FACTORS INFLUENCING HEALTH CARE PROFESSIONALS’ DECISION-MAKING REGARDING PARENTAL PRESENCE DURING INVASIVE PROCEDURES IN THE PICU

by

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A THESIS SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF MASTER OF SCIENCE IN NURSING in FACULTY OF GRADUATE STUDIES THE SCHOOL OF NURSING

We accept this thesis as conforming to the required standard

THE UNIVERSITY OF BRITISH COLUMBIA

April 1998

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Abstract
Children admitted to pediatric intensive care units (PICUs) experience invasive and painful procedures as health care professionals intervene to assess, monitor and manage critical health problems. Most of these procedures elicit fear, anxiety and/or pain on the part of children, producing significant effects on them, their parents and health care professionals. Involving parents in the performance of procedures is a practice that has been researched in other care settings; research knowledge regarding the use of such a practice in the PICU is sparse. The purpose of this study was to identify factors influencing health care professionals’ decision-making regarding parental presence during invasive procedures on a child in the PICU. Guided by the qualitative method of interpretive description, data was collected from fifteen PICU nurses and physicians interviewed regarding their decision-making. Data analysis was validated, clarified or revised by the study participants to reveal three possible decisions mediated by one of two goals identified by the health care professional for the procedure; in turn the goal and the decisions were influenced by many other mediating and contextual factors identified by participants. These findings contributed to the development of a schematic representation of decision-making that reflects the complexity of decision-making currently and could be used as a structure to further discuss the issue of parental presence during invasive procedures in the PICU. Participants identified that discussion regarding the decisions made and the factors that influenced them is important and that it currently does not occur. Participants identified some influences on their decision-making that are unique from those identified in literature regarding other care settings. Highlights from the findings include: the child’s voice is rarely represented; health care professionals frequently circumvent parental involvement in decisions regarding invasive procedures on their child in the PICU in ways perceived as protection, or alternatively as control; and other family-centered care principles, such as forming collaborative partnerships, are not reflected currently in decision-making regarding parental presence during invasive procedures in the PICU. Implications for health care practice, education and research arising from the findings are identified.
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Acknowledgments

To the fifteen participants:
Thank you for your time, your stories, your feelings. You truly challenged my current thinking and inspired my future practice.

To my three committee members:
Thank you Barbara Paterson for your amazing insight and dedication. Your contribution to my development through this process reaches much further than this writing. Thank you, Sally Thorne, for your critical thinking abilities, support and enthusiasm that you shared so readily. Thank you, Katharyn May, for your thoughtfulness and availability.

To my colleagues:
Thank you Susan Calvert, Maryanne McCallum, Bev Pister and Susan Wynne, my wonderful study group. Thank you, Gwen Remple and Bev Pister for contributing, editing, and inspiring. Thank you, Tony David for the collaborative practice of parental presence during an invasive procedure. Thank you, members of Partners in Care Committee for continuously teaching me what family-centered care really looks like.

To my friends:
Thank you Karen Ryall, Mary Spencer, Lori Shortridge, Andrew Macnab and other teammates for your encouragement and Tracie Northway for your unwavering optimism. Thank you Carrie Almas and Dorothy Hamilton for never asking me if I was still working on this. Thank you Donna Atkinson and Gay Langlois for keeping me 2/3 sane.

To my family:
Thank you to the Jeffersons and the McCarthys for support that goes deeper than words. Thank you Louis Jefferson for having faith that I could complete this - no matter what. Thank you Alexa and Angela Jefferson for the continuous reality checks and laughter. May you fulfill your dreams too.

This project is dedicated to the memory of my father, Alexander James McCarthy. I'll never forget, "He said you could do anything you want." Thank you.
CHAPTER ONE: INTRODUCTION

Children admitted to pediatric intensive care units (PICUs) inevitably experience invasive and painful procedures as health care professionals intervene to assess, continuously monitor and manage critical health problems. In fact, while advancements in knowledge and technology lead to improved physiologic outcomes for critically ill children, there is a concomitant increase in the number and type of invasive procedures performed on children in PICUs (Curley & Meyer, 1996). Most of these procedures elicit fear, anxiety and/or pain on the part of children, producing significant effects on them, and in turn, on their parents and the health care professionals involved (Kutner, 1996). In fact, school-aged children have classified invasive procedures as the worst part of hospitalization; and increased experience increased the strength of their fears of these procedures (Bossert, 1994). In order to help children cope with procedures and hospitalization as effectively as possible, research-based evidence is necessary. Such evidence has the potential to benefit children, parents, and health care professionals involved in care of hospitalized children.

Involving parents in the performance of procedures is one practice change that has been incorporated in other care settings, e.g., pediatric oncology and ambulatory areas (Gonzalez, Routh & Armstrong, 1993; Jones, 1994; Romaniuk & Kristjanson, 1995). Although there is literature which recommends increased visitation for parents in the setting of pediatric critical care (Etzler, 1984; Kasper & Nyamathi, 1988; Tughan, 1992), research knowledge regarding the presence of parents during procedures performed in the PICU is necessary.

**Background to the Problem**

The substantive knowledge related to health care for children has changed and progressed enormously in the last fifty years; it is not surprising that there has been a concomitant change in the delivery of health care. At one time, physicians and nurses assumed the responsibility for both knowledge and delivery of care upon the child's arrival to the hospital. These health care professionals discouraged
visiting, only directing families when to come and pick up their child upon discharge (Brown & Ritchie, 1990; Sainsbury, Gray, Cleary, Davies & Rowlandson, 1986). The goal of this type of care, also termed "the medical model of health care," was the achievement of a stable anatomical and physiological state for the child in ways decided by physicians and nurses (Cronenwett & Brickman, 1983; Darling, 1983).

Increasingly since the 1970s, changes to the delivery of health care for hospitalized children are being made by progressive families and health care professionals. Now, psychosocial, ethical and developmental issues in the care of hospitalized children are commonly addressed in the literature and in the mission statements of children's hospitals (Curley & Meyer, 1996; Jackson & Saunders, 1993; Wong, 1997). Much of this concerns a new philosophy of care for children in hospitals, namely, family-centered care (Johnson, Jeppson & Redburn, 1992).

The philosophy of family-centered care has been developed and adopted as the standard in many children's hospitals in the last twenty years (Johnson, Jeppson & Redburn, 1992). According to Edelman (1991), it is practically, morally and legally the best way to provide care to children and their families. Certainly, as a parent and nurse experienced in the care of children, this philosophy 'feels more right' for me, both personally and professionally, as compared to the medical model. One's health and health practices are personal and value-laden; thus, health care professionals who "do with" rather than "do for" seem more in synchrony with this view of health and health practices. Other health care givers and recipients have reported this also (Ayer, 1978; Kleinman, Eisenberg & Good, 1978; Rennick, 1986; Robinson & Thorne, 1984; Romaniuk & Kristjanson, 1996).

As well as employing the term "family-centered care," the founders of the Association for the Care of Children's Health (ACCH) provide materials to assist health care professionals with the implementation of family-centered care (Johnson, Jeppson, & Redburn, 1992). Despite this, the care of children in institutions which espouse a family-centered philosophy varies considerably between hospitals, units, and health care professionals. With respect to procedures performed in the PICU, one of the variable aspects is
whether or not parents are given the option of being present during a procedure on their child. The practice of family-centered care by health care professionals includes establishing a collaborative partnership with parents that considers the family's individual needs and abilities (Johnson, Jeppson & Redburn). It seems logical that offering choices regarding involvement in all aspects of care is part of this collaborative partnership. Moreover, a few proponents of family-centered care and experts in pediatric critical care alike recommend offering choices and encouragement to parents regarding presence during procedures in the PICU (Curley & Meyer, 1996; Johnson, Jeppson & Redburn; Kuttner, 1993; McGrath, 1996).

Despite the wide acceptance of the principles of family-centered care, health care professionals often do not give parents a choice of remaining with their child during a procedure (Arango, 1990; Bauchner, 1991; Brown & Ritchie, 1990). Presence during procedures was one of the priorities identified as a need for research following a consumer survey of a sample of parents of children in the PICU at British Columbia's Children's Hospital (BCCH, 1995). As well, presence during procedures was identified as one of the key goals for the year by the hospital's parent advisory members of the Partners in Care Committee (PICC meeting, BCCH, September, 1996). Thus, changes in practice with respect to parental presence during procedures are desired at both the hospital and unit levels.

**Purpose of the Study**

In order to be involved in the implementation of possible practice changes with respect to parents' presence during procedures in the PICU, I wanted to know more about the issues entailed. Upon looking to the literature, I found no definitive research to indicate if, when, and how it is appropriate to involve parents in procedures in the PICU. It is evident from related research that some children and parents want to be given a choice of parents remaining for procedures (Bauchner, 1991; Berman, 1991; Tughan, 1992). It is also evident that current experts advocate choices for parents' participation (Curley & Meyer, 1996; Kuttner, 1996; McGrath, 1996), and that offering choices is predominantly at the discretion of the health care professionals involved (Hunsberger, Love & Byrne, 1984; Barnsteiner, Gillis-Donovan, Knox-Fischer...
Parents have indicated that often the decision regarding their presence during procedures is made by health care professionals (Bauchner, 1991; BCCH, 1995). Health care professionals are influenced by factors related to their knowledge, experience and personal variability when making clinical decisions (Hamers, Abu-Saad & Halfens, 1994); however, the factors influencing health care professionals' decision-making pertaining to parental presence during procedures in a PICU have been largely unexamined. The purpose of this study was to identify factors which influence a health care professional's decision regarding parental presence when a child is undergoing invasive procedures in a PICU.

**Research Question**

The question addressed in this research was: What factors influence health care professionals' decisions regarding parental presence during an invasive procedure on a child in a PICU?

**Definition of Terms**

Health Care Professional - Generally this term refers to any person in a position in the health care field who has a specific knowledge regarding caring for children's health, including social workers, child life specialists, respiratory therapists, etc. For the purpose of this study, a health care professional referred to a physician or a nurse as these are the two groups most often involved in procedures in the PICU.

Invasive Procedures - In this study, invasive procedures referred to those procedures which infringe on or break into tissues and/or elicit pain, e.g., chest tube insertion or removal, endotracheal intubation or extubation, suctioning, intravenous insertion or removal, urethral catheter insertion, cardiopulmonary resuscitation, etc. Non-invasive procedures in this study were termed as "caregiving." Caregiving referred to care including non-invasive, usually non-painful procedures frequently done in a PICU, e.g., assessments, bathing, examinations, turning and positioning, checking line sites and changing tubings, stripping chest tubes, applying cardiac electrodes, specimen sampling from indwelling lines, etc.
Assumptions

I began this research with values, beliefs and assumptions that affect how I viewed and studied this topic. As is possible, I need to be aware of these and explicate them for the readers (Dreher, 1994). In general, I believe in the philosophy of family-centered care; in particular, I believe that anything affecting the child has significant health effects on the parents and vice versa. I assumed that there are optimum conditions for the performance of procedures in the PICU, that achieving these conditions has the least negative effects possible on the child, and that parents want these optimum conditions to exist for their children. I assumed that pursuing optimum conditions for the performance of invasive procedures can and should be done by health care professionals in collaboration with parents. I assumed that health care professionals can reflect on the factors which influence their practice, and that they can share this information honestly and effectively.

Philosophical Perspective

From a philosophical perspective, I believe there is much knowledge which can be uncovered regarding the factors that health care professionals consider and apply when deciding what to do about the presence of parents during invasive procedures. From a research perspective, I do not believe that one truth or theory considering all possible factors could be uncovered. The subject of parental presence during procedures is a contextual one that, in my experience, reveals varied, and frequently emotional, responses from many children, parents and health care professionals.

To incorporate my philosophical perspectives regarding research and parental presence during invasive procedures as described above, I used a qualitative method of research. Morse and Field (1995) point out that "the qualitative researcher's emphasis is on the construction of the theory, and the quantitative researcher's emphasis is on the testing of the theory" (p. 2); moreover, qualitative research seeks to describe a relatively untouched event, from the viewpoint of those involved, and in the naturalistic setting (Morse & Field). In this study, I sought first to describe the factors regarding parental presence...
during invasive procedures as perceived by the nurses and physicians making the decisions about these procedures in the PICU setting; I then sought to interpret the themes that emerge from these descriptions. A methodological approach from the qualitative perspective which especially suits this study is interpretive description (Thorne, Kirkham & MacDonald-Emes, 1997). As appropriate for this method, a framework is needed which "...orients the inquiry, provides a rationale for its anticipated boundaries, and makes explicit the theoretical assumptions, biases, and preconceptions that will drive the design decisions" (Thorne, Kirkham & MacDonald-Emes, p. 173). The framework used to later organize results may be different due to the data emerging from the study; this avoids an urge to fit the data to the predetermined framework. Using the approach of interpretive description, the framework is derived from analysis of the range of existing knowledge on the subject (Thorne, Kirkham & MacDonald-Emes).

Upon reviewing the range of literature available on the topic of parental presence during invasive procedures in the PICU, it became evident that health care professionals working in PICUs have access to sound knowledge regarding the philosophy of and rationale for family-centered care, the experiences of parents whose children have been in PICUs, the effects of parental involvement in caregiving to hospitalized children, the effects of parental presence during invasive procedures on children in care settings other than the PICU, and the effects of family members' presence during resuscitation procedures on adults or children. These five areas were used as an analytical framework not only to review the literature but also to inform the data collection process in order to reveal factors which health care professionals consider when making decisions regarding parental presence during procedures in the PICU.

**Significance of Study**

Children may have long term deleterious effects from situations like being separated from parents (Bowlby, 1960), experiencing pain which is mismanaged (Grunau, Whitfield & Petrie, 1994) and experiencing unrecognized fears following invasive procedures (Kuttner, 1996). Results from this study contribute to knowledge regarding these situations because factors that influence health care professionals'
decisions in these situations are identified. With respect to the factors influencing health care professionals, it has been found in previous studies that extensive philosophical changes to health care practice are made sometimes without adequate preparation of staff (Barnsteiner, Gillis-Donovan, Knox-Fischer & McKlindon, 1994). This results in mixed messages being sent to both health care recipients and providers.

To further illuminate the significance of this study, I would like to share two stories - one from a PICU nurse and one from a PICU mother (used with permission). I casually mentioned to a PICU nurse in the library that among other articles, I was interested in searching for literature on parental presence during procedures on children in the PICU. She replied with conviction, "It's not a good idea to have parents there." I asked why she thought that. She shared this story:

There was a Mom who wanted to stay while we resuscitated her child who had just come from the operating room a few hours earlier. So we [the physician and nurse] said "OK", and Mom was standing at the foot of the bed. She didn't speak English; she started to scream and cry and we couldn't hear a thing. [Doctor] was telling me what he needed me to give next and I couldn't hear him. We asked her to stop screaming and she couldn't. It was awful. So we had to ask the support person who was with her to take her out to the waiting room. It was the only way we could carry on resuscitating [child].

When I questioned her about the child's outcome, she replied that the child had not been revived.

The second incident involves a parent who, upon hearing that I worked in the ICU, asked me why she was allowed to stay for a procedure on some occasions but not on others. When questioned regarding the circumstances, this was her story:

My son uses non-verbal communication and so I am one of the few people who knows how to prepare him for, and calm him during, procedures. He's had a central line put in his arm before, on the pediatric unit. I was there, talked him through it, and he stayed relaxed and they had no trouble putting it in. Then I guess it came out while I wasn't here and I didn't even know they were putting another one in. His arms go into spasm and contract right up when he's upset. So they couldn't get it in. They had to ask for the line to be placed in ICU under sedation. I arrived then and asked to come in, explaining to the people in ICU that I had been there before when it was put in. The response was "If you're there, I'm not." That time I couldn't be there. I guess he got his sedation instead and they put it in. He slept for quite awhile after. I don't want to go through that again.

Both the staff nurse and the mother involved in these stories seemed to need explanations and help to understand what factors ought to be considered when determining whether a parent is present during an
invasive procedure on a child. Can health care professionals feel assured of the outcome of resuscitation if they feel that parents' presence is negatively affecting the efficiency of that resuscitation? Can a mother feel assured that her absence did not contribute to an extra procedure, extra medications and an unknown experience of fear in her child? These questions face most parents and health care professionals involved in caring for children. I believe that the results of this study assist health care professionals and families faced with these questions regarding parental presence during invasive procedures in the PICU; consequently, children undergoing invasive procedures benefit.

**Summary**

This chapter was an introduction to the study, including its purpose and the background which prompted its inception. The philosophical perspective of the study was introduced, an analytical framework was proposed and necessary definitions, assumptions and beliefs were identified. The significance of the potential results from this study was articulated.

Chapter Two contains a review of the literature, organized according to the analytical framework proposed in this chapter. This framework is discussed further also; a schematic representation of decision-making as it is currently perceived is offered. Chapter Three outlines relevant information with respect to the research design, comprising the method, the setting, the sampling, the population, the ethical considerations, the limitations and the significance of the study. Chapter Four describes the participants, their decisions regarding parental presence during invasive procedures in the PICU, and the factors that influenced those decisions. Chapter Five discusses highlights from the research findings, comparing these highlights to findings from the literature that was reviewed. Chapter Six presents the summary of this research study and the implications of the research findings for health care practice, education and research.
CHAPTER TWO: LITERATURE REVIEW

Very little was found in the literature regarding the involvement, or even the presence, of parents when procedures are performed on their child in the pediatric intensive care unit (PICU). Many experienced professionals recommend that a philosophy of family-centered care be practised in the PICU (Lewandowski, 1992; Curley & Meyer, 1996) and currently, major hospitals caring for children in Canada have adopted a family-centered care focus in their mission statements. These hospitals include British Columbia’s Children’s Hospital, Hospital for Sick Children in Ontario, Montreal Children’s Hospital in Quebec, and Isaac Walton Killam Hospital in Nova Scotia. Research from some of these hospitals, however, reveals that there are problems with the practice of family-centered care from the parents’ perspectives, such as the lack of choice given to parents regarding presence during procedures (BCCH ICU Survey, 1995; Brown & Ritchie, 1990; Tughan, 1992; Young, 1992). This leads me to wonder whether the mission of family-centered care practice includes parental presence during invasive procedures in the PICU.

In an attempt to illuminate the practice of parental presence during procedures, the literature examined in this review was selected primarily from the disciplines of nursing and medicine, and to a lesser extent, dentistry and psychology. The search strategy screened literature that focused on parent participation, family-centered care, the hospitalized child, and/or professional and family relationships; where possible this literature was limited to practice in the PICU. The literature reviewed was not limited to formal research-based reports; clinical anecdotes and informal interpretations based on practice have also been reviewed. As endorsed by Thorne, Kirkham, and MacDonald-Emes (1997), the use of clinically based anecdotal literature is appropriate for research which is primarily qualitative in nature, and focused on humanistic and holistic topics. In cases where literature was research-based, its significance and legitimacy has been analyzed.

To present this review of the literature related to parental presence during procedures, this chapter
is organized into the five sections identified in Chapter One: 1) family-centered care theory, 2) the parental experience in the PICU, 3) parental involvement in caregiving during hospitalization, 4) parental presence during invasive procedures, and 5) family member presence during resuscitation. This chapter ends with a summary of the literature review, a description of the study's analytical framework that incorporates topics from these five sections and a schematic representation of health care professionals' decision-making as perceived currently.

**Literature Review**

**The Shift from Traditional Health Care to Family-Centered Care**

Although the philosophy of family-centered care does not specifically address the question of parental presence during procedures in the PICU, the philosophy can provide a context in which to discuss parental presence during procedures. The adoption of family-centered care, especially in care of the hospitalized child, has been advocated in the literature since the 1980s (Arango, 1990; Johnson, Jeppson & Redburn, 1992). To ground the discussion in the following sections, this section shall include why the shift to family-centered care was advocated and a review of the key elements of family-centered care. These key elements provide the link between family-centered care and parental presence during procedures.

Classic studies in the 1940s and 1950s revealed that a child's hospitalization without parents' presence has disastrous effects on the young child (Bowlby, 1960; Robertson, 1958; Spitz, 1945). In 1945, a psycho-analyst, Rene Spitz used the term "hospitalism" to describe the problematic behaviour of children who grew up in institutions without a primary attachment as compared to those who grew up in institutions with attention to primary attachment relationships. In his book, *Attachment and Loss* (1982), John Bowlby, another psycho-analyst, wrote of the results of classic studies which he and his colleague, James Robertson, conducted from the late 1940s throughout the 1960s. These studies also initially focused on the mental health of children growing up without parents and showed that a young child needs a consistent and intimate relationship with a permanent caretaker in order to protect the child's future mental health. While
Robertson and Bowlby looked further into these results, Spitz (1950) identified the "fear of strangers" response in eight-month-old infants. Bowlby and Robertson later differentiated the fear of strangers response from the now familiar response of "separation anxiety" (Bowlby, 1960). Prugh, Staub, Sands, Kirschbaum, and Lenihan (1953) identified responses including crying, withdrawal, activity disturbance, and loss of bowel and bladder control when children aged two to five were hospitalized; moreover, these responses were more frequent in a control group with weekly parental visitation than in an experimental group with daily parental visitation. As the length of hospital stay increased, young children in the experimental group decreased their frantic crying when parents left, perceived by the investigators as a sign that children believed parents would return. Following on this study, Robertson (1958) identified that protest, despair and detachment were three progressive responses shown by a child over six months of age when hospitalized and cared for by strangers in the absence of parents. Bowlby's (1982) analysis of these studies focused on the concepts of attachment, separation and loss in young children. Overall, the results of this seminal research contributed to a practice change with respect to childhood hospitalization. These results ended the notion that parents should be kept away during a child's hospitalization because the child cried more when the parent was present and when the parent left the hospital. A shift was made to allow parents to be present during their child's hospitalization (Berman, 1991; Knight, 1995).

Specific to critical care, increasingly, professionals and families have desired a shift away from the traditional delivery of care which primarily precluded families from the ICU (Harvey, Ninos, Adler, Goodnough-Hanneman, Kaye & Nikas, 1993; Page & Boeing, 1994; Tughan, 1992). According to Curley and Meyer (1996), the reasons for historically keeping families out of the PICU ranged from reducing the infection risk to protecting the families to decreasing crying by the children to maintaining the paternalistic stance of the staff. In a study in 1980, Rothstein, a physician, found that "helplessness on the part of the parents of children in the ICU is to some extent augmented by the fact that they are excluded from taking an active role in the care of their child" (p. 619); on the other hand, he believed little could be done as "for
the child in a coma or the child on a respirator who is heavily sedated or receiving muscle relaxants, communication is not possible" (p. 619). Pediatric critical care knowledge and experience has expanded over the past several decades, however, and beliefs such as the impossibility of communicating with a child in a coma or on a respirator have been dispelled. As well, professionals working in the area have described problems with the traditional forms of health care in the increasingly technologically-oriented ICU with increasingly information-oriented and culturally diverse families (Dungan, Jaquay, Reznik & Sands, 1995; Molter, 1994; Moynihon, Naclerio, & Kiley, 1995; Philichi, 1988; Rennick, 1986; Rushton, 1990a, 1990b). The evidence seems clear that children should rarely be in hospital without a family member present, including in a PICU setting.

It has been suggested, mainly in the last twenty years, that families want to be more involved in the health care and illness experiences of their family members (Hampe, 1975; Kleinman, 1978; Kleinman, Eisenberg & Good, 1978; Miles, 1979; Robinson & Thorne, 1984; Thorne & Robinson, 1988). Researchers focusing on the illness experience as a family or as a cultural phenomenon, rather than an individual experience, found that families with ill adult or child members entering relationships with health care professionals "assumed that initially they would be recognized as integral to illness management and thus, they expected to be informed, consulted, and involved in care" (Robinson & Thorne, p. 599). Furthermore, when these expectations were not met, there were negative impacts on, and responses to, health care (Darbyshire, 1993; Hampe; Kleinman, Eisenberg & Good; Thorne & Robinson).

If families with ill adult members expect to be more involved with their care, it can be reasonably assumed that parents whose children are in hospital will also expect to be involved. In North American society, parenting includes accepting the legal, moral, physical and emotional responsibility for the care of one's children (Johnson, 1990); concomitantly, parenting includes monitoring and maintaining the child's health (Knafl, Cavallari, & Dixon, 1988). In the United Kingdom, Coyne (1995) also found that parents see participation in their child's hospitalization as "an unconditional aspect of being a parent" (p. 73).
Assuming hospitalization in a PICU is among the worst possible scenarios for any parent, the responsibility for their child's care will be felt strongly by many parents with a child in the PICU. The PICU admission may be a time for increased parental involvement because families with hospitalized children are ordinary families under extraordinary stress (Leff & Walizer, 1992). From clinical experience and the narratives of parents and children, Leff, Chan and Walizer (1991) support the formation of partnerships between families and professionals as "parents know their child best" (p. 235).

The founders of the ACCH have attempted to help health care professionals by constructing nine key elements of family-centered care (Johnson, Jeppson & Redburn, 1992). In turn, the members of Partners in Care, a parent advocacy committee at BCCH, have adapted these key elements into the following definition and five guiding principles, published in a brochure (BCCH, 1997):

Family centred care is an approach to children's health care that respects and supports the central role that families play in their child's life and believes in the importance of families as partners on the health care team. Family centred care is marked by: ...respect, ...information sharing, ...collaboration, ...confidence building, ...and family-to-family support (p. 3).

Operating from these principles, several researchers have investigated parent participation and its relationship to family-centered care (Coyne, 1995; Gill, 1987; Hatton, 1995; Jones, 1994; Knafl, Cavallari, and Dixon, 1988; Lau, 1993; Neill, 1996a, 1996b). In one extensive research project investigating parent and nurse perspectives regarding pediatric hospitalization (Knafl, Cavallari, and Dixon), two groups of parents were differentiated according to the level of involvement they desired. Level One parents believed that nurses and physicians should have complete authority and decision-making while Level Two parents expected to be treated as equal decision-makers with physicians and nurses. It would be interesting to know if information like this is used by health care professionals determining parental desires regarding parental presence during procedures; it would also be interesting to know if Level One or Two parents change their desired level of involvement over time. In a qualitative study, Coyne found that parents wanted to be partners in their child's care because of concern for the child's emotional development and that this was influenced by their belief in their responsibility to their child, desire for consistent care of
their child, and previous experiences with the child's hospitalizations.

It appears that encouragement and acceptance of the individual parents' level of participation in the care of their child is integral to forming partnerships and to family-centered care. For example, Gill (1987) described parent participation as a recognized coping method for a family whose child has been hospitalized and later affirmed that in order to achieve family-centered care in hospitals, an increase in parent participation was needed (Gill, 1993). DePompei, Whitford and Beam (1994) wrote about the efforts to further implement family-centered care practices in their institute. One family-centered care priority for their institute's toddler and preschool-age division was developing a protocol to encourage parents to be with and comfort their child during procedures. Ahmann (1994a, 1994b) identified the need for the care of children in hospitals to progress to further implementation of the key elements of family-centered care. She stressed that in order to promote the family's role in the child's life, changes were necessary as "...parents may feel unimportant to the child when medical professionals "take over"" (p. 114). I would suggest that presence during procedures could be one change to help alter that feeling of parental unimportance.

In order to partner with parents completely, it would seem that achieving the family-centered care principles of information sharing and collaboration are necessary. In the achievement of these principles, problems have been experienced. Currently, the principles of information sharing and collaboration are enacted differently in different health care institutions. Although parents and professionals both usually want the same outcomes for ill children, the two groups differ in their interpretations about how to achieve these outcomes and how much families are involved (Brown & Ritchie, 1990; Gill, 1993; Neill, 1996b; Robinson, 1987). Kawik (1996) found that parents in her study wanted to be involved in partnerships but reported coming in contact with nurses who did not relinquish control nor give adequate information to parents. Neill (1996b) found that parents identified paternalistic professional attitudes as problematic. It seems the definition of a partnership differed between parents and health care professionals with respect to
information sharing and collaboration; concomitantly, parent participation and the provision of family-centered care were negatively affected.

It appears that while professionals believe that care in the hospital should be family-centered, their practices are not always consistent with this belief. In addition, Etzler (1984) reviewed literature on parents' care in PICUs and found that none of the interventions suggested in twenty-nine articles between 1953 and 1983 were supported with research. While there is more evidence-based knowledge available today, it appears that the ideals of family-centered care have not been fully realized (Hill, 1996). Overall, the literature reviewed on family-centered care indicates that applying the principles of family-centered care is problematic, especially for health care professionals. This is an indication that more definitive research is needed to describe and understand perspectives on family-centered care.

The Parental Experience in the PICU

While family-centered care was being encouraged as the basis for hospital pediatric practice, parents in the PICU became the focus of much research in the 1970s and 1980s. For the most part, this research attempted to identify parental stressors (Carter, Miles, Buford & Hassanein, 1985; Freiberg, 1972; Heuer, 1993; Jay, 1977; Johnson, Nelson and Brunnquell, 1988; LaMontagne & Pawlak, 1990), describe parental needs (Etzler, 1984; Farrell, 1989; Fisher, 1994; Green, 1979; Hickey & Rykerson, 1992; Kasper & Nyamathi, 1988; Miles, 1979; Philichi, 1988; Rennick, 1986), or discuss parental satisfaction (BCCH, 1995; Tomlinson, Kirschbaum, Tomczyk & Peterson, 1993). As well, Martha Curley, a clinical nurse researcher, implemented an experimental intervention program and measured effects on parental stress in two PICUs (Curley, 1988; Curley & Wallace, 1992).

The Parental Stressor Scale: Pediatric Intensive Care Unit (PSS:PICU) instrument was developed by Miles and Carter (1985) to assess parental perceptions on seven dimensions of stress to which parents are exposed in the ICU. The seven dimensions of stress consisted of sights and sounds, parental role revision, child's behaviour and emotions, child's appearance, staff behaviours, staff communication, and
procedures. Several researchers identified parents' highest stress scores in the dimension of parental role revision (Carter, Miles, Buford & Hassanein, 1985; Freiberg, 1972; Heuer, 1993; Jay, 1977) while the two dimensions of procedures and child's behaviour tended to have the highest number of "not experienced" answers (Carter, Miles, Buford & Hassanein). Perhaps the high stress scores for the dimension of parental role revision were related to the lack of exposure of parents to the child's behaviour and procedures. In fact, Johnson, Nelson and Brunnquell (1988) found that parental role changes were not the highest stressor for the parents in their study but that the child's behavioural and emotional responses were. This finding was possibly influenced by the practices of family-centered care which predominated in this study setting, one of which was unrestricted parental visitation. Perhaps because the parents were encouraged to continue their parental role, they were able to shift their focus to their child's behaviour. This is similar to results from a study by Proctor (1987) who found that mothers whose children were in units with liberal visitation had significantly lower anxiety scores than mothers in units with structured visitation. Family-centered care practices may also have contributed to results found by Heuer (1993) whose study is more recent than some of the others done with the PSS:PICU scale. Looking at the most often identified stressors for parents in PICU, Heuer found that the procedures dimension of the PSS:PICU scale was reported as the second most stressful dimension. Moreover, fathers reported suctioning as significantly more stressful than mothers did; this was explained by the increased exposure which mothers had to this procedure as compared to fathers who were not present as often. Heuer also reported that, in an open ended question on the questionnaire, parents responded that one of two concerns was that "parents were not able to continually stay with their child" (p. 128).

There have been many studies attempting to identify the most significant needs of families whose children are in the ICU (Etzler, 1984; Fisher, 1994; Green, 1979; Kasper & Nyamathi, 1988; Miles, 1979; Philichi, 1988). These studies indicated that the need given the highest rating most often by parents was the need to "be with their child." Another important need identified was to "participate in their child's care.
in any way possible.” The need for frequent and honest feedback was also cited often as vital for parents (Kasper & Nyamathi). It is questionable if this would be an expressed need of parents if the need to be with their child was optimally met. It appears from the results of another study on parental stressors in PICU (Miles & Carter, 1985) that there is an intimate relationship between the stressors and needs of parents. In this study, being allowed to stay as much as possible was ranked by parents as the most helpful coping strategy to deal with stress.

The next two studies to be described in this section sought to establish factors related to parental satisfaction with care in the PICU (BCCH, 1995; Tomlinson, Kirschbaum, Tomczyk & Peterson, 1993). The results of a study by Tomlinson et al. are included here because the authors described the bone marrow transplant unit at their hospital as a pediatric critical care area (not the case in all hospitals). This study investigated the relationships between maternal satisfaction, child acuity and characteristics of the child's primary nurse. Findings were not as expected by the authors, i.e., no relationship was found between nursing attitudes regarding family involvement and maternal satisfaction with nursing. Rather, maternal satisfaction was positively related to the competence of the primary nurse (as measured by the length of the nurse's experience) and to the child's acuity, and maternal vigilance was negatively related to the competence of the nurse and the staffing levels in the unit; that is, mothers were more satisfied when the nurse was experienced and when the child was more acutely ill, and mothers decreased the number of hours they stayed in hospital when the nurse was more experienced and when staffing levels were high. The investigators interpreted these findings as indicating that mothers were more concerned with nursing competence than with their own satisfaction regarding their child's acuity or the nurse's positive attitude to parental involvement.

In the recent BCCH ICU Clinical Consumer Survey (1995), parents were asked for their perceptions of the quality of care in the following five dimensions: involvement of families with decisions, quality of patient care and support, communication and information provision, management of pain and
involvement with tests and procedures, and the quality of the ICU environment. Highlights from the families' responses are represented in Table 1 (the responses for the dimension of parent involvement during procedures are discussed under the related section in this literature review). From these results, the following priorities for changes were identified by the researchers: to improve methods of communication with parents, to revise the visitation policy, to improve consistency of core nurse assignments, to improve the physical environment, and to develop family resources.

Table 1: Satisfaction of Parents regarding PICU Quality of Care

<table>
<thead>
<tr>
<th>Quality of Care Indicator</th>
<th>Percent Satisfaction</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participation in child's care and decision-making (enough)</td>
<td>70</td>
</tr>
<tr>
<td>Amount of visiting time for family (enough)</td>
<td>90</td>
</tr>
<tr>
<td>Flexibility of visiting time</td>
<td>55</td>
</tr>
<tr>
<td>Amount of visiting time for non-family members (enough)</td>
<td>70</td>
</tr>
<tr>
<td>Child treated with respect and dignity</td>
<td>94</td>
</tr>
<tr>
<td>Sensitivity to and management of child's pain (enough)</td>
<td>90</td>
</tr>
<tr>
<td>Very good or excellent care received by child</td>
<td>90</td>
</tr>
<tr>
<td>Family members treated with respect and dignity</td>
<td>85</td>
</tr>
<tr>
<td>Nurse availability for communication / information</td>
<td>61</td>
</tr>
<tr>
<td>Physician availability for communication / information</td>
<td>19</td>
</tr>
<tr>
<td>Relationship of confidence and trust with nurse</td>
<td>83</td>
</tr>
<tr>
<td>Relationship of confidence and trust with physician</td>
<td>74</td>
</tr>
<tr>
<td>Experienced consistency in nursing assignment</td>
<td>54</td>
</tr>
<tr>
<td>Waiting areas adequate</td>
<td>50</td>
</tr>
<tr>
<td>Accommodations adequate</td>
<td>72</td>
</tr>
</tbody>
</table>

Note. The data in Table 1 are from ICU Clinical Consumer Survey by British Columbia's Children's Hospital, 1995 (Summer), Vancouver, British Columbia: Author. Copyright 1995 by BCCH. Adapted with permission.

Some health care professionals in PICUs have paid attention to research results regarding parents' stressors, needs and satisfaction, knowing that helping parents ultimately helps the ill child (Philicchi, 1988). The clinical nurse specialist at Boston's Children's Hospital was prompted by this knowledge to do
an intervention study to decrease parental stress (Curley, 1988). Curley placed 33 parents into two sequential groups: parents in one group were given routine care while parents in the following group were given an intervention. The intervention was derived from a mutual participation model, originally developed for use with chronically ill adults, by Szasz and Hollender in 1956 (cited in Curley). The central theme in this model was the establishment of an empathetic partnership. This model was operationalized by Brody in 1980 (cited in Curley) and used in the outpatient setting. Curley then adapted the mutual participation model to include the following four steps for nurses to implement: 1) the establishment of a caring relationship with the parent; 2) the assessment of parental perception regarding their child's illness (including their beliefs and values regarding health and illness); 3) the determination of parental goals and expectations; and 4) the negotiation of participation in caregiving. This model of care constituted the intervention for the experimental group of parents. For both the control and the experimental groups, the PSS:PICU inventory was then used to compare stress scores between the two groups. Stress scores revealed significant differences between the two groups, especially with respect to the dimension of parental role revision (the dimension most frequently a source of stress for PICU parents). The group exposed to the nursing mutual participation model of care had lower parental stress scores. In a replication of this study (Curley & Wallace, 1992), results were measured in another PICU in an attempt to eliminate the Hawthorne effect. The intervention was given by the bedside nurses rather than the clinical nurse specialist. Findings supported the initial study; stress scores were lower for those in the intervention group. Similar findings have been noted in adult care areas by nurses employing interventions to assist spouses of critically ill or dying patients (Dracup & Breu, 1978; Hampe, 1975). Dracup and Breu found that spouses felt their needs (in categories identified by Hampe) were met significantly more often when they experienced nursing interventions like twice daily phone calls, primary nurses, flexible visiting hours, and spouse-nurse conferences every shift for provision of information and ventilation of emotions. It seems that there are interventions that can be used in order to improve the responses to stress which spouses and
parents have when their loved one is admitted to hospital. Interestingly, both interventions described (Curley; Dracup & Breu) were based on similar elements as those which are key to family-centered care.

**Parental Involvement in Caregiving**

As collaboration and forming partnerships are key to family-centered care, parental choice regarding the level of involvement with a child's care seems to be indicated. Confidence building is also a key element in family-centered care practice; confidence building is needed to encourage as high a level of involvement as possible by parents, based on information related to the detrimental effects of parent-child separation. Although little was found in published literature regarding presence of parents during invasive procedures, especially in PICUs, there was published research regarding parental participation in non-invasive caregiving (Berman, 1991; Callery & Smith, 1991; Dunn, 1979; Kawik, 1996; Ogilvie, 1990; Seidl, 1969; Seidl & Pillitteri, 1967). This research was aimed at illuminating parent-professional relationships.

Seidl and Pilletri (1967) developed and validated a scale aimed at measuring health care professionals' attitudes toward parent participation. A similar scale was used in subsequent studies on parent participation (Gill, 1987; Gill, 1993; Johnson & Lindschau, 1996; Seidl, 1969). While Gill (1993) found that most respondents were in the parent participation attitude category ranges of "accepting" to "most accepting", Johnson and Lindschau found that the majority had a neutral attitude towards parent participation. This could be related to the sample; the former respondents were all members of the American Association for the Care of Children's Health (ACCH - a private and voluntary association) while the latter were staff at an Australian women and children's hospital. In both studies, having ever been married or a parent were related to significantly more accepting attitude scores as was nursing in a specialized care unit. Being a parent was also found to be related to accepting attitudes in 1969 (Seidl). While the factors of age, educational level or positions with less direct family contact, and number of years employed were positively associated in Gill's and Seidl's studies, these factors were not related in the study
by Johnson and Lindschau. This could be related to the smaller sample size in the latter study. One of the problems interpreting the meaning of the findings in Gill's study is related to the population, one which can be presumed to be family-centered, as deduced from their memberships in ACCH. Thus, Gill recommended that research utilizing interviews and observations of health professionals in hospitals would further illuminate the questionnaire findings regarding attitudes of health professionals to family-centered care and parent participation.

Berman (1991) conducted informal meetings with nurses in a children's hospital to discuss their beliefs and values about pediatric nursing with a view to developing a philosophy of care for their hospital. Among the group, 95% supported the family-centered care concept which they believed included open visiting, rooming-in, and participation of parents in the regular daily care of their child. However, other comments regarding the "time-consuming" or "over-involved" nature of some families indicated that the spirit of family-centered care might not be totally valued. Most of the nurses in Berman's study agreed with parents performing routine care, such as bathing, but not traditional nursing care, such as checking a temperature. The criteria that the nurses used to assess parents' abilities to be involved in more than the basic care of their child were vague. When asked about how much control and involvement in decision-making parents wanted, this group of nurses expressed the belief that parents would want minimal involvement due to their distressed emotional state, and that the level of involvement desired was negatively correlated to the severity of the child's illness. Nurses who were parents, or who worked in specialty areas like critical care, emergency and psychiatry were more likely to believe parents could be trusted with increased involvement. As indicated above, both of these factors, being a parent or nursing in a specialty area, have been associated with higher parent participation attitude scores in other studies (Gill, 1993; Johnson & Lindschau, 1996; Matheson, 1996; Seidl, 1969). Berman believed nurses who were parents had experiences which allowed them to relate more to parents in their professional lives. Berman attributed the positive attitudes towards parent participation by nurses in specialty areas to either higher
self-esteem as specialized team members or to longer career experiences as nurses. Berman concluded that nurses' attitudes overall did not reflect an orientation to family-centered care and that the attitudes they did have were related to their beliefs about families and nursing, and varied according to their education and experience.

It seems that practice changes with respect to pediatric hospitalization, family-centered care and parental involvement with caregiving occurred before most health care professionals were philosophically ready. Brown and Ritchie (1990) interviewed twenty-five pediatric nurses and described six different roles which nurses and parents took when caring for children in hospitals. Characteristics of the child, the parent, the nurse and the environment as well as interpersonal conflict were described by these nurses as characteristics that influenced parental and nursing roles in providing care to hospitalized children. Specifically, the age, emotional state and behaviour, personality and ongoing care requirements of the child influenced the roles of parent and nurse. Similarly, the personality, emotional state and comfort level of the parent were considered to influence the role according to this group of nurses. Hospital policies and regulations as well as time constraints were environmental characteristics involved in determining what roles nurses and parents would play. According to Brown and Ritchie, identification of interpersonal conflict as a characteristic which affected roles was made by only six of the twenty-five nurses even though every nurse revealed strong feelings when discussing the conflicting reactions of parents and nurses with differing expectations. This suggested that there were probable personal influences on decisions made by nurses around parents' involvement, influences of which the nurses were not consciously aware. Brown and Ritchie believed that the nurses' responses revealed that the variation in involvement of parents was related either to philosophy of the individual nurse or the philosophy of the head nurse, and that overall, there were barriers to nurses changing their practice to be more consistent with family-centered care. A few other studies have found that changing practice was related to a lack of formal education related to family-centered care and that this was true for other health care professionals as well as nurses (Dunn, 1979;
The shift to family-centered care may be responsible for similar problems experienced by health care professionals in adult care settings, especially with respect to visitation in critical care areas. Much literature related to families and critical care in the last fifteen years concerned critical care visitation (Biley & Millar, 1992; Brannon, Brady, & Gailey, 1990; Dunkel & Eisendrath, 1983; Freismuth, 1986; Fuller & Foster, 1982; Guiliano & Guiliano, 1992; Heater, 1985; Kirchhoff, 1982; Simpson, 1991; Stillwell, 1984; Tee & Struthers, 1996; Titler & Walsh, 1992; Youngner, Coulton, Welton, Juknialis, & Jackson, 1984). Most of the authors of this literature discussed this topic in relation to the rationale behind current visitation policies in critical care areas. Issues of inflexible and inadequate visitation were obvious in these discussions; these issues were not shown to be related to the needs or desires of patients or families (Gray, 1997; Lewandowski, 1997; Mullin, 1992). A most revealing and detailed report by Dunkel and Eisendrath (1983) addressed the attitudes and reactions of staff participating in informal focus groups. They discussed effects of more open visitation for family members which the authors categorized as environmental or psychological effects for staff. Factors which were identified under the environmental category were negative ones for staff, i.e., staff were concerned that more visitors caused decreased space for, and concentration on, the patient. Factors under the psychological category were both positive and negative. The increased time which family members were present in the ICU contributed to some positive effects: increased trust between the family and staff which positively affected the patient's trust; personalization of a patient who was unable to communicate well; provision of feedback to staff of accomplishments based on the outcomes of patients when they had left the ICU; provision of another staff role as family supporter, especially when lives were not saved and the staff member's usual role was unachievable; and a chance for staff to more completely grieve with the family, thus providing closure. Effects classified as negative, psychologically, included: the sometimes unrealistic expectations of families which were more likely to be taken on by staff, leading to increased stress; the fear of staff related to asking the family to leave,
especially during procedures which were painful for the patient, or for procedures which were of uncertain value; the peer pressure of having some professionals who were more effective with families than others; and the sense of loss when a patient died or did not do well was heightened by the increased knowing that occurred when the patient's family was present more often.

One wonders if these negative psychological effects for health care professionals are serious enough to warrant halting the shift to family-centered care. Leff, Chan and Walizer (1991) studied narratives from physicians and parents of ill children to analyze the challenges which health care professionals faced. Both physicians and parents described health care professionals' feelings of grief, mourning, overidentification, fear, guilt and blame as major challenges in caring for ill children. These challenges sometimes resulted in the emotional withdrawal of professionals and contributed to insensitive and ineffective communication to ill children and their families. Likewise, physical and emotional withdrawal have been reported by nurses caring for families they found challenging (Brown & Ritchie, 1989). Frader (1979) also reported that coping with the emotional stresses in PICUs was difficult for inexperienced physicians. However, Leff, Chan and Walizer, and Frader also reported that these emotional responses occurred regardless of the involvement of families. In fact, it could be that establishing partnerships helps both parents and health care professionals to mediate the emotional responses associated with caring for critically ill children (Johnson, Jeppson & Redburn, 1992).

**Parental Presence during Invasive Procedures**

The literature reviewed with respect to family-centered care and parental involvement in caregiving indicated that collaborative partnerships are key to the achievement of family-centered care and are desired by many parents and health care professionals (Anonymous, 1992; Arango, 1990; Gill, 1993). A collaborative partnership would involve mutual choices regarding caregiving to the child, including parental presence during invasive procedures (Johnson, Jeppson & Redburn, 1992). As previously stated, parental presence during invasive procedures was referred to as an uncommon practice in literature.
reviewed (Brown & Ritchie, 1990; Tughan, 1992). In order to understand factors which are influencing the uncommon practice of parental presence during procedures, research literature was investigated. Although literature specific to PICU was not located, selected research reports are included in this section regarding the question of parental presence and invasive procedures in general (BCCH, 1995; Bossert, 1994; Humphrey, Boon, van Linden van den Heuvel & van de Wiel, 1992; Hunsberger, Love & Byrne, 1984; Pederson & Harbaugh, 1995; Woodgate & Kristjanson, 1996), and in specific health care settings: outpatient clinics (Gonzalez, Routh & Armstrong, 1993; Savedra, 1981), pediatric oncology areas (Goodell, 1979; Jones, 1994; Melnyk, 1995; Kuttner, 1993; Romaniuk & Kristjanson, 1995), preoperative and postoperative anesthetic care areas (Brunke, 1989; Dew, Bushong & Crumrine, 1977; Fiorentini, 1993; Hall, Payne, Stack & Stokes, 1995), dental procedure areas (Frankl, Shiere & Fogels, 1962), pediatric emergency rooms (Bauchner, Vinci & May, 1994; Bauchner, Vinci & Waring, 1989; Bauchner, Waring & Vinci, 1991), and burn units (Doctor, 1994; Foertsch, O'Hara, Stoddard & Kealey, 1996; George & Hancock, 1993).

Parental Presence and Invasive Procedures in General

In the BCCH PICU, parents were surveyed regarding their perceptions of the way procedures were handled during their child's stay (BCCH, 1995). Of 51 parents responding, 96.4% replied that their child had minor procedures (examples given of IV insertion and suture or chest tube removal) while in ICU. Forty-three percent were “not present” while 27% stated they were “present sometimes” for their child's procedures. Of the times parents were not present, half of them were asked to leave by staff and more than half of those would have preferred to stay. Overall, the parents, whether they stayed or left, believed there were benefits for: the child (97%), the parent (93%), and the hospital staff (69%). Most agreed with the following positive benefits: 1) to the child - to calm and reassure the child, and to help the child deal with pain; 2) to the parent - reduction of stress and anxiety, and especially reduction of worry of the unknown; and 3) to the staff - sensitization to the family role, helping staff to understand the child, and direct
assistance to staff by supporting the child. Interestingly, parents indicated a reluctance to reply to questions in ways contrary to practices they had experienced in the PICU. Comments like "The doctor / nurse knows best" or "I'm learning a new way in this country" (BCCH, p. 23) were made. Moreover, while one third of families experienced anger related to care in the PICU, only one half of those families reported that they had voiced their complaints. A study using qualitative methodology to examine parents' experiences with a child in a surgical ward also reported great hesitation on the part of parents to criticize care (Callery & Luker, 1996); this hesitation was somewhat overcome by the contextual nature of relating stories rather than filling in a questionnaire.

In 1984, Hunsberger, Love and Byrne reviewed literature regarding approaches used by health care professionals to help children and parents cope with procedures. The approaches were classified as having the purpose of providing information and preparation, providing emotional support, or promoting a sense of control. The presence of parents was classified under providing emotional support and the reason for varying practices regarding parental presence was summarized as being based on comfort levels and experiences of the health care professionals involved.

The painful procedure of venipuncture has been studied in relation to its effects on children (Humphrey, Boon, van Linden van den Heuvell & van de Wiel, 1992). One might assume that venipunctures would not cause high levels of distress for school age children and adolescents and that increased exposure to venipunctures would decrease levels of distress. In fact, some pediatricians in one institution claimed that research was unnecessary because of these assumptions (Humphrey, Boon, van Linden van den Heuvell & van de Wiel). Results indicated, however, that high levels of distress were common and increased as the age of the child decreased. All 223 of the children in this study had previously experienced over five venipunctures with a mean of 40 venipunctures. Distress levels were not related to the previous number of venipunctures or to the gender of the child. Parents were not present for these venipunctures. The investigators recommended that, due to the levels of distress, the health care
professionals in the institution ought to look at their assumptions regarding the significance of this procedure for children and the presence of parents during the procedure.

In a children's hospital, 13 of 25 nurses responded that they were comfortable with parents staying with their child during painful procedures while six were comfortable with a parent restraining a child during a painful procedure (Brown & Ritchie, 1990). Moreover, the reasons which nurses gave for negative responses to parents' presence and/or assistance were related to their own discomfort with both the child's association of the pain with the parent and the parent's potential trauma. Nurses described preventing parents directly or indirectly from being present during procedures; they did not report any discomfort making decisions for parents; and they disapproved of parents who reacted negatively to these decisions (Brown & Ritchie).

It appears that health care professionals may want to protect families more than the families need or want to be protected. Similar to the accounts of nurses in the study of Brown and Ritchie (1990), Berman (1991) found that nurses wanted to protect parents from stressful situations during emotional periods. Yet are levels of stress accurately read by health care professionals? Johnson, Nelson, and Brunnquell (1988) found that nurses' perceptions of parents' ratings on the PSS:PICU dimensions were higher for every dimension than parents' own ratings. Philicchi (1989) found that families adapted and functioned well during their child's intensive care hospitalization, and in fact, their coping scores were higher than the available norms. In 1990, Graves and Ware reported numerous differences between mothers', fathers', nurses' and physicians' ratings of parental stress on scales related to a child's hospitalization. These three studies' findings were endorsed by results of a study by Graves and Hayes (1996) that also found that nurses rated parents' stress higher than parents rated their stress and nurses were not as likely to identify a family's strengths as their needs. The results of the three studies cited corroborate evidence that nurses may be incorrect in assuming that parents need protecting, a classic function in the traditional delivery of health care (Cronenwett & Brickman, 1983). Furthermore, "the Medical Model of
Helping is inappropriate when there is no verified risk to the patient" (Brown & Ritchie, 1990, p. 32). In fact, there are instances when parents are expected to master emotional states in order to perform medical procedures. For example, many hospitals have programs as described by Moynihan, Naclerio and Kiley (1995) in which teaching for families of children with heart defects and other high risk health problems includes being taught resuscitation skills by health care professionals who expect parents to perform this procedure under conditions of presumably great duress. It seems there are discrepancies in expectations between what parents can handle inside versus outside hospitals, and in the presence versus the absence of health care professionals.

Pediatric nurses have identified parental presence as one technique for non-pharmacologic pain management, especially during procedures (Pederson & Harbaugh, 1995). Moreover, other techniques which these nurses identified as helpful for children could be implemented by parents, e.g., imagery, distraction and relaxation techniques. This group of nurses did not express personal discomfort with parental presence during procedures as did groups in 1979 (Goodell) and in 1990 (Brown & Ritchie).

In a study to assess management of post-operative pain by pediatric nurses and parents (Woodgate & Kristjanson, 1996), results from participant observation and interviews shed light on contributions of parents to pain management and on the desires of children. While both parents and nurses monitored the child's pain, parents mainly spent time on comforting activities while nurses spent time on technical care activities. Parents perceived that the psychological and physical comfort which their presence gave the child was the most important activity they performed and the children identified that the most significant contribution to their pain management was their parent's presence. Knowing the child was identified as a major contributor to both assessment and management of pain by nurses and parents.

Assessment and management of pain are key to providing physical and psychological comfort for hospitalized children. The main two fears of hospitalized school age children have been identified as being away from family and having invasive procedures (Bossert, 1994; Hart & Bossert, 1994). Chronically ill
children have even higher scores for fear of invasive procedures than acutely ill children (Bossert). In a survey comparing responses of school-age children with adolescents regarding venipuncture in an emergency room, results indicated that children were twice as likely as adolescents to want parental presence during the procedure (May, Bauchner & Pearson, 1993). The use of strategies, such as, diversion, imagery and positive self-talk, to cope with the procedure were similar for both age groups, except for the strategy of verbal pain expressions. School-age children were significantly more likely to believe that crying or screaming would help them to cope with procedural pain.

Parental Presence during Invasive Procedures in Outpatient Clinics

In 1981, Savedra observed behaviours of parents and children during blood sampling from the children in an outpatient clinic. Results from this study included: parents did not significantly change their kind of personal responses or comforting behaviours pre- or during blood drawing; during the post-blood drawing period, parents significantly increased nonverbal comforting strategies and passive personal responses while they decreased verbal comforting strategies; no significant differences were found between comforting strategies of parents and the children's behaviour; and Black, Asian and Latino parents indicated verbal and nonverbal personal distress more often than Caucasian parents. Eighty percent of parents wanted to be present and none were disruptive during the procedure although two of sixty parents gave suggestions for how to sample their child's blood. Savedra concluded that the children's behaviours post-blood sampling indicated that the parent's presence was helpful. The evidence for this conclusion was not specified.

In another out-patient clinic, Gonzalez, Routh and Armstrong (1993) randomly assigned mother-child dyads in an immunization clinic into one of three groups, a control group, a maternal distraction group, or a maternal reassurance group, and measured distress scores displayed by the child. Distress scores were significantly lower for children in the maternal distraction group while children in the other two groups had similar scores. Specifically, children whose mothers focused on distracting them cried less
than children whose mothers focused on reassuring them or were not instructed to become involved.

**Parental Presence during Invasive Procedures in Pediatric Oncology Areas**

In 1979, Goodell found that nurses working in pediatric oncology units agreed that parental presence was a positive change for the child but many were "threatened" by parental presence. Factors which appeared to improve the nurses' comfort response were: previous exposure on units where parents were significantly involved, and extra education and preparation for parental involvement programs.

Clinical practitioners in the area of oncology reported major changes regarding parental involvement in invasive procedures in the last twenty years (personal communication with clinical nurse specialists, nurses, psychologists and physicians working in BCCH Oncology Program, 1997). Parents have not only been present during invasive procedures but have been involved in helping to manage their child's pain (Kuttner, 1993; McGrath, 1996). It appears that practices with respect to procedures in this area advanced differently than in other pediatric health care settings, probably due to the repetition of invasive procedures such as venipunctures, lumbar punctures, and bone marrow aspirations, for children on therapy regimes for cancer. As well, oncology treatment is mainly given on an outpatient basis with expectations that parents will assess and manage many of the ongoing complications of both the cancer and its therapy. Thus, research in this area appears to be at a different level than in some other areas, as can be seen by the following reports.

A study by Jones (1994) focused on the effect of parental participation on the child's behaviour in hospital. Jones measured parental participation by assessing parent activities related to four categories: stimulation-entertainment, comfort, activities of daily living, and therapeutic care. The latter category included activities like staying with the child for painful procedures. The child's behaviour was assessed on three scales: Cooperation Scale, Manifest Upset Scale, and Activity Scale. Results revealed positive relationships between parents who participated in all four categories of activities and the child's behaviour; that is, when a parent was involved in direct care like being present during painful procedures as well as
being involved in routine care and emotional support, the child was more cooperative, less upset and had an increased activity level. Limitations of this study included the sample, which was small and select. All 13 children were diagnosed with leukemia, in hospital for repeat admissions and undergoing preplanned treatments. Melnyk (1995) addressed this limitation; children in her study had unplanned admissions to hospital and were admitted with varied medical diagnoses. Results indicated that parents receiving preparation regarding the parents' role and the child's expected behaviour during an invasive procedure could provide the most support to their child.

In 1995, Romaniuk and Kristjanson interviewed parents of children hospitalized because of cancer. Interviews focused on roles of nurses and parents. Results indicated that two kinds of care, namely parent care and nursing care, were mediated by the parent-nurse relationship. Parent care effectively contributed to directly caring for the child, such as, supporting the child through painful procedures, but only if the relationship between the parent and nurse was characterized by fostering of parental participation and promoting of family-centered care. The nature of investigation in this study appears multi-faceted, that is, the effects of the parent-professional relationship on parental contribution during a child's invasive procedure were examined rather than merely the effects of a parent's presence during a procedure.

Parental Presence during Invasive Procedures in Surgical Care Areas

The surgical care area, including the pre- and post-operative care settings, has been the setting for studies on parental presence during procedures (Brunke, 1989; Dew, Bushong & Crumrine, 1977; Fiorentini, 1993; Hall, Payne, Stack & Stokes, 1995). In the BCCH Post-Anesthetic Care Unit, Brunke (1989) compared effects of parental presence on the behaviours of two groups of preschool children following eye surgery. Results of analysis of videotapes of the children indicated that the same behaviours were displayed regardless of parental presence, but duration and frequency of some behaviours were significantly different between the two groups. Children in the parent-present group cried, complained, and
asked for fluids more while children in the parent-absent group rubbed their eye, protected their eye from others and kicked more. None of these behaviours was solicited by parents or nurses. Children in the parent-present group asked for, and were given, hugs and body contact more often than the children in the parent-absent group; as well, children in the parent-present group admitted to having pain more frequently. Brunke concluded that parents' presence in the post-anesthetic recovery room contributed to more effective coping with both the hospital experience and with pain.

In a report referring to parental presence before and after anesthesia, Hall, Payne, Stack and Stokes (1995) stated that the practice of parental presence during induction was common in Britain while parental presence during recovery was uncommon. This finding was the same in 1987 (Day, 1987; Glasper & Dewar, 1987). To assess the need for a change in this practice, 150 parents were invited into the recovery room to be with their child and a survey was completed following in order to assess parental and staff attitudes. Parents expressed personal comfort both before and after being with the child in the recovery room, and all believed their presence was helpful to the child. The sentiments of these parents were comparable to those expressed by parents in a study in 1977 on parental presence in a recovery room (Dew, Bushong & Crumrine, 1977). Half of the staff, on the other hand, began the study believing that the program would not help the children and could harm the parents (Day; Glasper & Dewar). The researchers reported that staff attitudes were 98% positive by the last half of the program. A similar progression in staff attitudes from resistance to support for parents in the recovery room was found by Fiorentini (1993).

**Parental Presence during Invasive Procedures in Dental Services Areas**

In an early study on the effects of parental separation in the dental office, behaviours of two groups of preschool-aged children were classified as positive or negative by the investigators (Frankl, Shiere & Fogels, 1962). One group of fifty-six children was observed with a parent present while another group matched for age, gender and socioeconomic status was observed without a parent present. The children in the parent-absent group demonstrated the most negative behaviours, especially when they were three to
four years of age. The investigators concluded that a parent was beneficial in the dental office. The way the behaviours were classified at the time of this study was interesting. "Negative" from the viewpoint of the dentist probably corresponded to "positive" from the child’s perspective; i.e., crying, displaying fear and refusing treatment might now be classified as effective coping strategies for a preschool-aged child.

Parental Presence during Invasive Procedures in Pediatric Emergency Room

The emergency room is a site of frequent procedures on children. One health care professional at Boston Children's Hospital, Howard Bauchner, has studied several aspects of parental presence during procedures (Bauchner, Vinci & May, 1994; Bauchner, Vinci & Waring, 1989; Bauchner, Waring & Vinci, 1991). For example, physicians and nurses have ranked different procedures as more or less appropriate for parental presence (Bauchner, Waring & Vinci). It is unclear whether procedures were ranked according to the degree of invasiveness of, or the frequency with which the professional was likely to have performed, the procedure. In a commentary regarding procedures, Bauchner (1991) addressed the issue of pain as being central to health care professionals’ decision-making when performing procedures on children. Health care professionals’ beliefs about their need to, as well as their ability to, manage a child's pain influenced what they did, including whether they asked parents to be present. Specifics on health care professionals’ decisions were not identified.

In 1989, Bauchner, Vinci and Waring found that 78% of parents wanted to watch a procedure (a venipuncture) because it would help the child (91%), the parent (80%) and the physician (73%); the remaining 22% did not want to watch because of fear (54%) and harm to the child (41%) while 7% of this group did not understand what the procedure involved. Parents who wanted to watch were more likely to have had other children who underwent procedures, were African American rather than Hispanic or Caucasian, and had higher education. In 1991, Bauchner, Waring and Vinci took the study of parental presence during procedures beyond a theoretical level and observed what actually happened in the emergency room that determined whether a parent stayed or left. Fifty young children had either a
venipuncture for blood sampling or a catheter insertion while 62% of their parents stayed. Once again, parents were significantly more likely to stay if they had previously stayed with a child undergoing a procedure. Reasons for staying were because their child wanted them to (90%), to know what was happening (77%) and to calm their child (81%); and 43% said the nurse or physician had asked them to stay. Of the 38% who were not present with their child, 42% would have liked to be, 26% did not want to be, and 32% did not know they had a choice. Observations of the interactions indicated that, even when parents were not requested to leave, nonverbal actions by professionals included turning their backs and pulling curtains.

In 1993, Bauchner, Vinci and Pearson randomized 300 parent-child dyads to one of three groups: 1) parents were present and taught how to comfort their young child during a procedure; 2) parents were present with no instructions; and 3) parents were not present (the procedure was a venipuncture, an intravenous cannulation or urethral catheterization in the emergency department). Approximately 90% of the parents in the intervention group were effective at using the comforting instructions, felt comfortable and were very satisfied with care. Less than half of the parents who had not been taught comforting techniques used them spontaneously. Over 90% of both groups who had been present would want to be present at a subsequent procedure as compared to 53% of those who were not present. Although criteria for being in the study were not given, one can assume that the children were ill enough to require a procedure in the emergency room; however, they were probably not critically ill. An overall comment about the value of this research suggested that the relationship of the parent-child dyad was benefitted beyond the measurement of the procedure done in the emergency department. When parents are taught how to help their child, benefits to the overall relationship as well as to inevitable future incidents will be realized.

**Parental Presence during Invasive Procedures in Pediatric Burn Units**

Three reports regarding parental presence during burn wound care were found in recent literature (Doctor, 1994; Foertsch, O'Hara, Stoddard & Kealey, 1996; George & Hancock, 1993). Behavioural
distress scores were measured in two quasi-experimental studies with the following results: no significant difference between parent-present and parent-absent groups (Doctor), and higher distress scores in parent-present groups (Foertsch et al.). Similarly, in a report regarding a new burn wound care program where parents were present (George & Hancock), nurses involved believed that there was increased acting out by the children. Despite the evidence that behavioural distress was not decreased by parental presence, the investigators in all three studies concluded that parental presence during burn wound care was beneficial for children, not harmful for parents, and sometimes beneficial for parents, especially in the long term. A reason given to explain increased behavioural distress measurement when the parent was present was that the child was secure enough to express emotions.

In a comment regarding the recommendation of George and Hancock (1993) for parent participation to reduce burn pain, an editor, Mary Gordon (1993), expressed that although the idea was interesting, further study was needed prior to implementation. Yet it appears there was no evidence to substantiate the previous practice of not having parents participate to reduce pain. In fact, following results like those in the classic studies related to infant separation and mental health, it would appear that it would be better for parents to be present than not. It seems that evidence is required in order to change practices for which there is also no evidence.

Much of the research available concerns parental presence during preplanned procedures performed in non-critical care areas or emergency procedures performed on non-critically ill children in critical care areas like the emergency room or the post-anesthetic care unit. It is questionable whether this can be extended to apply to the practice of parental presence during procedures in an area such as the pediatric intensive care unit. Indeed, one of the few hospitals to document encouragement of family members' presence during the procedure of resuscitation reported that "family members are requested to step out when invasive procedures are required" (Hanson & Strawser, 1992, p. 105). One wonders what the definition of an "invasive" procedure is, especially during cardiopulmonary resuscitation, who
Family Member Presence during Resuscitation

It has already been noted that procedures suitable for parental presence, and those deemed unsuitable, appear to be differentiated on many variables including degrees of invasiveness and painfulness. Cardiopulmonary resuscitation is a procedure that also reflects considerable variation on such factors as invasiveness and painfulness. It has also been noted that this procedure is taught to family members caring for those in a high risk category (Moynihan, Naclerio & Kiley, 1995), as well as being taught to the general public for first responder purposes. More recently, discussions on the presence of family members during resuscitation by health care professionals in hospital settings (Hanson & Strawser, 1992; Macnab, 1996; Post, Redheffer & Brown, 1989; Wise, 1996) and at public events (Adams, Whitlock, Baskett, Bloomfield & Higgs, 1994) can be found in the literature. For the most part, these discussions seem to have been prompted by pleas from family members to see their loved ones at the time of resuscitation. Health care professionals were then required to examine their reasons for keeping families out during resuscitation.

Post, a hospital chaplain (Post, Redheffer & Brown, 1989), and Hanson and Strawser (1992), two nurses, described the experience of family presence during cardiopulmonary resuscitation in the emergency department in which they worked together. In their institution, for several years (since approximately 1982), family members have had the role on the resuscitation team of providing support to their relative being resuscitated. The times which they may enter the resuscitation room to do this are controlled by the team members, including the member assigned to be the family's support person. The decision to initiate this program came after a survey indicated that 72% of 18 family members of recently deceased patients responded that they would have preferred to be present during the resuscitation (Doyle, Post, Burney, Maino, Keefe & Rhee, 1987). In a survey of 47 families who were present during resuscitation in the first two years of the practice, 97% would choose to be present again, 76% shared that their grieving had been
facilitated, and 60% believed that their loved one had been helped (Post, Redheffer & Brown).

A second anecdotal experience regarding relatives watching resuscitation was documented in the literature (Adams, Whitlock, Baskett, Bloomfield & Higgs, 1994). Adams watched her younger brother being resuscitated following a fall from a horse during a public event. She wrote movingly about the experience and made several significant comments. She expressed relief that the area was screened off so there was a small measure of privacy for herself watching and so that her mother could be protected from the scene (her father did watch for some of the time). She expressed frustration that people kept trying to remove her. Overall, her message to health care professionals was:

People in these circumstances should be encouraged to follow their instincts. They should be made welcome if they wish to stay and be kept updated. It is a very frightening experience to someone who does not understand what is going on in front of them, but the overwhelming desire is to stay close to the injured person. This overrode any fears that I experienced (p. 687).

It is not known from the reports in the literature about family presence during resuscitation (Hanson and Strawser, 1992; Post, Redheffer & Brown, 1989) whether any resuscitation procedures were successful. This seems strange despite the fact that there is a high mortality rate for both children and adults who require cardiopulmonary resuscitation (Chameides & Hazinski, 1994; Grauer & Cavallaro, 1992). Macnab (1996), a pediatric critical care physician, recommended that parents be allowed to be present during pediatric resuscitation as it may help the parents' grieving and acceptance of the child's death. It appears that family member presence during resuscitation may be viewed more as a way of being present for the death and confirming that every effort was made rather than as a way of supporting the family member during an invasive procedure.

One of the earliest qualitative studies done to investigate families' needs when their loved ones were dying was by Hampe (1975). Hampe discovered that along with the needs “to be informed of the condition” and “to be assured of pain management,” grieving spouses also had a need “to be with” their loved ones as they died. Grieving spouses identified that the least supportive behaviour of health care professionals was asking them to leave the bedside. As Adams so vividly described her experience with an
unexpected death (Adams, Whitlock, Baskett, Bloomfield & Higgs, 1994), so too many spouses described not wanting to leave before expected deaths (Hampe, 1975).

The families' wishes with respect to their presence during resuscitation may vary from the wishes of health care professionals regarding family member presence. In an informal survey of nurses in an emergency department where a program of family members' presence during resuscitation was to be started, fear of family members disrupting care and fear of health care professionals' losing control of their emotions were the most common reasons which the nurses voiced for not wanting the program (Hanson & Strawser, 1992; Post, Redheffer & Brown, 1989). Following experience with this program, nurses reported that, in actuality, disruption by family members happened rarely to never and that, although they were able to maintain professionalism during the resuscitation, reactions after the resuscitation were more emotional, due to the family members' presence. Despite this, 71% of the nurses and physicians endorsed the program.

A nurse's response of increased emotion when more was known about the patient or when family members were known has also been reported by critical care nurses following involvement with unsuccessful resuscitation (Isaak & Paterson, 1996). Because knowing the patient either directly or indirectly results in increased emotional responses, it seems quite reasonable that health care professionals could use distance as a mechanism to attempt to control their emotional involvement with patients who may die.

Wise (1996) cited a report from the British Resuscitation Council which recommended that family members be supported to watch resuscitation attempts and that any added stress resulting for health care professionals be managed by education and support. This recommendation came despite the fact that most physicians in Britain were not in favour of the practice. Interestingly, those who were in favour mainly worked in the emergency and pediatric areas. Four physicians involved in the debate following the death of Adams' brother (Adams, Whitlock, Baskett, Bloomfield & Higgs, 1994) gave varying opinions on whether relatives should be allowed to watch resuscitation. Three of the four physicians supported the practice of allowing relatives to stay, while the fourth expressed that detailed information about the resuscitation and
time with the body following resuscitation were more important. The main reasons given for support of the practice of family member presence during resuscitation were providing companionship for the dying person and helping the relatives later with grief. The reasons given for asking the relatives to leave were related to the possibility of hindrance of the procedure and trauma to the observer.

Summary of Literature Review

Several themes surfaced repeatedly in published literature regarding the presence of parents during invasive procedures. These themes contribute to the development of this study and may contribute to the analysis of the findings. It is apparent that there are effects on and/or benefits for the members of the three groups involved, i.e., children, parents and health care professionals.

Children, for the most part, do not want their parents to leave them during hospitalization (Bossert, 1994; Bowlby, 1982). It is also evident that most children do not want their parents to leave during invasive procedures (Tughan, 1992; Woodgate & Kristjanson, 1996). There is some evidence that the number of children who do not want their parent present increases with advancing age (May, Bauchner & Pearson, 1993). It is unknown exactly why that is or which factors influence school-aged children and adolescents to want parents present versus absent. It would seem reasonable to say that where possible, all children should be given a choice regarding parental presence during an invasive procedure. In the PICU, however, children often are unable to indicate what they want even when they are old enough to do so. From the viewpoint of the children, it could be beneficial to follow the recommendation of Leff, Chan and Walizer (1991):

For all children, especially those exposed to multiple invasive treatments over a prolonged period of time, parental participation fulfills a crucial need. Children's cries and protest occur within the safety of their parents' presence. They have not been abandoned to face their fate alone. The most important people in their world, their parents, are there to help them through the terrifying ordeal. In the vast majority of situations, as few barriers as possible should stand between parents and their children in need (p. 235).

There is some evidence that parents would like a choice regarding presence during an invasive procedure on their child (Berman, 1991; Tughan, 1992). Some of this evidence is theoretical (Bauchner,
Vinci & Waring, 1989; BCCH, 1995); some is based on actual presence (Bauchner, Vinci & May, 1994; Hall, Payne, Stack & Stokes, 1995). There are findings indicating that children's behavioural distress in unchanged or higher during burn dressing changes when parents are present (Doctor, 1994; Foertsch, O'Hara, Stoddard & Kealey, 1996). There are also findings that a parent's absence in the dental office resulted in the most negative behaviour in young children, especially aged three to four years of age (Frankl, Shiere & Fogels, 1962). There is some evidence that parents can help their child during procedures (Brunke, 1989; Pederson & Harbaugh, 1995; Woodgate & Kristjanson, 1996); moreover, this especially happens with certain actions by parents while present (Gonzalez, Routh & Armstrong, 1993; Romaniuk & Kristjanson, 1995). The meaning of these conflicting findings is open to interpretation.

Parents find changes to their role as parents very difficult when their child is in PICU (Carter, Miles, Buford & Hassanein, 1985; Jay, 1977; Miles, 1979) and they have a need to be with their child frequently (Fisher, 1994; Green, 1979; Philichi, 1989); when visitation is liberal, this difficulty may be helped (Heuer, 1993; Johnson, Nelson & Brunnquell, 1988). There is some evidence that some parents and family members would like to be given more choices regarding involvement in caregiving and during invasive procedures (Brown & Ritchie, 1990; Doctor, 1994; Lutz, 1986). It is also significant that at the current time health care professionals may only be hearing about the desires of a small number of those who want more choices. Those who are too overwhelmed by their child's situation or who do not believe they have a voice in health care decisions are unlikely to express their thoughts. For example, it has been found that although families rarely complained about restricted visiting hours in critical care units, they were very glad to have restrictions removed (Holl, 1993; Flint & Walsh, 1988; Tughan, 1992). Similarly, in the BCCH PICU survey (1995), one third of the families reported being angry about some aspect of the care given while their child was in ICU; however, only half of them talked to the staff about their complaints. When asked the question, "If you were asked to leave by hospital staff, would you have preferred to be able to stay with your child?", a few parents responded that, "The doctor / nurse knows
best." (BCCH, p. 23). Comments made by parents in the study of Callery and Luker (1996) endorsed this finding that parents are hesitant to criticize care. It could be that many more families would like to be consulted regarding options on their child's care but will not challenge the status quo.

Results from one study regarding mothers' views of nursing care for their child with cancer did indicate that a nurse's competence was of more concern for mothers than a positive attitude to parental involvement (Tomlinson, Kirschbaum, Tomczyk & Peterson, 1993). It could be that parental involvement was not important for these mothers; it could be that due to education differences, more junior nurses were those who had more positive attitudes. It would be interesting to see what parent's views would be if experience and competence levels were equal in nurses who varied on parental involvement attitudes.

Despite some evidence of a desire by children and families for parental presence during an invasive procedure, for the most part, family members are not present during procedures in many hospital care settings, including PICUs. It appears that this is due to decisions made by the health care professionals involved, with varying explanations given in the literature (Bauchner, Waring & Vinci, 1991; BCCH, 1995; Brown & Ritchie, 1990; Kawik, 1996).

There is some evidence that health care professionals respond to the decision regarding parental presence in ways that are related to their education (Dunn, 1979; Gill, 1993; Hunsberger, Love & Byrne, 1984; Letourneau & Elliott, 1996). If the philosophy of family-centered care was not advocated during their basic education program, it is possible that it will be difficult for them to practice according to principles of family-centered care (Brown & Ritchie, 1990; Dunn; Goodell, 1979; Letourneau & Elliott; Pederson & Harbaugh, 1995). Having the experience of parenting or nursing in a specialty area like critical care may be related to implementing more family-centered care practices (Gill, 1987; Gill, 1993; Johnson & Lindschau, 1996). It is questionable whether the positive attitude to family-centered care comes before or after the parenting or specialty nursing experience.

Parents and health care professionals have different priorities and expectations. There is some
evidence that health care professionals perceive parents to have more stressors and emotional problems than parents perceive that they have (Brown & Ritchie, 1990; Graves & Hayes, 1996; Hall et al, 1995; Philicchi, 1989). In the studies by Graves and Hayes, and Philicchi, parents of children in general wards or in PICU were found to be coping, and had adapted to, rather than been overwhelmed by, their stress. It appears that this need to protect families may be related to the effect of observing stressed parents or to the paternalistic attitudes of traditional health care practitioners. In addition to evidence that health care professionals are protecting parents, there is some evidence that decisions regarding parental procedures are made to mediate the health care professional's response (Bauchner, 1991; Dunkel & Eisendrath, 1983; Frader, 1979; Hanson & Strawser, 1992; Leff, Chan & Walizer, 1991; Wise, 1996). Fear of losing control of emotions and awareness of mismanaged pain and suffering appears to be greater when parents are present than when they are not present.

There appears to be some movement towards parental presence during procedures, even in areas like the operating room (Gregory, 1989) and during procedures like resuscitation (Hanson & Strawser, 1992; Macnab, 1996; Wise, 1996). However, the rationale of health care professionals for these practice changes is unknown. This is especially significant since the PICU may have factors related to decision making that are not relevant in other areas. For example, many of the studies which have been done involved procedures which were non-urgent, anticipated and in non-critical atmospheres, e.g., immunizations. The decisions regarding parental presence may be different for procedures in a PICU which are urgent, unanticipated and sometimes performed in life-threatening situations, e.g., intubation of a child with respiratory failure. Another factor which could be related to decisions made differently in PICUs as compared to other areas is the child's length of stay. Most children stay for only two to three days in the PICU. Rennick (1986) believes that this factor determines the viability of involving the parent in their child's care in the PICU because of the time required for teaching and building confidence in parents.

It is apparent in the literature that, although parental presence during invasive procedures has
benefits for children, parents, and health care professionals, little is known about the factors which influence professionals making decisions to involve or exclude parents in invasive procedures, particularly in PICUs. This study sought to address this much needed area of research.

**Analytical Framework**

Morse and Field (1995) address the varying viewpoints of researchers involved in the controversy regarding the use of literature reviews and frameworks for research in the qualitative tradition. A balance is recommended between ignoring all literature and reinventing research-based knowledge, and reporting all literature and becoming biased by it. With respect to the method of interpretive description, Thorne, Kirkham and MacDonald-Emes (1997) made the resolution regarding the use of literature reviews and frameworks more specific. These researchers recommend that a) existing knowledge, both research-based and clinical-based, be used to construct a new inquiry, and b) this existing knowledge be analyzed to develop an analytic framework for the new inquiry. This analytical framework then is used to provide rationale for the design and the decisions made with respect to interview content and purposive sampling.

When I initially considered the question of parental presence during invasive procedures in the PICU, I was directed towards a small amount of literature on the presence of parents during invasive procedures in other areas. At that point, I mainly was interested in the effects of parental presence on a) the critically ill child and b) the parent(s) and family. Upon analyzing this literature, it became evident that the effects on the child and family cannot be considered in isolation of at least two more concepts a) the philosophy of care and b) the area of care. This realization then gave me a broader view of the possible factors affecting the question of parental presence during invasive procedures in the PICU. Thus, I directed my continuing search towards accessing literature on family-centered care and PICU experiences. Among both the research and clinical literature, I found significant references to parent-professional relationships and their effects on care in general and parental presence during invasive procedures in particular. This led me to look for research on parent-professional relationships. Finally, resuscitation, as a variant on the
procedure theme, became added to the literature reviewed as I became aware of a trend towards discussing the advantages, disadvantages and family wishes regarding family members' presence during resuscitation efforts.

Following analysis of the results of this literature review and using the direction given for analytic frameworks for the purpose of an interpretive description (Thorne, Kirkham & MacDonald-Emes, 1997), I initially looked for and described data from participants according to the following five themes:

1. information related to the practice of family-centered care in this PICU,
2. information regarding the parental experience in this PICU,
3. factors influencing parental involvement in caregiving to a child in this PICU,
4. the factors which are considered when making decisions regarding parental presence during invasive procedures in this PICU, and
5. the factors which are considered when the decision relates to the invasive procedure of resuscitation of a child in this PICU (this procedure was looked at separately as there was literature regarding this specific procedure).

Figure 1 represents a schematic representation of health care professionals' decision-making as it was initially perceived. The health care professional's decision for parental presence or parental absence was viewed as influenced by the health care professional's perception of the benefits / disadvantages to those involved in the procedure. In addition, decisions for parental presence were perceived to contribute to similar decisions in future.
Figure 1: Schematic Representation of Decision-Making

Health Care Professional Makes

Influenced By

Increases pressure to remain

Decision Regarding Parental Presence

Parent(s) Present

Parent(s) Absent

Benefits to child, family & professionals

Disadvantages to child, family & professionals

Perception of
Summary

In this chapter, the literature deemed pertinent to the question of parental presence during procedures in the PICU was reviewed. My selection of pertinent literature was informed by specifics of the research method of interpretive description. Research was not located regarding parental presence during invasive procedures in the PICU specifically; however, there is evidence that the practice of parental presence during procedures has known benefits in other care settings. It seems possible that there may be additional benefits to elucidate regarding parental presence during invasive procedures in the PICU. It is evident that health care professionals currently make or contribute to decisions regarding parental presence during invasive procedures; therefore, there is a need to explore and describe the factors which influence health care professionals' decisions regarding parental presence during invasive procedures in the PICU.
CHAPTER THREE: METHODOLOGY

It is evident from the preliminary literature review that there is potential knowledge to be explicates from research investigating the factors influencing health care professionals' decisions regarding parental presence when a child is undergoing invasive procedures in the PICU. In order to explicate this knowledge, I chose the qualitative method of interpretive description (Thorne, Kirkham & MacDonald-Emes, 1997). In this chapter, I outline rationale for this research design, describe the sample, setting and procedures for data collection and analysis, and refer to rigor, ethical considerations and limitations of the study.

Research Design

I chose a qualitative method to study the question of parental presence during invasive procedures in the PICU for two reasons: my worldview and the nature of my research question. With respect to my worldview regarding nursing, I believed that much of nursing knowledge and practice is holistic and contextual; that is, there are multiple realities, the facets of which depend on the context which the situation presents for the individuals involved. Similarly, with respect to this question, I have experienced vastly different responses from health care professionals regarding the question of parental presence during invasive procedures in the PICU. The meaning which health care professionals assign to this question appears to be deeply grounded in their worldview, varying over time and in different situations. As well, the individualized approach recommended in the philosophy of family-centered care corresponds to a non-traditional, naturalistic worldview. As Dzurec (1989) points out, the quantitative approach is directed towards discovering commonalities among a group of participants and directed away from the individual in context. The qualitative approach is identified as suitable to study this question because it keeps the focus on the individual in context (Munhall & Oiler, 1986). Morse and Field (1995) identify two other factors related to the choice of a qualitative approach that are applicable in this particular study, the maturity of the concept and the characteristics of the setting. The maturity of the concept is frequently assessed by the
amount of literature available on the question. Little was found in published literature regarding the
question of parental presence during invasive procedures in the PICU. Qualitative research results can add
the richness and density of informative responses which such a question requires. In addition, the
characteristics of the research setting in this study were suited to a qualitative approach. From the
responses to the BCCH ICU parent survey (1995), the current practices regarding parental presence during
invasive procedures in the PICU were a) variable and b) related to factors not explicated to parents.
Participants in this qualitative study identified many factors influencing decisions made by health care
professionals; other kinds of studies, including quantitative ones, can then follow.

Thorne (1991) addresses the usual types of qualitative methods which nurses use and the ways
which these methods are best suited to disciplines which are not seeking applicable knowledge. Nurses
work with people. Nursing research should contribute to a nurse's ability to perform this work. With
respect to this research study, the results can be applied by PICU nurses when assisting children, parents
and other health care professionals to understand the factors which are considered when determining
parental presence during invasive procedures. Further application of the results includes trying
interventions which influence the identified factors and concomitantly, the decisions made by nurses
regarding parental presence during invasive procedures. In order to address the discrepancy between the
applied discipline of nursing and the more theoretical aims of the current qualitative methods used, Thorne
also encourages nurses to identify different qualitative methods. In response, Thorne, Kirkham and
MacDonald-Emes (1997) proposed the method of interpretive description, a method which "involves
description of and interpretation about a shared health or illness phenomenon from the perspective of those
who live it" (p. 171). Using this method in this study, the description was derived from the responses of the
research participants, while the interpretive aspect was admittedly constructed by myself as the researcher
according to the sources of knowledge and experience that I accessed in order to present the findings. This
method of interpretive description, which gave direction to the analytical framework outlined in the
previous chapter, also gave direction to the selection of participants, the data analysis and rigor in the proposed study (Thorne, Kirkham & MacDonald-Emes).

Sample

The population of possible participants for this study were health care professionals involved in performing invasive procedures in the pediatric intensive care unit, and thus, contributing to decisions regarding the presence of parents during their child's procedure. For the purpose of this study, the population was narrowed further to physicians and nurses working in the PICU in a tertiary level children's hospital. Although other health care professionals perform invasive procedures in the PICU, e.g., respiratory therapists, surgeons, physiotherapists, this rarely occurs without an ICU nurse or physician in attendance. For this reason, only health care professionals who were nurses or physicians working in the PICU were included in the sample.

The sample size was anticipated to be approximately ten participants. Participants were recruited initially based on their interest and willingness to be involved (the procedure for approaching participants follows in the next section). Following the analysis of data from the first few participants, theoretical sampling principles guided the recruitment of subsequent participants (Morse, 1995). Theoretical sampling was used in conjunction with direction from the analytical framework. For example, the analytical framework is derived from literature that suggests that health care professionals have perceptions to share regarding their experiences with family-centered care, parental involvement with care, parental experiences in PICUs, and parental presence during invasive procedures or resuscitation. The population of nurses and physicians in the PICU is considerably diverse with respect to career paths. It was anticipated that there would be health care professionals representing variations on each of the themes presented in the literature. For example, there would be health care professionals who encourage parents to participate in specific procedures because of previous experience with this practice as suggested by Goodell (1979); there would be health care professionals who are aware of the emotions of parents and wish to protect them as those in
the study of Brown and Ritchie (1990). It was also anticipated that interest in participating would be initially higher among physicians and nurses who are very aware of the factors which influence their decisions. Once data was collected from initial participants, the data was analyzed to suggest characteristics of participants who should be actively sought. For example, the first five participants emphasized the uniqueness of decisions made regarding children coming to PICU from certain programs; this prompted me to seek health care professionals with relevant experience. In this way, the potential scope and breadth of the data to be generated was pursued. Conversely, if the data could not give strength to potential scope and breadth, limitations to interpretation of data would be identified (Morse). For example, where participants’ experiences of a similar nature are minimal, the findings and factors identified are noted as such; likewise minimal diversity among sample participants would be noted.

Procedure for Approaching and Informing Participants

In order to identify interested participants and to consider the research protocols of the particular unit involved, I first discussed the proposed study at a program management committee meeting. The committee is multidisciplinary with representatives from nursing, medicine, respiratory therapy, and allied health who hold positions in upper and middle management. For example, the director, equipment coordinator and PICU supervisor for the respiratory therapy department are all members. All five pediatric intensivists are members of this committee while the medical fellows are not. Nursing is represented by the patient services director, the clinical nurse leaders, the instructors, the equipment coordinator, and myself as the clinical nurse specialist. The purpose of the discussion at this meeting was to explain the study, answer questions, and arrange for presentations to staff. The purpose and procedure for the study was then described at the ICU nurses’ regularly scheduled professional development sessions, held three times, and information sent for presentation at the regularly scheduled physicians’ meeting. Finally, to ensure that all ICU staff were aware of the study, the Participant Information letter (Appendix A) was placed in each ICU physician's and nurse's mailfile. I intended to leave it to interested staff members to contact me to arrange
for an interview meeting. In actuality, only the nurses approached me to be interviewed; I turned away nurses who came forward after the first ten volunteers. Conversely, I recruited (easily) all five physicians, who seemed unaware of receiving their letters.

As mentioned, I am also a staff member in this PICU setting and know all staff who work there. As pointed out by Morse and Field (1995), this can be useful, especially at the beginning when recruiting participants because there may be a level of acceptance of a known researcher. Also, I was aware of cultural aspects of the PICU which might have an impact on the results of the study. The nurses who work in the PICU vary greatly in age, educational background, experience in other nursing areas and other PICUs. Of approximately 100 nurses, all have been nursing for at least five years; most work on a team rotation where they consistently work with the same nurses. There are five full-time medical intensivists and three medical fellows. All have varying experiences and educational backgrounds. The critical care setting is typified by one-to-one nursing assignments and direct immediate contacts between the nurses and the physicians who rotate through on-call schedules. It has been noted that physicians and nurses who work in many critical care settings become very familiar with each other's styles as they closely work together in emotionally charged, urgent situations (Curley & Meyer, 1996). I would suggest that this familiarity of health care professionals' styles exists in this PICU where the staff turnover is minimal. It is also possible that participants are familiar with each other's decision making with respect to parental presence during procedures; many staff may also have been influenced by, or have adopted, each other's decision making. This may have had an impact on the data collected in the study.

**Data Collection Setting and Procedures**

I arranged to conduct the interviews with each participant at a mutually convenient time and place; this varied considerably, from rooms in the institution to personal homes, and from work time to leisure time. Privacy, ability to tape the interview and maintenance of confidentiality throughout were paramount to choosing the setting for both the initial interview and the follow-up meeting. Consent forms were
explained, agreed to, signed and copied for each participant before the initial interview. The first interview with each participant began with the collection of demographic data (Appendix C); both first and second interviews were at least forty to sixty minutes in length, occasionally with brief interruptions. All tapes of the interviews were transcribed as accurately as possible by an experienced transcriptionist, and checked when I believed it necessary.

The establishment of rapport with the participants being interviewed was as important as the questions I asked (May, 1989). Before I began with the open-ended questions in the interview guide (Appendix D), I wanted to be assured of the participant's comfort in commencing the interview. Because I worked in the same setting as the participants, I endeavoured to be aware of their comfort with my part in the interview. I was particularly concerned about the participants' understanding of the confidential and non-judgemental aspects of the interview. Although I am not in the position of directly evaluating any participant, I am considered part of the nursing management team by health care professionals working in the PICU. Moreover, I am aware that there have been very strong responses from some staff regarding recent changes initiated by the nursing management team to enhance family-centered care in the unit. At all times, I needed to be aware of my role as an insider (Morse & Field, 1995). I employed strategies outlined under the rigor section in order to prevent bias and maintain awareness of my separate roles of clinical nurse specialist and researcher. I also needed to clarify the purpose of the research with the participants, stressing that I was looking for differing opinions to make the research data richer. I emphasized that data which could reveal a participant's identity in any way would not be reported.

May (1989) emphasizes that an important part of the interview is balancing consistency with flexibility while "getting the story." It is important to allow flexibility in order to get depth; it is not necessary for complete consistency in all interviews. May also believes researchers can expect the beginning interviews to be more flexible while the remaining interviews tend to focus more on consistency. In this study, the interview questions (Appendix D) were used as guidelines. Adjustments were made to the
questions based on the data collected and analyzed; this is appropriate for interviews in most qualitative studies (May). The approach to the interviews was semi-structured; that is, I organized questions according to the analytic framework which was derived from the literature review (Appendix D). I was flexible regarding the scope and depth of the interview, however, especially with respect to input which the participants believed necessary. This is suitable for interviews in which the researcher does not already know most prominent features of the research topic (Polit & Hungler, 1987). Following the initial interviews, I began the follow-up interviews after initial analysis of the data from all participants. Revisions made during each follow-up interview were incorporated into the subsequent follow-up interviews. The length of time between the two interviews was between one and two months, as anticipated.

I maintained field notes following each interview as recommended by May (1989). In these notes, I articulated my observations and impressions regarding the interview process, and recorded important information which came up following the official ending of the interview. These field notes are consistent with my view regarding the contextual, holistic nature of the topic. Throughout the two and a half months of data collection, incidents occurred in the hospital that greatly affected staff, including some of the participants. For example, a child died of a procedure-related error, an incident that not only involved many staff personally but was also much publicized in the popular media. Most of the participants discussed this incident and the benefits / disadvantages of parental presence versus parental absence. I was also aware that I was influenced by incidents occurring in the hospital. Consequently, I reflected on and journalled about these incidents throughout the period of data collection and analysis.

Data Analysis Procedures

In order to analyze the data using procedures faithful to the qualitative spirit, Thorne, Kirkham and MacDonald-Emes (1997) recommend that researchers use an inductive analysis process. To do this, I followed the key principle of viewing the whole, or the gestalt (Burns & Grove, 1993), rather than
concentrating solely on the parts. In order to apply this principle, Thorne et al. suggest avoiding complex
coding systems; they suggest employing endurance and patience, and immersing oneself in the data prior
to, and throughout, the analysis. During this research study, I also had the benefit of objective and
experienced researchers on my committee to encourage my endurance and patience, and assist with
interpreting the meaning behind the coded data. Following this principle of conserving 'the big picture'
augmented the suppositions with which I, as a neophyte researcher, began. My initial suppositions
considered the question of parental presence during invasive procedures as a contextual question, one
about which multiple perspectives exist. For this added reason, I avoided complex coding systems as they
believe the nature of topics in context.

Knafl and Webster (1988) identify principles to follow and techniques to use when analyzing
qualitative data. They cite four purposes for collecting qualitative data: instrumentation, illustration,
description and theory building. The purpose significant for the data collected in this study was that of
description. When analyzing data collected, I identified categories for the data, with assistance from my
thesis chairperson. The data was then broken down and coded accordingly. Following the initial category
breakdown on the transcripts, data was organized according to category and analyzed to identify possible
subcategories within and across categories. Factors that influenced the participants' decisions regarding
parental presence during procedures became readily identifiable within and across the categories. Factors
that influenced the participants' decisions at different points in the decision-making and in different ways
became apparent. I depicted my interpretation of the data analysis using a schematic diagram of decision-
making with factors identified in categories. I then presented this to the participants in the second
interviews both visually and verbally to generate their response to validate, clarify or revise the data
analysis.

**Methodological Rigor**

Attention to rigor in the study's method is paramount when using a design which lends itself to a
continuously evolving process (Thorne, Kirkham & MacDonald-Emes, 1997). I chose to do this study because of deep convictions regarding how I view the world and this topic. I was also responsible for the evolving nature of the sampling, data collection and analysis. To maintain rigor throughout this process, I needed to be aware of the biases arising from my convictions and worldview. To assist with this, Paterson (1994) recommends the use of a reflective journal for the researcher; I used such a reflective journal and included field notes in it.

Another threat to the rigor of a qualitative research design is reactivity (Paterson, 1994). Reactivity refers to the nature of the interaction between the interviewer and the interviewee which affects the process, and thus the content, of the interview. There are five common sources of reactivity identified by Paterson which I considered with respect to this study.

Emotional valence is a source of reactivity which refers to the quality of the trust feelings between the interviewer and interviewee. With respect to this study, I interviewed health care professionals with whom I am friends as well as close colleagues. I interviewed them on a topic that is controversial; and the participants may have interpreted what my stance is likely to be. This may have affected the quality of the trust relationship between the participant and myself, and thus, also affected the responses. I needed to inform the participants clearly that I was looking for the diversity of opinions which exists regarding parental presence during invasive procedures in the PICU.

A second source of reactivity arises from the distribution of power. Because of the distribution of power, I needed to consider that the nurses, physicians, or I may have altered our usual responses to the interview questions and answers because of a need to please each other. Some participants may have perceived my power as greater than theirs and so, wished to please me. I may have been eager to promote comfort on the part of participants who were 'helping me out', assigning them power over me. I noted perceptions of power differentials in the field notes on some occasions.

The third source of reactivity, the goal of the interaction, could very well have been an issue in this
particular research study. The participants may have been aware that there are groups in the hospital who wish to change current practices with respect to parental presence during procedures. For example, it may be well known that the Partners in Care committee, of which I am a member, has this goal on their agendas. Moreover, there are other studies and similar practice changes occurring in the hospital simultaneously; for example, parental presence during induction of anesthesia was being initiated in the surgical area; interpersonal relationships between families and nurses on another unit was being researched; and the Partners in Care committee are recruiting for a full-time parent advocate position. The meaning of all of these goals and changes may have contributed to the goal which the participants assigned to the interviews in this study, and affected participant responses.

The fourth source of reactivity described by Paterson (1994) refers to the perceived importance of the interview by both the researcher and the participant. The participants and I each had our own perception of how important the interview was; sometimes these perceptions were not in agreement. For example, as an insider, I neglected to seek in-depth answers to questions that I thought I already knew the details of because of working in the PICU. The participant may have believed that this neglect was due to disinterest in the interview, which in turn could have affected the participant's responses. According to Paterson, perceptions of importance of interview questions and answers should be checked out whenever necessary in order to look for disagreement between perceptions.

The fifth source of reactivity refers to normative or cultural criteria. Knowledge of this source of reactivity led me to consider the culture in the PICU involved in the study. As in all units, there is a culture regarding the standards of behaviour. To illustrate the existence of this culture, I reflect on my practice as an educator in this PICU. It is frequently a source of amazement to myself and my colleagues how cultural standards vary across units and between teams of staff in this unit. When nurses from other units start in this PICU, they often comment on the variations between cultural standards in this unit and the one they left. From shift to shift in this unit, reactions to changes and education sessions are quite varied, depending
on the teams of staff involved. Because of the cultural standards specific to this PICU, the participants may have felt pressured to give certain responses to the questions that I asked. Many participants shared similar experiences with certain health care professionals.

Having considered five sources of reactivity and their potential effects on my study, I became aware of their occurrence during the data collection. There are ways of identifying the reactivity which arises due to these five sources (Paterson, 1994). Throughout this study, I reflected on the interviews and the data collected, analyzing what was transpiring in the interviews, bearing in mind the five sources of reactivity. My reflections were included in my journal. In sharing my reflections as well as the study data with experienced committee members, I endeavoured to a) maintain awareness of the effects of reactivity on the rigor of the study and b) decrease or report the effects in the final analysis.

As a final check for rigor in this study, I utilized the following strategy identified by Sandelowski (1993) and endorsed by Thorne, Kirkham and MacDonald-Emes (1997). In order to check validity of the analysis related to researcher bias, I shared with the participants the analyzed data, rather than the raw data. The analyzed data included not only the descriptions from the participants of the factors influencing their decisions regarding parental presence during invasive procedures but also my interpretation of their combined descriptions. I asked the participants to locate in the analysis where their perspective either did or did not fit, and why. This provided an opportunity for input from the participants regarding the validity of the researcher's perspective and prompted their responses to the other participants' perspectives. There were some differences in the analyzed data as presented to the first participant in comparison to the fifteenth participant.

**Ethical Considerations**

The rights of the participants are protected by following ethical procedures. Approval for this research proposal was received from the In-Hospital Research Review Committee and the University of British Columbia Behavioural Research Ethics Board. The consent form (Appendix B) was obtained with
my comfort that the participant was informed and aware of all pertinent aspects of the study (verbally and with an information letter, Appendix A). Confidentiality is being maintained by careful handling of the tapes and the forms containing the participants' names; the tapes, forms and transcripts are locked in a filing cabinet drawer. Each participant is referred to by a letter code. Similarly, careful reporting of all data in the thesis report, in publications, and in verbal or written presentations is ongoing to ensure participant confidentiality. Measures are being taken to protect participants who could be recognizable by demographic features; for example, each participant's gender is referred to as female in this report. I was alert to signs of discomfort on the part of the participants with the interview process and kept the participants informed of their freedom to refuse or withdraw participation at any time. As a final ethical consideration, I asked for and received every participant's input on my analysis of the data.

**Limitations**

One limitation of this study is related to its generalizability. The participants were all staff members from the PICU who volunteered to participate. As such, they may have particular characteristics which non-volunteers do not have. Perhaps they volunteered because they really care about the question of parental presence during invasive procedures in the PICU. Perhaps they have a strong commitment to be involved in research, to be family-centered or to have a voice in the PICU. Perhaps other staff members chose not to be involved because of their relationship with me and/or awareness of my views on this topic; thus, the responses of this group of participants are not generalizable to all PICU health care professionals due to this predictable sampling bias.

A second limitation is related to my inexperience as a researcher. While I have a passionate curiosity about this topic, I have not previously conducted research at this level. This may have affected the quality of the interviews, the purposiveness of the sampling, the quality of the data generated and its analysis. As pointed out by many experienced researchers, conducting interviews and engaging in methods of qualitative research are advanced skills (May, 1989; Paterson, 1994; Thorne, 1991). The members of the
thesis committee, however, are experienced researchers, and were alert to the potential effects of my inexperience when proposing the study, conducting the interviews, analyzing and interpreting the data, and writing the thesis report.

The nature of the type of knowledge sought in this study presented a challenge in that some of it may be what Altheide and Johnson (1994) refer to as "tacit knowledge." Benner and Tanner (1987) describe this tacit knowledge as manifested in the way that expert nurses practice without necessarily being conscious of the factors affecting their decisions. Recent literature regarding reflection suggests that while reflection-in-action may be difficult, reflection-on-action may enable nurses to articulate the factors affecting their decisions (Atkins & Murphy, 1993; Fitzgerald, 1994; Saylor, 1990). Fitzgerald defines reflection-on-action as "the retrospective contemplation of practice undertaken in order to uncover the knowledge used in a particular situation" (p. 67). Schon (1991) proposes that reflection-on-action is indeed one way for practitioners to identify the factors, knowledge and skills used to arrive at a clinical decision.

On the basis of this reflection literature, I believe that the interviewing process is one way to facilitate such retrospective contemplation of practice regarding parental presence during invasive procedures in the PICU. In this way, the interviews served as opportunities for participants to engage in reflection-on-action, and valuable information was illuminated regarding the factors which influence health care professionals' decisions around parental presence during invasive procedures in the PICU. It is also inevitable that some factors, knowledge and skills used by the participants when in the situation were not available to conscious communication; therefore, the interpretation of the interviews is skewed in terms of addressing only the factors and reasons which were not beyond conscious knowing.

Significance of the Study

As previously mentioned, nursing research results should contribute to a nurse's ability to nurse people. With respect to research results regarding parental presence during procedures on children in the PICU, the contribution is minimal. There are quantitative findings which contribute to the nurses'
knowledge in this area. For example, the findings of Gill (1993) gave rise to percentages of nurses with particular education or parenting backgrounds who had more accepting attitudes towards parent participation. Findings from this qualitative PICU study, however, add context to the available quantitative findings. This context contributes to the applicability of the knowledge currently available (Hamers, Abu-Saad & Halfens, 1994). Indeed, Callery and Luker (1996) believed the qualitative methodology used in their study contributed to the quality of the information from the participants by empowering them. Where the participants were hesitant to merely criticize care, they were eager to relate significant issues by telling a reflective story. Similarly, I found that participants in this study were able to reflect upon and articulate their decision-making while relating actual situations - even those who were initially concerned that they did not know what factors influenced their decision-making. Thus, the findings in this study add to the body of clinical knowledge from which practitioners derive their decisions in everyday practice.

Summary

In this chapter, the research method of interpretive description which was used in this study is described. From unstructured interviews with nurses and physicians working in a PICU, data was generated regarding factors affecting their decisions regarding parental presence during invasive procedures. Theoretical sampling was used to identify participants from whom data was gathered. This data was analyzed and emerging themes interpreted with validation from the participants. Methodological rigor and limitations are considered, especially with respect to my relationships with participants in my role as an insider. Similarly, ethical considerations which were and are being employed to protect participants have been presented.
CHAPTER FOUR: PRESENTATION OF THE FINDINGS

This chapter begins with a brief characterization of the participants who described their care of children and families during invasive procedures in the PICU. Following this, the participants' descriptions of care during invasive procedures are presented as the research findings. The data were analyzed and coded according to categories that emerged throughout data collection. The categories to be presented here included: the professional's initial decision, mediating factors which influenced the initial decision, and contextual factors which further influenced the initial decision and/or its final outcome. Second interviews with each participant resulted in clarification, validation or revision of these categories. For example, initially it appeared that a health care professional's goal for a procedure varied on a "parent presence" continuum from restrictive to open. The participants emphasized that, at times, parental presence does not reflect a health care professional's philosophy about parental involvement but is simply a lack of attention to this issue. Upon their suggestion, I asked the participants to reflect on the goal(s) of procedures in the context of parental presence, rather than only on parental presence. This input resulted in a revision of the parent presence continuum to two different primary goals which health care professionals choose for a procedure. The other categories and factors were similarly clarified, validated or revised and this revised interpretation of the data is presented in this chapter.

In general, most participants shared that, prior to the research interviews, they had never really thought about the factors that influenced their decisions regarding parental presence during invasive procedures. Through the process of sharing their stories in the research interviews, they reflected on what they experienced and believed regarding parental presence during invasive procedures. By the second set of interviews, many were sharing recent observations that they had made because of their previous reflections on this topic in the first interview.

Description of the Participants

Fifteen health care professionals, ten nurses and five physicians, participated in this study.
Education among these participants varied. Nursing education was at the diploma, baccalaureate or graduate level, many nurse participants also having completed post-basic specialization in pediatrics, critical care or pediatric critical care. Likewise, the physicians had varied educational preparation, including medical degrees and degrees in other fields; all had fellowships in pediatric critical care and other specialties, completed or in progress. Clinical experience among participants also varied; all had extensive experience in pediatric health care settings, ranging from six to nineteen years, with the majority of that experience being in pediatric critical care. Many of the participants had cared for children with cardiology, oncology, post-anesthetic and developmental needs in their previous pediatric practice. On a personal level, about half of the participants were parents of between one to three children, ranging in ages to sixteen years. Nine of the participants were female and six were male. For confidentiality purposes, all indications of participant gender in this report will be feminine.

The participants were asked whether there was any other personal data that they believed affected how they viewed the research topic. A few replied there was not; the rest offered personal or professional experiences. These experiences included hospitalization of themselves as a child or of close family members, a focus on pediatrics or family-centered care that characterized their professional education, closeness among their families of origin, and exposure to many diverse clinical practices early in their professional education. Interestingly, these experiences were believed by participants to contribute to their "liberal views" regarding parental involvement, although individual participants' practices varied widely in this regard. Participants were asked what a "liberal view" was and where they saw their practices fitting with respect to general practice in the PICU.

I'm liberal, and you know that because, when someone asks you over to take out a chest tube and you say to them, "Do you have any objections to the parents being present?", a lot of them get a surprised look, and they haven't even thought of that. It may be in my head, but it seems to be that less people now ask parents to leave for suctioning. So I think I see people relaxing....But I find for chest tube removal and extubation, that people are still not comfortable.

I haven't a clue (whether attitude and practices are typical of others in ICU). I actually haven't a clue because I don't, you know, you're never around when other people are doing procedures, and
you're on (on duty) when other people aren't on. I actually don't know. It may be a bit more permissive because I've noticed that some of the others get a bit more upset by parents being around when they're around....I suspect I'm probably a bit more permissive.

Of the three participants who replied that there were no pertinent experiences to share, two believed they were liberal regarding parental presence during invasive procedures while one did not.

**Health Care Professionals' Decision-Making**

**The Decision**

Participants identified three different decisions which could possibly be made regarding parental presence during invasive procedures in the PICU. The decision most often made was asking parents to leave. Another possibility was parents being present for a procedure because they happened to be there and were not asked to leave. The third decision was giving parents a choice to be present for a procedure.

**Asking Parents to Leave**

Participants reported that for most invasive procedures, parents were asked to leave. The majority of participants agreed that it was unusual for health care professionals to invite parents to be present during invasive procedures. They also reported that it was unusual for parents to challenge decisions of health care professionals, whether asked to leave for routine caregiving, like a bed bath, or for an invasive procedure, like a central venous line insertion. Participants believed this was either related to a parent's desire to leave or to a parent's need to protect their relationships with those responsible for taking care of their child.

I think a parent will always consider the effect of challenging health care professionals on their child....They're always going to think about what's best for their child and if they piss the staff off, it might affect the child's care. Now that's not the right way to word it but, um,...I mean that's being really blunt about it....Yeah, I think they do consider, they weigh the consequences of asking to stay, you know. If they say, "Can I stay?", and this nurse who they perceive to be very authoritarian says, "No, you can't", the parent is going to say (to themselves), "Is this nurse going to be upset by pushing this? Is it worth it?" Because regardless of how hard the parents push the nurse, they know that that nurse still has to look after the child.

Participants reported that, most often, specific reasons were not given to parents for asking them to leave, largely because giving parents rationale for this practice did not seem necessary. Only one participant responded that she always asked parents to leave. She believed that there needed to be a consistent rule
about parental presence so that parents could not accuse her of "discrimination."

In general, I believe there's an ethical dilemma and the dilemma is if you are going to even personally have a policy, it has to be universal. So I cannot allow one parent in and not another...I have to treat them all the same so that I don't set up any incidents. So then I say, "I'm going to treat them all the same and they're either always going to be present or they're never going to be present" - and then the decision is very easy.

A few participants reported that there were occasions when parents insisted on staying after they had been asked to leave. On these occasions, parents stayed for the procedure despite the professional's reservations; participants were unable to recall any times when this was not the outcome of a parent's refusal to leave.

Unaddressed Parental Presence / Absence

Some participants described performing procedures on children with parents present simply because they were there; their presence or absence was not addressed by the health care professional. Reasons for this varied from lack of time to address the situation to lack of concern regarding their presence. A few participants who were unconcerned about a parent being present for a procedure also assumed that if a parent was there, "someone else" must have made a decision that this was the best practice for the situation. All participants believed that parental presence for procedures in any given situation was indeed a question which necessitated a decision. Variation among participants was demonstrated only regarding questions of "who should make the decision" and "what should be the decision" for each situation. Most participants stated they were unhappy about situations when parents were present because no one had addressed the issue with the parents. Participants shared concerns about the problem of lack of parental support in these situations and the potential for unknown trauma to parents. While beliefs regarding the extent of this problem varied among participants, all participants believed health care professionals were responsible for this problem.

Giving Parents a Choice

Sometimes, participants made decisions to give parents a choice regarding remaining for an invasive procedure on their child. Participants found that, when given the option, sometimes the parents
chose to stay and sometimes they chose to leave.

Sometimes I'm quite surprised at the parents that go (leave) and what (the procedures) they go for. But I always get from them a real sense of relief when you ask them if they want to stay and if they say yes, it's obviously quite important for them to stay....I just get the sense of relief from them and maybe my assumption would be they just wanted to become more in control and know they're being considered in the picture.

These participants were asked whether they ever had discussed with parents their reasons for choosing to leave. Most indicated that they had not thought about this. A few participants had done, however, as in this example:

If I ask a parent to stay and they say, "No, you know, little [name] cries more when I'm here", then I need to explain why children usually cry more in parental presence. That would probably be the only time where I would question their decision to leave. I use that opportunity just to say, "Often children will cry more because they feel they can express themselves when parents are around and they're actually feeling, you know, more at ease and it's not necessarily a bad thing." But I know, that what I do always say to parents is "Don't feel bad if you want to go; that's quite OK"....I don't know but I do know that I don't want them to feel guilty about not staying. I see that as their choice.

All participants felt strongly that parents should not be made to feel that they "had to stay" or to feel guilty that they "couldn't stay." While parents sometimes were offered a choice to stay for a procedure, they were not usually encouraged to stay for the sake of their child, as in this example:

I've seen where the kid is just so different when mommy is holding, singing, talking, whatever like that. There was an IV start that the mom stayed for and that was because I knew, I had watched this child....I can remember saying, you know, to the mom that it would help her little boy if she were there. Whereas I don't in general say that but I think my rationale for this is because I don't want to put a sense of guilt on a parent's face..."If you want to stay, you can stay; if you don't, you don't have to stay."

Some participants believed that there were differences in the way parents were informed about procedures and their choice regarding being present, and that this could account for whether parents chose to stay or leave. These participants believed that parents perceived whether the health care professional was "allowing them to stay" or "welcoming them to become involved." These participants believed there was a balance between the needs of all those involved with the procedure, the needs of the child, the parents and the health care professionals. Some participants admitted they were now embarrassed to recall previous
practices with parents.

I used to find out when they're going for coffee. Or, God, I'm empty-headed because, I'd say things like, "Well, maybe do you have some phone calls to make, like phone the rest of the family to let them know the surgery is over?" It gives them permission to leave but what I'm actually doing is completely based on my need to do something horrible to their child while they're not there. And I don't do that anymore. I'll say, "If you need to make some phone calls feel free to go whenever. I have some things I need to do for your child. And you're welcome to stay while I put this N/G tube down or put a Foley catheter in" or whatever. And again I give them the information and ways of helping their kid.

A few participants reflected on situations where they felt more comfortable than usual with the way the issue of parental presence during procedures was discussed with parents. These situations were often ones where participants knew what the parents wanted to do, as the parents had shared, with the participant or another health care professional, how performing certain kinds of care did or did not help the parents to cope with their child's illness. A few participants acknowledged that a proactive way of approaching parental presence during invasive procedures would be ideal, admitting that it would be very unusual in current practice.

It's interesting because talking, talking some of this stuff through to you, I realize that although I do a fair job, I think that in an ideal world, you would really plan this procedure stuff well in advance so you're not asking the doc as he rolls up with a central line cart. You've asked him on morning rounds and you've talked, do you know what I mean? But we don't, we don't talk it through but that would be the way to go. It would be to discuss it with all the staff; discuss plan A - if parents want to be present; plan B - if they don't. And then I never follow up with the parents to ask them, "How did that go? Was there anything that we could have done differently or that might have made it better?" Or discuss it with staff; we don't do that stuff.

Another participant introduced the idea of anticipatory planning for what parents would or would not want to be involved in. She suggested that the care plan could be used to indicate what parents would like to do, not only during procedures on their own child but also when other procedures, especially resuscitations, were happening with other children in the unit.

Many of the participants voiced concern regarding the fact that health care professionals do not discuss topics such as their beliefs regarding parental presence during procedures with each other; some participants added a concern that this topic was not discussed with parents. Some participants wanted these
discussions to yield guidelines for making decisions regarding parental presence during procedures. These participants expressed that guidelines would assist them to feel more comfortable making decisions regarding parental presence during invasive procedures and help health care professionals to make decisions which were more consistent with each other. Conversely, a few of the participants wanted to make the decision regarding parental presence autonomously and were very adamant that this was a decision that only the health care professional involved with the procedure could make.

I'm very kind of definite on that. There are some things I agree with and some I just don't agree with parents seeing. I think I'll feel that way and even if all the rules change, I'll still keep that way. For even if somebody were to say, "OK, parents are to stay for every single procedure," if they're my parents, I'd still ask them to leave. And I don't think anybody has the right to tell me anything else because I'm right there and their child's advocate and I have to be in a position to make that judgement.

One participant stated that the decision about parental presence was unique to the PICU as well as to the health care professional involved and should not be based on what happened in other areas of the hospital or what happened concurrently with other health care professionals in the ICU.

I have done LPs (lumbar punctures) with parents there....Well, what was different is I didn't have the authority. The one or two times I was doing them (LPs), the parents were given permission by the attending and I didn't have authority. That's their preference....In Emerg when parents walk in (during resuscitation), things are going fast enough. Most of the time, you don't notice it but when you do, it's not the time to make an issue of it. Also in our ER, I'm not in charge. The ER physician is in charge. I may be uncomfortable with it but it's not my decision.

One participant questioned why only the presence of parents during procedures was discussed for an issue regarding family-centered care. She brought up the question of sibling, grandparent, friend, etc., presence during procedures. Due to an experience with a sibling of a child who had died, this participant felt the need to expand the discussions of "parental presence" to "family member presence."

One of the experiences I had, this one, was a very positive one for me. I don't know if it would always be this positive. But I had a little one, oh I think she was a nine year old East Indian girl who was in spot, yeah, was in spot six, and she was dying. What was she dying from? I don't remember seeing a dressing actually; it wasn't a head injury. I don't think she was from oncology because she would have been in an isolation room...Anyway she was dying. She had a little brother who was five or six...There was a lot of family at the bedside, extended family at the bedside. Mom was wailing; all of the women that were there were wailing. All of the men that were there, there were probably eight people at the bedside, the men were chanting and there was
an uncle who was kind of the contact person. And Mom, I wasn't concerned that Mom was beside herself with grief, she was doing what the uncle had said was appropriate. The women, that was their role in this situation was to cry. The sibling was outside, the little boy was outside and I talked to the uncle and he talked to the Mom about bringing the little brother into the unit. And he came in and I talked to him about the fact that his big sister was dying. His comment was she looked like she was sleeping. And I said, "Yeah. She looks like that, and she's going to go to sleep and she's never going to wake up." And he got on the bed - like I offered him, I said, "Do you want to sit beside your sister?" - and he wanted to give her a kiss and he wanted to talk to her. And he got up on the bed and he gave her a kiss. The Mom continued you know, no more, no less, continued with the weeping and the family continued on. It went on for, you know, him sitting on the bed was less than five minutes. It wasn't a long period of time but then he got off, like he went, he was taken out with a family member and was just standing around. The family did not stay for her actual death, they left the unit. But after she had died, the uncle came back and said that Mom had said how much she appreciated the fact that the little boy had a chance to come in and say goodbye. And it, like I wasn't sure. Is this going to work? I wasn't sure, um, but it seemed to be a good situation for this kid, for this family. Again she had equipment and she was intubated and when they talk about it scaring the kids? And I mean he got right down to it -"She looks like she's asleep." And this bit about, you know, I said that she's going to sleep and he sort of repeated back to me, "So she's never going to wake up"....Whether he understood it? The reality, no, no; but the sadness and the seriousness of the situation, yes.

Other participants agreed that, currently, only parents were referred to when making decisions about a family member being present when an invasive procedure was being performed on the child. One participant related that an incident came up prior to her second interview where an adolescent coming in for an overnight test asked if a friend could come and stay overnight with her in the ICU; the request was refused. The implications of the relationship of a child's support person was discussed with many of the participants and some concerns were raised. All were in agreement, however, that currently the main relationship referred to by health care professionals was that of the parent-child relationship.

Mediating Factors Influencing the Decision

Of the three possible decisions regarding parental presence during procedures, the one initially chosen by participants was mediated or influenced by their primary goal for the procedure. Two primary goals that the participants claimed when making decisions regarding parental presence for a specific invasive procedure were identified in this study. One primary goal was to perform the procedure with the desired outcome of maximal efficiency and minimal disruption. The other primary goal was to perform the procedure while maintaining the integrity of, and minimizing disruption to, the parent-child relationship.
The choice of the primary goal was influenced by mediating factors at the outset. Four mediating factors discussed by the participants were: the professional's beliefs regarding family-centered care, the professional's personal and professional experiences, the length of time available, and finally, "the phase of the moon" or a combination of undefinable factors. Once the primary goal was chosen and the process of decision-making for a specific procedure had begun, contextual factors further influenced the initial decision. These contextual factors related to the nature of the environment, the nature of the procedure, and the nature of those involved with the procedure.

**Primary Goal for the Procedure**

The health care professionals began with a primary goal regarding a procedure's outcome, considered how a parent's presence or absence would affect the achievement of that goal, and then progressed to making the final decision about parental presence while considering, or dealing with, other factors as they arose. Some health care professionals relied solely on one of the goals when making a decision regarding parental presence during invasive procedures. For example, some were more efficiency-oriented than parent-child-oriented while others were most often parent-child-oriented. One participant likened this to an article she had read in nursing school regarding "task-oriented versus people-oriented nurses." Other participants shifted their primary goal dependent on the situation.

The health care professional's primary goal for a procedure was influenced by a number of mediating factors. These mediators acted by having an effect either on the health care professionals' general approach to the issue of parental presence during invasive procedures or to an individual procedure. For example, a personal or professional experience with parental presence might have influenced the participant for future procedures in general or for the next few procedures performed.

**Maximal efficiency and minimal disruption.**

At times, the participants referred primarily to the technical success of the procedure when they shared their stories regarding their decisions about parental presence. Technical success included
performing the procedure with the desired outcomes of maximal efficiency and minimal disruption. This goal was often thought to be compromised if the parent was present, for varying reasons.

I sometimes feel I get better co-operation from a child when their parent isn't there and those are probably the times when I will just sort of wait for a parent to leave. And then, it could be something as routine as doing a suction or taking out an IV (intravenous catheter) that's not in...I can be in and out and done faster than if they're there.

Of course I always ask them to leave. I usually explain what I'm going to do and I will also explain why I'm asking them to leave, particularly if they're interested or if there's any resistance......I promise them the child will feel no pain, and sometimes I will explain that I'm better, if procedures are difficult, I'm better if I'm not feeling like I'm being watched by someone who has a vested interest in the child. So it's nervousness and I will tell them that, that I do better.

At times, however, the participants believed that parental presence facilitated such a goal.

I let anyone come in anyway if they want to. I suppose in an older child you've got more chance that the mother's presence is actually going to help you, you know. With a baby, it's not of much use...um but with an older child, I might actually go out of my way to encourage it, in a child where I think the mother's presence might actually make the whole thing a little bit calmer.

Other times, the primary goal of the participant was maximal efficiency and minimal disruption and the parent was present or absent during the procedure because of other factors that arose unrelated to whether presence or absence best met the goal. One such situation was during an admission of a critically ill child when the unit was very busy, and the health care professionals were too distracted to make a conscious decision about parental presence.

In fact, there was so much action that there were three nurses at the bedside and he was extremely unstable and the parents were given very bad news....All this rush is happening and there's also two doctors at the bedside as well and they're putting other lines in and his chest was enormous. The parents are at the bottom of the bedside watching everything that's going on. Nobody had time to turn around and say stuff to them.

**Maintaining the parent-child relationship.**

For some participants and in some situations, the primary goal for a procedure was maintenance of the relationship between the parent and child. Participants' stories indicated that generally parents were offered a choice to be present when the main goal of the professional was maintenance of the parent-child relationship. One participant discussed how she advocated for parental presence during a procedure
because it encouraged a stronger connection between the parent and child.

And the parent wanted to be there. So she was up at the top of the bed and she just held the child - he was lying over on his right side - she just put her hand on his head and held his arm up. I told her what to look for in terms of, that his eyes were going to bounce back and forth and that he didn't need much stimulation because there may be some hallucinations involved and things like that. I said "Just sit with him quietly, and just be with him." And this mom was completely focused on this corner of the child that she could see underneath the dressings. I don't even think she watched the chest tube go in; she just sat there and looked at her little guy and then as he woke up, as he sort of came out of it, by then you know, we'd dimmed the lights and closed the door, just kept everything really calm and I just told the mom, "What he needs now is calm, quiet. He might just need someone to hold his hand but he doesn't need stroking, he doesn't need whispering, he doesn't need talking, he just needs quiet" and she was fine.

At times, offers to maintain a parent-child relationship during an invasive procedure resulted in a parent not staying for the procedure. In the following example, the participant interpreted that the parent's decision reflected discomfort with observing the procedure:

I felt at that stage, it was kinder to the child to have the father around so, although I usually ask the parents to leave, in this particular case, I asked the father to stay. I said "Would you like to stay? I think she's going to be better off." And believe it or not, the father said that he didn't want to be there and so he left.

Other participants whose primary goal focused on maintaining the parent-child relationship stated they liked it best when they could first establish relationships with the parents and then give them choices about remaining or leaving during an invasive procedure.

It gives them some control over the situation in the sense that, you know, I mean I'd ask them the history of the child with IV starts, etc., to try and get some input from them which comes with establishing a relationship and also recognizing their relationship with the child as the primary caregiver. I think our environment is so controlling in the sense that because it's critical care and technical, we take so much away from the parents and they still know the kids better than any of us. So why, why shouldn't they be able to have their input into something like that?....Dad stayed and he was really good about telling me, you know, "They've tried this hand so many times..., maybe it would be better..., she's a really difficult start...," and he was really good about giving me feedback. Then he held her, even though she was pretty sedated, he held her and he talked to her and you know he watched what I was doing .... but I don't think I got it (the IV).

There were a few participants' stories where parents were asked to leave because maintaining the parent-child relationship was the health care professional's primary goal and it was thought that parental presence would compromise that goal. A few of these situations were prompted by a belief that almost half
of the participants mentioned. This belief concerned maintenance of the child's trust in the parent by ensuring that the parent was not involved during the procedure but came in after the procedure as "the rescuer."

I find anyway, with the cardiac kids, parents with long term cardiac kids will leave because they don't want the child to associate them with painful procedures. I'll usually ask them "Do you want to leave for this?," and I've often said to parents, "Sometimes you coming back in is the whole comfort of this procedure being over and sometimes when you're there, you can be associated with it," and they kind of go, "Yeah." I find at times that's the way they actually think, "It's better if I'm not here for some procedures."

Participants who asked parents to leave did so at times because they wished to acknowledge the parents' role of protecting their child. For example, one participant related that she had agreed to a mother's request to be present for a central line insertion, assuming that this experienced mother knew what was involved with the procedure about to be performed. The parent got very upset during the procedure, left the room and acknowledged afterwards that she was not prepared for what she saw and that it was very upsetting.

Following the incident, the participant reached the following conclusion:

This event actually reinforced my views that having your child attacked by someone else, even with a depressed level of consciousness and knowing that it's good for your child, but at the same time, it's an attack, basically it's a physical attack. I mean I'm just stabbing the child. And if my child were to have something like that, I wouldn't like to be present at all because I think it's a very fundamental instinct, a very basic instinct to defend them and if you see someone that you feel very much for and you see what's going on, it's not pleasant and that's why I like the parents not to be there for that procedure.

This view regarding a parent's protective instinct was reiterated by other participants. A few participants were willing to give parents the choice regarding whether the parent-child relationship would benefit more or less from the parent's absence. Other participants firmly believed that part of their role was to make the decision and that the best way to protect the parent-child relationship was through parental absence during an invasive procedure. As one participant put it:

If the child is really crying and the mom is really anxious, sometimes it's not a good idea if they're there for the invasive procedure. Like I think a lot of the times it does depend on the parent and how they can cope with it, you know. Maybe for some really anxious parents, it's better for them not to be there during invasive procedures and then for other parents that can take it, alright then.
In the examples above, the participants wanted to protect parents by encouraging absence from procedures, believing that protecting the parents would also maintain the parent-child relationship. In two other examples, the participant chose to protect the child believing that this would maintain, or not worsen, the parent-child relationship:

The parents were actually creating more anxiety in the child than they were allaying. And then that changed the whole purpose of having the parents around, so I asked them to leave.

One exception to parental presence being beneficial was in a child who had been abused who was a pre-schooler and it was documented that she was frightened of her stepfather, so I can't have him at a procedure.

In these situations, health care professionals viewed the parent-child relationship as complicated and problematic. The participants' decisions related to the parent-child relationship were different than in parent-child relationships that were not considered to be problematic.

Choosing between the two goals.

If a choice was considered necessary between the goals of technical success of the procedure and maintaining the parent-child relationship, the former would generally take priority. One participant discussed a family who were perceived to be purposely annoying staff by "asking questions to try to trip them up and snickering about doing that." The participant believed that in this instance, she could legitimately say to parents:

"In order that I do this procedure to the maximum efficiency, I'm going to ask you to leave" and I would have no problems with doing that because once again, although I'm very family-centered, I do believe that your number one priority is the child. If you're going to be really effective doing the procedure, I don't feel bad in asking the parents to leave.

Another participant discussed that although most often parents should be given a choice about staying or leaving, "It's not a perfect world and erring on the side of caution to the benefit of the child" was sometimes asking parents to leave because of certain factors arising in any given situation. While a few participants had never performed a procedure with a primary goal of maintaining the parent-child relationship, all participants attested to having performed a procedure with a primary goal of maximal
efficiency and minimal disruption.

Mediating Factors Influencing the Primary Goal

Four mediating factors influencing the primary goal the participant relied upon to make the decision regarding parental presence during procedures were identified: the professional's beliefs regarding family-centered care, the professional's personal and professional experiences, the length of time available, and the "phase of the moon."

Beliefs Regarding Family-Centered Care

The participants were asked how the issue of parental presence during procedures fit with the practice of family-centered care. Significantly, half of the participants asked for a definition of "family-centered care," either indicating that they had never heard the term, they were unsure of the meaning of the term, or that they wanted clarification regarding my definition. For two of the fifteen participants, parental presence during procedures had "nothing to do with family-centered care." Both participants subscribed to parental absence during invasive procedures. They indicated that the presence of parents during procedures was "carrying things too far," that care can be family-centered without parental presence during invasive procedures, and that the more parents were allowed, the more "demanding" they would become. As one participant put it, "parents will want to come and watch open heart surgery next."

Responses from the other thirteen participants indicated that parental presence during procedures was an issue intimately related to family-centered care.

I guess basically whatever you're doing to the child is what you're doing to the family. Now sometimes your child is paralyzed and sedated and just completely snowed. So they don't, I don't think the child cares what's going on. They're sort of swimming around in their brain and they're not really aware of anything. But the family is conscious and completely with it, and in a heightened state of awareness. So I want to treat them (the family) because they're just an attachment of that child really. You know whatever I'm doing to that child, I'm really doing to the family.

I think we need to really keep to it, I mean beyond recognizing that (family-centered care) and saying things like "Well, it's not my child" and "The child belongs to their parents." They ought to be there. We shouldn't be making this decision. I don't think you can separate parents' presence from family-centered care. I think you either include the whole family and negotiate what works
best for them. Or you are dealing with two separate entities, the child and the parents, and I don't think you can do that.

Some participants' beliefs about the relevance of family-centered care were congruent with their stated practices; those who believed in family-centered care involved or considered the family when making decisions regarding parental presence during invasive procedures. For a few other participants, beliefs regarding family-centered care were incongruent with their practices. One participant realized during the interviews that although she believed that a choice of parental presence during procedures was philosophically part of family-centered care, she often did not consider maintenance of the parent-child relationship to be a goal for an invasive procedure; rather she often pursued the primary goal of maximal efficiency and minimal disruption with a decision to ask parents to leave. As with all other participants, she personalized her stories and talked about what she would want if she were a parent in the situation. This participant also realized that she was not treating families as she would want her family to be treated if her child was in hospital.

And so it (parental presence during procedures as part of family-centered care) fits into my way of thinking. But in practice I don't see it happen and yeah, that's maybe an easier way to do it, is to do it (an invasive procedure) when they're (parents) not around....I mean, you can have this philosophy but you don't think about it, how it relates to your practice.

Personal and Professional Experiences

The participants believed that some past experiences were significant for them in mediating the decisions they made regarding parental presence during procedures. These experiences related either to their personal or professional lives, and had made an impact on them as individuals, and thus, on their beliefs and decision-making regarding parental presence during invasive procedures in the PICU.

Some participants shared experiences that indicated why they believed they had a family-centered approach, and thus, were more open to parental presence during procedures. Participants who had lived in different cultures or whose cultural identity was different from that of the dominant group believed that such an experience helped them to be more flexible and understanding of the need for a family-centered
approach. One participant stated that her educational background had included indepth study of philosophy and psychology that she applied in her nursing practice, and helped her to incorporate the need for family-centered care and parental presence. Yet another referred to early and numerous personal experiences with hospitals (some details changed to protect the participant's identity) as affecting the way she viewed families’ presence during an invasive procedure.

My mom was critically ill for some time when I was young and has been in different hospitals at different times; my grandfather was in another hospital. Between these times and my own experiences in other hospitals, I've always been struck by the restrictive nature of these places towards families and friends.

Some participants admitted that their past experiences had not been integrated into their practice. A few related having early and ongoing experiences with emergency departments and hospitals in which they perceived a need for family presence, but recognized, however, that in their own practice, they often expected parents to leave during an invasive procedure. Although they perceived this a contradiction to some degree, they believed that there were factors that they had not seen as a patient or family member of a patient that contributed to their decision to ask parents to leave during an invasive procedure.

A few participants shared early professional experiences that had significantly shaped their belief that there are problems with parents watching invasive procedures on their child, as in the following example:

This was just bizarre where it was a child who had a chronic illness that was brought in, in respiratory distress, and she was in the intensive care. And our parent's room was next door. The two rooms were kind of joined together and the door was open slightly. I had the mom sitting down and was asking her questions going through the admission. She said "What exactly is going on right there?" And I said, "Oh well, they're probably going to intubate the child and basically what's happening is...," but she didn't listen. She pushes past me, goes out and the doctors were putting the tube in. And she said, "If you don't intubate and resuscitate that child properly, I will sue you for every penny that you are worth." And the doctor was sort of quite new to the hospital and now his hands were shaking even more, (laughs) and I remember thinking, "I'm never having parents (present) in an invasive procedure."

Early traumatic experiences did not always result in shaping restrictive future practices. Other participants shared similar professional experiences but were able to separate them from most other situations when
parents were present. In the following example, the participant stated that this was one upsetting experience with the practice of parental presence during a resuscitation but she still believed that this practice could be a positive one.

The first experience I had with a parent during resuscitation was in a newborn ICU. There was a baby who was not doing well, not doing well at all. And the parents knew this. Mom was too sick herself to come in and see the baby and we couldn't take the baby to her. It was just an awful situation. Dad was about as stressed as you could be, running back and forth between the ICU, the neonatal ICU. Dad was in visiting and the doctors were just about to discuss DNR (Do Not Resuscitate) orders with Dad because this baby was profoundly brain injured. He was really sick, and he aspirated and then he arrested before they had this discussion with Dad. Dad was standing right there. It was my patient. Everybody was there within a millisecond and the person working next to me - it was a fairly small unit - she took Dad a few feet away. So we all get in and he was yelling "I'm staying, I'm staying. I need to see this". And we were running a full code on this child and the father got quite upset and almost obstructive and this nurse had to physically pull him back and say "Let her do her job, let her do her job." Meanwhile, of course, there were other parents in the unit that the nurses had to go and speak with and give them the opportunity to leave. I think the resuscitation probably went on for about fifteen to twenty minutes longer than it should have....We took it farther than appropriate but we did it for the parents and the dad. The physician finally turned to the father as I was still doing compressions and he said, "I'm sorry, there's nothing more we can offer your child. Your child has died." And the father was really upset, I'll never forget. And he just literally ran to his child and we all just stepped back and the thing that still haunts me is that we didn't really follow up with that dad. Like we took him and his baby off in to a quiet room and then to the ICU to be with his wife because she needed to know. And that was just profoundly upsetting and I never did find out how they did, whether watching this, profoundly damaged this man or whether being moved would have done more damage. So that was barely into my career...

The participant indicated that this experience had not affected her decisions regarding parents staying for procedures but rather it affected how she facilitated parental presence during a procedure and the follow-up she provided for the parents involved.

Similarly, other participants told stories about parents fainting or other negative experiences they had when parents were present during invasive procedures. They emphasized, however, that these were infrequent occasions. Many of these participants stated these experiences did not affect them negatively in the long term and that they continued to uphold the need for parental presence during an invasive procedure. "I can think of a couple parents who weren't helpful but if you consider that I've been doing this for nearly ten years, that's not that many, is it?" In the second interviews, many participants stated they
could see upon reflection of their first interview how past experiences affected their practice regarding parental presence. They perceived that the nature of the influence of past experiences depended upon the meaning the experience had for the individual as well as the individual’s interpretation of the experience.

**Time Frame Available**

The time frame within which the procedure needed to be performed was frequently discussed as influencing the participants’ primary goal regarding parental presence during an invasive procedure. Participants talked about how time frames mediated the primary goal for the procedure and the length of time they would have to use towards making the decision regarding parental presence for a procedure.

Some procedures need to be done without time for planning while others can be planned. For example, when an intravenous infusing a critical medication is interstitial and stops infusing, another catheter needs to be placed in another site as quickly as possible. Other procedures are not as time-bound and so are planned more electively. For example, when an arterial line is leaking slightly around the site because it has been in use for over a week and needs to be changed, this procedure can be done anytime during the shift.

You see, the problem is there’s not very many elective intubations where we’re all set up, we’re going to do an intubation and this is what we’re going to do, with lots of time to do it. Intubation is now. It’s like a code, they occur when they occur. Sometimes the parents are there for them because the parent happened to be there and no one actually asked them to leave. And that’s bad sometimes too; it depends again on how many people are available. If it was an emergency situation, like in-the-night scenario where you’ve got less staff and there’s just the primary people there, I would rather have the parents wait outside.

Participants stated they found short time-frames very stressful, which likely affected how they perceived other mediating and contextual factors influencing their decisions regarding parental presence during invasive procedures.

It wasn’t harder for me that she (Mom) was there and upset, but I had time. I mean I had done what I needed to do at that time for that patient. So I had time to deal with her and everything was happening in such a way that if we stayed an extra fifteen minutes, it wasn’t going to be a problem. If I’d had things to do right then and there, if I can sort of take that situation and put it in ICU where I was busier and I had to deal with an upset parent, it probably would frustrate me. I would have to prioritize, what do I need to do - do I need to take the blood gas right now? So do I have to
get someone else to deal with this parent? Or can I deal with this parent and take a blood gas in ten minutes? So I'd quickly have to assess which is more important.

"Phase of the Moon"

Several of the participants agreed that, at times, the only reason that could account for their decision regarding parental presence was happenstance, such as "the phase of the moon." Some participants went beyond the identification of mediating factors, indicating that not only were they aware of the main factors affecting their primary goal, but were also aware that there were times when they were very inconsistent in their decision-making regarding parental presence during procedures. These were times when the participants chose goals or made decisions that were unusual for them; they surprised themselves on these occasions, when either parents were asked to leave or asked to stay, in a decision that was contrary to their usual practice.

It all depends I think on, you know there's so many factors, and the phase of the moon and what I feel like (laughter). If I'm going to be bright and cheerful and happy, it's one way; the exact same position, if I've had a bad night and I'm tired, it might be different.

I know that as a professional, I give them (family) much less care at nighttime, as far as interactions, to explain things and have the patience for other people's needs beyond my patient's. On night shift because my energy levels are lower, I'm different. And I think that's OK, I don't know if other people are too, but I know that's part of my limitations.

Other participants pointed out that rules would always be broken and that uniformity in decision-making would never be possible.

Contextual Factors Influencing the Decision

Whether the participants actually asked a parent to stay or leave during an invasive procedure was not entirely determined by their primary goal for the procedure or the mediating factors of their beliefs, past experiences, the time frame available and the happenstance factors. The actual situation presented considerations that were unique. These related to the context of decision-making such as the environment in which the procedure would occur, the nature of the procedure, and the nature of those involved in the procedure. Most participants claimed that decisions about parental presence during invasive procedures
required consideration of these unique elements.

I mean, there would be times when I'd be terribly uncomfortable having a parent around and other times when it would be great having them around. So there's no happy medium and I think each, each case needs to be individually looked at.

The Nature of the Environment

When the participants described their decisions regarding parental presence during procedures, contextual factors related to the nature of the environment in which the procedure was performed could be identified. These factors included the site or unit in which the procedure was performed, the physical space in ICU and the activity in ICU.

Site.

Some participants considered the nature of the unit in which the procedure occurred to be a factor that affected their decision regarding parental presence. They believed that on some units parents were expected to be with their child but that this was not the case in PICU. A few participants also mentioned the culture of different units was more or less friendly to parental presence during invasive procedures. The PICU with its high level of technology was perceived by some participants as a less friendly environment to parents wishing to stay with their child during an invasive procedure. The PICU culture was also seen as similar to that of other highly technological areas like radiology, emergency, and anesthetic and surgical areas. Interestingly, participants had varying experiences with how the factor of the site for the performance of the procedure affected their decisions. A few participants had experiences with parents remaining in highly technological areas while others believed these areas to be strictly "out of bounds" to parents.

Space.

The physical bed space in which the procedure was being performed affected the participants' decisions regarding parental presence. In crowded situations, many of the health care professionals preferred that parents leave. Some of the reasons for this practice were the direct effect of parental presence
on the comfort of the people involved, and concomitant effects on the success of the procedure and the
safety of the child, as well as decreased room to deal with emergencies, including a fainting parent. One
participant referred to a situation where she needed to direct the parent where to stand to give the health
care professional enough room to remove a tube. Another participant believed that parents should not be
present if the procedure required added equipment, personnel and movement around the bedside. When
parents were present, participants differed on the "perfect spot" for an invasive procedure to be performed.
Some considered an isolation room as preferable for parents as the procedure occurred away from the
happenings in the rest of the unit and there was privacy during the procedure. Other participants stated they
would rather be in an open area as surrounding space could be used to accommodate parental presence,
and extra personnel and equipment were close at hand if there was an emergency.

Activity in PICU.

Busyness in the ICU varies from shift to shift, and from hour to hour during a shift, more
frequently than some areas. Thus, timing of the procedure with respect to what else was going on in the
environment was a factor that affected decisions of some of the participants to encourage or deny parental
presence during invasive procedures. Participants believed that decisions made regarding parental presence
too far in advance would need to change if the ICU suddenly became busy. Staffing patterns changed on
nights, weekends and holidays, with fewer staff present in the ICU. As with the factors of space and site
for the procedure, this factor was viewed differently by different participants. For some, the decreased
number of people in the unit meant that there was less help to support parents who were present for
procedures. If the unit was very busy, there could be both fewer people to help and more commotion,
including unpleasant sights and sounds, that could be viewed as a negative environment in which to have
parents stay. For other participants, decreased number of staff in the unit meant that there was more quiet
in which to concentrate on helping parents be present for procedures. One participant who was used to
performing procedures in many different areas, stated:
In the ICU in some ways, we are more lucky in that the personnel is there to assist. A little bit more often, there's another nurse who's able to help out. On the other hand, on the negative side, there's more complex things going on. There's more equipment, it's more cluttered. So there's pluses and minuses. Overall, the ICU is not a bad environment to have parents around.

The Nature of the Procedure

In this study, the type of procedure being investigated was not limited, other than to a delineation of "invasive." Many participants began the interview desiring a definition for "an invasive procedure." The type of procedure to be performed was a contextual factor which contributed to participants' decisions regarding parental presence. The main classification of type of invasive procedure appeared to be related to whether it was being performed by a nurse or a physician. Other factors identified by the participants that related to type of procedure were its degree of invasiveness, the length of time likely to be required to accomplish it, its associated potential complications, its degree of complexity, and its predicted outcome in the cases of resuscitation and treatment withdrawal.

Degree of invasiveness.

Several participants believed that the "more invasive" procedures should not involve parental presence. The delineation of "more invasive" was primarily between procedures performed by physicians rather than nurses. This sentiment was expressed by both physicians and nurses. One participant explained that parents could watch nursing procedures, like IV insertion, chest tube removal, suctioning, N/G tube insertion but that medical procedures, like line insertion, intubation, resuscitation, and lumbar puncture were "too invasive."

Several participants mentioned the existence of hospital policies for some particularly invasive procedures that stipulated parents could not be present. Upon reflection, they wondered aloud whether this was an example of unwritten rules of PICU, as they actually had not seen a written policy. General practice in PICU had been interpreted as hospital policy.

Like the policy is right now that they (parents) leave, right. So they're usually just sort of asked, "Please would you step out at this time?" or they're denied entrance at the door....Well, maybe it's an unwritten policy....It's just all I've ever seen happen.
Length of time involved.

Another participant classified types of procedures according to the length of time involved. Central line insertion could be prolonged and protracted with several attempts, and therefore, she believed that parent presence was usually "not good" for the parent. This participant viewed any procedure where a tube was inserted as "too invasive" and any procedure where a tube was removed as "a success." Parental presence at tube insertion was viewed as not preferable while parental presence at tube removal was not only preferable but necessary. "It's (tube removal) actually an achievement....You're reversing the trend and you're walking away from that child and pushing the child closer to parents."

Associated complications.

Some participants classified certain procedures as associated with potential complications that could lead to other procedures. For example, participants who told stories regarding parental presence during extubation usually referred to the potential complication of re-intubation if a child had airway or breathing problems after the tube was removed. For some participants, this potential complication meant that parents could not stay during a child's extubation because although these participants viewed extubation as "not that invasive," intubation was "too invasive," and therefore, parents were asked to leave during extubation. Other participants allowed parents to stay for extubation when complications were unlikely, or with the proviso that if reintubation became necessary, the parents would leave. "We actually extubated a child and he failed, and Mom was there and we told her, "Look, this is not going well," and she was the first one to say, "I'll go for a coffee."" Of the participants who had experienced parents staying for extubation, no one had encountered any problems regarding parental presence.

Degree of complexity.

The participants' description of factors related to the procedure that affected their decision-making was often complex. For instance, one participant stated that IV insertion could be short in the length of time involved and, therefore, appropriate for parental presence; however, IV insertion was also a tube
insertion, making it "too invasive," and therefore, not appropriate for parental presence. For this procedure, the participant suggested she might allow parental presence for a period of time but ask the parent to leave if the procedure was not accomplished in two attempts. Another factor contributing to the degree of complexity was the size of the child. For infants, most procedures are more complicated due to the small sizes of the tubes required and of the sites into which the tubes are being inserted. For some participants, the anatomical differences involved with some congenital malformations were perceived as causing increased difficulty during specific procedures.

Individual preferences regarding parental presence during certain procedures were evident. For example, a few participants felt strongly about parental absence during procedures they considered to be private and personal.

The one thing that comes to mind that I probably wouldn't be comfortable asking parents to stay for, although I have, is catheterization. Just because people find it really disturbing, you know. Like they say they find it disturbing but I'll still ask them, "Do you want to stay or not?" I don't know, maybe it's just because it's sexual or a private part. People get uncomfortable, not so much with boys.

Another participant suggested the procedure of inserting a rectal suppository in an adolescent male was a private procedure during which she would ask a parent to wait outside the curtains.

Participants considered some procedures to be harder to watch than others because of their "grossness"; e.g., the appearance of the child was unusual or the likelihood of seeing blood was high. Most participants responded with "ick" as these procedures were described in regard to parental presence; the qualitative and quantitative nature of the "ick response" varied depending on the participant and the procedure. One participant described her personal rating of procedures that would or would not affect parents negatively, based on the position of their child during the procedure. In this rating, lumbar punctures were the best and most common for parents to attend "because it's almost like a cuddling of the patient"; a central line insertion was perceived as the worst because of the "dehumanizing" position of the child lying in the Trendelenberg position, head taped down on the side and with green drapes over the
face; and chest tube insertion rated between the two because, although the child was not in a "cuddling position" for the parent, there were no drapes near the face.

The sterility required of an invasive procedure and the effects of parental presence on maintenance of sterility was a factor affecting decisions for some participants.

All procedures are different. A lumbar puncture is an absolute sterile procedure. You can really mess someone up if you introduce infection. So with oncology patients, they’re neutropenic plus the possibility of infection in the spinal cord. So I imagine parents are excluded as one less breather in the room.

Other participants gave consideration to the factor of sterility in their decisions about parental presence but believed it was not an "absolute factor."

I think chest tube insertion needs to be a little more sterile. I can't remember a parent being there for a chest tube insertion....I think my advice would be not to have them there; it's a little bit more of a surgical procedure but I would be flexible, I think, under the right circumstances.

One participant shared that she did not mention the sterility factor to parents because she believed they felt depreciated when this was used as the rationale for asking parents to leave. "People respond better to it (being asked to leave), if you tell them a personal thing (like nervousness)."

Outcome.

Resuscitation, as a type of procedure to be observed by parents, was considered differently by about half of the participants. A few participants worried less about their own skill performance when performing procedures on a child who had undergone a cardiopulmonary arrest as compared with a child who had not. Participants stated that the other reason that resuscitation was considered differently as a procedure was related to the outcome, that is, the child's probable death.

The vast majority of cardiac arrests are not resuscitated and even if they are resuscitated, most of the time, the children end up in a neurologically depressed state. I doubt that the presence of the parents would affect the outcome of the CPR. I'm pretty certain it will not affect the outcome of the CPR. Therefore, the only thing it's going to affect, is the comfort of the persons conducting the CPR. And that, I guess, is very much an individual thing. I tend to have some fairly clear and rigid criteria for CPR in my mind and therefore, it's almost automatic. For example, I would never persist beyond twenty, twenty-five minutes depending on the circumstances. It's been shown that cracking open the chest and other things doesn't make any difference....I have very clear guidelines for everything I will do in that situation.
Similarly, the procedure of extubation when treatment was being withdrawn was viewed differently from the procedure of extubation as part of active treatment. All participants believed that parental presence for the procedure of extubation was much different at the time of death. One participant, who was concerned that a child's resuscitation was too traumatizing for parents to watch, endeavoured to discuss end-of-life issues with parents as early as possible because in ICU, a child's arrest was often anticipated.

Usually a child who dies in the ICU, you can see it coming. There's no need for chest compressions because by that time, they've already had everything possible. Often, I've discussed those issues with the parents and given them the chance to be involved in the child's death in a more meaningful way (than being present for resuscitation).

The Nature of Those Involved

The predicted responses of the child, parent and health care professionals involved in the procedure were very important in determining the participants' decisions regarding parental presence during an invasive procedure. The participants predicted what these responses would be prior to making their decisions regarding parental presence. Accurate predictions and desirable responses were perceived as significant to the decision-making process. Desirable responses of the child, the parent and the health care professionals included an ability to react positively and cope well with all aspects of the procedure. These responses were related to the many contextual factors related to the child, parent and health care professionals involved with the procedure.

The child

Many of the participants who did not generally favour parents being present at invasive procedures conceded that, with certain children, the situation would be viewed differently. Several factors about the child were identified that influenced decisions about parental presence including the child's age, length of illness and hospital experience including previous ICU admissions, severity of condition, and levels of consciousness, sedation and analgesia.

The age of the child was relevant to the perceptions held by the participants regarding the benefit to the child to have a parent present. One group of children viewed as not requiring the benefits of parental
support was "the infants." Some participants defined the infant stage as lasting until about two months of age; others described infancy as lasting until six to twelve months of age. Apart from one brief reference to the positive effect of parental presence on the psychological environment of an infant, all participants believed that parental presence did not make any significant difference to infants.

Several participants believed there were more benefits for children in the age group of about one to six years of age to have a parent present during procedures. A number of participants, however, believed that children in this age group associated the parent with the negative aspects of a procedure and thus, it was better if the parent was not present. Instead, they believed the parent should come in to the ICU after the procedure to comfort the child and to be viewed as "the rescuer." All participants stated they had heard this principle in their practice from other practitioners. Many participants remembered being taught this principle in pediatric courses and many used it when talking to parents about the benefits of their presence at procedures. A few participants questioned its validity and believed that it was used for the benefit of the staff or parents involved, rather than for the child's benefit. One participant who believed that the child would blame parents for the procedure if the child was younger than about six years of age (although this age differed with different children), used this theory to discourage parents from staying. When a parent insisted upon staying, she stated:

We usually get the parents up by the head end, so the baby or child can see Mom and Dad and if they just look towards the child and keep the child's head away from what we're doing....we can focus on the IV. And also then the child perceives Mom as being comforting, as opposed to us who are poking and doing the mean part of the procedure.

This participant believed that older children "can decide that Mom is being good," and therefore, it was more beneficial for the parent to stay for the purposes of talking to, and soothing, an older child during the procedure. A few participants believed that awake three to six year old children "cooperated more" when parents were not present.

Most participants believed that older children and adolescents would benefit more from a parent's presence and if possible, they felt that the choice should be made by the child. If the health care
professional was in agreement that a parent could be present, then the child was usually asked for his/her view. The participants stated that they abided by the child's choice. Participants indicated that children, given a choice, generally wanted their parent to stay; a few had experiences with children, usually of adolescent age, who preferred not to have a parent there.

The lengths of the child's illness and hospital experience, including ICU experience, were factors that influenced the decisions made by the participants. The longer a child had been ill, and the longer or more frequently a child had been in ICU, the more likely it was that a decision would be made for a parent to be present at an invasive procedure. This was related to the needs of the child as interpreted by either the child, the parent or the health care professional. Some participants suggested that the responses of the parent and staff changed with time and increased length of relationship.

It's probably a different type of situation (with families of children with chronic illnesses). How can you ask those parents to leave for invasive procedures because they have children that have chronic illnesses? They've probably seen quite a few procedures being done and it would be quite difficult to ask them to leave.

The severity of the child's illness in terms of current acuity and long term outcome was identified as a factor that health care professionals considered when making decisions regarding parental presence. Generally, the sicker the child, the less likely it would be recommended that a parent stay during an invasive procedure. For example, a child who came to ICU from another in-patient unit for an elective procedure such as a central line insertion was more likely to have a parent stay than a child who had the same procedure after an acute middle-of-the-night admission who was not yet stabilized. One participant referred to the children "coming down from the wards" for a procedure as ones who were "not sick" and stated that parents should be given a choice regarding presence for those procedures. This same participant stated:

The sicker the child is, the more likely I would advise the parents not to be present. I would never tell them they're not to be present; if they insist then I'm willing to accept that but I will indicate that I would prefer that they would not be present... And there's two reasons for this. One is like I say, the sicker the child, the quicker you have to get it over and therefore you don't want to do anything you think might reduce the chance of getting things done quicker. The other thing is that
often a child who's come into the ICU was getting procedures done in Emergency, becomes acutely unwell, and the parents are distressed enough already because of how sick their child is. The child is being transferred to the ICU, and watching their child having procedures done increases their distress. In fact, I often advise them that this is the time they could maybe go and have a cup of tea or coffee while we get things sorted out.

Several participants stated that there was a point when they changed their minds about the wisdom of encouraging parents to leave when their child was very sick. When a child was critically unstable with a likelihood of dying, or when a child was dying or being resuscitated, at least half of the health care professionals changed their minds about advising parents to leave.

I can see why parents would want to be present (during resuscitation), and one of the parents who insisted on staying, said "If he dies, I want to be there." Therefore I can see the point of them being present, as most children who have CPR do die. I can also appreciate that even though it may be distressing for them to see the child having CPR and intubation and all the scary details of that, some parents will see their child die and go away happier having seen it, than being stuck in a room staring at a blank wall and then somebody comes in and says, "Your child is dead."

Two participants described experiences where the health care professionals involved encouraged parents to remain with their seriously ill child despite the invasive procedures being performed. In both situations, the participants were able to speak to parents about their experiences. The participants perceived that the parents found the experience to be beneficial and the participants also found the experience positive.

I did one admission where we went over to Emerg to pick up a child who had meningococcemia. And he was about six or seven, a really, really sick child. In the time that we actually got the transport monitor on him and got him heading over to ICU, he started to get neurologically quite drowsy and his parents were with us. And we literally went over to Emerg, took one look at him, and the physician I was with just said to the parents, "Come with me. I'll talk to you on the way down the hall." We pushed the stretcher ahead of them, and he explained to the parents who were running to keep up with us, what we were going to do. We came flying into room one, whipped into the room. And um, in that instance, it didn't seem to matter; I mean I told the parents as I went into the room, I told them they should have a seat right there and I said, "It's going to be a couple of hours before anyone can talk to you but we will talk to you," and the parents were OK with that. They didn't interfere, they didn't ask any questions, they just sat and watched. Sure enough when the doctor was finished his stuff, his lines and all of this stuff, he went out and talked to them....Parents sat outside the door of room one, looking through the windows, saw us intubate, put in a central line, put in the arterial line, put their child on a morphine infusion, gave him paralyzing drugs, start him on dopamine and epinephrine infusions all within about forty-five minutes.

And I looked after this child for the rest of his stay, I primaried (assigned to administer
and organize the plan for care; based on a nurse's request) him. And the one thing the mom said to
me was that it was fabulous to see somebody, to see a team take charge rather than seeing people
waffling. And she said that as soon as she saw everybody just descend on her child, she knew that
a) this was, the child was serious, and b) that everything that could be done was being done, like
we were just throwing the book at this child. And she said that was just the best thing she could
ever have seen because she knew, aside from being terrified out of her mind, she also knew that
these people knew what they were doing. She said there was a lot of bustling, and a lot of toing
and froming, and a little bit of swearing, you know; a lot of people sort of reaching for equipment
and saying, "That's not it" and going for something else and running in and out of the room. What
Mom remembers is seeing during central line insertion, and we'd already intubated by this point,
and he was fully covered in drapes and his head was turned over this way and I was on the other
side of the bed and (physician) was on the right side of the bed putting a jugular line in and I was
talking to her son. And I just had my hand - he was paralyzed and he was on morphine - but I just
put my hand on the side of his face and I was just rubbing the side of his face and telling him what
was going on and I was doing something else, I forget what it was because there was a reason why
I was on that side of the bed, probably doing an N/G or blood work or something. But I would just
touch him and talk to him from time to time and Mom remembers that. And for me, that was such,
I mean that was a minor part of the evening in terms of what was happening with this kid. But
that's what she remembers. She didn't see the line go in; she saw people, you know, she saw an RT
standing at the foot of his bed just stroking his feet as they were discussing things and when she
was telling me that, that blew me away because I thought, "Gosh, she saw things that wouldn't
have occurred to me."

In the second example, the participant described pushing parents to stay overnight on the ward because
their child was unstable and might need to go to ICU. The child did have to go to ICU and the parents were
present for the resuscitation.

And the parents and I stood looking at what's going on, and you can't really see very much because
it's a tiny baby with lots of people all around. The parents were very distraught, quiet, but
distraught. They couldn't really see what was going on exactly anyway, just a whole flurry of arms
going and reaching for things basically. The child came to ICU and did not survive. I talked to
them a number of months later. They felt very grateful that they had seen the team arrive, that they
knew that everything that could be done was being done. And they felt grateful for somebody
updating them. They didn't want any more information than what they already had seen. They
didn't need to be told exactly, you know, "This was done," "This was done," and "That was done.""They just, it was just enough to know that there was a whole bunch of people doing a whole bunch
of stuff, people running to help their child.

Finally, factors such as the child's level of consciousness and their level of pain and anxiety were
identified as influencing factors during decision-making regarding parental presence for invasive
procedures. Children cared for in the ICU varied in their level of consciousness at the beginning of
procedures, according to their conditions and medications, and during the procedures, according to
additional medications administered to manage pain and anxiety. Many participants believed that there was less need for a child who was not fully conscious to have parents present. All participants also believed in optimal pain and anxiety management for procedures. Many participants believed that the main reason parents wanted to be present was to comfort their child; thus, they reasoned that if the parent was assured of pain and anxiety management, then the need for their presence was negated or lessened.

I think any parent who's reasonable would accept that even if they feel upset that they were asked to leave, the fact that a) their child is unconscious, and b) the child is well sedated and didn't know they weren't there is OK...It's very hard on parents to see their child unconscious.

You see, when I'm doing these procedures, these kids are not going to be calmed by a parent because they are being calmed pharmacologically so the only reason the parent is there is for the parent's interest, not to perform a function. It's very different.

On one hand, parents were encouraged to leave when children were going to be well sedated. On the other hand, there were some unique situations that developed when parents stayed and staff were uncomfortable regarding the child being awake. In two situations, children were given an anesthetic/analgesic agent for the procedure of chest tube removal when the parents were present. The use of this agent was not typical for this procedure and the participants believed that the reason the medication was given related to the parent being present. One participant questioned the ethical nature of this practice.

We had one kiddy who needed his chest tube taken out and there wasn't a nurse to take it out so the intensivist had to...We told him that Mom had to stay because she was so good at settling this kid down; it was just hilarious listening to her talk to this child and it was so good. And what did the intensivist do? He gave the kid a whack of Ketamine to take the chest tube out. I mean the rest of us can't do that...If it's painful for the kid, why should they suffer without their parents there? And it's OK if they're in pain on their own, but we can't let the parents see them in pain? In this situation, the child was fine, the mom was fine, except then she had to deal with a kid who was totally stoned afterwards...I really think it was overkill and I think it was given for the sake of the physician, not for the sake of the child.

A few participants pointed out that sometimes it was the parents who believed that their presence was unnecessary if the child was unconscious or well-sedated. These parents felt that this was an opportune time to do things they needed to do outside of the unit as their child would not miss them. A few participants believed that the amount of sedation used did not affect their practices with respect to parents'
presence during procedures. For example, one participant involved with an arterial line insertion stated that a parent being present did not change her practices with respect to analgesia administration.

It was important to me for this little baby to be comfortable but I could not give more medication as this patient was very, very hypotensive and you could barely feel the arteries. The child was fairly well sedated and analgosed with morphine. On the other hand, I was tempted to give more sedation but again the blood pressure was already low and that would jeopardize the child medically. Local anesthetic would be difficult in such a small area. Actually the child did move a little bit with the needle poke and boy, I mean I didn't like the child moving either...but not just because the mom was there.

One participant discussed the significance of waking a sleeping baby before performing a procedure in order to be sensitive to the child's consciousness state; the other participants agreed that this was not common practice in the PICU.

The parent.

The factors that were identified often as ones that influenced health care professionals' decisions regarding parental presence during invasive procedures related to the nature of the parent, including a parent's requests, previous experiences, physical or emotional states and characteristics, relationships with health care professionals and relationship with their child.

If a parent requested to be present at an invasive procedure on a child, many participants considered the request as a factor towards making a like decision, i.e., they agreed to the parent's presence. Sometimes this was because the participant empathized with the parent's need to stay.

We allowed the parents to stay and actually the father was not comfortable around blood. So we discussed that with the physician and Dad said that he wanted to stay. He acknowledged his fear of blood and we talked through how things were going to look and his options if he felt like he needed to leave....This was a resus for an oncology child who ended up dying a few hours later which really to me made the whole issue important because what happened was that both the parents stayed and the dad was fine with it. He said a couple of times, "It looks a bit bloody" but he honestly wanted to be there for his child and he was there and she died a few hours later so it was, I'm sure that he would have good memories of that.

The participant involved with this resuscitation experience stated that, in this situation, one of the health care professionals did not like parents staying for procedures. The participant had intervened on the parent's behalf; interventions based on requests were common for other participants as well. "I look at what
their needs are for staying or if they've vocalized a need to stay...I will ask other staff if I know there's a pressing need for the parents to stay.” Other participants reported that they agreed with parents' requests to be present for procedures because they felt it was ultimately the parent's right, regardless of other factors that would have encouraged them to make a different decision.

Just the fact that they (parents) want to be there, they, as adults, must have worked through this. They know, anybody knows, that things aren't going to look pretty; they must have factored that into their decision.

She (Mom) wanted to stay. And I don't think that helped, she was so anxious and the child was so anxious but anyway it got done....I don't think it helped the child because she was so anxious...God only knows if it helped her - she was so up in the air. But it didn't bother me...It's her right as a parent.

As well as requesting to be present at a procedure, parents sometimes had indicated to the participants that this was not the first time that they had been present during a similar procedure. Previous experience of being present at an invasive procedure was a very strong influencing factor for some participants, again in the direction of a decision for parental presence. Decisions against parental presence had already been made in the following two examples but these decisions were reversed based on the parents' previous presence at a similar procedure.

The mom was there and I said, "Oh, you know, he's (surgeon) just going to pull out the line now. Would you care to step outside?" This mom had been in before and had another child who went through something similar, and she went, "Oh, I've seen it all, you know." And I said, "Well, that's fine by me."

The RT (respiratory therapist) said to me, "Can you ask the mom to leave for the extubation?" I said, "Yeah, sure." So I said to the mom, "Oh and do you mind leaving? We're just going to extubate him and then, I'll come out and get you. It will probably be about ten minutes or so." And she said, "Well no, I don't really want to because I was here when he was extubated before." And I said, "OK. Are you happy enough then with staying?" And she said, "Yes, that's fine." I said, "OK. Well if you want to just sit down at the bottom of the bed, if that's OK." And she says, "OK." So I went over to the RT and told him, "She's not going to leave." And he said, "Oh, damn" (laughs). He wanted her to go. So anyway, we had to do the procedure with her standing, with the mom sitting at the bottom of the bedside. Once again, she was very calm; she didn't quote, unquote, interfere, do you know what I mean? She didn't sort of say anything; she just watched. We extubated the child, fine, no problem. So you know, I said to the RT later, "I can't push it if mom wants to stay and she's been there for an extubation before, I can't push her out the door"....I thought if she's been here before, then it's not up to me to tell her to leave this time. Why, why should I do that?...Maybe if she hadn't, if she hadn't have been there for the previous extubation, I
would have said to her, "OK now, do you mind just stepping outside for ten minutes?" A lot of the times, you don't have to ask the parents to leave; a lot of the time, they just go.

At the second interviews, some participants identified the double bind nature of the previous presence of parents at a procedure. If this factor alone determined a health care professional's decisions, outcomes for parents would never change; that is, a parent who had not seen a procedure would not see one while this health care professional was involved and vice versa. One participant discussed a procedure where a parent stayed because the participant thought the mother had seen the procedure before. In this case, the participant reported that the mother became upset and left the procedure, confirming her belief that parents should not be present at traumatic procedures like central line insertions.

The experience a parent had in hospitals, in PICUs, and with procedures in general, was considered by the health care professionals in making decisions regarding parental presence. The more related experience a parent had, the more likely it was that the health care professional would decide parents could be present at an invasive procedure. Participants discussed related experience as the experience of: families with children who had been hospitalized with a chronic or long-term illness and perhaps been in ICU before; families whose children had acute illnesses but had been in ICU for about a week or more; families who had previous experience with children in hospital or ICU; and families who had one of more health care professionals as members.

A child with a long term chronic condition who is back in for procedure after procedure, the parents become so knowledgeable that, "Yes, they should be here for every procedure," because it's just another step in a continuation of years of care that they've been giving. They do a lot of the stuff at home anyhow, so again it depends on the parameters....But for a kid in for a heart operation who'll be with us for twenty-four hours and having one central line wired, I would say, "Probably don't keep the parents here," because in the overall scheme of things, they're not going to really need to know that. And they don't need to be present for completion (a child's impending death); it's just another stressor that they don't need right now.

The kid had been in the unit for about a week to ten days by this point and I'd see her (Mom) there everyday. So I know that she had seen lots of minor things before; that she was sort of desensitized, not desensitized, that's not the word, but she'd seen a lot of things happen around her. Um, so the whole environment wasn't completely overwhelming and in talking to her, she seemed to be quite capable and reasonable, and just wanted to be there.
In the first example, the participant believed there was a unique purpose for the parent to be involved in the procedure, i.e., care of a child with a long-term illness was involved. This belief contributed to decisions against parental presence for procedures when a child with a short-term illness was involved. In the second example, the participant referred to the parent's experience and her emotional state when making the decision. The participant perceived the mother to be comfortable with the situation, and therefore, the participant felt comfortable with her being present. This comfort level was not perceived to occur with parents of a child with an acute problem and a short ICU stay, and thus, this situation was viewed differently by participants.

Another significant factor that contributed to the outcome of decisions regarding parental presence during procedures was the perception of the physical and/or emotional state of the parent in question. The participants considered the emotional and physical state of the parent, the trauma of the procedure and other contributing factors, such as the severity and length of the child's illness, in order to assess the potential effects of the added stress on the parent if present at the procedure. A decision was then made regarding whether "the parent could handle it." Most participants believed that the parent's response if present during the procedure was very important, and that it was the health care professionals' responsibility to predict the response and to make a decision that would protect the parent's physical and emotional state as much as possible.

I think sometimes when you ask a parent, "Would you like to stay for this?," they feel obliged to. So I kind of always qualify it with saying something to the effect of, "You know, this is a little bit invasive and you know, she's going to cough a bit and it may be hard to watch." And sometimes they'll opt to leave but sometimes they'll stay and I know it's going to upset them because they've no real idea of what's going to happen.

If I thought parents would be really, like just have got to a level - sometimes in ICU, people do get to a level where they just can't take it anymore. And I think, as their nurse, you should know that. And if they've never seen a certain procedure before, there are times where I will not give them an option. I watch them for my first hour or two, talk to them, I listen to them for awhile, and you know when they've gone beyond coping with anything...I'll tell them to leave. I actually, I don't ask them, I tell them. You know, in a nice way, but I do actually tell them.

Participants pointed out that many parents were affected physically when their child was in PICU.
While anxiety was common in most parents, participants perceived that some parents coped with their level of anxiety and others did not. When parents indicated that they were not coping, e.g., "appearing zombie-like rather than just crying," participants were reluctant to risk worsening parents' physical or emotional responses. Some participants worried about parents fainting when present during procedures in ICU; other participants observed that parents sometimes fainted following entry to the ICU or to the waiting area. For the latter group of participants, fainting was considered a rare response by parents during procedures and one that could be coped with by PICU staff.

Many of the participants believed that parents' responses to a procedure would be different if the parent was not relatively stable emotionally at the time of the procedure. Emotional responses of anger, suspicion, grief and aggression, as well as "the ick response" on the part of parents, were ones that influenced the participants' decisions. For example, one participant expressed that crying parents were too anxious to be present for procedures. When anger or suspicion were perceived to be prominent emotions of the parent, participants varied regarding their decision-making on parental presence during procedures. For most of the participants, these emotions were definite influences on their decisions.

If they're very hostile, towards all the team members, if they're snarly at people, if they make threats, things like that,...This one child came over, and I think the baby had been flown over and the mom had to take a ferry. I understand she was probably very distraught but the baby had been here before, so this was kind of a chronic problem. So it wasn't anything super-acute and the mom had been going through this for a couple of months already. So I go to the door to greet her when she comes. I said, "Oh, I'm (name), and I'm your baby's nurse today." And she said, "You're witches, you're all witches." I thought, "OK, this is going to be a tough one" (laughs). So someone with that kind of anger, I would be more reluctant to test their patience, put them in situations that they are going to find more stressful.

That's unfair (that I ask suspicious parents to leave for procedures) because it's usually parents that are driving me nuts. Like, ask you twenty thousand questions about the same thing over and over again; it's just obvious that they're not getting it. Or people that are controversial, like try to pit staff against staff and you just feel like they're waiting for you to screw up. You know that they are angry and those are usually people that are angry about something that's happened to their child that's unfair - like a sudden trauma or something like that. They're looking for somebody to blame. So I'm always very cautious because in the back of your mind, you've got legality worries, you know. And you don't really want to screw up on something like that.

During the second interview, participants who had initially reported being very restrictive with
parents who were perceived as angry or suspicious, could understand why other participants purposely made very liberal decisions, i.e., decisions in favour of parental presence. Views related to the legal implications of both presence and absence were discussed. All agreed that a significant reason for considering parental states prior to parental presence concerned the participants' feelings of responsibility for protecting the parents from negative or traumatic experiences. A few participants considered that parents who were critical or suspicious of those caring for the child should be present during procedures.

The mother was a nurse, and this child, due to medical error and people missing things, was very sick, and the child unfortunately had a lot of complications. She (Mom) got in a state where she was immensely suspicious of every, everything done to her child and the child needed a central line put in. She said she would like, I invited her to be present. She was very pleased. I also told her that I was going to be teaching the other person to do the line and she accepted it. I told her she was one of the most critical persons there. And I thought it was important that, a) she was present so she could see what was going on if she wanted to, and b) it's a teaching school and we have to teach people and it's very important.

A few participants had particularly strong feelings regarding the emotional responses and needs of parents as related to the decision regarding their presence during an invasive procedure. One indicated she believed it was wrong to allow parents to be present when upset and the other indicated that it was wrong to prevent parents from being present. The first participant shared an experience that had affected her beliefs regarding parent's emotional abilities to handle watching invasive procedures being performed on their child. She was taking care of a very sick child soon after admission to the ICU during a particularly busy time. No one had the time to tell the parents that they should wait outside the ICU while procedures were being done or that there was a phone at the door to use to check before entering. The parents watched many of the invasive procedures being done, without explanations or support, going in and out of the unit on their own. While the child was having a computerized tomography (CT) scan, the participant went for a dinner break. On her way back, she observed the parents standing in the corridor outside CT scan.

Their faces just looked like they'd seen a ghost and the mom said, "Is he dead? What's going on in there? And nobody's, everybody is running in and out of the room. What's happening, what's happening?" So I went in and what had happened was they had run out to get the resus cart just in case, and they were getting drugs from ICU, and so on and so forth. So anyway, I said to the resident, "You better go out and just speak to the parents and just let them know what's going on."
So he went and told them. Anyway they came back to ICU and everything settled down. Then I'm on my second night and working with the mom, and I said to her, "How did you feel standing at the bottom of that bedside watching everything that was going on? It must have been really stressful for you." And she said, "Well, it was nice to see the nurses and doctors working so hard trying to save my son. But the only thing I can describe, the only thing that I can describe is the pure and utter fear. I wanted, in some ways, I wanted to see what you were doing but in other ways, I couldn't stay there because the fear was just too much. I could hear the doctors saying things, but I didn't understand what they were saying and I didn't want to ask them because they were so busy. It's one of the most horrendous experiences of my life." And I said, "Do you think you should have been here for it, or do you think we should have just kept you out in the waiting room?" And she said, "Well, it's so hard to say."

And I felt that they, I felt that they shouldn't have been there. I felt it would have been better if maybe somebody had gone out into the waiting room, brought them in for five or ten minutes, and said "Right, OK, this is what's going on," and explained it rather than them being at the bottom of the bed and not understanding what's going on because they looked so frightened....It wasn't really difficult because again these parents were very, what's the word, they'd stood at the bottom of the bed, quietly. But I felt I wasn't carrying out my job properly that day because I couldn't stop to speak to them, you know. And that is a big part of it too, and I couldn't do that that day. And I felt bad anytime I got a chance to look at them. And I'm thinking to myself, "Somebody should be over there talking to his parents, telling them what's going on." But then, the next thing it's, "Oh, can you get us some..., can you get this, can you get us that? His blood pressure is going down...his blood pressure is going up."

The second participant emphasized the problems which arose for parents when health care professionals assumed that absence was better for the parents' emotional state.

We had a kid who'd come in who was a transplant from one of the outlying hospitals and he was a known cardiac problem but the family had just moved out like just within two months from (city). I think he was about three or four, he could have been five and he'd been treated his entire life in (city) so coming out here was a big transition for the whole family but especially for them because of this poor child's care.... When they hooked him up to the monitor, his rhythm was really bad and so they started to resuscitate him again. The cardiologist doing a locum here said he wanted someone to be there for Mom and I was extra....So later we were in the waiting room and she said, "I want to see him" and I said, "Well they're working really hard on him" and she said, "I want to see him, he's deaf, he can't hear anything. He doesn't know what's going on. How would you feel if..." And that was it, that totally did me in. I said, "OK I understand, like I do understand what you're saying, and I know this isn't right. I'll go see." So I went back and I talked to the intensivist, who just barked at me, and said, "Does she want to see him dead or alive?" And I said, "Well, she doesn't want to get involved in participating in the resuscitation. She just wants to know that everything is being done. Why can't she stand back and watch if I'm with
her?" And he said again, "Does she want him to be dead or alive? I don't have time." And I said, "It has nothing to do with your time." I just knew by looking at him that I should shut up. So I backed away and I went back. And the cardiologist came out with me and I just looked at him and said, "She really wants to be there." And he said, "Come with me." So he took her with me and we just stood by this doorway where you could see what was going on. And by this time they had him so that he was, they were able to stop compressions and they just had him on full support. And so Mom was there and then I went up to the intensivist and said, "She really needs to talk to the child and let him know, you know. She wants to communicate to him that she is there" I said, "He's deaf." And so he said, "OK." So she went up and she just held him and kissed him. And then, she'd called her husband and he was driving in, so we left and were waiting for her husband to show up. They were doing some more tests or something. So I took her for a walk and we walked outside here and she was just a mess, just a mess. And I had the pager so they were going to page me as soon as her husband showed up. And he showed up and came into the quiet room and by that time the cardiologist came in and said that he had died. It was really awful .... And the husband just, was just, I mean he never got to see him partially alive or say good-bye before he died. So Mom at least felt better that she had...But I think there's people that if they want to watch, should be allowed to watch. My only concern is that there's someone there to support them but this lady had the knowledge, you know, and really needed to be there. Like she really needed to be there, she wasn't trying to ask me for anything. She just needed to be there and sometimes I don't know why we make the decisions we make and it really bugs me. Like, I'll never forget her, I'll never forget her, ever.

In the second interviews, participants discussed the significance of "the ick response" or other emotional responses of parents, like anger or crying. Some participants stated they could understand how it might help parents if health care professionals took a more objective view of the significance of parents' emotional responses. These participants reported that a parental response of, "Oh, that tube is huge, how gross!" after a tube removal was not a reason to prevent parents from being present for a procedure.

Participants expressed that emotional release responses on the part of parents could be appropriate, positive and possibly therapeutic.

But she (Mom) started to cry and the whole way through it (suctioning procedure), she cried. I'm not sure if she'd ever been there for it before but she cried. I went over and put my arm around her after, and said, "You know, I know it looks awful. She's getting a bit better and stress is hard to deal with. It's easier to let go now, so don't worry about it"....I think for her, it was a release in a lot of ways because the child was getting better. I think most people during the really highly stressful times, they're much stronger. They kind of, they take a breath and that was her chance to have a reason to cry in public. That's the way I looked at it anyway, and she was fine after she got upset.

A few participants believed that health care professionals do not have to take sole responsibility for all of parents' physical or emotional responses if present for invasive procedures on their child.
Some participants worried that parents might become aggressive and would physically disrupt the procedure in some way. One participant expressed that she thought of this when emergency admissions came in following trauma. In such situations, there was no time to meet parents and find out how they might respond prior to having them at the bedside where their child has had precarious lines inserted. Participants stated they have not experienced procedural disruptions by parents often; the experience was more rare than that of parents who fainted during procedures. The experience could be significantly memorable, however, as described by this participant who referred to a resuscitation of a child in shock:

The child looked like he'd been in an accident, he came in so sick - usually first admission leukemia kids are not that sick. The mother was weeping and sobbing and just hanging on to him and we couldn't get to the child, you know. We had to sort of take her to the other end of the room and luckily we had enough people there that someone could just be with her and hold her hand. Unfortunately in that case, she didn't speak very much English and unfortunately, we didn't have anybody who spoke her particular language right there at the time. She was in hysterics and we just had to keep going, and doing things, and saying, "It will be OK." We tried pantomiming and stuff, but it was just a schmozzle and the tension in that room was way up in the ceiling. It was awful.

In this example, there was reference made to a language difficulty on the part of the parent. This was a factor which participants identified as missing when the initial data analysis was discussed with them. Yet they all agreed that the ability of a parent to speak English indeed affected whether a parent would be encouraged to stay. For example, if the parent's command of the English language was poor, it would prompt many participants to decide in favour of asking the parent to leave. Participants explained that they could not feel comfortable that parents understood what was going to happen or that they could deal with problem responses of parents in the middle of the procedure. Another characteristic of parents mentioned was a cultural slant towards a harsh tone or non-soothing mannerisms with the child; participants hesitated to invite parents to be present if their voices were strident or harsh. In such cases, the participants were worried about the effects on themselves and the child.

When this factor regarding personal characteristics of parents, or "parent type," first came up in an interview, some participants adopted hushed tones, hesitant manners, and worried expressions. They
identified that they were aware that they were being judgemental when they used factors such as a parent's cultural mannerisms to make decisions which might affect the parent-child relationship. When more time and thought was given to this factor in the second interviews, some participants talked about the ethics of non-assertive parents being less likely to be invited to be present during procedures. Factors such as age, gender, culture, career and education were believed to be likely determinants associated with varying assertiveness levels of parents, and thus, with decisions regarding parental presence during procedures. Participants also mentioned factors like "how the parent and health care professional click" as affecting their decisions regarding parental presence. Participants talked about potential differences in their responses to requests from "sweet moms with big brown eyes" versus "aggressive dads with large muscles" versus "quiet parents who defer to health care professionals."

Participants reported that the relationships that had been established between the child or parent and the health care professionals differed in many respects, including in the development of trust. The nature of these relationships influenced the decisions of the health care professional with respect to parental presence during procedures. One participant found that if parents were "calm and trusting," their response was "fine" even if the procedure was difficult. As a primary or core nurse of a child needing an IV start, this participant had built a rapport with the parents, and this affected her decisions regarding parental presence during procedures. "In that particular circumstance (parents staying for IV start without really being asked one way or the other), I think it's an element of trust and I think it's an element of confidence...and they've actually told me they do feel that way with me." The participants identified that a trust relationship was necessary between the child, parents and the health care professionals. For example, one participant believed that certain parents would worsen the experience of the procedure for the child if the parents did not attempt to foster their child's trust in the health care professional.

There are a whole range of parents and attitudes and issues that make parent's attitudes towards medical staff...For instance, if you have a parent who comes along with a child who needs an IV for instance, and while you prepare, they sort of mention, "Well, (child) always had his IV done by (doctor), and he always gets it first time," this automatically implies criticism or a potential of
criticism. I wouldn't necessarily exclude them from the procedure but you certainly heighten the sort of general tension around the child. And I find when parents make comments like that, um, they probably wouldn't be very helpful. The other group of parents who wouldn't be helpful are those who tell the child either a) you know, "Don't worry, once this nasty doctor has done this, then you know, there will be kisses or cuddles." They therefore emphasize to the child that this nasty person does nasty things. Or b), if they tell the child, "This won't hurt," then the child won't trust you the next time because you haven't told them the truth. So that's a main reason for excluding parents.

The relationship between some parents and their child was identified by participants as a factor that could influence their decision to ask parents to stay or leave during a procedure. Participants related experiences that occurred with families who were very involved with their child's hospitalization. These families were sometimes described as "different, they are there all the time." Participants described times when parents were present for procedures because they were very involved with the child's care and they insisted on being present. A few participants believed these parents had different relationships with their child. For example, participants suggested that the involvement of parents of children with oncology problems was much different than the involvement of parents of children with other problems. In discussing why this might be, one participant expressed:

For oncology parents, sometimes these procedures actually don't matter as much. You've already hit them with the biggest rock you could throw at them when you told them that their child might have cancer and you're going to do certain tests; tests are almost minor then.

It was believed that these parents often made decisions to be present for their child "through everything" with the outcome of, a) either watching their child survive and being aware of how miraculous that was, or b) knowing that they had "tried their damnedest to make the outcome positive." A few participants expressed that probably parents who were present all the time when their child was in hospital were also very involved with their child at home.

The health care professionals.

In their experiences regarding decisions related to parental presence during procedures, participants stated that their decisions were also affected by various factors related to themselves and other health care professionals present for the procedure. The factors they identified were the primary goals of
the person performing the procedure or of the health care professionals involved in making the decision, the skill and/or confidence levels of those involved, the "learner" status of someone involved, and relationships with the family and other health care professionals involved, including the roles and number of those staff.

Participants discussed two situations that revealed how the decision regarding parental presence during procedures was influenced by primary goals of those involved with the procedure, i.e., those procedures performed by self (nurse or physician), and those procedures performed by others (usually another nurse, physician or respiratory therapist). Participants identified that there were two significant issues: who made the decision, and who then discussed this decision with the parents. Nurses, and sometimes physicians, made the decisions regarding parental presence for procedures they would perform themselves; core nurses, that is, a nurse caring for a child in a primary fashion, sometimes made or influenced decisions of physicians or other nurses; and nurses often made decisions in procedures performed by physicians, respiratory therapists and other personnel coming into the ICU (e.g., lab technicians, surgeons).

I always ask the physician first. If the parents know that there is a line going in, and if they say, "I'd like to stay," then I always try and convince the physician. Sometimes I'm successful but I would say most of the time I'm not. It depends on the confidence of the physician. Some are comfortable and don't mind if parents stay; they're confident, really good and just come in, take command and put it in. Others don't want a parent peering over their shoulder as they perceive it as quite threatening, probably the same way I did when I first started doing procedures and things with a parent there.

If it's a nursing-driven procedure, and I'm doing it myself and I know the parents and they're comfortable, then I do not ask them to leave unless there is some circumstance within the dynamics of that family being there. If it's another nurse doing the procedure, I would ask that nurse and there are always variations between colleagues whether or not they want the parents to stay. But most of my experience has been that it's whether the parents want to stay or not....If a physician is involved, I would not have the parents stay, strictly because it's sort of generally perceived that the doctors don't want the parents at the bedside. If it's a less invasive procedure that the resident is doing and you have parents that are together, and they ask if they can stay, then I will ask the resident or intensivist if the parents can stay.

If the nurse's primary goal was maximal efficiency and minimal disruption, believed to be best met by
parental absence from a procedure, the parent had usually already left by the time the person performing
the procedure arrived because the nurse had asked him or her to leave. Physician participants often found
that the issue of parental presence was not discussed with them prior to many procedures they performed.

I think that the nurses pre-select a lot as well. So I think that I probably rely on that a lot, that the
parents who nurses feel will not benefit from being at the bedside have been asked to leave,
probably in a very constructive way, already before I arrive there. And I've heard them speak about
that; the nurses explain the procedure, explain what they're going to do and explain that the routine
is for the parents to leave. So all that's done before I arrive. So I suspect that the parents that are
left there when I do a procedure in this ICU, it's already been pre-selected by the nursing staff, I
don't know...

Participants varied on whether they informed parents of why they were asking them to leave. Some
did; many did not. A few participants admitted that they had not always told parents there were going to be
procedures performed.

Last time, we did it (inserted a urethral catheter), we snuck it in when the parents went out for
dinner....That was based on previous knowledge....I had met them in emergency and upstairs,
bringing in a one year old who was diagnosed with a heart problem which had been missed. I
helped with the urinary catheter for this little child and we had a lot of trouble getting it in and
Mom was hysterical. They (the parents) were in mourning as their child came in with a respiratory
infection and they discovered the heart problem. The mother was having an especially hard time
coping. Then I got him a couple of months later in ICU after his heart repair....She wasn't
hysterical then but she needed answers almost before you could even anticipate them. She couldn't
relax. And then her child came back (from the operating room) without a catheter in. So when they
left for dinner, I got it in and then went out afterwards to meet them to tell them and as I told her,
she was going, "Oh my God, that was the one (procedure) we had so much trouble with last time.
He had one (urethral catheterization) in Emerg."....I just thought it was easier not to have her there.
We just popped it in. The child was still half asleep from medications. It went in easily, and in that
case, I just would not have wanted the mother to be inside (the unit).

Other participants reported that they had stories which they "used" as rationale when talking to parents
about leaving for procedures. Nursing participants varied on whether they thought it was their role to tell
the parent to leave when the decision was based on the physician's primary goal and influencing factors.

I don't think it's appropriate for them (physicians) to use an intermediary. I don't think it's
appropriate for that physician to say, to tell the nurse to tell the parent or anybody else. I think that
is between the physician and the parent.

For the procedure of resuscitation, where more health care professionals were present, both nurse
and physician participants thought that the whole group should be consulted if the parents were going to
stay. Many participants believed that quite often health care professionals who did not want parents to stay for procedures such as resuscitations, had reasons related to their lack of confidence in their skills; therefore, participants worried that if they allowed parents to stay, health care professionals would be distracted and the resuscitation might not go as well.

Health care professionals' skill and confidence levels, with respect to the actual performance of the procedure and to interacting with parents, were identified by the participants as factors affecting decisions regarding parental presence. Skill and confidence levels were frequently related; problems with either the skill or the confidence level of the person performing a procedure generally meant that the parent would be asked to leave during the procedure.

I think for me, it depends on how good I am with the procedure. With a central line or an arterial line, I'm fairly confident of, that what I am doing, that my performance won't be affected but I can see that if you're not confident with the technique, that having the parent, or having anyone, watch you for that matter....I can remember as a resident, I can remember even having a staff person or even having a nurse or a medical student or anybody watching you, makes you feel more self-conscious. So I think that the less confident you are with the procedure, the less comfortable you would feel and it (parental presence) may affect your performance.

I have no objection to them being present. The only reason I would consider it unwise for them to be present is if I feel that this would make matters a bit worse for the child. Now the only way it would make matters be worse for the child is that if by their presence, I get stressed and nervous. Therefore I, um if I'm doing a line, if I missed a line or something, then the child will have to undergo two or three stabs because of my nervousness. At the same time, I recognize that evidence of the parents during a stressful procedure for the child, if the child is awake and conscious and nervous, it will often be helpful to the child and it's sometimes helpful to the parents....But if I feel that they would actually be distressed by seeing their child distressed, this will always make medical people uncomfortable and be worse in respect of the child.

Whereas nurse participants voiced that they felt comfortable asking other nurses to do procedures if they lacked confidence and parents wanted to stay, physician participants did not. For some participants, comfort levels changed with experience and for others, they had not.

I think a lot of, a lot of the way I think about it is my own confidence. I know when I first started out, certainly when I first started out in neonatal ICU, I was terrified of parents. I found them really threatening. I found when they came in because I wasn't sure of my own skills, if I was doing something like suctioning and they were watching me, I thought they're probably looking at me wondering why I'm not doing it the same way as the other person and I found it really threatening. I was so relieved when parents left. And the same thing when I started in the ICU, it was, "Oh my
God, parents are watching me do this and what if I don't do it right? And what if they ask me a question in the middle of this?"

Some participants reported that they had experiences with parents staying for procedures where complications occurred, either by chance or because of an error by the performer. They had handled the parents' questions, sometimes with difficulty and misgivings; some felt that it was better that the parent had been present during the procedure.

As well as technical skill with the procedure, skill in talking to parents was a factor identified as related to decision-making regarding parental presence during an invasive procedure. Participants stated they asked parents to leave when they felt unable to deal with the parent responses and needs which resulted from watching the procedure.

They have their own issues; it's not to do with the child and the pain on the child. It's just their own needs, and that's not what I'm there for necessarily. If they have needs that relate to patient care and my helping them support the patient, and again, it's not a real cut and dried thing. But that particular woman who had a history of, she was a needy person that had nothing to do with the fact that her child was in hospital. So I don't have sometimes the energy or the skill to give help in those kind of issues of taking care of the parent.

Some participants worried less about meeting all of the parents' potential needs and shared responsibility for the child's care more readily.

Well, I would again let the parents know who I am, what I'm going to do in brief, and ask do they want to stay? If they want to stay, I would explain in detail what I'm going to do, and go for it. I think that's, um, a skill that I have and a skill that I think you have to have when you're working around parents. And it sounds a terrible thing to say, but you have to have the skill to be able to bluff your way through things sometimes. So that if I attempted an IV and it didn't go in, don't go into immediate panic. Just explain what's happened and start again. I don't have a problem in "failing," if that's the right word, in front of parents. That's fine by me.

This is the worst experience they'll (parents of a child in ICU) ever have in their whole lives. So whatever you can do to make it just even a smidge better, counts later. Later on when they think about their child, hopefully there are aspects of the experience that give them some comfort. I used to think I had to solve everything, and now I've got to the point, if in twelve hours, I can make it a little better, I've done a good job.

Whereas these participants related that experience and time increased their confidence in managing parents' presence during procedures, some participants related that experience and time increased their
confidence in asking parents to leave. This confidence sometimes was used to ask parents to leave for routine caregiving, like bed baths on their child, or to leave for invasive procedures.

I think, the longer you work in intensive care though, the easier it becomes to sort of deal with the parents, if you know what I mean. Maybe it's because you become more, you become better at explaining things, I suppose. But it definitely does become easier to handle...to handle them, yeah. And so when it does come to procedures, I used to get embarrassed asking parents to leave. I used to feel bad about it but not, not anymore.

Participants believed that some of the parenting needs or behaviours perceived as problems with respect to parenting a child in hospital would be more effectively "changed in other hospital areas than ICU." For example, some participants explained that they asked parents to leave if they were perceived to be unhelpful to their child. When asked if this was discussed with the parent involved, the participants replied that usually they did not address or attempt to change parenting skills with respect to the procedures a child was undergoing in ICU. The assumption was that health care relationships and children's developmental needs were not as pertinent in the ICU setting as other issues.

In end-of-life situations, participants reported that it was easier to focus on the needs of parents and "forget" about their own needs with respect to a lack of skill or confidence with procedures.

One of the women working in (department) said she knew the mother through church. The mother had had a premonition that she was going to lose that child and it was very comforting for her when she sat through the resuscitation and was there singing to her child. She sat at the end of the bed and she never got in the way. We had called in a second doctor - because this arrest had been totally out of the blue - who usually doesn't go with them being present...But she wanted to be there and apparently it helped her cope with the whole thing after...And so nobody asked her to leave or said anything about the singing....I was probably in worse shape than her because it was just devastating seeing this post-op child come back, was OK for a couple of hours and then we couldn't get him back. And yet she was much calmer...

The participant sharing this experience had not really agreed with parents being present during resuscitation because of concern regarding the graphic sights that parents would see. As she reflected on this positive experience, she thought about the assumptions of health care professionals making decisions and not giving parents choices. She identified assumptions like the need to protect parents from seeing procedures, and the need to perform the procedures in private to maintain comfort for health care
professionals.

Some participants suggested that lack of health care professional confidence was "not a great reason" for a health care professional to ask a parent to leave for an invasive procedure on their child. These participants suggested that confidence with parental presence during procedures was learned with experience and practice.

As I got more confident in what I was doing and my ability to manage different things at the same time, I got, I think I got the balance right. I know what to say to the child, what to say to the parents, what to tell the parent about the procedure because I think that's probably the most important part of it is, how do I tell the parent what I'm doing and how they can cope with it and how they can help their kid? Now that I know what to say and how to manage all this, and manage the task itself, it's OK. Like, I'll let them in for anything - I shouldn't say let them in. I won't ask them to leave; it's their choice.

These participants reported that they did not feel that a parent's assessment was necessarily affecting their skills; and that if the parents' presence was making the health care professional nervous, that was not the parent's problem.

There are certain times where you feel you're being assessed, where you know you're being assessed, and especially if it's with a family that have been, that have not necessarily got good working relationships with the staff. Whether or not that affects my skill at a procedure? You're inclined to think it must do but I'm not, I'm not really sure that I can say "yes" to that. It may at a subconscious level, but at a conscious level, I think that what I do is, I just focus on what I'm doing. I think because I feel that it's the parent's right to be there, I feel good that they're there and I just get on with the procedure.

If I'm getting nervous about something, that's my problem, I guess....I mean if I go to the hairdresser and she's having a bad day or she's got a really bad headache, that's not my problem. If she looks at my head of hair and says, "Oh my God, this is going to be a really bad haircut because this girl has got such thick hair," that's not my problem. That's what she does. So I see this as the same thing (laughing). In here, if I get nervous because I've got a parent peeking over my shoulder, I might say to them, "I'm a little nervous because I've got you watching me." But that's my problem. If I'm nervous and if I don't think I can do it, then I'll find somebody else who's going to do it. You know, if I look at a kid who's got no veins and I've got a parent sitting there, I'm going to go and get somebody who's really slick at IVs to do this because I might be nervous. That's my problem; it's not the parent's problem.

This view regarding a health care professional's nervousness being a problem which should not be used to keep parents out was discussed in the second interviews with participants. One participant who discussed her nervousness with health care professionals and parents as justifiable rationale for asking parents to
leave, stated that attributing the problem of nervousness only to the health care professional was not valid. "It is invalid that being nervous is just the professional's problem because it's not your fault and the child will suffer for it if you can't get the line in. So it becomes the parent's problem."

Another factor identified by all participants as one which influenced their decisions regarding parental presence during procedures concerned the "learner" status of students or health care professionals who were performing procedures for the first times. It appeared that, for many participants, there were two issues when it came to learners performing procedures. One issue was around the comfort level of the learner performing the procedure if parents were present. The second was around the comfort level of the parents if they were aware that a health care professional was performing a procedure for the first time on their child.

I have helped a resident put in lines when a parent was there. And he had the parent, he had the staff peering over, no the fellow peering over his shoulder and had me holding the child. And he didn't get it first off...And so he didn't get it on the second try, and the fellow came and readjusted his position....And I jokingly said, "Nothing like a large audience." And he goes, "Oh, that's not the problem. It's just a lack of caffeine today." And he just made a joke about it, but it was obvious that he was feeling a little bit stressed by having this audience. But the mom was fine.

And then enters a whole other ethical dilemma. Often when I'm teaching someone to do these procedures, a different protocol is being taught. There's a difficult one: do you tell the parents this is the first time this person has ever done this procedure? Because there always will be a first time...I've never told them....When you're teaching someone to do a procedure, it's a much longer procedure than if you're not teaching someone because you're going step by step. It takes longer, it's done in a slightly different way because you're walking someone through the steps.

It appeared that this factor elicited the same form of double bind situation that occurred with the factor of parental previous presence. While at least half of the participants believed that learning was a valid reason to ask parents to leave, many other participants expressed the concern that once the health care professional was initiated to parental absence, it would be difficult to incorporate parents in future procedures. They also believed that there were other ways of dealing with the stresses of learning besides asking parents to leave.

Well I think, I probably was, because of my fairly wide range of experience, exposed to a number of different people doing procedures in different ways. So I was fortunate enough not to build up
a, a phobia about any one thing in particular. I think it is quite important to have people discuss these things. And it's quite important to teach the juniors that having a parent present is not a bad thing for the child. In fact I've done it when I teach procedures...If all your teachers have always excluded the parents, you are going to think that having a parent around is bad and therefore, you will exclude them when you do them...I've seen procedures done with parents, without parents and I've made up my own way....And often, they are a help if you approach the thing the right way.

Again, there was a difference between nurses and physicians regarding this issue and its effects on decisions made regarding parental presence during procedures.

When you look at nursing students on the floors, parents are there. I mean, wasn't that your biggest fear as a nursing student was when there was someone there observing you, some of the family? We're expected to do our jobs with families around. So why can't they (resident physicians) do theirs with families around?

The role of the staff member involved in making the decision, as well as the relationships of those involved with the procedure, were factors that influenced a decision regarding parental presence. If they were a child's primary caregiver in ICU or the person performing the procedure, participants usually looked at the decision as more distinctly theirs to make. Conversely, as a nurse or physician asked to function in the role of an assistant, many participants felt they would be less comfortable entering into a decision regarding parental presence unless asked.

I think actually if I'm being honest, probably I am less considerate of the other RN if it's my child (child being cared for)...And I'm more considerate if I'm in charge approaching them because I suppose I see that as a bit of a territorial thing. I would be piqued if somebody came to my bedside and dictated how things were going to happen with my child. So I sort of assume it works the other way. So if it's my child, I will probably say to them, "The parents would like to be present for this procedure. Is that going to work for you?" out of the earshot of the parents.

Some participants encouraged a great deal of involvement on the part of families because of comfortable relationships with all persons involved.

I find it easier when I know the doc because I've sort of worked out how best to word things according to a different personality....To increase the chance that they'll allow parents to be there, should they want to be, I can be very manipulative....I can think of an oncology child who was very sick and I remember approaching the physician just to say, "This is a very hospitalized family and they're very used to procedures. Assuming that adequate nursing can be offered, would you object to parents being there when you put the line in?" To me that's a little bit different than saying, "Can the parents be in for line insertion?" And it is manipulative, I know but it's, you know...The response tends to depend on the situation and also the mood of the individual, but it, well it does though, doesn't it, you know. We all have good days and bad days, and so sometimes it
works and sometimes it doesn't.

The participant who repeatedly asked a group of health care professionals if a mother could see her son during resuscitation procedures believed that hierarchical relationships among health care professionals influenced the decision regarding if and when the mother could be present. As a nurse supporting a mother, the participant thought she was in the best position to make the decision regarding parental presence and its potential effects on the mother; the participant also believed she knew that the other health care professionals would make the same decision if they had developed the same relationship with the mother. The health care professionals performing the resuscitation believed they should have input about the effects on themselves and their perception of the potential effects on the child, and thus, did not consent to the nurse's request for the mother to be present. The cardiologist made the final decision based on the participant's plea, presumably feeling confident that he could accept whatever consequences occurred with respect to the mother's or the health care professional's reactions.

Well, I'm not sure if it's my training or where it's come from but I definitely have a division between the hierarchy of nursing and medicine to a certain extent. Like when push comes to shove, what they (physicians) say goes, you know, for the most part. I mean there's times when it gets ridiculous. But you know when they're trying to work to save a kid's life, I feel uncomfortable challenging them at that time. But I felt really unsettled with that one.

The conflicting nature of the hierarchical structure between nursing and medicine in this and similar situations was evident to all participants. It was also evident that many parents would not have been able to keep up the level of insistence which was necessary to enlist cooperation on the part of the health care professionals. Finally, the difficult nature of the role of playing the intermediary between the main two people involved in the decision, i.e., the health care professional performing the procedure and the parent, was identified by the participants as being a factor which influenced the outcome. Participants believed that the nature of the relationships between the health care professionals involved with procedures was of significant importance as a contextual factor influencing decisions regarding parental presence with procedures.
To be honest I usually just tell the RT (respiratory therapist) that the parent is going to stay. I mean, no, that's not true (laughter). It depends on who it is. Some of them I will tell because I know that they will tell the parents to leave if I don't get there first. Usually what I say is, I tell the parents that we're going to take the breathing tube out and that they're quite welcome to stay. "It's a bit mucky; it's going to make the kid cough." I mean I fill them in on the realities of what it's going to look like...And I try to do it within hearing distance of the RT so that the RT then doesn't have a choice....If the RT has already said something, I can't jump in and say, "No" unless I've already discussed it with the parents....But I can't contradict the RT because that's sort of unprofessional and kind of sneaky....After the parents have gone, I will say something to them (the RTs), like, "I usually let the parents stay because most of them want to see this and I don't mind." But I don't seem to be able to do that with physicians.

Just as the role of the health care professionals involved with the procedure affected the decisions, so did the number of staff available to take the role of parent support for the procedure. The participants mentioned that it was important to have enough staff so that someone who was comfortable with the role could stay with the parents. Some participants felt that having someone to fulfil this role was not a problem as frequently as others believed it was. One participant voiced concern that, although having someone to support the parent was ideal, this factor should not be used as a reason to prevent parental presence.

**Summary**

In this chapter, the findings concerning health care professionals' decision-making regarding parental presence during invasive procedures in the PICU are presented. The study participants validated, clarified or revised the data analysis to reveal three possible decisions, that is, asking parents to leave, not addressing the issue and giving the parents a choice. These decisions were mediated by one of two goals identified by the health care professional for the procedure; the goal of maintaining the parent-child relationship or achieving maximal efficiency and minimal disruption was chosen, influenced by mediating factors related to the participants' beliefs regarding family-centered care, personal and professional experiences, time available and happenstance factors. The resulting decision was also influenced by contextual factors related to the nature of the environment, the procedure and those involved in the procedure, that is, the child, the parents and the health care professionals. These findings reveal themes to be discussed in the next chapter.
CHAPTER FIVE: DISCUSSION OF FINDINGS

In this chapter, significant aspects of the findings regarding health care professionals’ decision-making about parental presence during invasive procedures in the PICU are discussed. To commence, a revised version of the schematic representation of decision-making, Figure 1, that was presented in Chapter 2, is offered (Figure 2). This schematic representation was revised to incorporate the factors that influenced participants’ goals and their decisions when performing procedures in the PICU; these factors were not clearly articulated in the schematic that was derived from the review of relevant literature (Figure 1). The purpose of the revised decision-making schema is discussed.

Four themes apparent in the research findings will be explored in this chapter: 1) the issue of parental presence during invasive procedures is currently not discussed by health care professionals in the PICU, 2) some factors that influence decision-making in the PICU are unique from those previously addressed in the literature, 3) parental involvement during the performance of invasive procedures is circumvented in many ways by health care professionals and 4) family-centered care principles frequently are not reflected in the decision-making regarding parental presence during procedures. I wish to explore these themes because of the consequences that may result, consequences that have a negative impact on decisions regarding parental presence during invasive procedures, and ultimately, on the child’s and family’s care in the PICU. In light of these consequences, the revised decision-making schematic representation is then used to organize ways the negative impacts that currently pose problems for PICU staff and families could be addressed.

Health Care Professionals’ Decision-Making

Revised Schematic Representation of Decision-Making

The notion that the participants begin the decision-making process with a primary goal in mind for the procedure is the main difference between the initial schema offered (Figure 1) and the revised schema (Figure 2). Prior to this study, I thought that health care professionals’ decisions regarding parental
presence would be influenced by specific factors. These influences would then determine whether parental presence or parental absence was the outcome of the decision-making. The research findings pointed to another reality; that is, health care professionals are influenced by specific factors, mediating factors, to choose a primary goal to achieve during the invasive procedure. Either maintaining maximal efficiency and minimal disruption, or maintaining the parent-child relationship is chosen as the primary goal. The health care professional is then further influenced by specific factors, contextual factors, that determine which of three possible decisions will best allow achievement of the primary goal. The three decisions include: asking the parent to leave, not addressing the issue, or offering the parent a choice between staying and leaving.
Figure 2: Revised Schematic Representation of Decision-Making

**Level 1**
Health Care Professional Chooses Primary Goal for Procedure

**Mediating Factors**
- Beliefs regarding Family Centred Care
- Personal & Professional Experiences
- Time Frame Available
- Happenstance

**Level 2**
- Maximal Efficiency & Minimal Disruption
- Or
- Maintain Parent Child Relationship

**Contextual Factors**
- Nature of Environment
- Nature of Procedure
- Nature of Child, Parent & Health Care Professionals

**Level 3**
Health Care Professional Makes Decision Regarding Parental Presence

**Level 4**
- Ask to Leave
- Do Not Address
- Give Choice Re: Presence
The revised schematic highlights the complexity of the health care professionals' decision-making. The initial schematic, Figure 1, simplified the decision-making process entailing the consideration of benefits and disadvantages to parental presence as compared to absence, thus pointing to a more linear, almost quantitatively-derived, decision. The revised schematic, Figure 2, on the other hand, illustrates the complexity, first in determining whether efficiency or family-centeredness is the best goal in the particular situation, and second, in determining which decision might best achieve the goal. This exemplifies the contextual nature of the decision-making in each unique situation, influenced by factors identified and categorized in Table 2, and incorporating the environment, the procedure, and those involved.

**Table 2: Contextual Factors Within their Categories**

<table>
<thead>
<tr>
<th>Nature of Environment:</th>
<th>Nature of Those Involved:</th>
</tr>
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<tbody>
<tr>
<td>Site</td>
<td><strong>The Child:</strong> age, length of illness and hospital experience including previous ICU admissions, severity of condition, levels of consciousness, sedation and analgesia</td>
</tr>
<tr>
<td>Space</td>
<td><strong>The Parent:</strong> requests, previous experiences, physical or emotional states and characteristics, relationships with health care professionals and relationship with the child</td>
</tr>
<tr>
<td>Activity in PICU</td>
<td><strong>The Health Care Professionals:</strong> primary goals of those involved, skill and/or confidence levels, learner status, relationships with the family and health care professionals, including the roles and number of staff</td>
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To illustrate the complexity of health care professionals' decision-making prior to commencing a procedure, the following example is offered: the health care professional chooses a primary goal, influenced by factors such as beliefs regarding family-centered care, previous experiences with parental presence or absence during the same type of procedure, and the length of time available for preparation.
prior to commencing the procedure; the health care professional then makes a decision that will best achieve the primary goal, influenced by factors such as the busyness of the PICU, the severity of the child's illness, potential complications associated with the procedure, the parents' relationship with the child and with the health care professional, and the skill of the health care professional's assistant for the procedure. The contextual nature of the influences on decisions made regarding parental presence during invasive procedures in the PICU is congruent with the decision-making process as addressed by investigators of clinical decision-making and clinical judgement (Benner, Tanner & Chesla, 1996; Hamers, Huijer & Halfens, 1994).

**An Important but Unaddressed Practice Issue**

In this study, I perceived from the participants' descriptions that the issue of parental presence during invasive procedures is one of some significance. This finding is not unexpected as it is congruent with current theory regarding the principles and practices of family-centered care (BCCH Partners in Care, 1997; BCCH ICU Survey, 1995; Johnson, Jeppson & Redburn, 1992; Tughan, 1992). For example, in their chapter on Critical Care, authors Johnson, Jeppson and Redburn addressed the issue of parental presence during procedures.

The parent's presence is the single most important factor for the child's psychological comfort and safety. Therefore, staff attitudes and unit policies and practices must ensure that families are welcome at all times and supported in their caregiving roles. Policies that welcome families 24 hours a day are essential. Parent visiting must not be restricted during medical rounds, when procedures are performed, or if an emergency occurs with another child on the unit. Children need their parents at these very stressful times (p. 379).

This quote identifies parental visitation and parental presence during medical rounds or emergencies as issues in addition to parental presence during the performance of procedures. Likewise, most participants in this study also raised these issues during the interviews. As with parental presence during invasive procedures, participants identified that parental visitation and parental presence during medical/nursing rounds are of similar nature and import in their PICU. Similarities among these issues included: beliefs and assumptions of staff regarding these issues vary greatly; numerous identified factors
govern practices related to the issues; and inconsistencies pose problems to parents when practices are enacted differently by different staff.

There are some differences among these parental presence issues, however. The issues of parental visitation and parental presence during rounds are generally addressed in this PICU by frequent discussions at both management and staff levels, and by written guidelines. Conversely, there are no written or unwritten guidelines to consistently direct decision-making regarding parental presence during invasive procedures. Furthermore, the participants' experience was that the issue is not discussed by staff in their daily interactions with each other despite the fact that the lack of clear guidelines and consistent philosophy leads to problems for both staff and parents. The participants identified several concerns that arise from the fact that practices regarding parental presence during invasive procedures are not generally addressed in the PICU.

One concern identified by participants is that parents are frequently confused as a result of inconsistent messages from staff. This confusion sometimes escalates to frustration, anguish or anger. Secondly, staff experience moral distress when observing other health care professionals who do not enact a particular philosophy regarding parental presence during invasive procedures. For example, a nurse experienced some distress asking a parent to leave for an IV insertion after another nurse on a separate occasion had encouraged the parents to stay. If the latter nurse had portrayed a similar philosophy, the former nurse believed she would not have experienced this distress. This feeling of distress is amplified when the staff are actually involved or implicated in decisions with which they do not agree. For example, when a participant reported to a parent that permission from the resuscitation team for parental presence was discouraged, the participant's distress was even greater because she did not agree with the decision. Presumably, this same amplified distress was felt by members of the resuscitation team whose philosophy was different than that of the participant. Overall, I believe that these unresolved feelings of parents and health care professionals have a negative impact on all those involved, their relationships with each other,
and consequently, on the critically ill child undergoing the procedure. I believe that the distress experienced by the nurses and parents involved with the IV insertion could be transferred to the child, resulting in increased anxiety and delayed recovery. To resolve these feelings and lessen this impact, it is necessary to identify potential reasons for the lack of attention to the issue of parental presence during invasive procedures in the PICU.

Participants did not explicitly give reasons why decision-making regarding parental presence during procedures is not discussed by staff in the PICU. This may be, in part, due to my own lack of explicit attention to this aspect of the findings. The literature regarding the traditions and culture of a PICU suggests some reasons for the lack of attention to this issue. One reason suggested is that health care professionals in critical care settings, compared to other in-patient settings, have historically assigned less value to the issue of family member presence (Lewandowski, 1992; Marsden, 1992). Rather, health care professionals in critical care settings may assign more value to the achievement and maintenance of physiological stability for a child undergoing an invasive procedure. The precedence of physiological stability over socio-emotional stability is evidenced in the primary goal frequently pursued by many of the participants in this study. In situations in which health care professionals believed that parental presence might disrupt the procedure and decrease efficiency, a priority was made. Maximal efficiency and minimal disruption were usually prioritized over enhancement of the parent-child relationship even among some participants who viewed parental presence as important. It seemed that health care professionals assumed that inefficiency could alter the success of the procedure and thus, the physiological stability of the child. The value assigned to achievement and maintenance of physiological stability is reflected also in the ways that participants described the influence of the procedure’s degree of invasiveness and the child’s condition and outcome on their decisions. For example, as the severity of the child’s illness and the invasiveness of the procedure increased, so did the likelihood of decisions to ask parents to leave in order to achieve maximal efficiency, until such point that a probable negative outcome negated the need for efficiency.
Decisions such as these could be related to health care professionals’ experiences performing procedures when children are physiologically unstable. These experiences are memorable and distressing for those involved. For many of the PICU health care professionals, parental presence during invasive procedures has not been a common experience in the past. It may be expected that health care professionals would revert to old assumptions and values. Focusing on the technique and immediacy of the procedure itself seems more important when children are physiologically unstable. It is not surprising, therefore, that health care professionals in PICU do not discuss the complexity of a practice that is viewed as one in which the answer is obvious.

Authors of relevant literature cite another potential reason for health care professionals neglecting to discuss the issue of decision-making regarding parental presence during procedures, that is, the interaction between certain personality characteristics of health care professionals in critical care areas and certain emotional topics. For example, Jefferson and Northway (1996) and Laing (1994) identify that nurses and other staff in critical care areas are less likely to attend debriefings to access emotional support following traumatic stress experiences. Rather, these authors report that these health care professionals believe that they either should not feel emotional trauma or should be able to manage their feelings on their own. Isaak and Paterson (1994) indicated, in their study of critical care nurses who had participated in unsuccessful resuscitation, that critical care nurses may distance themselves emotionally by avoiding interactions with families and by shielding families from witnessing unpleasant events. This literature suggests that the emotional nature of the decision regarding parental presence may render it more difficult for health care professionals in PICU to discuss.

Avoidance of difficult, emotionally-charged issues could be related to personality characteristics of health care professionals in PICU. I question whether such avoidance also reflects socialization into the culture of critical care. One participant in this study mentioned that parental absence was a “rule” for certain procedures; with further reflection, this health care professional who had recently joined the PICU
staff, realized that she just had the impression of "rules." Another participant expressed that while she wanted to be family-centered in her approach, she rarely observed parents involved in decisions about their presence during procedures. She stated she needed a role model to support practices associated with a family-centered approach. Are health care professionals in PICU reluctant to discuss the issue of parental presence with others because of fear of rejection or dismissal by their colleagues? For example, a nurse, who believes that parents should not stay during invasive procedures, may be hesitant to reveal this belief to colleagues who hold contrary views because this belief may be interpreted as evidence of lack of caring or lack of professionalism. Similarly, nurses who believe that parental presence during invasive procedures is important may not share this belief with colleagues for fear of appearing unconcerned about efficiency. It is interesting that the avoidance pattern that health care professionals are socialized to use to deal with the conflict related to parental presence during invasive procedures may be contributing further to the very problem that it seeks to manage.

Is the presence of a hierarchical decision-making system that was described by the participants another factor involved with health care professionals' silence in relation to parental presence during invasive procedures? Analysis of the participants' experiences indicated that nurses usually had precedence over RTs, lab technicians and inexperienced or unassertive physicians when it came to making decisions about parental presence; however, experienced or authoritarian physicians often assumed dominance over a nurse's decision. The hierarchy among nurses was less clearly defined although criteria such as being a primary or charge nurse, a very senior or very assertive nurse, were involved in determining who made the decision regarding parental presence during invasive procedures. The existence of hierarchical relationships is not unusual in industry or health care (Fagan, 1996; Kramer & Schmalenberg, 1988a & 1988b; Peters & Austin, 1985), although much of the health care literature has focused only on physician-nurse relationships rather than relationships between nurses and allied health professionals. The significance of hierarchical decision-making in this context is that persons who view themselves as
subordinates in decision-making are unlikely to discuss contentious issues with individuals seen as authorities; likewise, authority decision-makers are unlikely to consult perceived subordinates (Kramer, 1990; Peters, 1985).

In summary, parental presence during invasive procedures is an important issue that seems not to be explicitly addressed in the PICU where study participants work. Lack of explicit attention to this issue raises several concerns relevant to this study. Specifically, these concerns relate to the ways that parents, staff and children may be negatively affected by decision-making without focused explicit discussion of the factors influencing such decision-making. The potential reasons that have been addressed to explain this lack of explicit discussion include: the culture of the PICU, the personality characteristics of critical care staff with respect to discussing emotional topics, and the existence of hierarchical relationships among staff. These issues ought to be examined for their impact both on parental presence during invasive procedures and on the larger issues of partnerships and collaborative relationships.

While the participants identified that they did not discuss decisions regarding parental presence during invasive procedures with their colleagues, they readily described situations and identified factors from these situations that influenced their decisions. Some of these factors are similar to those discussed in relevant literature. Other influences seem unique to the decision-making of these participants working in a PICU and are pertinent to this discussion.

Unique Influences on Decision-Making in PICU

While research regarding the issue of parental presence during invasive procedures in the PICU was not located, some findings from related literature resembles the results of this study. For example, some findings from studies researching parent-professional relationships and parental involvement in caregiving (Berman, 1991; Gill, 1987, 1993; Johnson & Lindschau, 1996) are reflected in the primary goals participants chose or in some of the factors that influenced their decisions regarding parental presence for procedures in the PICU. I was struck by the similarity between some factors influencing
participants’ decision-making regarding parental presence during invasive procedures in PICU and the factors identified by nurses as influencing the roles adopted by parents and nurses caring for hospitalized children in a study by Brown and Ritchie (1990). In the PICU study, participants identified contextual factors related to the nature of the environment, the procedure, and those involved. In Brown and Ritchie’s study, pediatric nurses indicated that modifiers of nurses' and parental roles were related to various characteristics of the child, parent, nurse and hospital environment. Time, for example, was perceived to be a significant influencing factor on parental involvement in both studies.

The analysis of findings in the PICU study revealed influences unique to this research. Some influences on decision-making regarding parental presence during invasive procedures in PICU were not identified in findings of other research regarding parental presence during caregiving or parental presence during invasive procedures in other care settings. Many of these unique findings can be traced to beliefs and assumptions made by the participants in this study pertaining to the nature of the parent, the health care professionals involved, the procedure, or the child. These beliefs and assumptions may be unique to the participants of this group and may not reflect those of health care professionals working in non-PICU settings.

Unique Influences Related to the Parents

Factors related to the parent were frequent and strong influences on health care professionals’ decisions regarding parental presence during invasive procedures. While other studies have reported factors related to parents that determine caregiving practices of parents and nurses (Berman, 1991; Brown & Ritchie, 1990), some descriptions related to parents in this study seem unique to PICU. These can be discussed according to the health care professionals’ perceptions of parental stressors in PICU and the health care professionals’ experience of feedback from parents who have been present during procedures in PICU.

Participants believed that stressors for parents of children in PICU are enormous in number and
impact. Several participants perceived the effects of these stressors as very negative for parents both when present in general or when present during invasive procedures. These participants believed that procedure-related stress would have been avoided if parents had not been present and that parental absence would have been less stressful for all involved. Many participants believed that parents in PICU feel helpless and somewhat superfluous in the care of their child and that involving parents in general care of their child is important. This belief, however, did not necessarily influence their decisions regarding parental presence during invasive procedures. The belief that being present during invasive procedures was too stressful for parents precluded the participants' view that parents need to be involved in their child's care. It appears that health care professionals may not equate a “normal” parental role with consenting or declining to observe or support one's child during an invasive procedure.

Parental role revision was the source of stress most often identified by parents surveyed while their child was in PICU (Carter, Miles, Buford & Hassanein, 1985; Freiberg, 1972; Heuer, 1993; Miles, 1979). It is not clear in the research findings if stress related to parental role revision could be decreased by presence during their child's invasive procedures. It remains unclear if parents would experience a concomitant increase in any of the other dimensions of stress, such as those of the child's appearance and behaviour, or of procedures, if they were to be present during an invasive procedure on their child. In this regard, it would be important in future research to investigate which stressors parents find more negative or difficult to cope with if they remain in the room during an invasive procedure. For example, would the stress of coaching your child through a difficult procedure in a chaotic unit be greater than the stress of being asked by your child to stay but having to tell him or her that you could not? Other researchers have identified that the parental need given the highest rating by parents in the PICU is the need “to be with their child” (Etzler, 1984; Fisher, 1994; Green, 1979; Kasper & Nyamathi, 1988; Philichi, 1989). These studies do not go into detail, however, regarding parents needing to be with their child during the performance of invasive procedures; thus, research evidence that might help health care professionals
make decisions regarding parental presence during procedures is lacking. It is significant that in all
discussions of parental presence during invasive procedures, it is not entirely clear in which ways parents
need to be with their child; that is, do they need to be merely visible to the child or do they need to assume
an active role in supporting the child throughout the procedure?

A finding in a recent research report (Heuer, 1993) that is similar to one in this PICU study
suggests that parents may be less stressed by presence at procedures than by parental role revision. While
the response of “not experienced” was most frequently given for levels of stress related to procedures
(Carter, Miles, Buford & Hassanein, 1985; Freiberg, 1972; Miles, 1979), a more recent study (Heuer,
1993) reported that procedures were the second most common stressor for parents. There was evidence,
however, that the procedure of suctioning was less stressful for those parents who observed the procedure
frequently. There is also evidence from studies conducted in other areas that almost all parents who have
once been present during an invasive procedure would want to be involved again, e.g., present at induction
of anesthesia, present during an invasive procedure in emergency, present during a burn wound dressing
change, or present in the post-anesthetic care unit (Bauchner, Vinci & Waring, 1989; Bauchner, Vinci &
Pearson, 1993; Fiorentini, 1993; George & Hancock, 1993; Hall, Payne, Stack & Stokes, 1995; Jackson,
Marcell & Benedict, 1997). It seems from the participants in this PICU study that not only were parents
more likely to want to stay again, but health care professionals were more likely to invite them to stay
again. The factor of a parent’s previous presence was a strong influence on health care professionals to
offer parents a choice regarding being present for an invasive procedure on their child in the PICU. One
wonders if there is, as was suggested by the participants, a “settling in” period for PICU parents after
which parents would find less stress associated with staying for a procedure than with parental role
revision. If so, it is possible that this period of time until parents are comfortable could be accelerated by
early exposure to the unit and the procedure. An additional explanation for the participants’ reluctance to
offer parents, unknown to them and with little or no previous PICU experience, the opportunity to stay
during their child's procedure, may be that the health care professional requires past experience to validate
that the parent will be able to handle the stressors associated with remaining during an invasive procedure
and not impede the procedure. It is unknown if there are other life experiences, apart from experience in
PICU, that might assist parents to cope with stresses related to staying during invasive procedures. For
example, a parent who has cared for a child with a severe debilitating illness at home might be able to
handle the stress of being present during invasive procedures in PICU as would a grandparent with
previous experience during invasive procedures in an adult ICU with a critically ill partner.

The length of a child's illness was a factor that strongly influenced many of the participants’
decisions regarding parental presence at invasive procedures. The average length of stay in a PICU is short
and many admissions to PICU are unplanned; therefore, the opportunity for parents to have frequent
experience with a specific procedure may be limited. The fact that health care professionals in other areas
do not indicate quite the same concerns regarding parental presence as do those of health care professionals
in PICU is perhaps related to health care professionals’ perception of the greater parental stress related to
having a child in a critical care unit.

Several participants often concluded, based on their previous experiences with parents in PICU,
that remaining during an invasive procedure was entirely negative for the parent because of parental
statements that indicated the experience had been difficult or because the parent was visibly upset.
Although they readily acknowledged that parents could make a child feel more comfortable and supported
at times, they generally regarded parental presence during invasive procedures as making an already
horrendous situation extremely negative for the parent involved. Study reports in the literature have
previously revealed that professionals face difficult and stressful feelings related to parental or family
involvement with caregiving to critically ill patients (Dunkel & Eisendrath, 1983; Frader, 1979; Isaak &
Paterson, 1994; Leff, Chan & Walizer, 1991). In these studies, grief, fear, overidentification, guilt and
blame are among the emotional challenges attributed to interacting with very ill children or adults, and
their families; health care professionals used emotional and physical distancing to help with these emotions. Interestingly, in this PICU study, participants did not explicitly identify these challenges as factors influencing their decisions regarding parental presence during invasive procedures; however, their general reticence to avoid parental stress may be related as much to their distancing to mediate their personal stress associated with the situation as to a genuine concern for parents' welfare. It would be of interest to investigate whether health care professionals employ this and other self-protective mechanisms during the performance of invasive procedures in PICU.

**Unique Influences Related to Health Care Professionals**

In this study, there were findings pertaining to health care professionals that were not indicated in the literature. These findings related to characteristics of the health care professionals in PICU. In several studies, researchers reported correlations between characteristics of health care professionals and their attitudes towards parental participation (Berman, 1991; Gill, 1987, 1993; Johnson & Lindschau, 1996). These results are mainly not reflected in this PICU study, making it unique in this regard. While the fifteen participants varied greatly in personal and professional characteristics, such as being a physician or a nurse, male or female, partnered, a parent, having higher education, length of experience in PICU or other pediatric areas, noticeable differences in the primary goals typically chosen or decisions made regarding parental presence during invasive procedures did not appear to relate to these characteristics. Two characteristics that appeared to have some bearing on participants' family-centered attitudes towards both parental involvement in caregiving and during invasive procedures were working in a managerial position or having previously worked in a family-centered unit. The correlation between the factor of a managerial position and a more positive family-centered attitude would be similar to a finding by Gill (1993). Being in a managerial position may affect individuals' family-centred attitudes because such positions generally require additional post-basic education, more skills in interacting with parents and colleagues, and a global rather than a specific awareness of health care.
Several participants addressed the association between having previously worked in a family-centered unit and their outlook on family-centered care. Some participants also identified that the decisions they made currently were influenced by the unit on which they were practising and the kind of involvement that they believed would be expected by parents on such a unit. Contrary to results by Berman (1991), Gill (1993), and Johnson and Lindschau (1996), participants were less likely to mention specialty areas like emergency, radiology and the PICU as areas that parental presence was expected than non-critical care areas like oncology, adolescent care or cardiology. This difference could be agency-specific. It could be related to the distinction between having a positive attitude towards family-centered care and inviting parents to be present during invasive procedures. The latter practice would reflect only one aspect of the former.

Unique Influences Related to the Procedure

The nature of the procedure influenced participants' decisions regarding parental presence during invasive procedures. They suggested that the procedure's degree of invasiveness, associated urgency, and required performance skills as well as the extraordinary nature of the situation in which procedures were commonly performed may be unique to the PICU setting. They stipulated that there is sometimes little time to explain procedures in detail and consequently feel assured that parents are fully prepared. Many participants argued that because of this, the most reasonable and prudent action is to ask parents to leave. A few other participants countered that, while procedures performed in PICU were of greater difficulty and risk, resources provided were also of greater quantity and quality. Skilled personnel, superior technological equipment, as well as many educational opportunities are available in the PICU. These participants, many of whom were expected to work with parental presence during invasive procedures in other areas, pointed out that the control lost to procedure-related difficulty and urgency should be counterbalanced by the control gained from being in the PICU environment.

The urgent nature of procedures typically performed in PICU may very well be unique with
respect to parental contribution to pain management. Many participants reported that parents might be helpful in managing a child’s pain for less invasive, shorter or more routine procedures but not for more invasive, lengthy or complex procedures. While other researchers have supported parental presence to help manage a child’s pain, the procedures were either specified as “minor procedures” (Bauchner, Vinci & Waring, 1989; Bauchner, Vinci & Pearson, 1993; BCCH, 1995; Gonzalez, Routh & Armstrong, 1993) or the specific nature of the procedure was not addressed (Pederson & Harbaugh, 1995, Tughan, 1992; Woodgate & Kristjanson, 1996). More details regarding the nature of the procedure and associated pharmacological management may be required in order to appropriately compare practices regarding parental presence in the PICU with practices in other patient care settings.

It is apparent in the findings of this research study that the degree of invasiveness of a procedure may be less of an influencing factor on decisions regarding parental presence than the associated skill required of the performer. For example, a central line insertion may be considered by a medical resident to be too invasive for parental presence; the same line insertion may be considered not that invasive by an experienced cardiovascular surgeon. Further study is warranted concerning the outcomes of parental presence when the performer of the procedure is unskilled versus skilled and when the performer is confident versus not confident in the procedure.

Parental presence was viewed differently by many participants when procedures were performed on a child whose outcome was likely to be death. For example, extubation as part of the withdrawal of life support, procedures performed during the bigger procedure of resuscitation or procedures performed on a child who did not have much hope for recovery were more likely to be interpreted by participants as procedures where parental presence was beneficial, or even necessary. For example, in situations involving cardiopulmonary resuscitation (CPR) where the child was not expected to survive, participants claimed that they would be less concerned about their skill performance and parental presence would be unlikely to affect these skills. This often was a direct contrast to their statements regarding parental presence in other
situations in which death was not an expected outcome. While the issue of family member presence during resuscitation has been similarly addressed a few times recently in the literature (Adams, Whitlock, Baskett, Bloomfield & Higgs, 1994; Hanson & Strawser, 1992), the finding is still unique enough to analyze the underlying reasons. Perhaps health care professionals are more encouraging of parental presence during CPR situations when death is expected because the parents would witness that the health care professionals had tried their best to save the child. Isaak and Paterson (1994) discovered that nurses in adult ICU emphasized to families of the deceased that they had done everything possible to save the client. They did this both to offer condolence to the family and to convince themselves that the death was unavoidable. It is also possible that health care professionals may be more open to parental presence during CPR of a child who is expected to die because they feel that the parents are more likely to be focused on the child than on the professional’s competence.

The conditions under which parental presence occurred were very important to the participants; this finding may be unique to the PICU experience. In PICU, invasive procedures may be performed under sudden and unplanned conditions, and when there are few extra resources to assist with preparing and supporting parents throughout the procedure. Most participants found it very distressing when parents were present during procedures simply because the health care professionals involved did not have the time or judgement to address the issue. Similar distress was expressed when parents stayed for procedures without adequate preparation or emotional support.

**Unique Influences Related to the Child**

Participants discussed benefits and detriments of parental presence for parents and health care professionals far more often than for the child. This is particularly noteworthy when it is the child who undergoes the invasive procedure. Apart from a few instances, I was struck by the lack of health care professionals’ discussion related to the needs of the child in regard to the primary goals they chose or the decisions they made for procedures. Absence of the child’s voice is one of the unique findings in this
study. I question whether this finding may be unique to PICU and why it occurred.

Participants made references to a few characteristics of the child that influenced their decisions in regard to parental presence. The participants' references to characteristics of the child's illness, age and levels of consciousness and pain management illustrate their lack of attention to the child's needs in decisions regarding parental presence. Participants referred indirectly to the child when discussing a child with a long-term or chronic illness, believing there was a greater need for those parents to be present for procedures. Children from the oncology program were mentioned by every participant as being unique; health care professionals were much more likely to allow parental presence during invasive procedures on these children. Their reasons for this decision, however, did not necessarily relate to the benefits of parental presence for the child. Several participants believed health care professionals in PICU respond differently in decision-making regarding a parent remaining with a child who has cancer because of an awareness of parents' expectations to stay with their child, commensurate with the oncology program's family-centered philosophy. Many children in PICU, however, do not have oncological or long-term illness, but an acute illness. In general, participants did not perceive any general, or development-related, benefits of parental presence for the child with an acute illness undergoing a procedure. This may be unique to the PICU experience, as may the participants' view of the relationship between the effects of parental presence during invasive procedures and the child's age.

Participants held assumptions and beliefs associated with age-related effects of parental presence during invasive procedures on the child. These included that infants are not affected by a parent's presence and parental presence is detrimental for preschool age children because they will blame their parents for the procedure. These beliefs and assumptions are different to those of health care professionals working in areas other than PICU, who have reported in research studies that parental presence during invasive procedures was beneficial for the young child (Bauchner, Vinci & Waring, 1989; Bauchner, Vinci & Pearson, 1993; Bossert, 1994; Doctor, 1994; George & Hancock, 1993; Hall, Payne, Stack & Stokes,
Pain management has been reported by other researchers as a significant issue related to invasive procedures on children (Bauchner, 1991; Bauchner, Vinci & Pearson, 1993; Bossert, 1994; Doctor, 1994; George & Hancock, 1993; Humphrey, Boon, van Linden van den Heuvell & van de Wiel, 1992; Pederson & Harbaugh, 1995; Woodgate & Kristjanson, 1996). Results from these studies included that: parents who were taught such techniques as imagery, distraction or relaxation, believed they comforted their child physically and psychologically; nurses and parents believed that "knowing the child" was the reason parents were able to contribute significantly to pain management; and children believed their parents' presence made the most significant contribution to their pain management. These findings are not reflected by the findings in this PICU study. Participants reported that parental involvement in using psychological pain management techniques during invasive procedures in PICU is rare. When a child's level of consciousness is such that these psychological techniques can be used, other factors inherent in PICU, such as short time frames available for procedures, health care professionals' lack of expertise in teaching parents these techniques, and the short length of stays common to PICU, interfere.

Participants indicated that they were more likely to allow parents to stay and contribute to pain management during an invasive procedure when the child: was older; had longer experiences with illness and hospitalization; and had well-established relationships with health care professionals. These decisions, however, were not related to the parents' abilities to help manage their child's pain during invasive procedures or to the participants' awareness of evidence that increased exposure to painful procedures increases children's fears (Bossert, 1994). Rather, the decisions were generally related to the perception of comfort levels for both parents and health care professionals. Health care professionals may be comfortable with parents' responses when they have previous experience with procedures and hospitalization because they have "proven" their ability to cope with the stress of remaining with their child. As well, these parents
may be likely to request to stay with their child because they are more familiar and comfortable with hospital procedures and staff than a parent who has no previous PICU experience. As the child's age increases, the child and the equipment used in invasive procedures become larger, making performing the procedure easier and shorter than when the child was younger.

Conclusions could be reached from the research findings that parental presence promotes judicious, or injudicious, pharmacological pain management for the child undergoing a procedure in PICU. Participants reported a few instances where unusually potent analgesics and sedatives were used for procedures when parents were present, apparently to reduce the parent's stress when observing the child's discomfort. A somewhat contradictory finding was that decreased levels of consciousness, due either to their critical conditions or pharmacological management, was a prime reason indicated by participants that parental presence during a procedure was inconsequential from the child's perspective.

Health care professionals may be oversimplifying the effects of parental absence on the child by assuming that effects which we cannot see or measure do not exist. Gross (1992) explored the recollections of children who had been pharmacologically paralyzed in the PICU and found that some children could recall pain and discomfort; some children were also aware of their family's presence. I believe that attributing meaning to children's behaviours to decide what affects them in a positive or negative way with respect to parental presence during invasive procedures may be much more complex than that presented by the participants. For example, in a study by May, Bauchner and Pearson (1993), many school-age children reported that they believed crying or screaming helped them cope with procedural pain. Measuring distress during procedures, with and without parents, and even assessing for correlations with pain score differences still may not give health care professionals the answer to the question, "What is best in terms of parental absence or presence during invasive procedures for the well-being of the child?"

Further investigation is also indicated to answer questions arising from examination of health care professionals' beliefs and assumptions around the needs of children related to their ages and illnesses.
There is a lack of research-based evidence regarding the issue. Much of the research has been devoted to classic studies that found detrimental effects of parents' absence on young children, usually referring to long term effects related to long term absence (Bowlby, 1960 & 1982; Prugh, Staub, Sands, Kirschbaum & Lenihan, 1953; Robertson, 1958; Spitz, 1945). When asked about the relevance of attachment relationships and separation anxiety for children in the PICU, participants were unaware of related evidence from these studies or did not associate it with potential detrimental effects of parental absence on children undergoing invasive procedures. I wonder if this body of research has been sufficiently disseminated to and questioned by practitioners and policy-makers within PICU settings. In addition, with the drastic changes in health care delivery in the past decades, I believe more contemporary and contextual research would be helpful in locating the child's voice regarding the issue of parental presence during invasive procedures in the PICU.

The child's perspective, thus, is not the focus during health care professionals' decision-making regarding parental presence in the PICU, even when the child's age, illness or levels of consciousness and pain management are considered. Health care professionals' beliefs may or may not be accurate. I wonder if there might be more appropriate responses to the problems underlying the beliefs than mere parental presence or absence at procedures. I also wonder if there are times when a child could be asked for input prior to admission; times when their voice could be heard by pursuing creative ways, in conjunction with those who know and care about them most. An example of such a time is exemplified in a plan of care developed by Hatton (1995) with a child prior to a PICU admission.

It seems to me that the message that a health care professional sends when ensuring that a child's needs are attended to when performing a procedure in the PICU is very powerful. The child, the family and the other professionals would be part of an emphasis on the importance of the child and of parenting. This emphasis could have far-reaching effects. For example, many of the parents in the PICU are parenting newborns, often for the first time. Even if we cannot measure the effects of parental presence on the infant, would the message that parenting is important and all-inclusive be sent if we discussed parental presence
during invasive procedures with children and families?

**Circumvention of Parental Involvement during Invasive Procedures in the PICU**

In several studies, parents and health care professionals have identified the current practices with respect to parental presence during invasive procedures (Bauchner, Waring & Vinci, 1991; BCCH, 1995; Brown & Ritchie, 1990; Hunsberger, Love & Byrne, 1984; Tughan, 1992). These studies found practices similar to ones identified regarding parental presence in this PICU study where participants identified practices related to one of three possible decisions, that is: asking parents to leave; not addressing the issue and parents staying; and giving the parents a choice to remain or leave. The most common practice identified in all studies, including this one, was asking parents to leave.

Asking parents to leave is only one of the ways health care professionals precipitate parental absence from procedures. Nurses in one study (Brown & Ritchie, 1990) described ways that they prevented parents from being present during procedures in general pediatric areas without explicitly addressing the issue. In an emergency department, an observer watched health care professionals exclude parents by such behaviours as pulling curtains and turning their backs to parents (Bauchner, Waring & Vinci, 1991). Likewise, in this study, many participants identified ways that they circumvented parental involvement during invasive procedures in the PICU. Further analysis of how health care professionals practice circumvention of parental involvement and the possible reasons for, and consequences of, the practice is required.

When questioned regarding how they discussed their decisions regarding parental presence with parents prior to procedures, some participants acknowledged that they did not always discuss this decision. They realized that they sometimes waited for parents to leave before commencing procedures or ensured that procedures were completed before parents were ushered in for their initial ICU entry or arrived back from a meal break, etc. While several reasons were identified for this, I believe the most plausible and common reason communicated to me by participants related to “protection of parents,” a perception that
circumventing parental involvement minimizes the parents’ stress.

Participants emphasized “knowing” the parents before they felt comfortable that parents “could handle” procedural presence. A child’s admission to PICU was viewed as very stressful for parents in and of itself; invasive procedures were viewed as adding to this stress. Many participants believed watching one’s own child undergo a painful and unusual, or often “gross,” procedure would be very traumatic; furthermore admitting a desire to leave because of this could make parents feel guilty. Participants were concerned that the unusual and potentially frightening behaviours and expressions of staff when complications or unstable situations occur during a procedure would be too distressing for parents. The possibility of children in the younger age groups associating their parents with painful invasive procedures also concerned the participants. These assumptions contributed to the participants’ belief that parents need to be protected from sources of parental stress by health care professionals when their child is in the PICU.

Similar assumptions and practices have been identified in literature related to health care professionals’ roles in areas other than PICU. Brown and Ritchie (1990) described a similar finding identified by most nurses in their study, that of “being a gatekeeper.” An example of being a gatekeeper related to the way nurses dealt with their discomfort regarding parental presence during painful procedures. These nurses reported they tactfully ensured parents were not present for procedures in order to prevent trauma for either children or parents or both. Berman (1991) also found that nurses wanted to protect parents during emotional periods. Brown and Ritchie found that half of the nurses who felt comfortable with parents remaining for procedures did not feel comfortable with parents restraining their child during procedures, mostly because children would “blame” their parents.

It could be perceived as commendable that health care professionals are concerned with protecting parents from the stresses of disturbing situations. It could also be perceived as detrimental that health care professionals are preventing some parents from participation in a process that might improve their anxiety levels and coping skills in the short-term (Miles & Carter, 1985), and their relationships with, and
parenting skills of, their child in the long-term (Bauchner, 1991). A few participants did view parental presence during procedures as a potential opportunity for parents to learn about their child’s responses and about health care delivery, and also to feel a valuable part of the team. Participants usually specified, however, that there were no guarantees that parental presence during an invasive procedure would be positive rather than negative for parents. Contextual factors like the success of the procedure with respect to sedation and analgesia levels of the child and ease of completion of the procedure by the health care professional were viewed as possibly affecting the perceptions of parents to varying extents. Perhaps parents are influenced by a different set of mediating or contextual factors than those identified by the participants with respect to remaining during procedures on the child. Currently, it is difficult to know what might influence parents as they are rarely involved in health care professionals’ decision-making process.

A potential problem with health care professionals’ endeavours to protect parents has been revealed by investigators who have compared parents’ and nurses’ ratings of parental stress levels and coping abilities (Graves & Hayes, 1996; Johnson, Nelson & Brunnquell, 1988; Philicchi, 1989). These investigators have reported that health care professionals overestimate parents’ stress levels and underestimate parents’ coping and adaptation skills. It is likely, then, that health care professionals overestimate parents’ needs for protection, making practices to meet these needs unnecessary and possibly unhelpful. Overprotecting parents, moreover, is contradictory compared to other health care practices. For example, parents of children at risk are taught CPR techniques to use; performing CPR on one’s child could be more stressful than staying during an IV insertion.

Perhaps circumvention patterns of health care professionals develop in a circular fashion. That is, those health care professionals who do not invite parents to be present will not change attitudes with experience, and will thus not invite parents to be present. One can deduce that when parents are protected by absence from procedures, factors contributing to parental presence are negated. Parents will continue to
be absent related to factors such as lack of previous related experience, lack of relationships with health care professionals, and lack of requests to stay. Another practice contributing to parental absence from procedures is that health care professionals discuss elective procedures on rounds. Parents are not allowed in ICU during patient rounds; therefore parental presence is handled on a post hoc basis that itself contributes to decreased likelihood of decisions for parental presence. If parents have been present during an invasive procedure before, they are more likely to want to be present again and health care professionals are more likely to let them be present again.

Survey results have been reported indicating that about a two to one ratio or 90 and 45 percent of parents and health care professionals respectively believe there are benefits to parental presence for the child, parents and health care professionals during procedures (Bauchner, Vinci & Pearson, 1993; Bauchner, Vinci & Waring, 1989; BCCH, 1995; Fiorentini, 1993; Hall, Payne, Stack & Stokes, 1995; Jackson, Marcell & Benedict, 1997; Savedra, 1981). Often, both percentages increased following practice changes. This is contrary to beliefs expressed by study participants. In this PICU study, many of the participants believed that, especially for parents, there were more detriments than benefits related to parental presence during invasive procedures. Many participants, moreover, believed that parents perceived this also. Several participants reported that they believed that parents were relieved regarding the opportunity to leave during invasive procedures; this belief was based on observations that often when informed about the forthcoming procedure, parents did not wait to be asked to stay or leave but simply left. Participants also reported that parents rarely disagreed with health care professionals’ decisions. This was again interpreted as agreement with, and perhaps relief at, the decision.

Some parents may very well be relieved when they are asked to leave for invasive procedures. I would suggest, however, that there may be other reasons for parents’ seeming agreement with health care professionals, such as a reaction from previously being asked to leave or told that they could not stay. I would also suggest that options to be present vary in whether they are offered in a negative, neutral or
positive manner by health care professionals. A parent whose child is in PICU is likely to be experiencing considerable emotional upset and not have the energy to disagree with a health care professional. As pointed out by a few participants, parents may believe unquestioningly in health care professionals in a PICU, as they are considered the experts; this belief is similar to beliefs reported by chronically ill individuals and their families when experiencing the stage of "naive trust" in health care relationships (Thorne & Robinson, 1988). Similar possibilities have been reported by parents in a PICU survey (BCCH, 1995). Respondents in this survey were hesitant to reply that they wanted a practice outside of the observed standard although half of the parents who were asked to leave reported that they would have preferred to stay. Parent respondents also indicated that health care professionals knew best about the practice of parental presence during invasive procedures. It also is relevant that half of those parents who experienced anger regarding practices in PICU reported that their anger was not voiced (BCCH).

Parents may be concerned about possible retribution if they anger health care professionals who then care for their child. Parents’ fear of retribution to their child by staff is a finding I believe to be quite concerning. When parents assume a defensive position of protecting their child by "second guessing" what will please or anger the health care professional, it becomes difficult to know what parents really want or need. The practice of family-centered care, under these conditions, is compromised. Fear of retribution could contribute to parental stress levels and thus to health care professionals’ perceptions of parental ineffectiveness in helping children during stressful invasive procedures. Beliefs regarding best practice related to parental presence during procedures may be, therefore, currently inaccurate. In addition, participants reported that decision-making was much less complicated when parents made their wishes known with respect to both caregiving to, and invasive procedures on, their child. The consequences of parental fear of retribution are many: the parents’ composure may be threatened; the child’s well-being may be dismissed; and the health care professionals may remain unaware of valuable input regarding a child’s care.
While participants did not report any concerns that parental “interference” would directly influence the care they gave to the child, parent-professional relationships were obviously affected when parents disagreed with health care professionals regarding practices. Some participants were unaware of the effects that worrisome parent-professional relationships might have on parents; moreover, the pervasiveness of parental concern has been previously documented. Thorne and Robinson (1988) reported that parents of chronically ill children feel extreme anxiety regarding the possibility of jeopardizing care; this feeling was common in the second stage of health care relationships, namely, disenchantment, and often resulted in parental passivity despite concerns regarding health care professionals and their practices. Parents and families need to become aware of the stages of health care relationships and of strategies they can use to deal with effects of health care relationships on themselves and their child (Thorne, 1993). For example, the consequences of saying “No” when asked to leave could be discussed with families. Similar examples to this are cited by Thorne as a way that parents “challenge the social order” (p. 195-196).

Changes are indicated in both the way professionals offer choices and the way they encourage parents to communicate their wishes. I believe this might assist parents to confront their fear of retribution and replace it with the courage to participate effectively with health care professionals. Use of these strategies by parents may result in concomitant changes in health care professionals who may then change practices to meet the needs of the child and family. I believe that open and frank discussions are needed to address this worrying issue constructively.

After participants described how parental presence during invasive procedures was sometimes circumvented by being performed when parents could not be present, I asked them whether they discussed these procedures with the parents at a later time when giving information regarding the child’s care. Participants said that sometimes they told the parent about the procedure, sometimes the parents asked about obvious signs of a procedure having been performed, and other times parents did not ask and the information was consciously not offered. When discussing “sneaking in” procedures during parents’
absence, I perceived that the participants became uncomfortable. It seemed as though they had not reflected previously on this practice or its consequences. A few participants believed the practice was justified as stress to parents could be prevented; certainly they did not believe they had experienced any problems from parents because of the practice. Other participants believed that the practice of intentionally performing elective procedures in parents’ absence could be detrimental. These participants raised issues such as the legal nature of informed consent as well as the trust relationship between parents, children and health care professionals. The development of trust and a partnership with families is unlikely to develop in conditions where the performance of procedures and their effects for the family are not consciously addressed. I also believe that, just as participants voiced their need for some autonomy in practice, parents also may need some autonomy in deciding what effects of absence or presence during invasive procedures might be detrimental for them and their family.

Performing procedures without parental knowledge could have legal implications. Serious procedure-related complications and/or human errors can, and have, occurred during times when parents are present or absent. Participants varied regarding their beliefs that parental absence or presence at these times would result in the “better” outcome for parental coping and parent-professionals’ relationships. Many participants thought the better scenario was parental presence so parents might know and possibly understand what had actually happened rather than suspecting other happenings. Participants related experiences involving procedural errors or serious complications that occurred when parents were present. In these situations, most participants believed it had been better that parents had been present.

Alternatively, a few participants worried that, if parents were present when errors or serious complications occurred, they could misinterpret what happened and could also detract from health care professionals’ ability to handle the complication. In such situations, some health care professionals were inclined to circumvent parental presence during invasive procedures due to lack of skill or confidence in performing procedures or interacting with parents.
As well as legal implications, there are ethical implications related to how health care professionals circumvent parental involvement with procedures. One such ethical implication is related to a disturbing factor mentioned by every participant, that of the perception of “parent type.” Participants in the PICU study reported that a factor influencing their decisions concerning parental presence during invasive procedures was related to personality characteristics of the parents. For example, one participant described that if she perceived a parent’s voice to be “harsh” or “strident,” she would be less likely to ask him or her to stay for the procedure. Many of the participants believed perceptions of culturally-related characteristics would similarly affect decisions. For example, participants acknowledged that non-English speaking or poorly-educated parents would be less likely to be allowed to stay. It is disturbing to hear that participants varied their decisions regarding parental presence during invasive procedures based on parents’ personality characteristics. Many participants were obviously concerned about the ethical issues involved with this practice.

Perhaps the aim of some circumventions of parental presence is to protect the child; an extreme example of this is observed in health care professionals’ decision-making during invasive procedures performed in the PICU on children with abusive parents who currently are rarely asked to stay. In a recent study on parental presence during invasive procedures in an emergency room, a father stayed with his child despite beliefs that shaking by the father had caused the child’s seizures (Sacchetti, Lichenstein, Carraccio & Harris, 1996). Determining best practice for such a child is difficult. Savedra (1981) reported that during the procedure of a child’s blood sampling, parents’ comforting strategies and personal responses varied but the children’s behaviours were not significantly different. According to Savedra’s observations, it may not be necessary to worry about the effect of the parents’ response on the child in some situations.

Another possible reason that health care professionals circumvent parental presence is because of fear that parents will disrupt the procedure, either directly or indirectly, e.g., by fainting. Reports in the literature have indicated that when present, parents’ behaviour is not usually disruptive to their child’s
procedure (Brunke, 1989; Fiorentini, 1993; Pederson & Harbaugh, 1995; Sacchetti, Lichenstein, Carraccio & Harris, 1996; Savedra, 1981). Likewise, several participants in the PICU study reported parents rarely disrupted a procedure. To the contrary, participants usually found that parents were very “cooperative.” For example, parents would point out the best IV sites, or if their child needed to be reintubated following the procedure of extubation, parents were often the first to suggest that they should leave. A few participants did share experiences when a parent reacted in a manner perceived to be disruptive during a procedure. While memories of these situations were vivid and distressing for participants, these participants usually indicated that these experiences did not make them more likely to believe that other parents would disrupt a procedure. Ironically other participants who had never experienced any problems but were concerned that this could happen, believed that fear of disruption was a valid reason to keep parents away during a procedure.

It would be valuable to know how often parents disrupt procedures and the outcomes of such disruptions. Some participants believed they could accurately assess parents’ likelihood to disrupt a procedure if given some time to discuss the procedure beforehand. It could be that parents who are invited for procedures or given time for discussion prior to staying for procedures are unlikely to be the “disruptive type.” Another relevant factor may be in the way the parents’ behaviour is perceived, that is, as either positively or negatively disruptive. If parents who question a professional’s technique are regarded as negatively disruptive, they will most likely be asked to leave; if, however, the professional views such questions as constructive and indicative of the parent’s commitment to the child, the parent would likely be encouraged to remain.

When I discuss the results of this study with participants and other health care professionals in PICU, the issue of “control” by health care professionals is identified frequently. Yet the negative connotation of “control” of parents when the intent conveyed by participants was positive, led me to the conclusion that “protection” of parents was a more encompassing term than “control” of parents in many
situations. Some practices of health care professionals could be interpreted as moving the issue of parental absence beyond the intent of protection of parents; these practices were in fact, controlling. Protection, in some instances and by some health care professionals, becomes control when practices occur like health care professionals “sneaking in” procedures or preventing all parents from staying because one might faint. While this theorizing is beyond the scope of this study, I believe that the concerns identified above raise important questions pertaining to the issues of family involvement in caregiving and parental presence during invasive procedures.

In summary, I believe that many issues are raised by the practice of circumventing parental presence. Health care professionals need to address issues like the following: differences between a parent versus a family member versus a visitor; parental presence versus parental involvement or assistance; effective management of procedural pain; value or purpose of invasive procedures and contribution to patient outcomes, including procedures that result in potential complications; responsibilities of discussing the associated problems of procedures; and learning of health care professionals. Discussions of protection versus control and resulting consequences need to be discussed by parents / families and health care professionals in order to bring partnerships and collaborative practice into play.

**Omission of Family-Centered Care Principles in Decision-Making**

Family-centered care principles direct health care professionals to form partnerships, engage in collaborative decision-making and build confidence in families’ abilities to support their children. It follows that health care professionals operating from family-centered care principles ought to involve families in decision-making regarding parental presence during invasive procedures. This research study revealed that, in actuality, parents were rarely involved as partners in decision-making; in fact, participants’ decision-making often did not include offering parents choices regarding presence or absence during an invasive procedure on their child. In this way, participants’ decision-making rarely reflected family-centered care principles. Analysis of the findings of this research study also reveals possible reasons for the
lack of family-centered care principles in decision-making. These reasons related to: the participants’ inadequate knowledge of family-centered care principles, participants’ beliefs regarding application of these principles, the discrepancies between participants’ beliefs and their practices, and the fact that the decisions are made by health care professionals rather than made jointly with families.

About half of the participants required a definition of family-centered care in order to respond to my questions regarding the relationship between family-centered care and parental presence during invasive procedures in the PICU. This finding may be significant, as while the hospital’s mission statement clearly supports family-centered care, many participants were not conversant with its principles. This raises what I believe are important questions, that is, “Is this finding representative of the awareness levels of other PICU staff and what is the source of this lack of knowledge?” Barnsteiner, Gillis-Donovan, Knox-Fischer and McLindon at Children’s Hospital of Philadelphia reported in 1994 that it is not uncommon for philosophies and/or mission statements to change in large institutions without the necessary education which ought to accompany such a change. To complicate matters, the term “family-centered care” reveals some aspects of its meaning without indicating the breadth of the principles involved. For example, some health care professionals may be led to believe that interacting with family members as well as caring for the child constitutes “family-centered care” in comparison to “non-family-centered” or “patient care” which would constitute caring for the child only. This was revealed in statements such as those by one participant who indicated that “family-centered care is not new,” believing that inclusion of parents in medical interactions with children meant that the practice of “family-centered care” had been common in the care of children for many years. Other participants believed the care given in a children’s hospital was much more inclusive of family members than care given in adult care facilities they had experienced, and thus, these participants viewed care at a children’s hospital as more “family-centered.”

The participants’ perception that family-centered care encompassed a limited scope of practice is congruent with statements of pediatric health care professionals in studies regarding perceptions of family-
centered care conducted by Berman (1991), Brown and Ritchie (1989) and Letourneau and Elliott (1996). Nurses and other health care professionals in these studies did not fully appreciate the breadth of practice encompassed by "family-centered" care, assuming that giving parents information, visiting privileges and psychosocial support encompassed family-centered care. To acknowledge that families differ in their needs and wants, family-centered care mandates the provision of care that is individualized to the specific family. Many health care professionals have difficulty providing care that is as equally diverse as the families they encounter in practice.

Historically, requesting that parents leave during invasive procedures has been standard practice in the PICU of this study and a few participants expressed the view that the option of parental presence during invasive procedures was beyond the scope of family-centered care practice. It remains unclear how best health care professionals could become aware of a need to examine and/or change this practice, i.e., is education enough or are there other awareness strategies that might be more effective? The principles of family-centered care as outlined at BCCH do not explicitly state that parents are best helped by being given an option regarding being present during invasive procedures on their child in a PICU (BCCH, 1997) nor is there research-based literature indicating that the option is recommended. As a result, health care professionals are left to interpret the principles of family-centered care, including how these principles might apply during invasive procedures in a PICU. This situation results in uncertainty and inconsistency at best, and is not unique to this setting or this institution. Pediatric nursing literature abounds with examples of experts questioning the meaning of family-centered care principles related to "participation," "collaboration," "partnership," and "information-sharing" (Ayer, 1978; Callery & Smith, 1991; Coyne, 1996; Gill, 1993; Neill, 1996a, 1996b). For example, Coyne conducted concept analysis of "parent participation" and found it to be complex and multi-dimensional, both in terms of the meaning of participation and its congruence with family-centered care. The application of this and other concepts may become further complicated when applied in a PICU. For example, the presence of precarious lines and
tubes may make caregiving more difficult for parents in PICU. This is supported by examples in the literature in which experts question whether family-centered care is truly achievable in critical care areas (Marsden, 1992; Rushton, 1990a). I believe that health care professionals are currently practising without the kind of research-based evidence that is needed to support the option of parental presence during invasive procedures in a PICU; such evidence might assist health care professionals and parents who currently do not associate parental presence during invasive procedures with family-centered care.

Conversely, one might question whether such research-based evidence would influence the practices of participants who currently do not associate parental presence during invasive procedures and family-centered care. Indeed, this research suggests that health care professionals do not necessarily practice according to evidence or other professional bases of knowledge such as philosophies of care. During the interviews, I found it peculiar that all participants declared, often vehemently, their personal preferences regarding whether they would want to be present or not if their child or family member was having a procedure done. Many of the participants claimed that they frequently based their decisions on their desires. The significance of this lies in the personal rather than professional nature of the knowledge that health care professionals are using in their practice. It is an example of how difficult it is for professionals to transfer awareness regarding the importance and uniqueness of their own beliefs to actions demonstrating that beliefs of other families may be equally unique and important. Findings in other studies have identified that health care professionals’ practice is often more affected by their own beliefs than the institution’s family-centered care philosophy (Berman, 1991; Brown & Ritchie, 1990). These investigators concluded that nurses’ attitudes reflected their beliefs about families and nursing rather than an orientation to family-centered care.

Another notable finding from this study is that participants’ beliefs about family-centered care are often inconsistent with their practices, specifically concerning parental presence during invasive procedures in the PICU. Research findings related to inconsistent beliefs and practices of family-centered
care have been reported by Brown and Ritchie (1990) and Letourneau and Elliott (1996). Brown and Ritchie found that nurses lack knowledge about and experience with communication and conflict management skills, making it difficult for them to translate family-centered beliefs into practice. Letourneau and Elliott suggested that educational experiences for health care professionals do not focus on practical application of family-centered care theory. In this PICU study, many participants espoused views similar to those who promote family-centered care; participants echoed Leff, Chan and Walizer's statement, "parents know their child best" (1991, p. 235), or voiced Leff and Walizer's belief regarding families with hospitalized children being the same as they were before but just more stressed (1992). It was evident in this PICU study, however, that beliefs such as these were often inconsistent with practices that did not exemplify family-centered care. For example, a physician may believe a parent should be offered the option of being present during an invasive procedure and also believe that the timing of the procedure is such that parental presence could be detrimental. The two competing beliefs may result in a practice that is inconsistent with stated beliefs, such as performing the procedure without either offering parents the option of presence or discussing the beliefs that underlie the decision of asking the parents to leave.

There is perhaps another reason for the absence of family-centered care principles as revealed in professionals' decision-making regarding parental presence during invasive procedures in the PICU. I believe that, to date, the "family" is missing from family-centered care, especially in many aspects of PICU practice such as invasive procedures, because, if half of the participants in the study are not sure of the definition of family-centered care, it is unlikely that they have conveyed the principles of family-centered care to parents in the PICU. As Arango (1990) put it, family-centered care can easily become "buzz words," words that are used often and sound good but do not translate to any meaningful practices. Parent-professional partnerships cannot exist without parents who are ready to learn to become partners. Arango (1990) stressed the committed system and member level supports that are necessary to foster truly equal partnerships between parents and health care professionals. While referring to families of
children with special needs in hospitals and communities, Arango also emphasized the difficulties in
developing supports and partnerships. Along a similar vein, Gwen Hartrick (1997) lamented the
continuation of care focused on servicing health problems rather than enhancing family capacity. She
addressed the difficulties currently experienced in shifting from a mechanistic to a contextual worldview.
Arango and Hartrick are addressing the difficulties at a relatively primary level of health care. I believe that
this difficulty is enhanced in situations where health care professionals socialized to a primarily technical
world attempt to develop partnerships in the PICU with a family of a critically ill child and to empower the
family members to focus on the meaning of the critical care experience. It may be that health care
professionals in PICU perceive that family-centered care is far removed from the realities of tertiary level
health care because family-centred care has largely been presented in primary health care settings.

Some possible reasons that family-centered care principles are not currently integrated in the
practice of health care professionals making decisions regarding parental presence during invasive
procedures have been discussed. A partial solution to this situation could be for health care professionals to
break the silence and talk about why they currently make the decisions they do. Such a discourse could do
much toward helping professionals to become aware of their beliefs and how they influence their practice.
This PICU study revealed that collaborative partnerships in relation to such decision-making is negligible.

Integration of Schematic Representation of Decision-Making and Themes Discussed

The data which resulted in the revised schematic of decision-making regarding parental presence
(Figure 2) contributes much to providing an organized way to look at the findings of this study to the
research question, “What factors influence health care professionals’ decisions regarding parental presence
during an invasive procedure on a child in a PICU?” It also provides a way to view and address the
consequences of problems discussed in this chapter that currently have an impact on health care
professionals’ decisions. To begin, each of the four levels indicated on the schematic can be assessed for
relationships to the problems and for the possibility of changes as directed by the discussion. These
changes could cause concomitant changes to the influences of the mediating and contextual factors, again addressing some of the issues arising from the discussion.

The first level of the schematic refers mainly to "who" chooses the primary goal for the procedure. In order to address concerns raised throughout the discussion, such as the absence of the child's voice, overprotection of and lack of collaboration with parents, and hierarchical issues among health care professionals, perhaps the "who" in the decision-making process could be expanded. This expansion would incorporate others with a vested interest in the outcome of the procedure, e.g., the child when possible, the parents unless unable to be contacted or alternate wishes were previously expressed, and the health care professionals who know the child and/or will be involved with the procedure. The expansion of who chooses the primary goal may encourage discourse regarding the factors that will influence the decision made regarding parental presence.

One of the interesting findings of this study involved the health care professionals' choice of a primary goal for procedures. It appeared that both goals were not simultaneously viewed as equally valuable and equally achievable. This sometimes could be due to the large number of complex mediating and contextual factors existing in a given situation. While there may be occasions when either efficiency or family-centeredness is an obvious choice, perhaps on other occasions both goals could be pursued, especially if there is more than one individual involved in choosing the goal. Very early in the analysis of the data, I was struck by the overwhelming number of factors that influenced the participants' decisions regarding parental presence during invasive procedures. As pointed out by Hamers, Huijer and Halfens (1994), too much data can detract from sound decision-making. The possibility of pursuing both goals may be more likely when others are involved in decision-making allowing more objective assessment of the influencing factors.

The third level identified in the schematic is one where the contextual factors of the nature of the environment, the procedure, the child, the parents and the health care professional influence the decision
made regarding parental presence. Each of the contextual factors identified should be questioned for its applicability to both the PICU in general and the patient in particular. The detrimental impact of issues like the negative effects of parents’ characteristics on a child’s behaviour, the silent socialization process that results in health care professionals believing that parents should leave, the emotional stress for those involved in the procedure, and the lack of consideration to holistic health could be examined by attention to this level of the framework. Exploration of assumptions and beliefs related to each of the contextual factors is much needed in order to explicate points that prejudice and circumvention of parental involvement currently exist in the decision-making process.

Finally, the actual number of decisions identified in the schematic representation is three. By incorporating the changes outlined to the above three levels, the options at the decision level could be significantly altered. The two decisions remaining might be parental presence or parental absence as determined by the decision-making team. For example, the decision not to address parental presence could be negated or decreased in frequency by involvement of the family and other health care professionals in the decision-making process. This would lessen the impact of two problems experienced currently, that of health care professional distress when parents watch procedures with no support and that of circumventing parental involvement by “sneaking in procedures.” The decision, asking parents to leave, would also be modified by involvement of families and other health care professionals in the other levels of decision-making represented in the schematic.

A few general interventions required to help implement the changes as outlined above would include: education regarding family-centered care; added resources for families, (e.g., information pamphlets, teaching aids, and support groups); discussion among health care professionals and parents and children representatives of the issue of parental presence during invasive procedures to help uncover and clarify the assumptions and beliefs of health care professionals and families regarding parental presence during invasive procedures; and validation of the issues identified in this chapter with families and other
staff in the PICU to substantiate their impact on outcomes of care.

**Summary**

In this chapter, a schematic representation of decision-making (Figure 2) was used to illustrate what influenced health care professionals’ decision-making during invasive procedures in the PICU and to demonstrate how specific changes could address the negative consequences of such decision-making. Issues in relation to this decision-making were identified in the discussion of four themes arising from the research data, including the lack of discussion among health care professionals in the study regarding parental presence during invasive procedures in the PICU, the influences identified that were unique from those previously identified in non-PICU care settings, the circumvention of parental involvement during invasive procedures, and the lack of reflection of family-centered care principles in decision-making.
CHAPTER SIX: SUMMARY, CONCLUSIONS AND IMPLICATIONS

Summary

The purpose of this study was to identify the factors that influenced health care professionals' decisions regarding parental presence when a child undergoes invasive procedures in a PICU. The trend toward family-centered care stimulates families and health care professionals to examine all aspects of care given to children and their families. For children cared for in the hospital setting, the aspects of care examined have included parental visitation, parental involvement in caregiving and decision-making, and parental satisfaction with physical and emotional aspects of care. Recently, parental presence during the performance of invasive procedures has been studied in care settings such as emergency, pre- and post-operative care, and both ambulatory and in-patient medical and surgical areas. Health care professionals and parents have also expressed opinions regarding benefits to, and needs for, children to have their parents present during invasive procedures in the PICU. Actual practice, however, is widely variable; while parents have been present for any and every procedure in the PICU setting, parents are predominantly absent during procedures in the PICU. The literature reviewed did not offer research findings identifying conditions under which parents could or should stay during an invasive procedure on their child. This study addressed the question: What factors influence health care professionals' decisions regarding parental presence during an invasive procedure on a child in a PICU?

To incorporate my philosophical perspective regarding the importance of the context in which health care professionals currently make decisions regarding parental presence during invasive procedures, I elected to use the qualitative method of interpretive description to explore the research question. This method is ideal for initial explorations of phenomena, especially as presented by those experiencing the phenomenon in the naturalistic setting.

Fifteen health care professionals, ten nurses and five physicians, who are involved in decision-making regarding parental presence during invasive procedures in the PICU, participated in this
study. To capture descriptions of their decisions, I interviewed each individual, initially using a semi-structured outline, aiming to stimulate expansion on the details of situations when they had considered the question of parental presence during invasive procedures or related issues. The interview outline was guided by a review of literature believed relevant to the question of parental presence during invasive procedures in the PICU. This literature review included family-centered care theory, the parental experience in the PICU, parental involvement in caregiving in hospital, parental presence during invasive procedures in other care settings, and family member presence during resuscitation.

After analysis of verbatim transcripts of participants' interviews, factors influencing decision-making were identified and categorized. Second interviews with each participant were completed in order to clarify, validate or revise the categories and their related factors. Final analysis resulted in the identification of three possible decisions that participants made regarding parental presence: asking parents to leave; not addressing the question and parents stayed or left; and giving the parents a choice to stay or leave. These decisions were influenced by one of two primary goals, namely maximal efficiency and minimal disruption or maintenance of the parent-child relationship. Participants' primary goals and final decisions regarding parental presence were influenced by other mediating and contextual factors. The goal participants chose was mediated by four factors identified, including the professional's beliefs regarding family-centered care, the professional's personal and professional experiences, the length of time available, and "the phase of the moon" or an undefinable combination of factors.

The actual decision made regarding parents staying or leaving was influenced further following the determination of a primary goal for the procedure. This influence arose from factors related to the context of the individual situation in which the decision-making occurred and included factors related to the nature of the environment, the nature of the procedure and the nature of those involved in the procedure; i.e., the child, the parents and the health care professionals. Factors related to the nature of the environment included the site for the procedure, the physical space in ICU and concurrent activity in ICU. The nature of
the procedure referred to its degree of invasiveness, the length of time required to complete the procedure, its associated potential complications, its degree of complexity, and its predicted outcome.

The predicted responses of the child, parents and health care professionals influenced the decisions made regarding parental presence to a great degree. Factors identified by participants related to the child included the child's age, length of illness and hospital experience including previous ICU experience, severity of condition, and levels of consciousness, sedation and analgesia. Participants perceived that the nature of parents' responses was influenced by their requests, previous experiences, physical or emotional states and characteristics, relationships with health care professionals, and relationship with their child; these factors concomitantly influenced participants' decisions regarding parental presence during invasive procedures. Factors relating to the health care professional that influenced decisions included the primary goals of the person performing the procedure or of the health care professionals involved in making the decision, the skill and/or confidence levels of those involved, the status of being a "learner" involved with the procedure, and relationships with the family and other health care professionals involved.

Study findings revealed that the participants did not discuss with others the decisions they make regarding parental presence during invasive procedures in the PICU. Lack of explicit attention to these decisions, and the factors that influence them, results in distress and negative outcomes for families and for health care professionals. Several influences unique to the PICU were identified in this study, influences that have an impact on health care professionals' decisions regarding parental presence during invasive procedures in the PICU. Stress for parents with a child in the PICU was perceived by those observing them as tremendous; health care professionals want to protect parents from increased and unnecessary stress. Most procedures in PICU were viewed by the participants as potentially distressing to parents. Protection of parents during the performance of invasive procedures on their child was generally perceived as best accomplished by parental absence; consequently, the most frequent decision made by health care professionals was asking the parent to leave during invasive procedures on their child in the PICU. Health
Care professionals in this study reported that often they do not discuss their rationale for having parents be absent during procedures; similarly, parents are often unable to identify their wishes to health care professionals because of emotional distress or fear of retribution if they anger or displease health care professionals. In this way, parental involvement was frequently circumvented by health care professionals. The voice of the child was rarely represented in decisions made regarding parental presence during invasive procedures in the PICU. Health care professionals' beliefs and assumptions regarding the negative effects on parents present during invasive procedures in the PICU prevailed over beliefs regarding potential positive effects of parental presence for children who are ill enough to be in this setting. Lack of involvement of families in decision-making regarding parental presence during invasive procedures is contrary to the philosophy of family-centered care. Family-centered care principles were not generally incorporated in the health care professionals' decision-making regarding parental presence during invasive procedures in the PICU.

Study Conclusions

The following conclusions are derived from the study findings but it is important to recognize that these conclusions are based solely on the participants' experience; they cannot be generalized beyond the research sample:

1. Health care professionals in this study believed that the issue of parental presence during invasive procedures is important, that it is worthy of conscious and explicit reflection, and that current practices related to decisions regarding parental presence during invasive procedures should be examined as to their efficacy and outcomes.

2. Health care professionals in this study pursued a goal when performing procedures. Two such goals identified in this study were the achievement of maximal efficiency and minimal disruption, and maintaining the parent-child relationship; the choice between these goals is mediated by factors such as the health care professionals' beliefs regarding family-centered care, their personal
and professional experiences, the time frame available and happenstance factors. Decision-making regarding parental presence during invasive procedures in the PICU can be explored effectively using a framework that incorporates these goals rather than one that incorporates only the outcomes of decision-making, i.e., parental presence or absence.

3. Factors that influence the goal of the procedure, and the decision for parental presence or absence were readily identified by health care professionals in this study. Numerous factors related to the environment, the procedure, and those involved in the procedure influence health care professionals' decisions; these factors are best examined by their effect on the procedure's goal rather than their influence on the decision alone.

4. Children and their families were rarely involved in the participants' decision-making regarding parental presence during invasive procedures in the PICU; this practice could be partially responsible for problems currently associated with decision-making regarding parental presence during invasive procedures. While some factors that appear to be unique to PICU were identified by participants, uniqueness of the setting in this regard is questionable since health care professionals in the study reported that they currently do not discuss the issue and frequently circumvent parental involvement in decision-making and during invasive procedures.

**Implications for Health Care Professionals**

The findings of this study hold implications that are important for future practice, education and research within health care professions, as well as for the well-being of parents and their children in PICU.

**Health Care Practice**

Study findings suggest that nurses and other health care professionals in PICU are currently making decisions regarding parental presence during invasive procedures without supports that could assist in these decisions. This finding gives direction to those involved in managing health care delivery in the PICU and in the development of policies and standards for practice in the PICU. Specifically, explicit
guidelines for practitioners about how to make decisions regarding parental presence are unavailable. As well, the integration of the principles of family-centered care appears to have neglected decision-making regarding parental presence in PICU. Consequently, in addition to education, practising health care professionals might benefit from development of guidelines and role modelling of the principles of family-centered care applied to parental presence during invasive procedures. They could also benefit from discussions and other means to encourage reflection on practice and examination of their beliefs and assumptions regarding family-centered care and parental presence during invasive procedures.

Strategies to assist health care professionals to ensure that the child's voice is heard need to be developed. For example, history forms that focus on collecting data to be used for this purpose would be helpful; development of care plans with children prior to elective admissions has been a useful method of allowing children to have input into decisions before levels of consciousness, analgesia and sedation interfere. Many parents may feel comfortable developing such care plans with assistance and the use of resources, such as "Helping your child manage medical & surgical procedures," a brochure available through the Family Resource Library at BCCH (BCCH, 1995). Currently, health care professionals may not be aware of these resources. I believe this pamphlet could be expanded to indicate potential implications specific to PICU concerning parental presence during invasive procedures.

Ideally, interventions to assist health care professionals such as those suggested above are implemented collaboratively with multidisciplinary team members in the PICU. This could aid greatly in decreasing conflicts that occur currently as well as contributing to collaborative practice. I believe that collaborative partnerships with families cannot occur until these same collaborative relationships are evidenced among health care professionals. This notion is reinforced by Rushton (1990b). Managers in PICU can assess authority and decision-making structures to ensure that collaboration can develop in a supportive climate (Rushton).

Health care professionals need to seize opportunities to reflect on their practices regarding parental
presence during invasive procedures. Professional development and continuing education in PICU should focus not only on theory regarding family-centered care but on critical evaluation of one's own beliefs and values. Development of insight into the effects of personal beliefs and values on practices related to parental presence during invasive procedures is beneficial for all PICU professional staff. Professionals should be taught to differentiate between general practices recommended in following family-centered care principles and practices that individual health care professionals find impossible to support because of factors unique to the individual situation. Ways of handling these variations ought to be developed so that needs of families and health care professionals are met. As suggested by one participant, health care professionals in PICU rarely ask children and families after procedures how being present affected them. Such evaluation of care delivery has been recommended by Delbanco (1992) who advocates inviting the patients' perspectives both individually and collectively.

Health care professionals who are unfamiliar with theory related to developmental care of children ought to avail themselves of education programs and literature that may not have been available in their basic professional education programs. This would assist them to identify their role in making families aware of information that may help them to contribute to decision-making in a knowledgeable way. I believe that it is crucial for the health care professionals who are making the decisions regarding parental presence to be able to incorporate knowledge from empirical and experiential sources with knowledge from caring for the child. Currently, health care professionals making decisions are often those who are performing a procedure on a child whom they do not know; therefore, these health care professionals are unable to include knowledge of the child in their decisions. In such situations, the findings of this study suggest that decision-making could involve members of the family, as well as the parents, who could contribute to the child's and family's care effectively, e.g., siblings, grandparents, friends. Currently the definition of "family members" refers mainly to parents rather than family members who could best meet the family needs regarding parental presence during invasive procedures. To gain insight into how best to
meet the child's and family's needs, other resources in the hospital setting could be used, e.g., family advisory committees, patient and family libraries, child life specialists, and clinical nurse specialists from varying areas.

Nursing and Client Education

The main implication that the findings hold for education relates to the development of a practitioner's philosophical stance in regards to the issue of parental presence and the consequences of this for those with whom the professional has contact. For example, the way a professional views health, health care and families influences his or her decisions regarding parental presence during invasive procedures in the PICU; consequently the professional ought to be aware of this influence and reflective regarding the effects on decision-making. I believe that professional education has already begun to integrate concepts such as self-awareness and reflective practice into theory and clinical courses. Involving family members as teachers has proven to be effective when educating caregivers about family-centered care (Heller & McKlindon, 1996).

The findings also indicate that awareness of one's own beliefs is not enough to provide the nurse with a solid grounding in managing the complexity of decisions such as those involved with parental presence during invasive procedures in the PICU. The practitioner must also be able to interact with families such that their needs for information are identified and met in the best way possible. Development of such practitioner-family collaborative partnerships is a challenge that requires strong communication skills and conflict management skills. Continuing staff education in PICU should emphasize this skill development.

I believe that health care professionals could be playing a role in the education of consumers regarding this issue. For example, two reports in common media aim to provide consumers with increased awareness and information regarding possibilities. A local newspaper ran a story regarding a program in a hospital emergency department to keep a family member present during resuscitation procedures; the
practice change was cited to relate to the nurses' belief that "letting families be present at the time of crisis is the most effective intervention we can provide" ("Emergency Room Revolution," 1997). Similarly, a family magazine printed an article regarding the results of a research study (Bauchner, Vinci & May, 1994) cited among reviewed literature in this paper; the purpose of the article was to inform parents of possible roles they can play in calming their child during procedures in the emergency room ("Parents Do Fine", 1997). Health care professionals ought to be educated about the need for, and how to provide, this type of consumer education.

Health care professional education ought to provide learners with the knowledge and skills required to collaborate with professionals from other disciplines in such decision-making. While the procedures performed by nurses, physicians, respiratory therapists and physiotherapists may vary, most aspects related to decision-making regarding parental presence during procedures are identical. Facilitation of theory and practice development regarding such decision-making among those in related disciplines could be accomplished together.

Health Care Research

The study findings suggest implications for health care research. The relationships between parental stress and parental presence during invasive procedures in PICU warrant investigation. Evidence from this type of research could help health care professionals and families. Health care professionals' assumptions and beliefs should be further investigated with an aim to assess whether the factors currently influencing decisions regarding parental presence during invasive procedures affect procedures and outcomes as currently predicted. It appears that practices are difficult to change based on theoretical knowledge alone because of health care professionals’ deeply ingrained assumptions and beliefs. If the participants of this PICU study were to be involved in a research project, their current assumptions and beliefs could perhaps be influenced as well as tested. Investigators should determine whether there is a decision-making structure that could assist health care professionals to incorporate such a great number of
factors efficiently. Differences in the way that parents are present could be investigated to see what outcomes are specifically associated with these. For example, researchers could investigate if being present is easier for all involved if the parent is visible versus if the parent is involved in anxiety relief measures versus if the parent is restraining the child.

The involvement of children and families in developing appropriate questions to research regarding parental presence during invasive procedures, and in identifying possible corresponding interventions, should be explored. As well, researchers could explore whether family involvement would be beneficial in implementing and evaluating research results. I believe that groups such as the hospital family advisory committee are keen to be involved in this manner.

I noted that many participants could much better relay information about the situations in which they made decisions than they could identify what the influencing factors might be for such decision-making. I believe this may relate to the contextual and complex nature of the decision-making process and to the fact that the topic is currently unaddressed in discussions among health care professionals. Thus, I would suggest that these relationships could be investigated. A few participants suggested the idea of round table discussions with health care professionals and families; perhaps these participants could be involved in such a research project.

The participants' awareness of research findings pertinent to decisions regarding parental presence was lacking. Connections between different bodies of research are difficult to assess without discussion. For example, how can evidence related to parental involvement in caregiving be applied to evidence available regarding parental presence during invasive procedures? Similarly, connections between research evidence and actual practices need to be explicated. For example, how does evidence regarding separation anxiety in young children relate to parental absence during invasive procedures in the PICU? I believe that researchers play roles in disseminating research findings and stimulating evidence-based practice. Creative ways should be sought to connect changes in evidence with the importance of subsequent changes in
practices by health care professionals like the participants of this study. Involvement of practising professionals in research studies may be one way to encourage such connections between new evidence and practice changes.

Conclusion

In this study, I investigated the factors influencing health care professionals' decisions regarding parental presence during invasive procedures in the PICU. Participants identified that such discussion is important and that it currently does not occur. Although numerous aspects of this issue should be further investigated, this research represents an effort to make more explicit how and why health care professionals decide to ask parents to stay or leave during an invasive procedure. The findings contributed to the development of a framework that reflects the complexity of decision-making currently and could be used as a structure to further discuss the issue of parental presence during invasive procedures in the PICU.
REFERENCES


Holl, R. (1993). Role-modeled visiting compared with restricted visiting on surgical cardiac patients and family members. Critical Care Nursing Quarterly, 16(2), 70-82.


APPENDIX A: PARTICIPANT INFORMATION LETTER

UBC School of Nursing Letterhead

Factors Influencing Health Care Professionals' Decisions Regarding Parental Presence during Procedures in the PICU

For my UBC Master's degree thesis, I am conducting a study to learn about the factors which influence health care professionals' decisions regarding parental presence when a child is undergoing invasive procedures in the Pediatric ICU. I am aware that nurses and physicians are usually involved in making these decisions daily in the PICU and that there are many contributing factors for varying decisions regarding parental presence during invasive procedures. I am interested in this study because I believe that both health care professionals and families can benefit from the identification of these influencing factors.

This letter is to request nurses and physicians involved in procedures in the PICU to participate in my study. Participation would involve two meetings at a convenient time and place. In an initial interview lasting up to one hour, I will ask questions about experiences with parental presence during procedures. The interview will be tape recorded to ensure accurate data collection. A second tape recorded meeting of up to one hour will be to share results and ask participants to clarify my interpretation of the results. Confidentiality of participants will be maintained; participants will not be identified by name or inference in any reporting. The tapes will be identified by code numbering and only I will be aware of the tapes corresponding to each participant. The code numbering and tapes will be kept in a locked filing cabinet. The tapes will be listened to by a typist, myself, and two professors who are supervising my study.

Participation is completely voluntary; no one is under any obligation to participate. Participation is in no way part of employment at this hospital; nor will it affect the participant's employment. Participants will be asked to sign a consent form at the first meeting to indicate willingness to participate and be audiotaped. Participants are free to refuse to participate in specific parts of the interview. Furthermore, participants can decide to withdraw consent at any time without penalty. Participants will be asked for some demographic data, such as years of experience, educational background. Demographic data and results will be reported in my master's thesis, in a professional publication and at professional conferences.

There may be no direct benefits to participants in this study. Participants may gain an increased awareness of factors influencing decisions regarding parental presence during invasive procedures in the PICU.

If you are interested in participating or have any questions, please call me at xxx-xxxx or my thesis chair, Dr. Barbara Paterson, at 822-7490. Thank you for your consideration of the particulars of this study.

Sincerely

Rosella Jefferson, RN, BScN.
APPENDIX B: PARTICIPANT INFORMED CONSENT FORM

UBC School of Nursing Letterhead

Factors Influencing Health Care Professionals' Decisions Regarding Parental Presence during Procedures in the PICU

Principal Investigator: Dr. Barbara Paterson, UBC School of Nursing, 822-7490
Student Investigator: Rosella Jefferson, UBC Graduate Nursing Student Thesis, xxx-xxxx

Purpose:
I am aware that this study is looking at the factors which influence decisions regarding parental presence when a child is undergoing invasive procedures in the PICU. I am aware that I will be asked for some personal demographic data, to describe my experiences with parental presence during invasive procedures and to respond to questions related to factors which might influence these decisions. I understand that the results and their interpretation will be reported in Rosella's Master's thesis, in professional publications, in teaching materials and at professional conferences. I understand that possible risks of participating in this study could come from psychological discomfort from thinking about and sharing stories regarding my involvement during painful procedures on children in the PICU. Increased awareness of factors influencing my practice may be a helpful outcome of participation or there may be no direct benefits to me by participating in this study.

Study Procedure:
I understand that I will be asked to participate in two one-hour meetings with Rosella Jefferson, for a total of two hours. These meetings will be conducted outside of working time, at mutually convenient times. These meetings will be tape recorded. I am also aware that I can ask questions of the researcher and that the results and their interpretation will be shared with me before final analysis. At this time, I will be asked to clarify results and may have input into the interpretation of the results.

Confidentiality:
I know that my identity will be protected by code numbering of the tapes and that the only person having access to the code numbering is Rosella Jefferson. The tapes will be kept in a locked filing cabinet. I am aware that a typist transcriber and two professors who are members of Rosella's Committee will have access to the anonymous tapes, carefully maintained by Rosella Jefferson. In addition, any persons I mention on the tapes will not have their identity revealed at any time. At any time during the process, I can refuse to answer questions, request that the tape be turned off or erased. I can also end my involvement at any time.
Contact:
If I have any questions or desire further information with respect to this study, I may contact Dr. Barbara Paterson 822-7490 or Rosella Jefferson at xxx-xxxx.

If I have any concerns about my treatment or rights as a research subject I may contact the Director of Research Services at the University of British Columbia, Dr. Richard Spratley at 822-8598.

Consent:
I understand that my participation in this study is entirely voluntary and that I may refuse to participate or withdraw from the study at any time without jeopardy to my employment.

My signature indicates that I give permission for the information I provide on tape or interviews to be used in teaching materials, research journals, books, or articles.

I have received a copy of this consent form for my own records.

I consent to participate in this study.

________________________________________________________________________
Signature of Participant                      Date

________________________________________________________________________
Signature of Researcher                      Date
APPENDIX C: DEMOGRAPHIC DATA

Study: Factors Influencing Decisions Regarding Parental Presence during Procedures in the PICU

Nurse: ______  Physician: ______

Current Position: ____________________________________________

Educational Background: ______________________________________

________________________________________________________________

Other areas of experience:

________________________________________________________________

Total Years of Experience in Practice: ______

Years of Experience in PICUs:

________________________________________________________________

________________________________________________________________

Gender: ______

Experience as a Parent: _________________________________________

________________________________________________________________

Other personal or professional data mutually deemed to be relevant:

________________________________________________________________

________________________________________________________________

________________________________________________________________
APPENDIX D: INTERVIEW GUIDE

Study: Factors Influencing Decisions Regarding Parental Presence during Procedures in the PICU

Questions:

Tell me about a time when you had to make a decision about a parent being present during a procedure in the ICU?

How typical is this to your usual decisions regarding parental presence during procedures? Tell me about another time which illustrates this?

If not typical, how does it differ?

What circumstances would prompt you to do something different?

Depending on response, elaborate re:

caregiving vs. invasive procedures

invasive procedures vs. resuscitation

How do you think the whole issue of parental presence during invasive procedures fits into the practice of family-centered care?

Can you think of anything that would help you in your decision-making regarding parental presence during procedures?

We've talked about a lot of things today. Were there some things that you hoped we'd cover and haven't got around to?