | Study Design, Data Collection Methods | Description of Sample, Setting | Data Analysis | Strengths, Limitations |
|---|---|---|---|---|---|
| | | Interviews with parents proceeded simultaneously with data analysis; interviews continued until saturation of data was reached<br>Results of parent interviews then presented to nurses in focus groups for their response | | | • Research team maintained a paper trail of memos recording data analysis decisions<br>• Several parents had experienced hospitalization of their children at other hospitals and drew on this in their interviews – authors suggest this may contribute to transferability of results<br>**Limitations:**<br>• Recruitment |

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Table A4: Deciding the Extent of Parent Participation

| Author, Year, Title | Study Purpose | Study Design, Data Collection Methods | Description of Sample, Setting | Data Analysis | Strengths, Limitations |
|---|---|---|---|---|---|
| | | | | | procedure for nurses to attend focus groups not described<br>• Few nurses participated in the focus groups |
| Romaniuk, D.K. (1993)<br>The parent-nurse relationship in family-centred care of the hospitalized child with cancer: the parents' perspective | To describe parents' perspective of their relationship with nurses while their child with cancer is in hospital | Grounded theory approach<br>Unstructured, audio-taped interviews<br>Theoretical sampling led to variations in questioning as | N= 16 parents (10 mothers, 6 fathers)<br>Recruited through the pediatric oncology clinic of a children's hospital in Canada<br>Eligible parents | Constant comparative analysis | **Strengths:**<br>▪ Data analysis procedures clearly described<br>***Procedures for maintaining rigour:***<br>▪ Prolonged engagement in the field<br>▪ Peer debriefing with faculty and |

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Table A4: Deciding the Extent of Parent Participation

| Author, Year, Title | Study Purpose | Study Design, Data Collection Methods | Description of Sample, Setting | Data Analysis | Strengths, Limitations |
|---|---|---|---|---|---|
| | | study progressed | sent letter explaining study, followed up by phone call from researcher<br>Children aged 1 – 13 years | | colleagues<br>▪ Presentation of data to participants for feedback<br>▪ Detailed report of findings and methods<br>▪ Maintenance of journal during data collection, to identify potential assumptions and biases<br>**Limitations:**<br>▪ Use of participant observation in addition to interviews could enhance |

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Table A4: Deciding the Extent of Parent Participation

| **Author, Year, Title** | **Study Purpose** | **Study Design, Data Collection Methods** | **Description of Sample, Setting** | **Data Analysis** | **Strengths, Limitations** |
|---|---|---|---|---|---|
| | | | | | development of the conceptual framework. |
| Rowe, J. (1996)<br>Making oneself at home? Examining the nurse-parent relationship | To examine how nurses and parents cared for hospitalized children and the relationship that developed between them | Phenomenological influences<br>Participant observation over 12 m. period, including observations, informal conversations and formal interviews | 50 parent couples and 18 nurses included in observations and informal conversation<br>5 nurses participated in formal, taped interviews<br>***Setting:*** 8-bed infant and toddler section on a | Themes developed form data; data examined "in light of six indices….time, place, social circumstance, language, intimacy, social consensus" (p.103) | **Strengths:**<br>• Data analysis procedures described<br>***Procedures for maintaining rigour:***<br>▪ Author notes that use of indices described above strengthens interpretation of data<br>**Limitations:**<br>▪ intermittent observation |

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Table A4: Deciding the Extent of Parent Participation

| Author, Year, Title | Study Purpose | Study Design, Data Collection Methods | Description of Sample, Setting | Data Analysis | Strengths, Limitations |
|---|---|---|---|---|---|
| | | | pediatric unit in a general hospital in Australia | | periods, absence of formal interviews with parents<br>- No indication that analysis was checked by other researchers and/or participants |
| Webb, N., Hull, D. & Madeley, R. (1985)<br>Care by parents in hospital | To determine parents' current care activities, potential care activities and staff perspective on potential care activities | Cross-sectional, descriptive design<br>One-time administration of questionnaire to mothers and staff<br>Questionnaire consisting of a list | $N_{parents} = 80$<br>$N_{staff} = 54$<br>***Setting:*** acute medical ward in a university hospital in the UK | Frequencies reported for each care activity<br>Statistical analysis not described | **Strengths**<br>- administration of questionnaire via interview may help to ensure parental understanding of questions<br>**Limitations**<br>- limited description |

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Table A4: Deciding the Extent of Parent Participation

| Author, Year, Title | Study Purpose | Study Design, Data Collection Methods | Description of Sample, Setting | Data Analysis | Strengths, Limitations |
|---|---|---|---|---|---|
| | | of 31 care activities published by the British General Nursing Council | | | of tool development<br>▪ reliability and validity data for tool not provided<br>▪ small sample size and use of one setting limit generalizability<br>▪ limited discussion of study procedures |
| Ygge, B.M. & Arnetz, J.E. (2004)<br><br>A study of parental | To understand parents' views of factors influencing their participation in their hospitalized | Qualitative approach (unspecified)<br><br>Semi-structured interviews (some | 14 parents (12 mothers, 2 fathers)<br><br>Children with chronic illness, | Analysis: coding and categorization using constant comparison method | **Strengths:**<br>▪ Data analysis procedures described<br>***Procedures for maintaining rigour:*** |

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Table A4: Deciding the Extent of Parent Participation

| Author, Year, Title | Study Purpose | Study Design, Data Collection Methods | Description of Sample, Setting | Data Analysis | Strengths, Limitations |
|---|---|---|---|---|---|
| involvement in pediatric hospital care: implications for clinical practice | child's care | parents contacted researcher to provide more information after completion of interview)<br>Interviews took place at the children's hospital<br>Timing of interview in relation to hospitalization not specified | age not specified<br>Recruitment using snowball sampling via hospital's Parent Council<br>***Setting:*** University children's hospital in Sweden | | • Use of probes to ensure understanding of parents' comments<br>• Similar questions asked more than once<br>• Analysis and discussion of transcripts by both authors<br>**Limitations:**<br>• Use of a specified methodology would strengthen findings |

## APPENDIX B

Parent Participation Congruence Study CODE#________

## Demographic Questionnaire

Please respond to the following questions by marking the box beside your answer. If you prefer not to answer any question, please feel free to leave it blank. The information collected with this questionnaire is confidential, and will only be identified by number.

1. **What is your relationship to the hospitalized child?**
   1 Mother
   2 Father
   3 Other (Please specify______________________________)

2. **How old are you?**
   1 20 years or less
   2 21 - 30 years
   3 31 - 40 years
   4 41 - 50 years
   5 51 years or more

3. **Are you**
   1 Single (never married)
   2 Married
   3 Living in a common-law relationship
   4 Divorce/separated
   5 Widowed

4. **Which statement best describes your employment status?**
   1 Employed full-time
   2 Employed part-time
   3 Looking for employment (full or part-time)
   4 Stay-at-home parent
   5 Other (please
   describe______________________________)

5. **What is the highest level of schooling you have received?**
   1 Less than high school diploma
   2 High school diploma
   3 College diploma
   4 University undergraduate degree
   5 University graduate degree
   6 Other (please
   specify______________________________)

APPENDIX B

Parent Participation Congruence Study CODE#________

**6. Traveling from your home to McMaster Children's Hospital usually takes**

1 Less than 30 minutes
2 30 minutes to an hour
3 More than an hour

**7. My hospitalized child is a**

1 Girl
2 Boy

**8. How old is your hospitalized child?** ________________________

**9. Before this admission, how many times has your child been in the hospital?**

1 Never
2 1 time
3 2 times
4 3 times or more

**10. How many children under the age of 18 years (including your hospitalized child) are in your family?** ________________________

**Thank you for completing this questionnaire!**

# APPENDIX C

## Permission to use tool

**From** Angel Brandwein <Angel.Brandwein@asu.edu>
**Date** Fri, 15 Jun 2007 17:03:51 -0700
**To** Daria Romaniuk <romaniuk@ryerson.ca>
**Subject** RE: follow-up re: request to use tool

Oh thank you so much Daria: the request forms are just a formality for our files – please feel free to go forward and to keep us abreast of interesting outcomes!

- Angel

*Angel Brandwein*
Executive Assistant to the Dean
ASU College of Nursing & Healthcare Innovation
*Dream · Discover · Deliver*

*Mail code [illegible]*
500 North 3rd Street
Phoenix, AZ 85004
*(602) 496-2200 office*
*(602) 496-[illegible] fax*

Angel.Brandwein@asu.edu

**From:** Daria Romaniuk [mailto:romaniuk@ryerson.ca]
**Sent:** Friday, June 15, 2007 7:35 AM
**To:** Angel Brandwein
**Subject:** follow-up re: request to use tool

Hello Angel,

I am following up on my request to use the Index of Parent Participation/Hospitalized Child in my PhD study. On May 25, I faxed the application form and mailed the hard copy as well. Please let me know whether these were received. If these were received, can you tell me about the status of my request? I have attached electronic copies of the documents I faxed/mailed.Thank you for your assistance in this matter.

Daria

Daria Romaniuk, RN, MN, PhD(Student)
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Ryerson University School of Nursing
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M5B 2K3
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APPENDIX D

Parent Participation Congruence Study

Code Number _____

## INDEX OF PARENT PARTICIPATION/HOSPITALIZED CHILD– Actual Activity

*Adapted from the **INDEX OF PARENT PARTICIPATION/HOSPITALIZED CHILD** by*
Bernadette Mazurek Melnyk, PhD, RN-CS, PNP
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Below is a list of 36 activities that you may have done for your child in the last 24 hours. Some parents do few of these things while their children are in the hospital, while some parents do more of these things. There is no set number of things that you should have done for your child. Please make a checkmark on the line in front of each activity that you are sure you did for your child in the last 24 hours.

**Today's Date:** _________

__1. Fed child or set up his/her food tray (such as opened milk carton, cut up food).

__2. Helped with elimination (changed diaper, walked child to the bathroom, placed child on bedpan).

__3. Bathed child/sponged with a washcloth.

__4. Encouraged fluids (if told that this was important or appropriate to do).

__5. Kept track of how much child ate or drank and told nurse or recorded the amount on an intake and output sheet.

__6. Kept track of how much or how often child urinated and told nurse or recorded it on an intake and output sheet.

__7. Kept track of when child had a bowel movement and told nurse or recorded it on an intake and output sheet.

__8. Took child to playroom if allowed.

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__9. Comforted child when upset (does not include comforting during a painful procedure such as when having blood drawn or a needle given).

__10. Comforted child during a painful procedure (such as when having blood drawn or a needle given).

__11. Spent quiet time interacting with child (talking, reading, coloring, drawing, watching TV).

__12. Held or rocked child.

__13. Told nurse about something your child needed.

__14. Told nurse about child's daily routines or his/her likes or dislikes without being asked to do so.

__15. Told physician about something your child needed.

__16. Asked nurse for information about child's condition.

__17. Asked nurse for information about child's care.

__18. Asked physician for information about child's condition.

__19. Actively played with child in room (games, blocks, etc).

__20. Stroked child/rubbed back.

__21. Brushed teeth/performed mouth care.

__22. Made a decision regarding your child's care.

__23. Played with child for the purpose of getting him/her to talk about or show feelings by use of puppets, dolls or stuffed animals or used role play (such as letting child pretend to be a doctor or nurse while mother pretends to be the patient).

__24. Changed clothes or pajamas.

__25. Settled for sleep or nap.

__26. Combed/brushed hair.

APPENDIX D

__27. Helped nurse give medication (would include getting child to cooperate).

__28. Talked with child about why he/she is in the hospital (would include talking about his/her illness or injury).

__29. Asked a nurse or doctor to describe a certain test or procedure so that you could tell your child about it.

__30. Let child know what to expect about a treatment or test (such as an x-ray, needle, IV).

__31. Talked with child about why he/she needs a test or treatment (such as x-ray,needle, IV).

__32. Asked a nurse or physician about how your child was during the time you were not with him/her.

__33. Suggested to a nurse or doctor a different way or time of doing something that you thought would be better for your child.

__34. Took child for a walk, if allowed.

__35. Asked the nurse or doctor to explain something that you did not understand.

__36. Talked with another parent or person (besides a nurse or doctor) to gain more information about some part of the hospital experience or your child's illness or injury.

Where there any other activities that you performed for your child that are not on this list?

______Yes ______No

If yes, what where they?

Thank you for answering this questionnaire!

## APPENDIX E

Parent Participation Congruence Study

Code Number _____

## INDEX OF PARENT PARTICIPATION/HOSPITALIZED CHILD– Desired Activity

*Adapted from the* ***INDEX OF PARENT PARTICIPATION/HOSPITALIZED CHILD***
*by*
Bernadette Mazurek Melnyk, PhD, RN-CS, PNP
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Below is a list of 36 activities that you may have wanted to do for your child during the past 24 hours. Some parents want to do a few of these things while their children are in the hospital while some parents want to do more of these things. There is no set number of things that you should want to do for your child. Please make a check mark on the line in front of each activity that you wanted to do for your child, whether or not you actually performed it, in the last 24 hours.

**Today's Date:** _________

__1. Feed child or set up his/her food tray (such as opened milk carton, cut up food).

__2. Help with elimination (change diaper, walk child to the bathroom, place child on bedpan).

__3. Bath child/sponged with a washcloth.

__4. Encourage fluids (if told that this was important or appropriate to do).

__5. Keep track of how much child eats or drinks and tell nurse or record the amount on an intake and output sheet.

__6. Keep track of how much or how often child urinates and tell nurse or record it on an intake and output sheet.

__7. Keep track of when child has a bowel movement and tell nurse or record it on an intake and output sheet.

__8. Take child to playroom if allowed.

## APPENDIX E

__9. Comfort child when upset (does not include comforting during a painful procedure such as when having blood drawn or a needle given).

__10. Comfort child during a painful procedure (such as when having blood drawn or a needle given).

__11. Spend quiet time interacting with child (talking, reading, coloring, drawing, watching TV).

__12. Hold or rock child.

__13. Tell nurse about something your child needs.

__14. Tell nurse about child's daily routines or his/her likes or dislikes without being asked to do so.

__15. Tell physician about something your child needs.

__16. Ask nurse for information about child's condition.

__17. Ask nurse for information about child's care.

__18. Ask physician for information about child's condition.

__19. Actively play with child in room (games, blocks, etc).

__20. Stroke child/rub back.

__21. Brush teeth/perform mouth care.

__22. Make a decision regarding your child's care.

__23. Play with child for the purpose of getting him/her to talk about or show feelings by use of puppets, dolls or stuffed animals or used role play (such as letting child pretend to be a doctor or nurse while mother pretends to be the patient).

__24. Change clothes or pajamas.

__25. Settle for sleep or nap.

APPENDIX E

__26. Comb/brush hair.

__27. Help nurse give medication (would include getting child to cooperate).

__28. Talk with child about why he/she is in the hospital (would include talking about his/her illness or injury).

__29. Ask a nurse or doctor to describe a certain test or procedure so that you could tell your child about it.

__30. Let child know what to expect about a treatment or test (such as an x-ray, needle, IV).

__31. Talk with child about why he/she needs a test or treatment (such as x-ray, needle, IV).

__32. Ask a nurse or physician about how your child was during the time you were not with him/her.

__33. Suggest to a nurse or doctor a different way or time of doing something that you think would be better for your child.

__34. Take child for a walk, if allowed.

__35. Ask the nurse or doctor to explain something that you do not understand.

__36. Talk with another parent or person (besides a nurse or doctor) to gain more information about some part of the hospital experience or your child's illness or injury.

Are there any other activities that you wanted to perform for your child that are not on this list?

______Yes ______No

If yes, what are they?

Thank you for answering this questionnaire!

APPENDIX F
Study Flyer

McMaster University

**Faculty of Health Sciences**
**School of Nursing**

1200 Main Street West
Hamilton, Ontario, Canada
L8N 3Z5

Phone 905.525.9140
Fax 905.524.5228
http://www.fhs.mcmaster.ca/nursing

# To: Parents of children admitted to units 3B and 3C

You are being invited to participate in a research study because your child has been admitted to McMaster Children's Hospital.

## Why is this study being done?

The purpose of this study is to learn more about how parents participate in their hospitalized child's care. The study results may help us to improve the way we provide care to children and families.

## What will I be asked to do?

If you volunteer to participate in the study, you will be given a set of questionnaires to complete. It will take you about 15-20 minutes to fill out these questionnaires, which will ask you about how you participated in your child's care in the hospital. Information will also be collected from your child's chart.

## When will the study take place?

The study is currently underway on units 3B and 3C.

## For more information, please contact:

Daria Romaniuk, RN, MN
PhD Student, McMaster University
416-979-5000 ex. 6310
romaniuk@ryerson.ca

School of Nursing

## APPENDIX G

McMaster University

Faculty of Health Sciences
School of Nursing

1200 Main Street West
Hamilton, Ontario, Canada
L8N 3Z5

Phone 905.525.9140
Fax 905.524.5228
http://www.fhs.mcmaster.ca/nursing

## PARTICIPANT INFORMATION SHEET AND CONSENT FORM

## Congruency Between Parents' Actual and Desired Participation in the Care of their Hospitalized Child

My name is Daria Romaniuk. I am a Registered Nurse, an Assistant Professor in the School of Nursing at Ryerson University and a student in the Nursing PhD Program at McMaster University, Hamilton, Ontario. As part of this program I am doing a research study. My research supervisor is Dr. Linda O'Mara. The other members of my study committee are Dr. Janet Pinelli, Dr. Dauna Crooks and Dr. Mabel Hunsberger. If you have any questions or concerns about this research study, please feel free to contact me, Ms. Daria Romaniuk (416-979-5000 ex.6310). You may also contact Dr. Janet Pinelli (905-525-9140 ex.22253) or the Ryerson University Research Ethics Board. c/o Office of the Vice President, Research and Innovation, Ryerson University, 350 Victoria Street, Suite YDI 1100, Toronto, Ontario, M5B 2K3,(416)979-5042.

### Purpose of the study

Parents help to care for their hospitalized children in many ways. In some cases parents give more or less care to their child than they want to. The purpose of this study is to compare parents' actual participation in the care of their hospitalized child with their desired participation in this care.

### Procedures

You are being invited to participate in this research study. If you volunteer to take part, you will be asked to fill out three questionnaires while your child is in hospital. It will take you about 15-20 minutes to finish these questionnaires. In addition, the researcher will read your child's chart to collect information about your child's admission to hospital and diagnosis. If you like, a summary of the results will be mailed to you when the study is finished.

### Potential Risks and Discomforts

There are no identified risks with participating in this study.

### Potential Benefits to Participants and/or to Society

You may not benefit directly from taking part in this study. However, some parents find that answering questionnaires helps them to think about their experience and learn from it. As well, the results of this study may help to change and improve nursing care of children in the hospital and their families.

### Payment for Participation

You will not receive payment for participating in this study.

## APPENDIX G

**Confidentiality**

All of the questionnaires you complete will be labeled with a code only. No personal information, such as name, address, phone number or OHIP number will be recorded. The finished questionnaires will be read only by the researcher and maybe her committee members. All questionnaires and signed consent forms will be kept in a locked cabinet.

**Participation and Withdrawal**

Whether or not you participate in this study is up to you, and your choice will not affect the quality of care you and your child receive. If you volunteer to be in this study, you may withdraw at any time. You have the option of removing your data from the study. You may also refuse to answer any questions you don't want to answer and still remain in the study.

**Rights of Research Participants**

This study has received ethical approval from the Research Ethics Board of the Hamilton Health Sciences/McMaster University, Faculty of Health Sciences and the Ryerson University Research Ethics Board.

If you have any questions regarding your rights as a research participant, you may contact the Office of the Chair of the Hamilton Health Sciences/Faculty of Health Sciences Research Ethics Board at 905-521-2100, ext. 42013.

### CONSENT STATEMENT

SIGNATURE OF RESEARCH PARTICIPANT

I have read the preceding information thoroughly. I have had the opportunity to ask questions, and all of my questions have been answered to my satisfaction. I agree to participate in this study. I understand that I will receive a signed copy of this form.

Name of Participant (please print)

Signature of Participant Date

**Consent form administered and explained in person by:**

Name and Title

Signature Date

APPENDIX G

**Signature of Principal Investigator**

________________________________________
Name and Title

___________________________________ ________________
Signature Date

APPENDIX H

# Request Form for Report of Study

I would like to receive a summary of the research report.

Please send a copy to:

Name________________________________________

Mailing address__________________________________

________________________________________

________________________________________

________________________________________

APPENDIX I

## General Instructions for Completing Questionnaires

Thank you for volunteering to participate in this study. This packet contains three questionnaires:

1. (printed on pink paper) - asks about you, your family and your child.
2. (printed on blue paper) – asks you to think about which care activities you would like to do today.
3. (printed on yellow paper) – asks you to think about the care activities you performed today.

Please fill out these questionnaires to the best of your ability. Once you are finished, please put them back in the envelope, seal the envelope and return it to the nurses' station.

**THANK YOU!**

APPENDIX J

## Demographic data: participants' children

| Code # | Admit date | Questionnaire date | Length of Stay (at time of questionnaire) | Diagnosis | Data | |
|---|---|---|---|---|---|---|
| | | | | | Illness | Admission |
| | | | | | 1 Chronic<br>2 Acute | 1 Planned<br>2 Emergency |
| | | | | | 1 Chronic<br>2 Acute | 1 Planned<br>2 Emergency |
| | | | | | 1 Chronic<br>2 Acute | 1 Planned<br>2 Emergency |
| | | | | | 1 Chronic<br>2 Acute | 1 Planned<br>2 Emergency |
| | | | | | 1 Chronic<br>2 Acute | 1 Planned<br>2 Emergency |
| | | | | | 1 Chronic<br>2 Acute | 1 Planned<br>2 Emergency |
| | | | | | 1 Chronic<br>2 Acute | 1 Planned<br>2 Emergency |
| | | | | | 1 Chronic<br>2 Acute | 1 Planned<br>2 Emergency |
| | | | | | 1 Chronic<br>2 Acute | 1 Planned<br>2 Emergency |
| | | | | | 1 Chronic<br>2 Acute | 1 Planned<br>2 Emergency |

### Definition of categories:

Chronic illness – child's current diagnosis is related to an ongoing health problem
Acute illness – child's current diagnosis has not been preceded by a related, ongoing health problem
Planned admission – reason for admission was anticipated and child's admission date was set in advance
Emergency admission – child's current health problem was not anticipated

# APPENDIX K

Comparison of Item Frequencies Both Scales (N = 191)
*(In descending order of frequency on both Actual & Desired Scales)*

| Item | Actual & Desired | | Actual Only | | Neither Scale | |
|---|---|---|---|---|---|---|
| | f | % | f | % | f | % |
| Spent quiet time interacting with child | 171 | 89.5 | 5 | 2.6 | 3 | 1.6 |
| Comforted child when upset (does not include comforting during a painful procedure) | 167 | 87.4 | 5 | 2.6 | 5 | 2.6 |
| Stroked child/rubbed back | 164 | 85.9 | 9 | 4.7 | 13 | 6.8 |
| Settled for sleep or nap | 163 | 85.3 | 4 | 2.1 | 12 | 6.3 |
| Helped with elimination | 163 | 85.3 | 9 | 4.7 | 6 | 3.1 |
| Told nurse about something your child needed | 160 | 83.8 | 8 | 4.2 | 8 | 4.2 |
| Fed child or set up his/her food tray | 159 | 83.2 | 7 | 3.7 | 15 | 7.9 |
| Changed clothes or pajamas | 155 | 81.2 | 8 | 4.2 | 7 | 3.7 |
| Held or rocked child | 146 | 76.4 | 4 | 2.1 | 17 | 8.9 |

## APPENDIX K

Comparison of Item Frequencies Both Scales (N = 191)
*(In descending order of frequency on both Actual & Desired Scales)*

| Item | Actual & Desired | | Actual Only | | Neither Scale | |
|---|---|---|---|---|---|---|
| | f | % | f | % | f | % |
| Asked physician for information about child's condition | 138 | 72.3 | 5 | 2.6 | 13 | 6.8 |
| Asked nurse for information about child's care | 133 | 69.6 | 7 | 3.7 | 20 | 10.5 |
| Asked nurse for information about child's condition | 132 | 69.1 | 13 | 6.8 | 20 | 10.5 |
| Comforted child during a painful procedure | 129 | 67.5 | 4 | 2.1 | 17 | 8.9 |
| Kept track of how much child ate or drank and told nurse or recorded the amount on an intake and output sheet | 120 | 62.8 | 18 | 9.4 | 31 | 16.2 |
| Encouraged fluids | 118 | 61.8 | 6 | 3.1 | 39 | 20.4 |
| Kept track of how much or how often child urinated and told nurse or recorded it on an intake and output sheet | 116 | 60.7 | 22 | 11.5 | 31 | 16.2 |
| Bathed child/sponged with a washcloth | 115 | 60.2 | 4 | 2.1 | 31 | 16.2 |
| Helped nurse give medication (would include getting child to cooperate) | 114 | 59.7 | 7 | 3.7 | 40 | 20.9 |

## APPENDIX K

Comparison of Item Frequencies Both Scales (N = 191)
*(In descending order of frequency on both Actual & Desired Scales)*

| Item | Actual & Desired | | Actual Only | | Neither Scale | |
|---|---|---|---|---|---|---|
| | f | % | f | % | f | % |
| Actively played with child in room (games, blocks, etc) | 106 | 55.5 | 9 | 4.7 | 49 | 25.7 |
| Asked the nurse or doctor to explain something that you did not understand | 106 | 55.5 | 8 | 4.2 | 27 | 14.1 |
| Took child for a walk, if allowed. | 106 | 55.5 | 5 | 2.6 | 22 | 11.5 |
| Kept track of when child had a bowel movement and told nurse or recorded it on an intake and output sheet | 105 | 55.0 | 22 | 11.5 | 26 | 13.6 |
| Made a decision regarding your child's care | 104 | 54.5 | 4 | 2.1 | 32 | 16.8 |
| Combed/brushed hair | 87 | 45.5 | 2 | 1.0 | 66 | 34.6 |
| Told physician about something your child needed | 79 | 41.4 | 10 | 5.2 | 42 | 22 |
| Talked with child about why he/she is in the hospital | 79 | 41.4 | 7 | 3.7 | 78 | 40.8 |
| Brushed teeth/performed mouth care | 79 | 41.4 | 4 | 2.1 | 60 | 31.4 |

# APPENDIX K

Comparison of Item Frequencies Both Scales (N = 191)

*(In descending order of frequency on both Actual & Desired Scales)*

| Item | Actual & Desired | | Actual Only | | Neither Scale | |
|---|---|---|---|---|---|---|
| | f | % | f | % | f | % |
| Talked with child about why he/she needs a test or treatment | 77 | 40.3 | 4 | 2.1 | 83 | 43.5 |
| Took child to playroom if allowed | 76 | 39.8 | 6 | 3.1 | 41 | 21.5 |
| Told nurse about child's daily routines or his/her likes or dislikes without being asked to do so | 72 | 37.7 | 8 | 4.2 | 54 | 28.3 |
| Let child know what to expect about a treatment or test | 70 | 36.6 | 7 | 3.7 | 87 | 45.5 |
| Suggested to a nurse or doctor a different way or time of doing something that you thought would be better for your child | 70 | 36.6 | 8 | 4.2 | 61 | 31.9 |
| Asked a nurse or physician about how your child was during the time you were not with him/her | 68 | 35.6 | 8 | 4.2 | 64 | 33.5 |
| Asked a nurse or doctor to describe a certain test or procedure so that you could tell your child about it | 58 | 30.4 | 6 | 3.1 | 81 | 42.4 |

## APPENDIX K

Comparison of Item Frequencies Both Scales (N = 191)
*(In descending order of frequency on both Actual & Desired Scales)*

| Item | Actual & Desired | | Actual Only | | Neither Scale | |
|---|---|---|---|---|---|---|
| | f | % | f | % | f | % |
| Talked with another parent or person (besides a nurse or doctor) to gain more information about some part of the hospital experience or your child's illness or injury | 49 | 25.7 | 8 | 4.2 | 87 | 45.5 |
| Played with child for the purpose of getting him/her to talk about or show feelings by use of puppets, dolls or stuffed animals or used role play. | 29 | 15.2 | 6 | 3.1 | 126 | 66.0 |

## APPENDIX L

### Content Analysis of Parents' Written Comments

*(Shaded statements indicate that, within the category, the same participant listed the activity as both actual and desired)*

| **Category** | **Sub-category** | **Activity** | |
|---|---|---|---|
| | | **Actual** | **Desired** |
| Participation in Physical Care Activities | ADL | • Wash hair (2)<br>• Bring in food (2)<br>• Provide blankets, towels<br>• Clean up after child vomited (2)<br>• Made bed/changed sheets (5)<br>• Feed ice chips | |
| | Complex ADL | • Set up feeding pump<br>• Administer feeding via pump<br>• Make formula<br>• Feed infant with syringe<br>• Prepare Epsom salts bath | |

# APPENDIX L

| Category | Sub-category | Activity | |
|---|---|---|---|
| | | **Actual** | **Desired** |
| | Technical Care | • Gastrointestinal tube (G-Tube) site care (2)<br>• Tracheotomy (trach) care<br>• Give non-intravenous (non-IV) meds<br>• Disconnect nasogastric tube (so child could walk)<br>• Suctioning (unspecified)<br>• Disconnect equipment (unspecified)<br>• Re-connect electroencephalograph wire<br>• Assist nurse with dressing change to burn<br>• Apply Polysporin to chin every 4 hours<br>• Accompany child to physiotherapy (2) | • G-Tube site care<br>• Trach care<br>• Give non-IV meds<br>• Troubleshoot IV issues (e.g. occlusion) (2)<br>• Central venous line dressing change<br>• Participate in physiotherapy treatment |
| Psychosocial Care of Child | Support child | • Develop/implement reward program for child | • Develop/implement reward program for child |

APPENDIX L

| **Category** | **Sub-category** | **Activity** | |
|---|---|---|---|
| | | **Actual** | **Desired** |
| | | • Teach child about treatment plan/.milestones<br>• "…loving and keeping my child happy"<br>• Explain other children's illnesses<br>• Help child with homework | • Accompany child to operating room for induction |
| | Entertain Child | • Take child for a walk (2+1)*<br>• Take child to ride bike in playground<br>• Sing to child<br>• Read to child<br>• Water play (in basin) with child<br>• Watch movies with child<br>• Paint with child | • Take child for a walk (2+1) |
| | Maintain child's connections | • Help child talk to family and friends on phone (2)<br>• Bring family to visit | • Help child talk to family and friends on phone (3) |
| Meeting Parental Needs | Need for assistance | • Called nurse when needed to leave child (waited a long time for nurse to come) | • Encouragement from RN to reluctant child re: oral hygiene<br>• Assistance with clothing change complicated by tubes<br>• To be able to rest comfortably in bed |

APPENDIX L

| Category | Sub-category | Activity | |
|---|---|---|---|
| | | Actual | Desired |
| | | | beside child (not possible with crib, difficult with pull-out chair)<br>• Need for overall assistance (2) (one of the parents noting this was physically disabled)<br>• Room for both parents to stay overnight<br>• Assistance with showering child |
| | Need for information | • "Instructed on equipment by technician"<br>• "Found out if kitchen facilities brought water"<br>• "Learned to use bed" | • Needed more information re: isolation procedures |
| | Need for security | • Stayed with child for long hours during day and overnight to ensure child received necessary care and to provide support | • Need to be assured that necessary care will be provided and child will receive emotional support in parents' absence.<br>• Need to feel comfortable to leave child alone while sleeping |
| | Need for control | • Coordination of treatment plan for child with rare disorder | • Coordination of treatment plan for child with rare disorder |

APPENDIX L

| Category | Sub-category | Activity | |
|---|---|---|---|
| | | Actual | Desired |
| | | | - "More ability for timing of certain checks/procedures so as not to interrupt child's schedule" |

*2+1 indicates that 2 participants reported this activity as both desired and actual, one reported it as desired only and one reported it as actual only

Shaded Areas indicate that item in the sub-category was reported as both Actual and Desired by the same individual.