

**PEDIATRIC NURSES' NARRATIVES REGARDING
WORKING WITH FAMILIES THEY PERCEIVE AS
OBSTRUCTIVE**

By

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ABSTRACT

The experience for nurses working with families perceived to obstruct care in the context of Pediatric hospitals is a phenomenon largely ignored in the literature. Much of the research has focused on the causes of difficult working relationships between RNs and families from the parents' perspective, without exploring the experience for RNs in any depth.

Families increasingly expect that care will be provided in a family focused manner and pediatric nurses strive to meet that standard. However, the reality of successfully engaging with all families to provide such care is complex and not always successful. In this qualitative study, narrative inquiry was used to explore the meaning for RNs of their experience in working with families who they perceived obstructed care. Eight RNs participated in this study, they had been qualified for at least five years and were currently working in a tertiary pediatric setting. In-depth interviews were analyzed to explore the content, structure and interpersonal factors within the RN's stories. The study findings suggest that the RN's experience working with these families has a personal and professional impact, which is not acknowledged formally or addressed in a proactive manner.

Four main narratives were identified in this study: *Anticipating the worst, Questioning of self, Failing to connect and making sense of the hurt*. In addition, one sub-narrative emerged from the data titled *Avoidance*. The findings that emerge from this research are important to practitioners, educators, researchers and administrators and suggest that RNs require increased support in order to provide quality care to the "obstructive" family.

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This work has touched on some difficult situations involving parents and nurses. Let us not forget the vast majority of successful partnerships between parents and nurses that foster care for which we can rightfully be proud.

Finally to my three boys' I am forever indebted!

CHAPTER 1: INTRODUCTION

"As the night shift neared to an end I was filled with guilt at the secreted knowledge that I had not laid hands on the baby in my care, not even to check the nasogastric tube placement through which the baby was fed. How could I have let that happen? What sort of role model could I call myself? What if the tube was in the lungs? What would my colleagues think? How will I chart in a way that even begins to explain the barriers to delivery of care that could justify my actions?

Why did that parent make me so mad?

What was their problem?

I left the unit at the end of my shift dissatisfied, resentful, and completely drained".

(Personal Communication, Staff Nurse, Spring, 1999).

The substantive knowledge related to the delivery of paediatric nursing care has changed dramatically in the last fifty years. At one time, physicians and nurses assumed total responsibility for a child in hospital and made all decisions about treatment (Brown & Ritchie, 1990). The child was seen as "an isolated being", far removed from the context of the family. This decontextualisation was perpetuated within the hospital setting. The child would be dropped off at the doors of the hospital by the parents. There was no family contact until discharge, at which time the parents were permitted to collect their child (Johnson, 1990). Bowlby, Freud, and Robertson pioneered research in the early 1950's, which identified the psychological damage that occurred to young children when they were separated from their families during hospitalisation. As a result of this work, advancement of our knowledge regarding appropriate developmental, psychological, and ethical care has guided current paediatric health care practices.

Within a present day paediatric hospital, family members typically spend a significant amount of time providing care and making decisions for their sick child (Brown & Ritchie, 1990). Paediatric nurses now provide care for the child and family as one unit. *Family-centered care* is the broad term used by health care professionals to identify the model of care as child and family focused. Family-centered care is a philosophy rooted in the belief that all families are caring and want to nurture their children; it acknowledges the centrality of the family in the child's life (Ahman, 1994). Professional and parent partnership is a key theme in supporting parents in their central caring role. Family-centered care spans the continuum, from allowing families into a hospital setting as "visitors" to more commonly embracing families as "partners" in care. This model of care has resulted in dramatic changes in the role expectations of both parents and nurses.

As with any change, elements of the shift towards a family-centered care model are challenging (Hartman, 1995; Wells et al., 1994). Liaschenko (1994) acknowledges the gap between the vision of nursing and the day-to-day reality in the nursing world. She suggests, "While the ideal of nursing may be envisioned as a matter of our fully engaged selves rendering exquisite care to an ever cooperative and grateful patient, the reality of practice can be quite different" (p83). Her suggestion is equally applicable to the ideal of nurses working with families.

As advocacy has mounted for the adoption of family-centered practice within paediatric settings nurses have said that feelings of guilt and discomfort are associated with working with some families. For these nurses the experience of "not liking" a family, or failing to "please" a family do not fit with their image of nursing as a

caring culture. The result is a lack of open communication about the difficulties encountered with some families. Unprofessional behaviour can manifest as nurses become increasingly frustrated. Furthermore, working within a non-supportive workplace can leave nurses feeling further rejected (Blum, 1995).

Background to the Problem

In my work setting within a surgical inpatient unit, I was particularly struck by the way in which having an “*obstructive family*” on the unit could negatively affect the work environment. In listening to both families and nurses, it became apparent that there were multiple conflicts, when nurses identified families in such a way. The staff was polarised on issues of how to “manage” particularly obstructive families and often felt guilty at their own sometimes-unprofessional behaviour. Furthermore, the experience of working with obstructive families appeared to reduce the amount of positive mental energy that the nurses had for other families. The most striking element was that, without intervention, the nurse, child and family appeared to be negatively impacted. This is broadly reported within the literature to occur in a variety of clinical settings including psychiatry, paediatrics, gerontology, and emergency areas (Baker, 1994; Breeze & Repper, 1998; Cruikshank, 1995; Scharer, 1999; Vinton, Mazza, & Kim, 1998) as well as among several types of health care professionals (Coffman, 1997; Groves, 1978; Holloway & Wallingra, 1990).

The challenges of providing family-centered care are well documented. The challenges for families and nurses include multiple stresses, differing role expectations (Darbyshire, 1993; Johnson, 1990), and communication shortfalls.

For families in hospital the stresses are multiple and multifactorial; they include fatigue, loss of control, uncertainty, disruption to routines and family life, and financial difficulties (Callery & Smith, 1991; Darbyshire, 1993; Thurman, 1991). Often there is only enough room for one family member to stay with the child leading to physical separation of the family unit. This separation leads to hardships, such as emotional isolation for the resident parent. Tensions are felt by the nurses and the family as each party struggles to care for the child in a challenging environment (Cleary, 1992). If the nurse/family relationship is going to be successful, patience, tolerance, and flexibility from both parties is required. When one or both parties are stressed, working together becomes more difficult (Dunkel & Eisendrath, 1983; Tanner Leff et al., 1991).

The family today is more likely to expect full involvement in decision making for their child and, by necessity, nurses and families must work in close proximity (Hartman, 1995). The evolution of family-centered care, the increasing health care knowledge within families, and the rise of consumer expectations all mean that the nurse is not necessarily accepted by the parents as an authoritarian administrator of predetermined nursing care. Furthermore, families do not necessarily perceive themselves to be the passive recipients of nursing care. Callery and Smith (1991) suggest that the nurse and the family often have incongruent expectations of each other's needs and roles. Nurses socialised within their professional culture to "care" assume that their efforts to support families will always be welcomed and are ill prepared to deal with a rebuttal that comes with mismatched nurse/parent expectations (Cheuk et al., 1997; Gallop & Wynn, 1987; Hartman, 1995; Waterworth

& Luker, 1990). Inconsistent approaches towards the family by nurses serves to further exacerbate the family's confusion about roles (Callery, 1997) and jeopardises trust within the relationship (Thorne & Robinson, 1988a).

Communication breakdowns occur between nurses and families for many reasons (Jones, 1995; Robinson, 1987; Vinton & Mazza, 1994). Within the process of communication, or lack thereof, assumptions rather than knowledge underlie the actions and comments of both parties. Time to understand each other's needs/roles, language barriers, and multicultural issues is often unavailable and adds to the complexity of nurse/family interaction (Hartman, 1995).

In addition, the hospital employer presently has an expectation that the paediatric nurse will collaborate successfully with the family to provide care for their sick child. These expectations of the nurse come at a time when the current nursing shortage has resulted in reduced availability of experienced nurses within inpatient settings (RNABC, 1999). In addition, the reduction in available nursing resources means that nurses no longer have the necessary time to build rapport with the family, to ask the families what it is that they expect from hospitalisation, or to ask the families about their previous health related experiences.

Regardless of the described challenges, in the vast majority of situations families and nursing staff are able to work together to care for the sick child. A family that is perceived to be obstructive to the care offered by hospital nurses may cause a negative reaction from the nursing staff towards the family, with detrimental impact to the care of the child (Barnsteiner and Gillis-Donavan, 1990), to the family (Thorne & Robinson, 1989), and to the job satisfaction of the nurse (Zigrossi, 1992). Such

labelling of families by staff serves only to perpetuate the rift between individual staff and families (Sugden, 1985).

Of particular interest is that other issues related to nurses' interpersonal relations have received attention within the literature, including the burnout of nurses (Brown-Ceslowitz, 1989; Duquette, Kerouac Sandu & Beaudet, 1994), the need for critical incident stress management programs (Jefferson & Northway, 1996; Spitzer & Burke, 1993) and concerns surrounding the co-dependent nurse (Berger et al., 1999; Wolgin, 1992). However, researchers have failed to describe the experience of nurses working with obstructive families, and focus instead on the cause of conflict between nurses and families. It is unclear why this gap exists. It is important to encourage careful thought about this topic and raise issues that I believe have been largely ignored. It is in this way, that we will advance our knowledge about the professional and personal experiences of nurses working with families.

Purpose of the study

I believe much knowledge can be uncovered about the difficulties staff encounters in providing family-centered care. Much of the current work concentrates on the benefit to families of family-centered care. In contrast, the challenging practice issues for nurses working with families they perceive to be obstructive have been largely ignored. Varcoe (1997) argues that for a system to pursue an ideal and yet fail to provide the tools with which to achieve that ideal is unethical. Frank (A. Frank, Personal Communication, January 15th, 2000) suggests "when faced with a person's reality, we have a responsibility to deal with it". I contend that the nursing profession is a strong advocate for family-centered care but the profession has failed to

acknowledge or address the struggles for RNs providing such care, especially when the nurse/parent relationship is not working. While the literature reveals some causes of conflict, the actual experience for nurses is not discussed in any depth. Mazhindu (1998) argues that nursing does itself a disservice, as the needs of nurses are ignored, and the emotional damage remains unmeasured.

The purpose of this study was to examine nurse's perceptions of their work with families who they perceive obstruct their care. It was hoped through the stories told by RN's, to uncover personal meanings, beliefs, and attitudes that are constructed in the context of their work with such families.

Research Question

The question explored in this research was: What meaning does the experience of working with families perceived to obstruct care, hold for nurses?

Definition of Terms

Family- The term is used to refer to anyone who is a significant caregiver of the child, both in and out of the hospital environment, who is usually involved in decision making for the child, and who may or may not be the parent.

Obstructive - The Chambers 20th Century Dictionary defines this term as "tending to obstruct: hindering" (p 873). The context of this study must be considered when further defining such a concept. I was unable to find a nursing author who had attempted such a definition, and struggled to clarify distinctions such as difficult, challenging, complex, unreasonable, and needy. Since I was unable to quantify "obstructive" in terms of specific behaviours, I made the decision to allow the nurse to frame the so called obstructive family within her own professional context as a

family perceived by the nurse to negatively affect his/her care delivery to the child. This definition is not intended to describe the family who requires a reasonable degree of flexibility, the family who is having an “off day”, or the family requiring extensive teaching or emotional support. Rather, this definition lends itself to the family that may exhibit behaviours such as mistrust, aggression, and non-compliance with treatment. Examples of the obstructive family might include the family who prevents the nurse from any physical contact with their child, or a family that refuses to provide information that would help the nurse care for the child.

Nurse - For the purposes of this study, the writer uses the term nurse to indicate an RN, who works either full time, part time, or on a casual basis. There is no differentiation in this study between diploma or degree-prepared RNs.

Care- This concept implies nursing care offered to family members, including the child, within the context of an acute care setting- in this study, a tertiary level hospital.

Assumptions

In order that I adhered to the standards of rigor in qualitative research, I needed to be aware of my assumptions and to make these known to the reader. To raise personal awareness about my assumptions, I maintained a journal throughout the study. This process encouraged me to constantly question my assumptions in a thoughtful, reflective manner.

I began this research with a belief system evolved through my work as a nurse in a tertiary paediatric setting for the last fifteen years. Values and assumptions have resulted from that work experience, and throughout my ongoing education. I assumed

that it is only a minority of families that nurses' work with who are perceived to be "obstructive". Also, I believe that the experience of working with families perceived to be obstructive has the potential to negatively impact a nurses' practice of family-centered care, and to be potentially emotionally damaging to RNs. This assumption introduced a further assumption that nurses wish to work with families in a way that is family centered.

A final assumption is that nurses who are supported in their care of obstructive families will experience higher work satisfaction than those who receive no support, and that by offering resources to support nurses working with obstructive families, that there will be benefit to families. In turn, I am assuming that by benefiting the family, there will also be benefit to the child.

Significance of Study

The ramifications when parent/nurse relationships break down are potentially immense. Many families return repeatedly to the acute health care setting. With unresolved conflict, and with each repeated admission, tensions rebuild, and the potential is for the nurse/family relationship to spiral down a negative pathway. While the available research concentrates on parent/ family perspectives of family-centered care, this work explored the other side; the nurse's perspective. This study will provide insights into the experience of nurses that will potentially lead to further research, and an improved understanding of the experiences of nurses.

Summary

This chapter introduces the study and offers the background, which inspired the inception of this work. The research question, definition of terms, assumptions, and personal philosophy were described. The significance of the potential results from the study was identified.

Chapter two will contain a review of the available literature relevant to both nurses and families working together within a hospital setting. Chapter three will outline 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 will describe the participants, and the findings of the study. Chapter five will conclude with a discussion of the findings, and the implications of the research findings for health care practice, administration, education and research. A short summary will conclude the study.

CHAPTER 2: LITERATURE REVIEW

At the heart of paediatric nursing lies the working relationship with the child's family. Goldberg (1994) suggests the quality of interaction between patients and staff underlies the overall quality of care. While a mass of literature conveys the parent's perspective on the quality of care (Callery & Smith, 1991; Darbyshire, 1993; Hayes & Knox, 1984; Rowe, 1994; Robinson, 1987), minimal literature exists that deals directly with the impact on paediatric nurses when working with families that they perceive to be obstructive to care. The literature that is available tends to focus on family/patient behaviours (Groves, 1978), on strategies of conflict resolution (Cox, 1991), and/or on the causes of the conflict (Hayes & Knox, 1984; Graves & Hayes, 1996; Robinson, 1987), rather than on the impact of the poor relationship on the nurse (Brown & Ritchie, 1990). Furthermore, most of the additional literature is neither research based, nor paediatric orientated, nor written to conform to usual academic standards.

In an attempt to identify the available literature, I accessed several databases including CINAHL, MEDLINE, PSYCHINFO and SOCIOFILE. These databases provided access to publications in the fields of medicine, social work, psychology, psychiatry, administration, gerontology, and nursing. Words or terms used to search included family, family-centered care, nurse, conflict, interpersonal relations, family relations, aggressive, working conditions, parents, major caregiver, inappropriate, job satisfaction, difficult, obstructive. I also looked at words/terms that opposed the notion of obstructive behaviours (e.g., good family-nurse relations, partnership qualities, ideal families with whom to work). In addition, I considered literature that

related directly to all patient groups rather than just families or parents, for the latter would have limited my research.

Despite the shortage of specific literature I made the decision to limit my literature search to the last ten years. Paediatric nursing, the delivery of family-centered care, the understanding family needs/expectations, and health care all have evolved so dramatically in the last decade that any use of dated literature would perhaps mislead, given the backdrop of vast contextual change. Yet, older literature was used where its content could be considered classic and/or where it raised important questions for consideration not found elsewhere. Glaser (1978) argues that entering into research with as few determined ideas as possible can increase theoretical sensitivity. As a mechanism to avoid over-immersion in the literature, I have therefore made the decision to be selective in the literature I read prior to my research; I have accessed approximately three quarters of the over-all available material.

In general, research literature is lacking that is directly related to experiences of working with obstructive families, especially given the huge amount of energy that is expended to promote effective family/nurse relations in paediatric settings. Interesting to note, the difficulties arising from poor working relationships for the nurse and family are described in the literature, but the impact for nurses of working more closely with families is conspicuously absent (Brown & Ritchie, 1990). In extensive articles, such as "Through the eyes of the patient" (Gerteis & Roberts, 1993), the authors look only at the parent's perspective and fail to acknowledge, define, and/or offer supportive strategies related to the challenges of working

effectively when the nurse-family relationship is problematic. The benefit to the family of receiving family-centred care is apparent in the literature; however, for the nurse, the benefit and cost of providing family-centred care remain unclear.

To study nurses and not the family, it must be acknowledged, is to decontextualise the interactions between the two; nurses do not operate in a vacuum devoid of families. However, the scope of a thesis by necessity limits this exploration to the nurse's perspective. I would suggest that the study will provide a basis for further research and that it comes at a time when paediatric nurses are experiencing immense pressure with little support in the delivery of care to families. Despite the limitations of the intended research, I feel it essential to include the family perspective in the literature search to provide the necessary context. Therefore, I have built on concepts introduced in Chapter One and broadened them to explore issues around family/nurse relationships, including the impact on the nurse, the child, and the family.

Several studies report that poor working relationships occur in a variety of clinical settings including psychiatry, home-care, paediatrics, gerontology, and emergency areas (Breeze & Repper, 1998; Cruikshank, 1995; McKeever, 1994; Scharer, 1999; Shapiro, 1993; Vinton, Mazza, & Kim, 1998), and among several types of health care professionals (Coffman, 1997; Groves, 1978; Holloway & Wallingra, 1990). Furthermore, several authors have described the emotional labour of nursing and yet have acknowledged that this goes largely unrecognised (Hochschild, 1983; James, 1989; Smith, 1992). Johnson and Webb (1995) suggest that with better recognition of the emotionally charged aspects of nursing we might

be better able to employ more constructive strategies for managing social relations in nursing. Sadly, there is no further elaboration on what these strategies might be.

The evolution of family-centred care

The intention of this literature search is not to analyse family-centred care. However, foregoing discussion of the family-centred model would be misleading since it does guide the nurse in her¹ practice of family care. Family-centred care is the broad term used by health care professionals to identify the model of care which is child and family focused and considered to be the optimal approach in paediatric nursing. It is a philosophy rooted in the belief that all families are caring and want to nurture their children (Ahman, 1994).

The history of paediatric health care delivery reveals vast changes have incurred in the level of family involvement. Bowlby, Freud, and Robertson pioneered research in the early 1950s, which identified the psychological damage that occurred to young children, when they were separated from their families during hospitalisation. This research has led to the introduction of family-centred care, a method that influences how paediatric care is currently delivered. The concept of family-centred care has continued to evolve around modern medical, social, economic, and legal phenomena leading to consideration of appropriate developmental, psychological, and ethical care. Ahman (1994) outlines a comprehensive framework from the National Centre for Family-Centered Care, which depicts nine key principles that guide professionals in their practice of family-

¹ The terms, *her* or *she*, are used throughout the text for the author's own convenience. It should be acknowledged that this material applies either to male or female nurses.

centered care:

- 1) Recognition that the family is a constant in the child's life while the service systems and personnel fluctuate
- 2) Facilitation of collaboration at all levels of health care such as program development and policy formation
- 3) Honouring diversity and individualism
- 4) Recognising family strengths and different methods of coping
- 5) Sharing with parents unbiased information
- 6) Encouraging and facilitating family-family support and networking
- 7) Understanding and incorporating the developmental needs of all children into the health care system
- 8) Implementing programs and policies that provide emotional support and financial support to meet the needs of families
- 9) Designing accessible health care systems that are flexible, culturally competent and responsive to family needs as identified by families.

Today professional and parent partnership is a key theme in supporting parents in this central caring role and there is recognition that the family play an essential role in their child's health.

The evolution of family-centered care, the increase of health care knowledge within families, and the rise of consumer expectations all mean that the nurse is no longer accepted by the parents as an authoritarian administrator of predetermined nursing care, and families are no longer the passive recipients of nursing care (Farrell, 1989). The literature is now punctuated with family perspectives on their experiences

of paediatric hospitalisation and with information on the trends toward increased family involvement in the care of their child (Ahman, 1994; Callery & Smith, 1991; Gerteis & Roberts, 1993; Hayes & Knox, 1984; Rowe, 1994; Thorne & Robinson, 1988b). Thorne and Robinson (1988a), in a paper examining reciprocal trust in health care relationships, review illness experience within the family. The authors suggest that families of either a child or adult who is sick assume, as they enter into relationships with health care professionals, that they will be recognised as essential to the care of that individual; they require to be informed, consulted, and involved in decision making. Derbyshire (1993), in an in-depth literature review, found consistent reports revealing that when these expectations were not met negative responses to health care resulted. Interpretations and applications of the principles of family-centred care vary enormously along a continuum, ranging from allowing a family to visit their child in a relatively unstructured way to the family being equal participants in decision-making.

The benefits of family-centered care

The benefits of family-centred care are worthy of consideration in the context of the nurse-family relationship because they remind us why it is necessary for nurses to interact with family members at all. Ahman (1994) suggests of family-centred care that “the philosophy embraces diversity of family structure, cultural backgrounds, choices, strengths and needs” (p.113). Central to the success of family-centred care is the notion of empowerment for both the family and staff.

The literature fully supports the benefit to the child when family-centred care is practised in a hospital setting (Robinson, 1987; Rowe, 1994). However, despite the

widespread belief and compelling argument that family-centred care increases effectiveness of care, and health outcomes for the child, there is little proven evidence. Certainly, as Bowlby demonstrated in the 1950s, continued parental involvement reduces separation anxiety and abandonment syndrome; allows for the child to respond appropriately and emotionally with the safety net of parents nearby; and allows for assessment by the parents who best know the child's so-called *normal* status. In addition, parents are often the best advocates for their child (Farrell, 1989). The personal comfort to the ill child of parents being close by is an additional benefit (Brown & Ritchie, 1990; Hayes & Knox, 1984).

The second beneficiaries of family-centred care are the family members. Neil (1996) in an extensive literature review of parent participation outlines three main beliefs of parents that are addressed within a family-centred care model of nursing delivery:

- (a) parents want to be involved;
- (b) parents believe that they make a difference and that their involvement benefits the child; and
- (c) parents need information to be effective.

Documented benefits of family-centred care to parents include a sense of increased control as their parenting role continues; some sense of normality of family interactions; and the ability to understand more about the child's needs and condition from the staff, since family members have increased access to staff. A key benefit of family-centred care is, when parents are included in the care of their child, they are more able to participate in decision making for their child. Miles, Carlson, and

Brunssen (1999) suggest nursing support reduces the stress and anxiety of parents while in hospital. Supportive behaviours from nurses include empathizing, education, reassurance, valuing, and problem solving with parents. Perhaps nurses are the third beneficiary of family-centred care--the satisfaction of successful working relationships with families has been described as a positive motivator for nurses to seek work or to continue to work in a paediatric setting (McKlindon & Barnsteiner, 1999). However, the literature is focused on the difficulties encountered and not on the benefits to the nurse of a successful nurse-family working relationship.

The context of the family-nurse relationship within the health care system

The evolution of family-centred care, coupled with the evolution of health care, has had an enormous impact both on family and health care professional roles within the hospital context (Popper, 1990) and on family-nurse relationships (McKlindon & Barnsteiner; 1999, Popper, 1990; Thurman, 1991). In addition, the structure of families has undoubtedly become more complex in Canadian society. The divorce rate has crept up, remarriage is thriving, and blended families are commonplace (Leff & Walizer, 1992; Milan, 2000). Fathers are more likely to spend time at home caring for their children (Leff & Walizer, 1992), and mothers are more likely to have employment outside of the house resulting in multiple caregivers for the child and arguably higher family stress levels. Furthermore, geographical mobility has divided families and has reduced internal support systems.

An increase in funding is required to provide the standard of health care that Canadians expect at a time when the Canadian dollar is falling in value and when cutbacks in Federal transfer of monies are common for health care. The Registered

Nurses Association of British Columbia (RNABC) (1999b) suggests that the relationship of reduced manpower resources to quality care is extremely complicated to assess. However, the RN (Registered nurse) workload has increased dramatically in the last decade due to reduced pre-operative admissions, reduced surgical stays, and an increase of acuity in non-critical care areas. In her thesis work, Rowe (1994) suggests that the reduced nursing work week has resulted in ample time to complete technical tasks, such as intravenous care and surgical dressings, but not to devote to building rapport with families. The increasing non-nursing duties imposed upon the RN, as ancillary staff has been reduced in numbers, have worsened the situation.

As previously discussed, many families no longer expect to be told the diagnosis of their child and then to be passive recipients of treatment (Farrell, 1989); indeed, often they expect to have more influence in their child's care (Hallstrom & Elander, 1997; Leff & Walizer, 1992) especially later in the illness trajectory of their child. Access to information known previously only by health care professionals is now widely available to families. This means that decision-making by health care professionals is more open to question by families and has introduced the notion to families that alternative health care options may exist. In addition, any media exposition of imperfections of our health care system may well contribute to the erosion of families' confidence with the health care system. Advocate and support groups offer families assistance in how to work more proactively with health care professionals throughout their child's hospital stay. British Columbia Children's Hospital has published a manual called *Partners* (2000). The manual serves as an

example of the change in approach contributing to a redefining of roles for both health care professionals and families as they relate to the direct care of the child.

Over the years, the life expectancy of children with chronic conditions has been dramatically extended (Leff, Chan & Walizer, 1989; Leff & Walizer, 1992), and the length of hospital stay has dramatically been reduced with care now transferred to the home setting (Robinson, 1987). Overall a dramatic shift has occurred in care resources from the inpatient setting to the outpatient setting (McKlindon & Barnsteiner, 1999) influencing where care is delivered and how it is delivered. These changes have reduced the time that the nurse and family spend together which in turn impacts the relationship building necessary for successful family-centered care.

What family behaviours contribute to the nurse's perception of obstruction to her care?

Family/patient behaviours are widely described in the literature. The term *obstructive* was not commonly used in the literature, and so I have utilized any literature that describes behaviors, which might reasonably lead the RN to perceive the family as obstructive. It is essential to keep forefront in one's mind that this study will represent the nurses' *perception* of so-called obstructive behaviours and may or may not represent reality. It is also worth considering family behaviours/qualities identified by nurses as "desirable". Qualities of a family member with whom nursing staff typically have good relations include the ability to discuss the child openly with staff, to ask for advice, to welcome the nurse's assessment and treatment and to work with the nurse to schedule care (Callery, 1997; Podrasky & Sexton, 1988). In an article outlining an informal discussion by a physician group, Drs Jellinek, Beresin,

Herzog, and Sherry (1991) define the “easy” parent as well organised, as having a list of questions, and as able to attend and react to responses. Interestingly, Podrasky and Sexton (1988) in their exploratory survey around nurse reactions to difficult patients found that RNs did not typically label patients who could not help themselves or whose behaviours were not modifiable, such as those mentally retarded, chronically ill, or infectious. Worthy of note, physical threat is rarely seen in paediatric settings and is more likely in emergency and critical care areas (Cruikshank, 1995).

Of interest is that the literature contains little material that seems frank in defining family behaviours that might contribute to a family being perceived as obstructive, and the most candid literature voiced the physician’s perspective rather than the nurse’s perspective. Groves (1978), in a highly subjective commentary entitled “Taking Care of the Hateful Patient”, suggests as a medical doctor that hateful patients are not those with whom one has a personality clash but rather those who fall into four behavioural categories; they are dependant clingers, demanders, manipulative help rejecters, and/or self destructive deniers. Jellinek et al. (1991) in a frank discussion, again from a physician’s perspective, describes the truly difficult parent as deniers, complainers and obstructors.

Diaz and McMillin (1991) discuss nurse/physician interactions and suggest that societal rules and sanctions are less concrete regarding communication patterns than are physical or sexual interactions, and that these behaviours are not as easily defined. Verbal abuse is a key behaviour that can play a part in the obstruction of care and is the most widely reported in the literature both in quantitative and qualitative studies. In a quantitative study done by Hilton, Kottke, and Pfahler (1994) 89% of

RNs in a large urban 1,000 bed medical centre in California reported they had received verbal abuse during their practice. A significant 47% of the RNs reported one to two verbal abuse episodes over a one-month period, 30% of which were received from patients and 19% of which were received from the families of patients at the centres. The researchers in this study found the nurses felt this abuse contributed to absenteeism and turnover to a “great” or “very great” extent. Of note is that physician and peer abuse was also widely reported and was reported to have had a more profound effect on the nurses than either patient or family member abuse. Cruikshank (1995) in another quantitative study randomly sampled 452 registered nurses and found similar results. She suggested that verbal abuse was widespread across health care facilities. Her recommendation was both a re-evaluation of what was once accepted as part of the job and a move towards problem resolution. Cox (1991) via an extensive survey found that physicians were the most frequent verbal abusers of RNs, followed by patients and then by families. These three solid quantitative studies have similar findings; however, it must be remembered that verbal abuse is only one behaviour that might result in perceived obstruction to the nurse’s care.

Behaviours identified by nurses that may or may not include verbal abuse include refusal to allow the RN to physically assess or treat the child, threats to report care which may or may not be followed through, derogatory comments, sarcasm, overly critical comments, unrealistic goal setting, and acts of maligning the RN to colleagues (Callery, 1997; Dunkel & Eisendrath, 1983; Jellinek et al., 1991). Breeze and Repper (1998) undertook an ethnographic study to look at the perceptions of the

care experience by users of mental health services. One of the selection criteria for the participants was that they were identified by nurses as “difficult”. The nurses identified these individuals as those who become at odds with staff and who are disruptive, who require inordinate amounts of staff time, and who compromise patient care. The nurses who were also participants in this study identified that they were more likely to feel challenged when their unit was understaffed.

Podrasky's (1988) and Kestler's (1991) work identifies six patient behaviours that lead to conflict with staff: directly and physically interfering with medical treatment, acting helpless, making excessive demands on staff time, acting with lack of compliance, creating alliances with families against the staff, using staff inappropriately, and being physically unavailable for making decisions or for providing emotional support to the patient. A research utilisation project by Wolf, Brennan, Ferchau, Magee, Miller-Samuel, Nicolay, Paschal, Ring, and Sweeney (1997) helps to identify how RNs can apply specific strategies to specific case studies as they relate to these difficult patient behaviours. Wolf et al. provides an excellent example of making explicit the results of research and of offering suggestions for how to apply recommended strategies in a clinical setting.

Zabora, Fetting, Shanley, Seddon, and Enterline (1989), on the basis of their quantitative study of oncology families, suggest that families under stress can behave in a way that is overprotective, hostile, and/or argumentative: 15% of the families on an inpatient unit were defined as engaging in conflict. This is one of the few studies that attempt to provide an estimate of the extent of the problem.

Jellinek, Beresin, Herzog, and Sherry (1991) describe the perspective of a group of physicians. This group described difficult parents as those who told the child, "I will protect you from him", if not in words, then in behavioural attitudes, and also as parents who were obstructive to tests and procedures. Difficult parents were seen to harbour previous bad experiences and to ignore the positives. Difficult families or parents were identified by Callery (1991) and by Podrasky and Sexton (1988) as exhibiting the traits of being "uptight and anxious". Others contend that patients become identified as difficult not when their behaviour is difficult so much as when they deny the authority and therapeutic value of the nursing staff (Kelly & May 1982; Gallop & Wynn 1987). Of interest is that Zigrossi (1992) found silence from families was cited by nurses as a form of verbal abuse.

Arthur (1992), in a critical review of the self-concept of nurses, suggests that interactions with difficult clients take up much nursing time and stand in the way of care in all settings. He argues that the client and RN are jointly a part of the problem; indeed, RNs in the study note that the difficult behaviour is at times commendable, such as when families see self-discharge and home-care are possible. Perkin, Young, Freier, Allen, and Orr (1997) suggest that patients and families, by acts of omission and commission, may be labelled as difficult, non-compliant, problematic, and/or manipulative. Perhaps the best example of extreme manipulation is the parent linked to a child with Munchausen by Proxy Syndrome where parent behaviours contribute to the child's illness and are concealed from the staff (Brown, 1997; Klebes & Fay 1995).

This section outlines family behaviours identified by staff in a variety of health care settings. The description suggests a broad scope of behaviours but fails to identify the extent of the problem or the impact on nursing staff of such behaviours. My sense from the literature is that the extent of nurse perceived obstructed care by family members remains significantly understated.

The culture of nursing as an influence on the difficult nurse-family relationship

As advocacy for the adoption of family-centred practice within paediatric settings has mounted, rhetoric by nurses around some of the difficult issues in working with families has become imbued with guilt and discomfort. Frank (Personal communication, Jan 15, 2000) suggests our society assumes that “bad things don’t happen to good people”. This assumption may have some applicability for nurses who may experience self-doubt about their skills with families and personal guilt when their relationship with a family is not working well. Podrasky and Sexton (1988) argue that, while in some cases a poor nurse-patient relationship may be the fault of the nurse, not all cases are simply the nurse’s fault, and conflicts should not be approached with this assumption. In a discussion paper, Tanner Leff and Walizer (1992) explore parent and professional interactions, adding the interesting perspective that sound nurse-parent communications are not synonymous with avoidance of disagreements.

Perceptions such as “not liking a family”, or “failing to please a family” do not fit with the “caring” image of nursing culture. Nurses are socialised within their professional culture to “care” and to assume that their efforts to support families will

always be welcomed; they are ill-prepared to deal with a rebuttal that comes with mismatched nurse/parent expectations (Cheuk, Wong, Swearse & Rosen 1997; Gallop & Wynn, 1987; Hartman, 1995; Waterworth & Luker, 1990). Rodney (1988) cites Holsclaw who, from as early as 1965, suggests that emotional risk might be thought of in terms of assaults on the professionalized self-concept of the nurse. Holsclaw suggests that the conflict situation arises as a result of the helping person's concept of herself as "restorer" and the patient's inability to be restored. This work referred to the physical ability to be restored, but I would suggest this could also be extended to the psychological aspects of nursing work and the family's ability/desire to allow nurses to work with family members.

As evidenced by the literature, RNs are not being vocal about the difficulties they encounter with families, and, as Malterud (1993) in her paper on power and knowledge suggests, "people who are not heard are not people who are in power"(p.366) If dialogue with colleagues, educators, and administrators does not happen, the strategies to work with families perceived to be obstructive will not be forthcoming. An issue within the nurse-family relationship is that interpersonal problems are rarely discussed in an open honest way; it is as if we fear we may offend or be criticized. Rather than face that fear, we choose to ignore or to jump to problem solving attempts without exploring the real reasons behind the interpersonal difficulties. There is much damage caused by not openly discussing these issues both amongst ourselves as professionals and together with parents.

Raatikainen (1993) undertook a qualitative study using questionnaires to gather data in order to examine power or lack of it in nursing care; Raatikainen

suggests that power as defined by several authors is the ability to affect outcomes. Study findings revealed that in a relationship that is dysfunctional between a family member and a nurse, many antecedents of power did not exist. The antecedents include trust, clear communication, caring and respect between two or more people, and self-confidence. Clearly, outcomes have the potential to be negatively impacted when any of these antecedents are lacking. Raatikainen also identified that nurses she described as powerful had an internalized view of family-centeredness. Davidhazar and Dowd (1999) suggest that nurses have not traditionally thought of themselves as powerful and argue that individuals should be aware of their power in order to avoid abuse of that power. They further suggest that nurse-client interaction is at the heart of the caring relationship but that unrecognized power can act as a barrier to meaningful communication. Finally, Callery, and Smith (1991) in a small study using critical incident technique, assessed responses to parents of hospitalised children and found that working with families who exhibit behaviours that lead to perceived obstruction to care cause the RN anger, frustration, and a feeling of powerlessness.

Nurses who are women and service providers may already be disadvantaged with stereotyping by society (Reverby, 1987; Suominen, 1997). This stereotyping may contribute to disrespectful interaction from families. It is possible that family members, as consumers, will wield their power and complain to those in “higher” positions than the nurse. One of the stereotypes to be increasingly challenged by the modern family is that the nurse is “in charge”. Brown and Ritchie (1990) interviewed nurses and found that they had an awareness of the control they could use to “punish” parents and that the parents could use their own power to exert control over their

child's care. The nurses in this study had a clearly defined sense of powerlessness over these issues and did not seem clear on how their use of power and control might contribute to their interpersonal difficulties with parents. Kawik (1996) and Perkin (1997) described the parent's perspective of working with nurses who did not want to relinquish control and who seemed difficult to work with. Holland (1993) describes a nursing hierarchy that indicates to everyone what their role should be; clearly the family member perceived to be obstructive would threaten this accepted hierarchy. Suomien, Kovasin, and Ketola (1997) describe the importance of routines and rituals within nursing that serve to secure order within the hospital structure. In addition, information withholding by professionals was identified in the same study to be problematic and maybe symptomatic of nursing culture and paternalism.

Neill (1996) found that parents identified paternalistic professional attitudes as a problem, which could influence decision-making processes. Knafl, Cavallari, and Dixon (1988), in an excellent study, compared two groups of parents and found that the groups had different perspectives on the role of health care professionals. Group One felt that nurses and physicians should have complete authority and decision-making power while Group Two felt that they wanted to have equal decision-making power with parents. Although group two had an overall higher level of education and more hospital experience, this study suggests that the concept of individual family assessment regarding their desired involvement in decision-making cannot be understated. In addition, Callery and Smith (1991) argue that nurses have the more powerful controlling position and may or may not use negotiation to attain the desired ends. Rowe (1994) in her descriptive narrative study of parent/RN relationships

suggests that greater opportunity for RNs to articulate their understandings of reality and possibility may assist them to further develop their practice expertise and use their relative power to nurture their relationships and practice.

A part of traditional nursing culture is that typically nurses value efficiency and industry. One of the issues with nurse-family relationship building is that often there are no explicit outcomes. In Callery's work (1995), nurses identified that the work of relationship building was not always recognised or valued; as some felt "a nurse is not doing her job unless she is busy," relationship building was not valued above busy-work (p. 995). When Rowe (1994) looked at the nurse-parent relationship, she concluded nurses appeared to have little insight into the nature or the possibilities of their relationship with parents. Additionally they were unaware of the negative or positive impacts their behaviour might have on parents or on their relationship. Brown and Ritchie (1989), who undertook interpretive research into nurses' perception of their work with families, suggest that RNs may lack insight into their relationship with parents.

The culture of the work environment is worthy of consideration. A nurse directly involved in conflict with family members is likely to discuss her concerns with her colleagues (Brown & Ritchie, 1989). This has the effect of creating a negative work environment and of influencing family assessment by colleagues (Sugden, 1985). Of additional significance is Johnson and Webb's (1995) research, which explored the impact of nurses labelling patients as good or bad. One of the key issues raised by this work was that of staff divisiveness: Staff became hurt by the way other RNs talked negatively about a patient. Sugden (1985) found there was

reluctance by a nurse to challenge another nurse's dominant perception of the patient, even when she liked the patient secretly. Wright and Levac (1992) concur that, when we negatively label families, we give ourselves permission to make less effort to intervene. Callery (1997) adds that labeling focuses the problem onto the labeled individual, alleviating the nurse of any responsibility to problem solve.

In their book "Nurses and Families: A guide to family assessment and intervention", Wright and Leahey (2000), I believe, do a disservice to RNs. They reject terms as resistance and non-compliance as not clinically useful; they believe that resistance and non-compliance are not unilateral phenomenon but rather are an interactional phenomenon. Wright and Leahey suggest that labels such as resistant and non-compliant describe a product of client-interviewer interaction; they prefer to use terms such as co-operation and collaboration because these are space-opening and inviting of the family point of view. This position, I believe, inadvertently contributes to the silencing of the RN voice by failing to acknowledge that resistance and non-compliance do occur in nurses' work with families. The intention is clearly to emphasize the unique co-operating styles of families, to view family strengths, and to avoid damaging relationships by labelling. I would argue however that to suggest that this phenomenon is a product of interaction leans towards blaming the nurse in part for the resistance and non-compliance.

The causes of nurse-family relationship difficulties

Darbyshire (1993) has suggested that the issues of parent participation and family-centred care are more challenging than previously assumed. While many professionals believe family-centred care is the ideal, practices are not always

consistent with that belief (Hill, 1996). The reason for this is not clear; however, it has been suggested that the change to family-centred care came before some professionals were philosophically ready to accept the model (Leff & Walizer, 1992). Letourneau and Elliot (1996) found multiple discrepancies between nurse's perceptions of family-centred care and its actual delivery. The authors argue that the elements of family centred care are designed to promote greater family determination, decision-making capabilities, control and self-efficacy. In contrast, the medical model of helping directs professionals to assume the roles both of evaluator and of controller of any treatments that encourage dependence on health care providers.

Communication issues undoubtedly contribute to the breakdown of the nurse-family relationship (Jones, 1995; Vinton & Mazza, 1994). For families in hospital, the stresses are multifactorial, and include fatigue, loss of control, uncertainty, disruption to routines and family life, and financial difficulties (Callery & Smith, 1991; Darbyshire, 1993; Leff & Walizer, 1992; Podrasky & Sexton, 1988; Thurman, 1991). When one or both parties are stressed, working together becomes more difficult and clear communication threatened (Dunkel & Eisendrath, 1983; Leff et al. 1991; Zabora et al. 1989). Cox (1991) suggests that verbal abuse is most likely to follow a stressful situation and may in fact be a coping mechanism.

Role confusion plays a major part in the difficulties between nurses and families. Inadequate time available or willingness to spend the time to thoroughly understand each other's needs, language, and cultural diversity all add to the complexities of nurse-family interaction (Hartman, 1995) and to role confusion. For instance, Rowe (1994) suggests that parents place themselves centrally as those

responsible for their children. Nurses, however, are more likely to place parents peripherally as visitors. Nurses often perceive involvement in functional terms so that the usefulness of parents may be judged and limited accordingly. The opposite role-confusion also exists where the integration of family-centred care has at times caused nurses to assume that families always wish to be involved (Waterworth & Luker, 1990). Knafl et al. (1988) compared two sets of parents desiring to participate in their child's care; they identified differences to include one group desiring passive involvement, the other group desiring active involvement in decision-making. Ogden-Burke, Kauffman, Costello and Dillon (1991) identified differences in parent desire to be involved and identified reluctance by parents who only wanted to be involved if the child's well being was threatened in some way. Robinson (1987) suggests a discrepancy exists among parent perspectives regarding how to enact the parent role and the RN's perspective on how the parent should enact the role. In the case of families of children with chronic illness, some parents will use the hospital admission for respite while others may feel particularly vulnerable and want full involvement. Hayes and Knox (1984) found similar information regarding the amount of information that families wanted to be told in order that they would not have to ask questions. What becomes evident is that nursing approaches are inconsistent perhaps because of a need for approaches to be highly individual with each family. In addition, professionals often perceive that parents are more stressed and suffer more emotional problems than the parents themselves experience (Brown & Ritchie, 1990; Graves & Hayes, 1996). The reason why this occurs is not made clear but may be due to a paternalistic tendency to overprotect parents; it remains as one example of

incongruent needs assessment. The potential outcome when incongruent nursing assessment occurs is that family and nurse will be opposing forces without necessarily intending to be or without understanding why. Most importantly, planned interventions will not meet the parents actual needs.

Adding to the challenges facing the RN and the family within the hospital setting is the advancement of technology and medical knowledge which has increased the number of children and families who are long-term users of the health care system. These families become frequent hospital users with needs that are often challenging to identify and to meet (Knox & Hayes, 1983; Thorne & Robinson, 1988a). Nothing in the literature distinguishes the nurse's experience of families with chronically ill children from families that spend a short course in the hospital. This gap in the literature needs further work, as it may lead to more appropriate resource allocation and awareness by nurses of the different needs of the two groups.

Rowe (1994) suggests nurses and parents place little importance on the relationship between the two groups. In addition, the suggestion exists that health care professionals lack or have difficulty practicing skills necessary for family-centered care such as communication skills, conflict management, and role negotiation (Brown & Ritchie 1989; Hayes & Knox, 1984; Callery & Smith, 1991). A better understanding of nurse's perspectives of working with obstructive families could provide an important foundation for developing new approaches to positively shape the nurse-family relationship.

The outcome of difficult RN/family relationships where the RN perceives the family to be Obstructive

Within the literature negative outcomes for the child, the family, and the nurse are described when the relationship between family and RN is difficult or breaks down.

Therapeutic relationships are defined by McKlindon and Barnsteiner (1999) as “an interactive relationship with a child and family that is caring, clear, boundaried, positive and professional” (p. 237). Perkin et al.(1997) suggests that deterioration in the quality and delivery of health care services is possible when therapeutic relationships break down. Barnsteiner and Gillis-Donovan (1990) concur when they suggest that the potential negative outcomes for the nurse, child, and the parent appear high when the RN/family relationship is problematic. They suggest that positive open communication facilitates informed decision making by the family.

Negative outcome for the child

Several authors posit that a poor relationship between health care professional and a patient has a marked negative outcome on the patient, for example Goldberg, (1994) and Waller et al., (1979). Perceived obstruction from family members may cause a negative reaction from the nursing staff towards the family, with an indirect detrimental impact to the care of the child (Kelly & May, 1982). Behaviours that nurses demonstrate in relation to conflict include withdrawal or avoidance of the family as well as attempts to control the behaviour of the family and labelling of the family (Sugden, 1985; Holyoake, 1999). These behaviours result in altered communication patterns affecting the decision-making of all involved parties with an

indirect impact on the decision making for the child's care. Waller et al. (1979) specifically comment that, in work with children and family where a poor prognosis for the child exists, relationships are important for all parties, since they may influence medical decisions.

Groves (1978) makes an interesting suggestion that, when a physician disowns or denies feelings that patients create, they themselves are more likely to make errors in diagnosis and treatment. Cox (1991) suggests that nurses are most preoccupied with their angry feelings about an upsetting event immediately after the incident and that the quality of care at this time may be compromised. While negative impact to the child might be a logical consequence of poor RN/family relationships, no definitive outcome studies clearly measure such assumptions.

Negative outcome for the family

Care for the family is clearly affected when the family member and nurse do not have a positive relationship (Rosenthal et al 1980; Thorne & Robinson, 1989). One of the responses to a perceived obstructive family is for nursing staff to label the family. The clinical reality of the "labeling" process is potentially damaging to the family (Perkin et al., 1997; Podrasky & Sexton, 1988). Bruhn (1991) suggests that when we label people we only refer to one aspect of that person, to the exclusion of other aspects of their nature. Holyoake's (1999) research on labelling demonstrates that patients labelled as "favourite" received more nurse-initiated interaction. Labelling of families perceived to be obstructive serves to perpetuate the rift between individual staff and families and may affect future admissions (Holyoake, 1999; Sugden, 1985). Johnson and Webb (1995) conclude that the incidence of social

judgemental labels was common, that labels could be temporary or permanent, and that some labels were subject to change over time. Callery (1997) found that labelling of families, and of mothers in particular, reduced the responsibility of the nurses; nurses would deal with “a problem mother” rather than deal with the problems within the relationship between themselves and the mother. Callery concludes that professionals are in a position to use diagnostic labels in a way that undermines the credibility of the mother, identifies the issue as the mother, and reduces the responsibility of the RN to that of dealing with a problem mother.

Multiple authors suggest the RN spends less time with families/patients deemed difficult to work with (Arthur, 1992; Brown & Ritchie, 1989; Carey, Jones & O’Toole, 1990; Groves, 1978). Specifically, Brown and Ritchie (1989) describe how nurse-family challenges cause the professional to emotionally and physically withdraw from the family resulting in communication inadequacies. The issue of communication is particularly relevant given the need to build a positive relationship between the family and the RN. Arguably, if the RN spends less time with a family and communicates less with them, decision making is done with less input from the family. Reduced involvement with decision making may be incongruent with the family’s needs.

Cleary (1992) suggests that when communication breaks down parents feel they are not trusted, that every move is monitored, that they are in competition with other parents, and/or that they have been abandoned by the nursing staff. In addition, for the family member, the nurse is often the first line of communication for medical concerns should physicians be unavailable; she is present twenty four hours a day and

spends more time with the family than with any other health care worker. Therefore, a dysfunctional nurse/family relationship may reduce the opportunity for the family to communicate about their child's progress and management. Callery (1997) found that parents were cared for on an ad hoc basis when their level of distress demanded immediate attention from nursing staff. The unpredictability of this work caused problems for RNs as well as for parents who could not be assured of care when they needed it. If the working relationship with the RN does not meet family needs, families become dissatisfied and frustrated. Once again, there are no outcome studies I am aware of that demonstrate compromise in patient care.

Negative outcome for the nurse

Nurses describe feelings of personal and professional conflict when role-confusion exists between parents and nurses (Brown & Ritchie, 1989). Perkin, Young, Freier, Allen, and Orr (1997) suggest conflicts occur between competing professional obligations, to patients, to patient's families, to colleagues, to the organisation and to self. According to Perkin et al., these conflicts result in personal suffering and distress amongst nurses who give care. Verbal abuse of nurses by families and staff is reported, by Zigrossi (1999), as causing feelings of anger, hostility, embarrassment, fear, and confusion. No data exists to confirm whether verbal abuse and/or obstruction to care are decreasing or increasing in frequency, but Cox (1991) suggests that it is a significant problem; that staff nurses feel insufficiently supported in their attempts to deal with it; that it debilitates patient care, RN morale, and emotional and physical well being; that it increases staff turnover; and that it has dramatic impact on job satisfaction. In addition, the RNs identified

that job security was threatened and that work productivity declined as the RN's thoughts were devoted to the incidents of verbal abuse. As a compensatory mechanism, the RNs increased their workload as an attempt to distract their thoughts from the incidents. RNs reported an incident of verbal abuse could occupy their minds anywhere from several hours to months. In a study discussed earlier, Cruickshanks (1995) reports nurse abuse in general is widespread in acute care settings; she finds that, in response to such incidents, RNs often reported the incidents to co-workers and supervisors and defended themselves verbally. Yet, shocking to note, 53% of the RNs ignored the abuse and an additional 17% considered leaving the profession as a result of the abuse. The link between turnover rates of both bedside nurses and nurse managers and verbal abuse is supported by other authors (Cox 1991; Hilton, Kottke & Pfahler 1994; Zigrossi 1992).

Janken (1974) believes that avoidance is a coping mechanism nurses use when they are in crisis and when they lack situational support. Such avoidance can eventually lead to attempts to bribe and to coerce the difficult client. When such attempts fail, RNs can experience frustration (Kestler, 1991; Prodasky & Sexton, 1988) and lowered levels of job satisfaction (Perkin, Young, Freier, Allen & Orr, 1997; Zigrossi, 1992). Podrasaky and Sexton (1988) outlined the nurse's internalised feelings of inability to satisfy the perceived difficult patient by feelings of inadequacy, incompetence, anger, and helplessness, which in turn caused other feelings including hatred, exhaustion, and weepiness. The RN's initial response to difficult behaviours was the fight/flight response; this could include hostile acts such as taking out their anger on a third party family member. The authors found the RNs

articulated their sense that “nurses need rights too” (p.18). Unprofessional behaviour can manifest as nurses become increasingly frustrated; their attempts to work with a family leave them feeling further rejected and experiencing guilt or feeling polarized as to how they should “manage” particularly “obstructive families” (Blum, 1995).

Brown and Ritchie (1989) interviewed twenty-five RNs to better understand their perceptions of their relationships with parents. They found evidence that nurses have difficulty in caring for parents and often have negative attitudes about parents. The same nurses clearly defined five types of relationships: negotiated, reciprocal, asynchronous, adversarial, and ineffective. The research suggests nurses’ relationships were often perceived to be social rather than professional, and the nurses descriptions indicated that they had difficulty with communication skills, conflict management, and family-centred care in their work.

Of significance is that environmental stressors at work have been demonstrated to increase burnout rates in staff due to physical and mental exhaustion (Brown Ceslowitz, 1989; Duquette, Kerouac, Sandhu & Beaudet, 1994; Holloway & Wallinga, 1990; Zigrossi, 1992). Spitzer and Burke (1993) point out that symptomatology associated with excessive or sustained stress may include reduced cognitive ability, such as diminished decision-making capacity, emotional reactions of increased anger, and irritability or guilt and depression. It seems a reasonable assumption that to deal with families perceived by RN’s to be obstructive on a long-term basis might contribute to long-term stress. Nurses are not the only staff who face challenges when working with families. Leff, Chan, and Walizer (1991), who reviewed narratives of physicians and parents of ill children, concluded the challenges

experienced by professionals working with families included feelings of grief, fear, over identification, guilt, and blame.

As demonstrated within the literature, a significant impact is made on the child, the family, and the nurse when the nurse-family relationship is not optimal. The available studies, however, tend to be of narrow focus, for example, researching verbal abuse without exploring the broader issues of obstructed care. With the exception of Brown and Ritchie (1989) and Leff, Chan, and Walizer (1991), who represent paediatric research based studies regarding nurse/family relationships, there remains a gap in terms of specifically addressing paediatric nurses' issues, and the studies done are rarely broad in scope or narrative in nature. In summary, a reasonable amount of both qualitative and quantitative work is available; however, specific research exploring the experience of nurses working with families who they perceive to obstruct their care is absent.

Strategies for the nurse working with a family that is perceived to be obstructive

The strategies offered within the literature are typically found in articles that are commentary in nature and that focus on conflict resolution strategies for the nurse without more deeply probing into the personal impact on the RN of working with families that they perceive to obstruct their care. Kestler (1991), in a discussion paper, suggests making contracts with difficult patients helps to regulate the relationship. She recommends the drawing up of mutually agreed upon contracts in order to make expectations, goals, and responsibilities explicit. In addition, Kestler (1991) notes that when dealing with difficult patients, the RN must be prepared to lower her

expectations regarding the working relationship with families. Arthur (1992) agrees that a solution to working with the difficult client is care plans and contracts.

Cox (1991), in an interesting and in-depth qualitative study, recommends the use of established policies, such as a *code white* strategy in situations of overt verbal abuse that have the potential to escalate. She recommends using a stop hand signal in situations where there are overt signs of aggression. Cox suggests improved education for RNs on how to deal with aggressive situations as well as general communication techniques, which could be worthwhile preparatory strategies. Conceding that role modelling behaviour alone is not enough, she comments that support from managers/administration and coaching for RN's on professionalism in abusive circumstances can also be helpful. Cox offers her advice with the intention that such coaching responds to situations of verbal abuse from staff aimed at the RN; however, I believe that it is reasonable to consider the principles helpful for difficult family situations. The nurses in the Cox study described assertiveness training and conflict resolution as the source of helpful techniques to reduce feelings of helplessness and danger. Noteworthy is that no differentiation exists with respect to experienced versus inexperienced RN's in these studies; such a differentiation would be of interest if it were available. Additionally Cox's study should be viewed with caution as the reader is provided with inadequate information regarding the methodology employed.

Coffman's (1997) phenomenological study explored the experiences of nurses working with families of technologically dependant children and illustrated that some RNs identified ways in which their own family background influenced their reaction to the chronically ill child's family. She suggests an implication for nurse

educators is to help the RN explore her own family background. Kestler (1991) concurs when she suggests that nurses' feelings should be acknowledged and emotionally supported; however, she does not make explicit how this could be done. Carey, Jones, and O'Toole (1990) suggest that when a person is aware of their feelings, he or she is more likely to cope effectively with negative interactions and to implement solutions. Jellinek et al.(1991) suggests that physicians need to communicate and be available emotionally for the parents so that difficult behaviour is not provoked. The parents defined as difficult by the paediatricians generally were advised to see a social worker, psychologist, or psychiatrist.

Holyoake (1999), in his ethnographic study looking at favourite patients, suggests the labelling process by nurses is influenced by preconceived references to past experiences. Education may be the key to raising awareness of this in order to reduce the extent of the potential damaging judgement of families. Perkin, Young, Freier, Allen, and Orr (1997) suggest that sometimes the differences between families and the RN cannot be resolved. In a study by Coffman (1997) of home care nurses working with families, a nurse persuades a mother whose child is acutely ill to take her child to hospital, saying, " I don't think the mom was real happy with me. But I'm not there to be her friend; I'm there as a patient's advocate" (p. 87). This nurse has clearly thought out her role and professional relationship to both the child and family. She appears to have justified in her own mind her differences with the parents and, in so doing, has anticipated potential negative feelings around the interaction. At the same time, this nurse was able to fulfil her professional obligation to provide the best possible care for the child. Results from the Zabora, Fetting, Shanley, Seddon,

and Enterline (1989) study suggest that families who are likely to be difficult to work with can be identified prospectively, which may help staff determine appropriate preventative interventions. With the exception of this study, the solutions discussed in the literature have a tendency to be generalised suggestions rather than provide specific directions to nursing staff on how to resolve difficulties working with families that they perceive to be obstructive. Furthermore, few of the studies demonstrate the effectiveness of the strategies that they propose via outcome research.

Ethical, moral and professional issues arising within nurse-family relationships

Benner and Wrubel (1988) discuss an ethic of “care and responsibility” as a central tenant of care giving. This ethic requires a balance of autonomy, intimacy, and reciprocal interdependence. If one takes the position that without forming an intimate relationship one cannot be cared for, the ethical implications for failing to connect with a family member become enormous.

Typically within the literature the central responsibility for the problem solving lies with the nurse (Thurman, 1991; Wright & Leahey, 1994). In the context of a partnership between the nurse and family, I believe this to be a flawed approach as it presumes one party can fix the problem independently. Thurman (1991) argues the role of professional is one of facilitator, consultant, and partner; she suggests professionals have an obligation to be responsive to the individual differences among families, whilst respecting family opinions and values. I would posit that these suggestions provide little support for the RN working with a family who has “unreasonable opinions or values”; indeed, they perpetuate the sense of failure for the

nurse working with such families. Unlike most partnerships there is little choice for the family or for the nurse as to who is cared for and who does the caring. There is no contract drawn up formally and little manoeuvrability when the relationship is problematic.

Varcoe (1997) argues that for a system to pursue an ideal, and yet fail to provide the tools with which to achieve that ideal, is unethical. The ideal of family-centred care has been held up with little attention paid to the need for resources. In fact, the myth exists that the assisting of family members in care reduces the amount of necessary nursing time required for the child. Certainly administrators have a role to play in both supporting RNs in the goal of providing family-centred care and in paying attention to the time required for this important work. Callery (1997) further suggests that we need to make explicit the “caring work” for parents if we are to justify appropriate staffing in terms of skill mix and levels. It remains unclear from the literature whether increasing available nursing time would provide a solution to some of the difficulties within RN/family relationships, but arguably allowing adequate time to communicate with families should help reduce the barriers to effective communication.

Spitzer and Burke (1993) argue that professional intervention such as stress management education that addresses such occupational stress becomes “crucial to safeguard quality patient care” (p149). Arguably quality indicators of family care should include monitoring of nurses communication skills with families and measurement rates of difficult nurse-family relationships.

Summary

In summary, many of the studies suggest that, for nurses, working with families can be difficult. The glaring gap is the lack of in-depth qualitative research exploring the experience for the RN. In this chapter, I review the literature deemed current and pertinent to the intended research theme of “the experience of nurses working with families that they perceive to obstruct their care”. My selection of literature was guided by topics related specifically to family nursing, including family-centered care, the context of an evolving health care system, and the outcomes of poor relationships between the nurse and family. It is evident that nurses do experience some challenges in their work with families but that the voices of nurses are buried in literature addressing other issues, which are primarily family-focused. The review of the literature illustrates that while there is discourse related to the difficulties of working with families, the topic is superficially explored as it relates to the experience for pediatric nurses, and much of the work is not research based. Therefore, this study is necessary to explore a gap in the available research and to gain an improved understanding of nurses’ perspectives of working with families that they perceive obstruct their care. Using the methodology of narrative inquiry, I will have access to nurses’ stories likely to include personal beliefs, experiences, knowledge, and attitudes about working with such families. My hope is that this thesis will spur further research that will be used to better support RNs in family work and thus to contribute towards improving care of the family. As such this chapter represents an introduction to some of the concepts that will inform my research.

CHAPTER 3: METHODOLOGY

In the research/literature review a gap exists in the available work exploring the experience of nurses working with families perceived by the nurse to be obstructive to care offered. My choice of methodology was guided by my desire to situate the nurses' stories within a larger context versus the "nurse blaming" tone prevalent within the literature. Qualitative research best affords the means to explore "experiences" that are subjective as well as contextually, historically and socially located. Frank (January 15th, 2000, Personal Communication) contends that context must be considered for hospital nurses who have little control over the setting or agency that they work in, and little choice as to the families with whom they interact. Context must therefore be taken into consideration if the research is to be meaningful in a clinical setting, and questions and responses must be grounded in the context in which they occur. Narrative inquiry takes context into consideration and is a research method that will allow me to develop a preliminary yet in-depth understanding of the meaning of the experience for nurses of working with families who they perceive to be obstructive. Analysis of narrative requires us to concentrate on how individuals express their understanding of their experience.

Clandinin and Connelly (1994) suggest that people by nature lead storied lives and tell stories about those lives. Researchers describe such lives, collect and tell the stories, and write narratives of experience. In essence, researchers become storytellers by using concepts and analysis to construct the meaning of a story. The focus of narrative inquiry is to construct worlds of meaning and to make sense out of

experience, which makes it a suitable method to explore the experiences of nurses working with families that they perceive to be obstructive.

In this chapter, I will outline the rationale for this research design, describe the principles of narrative analysis, and describe the sampling procedure, selection procedure and setting. I will detail the data collection methods and the procedure for approaching participants. Analysis will be explained, followed by a discussion of issues of rigor, ethical considerations, and limitations of the study to complete the chapter.

Research Design

My aim is to gain understanding of the experience of nurses by exploring the “emic” or insider’s perspective, which is crucial to the credibility of any qualitative study (Mischler, 1995; Field & Morse, 1995). There is a growing interest in narrative inquiry and its potential contribution (Polkinghorne, 1997). Within the last decade there is considerable recognition of the contribution narrative offers as an inquiry mode for knowledge development (Sandelowski, 1991). Narrative inquiry allows the human dimension of understanding to be expanded, whilst acknowledging that this knowledge is not complete, exact, nor static (Bartol, 1989). Narrative therefore represents personal reality at a particular moment in time; yet, that construct is changed as soon as the narrative has been offered. In addition, Mishler (1986) describes narrative inquiry as differing from traditional scientific inquiry and suggests that discourse and meaning should be restored to a central place in both theoretical and empirical work that attempt to reveal human experience. Since it is the human

experience of nurses working with families that interests me, narrative inquiry is an appropriate methodology for this study.

The Principles of Narrative Inquiry

The purpose of this study is to understand the meaning of the nurses' experience through the interpretation of language in order to gain an improved appreciation of their perspective. In order for this to happen, the researcher must pay particular attention to the voices of the participants by thorough analysis. Matheison and Barrie (1998) suggest that the participant in the interview process be provided space for reflection and be able to speak freely on their points of view.

Narrative inquiry involves an attentive exploration of the use of language and linguistic features that appear routinely in speech. By analysing the linguistic form and narrative structure the researcher is able to focus on aspects of meaning in language use. In this study, I have explored the participants' narrative to tap into the way in which nurses construct their experiences in working with families, which they perceive to be obstructive. During analysis I paid careful attention to what was emphasized, and how it was emphasized. In narrative analysis the identity of the storyteller, the nurse, is revealed as the narrator presents herself to the listener, the researcher. An additional and exciting aspect of narrative is the potential for the researcher to identify self in the stories of the narrators.

The underlying assumption of the process of storytelling is that individuals construct and express meaning through storytelling. Narrative inquiry is one of several modes of transforming knowing into telling, and as such it provides an approach to interviewing that has been used by researchers belonging to other

disciplines and for a broad range of studies (Mishler, 1986; Sandelowski, 1991).

Polkinghorne (1997) describes storytellers as “actors” in narrative who are given their own speaking roles and who interact with the “researcher protagonist”. Meaning is constructed in this way with the storyteller contributing to the story’s conclusion or end.

An acknowledgement of the process of interviewing is that both the individual providing the narrative and the interviewer are crucial to the narrative and that this narrative is jointly constructed; the storyteller has the knowledge, which is personal and the interviewer listens (Mishler, 1986). Questions and responses are jointly formed, developed, and shaped by the discourse between the participant and the interviewer. The relevance and appropriateness of the both questions and responses emerge through and are realised in the discourse itself. I was aware that I knew little about the questions I needed to ask and that the participants would help me to identify the salient areas for investigation as I moved forward with my study.

Sample

Morse (1991) argues that to sample randomly is to violate the principle of selecting the most experienced and knowledgeable people, therefore, to fail to select the best informants. Sampling in narrative inquiry requires the inclusion of individuals who will be able to provide a story that will best inform the research question. Sampling proceeded in a manner that was likely to enhance the researcher’s understanding of the research question. I sampled purposively from nursing staff working at a tertiary level Paediatric hospital in Western Canada. Although the available literature shows that there are several types of health care professional who

perceive families to be obstructive to the care that they offer (Coffman, 1997; Groves, 1978), for the purposes of this thesis, I limited this study to nurses.

The sample size was 8 participants. This small sample size is in keeping with acceptable numbers for a study using the methodology of narrative inquiry (Riessman, 1993). The number of the interviews was guided by the richness of the data provided where the goal was not to saturate but rather to focus around common stories arising from the analysis.

Selection Criteria

Participants were recruited on the basis of having recent or particularly memorable experiences working with families that they perceived to obstruct their care. At the time of the research, I was working at the hospital I had chosen for the study. I was in an administrative position within the hospital, and I was concerned that staff in areas I was responsible for might feel coerced to participate if approached by me directly. Recruitment strategies reflected the need to be sensitive to this concern. For these reasons, participants were purposefully selected from areas in which I was not directly involved, and selection involved individuals not personally known to me.

The rationale for selecting a tertiary level hospital was twofold. Firstly, as an experienced paediatric nurse, I was aware of the stories told by nurses, and I have witnessed the moral distress that comes with the feeling that one has “not done a good job” for a family, despite best efforts. I have sensed from RNs feelings of guilt, hopelessness, anger, and frustration that have not been formally acknowledged or addressed. The resulting shortfall has been that strategies are not available to support

nurses in their workplace. I hope to be able to offer insight into some of the difficult experiences for nurses in their work with families through my study. Secondly, while there is a general awareness of nurses being obstructed by families in other health care settings, I suspect the incidence is particularly high in a tertiary centre where there will be many acutely and chronically sick children as well as families with very high expectations of care delivery. I anticipated that the setting of a tertiary hospital would readily provide a pool of nurses with a wealth of stories to be told.

In the selected hospital, there is a continuum of nurses with experiences ranging from new graduates to those with several decades of experience in the field. I felt that most new graduates did not have the duration of experience as clinicians to have had sufficient challenges with families; nor had they had the time to reflect upon these situations. This statement should not be interpreted to mean that new graduates do not encounter issues such as family obstruction to their care nor that it is unimportant or invalid to explore their experiences; rather, that I wanted to explore the experiences of nurses who have worked with families for longer periods of time. There is no formula to estimate what length of experience is going to provide the best data, and I arbitrarily chose nurses who have worked in a tertiary level setting for five years or more.

Setting

Interviews were conducted at a time and place chosen by the participant. I suggested to the participants that most suitable was an environment that is private and that would allow for interruption-free time. For this reason, my preference was the participant's home but I was respectful if the participant wished that interviews be

conducted at the hospital for their convenience. Interestingly only one of the participants wished to be interviewed in their home and so typically I booked a room away from the participant's work unit and away from the areas for which I was responsible.

Procedure for Approaching and Informing Participants

Upon approval from the University Behavioural Research Ethics Board, and the hospital ethics committee, I commenced recruitment. I chose three units from which to start the selection process of RNs within the hospital, based on a broad range of children in terms of their illness type, frequency of hospitalisation, and their age. I introduced the proposed study by placing study recruitment notices in their mail sleeves on their unit (Appendix A). My intention was to rely on those interested in the study to approach me, as I believed that it would be those participants who wanted to share their "stories" and that such willingness had the potential to increase the richness of the data obtained. Recruitment of four of the eight participants occurred as a result of snowballing as RNs heard of the study from colleagues. Interestingly two of the participants told me that as they had discussed my study with RNs on two separate units, several of those RN's had suggested that they felt they did not have much experience of working with obstructive families, and no story to tell. The units where these RN's worked had at least two situations over the last three years requiring the Human Rights Officer to be called in to help diffuse volatile situations, and several other families where certainly some nurses in this study perceived their care to be obstructed. It would have been interesting if any of the RN's who felt that they did not have such experiences had come forward, as I suspect that their stories

and experiences might have been very different to the participants in this study. This will be further discussed in the analysis. I declined further volunteers only when the analysis indicated the data to be sufficiently rich with common stories.

Ethical Considerations

As I was a Patient Services Director within the hospital setting and responsible for staff performance management, I needed to be sensitive to the effect that I may have had on participants. The potential risk is for participants was to feel under pressure to participate and to feel vulnerable in terms of describing feelings and behaviours that might have been judged as unprofessional. To address this, I explained that my role is as a student researcher, and emphasized the voluntary basis for participating. Selection of participants consisted of RNs with whom I had no supervisory or evaluatory role.

Informed consent (Appendix B) was obtained from each participant prior to the first interview. Before participants signed the consent, they were encouraged to ask me or my thesis supervisor any questions regarding aspects of the study which were unclear. The participants' were reassured that their names would not be used in the transcriptions of the interviews. Their tapes and interviews were identified by a code number assigned to them by myself. Only the researchers had access to the tapes and transcriptions; the tapes and transcriptions were stored in a locked filing cabinet to which only I had a key. The tapes were erased at the end of data collection and transcriptions will be shredded in ten years following the completion of the study. The findings of the research may be published but the participant's names will not be associated with the study. Participants received a written summary of the results of

the research upon request and were asked to telephone me if they had any comments or questions about the research findings. Several of the participants' asked if I would lend them the thesis to read and that will be honoured.

Data Collection

Narrative inquiry can include several forms of data including diaries, letters, and conversations (Lieblech et al., 1998). For the purposes of this study, the data collection mode was interviews. The participants' chose where they were most comfortable telling their stories, and the participant and I chose a mutually convenient time. Privacy and an interruption-free environment were essential. The code of confidentiality was reviewed with each participant, and every effort was made to protect the participant's identity should he or she wish to be interviewed in their work setting. Consent forms (Appendix B) were signed before the initial interview. The interview with each participant began with some demographic data (Appendix C) prior to the audiotape commencing. The average length of each interview was hour. It seemed as even when there were more stories to be shared I often sensed the participants were drained and their body language indicated to me that they were ready to finish. When I verbally offered them the opportunity to finish, most of the participants did so.

To commence the interview I offered to tell a story. My story served the purpose of providing an example of a story with a beginning, middle and an end, and it helped to put the participant at ease. Two of the participants declined my offer to demonstrate storytelling, feeling comfortable to proceed immediately. I then proceeded to ask an open ended/broad question that encouraged the nurse to tell her own story of

working with obstructive families in her own way; I asked, “Can you think back to a time when you were working with a family whose behaviour made it difficult to provide the care you planned? Start where you like.” Questions were asked to clarify aspects of the stories, and prompts and probes were used to encourage extension of responses and completion of the story. I used my pre-set questions (Appendix D) as guidelines only, and was careful not to interrupt the narrator. I had a set of prompting and extending questions, such as, “What happened next, and what meaning does that have for you?”

When interviewing about potentially emotional topics, it is necessary for the well-prepared researcher to anticipate an emotional response from the participant and to have a supportive strategy to offer. To avoid a potential shift in my role from researcher to counsellor or administrator, I was prepared to ensure that the participant were aware of the resources available, such as their unit manager, the human rights Officer in the hospital, and/or the Registered Nurses Association of British Columbia (RNABC) as necessary and at the time of the interview. By providing the participant with the telephone numbers of the above resources, participants had the opportunity to discuss issues further, to debrief if necessary, or to seek advice on ethical dilemmas. As well, professional advice could be sought from these resources regarding how to handle future situations.

Overall the participants did not appear to be stressed during the interview. One participant was clearly emotionally distressed during the telling of a story and at the end of the interview I ensured that she was aware of the confidential counselling service offered through the hospital. Two of the participants were obviously moved

briefly at the start of the interviews, which was acknowledged. On each of these occasions I was also moved, in particular with the story of one participant, because I had also nursed that family and witnessed the devastating impact on the whole multidisciplinary team. I did not try to hide my reaction, rather to acknowledge during analysis that it must have had an influence on the stories that followed. How that influence played out is impossible to say.

A good rapport during an interview is essential. Consistent eye contact and occasional nodding can send messages of interest and respect for the participant. I endeavoured to make the interview process as comfortable as possible. Despite these measures, it would be misguided to ignore the power relations between the researcher and the researched. I endeavoured to be reflexive about these relations and to resist the temptation of reinforcing dominant ideologies such as exist in the literature, for example, that problems existing with family/nurse relationships are caused by and should be resolved by nurses. In addition, I made attempts to take into consideration my effect as researcher on the lives of the participants by journaling throughout data collection and analysis. I was aware that body language, facial expressions, and comments negative or positive related to the content of the participants data might impart a sense of being judged by the participant. In addition, I explained the purpose of the research, the benefit of gathering data that represented diverse experiences and the notion that experience and even interpretation is neither, right or wrong. During the interview, I remained alert to signs of unease by the participant such as avoidance of eye contact with me, short responses to my questions, and/or hesitancy to reply and restlessness. If any of these occurred, I was prepared to remind the participant they

could withdraw at any time without any fear of repercussion and in this way ensure that the participant was protected from any harmful aspects of the research process and at the same time more accurately obtain data that reflected their real life experiences.

It is worthy of note that the transcriptionist for this study struggled with some of the stories and had a particular emotional reaction to one of the stories that described a difficult working relationship for the nurse with a father of a baby who died. I was able to explain that this type of occurrence is rare and to listen to her concerns. Answering her questions however could only be done in a global sense versus specifically answering questions about the participants' story that would breech confidentiality for the participant and for the family. This example serves to remind us that the potential impact of an emotional interview cannot be understated

Data Analysis Procedures

Estabrooks (1989) describes the primary responsibility of the researcher as "to render accurately the lived experience of the participants so that the human phenomenon is presented as it is perceived by the participants" (p.394). The importance of analysis cannot be underestimated, and, since the researcher serves as the instrument of interpretation, the analysis must be rigorous, systematic, and unhurried if it is to be credible. Any personal assumptions must be thoroughly checked, and analytical consistency maintained throughout the entire process.

I did not use a theoretical framework as frame of reference to guide my analysis. The reasons were multifold. Many researchers consider social processes, such as the one in this study, to be too complex to approach with explicit conceptual

frameworks, preferring a more inductive, grounded approach. Miles and Huberman (1994) agree to a point but argue that with no framework or instrumentation the data cannot be cross-compared with similar work. Since it was not a goal for my work to be cross compared, I chose not to use a pre-set framework because of the potential to streamline analysis in a way which may be predetermined by the framework, more than the direction of the participants' actual narrative. Miles and Huberman suggest that a balanced approach that is not engineered by a framework is possible where the researcher has some background knowledge of the complexities and subtleties of a culture, and which may serve well to enable receptivity to local idiosyncrasies. The background knowledge was evidenced in Chapter Two.

I used Mishler's framework to distinguish between the structural, content and interpersonal aspects of the analysis. Mishler describes interviews as "speech events" that lead back to the interview, to the questions and responses of the interviewer and the participant. The concept of a speech event is based on the theory of language, speech, and social interaction; the concept can be analysed in several different ways. Mishler (1986) suggests a circular process occurs through which meaning and answers are created through the discourse between the interviewer and the participant, as they try to make sense of what the other is saying. It is the analysis of the relationship between the questions and the answers that creates the dialectical nature of the interview in narrative inquiry. Assessing meaning requires analysis not only of the content of the interview but of the process of the interview itself in order to understand how meaning is constructed and grounded.

The first of Mishler's elements is *structural* analysis, which refers to how parts of the text are internally connected through syntactic and semantic devices. Narratives are understood as stories with a temporal ordering of events and an effort to make sense of such events. As we tell stories, events are selected and given cohesion, meaning, and direction (Sandelowski, 1991). Temporal ordering results in making sense of stories, creating order, and connecting of events. Narratives are not time-bound and events may be described in a perceived and retrospectively constructed sequence. Polkinghorne (1997) suggests stories are recollections and recreations of the past. Both storytellers and listeners may draw on the past, present and future. Narratives help us to translate a secession of events and actions into a coherent whole.

Mathieson and Barrie (1998) argue that there is an important distinction to be made between narratives and stories. Narratives appear to have an open-ended quality while stories have a more self-contained quality. It is the open-ended quality of narrative I most wanted to explore, in order to hear stories not usually freely invited to RN's. Polkinghorne (1997) discusses the importance of plot in the structure of narrative and argues all stories have a plot. He states that a plot configures a story in four ways by marking the beginning and end, providing criteria for event selection, temporally ordering events moving towards a conclusion, and clarifying the contribution of events within the whole story. The second element of Mishler's analysis framework is the analysis of *content*. This interpretation of content includes the exploration of themes and their relationships to one another. The thematic analysis of narrative allows cultural values and personal identities to be identified

(Mishler, 1986). Analysis allows for individual particularities to be illuminated as well as relating an individual story to general cultural themes and value.

Mishler describes the necessity to analyze *interpersonal factors* as the third focus of narratives. The interviewer should always be asking, “in what way might the story be told differently if it was being told to a different listener”? Context is a crucial influence to an unfolding story, and specific factors include who the interviewer is, where the interview is being held, and how the storyteller and listener are feeling that day (Mishler, 1986). A story is the narrator’s presentation of events at a given moment in time and is shaped by the context of the interview. The researcher is the audience to whom the story is being told, to whom the participant is exposing herself. Therefore the unique aspect of this context must be included in the analysis. The interviewer brings his or her own level of skill to the interview, which will undoubtedly influence the storytelling and the direction of the interview (Mathieson & Barrie, 1998). The interviewer has a personal interest in the story being told and is an integral part of the participant’s account. The participant is at once the narrator, the subject of the study, and the collaborator. The participant has data desired by the interviewer and will tell a story that is fluid and that will change depending on the context.

Analysis began after the second participant’s interview. All of the tapes were transcribed accurately possible by an experienced transcriptionist. Firstly, I checked the transcribed data with the whole tape and found this to be invaluable in reminding me of aspects of the interview that I had forgotten and also for clarification. Pauses, repetitions, and false starts are important parts of language and were included in the

transcriptions for the purpose of analysis. Mishler (1986) warns against taking transcripts too seriously, as ambiguity and complexity are always present. The interviews were first read for their relevance to the experience of working with obstructive families. The stories included personal beliefs, experience, knowledge, and attitudes about working with these families. Parts of the interview that met the criterion for inclusion for analysis were located. Some participants told stories about other nurses' experiences, and these were included as a part of the narrative. Not all the interview was relevant to the experience of nurses working with families that they perceived to be obstructive, and so was not used. The interviews were expected to vary; such variances were included in the analysis as a significant object of inquiry and individuality. In themselves, the inconsistencies were not a problem.

Lieblich et al (1998) describe a five-step process that integrates a holistic perspective to the analysis process. I chose to use this data analysis process to guide my data analysis:

- 1) I read the transcripts several times in addition to listening to the tape until patterns emerged in the form of the foci of the overall story. By maintaining an open mind throughout the reading and by trying not to force themes, I allowed the text to speak. I made note of features used at the beginning and end of the text; the content was the main focus at this stage. Attempts were made to identify the orientation, plot, evaluation, and resolution of each story. Irrelevant data was identified and put to one side for later review
- 2) Making note of initial as well as overall impressions via my journal and noting unusual aspects of the story was helpful at this stage. Notes were made of unfinished

aspects of the story, of confusing directions taken or contradictions made, of emotion, and of inflection by the participant. These features in themselves were considered highly relevant.

3) I denoted themes by the time participants devote to recurring ideas, by repetitions they made, and by the amount of detail they offered. I viewed the story from start to finish and summarized the whole story to allow for comparison and interpretation. In addition, by making note of omissions or brief reference to a subject I hoped to identify focal significance.

4) Colour marking of the identified themes throughout the story facilitated reference to them. Repeated readings of the themes helped to focus on the important components of the stories.

5) I noted where each theme began and ended, noting transitions, context of each of the themes, feelings expressed, and relative salience for each theme in the text. Common and diverging patterns of the nurse's experience become clearer as analysis progresses.

Analysis then proceeded in a systematic fashion on three levels in accordance with Mishler's framework as described above, which incorporates structure, content, and interpersonal factors concurrently. The analysis of content focused on meanings, identities, and themes for the RNs working with obstructive families. Analysis of interpersonal factors took into consideration the influence of the participant, of the setting, and of the interviewer. Analysis of structure focused on how the RNs constructed their stories of working with obstructive families. Verb tenses, the

voice(s) of the storyteller, the shifts from the main story line, and significant statements, and the repeated words/phrases used throughout the story were analysed.

Colour coding was used to identify different narratives and/or narratives with subnarratives. Ideas were generated inductively from the data. My committee members helped to review the transcripts, discuss preliminary findings, and make subsequent interpretations. The final part of the process involved combining the above mentioned components of the analysis to synthesize the whole interview and to identify the common story(s).

Methodological Rigor

Sandelowski (1993) cautions us that if we invoke a set of rules in our efforts to gain credibility as qualitative researchers, we will only serve to destroy what we value in qualitative research. A common debate amongst qualitative researchers is about the methods of establishing the rigor of qualitative work as compared to the methods of quantitative work. To compare these two distinct domains is fruitless. Instead, Sandelowski argues it may be more productive to concentrate on ensuring the highest standards of rigor within the domain of qualitative work. Attention to rigor should aim to balance the requirements of credibility as well as to avoid stifling the data in order to conform to a positivist influence that stipulates rigid *scientifically* applied rules to a qualitative process.

Guba and Lincoln (1981) describe four factors relating to tests of rigor in qualitative research. *Truth value* is subject oriented rather than researcher defined; therefore, a study is credible when it presents a faithful description of a human experience those people described in the study would recognise as their own. Of

particular significance in narrative work is that the analysis is portrayed as the researcher's perspective, rather than as the storyteller's. The idea of empirically validating the information in one story against the information in another is, according to Sandelowski (1993), alien to the concept of narrative truth "and to the temporality, liminality, and the meaning-making function of stories" (p.4). However, for the purpose of member checking, an initial telephone call was made to every participant in order to clarify any aspects of the interview unclear to the reader. In addition, an interview synopsis was read to each participant, and feedback was asked for. In this way the participants had the opportunity to comment on the representativeness of the synopsis and the credibility of the interpretation was supported.

The concept of *applicability* guides the qualitative researcher to establish the position of all subjects in relation to the group of which they are members. The findings must reflect grounded life experiences, both atypical and typical. Guba and Lincoln (1981) suggest that from the quantitative perspective applicability refers to how well the threats to external validity have been managed, in order that the findings can be applied to other groups, contexts, or settings. There will be no attempt in my study to aim for the findings to be applied in other settings. The narratives represent only those who the stories belong to the individual participants. I chose to represent all of the findings, rather than select any particular participants, to overcome elite bias.

Consistency is a challenge in qualitative research in which the methodology emphasizes contextual and individual uniqueness. Narrative methodology is driven by

these values and so incorporates analysis of the interview situation as well as acknowledgement of individual uniqueness. Guba and Lincoln (1981) propose that auditability be the criterion of rigor and that another researcher could arrive at similar findings given the researcher's data, perspective, and situation. Sandelowski (1986) describes auditability as being achieved by an explanation, description, and justification of all the study details. I maintained records of my analytical and methodological decisions and endeavoured to avoid labels that could be misinterpreted. However, according to the principles of narrative inquiry, it may be that another interviewer would not arrive at similar findings due the influence that the interviewer has on the storyteller.

Neutrality, the final category, refers to the freedom of bias in the research process and results. Arguably, scientific objectivity is a socially constructed phenomenon and not possible to truly attain. Guba and Lincoln (1981) suggest that confirmability be the criterion of neutrality in qualitative work. Neutrality refers to the findings themselves rather than to the researcher, since in qualitative research engagement with, rather than detachment from, the participants is sought. This engagement between researcher and participant is in keeping with the principles of narrative inquiry. It was essential for me to remain aware that I did not start this study from a neutral standpoint. Confirmation of neutrality can only be provided once auditability and truth-value are established. Journaling and talking with other researchers was a helpful way of exploring biases caused by the effect that the researcher has on the participant and vice versa. The use of a reflective journal is upheld by Paterson (1994) as able to raise awareness of personal bias arising from the

researcher's worldview. I paid attention to the closeness of the researcher-participant relationship by focusing on how I may have been influenced by the participant and how I may influence the participant. As a way of practising reflexively, I kept a personal journal and asked for colleague/guidance feedback.

Limitations

By the very nature of the selection of participants, it is necessary to limit the generalizability of my work. For instance, by only selecting those RNs with five or more year's paediatric experience, I will not have heard the stories of newly graduated nurses, and I could not assume their experiences would be the same. A sampling bias is therefore created intentionally in order to find participants who have a story to tell. In addition, the recruitment strategy used in this study encouraged volunteer participation, which may have resulted in a sample with consistent or hidden characteristics not known to the researcher. For example, nurses who have had only positive experiences with families or those whose experience was devastating may not have chosen to volunteer for the study because they did not consider it worthy of attention or because they did not wish to revisit a negative experience. In addition, some people are not effective or comfortable storytellers and those who identify this as a personal limitation would have been reluctant to volunteer for such a study as this; therefore, opportunities to explore some experiences may have been completely missed.

In addition, I am unable to say with confidence that the experience of RNs in the setting of tertiary level paediatric hospital translates to any other setting, such as a community paediatric unit or home care setting. It is tempting to suggest there are

probably significant similarities, but research would be required to explore this further. In addition, I hope that the work will be valuable for other health care professionals working with families, but since their experiences cannot be assumed to be the same, additional exploratory work will be necessary.

A further limiting factor of this research is that this research has been conducted by a neophyte researcher. There are many skills inherent in solid research work in order to produce credible work, including interview skills and analytical work. My initial interview work required much fine-tuning and I needed to return to the early participants in order to gain a greater depth of data. My ability improved as I proceeded with data collection, however as a novice interviewer this should be taken into consideration. I aimed to address these concerns as much as possible by open dialogue with experienced researchers and appropriate checks with my committee members who are established qualitative researchers and who provided experienced and knowledgeable guidance.

I address the issues of doing research in a setting in which one is known by using/employing attentive sampling processes. However, it should not be assumed that these processes fully eradicate the interviewer having an effect on the content of the story. Equally possible is exaggeration of the power imbalance between interviewer and participant, and such an imbalance could affect data. The fact that the interviewer held an administrative role at the hospital cannot be disregarded as a potential limitation of the study.

In my experience of fifteen years in the field of pediatric nursing, I will undoubtedly have pre-conceived biases of which I am not even aware. I relied on my

committee to question these biases as they arose, and I kept a journal as a way of identifying my own thoughts that might have interfered with the research process. As well, I kept field notes at the end of each interview as a method of articulating impressions regarding the interview process and anything that was unusual about the process to assist me with analysis. One observation of my early analysis was that I tended to assume I understood the meaning of certain phrases offered by the participants, which had the potential to stifle exploration and further analysis. I believe that despite every attempt to address bias, my experience as a pediatric RN in the same setting as the participants must have influenced all aspects of this work, including the interview questions I asked and how I interpreted the data. While this may not have necessarily been a negative influence, I believe that the same study done by a nurse without pediatric experience could potentially look very different and should be acknowledged.

Summary

In this chapter I describe the methodological process of narrative analysis used in this study. Data was gathered from semi-structured interviews with RNs in a tertiary level paediatric hospital regarding the RNs experience working with families who they perceived to be obstructive to the care offered to the sick child. The ethical considerations employed to protect the participants are outlined in detail. Purposeful sampling is described, as is the setting and selection criteria for study participants. Mishler's philosophical (1995) framework identifies what needs to be included in the analysis, while Lieblech et al.'s (1998) holistic perspective guides the "how to" of

analysis for this narrative study. Methodological rigor is discussed as it relates to Guba and Lincoln's (1981) criteria, and the limitations of this study are offered.

CHAPTER 4: ANALYSIS AND FINDINGS

The purpose of this study is to explore the experiences of nurses working with families that they perceive to be obstructive. In this chapter, I outline the findings from this study, which emerged during interviews out of stories about working with obstructive families. Four common narratives and one sub-narrative from the stories are identified within the analysis of the research data.

This chapter begins with a brief demographic profile of the participants and a brief commentary on the general attributes of the narratives shared by participants in their interviews. I present a discussion of the analysis, using Mishlers' (1986) framework to explore the content and structure of the interviews. I will also examine the interpersonal factors that influence the analysis. Appendix E contains a detailed synopsis of each interview. Using a format that incorporates the voices of the participants, I conclude the chapter with a detailed account of each of the main narratives and the sub-narrative.

Description of the Participants: The Storytellers

The eight participants in this research were RNs with a minimum of five years of nursing experience (Table 1 includes demographic information about the participants). The participants included bedside RNs and clinical nurse leaders. The mean years of experience as a nurse were 17.5 years, with 14 years specifically in the field of paediatrics. All participants currently worked in acute care paediatrics. Four of the participants had attained a degree in nursing; one was currently enrolled in a masters program. The remaining four participants had a diploma in nursing; two were enrolled in a nursing degree program at the time of the study. The ages of the participants ranged from 28–55 years. All participants were female. Three of the participants had children. All of the participants were employed full and part time at a

children's hospital with an average working week of 36 hours. Their roles entailed regular direct contact with families.

Table 1
Demographic Characteristics of the Study Participants

Name	Gender	Age	Children	Current Position/Role	Nursing Education	Years as a Nurse	Years as Paediatric Nurse	Areas Worked in Pediatrics
Karen (A)	F	35-40	No	Clinical Nurse Leader	Baccalaureate degree. Currently masters student.	12	11	ICU, General paediatrics Cardiac
Barb (B)	F	35-40	No	Clinical Nurse Leader	Diploma. BSN in progress	16	7	Medical and Emergency
Susan (C)	F	25-30	No	Staff Nurse	Diploma. BSN in progress	6	4	Medical and Emergency
Betty (D)	F	50-55	Yes	Clinical Nurse Leader	Post RN Baccalaureate degree	26	14	Medical
Donna (E)	F	40-45	No	Staff Nurse	Nursing diploma	17	14	Oncology, Surgical, Medical specialities
Gail (F)	F	35-40	Yes	Staff Nurse	Baccalaureate Degree	14	14	Cardiology Respiratory
Mary (G)	F	35-40	Yes	Clinical Nurse Leader	Baccalaureate Degree	15	13	Medical
Lori (H)	F	55-60	No	Staff Nurse	Nursing Diploma	35	35	Medical, Float pool

Overall Impression of the Narrative Interviews

The participants stated they had no difficulty recounting stories about obstructive families they encountered in this work. They implied that telling their stories to the researcher served more than the agenda of the research; there was a component of therapeutic self-talk throughout the interviews in which the participants struggled to make sense of their role in such situations. This self-talk was located

primarily in the parts of the interview in which the participants abandoned their story line and focussed their commentaries on a philosophical and social analysis of such situations.

Participants needed little probing or encouragement to tell their story. At the onset of each interview, I stated that the focus of the interview was their experience and that there was not a right or a wrong answer to my questions. Some participants checked the usefulness of their narrative at this time by asking, “Is this what you want?” Once I confirmed that their narrative was useful, they appeared absorbed in their storytelling. Some participants exhibited nervous laughter at the start of the interview. This behaviour disappeared within seconds of beginning the storytelling. Towards the end of the interview, the majority of participants summarised their philosophical perspectives about obstructive families and nurses’ roles.

As could be expected, the interviews varied greatly in intensity, depth, content, and emphasis. All participants commented initially that they were “glad” to tell their stories. After some minor initial hesitation, they proceeded to tell their stories in a free-flowing manner. As outlined in Chapter 3, the interviews were analysed concurrently for structure, content and interpersonal factors (Mishler, 1996). What follows is a general sense of the narratives shared by participants in the interviews and of the interviews themselves. This will be discussed according to context, structure and content of the narrative interviews.

Contextual Factors

The context of the telling of a participant’s story, including that provided by the interviewer him or herself has an effect on the structure and content of what is said; it is crucial to consider this effect when analyzing the result. Thus, the context of the interviews in this study included myself as a researcher, one familiar to all participants as a pediatric nurse. I had predicted that the storytellers would actively

engage me as one of “them”, and they acknowledged this was the case in both direct and indirect ways. For example, during the interviews, participants often said, “You know what I mean.” This reference to insider knowledge was made in a global manner to refer to human and nursing experience, but it also occurred in the context of assuming an intimate knowledge of the job. During the interviews, several participants suggested I knew the family they were talking about, as if to elicit support and validation for their stories. Undoubtedly, I could relate to most of the stories and found myself remembering my personal experiences with four of the families identified in the interviews. During the interviews, I became acutely aware that my facial expressions and body language might send unintended or confounding cues to the participants about my expectations and unspoken research agenda. In addition, I acknowledge that, at times, the participants’ stories elicited powerful emotional responses and memories for myself as researcher. I journaled extensively in an attempt to remain aware of my responses to the data.

I saw no overt signs that my administrative role in the hospital intimidated participants; yet, my role may have been a factor in shaping their story telling. I did not detect any visible sign of participants’ discomfort in the interviews. Their body language and their willingness to discuss their stories in detail implied they were not hesitant to share their stories with me. I attended to the possibility of the reactive effects of my administrative role in my reflective journaling.

I was careful not to interview anyone known to me personally; yet, I am well-known in the hospital, and this may have had an influence on the stories told by participants. The temptation is to assume that their stories may have been less rich because they were constrained by my role. Contrary to this view, it is possible that their storytelling may have been enhanced because they knew that I had shared their experience or because they viewed me as having the influence to effect change in hospital policy regarding families. It is entirely possible that some participants may

have been reluctant to disclose experiences that may be interpreted as unprofessional because they feared retributive consequences. Yet, several participants told stories about avoiding and, in some cases, abandoning families.

The identity of the storyteller was a significant context of the participants' narratives. At times, those participants who were mothers admitted they experienced a competition of identities as they told their story; that is, they felt differently about the family's situation as a nurse and as a parent. They indicated they appreciated the family's position but also experienced a conflict when they were unable to carry out their professional role because of the family's obstruction.

The setting of the interviews deserves final consideration also, for it can be assumed to influence of context of interviews. The participants chose the interview setting; most preferred to be interviewed at the hospital. One participant chose to be interviewed in her home--of all interviews, this was the most relaxed. The hospital setting is likely to have had an influence on the participant in terms of the institutional expectation of family-centered care. In addition, the hospital administration, including myself, supports patient-focused care, and the hospital staff pride themselves on "customer service". These factors may have inadvertently conveyed that obstructed care should be tolerated and that RNs who are unable to resolve issues with obstructive families have failed.

Structure of the Narratives

Participants concurred that narratives about the experience of working with families that RNs perceived to be obstructive were easy to locate and were abundant. Generally, they structured their stories to have a beginning, middle and end. However, the stories were not always presented in a linear manner. Most of the narratives were of stories within a story and frequently the storyline was interrupted by another story to offer a comparative basis (i.e., stories of other families and

situations that helped to illuminate certain elements of the central narrative because of the differences and/or similarities they presented). One participant referred to an unforgettable experience with a family and repeated critical parts of the same story throughout the interview. Another chose to recall only a single story in which a common narrative—questioning of self--was notably absent. Her story was emphatic, passionate and remarkably clear.

Participants regularly repeated the central elements of their stories throughout the interviews. Such repetition provided the participant an opportunity to emphasize and summarize the meaning of their work with families perceived to obstruct their care. As well, repetitions of elements of stories were characterized by greater detail and clarity than the original story, and may reflect attempts to convince the interviewer of the validity of the story and appropriateness of their actions.

The beginning of each participant's story was typically presented in a concrete manner, describing the family and child's situation in detail and as factual information; it did not include elaboration on the meaning of the experience for the participant. The participants' personal experiences were introduced later in the storytelling, interspersed with concrete facts about the family. Sometimes, the participants' factual accounts of their stories resembled a change-of-shift report in its lack of subjectivity, personal detachment and methodical organization.

Participants used a variety of linking words, such as "you know" and "like", in their storytelling. Word repetition was used for emphasis, particularly descriptive terms such as "really", "huge", and "like". The pitch and intonation of the stories also varied greatly with storytellers. They were animated at times and quite "flat" at other times in their storytelling. The speed of the interviews varied enormously with some narrators "rattling off" stories and others narrating quite slowly. Some stories appeared easy for the narrator to tell, and these were typically told faster than were stories where recall was slower or where the story clearly held an emotional impact

for the narrators. There were many pauses throughout most stories, and, at times, pauses would signal either a shift the participant was about to make in the direction of the story or her discomfort with the situation portrayed in the story.

Participants often told their stories using the pronouns "I", "you" and "we". Frequently, their stories were told as if the story itself belonged to someone else; participants would not uncommonly use the first person and/or the third person in the telling of the story. Participants used the pronoun "you" when abandoning their personal story to expound on a personal theory or a philosophical perspective. They used the pronoun "we" when they were discussing shared experiences with other RNs. This occurred most often when they wished to emphasize that their stories, and their responses to situations detailed in the stories, were not unusual. They commonly related colleagues' experiences to emphasize the universality of challenges presented by families.

A variety of verb tenses were used throughout the stories to indicate either past or present. The future was also discussed but not as often. Often the narrators would intersperse their stories with questions in order to make sense of their experience. At times, questions were directed to the imagined family member in tones of disbelief, such as in the question, "How can you be so crazy? It's only oxygen." At other times, participants asked themselves questions such as, "Could I have missed something?" The tense would shift from past to present during reflective narratives, and there was evidence that the narrators in this study had used reflection about their past experiences to explain current practice and to plan what they would do if faced with a similar situation in the future.

Content

The four narratives are identified as anticipating the worst, questioning of self, failing to connect, and making sense of the hurt. The sub-narrative is identified as

avoidance. The participants' stories did not conform perfectly to any one narrative; rather the narratives shifted within or were combined in participants' stories. In fact, most stories had aspects that fit with at least two main narratives and with threads of the sub-narrative. The narratives were interlinked, and often interdependent. The narratives were identified in the analysis of participants' storylines depending on how often the narrative was told and what volume of storytelling was dedicated to that narrative.

All of the participants' stories were about parents of children in the hospital, not about any other family member. One of the striking elements of the analysis of participants' narratives is that RNs who individually told stories about the same family consistently described their experiences as encapsulating the same narratives, despite varied foci in their storytelling. Another observation is that participants' stories at times included experiences of non-nursing staff with families; these were generally offered to indicate that the experience of obstructive families is shared by others in the clinical setting. Another striking and consistent element in participants' stories is that the narrators never used the names of the parents. This may have been because of professional consideration in terms of protecting the confidentiality of the parents; yet, in two of the stories, the child's name was used. It is noteworthy that prior to discussing parents, participants commonly hesitated before referring to the parents as "them" or "the parents." The direct terms "Mum" and "Dad" were rarely used.

On several occasions, participants commented that the parents in their stories "had mental health issues". They believed that such issues clearly influenced the RN/parent interactions, the parents' response in a stressful situation, and their own response to the parent and to the situation.

The Narratives

In the following section, four narratives located within the twenty-seven stories are described. The narratives are presented mostly in the past tense, because this is how the narrators told the majority of their stories. These narratives represent the most salient storylines within the interviews, but there were also infrequent and/or incomplete narratives that have not been included in this discussion. The four narratives are identified as anticipating the worst, questioning of self, failing to connect, and making sense of the hurt. The narratives are not presented in order of priority.

Anticipating the Worst

In the narrative of anticipating the worst, the participants presented themselves as thinking about how the next interaction with an obstructive family might unfold. The main story line is this: *I've heard about this family and the difficulties my colleagues have had working with them. I can't face the next shift working with them. I tried to find a better way of working with them, but this failed. Nothing I could do made a difference so I avoided this family. I am not looking forward to seeing this family or families like this in the future. I still wonder if I could have done things differently?* An example of such anticipation can be found in a story told by Lori in Appendix E.

The common theme in this narrative was one of staff members warning each other about a certain family. Participants' anticipated the worst before they met the family. The warnings often involved "labelling families" as obstructive, a practice that participants acknowledged was "dangerous":

We were told, "Oh, they're just like the other... the other family only worse". That's before we even set eyes on them. So, right there, it puts everybody's... you know, everybody on edge that, oh, my god, you know, we're going to get another family that's going to be really difficult to care

for. And it sets up pre-conceived ideas, too, for the next time they come in. You know, for staff who knows them of course, we have a very negative attitude towards them and for new staff members that may not know them of course they're going to pick up on that too. So, it's almost like we're labeling people when maybe they shouldn't be labeled.

Anticipating the worst occurred in many ways but predominantly as a sense of dreading the patient assignment and viewing the next admission (of the child) with "trepidation". An outcome of this was that when the child was admitted to hospital nurses were reluctant to care for the child and interact with the family. This, in turn, negatively affected the quality and consistency of care offered to the child.

Participants initially developed strategies to reframe their expectations of working with the child and his or her family so that they would be less pessimistic about their interactions with the family. Some focused on the hope of overcoming obstructive relationships with relationship building. One offered,

So, that night shift, I put on a, ...somebody who I felt was a highly family-centered person who just has a sense of nurturing. It's just in her personality, her words, her manner, her demeanor. ... I just felt that she could really, if there was going to be anybody, it was be this person. So, she came on and I gave her just a little snapshot of what had gone on because I didn't want to prejudice how she was going to go into the room.

When initial attempts to interact positively with the family were not successful, most participants tried again. They resolved "to do better next time" and developed a new plan to work with the family. Participants often stated that at this point in their history with the family, they often felt they had learned enough to be successful in the future with this family and/or with families who were similar: they suggested, "this is how we would deal with this if it happened again". One participant suggested she

“would address issues much faster with more open communication”, now that she had more experience with such families.

When all planned strategies failed, participants voiced defeat, saying nothing they could do “would make a difference”. At this point in their storytelling, they often referred to the hopelessness of the situation by emphasizing that others had tried to resolve the situation and that they had also failed. One said,

Everybody had the same experience that I did, that it didn't matter at what point you went in your shift to introduce yourself and explain what your role was. To encourage collaboration on the white board, questions that [the parents] wanted answered for the day were encouraged. Generally, what the father would write down [on the whiteboard] would... was quite demeaning and verbally assaultive ... It was really obvious that I wasn't going to be able to explain any of that away, and I didn't really want to... that's how he felt. I couldn't sway his feelings, ... and it only got worse.

Ultimately these stories would end in a statement such as, “I avoided this family”. In anticipation of working with these families, nurses would call in sick, change their shifts to avoid working with the family or refuse to take care of the child.

The narrative of anticipating the worst was most frequently told by participants referring to the RN staff as “we” and the family as “them.” Embedded in the narrative is the acknowledgement that situations involving obstructive families are inevitable and hopeless; they are “ongoing issues that I [nurse] know will occur again and again.”

Most participants chose to deal with the family by avoiding the family during the child's hospitalization. Participants concurred that their lack of success in resolving

the family's issues caused them to reflect on what they had done or not done as well as what could be done differently in the future. One said,

Each experience makes you reflect back on... it always makes you think as an individual, what could I do or what could ... or that nursing aspect, like, "what could I do differently?" or, "can I improve this situation, not make it worse, but make it better?" or "make this experience good for both of us?" like, patient and the nurse. I mean, you always think about ways ... different ways of communicating or talking with the patient or trying to understand what's going on with the patients' family or any other kinds of issues, social or financial or emotional. Or just being here, like understanding that they understand why they're here or if that's ... that's obviously a stressor for them but I guess yeah, that would be something. But sometimes, it just doesn't happen that way, you always try to do that and it [the tension] never goes that way. Or you have the hope of trying to do that, and it just doesn't pan out.

Participants ended their narratives of anticipating the worst by predicting future encounters with the family as either problematic or hopeful. One described a situation on her unit with a family that "has tainted everybody forever. Like nobody wants to primary care because of that example, and they bring it up over and over again". Some participants remained optimistic that the next interaction with a family might be more positive than the previous one. "I've always been able to take care of challenging families, I can sort of break through ". However, others were wary of hoping for success in interactions with the family. One said,

I pride myself on being able to usually deal with difficult kids and families and had asked to have her for a second day in a row thinking that, well, you know, maybe I'll make some progress.

And I ended up being in tears that day and walking away, which I don't know that I've ever done before.

Those having similar experiences had learned there was a danger in being overly optimistic.

Questioning of Self

Participants' narratives of questioning of self were characterized by self-questioning and self-doubt. The main storyline for this narrative was this: *I had a hard time working with this family and figuring out how to be with them to build a positive relationship. I wasn't sure that I was doing a good job. I tried some of my usual strategies and they didn't work. I questioned if I had the authority to deal with this family. I didn't know what to do next so I tried to avoid interacting with this family as much as possible.* An example of this narrative can be found in the synopsis of Gail's interview (Appendix E).

In narratives involving questioning of self, participants began by describing their encounter with a family perceived to be obstructive as one in which they were uncertain "about what was going on." They presented themselves as perceptive nurses who often had "hunches" that the family was going to be difficult or problematic well before problems occurred. One participant said,

You know that something's wrong, and you can't figure it out. Like, as soon as we met Dad, a little flag went up. But you don't know if you're right or you're wrong about your assessment. You know that something's different about this guy, but you're not sure. And sometimes it takes a long time to get there.

This uncertainty for the RN about her assessment of the parents was exacerbated when the parents asked, "Well, why is this person doing it, and you won't?" Participants used phrases such as "walking on eggshells" to describe their response to situations that epitomize this narrative. They frequently did not disclose to colleagues

their angst about the family situation until many interactions with the family had occurred. This decision was related both to participants' perception that they may have been to blame for the situation and their reluctance to label the family or to conclude that there was a problem with the family that required outside intervention.

The questioning of self became pronounced and intense as the participants' narrative progressed. As families' behavior became increasingly obstructive and participants' strategies proved ineffective, each questioned whether he or she had done a "good job"; "It was just subtle things that you know aren't quite right. So you question yourself first. Am I tired today? What's going on?" She elaborated, saying,

It's just is that you question what you're doing. You're questioning your own assessment skills; you're always questioning so much, and then you go away wondering if your feelings are right and if you are doing your job properly and if your insight into these families is right.

Such questioning inevitably led to further questions about the participants' abilities and worth. "Am I a lesser nurse?" "Am I not a good person?"

Participants who shared narratives of questioning of self included descriptions of the many creative strategies they used to please the family and to try to resolve the family's issues, such as using a communication board in the child's room and assigning a primary nurse to the child's care. They also referred to the considerable amount of time with these families trying to find ways to resolve the problems they encountered with difficult families. These descriptions seem to be used to convince the listener of their professional expertise and commitment. When their strategies failed, participants resigned to questioning if the authority they held as staff nurses was sufficient to deal with obstructive families. One said,

Why does it have to be us that addresses [the conflict with family]?

So, it is almost better if it comes from somebody higher up or

whatnot. Like, when it's brought to their attention ... they do have more authority! Like you know, some families just don't look at us as having that authority to say, "Well you can't say that I can't do this or can't do that or can't wear this or can't wear that. Who are you to say that?" You know, so sometimes ... you don't feel like you have the authority. So, maybe that's part of it-the uncomfortableness that goes along with it. Maybe it is the authority. We don't feel that our word means anything when it comes to issues like that.

As the situation continued and was unresolved, participants stated they "didn't know what to do next". Their uncertainty about how to address the family situation forced nurses to reassess their ability and performance, and was reflected in statements such as "I don't", "I didn't", and "I hadn't", all of which appear in this excerpt:

It didn't seem to work. I just didn't know what to do. I hadn't been in that extreme an example before. I didn't think I lost my skills, but it was just kind of like I didn't know where to go ... to think of next. I was totally bewildered. And then I understood why nobody wanted to take [the child] two days in a row. But it was ... I don't know... I don't think it was a blow to my ego, but, ah, it was just not knowing what I had done wrong or what I could do right.

Ultimately the narrative of questioning of self led to participants minimizing their contact with the family and the child, or, as one participant said, "You think twice about it [checking on the family]." She would think, "Okay, I should go in and do this now. Well maybe I can wait a little bit longer, and then I can do something else at the same time." She reflected, "It's that you're maybe not quite willing to go in and face them."

Several stories revealed “last ditch” attempts by the RN to resolve the situation, such as calling in their supervisor, physicians or the Human Rights Officer to help resolve the problem. This approach often resulted in the writing up of contracts to provide guidance to the parents and sometimes nurses. The involvement of other professionals in the story served to validate the severity of the situation for the RN’s and also illustrated that others recognized the parents’ behaviour as inappropriate.

The participants had a unique way of telling the questioning of self-narrative. Often their hesitation and self-questioning revealed their efforts to make sense of their experience working with obstructive families. The participants who shared this narrative digressed from the story more than in other narratives. These digressions were often told in present tense as if the narrator was continuing to process their experience (e.g., saying, "I can't figure it out.").

Failing to Connect

In the narrative, failing to connect, there is an overarching sense of the participants' personal failure. The story line is this: *The parents were unreasonable and were mean to nurses. I felt that the solution would be to connect with them. Despite my best effort, I was unable to reach the family. I felt defeated.* An example of this narrative can be found in the synopsis of Loretta's interview (Appendix E). The narrative of failing to connect was recounted passionately by participants. They defined their inability to connect as occurring in both the physical and emotional domains. These nurses presented themselves as having the skills to effectively resolve their conflicts with obstructive families. Some spoke with pride, describing themselves as having a “reputation” for working successfully with obstructive families. So when these nurses found themselves in situations where they could not resolve the conflicts with families, they referred to them as “unreasonable”. Their

portraits of these situations were often characterized by descriptions of victimization of nurses. One participant told this story about one child's mother:

[She] was physically in your face, loud, and demeaning and [she] swore at you. So, a nurse would go in to give the medication, and she would yell at the nurse; she would accuse her of not doing the proper things for her child. In the space of one day, two of the nurses went in, and she yelled at them about medication or ... within, like, moments of their shift starting. And she was a larger woman and would be right into you're personal space, you know, right up close and personal, and you just felt all this tension and negative stuff.

Another nurse described a family's behaviour toward the nurses:

[They were] a triad – the mother, the son, and the daughter all fed into the same system that, you know, basically the nurse is bad, and we don't want you to get at us--even though they knew they needed the care. The child was sick! So the children were told not to, you know, talk to us or not to tell us anything if [the mother] wasn't there and things like that and they were also told to lie [to us].

Participants who shared narratives of failing to connect described the many strategies they used to try to connect with the difficult families. These strategies included supporting nurse-family collaboration (e.g., using a communication board to document messages to and from the family), providing consistent nurses to care for the child, and practices such as personal introductions to the family, in order to try to build rapport. By describing these strategies in detail, they portrayed themselves as caring and competent nurses. Despite these efforts they still failed to connect with obstructive families. In what appeared to be attempts to shift the blame for failure to

parents, some nurses told of incidents when a family retaliated. For example, some told of families who used the communication board to write demeaning comments about the RN's. Participants vividly described their sense of failure when they were forced to conclude that they were unable to "reach out to the family". One said,

Personally, [the nurses] were defeated, absolutely defeated because you want to do a good job. You want to feel that at the end of the day, even if it's a sad or bad day, that you've been able to provide comfort or relief for a member of the family--even if you can't do it for the whole family. But there's been someone you've been able to reach and touch that day. There was never a sense of that, ever, ever, ever.

Participants constructed the outcome of failing to connect with the family as defeat, both implicitly and explicitly, saying, "There seemed to be no way to connect with these families." This sense of defeat was reinforced by their resolve that "nothing would have made a difference". The participants also described their defeat in the context of how significant making a connection is to nurses' work and well-being. One nurse suggested that feeling connected with families was an essential part of the job satisfaction that contributed to the meaning of nurses' work life:

We've got a lot of nurses who worked here for along time, and they know those families. Especially with kids with chronic illnesses. They do come back to us on a regular basis and, for the most part, I think that the staff stays here because they like the kind of relationships that they can build with the patients and their families and they feel that they're a part of that care.

Typically, connection was described as "give and take" and "mutual respect". Implied in these narratives was the relationship between building a connection and good nursing care, as well as the value that nurses attributed to this aspect of their work with families. When participants believed that establishing an effective

connection was not possible with families, they gave up trying. Ultimately this led to the RN blaming the family for not being reasonable and avoidance of further encounters with the family. Descriptions of effective family-nurse connection were often used by participants to contrast their experiences with obstructive families, and this distance allowed the RN to avoid responsibility for failing to connect with families.

Making Sense of the Hurt

The narrative, “making sense of the hurt”, is the most frequent narrative shared by participants. The storyline of this narrative is this: *This family was obstructive. I tried to understand what the family was experiencing. The family continued to obstruct the care I needed to give to their child. I couldn’t do what I needed to do to give care to this child. I was hurt personally and professionally by the hopeless situation. I avoid the family and feel guilty.* An example of the narrative about making sense of the hurt can be found in Donna’s story (Appendix E). This narrative straddles all of the other narratives, either as the cause of the subsequent narrative or embedded within as a second dominant narrative.

Participants' stories of making sense of the hurt began as an encounter with an obstructive family that impeded the nurses' ability to provide physical care to the ill child. This encounter was followed by a period of trying to make sense of the situation and, in order to provide family-centered care, trying to understand the family's perspective and, at times, tolerating abusive or inappropriate behavior. One participant said,

We try to look at all the ways families are stressed out. Cause they’re all acute kids and the families are stretched and from different ... you know, look at all the things, from different communities. They’re separated from their children, and they have financial problems. We let them yell at us inappropriately because they had a bad day instead of

stopping the behaviour that we know is inappropriate. Because we're so nice and we'll just let it slide off our back this time, and we don't realize that it's happening over and over again to many of the staff.

Despite their determination and effort to understand and empathize with a difficult family, participants recounted that parents often prevented them from giving the care they felt the child required. One remarked, "I can't do what I need to do". Participants often constructed the conflict as "feeling as if I was in the middle" between the parent's and child's needs. Their frustration was clearly reflected in comments that the care of other children on the unit was compromised because they spent so much time working with an obstructive family. Considerable time and energy was required to do "damage control" to maintain some sense of order on the unit and with the child's care.

Participants who shared the narrative of making sense of the hurt personalised the experience of working with an obstructive family. They repeatedly described how they had been emotionally hurt by the family's behaviour and the resulting conflict. They were also hurt by their inability to care for the ill child or children as they wished. Their descriptions of hurt were animated and marked by adjectives, and the narrator progressed from using "I" to "we" as she told her story. The implication was that when one nurse is hurt by such a situation, a similar hurt is experienced and shared by the other nurses on the unit. One participant said,

It was just so ... it was so unreasonable, so unreasonable and when you take pride in internalizing the family-centre care model like we do--to say that a family is unreasonable just felt horrifying. It did! I thought ... this is a sham! I don't really believe what I think I believe, if I can say to myself, "[The family] should be taken away" And that's how I felt, and I don't think my experience was unique. I think a lot of people really ... well, I know in our [nurses'] debriefing, the

stuff that came out of there was we weren't sure if we really did subscribe to the family-centered care model, given the difficulty we had with this family. And we had to do a lot of talking about what that [family-centered care] meant, um, and we had to protect [ourselves]--there was more than just the family involved. There was our integrity as well. There was the family's integrity, and there was our integrity, and we had to work really hard on supporting and maintaining honor and integrity personally and professionally.

Conflict between nurses was apparent in some of the stories. For instance, parents would choose their "favorite" nurse(s) causing a sense of division between RN's and creating "two camps". Although some participants who told this narrative acknowledged that not all nurses agreed with the assessment of a family as obstructive at the beginning of the narrative; typically over time the nursing staff came to hold a common understanding of the family as obstructive. One participant said, "At times it seemed like people were totally divided but we came together really quickly and worked as a team". In addition, parents at times criticized a nurse's expertise and judgment. What appeared to underlie this concern for the RN was the question of whose expertise should take precedence in determining the child's care (i.e., who knows best?). On occasion "giving in" to the parent felt like compromising the care provided to the child by the RN.

The participants' narrative of making sense of the hurt was most often concluded with a statement about the hopelessness of the situation: "The problem doesn't get better. It doesn't go away". None of the participants who shared this narrative described a resolution of the situation. Instead, they commented on the overwhelming angst and powerlessness felt by all involved, particularly for the ill child. One said that the parents "were being undermined and [that they] were being undermined, and this baby was caught in the middle". She went on:

They were only being able to participate so far in their baby's life, and we were only able to participate so far from a nursing point of view, so nobody was really able to provide 100% care. I certainly had a strong sense of responsibility to this Mom and Dad because, yeah, it isn't the way I would have treated my baby. It isn't the way probably the majority of the collective would treat their child but that wasn't the point. This was their child and none of this was done with malicious intent, and that's ... at the end of it all, that's how I really felt, and I needed to support my staff because they hated this guy.

Some participants described experiencing "battle fatigue" and being unable to carry on or to devote any further energy toward resolving the situation; therefore, they tried to avoid the family as much as possible. They stated they felt "really guilty" about deciding to avoid a family but rationalized that they did not know what else to do.

The Sub-narrative: Avoidance

The sub-narrative, avoidance, was featured in participants' narratives as a consistent associate or secondary story that straddled the main narratives. Avoidance occurred in 18 of the 27 stories elicited in the interviews. Avoidance was generally discussed by participants as a necessary action if the nurse was to be able to look after *self* and balance her needs with the nursing care that the child and family required. Participants stated they were aware avoidance was not in the best interest of the child and they recognized that this behaviour fell short of optimal nursing practice. Although the nurses rationalized that they had no other option many continued to feel guilty and to question whether they had done enough. Underlying this dissonance was closely held ideals of what family-centered nursing should be and what "good" nursing entailed.

Typically, participants described avoidance as physical avoidance and discussed it in the context of what impact that avoidance might have on the child and family. Avoidance was defined by participants as physical because it involved a physical leave-taking and distancing from the child and the family (e.g., nurses would call in sick, change their shifts or refuse to care for the child).

When avoidance was the focus of participants' stories, they rarely used the first person and most often referred to the behavior of other nurses or to the nursing staff as a group. One said,

We had several people on the ward that refused to take [the child]-- just flat out refused--and sometimes a couple of [nurses]--because they were physically assaulted, and we were all verbally assaulted [by the family] and it was just a matter of they just didn't want to do it. Because we just didn't know how to handle it and didn't feel that anyway we handled it would be the right way. And [we] didn't need the stress. And yet we knew that this girl needed to be treated.

Many participants told stories about how they minimized their contact with obstructive families rather than avoid them overtly. This type of avoidance was achieved by strategies such as grouping care (i.e., doing everything for the child at once and then leaving the room for long periods of time) and waiting for parents to leave the unit before providing care to the child. One explained that by using such strategies, she was able to "go in to the room fifteen times" rather than the "twenty times" that was her usual pattern of caregiving. Other participants stated that they were "not as sociable" or apt to be as friendly with a family perceived to be obstructive. Emotional detachment was a common avoidance mechanism used by participants but some expressed guilt that they had been distant with the family and/or child. One said,

The last time they were in I found I was quite detached from [the family's and child's situation], and, in fact, the last time [the child] was in, I didn't even have her as a patient. I actually went through almost the whole shift before I realized I hadn't gone in and said hello. [pause] Well, when I realized that I was detached, I kind of felt guilty.

Participants often described avoidance in terms of the influence that working with an obstructive family had on their future interactions with other families. One told a story about how a nurse had worked with an obstructive family, and, because the situation had been "draining", she did not function as a primary nurse for another family for a long time after that. Others suggested that when there was a history on the unit of "tainted" nurse-family relationships, it was difficult to find RNs willing to work with any families perceived to be obstructive.

Participants rationalized that avoidance as the only viable option when obstructive families did not respond to nurses' strategies to resolve the conflict. It was remarkable that participants denied using confrontation as a strategy to resolve conflicts with families. They regularly referred to confrontation with families as something to be avoided, even when families provoked it, saying, "I just stepped away", or "You kind of let it slide." A more common strategy was to repeat to families the rationale for why nurses did the things they did. But when this had no effect on the family's behavior, participants admitted they often "gave up." One said, "I can't go in [to the child's hospital room] and say this for the fifty millionth time.... I'll just have to ignore it. Because I just can't do this anymore". Similar hopelessness and powerlessness was expressed by participants in phrases such as in the comments that nurses "can't make a difference", that they "don't have the power", or that the family or the situation "was too unreasonable."

Summary

The narratives and sub-narrative as they are presented in this chapter provide insights about the complexity and sense of futility that are inherent in nurses' experience of working with obstructive families. These narratives reveal much about what the participants valued and how they found meaning in their interactions with families. Although each participant's experience with families perceived as obstructive was unique in terms of context and the specifics of the conflict, the commonalties among their experiences is striking.

Most participants shared at least two main narratives, with the sub narrative, *avoidance*, within each of these narratives. Participants recounted most of their stories of families they perceived to be obstructive by vacillating between the dominant narrative *making sense of the hurt* and the other narratives, *questioning of self, failing to connect*, and *anticipating the worst*. The implications, which arise from the research findings for nursing education, practice and research, are described in the following chapter.

CHAPTER 5: IMPLICATIONS

This final chapter will begin with a summary of the research study, including the research design and findings. The focus of the chapter, however, will be the insights that have been derived from the use of narrative inquiry and from the research findings. The strengths and limitations of narrative inquiry, as well as the research design, will be discussed in the context of the criteria of rigor. The implications of the research findings for nursing research, education, administration and practice will be identified.

Summary of Research

The purpose of this study was to uncover personal meanings, attitudes and beliefs constructed by RNs in their work with families who they perceive obstruct care. The narratives provided by participants have contributed to the understanding of the experience of nurses working with families perceived as obstructive. The study participants conveyed four narratives and one sub-narrative. The first of the four narratives was *anticipating the worst*. In this narrative, the participants told stories about how they were forewarned about “obstructive” families by colleagues. Although this caused them to dread the possibility of working with the families, they remained hopeful that they “could work things out.” As their strategies failed, the RNs concluded that they were powerless to make a difference in the family’s behaviour and they avoided the family. The second narrative was *questioning of self*. In this story, when RNs identified that they had difficulty understanding and working with an obstructive family, they questioned their own ability to do a good job and their authority to deal with such situations. Ineffective interactions with families lead them

to conclude that they “didn’t know what to do next.” Ultimately, they avoided the family. The third narrative was *failing to connect*. In this story, parents were identified as being “unreasonable.” Participants used a variety of strategies in order to connect with the family but they were unable to “reach” them. This led to a sense of defeat. The final narrative was *making sense of the hurt*. In this story, RNs perceived the family to be obstructive but tried to give the family “the benefit of the doubt.” Despite various attempts to work with the family, nurses found they could not do what they needed to do in order to care for the child. This caused the participants to experience conflict and “hurt”, both personally and professionally. This story ended with a conclusion that the problem would never get better.

The sub-narrative of *avoidance* straddled all of the main narratives, resulting in inner conflict for the nurses. The participants acknowledged that to avoid a family was to provide less than optimal care. They rationalized that avoidance was necessary in order for them to cope with the emotional assaults of the situation. They also justified their avoidance of families in the context of being “unable to make a difference” in such unreasonable situations.

Implications of Research Design

Rigor as applied to this research study was explored in Chapter Three and that framework will now be used to evaluate the use of narrative inquiry and the research design in this study. As previously discussed in Chapter Three, my aim in selecting narrative inquiry was not to illicit truth, accuracy, consistency or outcome, but rather to get a sense of the impact for RNs of the experience of working with families that they perceived to obstruct their care. Indeed, narrative inquiry in this study has

provided the researcher with a method of gaining rich stories. However, at times, these stories were emotionally difficult for the participants to deal with and the aftermath was occasionally troublesome for them. One of the challenges in using narrative analysis in this study was the potential that participants' self-reflections could result in their awareness that they had provided care to these families that did not meet acceptable professional and institutional standards. At times, participants experienced moral distress in reflecting about particular situations with families. It was necessary after one interview to suggest counselling to a participant who was highly emotional about a situation with one family, many weeks after the situation had occurred. I also found some of the interviews distressing as I had worked with some of the same families on a different unit and found that the experiences of the participants were similar to mine. In addition, I had not realised how powerful some of the buried memories were for me and reflected on the fact that I had not dealt in any way with the issues that had been raised. An example of my avoidance in dealing with issues was a situation where a father had physically threatened staff on the unit that I had previously worked. The father's child was transferred to another unit in the same hospital where the staff experienced continued difficulties with the situation. With hindsight, follow up with all the staff involved should have been facilitated. When I was interviewing a participant who had worked with the same father I felt guilty for not following up myself or for seeing that other staff were supported. The interview was extremely painful for me as well as for the participant.

The first test of rigor that Guba and Lincoln (1981) have described is *truth value*. Truth value can be ascertained in part by a member check in order to validate

the findings. I returned to each of the study participants once the transcripts were complete at approximately one–two weeks after the interview. There is some caution necessary when applying this process to narrative inquiry because narrative represents personal reality at a particular moment in time; yet, that construct is changed as soon as the narrative has been offered. Once a story is told, it undergoes the process of continual change as the telling and passage of time change the meaning for the narrator. For the purpose of this study, the aim of the member check was to ensure that the participants agreed that the interview synopsis represented the content of the interviews it occurred at the time in order to add credibility to the interpretation.

The first member check was conducted over the telephone to check out assumptions not probed in the interview or to clarify aspects of the story not clear to the researcher during analysis. The second check was also conducted over the telephone and started with the researcher reading a synopsis of the interview to each participant. The feedback from the participants was that the synopsis reflected their stories. Their responses included “you’ve got that just right”, “that’s it” and “you’ve captured and condensed it all, to bring it together.” At times, I sensed on the telephone that for some of the participants, listening to their own story made them uncomfortable with the implied message of the story (i.e., that they had avoided the family). I validated this by verbally acknowledging that the participant seemed uncomfortable and that other participants in this study had similar reactions to hearing their synopsis. After the synopsis feedback, the member check continued to another level; the researcher read the four main narratives and the sub-narrative and asked the participant to respond whether these narratives adequately illustrated their experience.

None of the participants disputed the narratives. It was gratifying to get feedback from several of the participants who described the narratives as “wonderful” and as “awesome work.” One participant commented that the narratives had identified essential components central to successful relationship building in family-centred care. Other responses from participants during the member check included that some had found the interviews emotionally “draining.”

During the interview process, participants demonstrated their ability to story tell once they were clear about what was expected of them; that is, to provide an unstructured response to an open ended question, and that this was about personal experience versus a right or wrong response. Participants acknowledged that they rarely have opportunities to discuss personal perspectives about families perceived as obstructive because the institutional culture of family-centered care prohibits this. Several participants voiced the benefits of having participated in the research because it gave credence to an important work life issue. Some of participants also expressed hope that the research might result in some increased administrative and collegial support when they encounter families perceived as obstructive.

The second test of rigor as described by Guba and Lincoln (1981) is *applicability*. The sample size in this study is acceptable for a narrative inquiry; however, the sample was small and the selection was from a very specific, volunteer population. The selection was pertinent to the aims of the study because information was gained regarding the experiences of a group of RNs who worked closely with families and in the context of providing family-centered care. I make no attempts to generalise the results of this study to other populations or settings. Atypical and typical

responses were included in the data analysis to avoid elite bias. These processes are consistent with the principles and methods of narrative inquiry.

Consistency is the third of test of rigor suggested by Guba and Lincoln (1981). In narrative analysis, consistency is a challenge in that the method emphasizes context and uniqueness. Consistency was in part ensured by a paper trail comprised of interview transcripts, as well as journal entries and memos written by the research to identify methodological questions and insights. This does not imply that another researcher would necessarily arrive at similar findings because of the changing nature of stories offered by participants at different times and in different contexts. In addition, as the researcher, I was aware that during analysis, conversations with RNs regarding my study undoubtedly influenced my thinking and caused me to consider issues that I might otherwise have not considered. For example one participant suggested to me that families in her experience were more likely to be obstructive in non-critical care areas versus critical care areas. The participant's belief was that this was because in a critical care environment, there is a greater power imbalance between the RN and the family due to the RN's superior knowledge base and the family being under extreme stress. This conversation may have influenced me to consider power in more depth than if the conversation had not taken place. Lastly, my experience as a paediatric nurse will have undoubtedly had an influence on this research. For instance, my assumptions included my belief that nurses who are supported in their care of obstructive families will experience higher work satisfaction than those who receive no support, and that by offering resources to support nurses working with obstructive families, that there will be benefit to the family and to the child. These assumptions will

have influenced the directions taken throughout the research.

The last component of Guba and Lincolns' (1981) tests of rigor is *neutrality*. It was essential to address the potential of bias in order that my interpretation of data is as true to the participants' intended meaning as possible. My assumptions were made clear at the beginning of the study, and considered throughout. As well, throughout the study, I practiced reflexivity by the use of memos, journaling, and ongoing discussion with committee members about the interviewing process and my data analysis. Guba and Lincoln (1981) suggest that confirmability be the criterion of neutrality in qualitative work. Neutrality in this context applies to the findings versus the researcher since in narrative the interpersonal element of the interview is indeed analysed and valued. Confirmation of neutrality is only established once auditability, truthvalue and applicability are established.

The analysis process was scrutinized by my chair and second committee member for this study in order to enhance credibility, to strengthen the links within the data and to accurately portray the stories of nurses through careful writing. The final test of credibility will be if others find the narratives useful in understanding of the experience for nurses of working with families that they perceive obstruct their care.

Looking beyond the narratives: Implications of study findings

This research offered nurses an opportunity to recount their experience of working with families that they perceived obstructed their care. The narratives described in this investigation encapsulate some of the meanings of working with families perceived to be obstructive from the perspective of the nurses. The findings show that the experience of working with obstructive families held different meanings

for the participants in this study. The context for these stories was a nurse/family relationship where responses by a family to nursing interventions were both extreme and negative for the nurse. What emerged from the stories were three choices that could be chosen by the RNs when faced with an obstructive family. The first choice was that the nurses could continue to strive to overcome barriers created by the “obstructive relationship.” The second choice was that the RN could carry on working with the family as best they could under the circumstances, which usually meant providing less than optimum care. Finally, the third choice was that the nurse, as a way of coping, could neglect to proactively deal with the issues or could choose to avoid the family. Of particular concern was the finding that some RNs considered their relationships with a family no longer salvageable. The study findings have several significant implications for the ongoing care of the family and child and for the well being of the nurse.

The implications outlined include the areas of education, practice, administration and research, which need to be considered. Clearly the optimal nursing approach for the child and family is for the RN to try to strive to overcome barriers in order to promote as positive a working relationship as possible. I would suggest an overarching implication from the study findings is that RNs must be supported in their work with families if “best care” is to be provided. If all efforts to work with an obstructive family fail, ongoing education and support for RN’s may lessen the negative impact for them and foster a more positive attitude towards working with future families.

Family-centered care

The application of the principles of family-centered care in practice is not straightforward. Perkin et al. (1997) suggest that conflicts occur for the RN between competing obligations to patients, to patient's families, to colleagues, to the organization and to self. The professional obligation for the hospital nurse is to the client first and foremost before meeting her own needs. I would argue that in a setting where family-centered care is the accepted model of delivery and where parents and children needs do come first, the nurse's needs must be attended to in parallel if her personal and professional integrity are to be protected.

Barnsteiner, Gillis-Donovan, Knox-Fischer and McKlindon (1994) note that it is not uncommon for philosophies and mission statements to change in large organisations with a lag or absence in education for the staff involved. In addition, RNs may not fully embrace the hospital philosophy or the principles of family-centered care equally and several authors have demonstrated that RNs do not always have a strong understanding of family-centered care (Brown & Ritchie, 1989; Jefferson, 1998). Brown and Ritchie suggest that RNs may lack insight into their relationship with parents. Rowe (1994) suggests that many nurses do not appreciate the full extent of their role in providing information and how that directly affects parents' ability to participate in decision making.

In this study, the nurses recognized that *failing to connect* with families was a barrier to successful working relationship with families. Cleary (1992) suggests that there are certain qualities that the pediatric nurse needs to develop that are essential to building successful working relationships with families. Three areas for development

are highlighted:

1. The nurse needs confidence in her/his skills and knowledge to work in close proximity with the parents as an expert and with the necessary flexibility within the principles of nursing.
2. The nurse needs to be able to work without the safe framework of routine and hierarchy and the courage to question the accepted sub-culture if this is antipathetic to the philosophy of partnership.
3. The nurse needs a strong personal awareness and professional identity.

Family-centered care principles direct the nurse to form partnerships and make decisions collaboratively in order to work with families to care for their children. As family-centered care has become firmly entrenched in pediatric settings, advocate groups for parents have emphasized the necessity for families to “navigate the health care system” (British Columbia Children’s Hospital, 1999). Increasing parent rights, and education available to families has arguably improved the family’s ability to work with the health care team. In contrast, however, there is an absence of availability for advanced communication skills education for practicing RNs. It is these skills of clear communication, negotiation, assertiveness and conflict resolution that are essential for problem solving with families who can be challenging to work with and the these skills are to be essential for nurses in a pediatric setting (Cox, 1991). I would suggest that the partnership models described also extend to adult contexts. This has implications for Schools of Nursing who should consider education that fosters partnership as basic for undergraduates.

If the practice of working with parents in partnership is to be in accordance

with the tenets of family-centred care, nurse-patient ratios as measured by a workload measurement tool must reflect the time necessary to support this practice. Calculating nursing time spent with families according to a formula may fail to capture the amount of time necessary to provide family-centered care. If nurses are to provide successful family-centered care, pediatric hospitals should review the workload measurement tools they are using in order to be assured that the tool is the most accurate measurement of the amount of time required to effectively work with families, especially for the necessary complex work required with families who present a challenge. Nurses need to be prepared to defend their practice as it relates to nursing work, that is, the work of explaining, teaching, comforting and counselling that remains poorly voiced by many in the nursing profession and poorly supported by administrators in an era of fiscal constraint. Clearly, there is much more work to be done if the continued evolution of family-centered care is to be sustained, progressive and championed by nurses.

Role uncertainty

Despite volumes of literature and education about family-centered care available to pediatric RNs, it has been demonstrated that pediatric nurses do not always have a strong understanding of their role in successful partnership with families (Jefferson, 1998; Rowe, 1994). Increasing support for active involvement in health decision making and care has also created new expectations and challenges for families who are expected to work in “partnership” with health care providers. There is a booklet about family-centered care and a corresponding video that outlines for families how to interact with professionals in the hospital where the study was undertaken.

Case studies are used to make explicit partnership principles and appropriate problem solving for families when they have concerns or conflict with health care professionals. Access to this material is via the family resource library but the parents must take responsibility to actively seek out this resource; it is not routinely provided. It is noteworthy that in the study hospital the equivalent educational material is not available for health care professionals. It may be necessary to make reading materials regarding family-centred care more readily available to all RNs and families, not just to those motivated enough to seek it out. Providing access to educational material does not guarantee understanding of the material nor reading of it. However, it is possible that the information may provide the nurse and family member a point of reference when working together. The information may also encourage more open dialogue among and between staff and families. In addition, workshops that incorporate several modalities of learning and are co-facilitated by educators and parents will role model partnering and also reinforce roles.

Although it is largely assumed that the nurse is the holder of power within the nurse-parent relationship (RNABC, 2001), evidence that this is changing was clearly heard in some of the nurses' stories. Furthermore, the concept of family-centered care supports acknowledging the "expert knowledge" and rights of parents. Building working relationships in the context of changing roles and responsibilities can be expected to be challenging for both families and nurses. Undoubtedly, as parents have become more knowledgeable about their rights as health care consumers, they have assumed some of the power previously held only by health care professionals. Some of the nurses in this study responded to this challenge by turning to superiors or persons

of recognized authority, such as the head nurse or a physician, to deal with families that they found difficult or obstructive. These RNs believed they lacked the personal authority to follow through on some difficult situations. A similar theme is acknowledged by Callery and Smith (1991) who found that RNs felt powerless in response to obstructed care. The reliance placed on others, such as superiors, to problem solve may suggest that the nurse cannot solve the issue independently and must rely on powerful authority figures. Nurses must be supported and feel confident to problem solve conflicts with families before turning to those with more authority because ultimately, it is the nurse who must work out her relationship with the family.

In conflict situations recognizing and protecting the rights of families and health care providers is important. In the hospital where the study was undertaken there exists a recently revised human rights policy. Within the policy, there is reference to family members, patients, physicians, staff and visitors to the hospital that states that behaviours that violate human rights will be formally reviewed and subject to a disciplinary process. This policy is a step in the right direction as a support to nurses working with obstructive families but has not been effective because there is no straightforward way to apply a disciplinary process to non-salaried individuals. In addition, there is a need to more widely publicize this document to heighten awareness of the impact of such behaviours for both nurses and families.

The research findings suggest that inappropriate behaviour from families is better tolerated by RNs when they are confused about their boundaries and are hesitant to risk confrontation. Undoubtedly, the evolution of family-centered care has resulted in some misinterpretation by RNs regarding their role in the partnership. This

may contribute to the tendency towards over-accommodation by nurses for some parents described in this study and may further confuse all involved in the care of a child. The influence of the unit manager or head nurse on the acceptance and practice of family-centered care is well described (Gill 1993; Letourneau & Elliot, 1996). Leaders who offer expedient support, resources and acknowledgement to nurses for their efforts in developing partnerships with families will help nurses to approach difficult situations in a more empowered way (Chandler, 1991). Furthermore, empowered nurses will be able to ask parents the question, “What do you expect from me as your nurse today?” and feel equally confident to confirm what can and cannot be delivered, thereby establishing clearly defined boundaries in their practice with families.

Education for nurses can increase awareness of inappropriate behaviours that impact staff rights and factors that precipitate such behaviours. Specific education can help to clarify boundary issues and provide a sense of what behaviours are acceptable. An additional strategy for role clarification may be to develop a contract with parents that outlines what behaviours are acceptable for RNs and family members. The development of such a contract will require advanced negotiation skills. It is worth noting that the success of the contract will require negotiation skills and a willingness to participate on the part of the parent and the nurse. Role clarification may also help nurses to feel confident that their manager will support their efforts without fear of retribution for “stepping over the line.” Lastly, it has been suggested that self-assessment is helpful to clarify boundaries (RNABC, 2001) who suggest that seeking help from colleagues enables clarification of therapeutic relationships in complex

situations. RNABC also suggest that to make actions overt for clients is both professional and straightforward and encourage thoughtful self-questioning such as “Could there be a conflict between my needs and the clients needs?” or “Would I want other nurses know about this interaction?”

Job satisfaction

Stories about staff division were sometimes intertwined with narratives of working with obstructive families. The implications of staff division are broader than the context of work with any one particular family and the broken trust between colleagues can be highly destructive in any work environment. Teamwork must be supported when working with obstructive families and trust amongst RNs is essential if teamwork is to be successful. Building trust between individuals has the added benefit of improved team morale. It is my experience that someone not directly involved in the clinical setting best facilitates team building. This is less likely to be perceived by staff to be biased in favour of any particular group be they staff or family members and often sheds light on the root of the problem versus the less significant details.

The nurses in this study stated that their job satisfaction was enhanced when connection occurred in their relationships with parents. A working environment in which connection is fostered by role modelling and encouragement by the unit manager will likely result in nurses experiencing satisfaction from successful partnering with parents. In addition, there needs to be encouragement and opportunity for nurses to discuss openly with each other and administrators regarding their difficult experiences with families. This dialogue should serve not to discount the nurses’

struggles but rather to explore options that may work well with any family.

An interesting finding in this study was that nurses admitted they would often avoid obstructive families. They did this in a variety of ways, including taking time off scheduled work as sick days and negotiating their workload assignment. There were a number of unfortunate outcomes of such avoidance. The outcome for the child and his or her family was less consistency of caregiver and care-giving by nurses. Outcomes experienced by the nurses themselves were discomfort, guilt, defeat and powerlessness. Participants acknowledged that to avoid families was not an acceptable standard of care and was less than their usual standard of care. What is striking is that although they acknowledged this, they behaved as if they had no other option than to avoid the families they perceived as obstructive. Nurses need support and education to develop alternative plans to avoidance in dealing with obstructive families. In addition, they need to know strategies for effective relationship building with families and how to recognize when nurses need intervention from others to avoid situations in which avoidance is perceived as the only alternative.

Typically the central responsibility for problem solving issues with patients lies with the nurse (Thurman, 1991). This responsibility is typically situated in the context of family-centered care where the discourse of partnership with families emphasizes that professionals have an obligation to be responsive to the individual differences among families whose opinions and values must be respected. The results in an interesting paradox when nurses encounter families who because of past history, family dynamics or other factors, continue to be obstructive despite the nurse's efforts. Nurses know they are responsible for making families feel satisfied with the care they

are receiving in the hospital but at the same time, often feel unprepared and powerless in dealing with obstructive families who do not respond to their caring approaches. Because to admit that they are unable to effect a positive relationship with families is akin to acknowledging that one has “failed” as a family-centered nurse, many participants believed their only recourse in such situations was to avoid the family. For some, even talking about the situation to colleagues was viewed as too risky; it implied that one did not have the competence or commitment to be a family-centered nurse.

Unlike most partnerships, there is little choice for the parent or for the nurse as to who is cared for and who does the caring. There is no contract drawn up formally between the partners and little maneuverability when the relationship is problematic. Indeed, Kestler (1991) suggests that we may need to lower our expectations regarding family response to nurses and nursing care, which in turn may decrease the sense of self-defeat experienced by some nurses. Furthermore, Tanner Leff and Walizer (1992) suggest that proactive and candid discussion may be a key to solving some relationship problems between nurses and families.

Working with RNs to resolve conflict with families should focus on the different ways of moving forward with conflict in their work with families as well as colleagues in difficult situations. An important finding was in the story line “I don’t know where to go next” where nurses expressed how “stuck” they felt. A decision-making tool may be a useful reference guide for strategies/resources for RNs who find themselves in difficult situations with family members. For less experienced RNs who may be unsure about resources, this tool may be particularly useful. A decision-making tree may also be a useful guide for the nurse around defining boundaries and

acceptable behaviours. These initiatives all hold potential for enhancing nurses' job satisfaction.

Quality of care

Morse (1991) describes the "unilateral relationship" in which failure of the client-nurse relationship to successfully connect is dissatisfying for both parties and results in nursing needs not being met. This study has provided a rare opportunity to discuss implications for the delivery of quality care by RN's for families perceived to be obstructive to care. Participants in this study told stories about how the obstructive family became so difficult to work with that the nurse spent less time looking after their child. The notion of RN withdrawal and avoidance by in response to conflict is not new to nursing (Arthur, 1992; Kelly & May, 1982; Valentine, 2001); however, this behaviour has practice and education implications. Some of the participants identified that the physical care was provided but not the emotional care. Ironically, McQueen (2000) suggests that avoidance by nurses increases the client's emotional distress and resultant need for psychological support. I would suggest that in a pediatric setting, this behaviour by nurses and parents manifests as a dysfunctional cycle that results in further avoidance and further client/family distress and ultimately becomes overwhelming to all parties. In some situations, participants acknowledged that they had spent little time on providing physical care to the point of causing the nurse to question if she had adequately assessed the child. This insecurity left the RN with the concern that she might not recognise subtle yet significant changes in the child's status. To avoid a family or child because the family is obstructive does not meet the code of ethics for the nursing profession as mandated by the Registered Nurses

Association of British Columbia standards of practice (RNABC, 1999).

There are implications from the research findings for novice pediatric nurses in relation to the quality of care they are prepared to give children and their families. It has been suggested that novices need time to develop confidence, professional identity and typically in practice are more likely to demonstrate the need to maintain control in relationships (Benner, 1984; del Bueno, 1995) versus sharing control. Furthermore, Callery (1997) posits that for nurses to be able to practice “caring”, they need to be confident, expert communicators and skilful collaborators. The inexperience of novice nurses therefore does not provide the skill or experience base that is necessary for successful partnering with families. In addition, there is a need for basic undergraduate programs in nursing education to address the establishment and development of a professional relationship with families within the curriculum.

I would suggest that the research findings point to a role for a Clinical Nurse Specialist (CNS) to foster quality of care with families in the pediatric hospital setting. A CNS experienced in working with families may facilitate and role model expert family-centered care, as well as teach nurses strategies to address conflict situations with families. The CNS role is ideally suited towards case management (Lynn-Mchale & Fitzpatrick, 1993). The multiple benefits of case management with families perceived to be obstructive are well described in the literature (Girard, 1994; Goode, 1995) because rapport with a consistent health care professional may eliminate or dissipate the interpersonal tension between nurses and families.

It may be wise to consider different approaches for assigning nursing staff to work with chronically ill children and their family versus those children in for shorter

admission and not expected to need long-term follow up. In the sub-narrative *avoidance*, the participants identified the need for consistent members of the nursing staff to work with families perceived as obstructive; they stated that this was hard to achieve as the nurses often requested frequent changes with this assignment. In addition, at the hospital where the study was undertaken, there is a pediatric nursing history form that could be modified for families such as those whose child's care is prolonged or complex. The history taking for such children and their families could focus more than it does at present on the individualized needs of families and their views on quality care provided by nurses. Modification of such tools could take place after collaboration with parent advisory groups and bedside nurses within the hospital setting.

Supporting RN Practice

It is apparent in the research findings that nurses need specific resources, tools and strategies to deal with the stressors associated with their work with families perceived as obstructive. McQueen (2000) suggests that such helpful and defence strategies should be made explicit in nursing education. McQueen bases her suggestion on the demonstrated ability of experienced flight attendants to use systematic training in order to successfully manage their emotions in highly stressful situations. It is possible that such strategies applied to nursing education may enable appropriate separation of 'work' selves and 'personal' selves for RNs, resulting in less stress and ultimately less burnout for nurses. Critical Incident Stress Management (or a modified model) may be appropriately utilised in the more extreme situations of RN work with families perceived as obstructive when the resultant emotional issues have been

particularly difficult.

Johnson and Webb (1995) suggest that with better recognition of the emotionally charged aspects of nursing and by providing the nursing staff with coaching and feedback on the strategies used with obstructive families, we might be better able to employ more constructive strategies for managing social relations in nursing. Another idea in this regard arises from the suggestion by McKlindon and Barnsteiner (1999) that RNs focus in each change-of-shift report on family strengths and the positive aspects of interactions with the family. I would suggest that this should not be done to the exclusion of addressing the real issues affecting delivery of care, but as a complimentary activity. This may prove helpful as an exercise to reduce the amount of negativity that can overwhelm RNs involved in such situations.

As suggested previously, much of the participants' experience with families perceived as obstructive was not voiced to others. Taner Leff and Walizer (1992) comment that support from colleagues is crucial when working through challenging family/caregiver relationships. The authors suggest that non-judgemental team meetings may be a way of discussing complex, draining encounters with families. Such a forum provides the caregiver with a safe "base" in which to review threatening interactions and consider options that may make a positive change. A team approach to open and professional discussion may make the RN feel less isolated and help him/her to problem solve. Such an intervention must occur in the context of a unit and institutional culture that fosters nurses' disclosure about work-related stressors. To be listened to and to be heard is an essential dynamic if RNs are to be effective and feel supported in their work.

I suggest that education on family-centered care for RNs be site wide and offered to all staff and new orientees in order to provide a theoretical base that promotes a consistent approach by RNs to families. Such education could entail actual case studies in which the attendees were asked to analyse and pose strategies for resolving the nurse-family conflict. Judicious questioning to help the learner establish the relationships between observations and events (Field, 1986), as well as buddying of new staff by experienced nurses committed to family-centred care will encourage and support critical thinking as it applies to the practice of working with families.

Further research

This study explored only the RN perspective in regard to the research question; therefore, further research is required in order to explore the perspectives of the “obstructive” family. Families might indeed have alternate explanations and experiences in regard to this issue than do nurses. It would be interesting to know from the perspective of nurses and families if the duration of time that the nurse spends with the family has any influence on the perception of obstructive behaviours.

Arguably, early intervention may provide an opportunity to diminish dysfunctional behaviours and increase the success of strategies used by nurses to improve their working relationship with families perceived as obstructive. The use of assessment tools that identify challenging families who might benefit from early nursing intervention has been documented to be beneficial (Jellinek, 1991; Zabora, 1989). Outcome studies providing information on the efficacy of such tools in a pediatric setting would further measure the benefit of early intervention in relation to nurses’ work with families perceived to be obstructive. An additional benefit of such

tools is that they also have the potential to provide a “heads up” to senior and support staff of situations where nurses may require increased guidance in their work with a particular family.

The study narratives revealed that some nurses managed to work successfully with obstructive families while other colleagues had not. Investigating this phenomenon would potentially provide insight into an element of family-nurse relationships not previously explored. The participants’ accounts of working with families they perceived as obstructive were retrospective in nature. They may have forgotten or overlooked some of the actual details of these situations over time. The data collection method of participant observation would allow exploration of nurses in action with obstructive families. It is a methodology little used in research exploring nurses’ work with families.

Furthermore, research that focuses on differences between neophyte and expert practice in regard to working with families may also provide beneficial insight regarding the phenomenon under study, especially in the context of current workforce demographics and the increasing number of neophytes likely to be working with complex families in the near future. Specifically the information gained may provide insight into the novice nurse’s ability to cope effectively with obstructive families. This information would allow for better supports to be put in place to support novice nurse practice in order to prevent burnout and to foster quality of care provided by novice nurses to families.

There has been a significant context shift over the last ten years in the evolution of family-centered care. The scope and role of parents’ in the care of their

chronically sick hospitalised child has broadened tremendously with greatly increased responsibility for parents. Despite previous research on the specific needs of family members of a chronically sick child, I would suggest that with the changes in context that there is merit in repeating some of the earlier research, some of which is at least ten years old (Hayes & Knox, 1984; Robinson, 1987; Thorne & Robinson, 1989). In addition, the role of the CNS is well suited to work with families who are in the system long term (Schryer, 1993) and outcome assessment of the role as it applies to this work would be highly informative. Finally, outcomes associated with utilization of a critical pathway for families of a child with a chronic illness would provide a foundation for nurses' commitment to family-centred care.

What does the future hold?

The current context of health care must be considered if we are to effectively address the implications of this study. The Registered Nurses Association of British Columbia in 1999 forecast a deep and sustained nursing shortage for at least the next decade. In addition, the RNABC staff reports that currently British Columbia graduates only half of the necessary RNs to meet our needs to replace retiring RNs alone. Linked to these human resource issues is the growing concern that current levels and quality of service offered to families will be affected in a negative way. For instance, at the hospital where the study was undertaken, the number of inexperienced and novice nurses has increased dramatically over the last two years, diminishing the number of nurses experienced in working effectively with families. The nursing shortage may indirectly contribute to the erosion of family-centred care, and arguably to the deterioration of the nurse-parent relationship as nurses struggle with time

constraints and lack the experience and learned skills necessary for navigating such complex relationships as those described in this study.

With few exceptions, all of the narratives in this study were about families whose children had a chronic illness. This should not be surprising when we consider that children with chronic illness have an increasing life expectancy and therefore will have more encounters with the healthcare system than most children experiencing acute episodes of illness. This finding is particularly significant if the long-term consequences for chronically ill children and their families of a negative hospital experience and poor relationship building between RN and family are considered. The impact for the family includes lack of trust of staff, reduced likelihood of consistent nursing care, barriers to partnership with nurses, and reduced ability to make decisions regarding their child's care.

It is important to acknowledge that nurses will not always be able to improve an obstructed working relationship, or to provide optimal care to families, regardless of efforts put forward by both parties (Kestler, 1991). Furthermore, family goals may not always be congruent with nurses' goals, and some families may not wish to interact with nursing staff at all. Zabora et al. (1989) suggest that some families have a history of turmoil that preceded the patient's illness; such a history will also have an impact on the relationship building between the nurse and the family. It is apparent in this study, however, that nurses require collegial and administrative support in such situations, particularly because they may have difficulty reconciling the fact that their caring and care did not positively affect their relationships with certain families.

Historically nurses have had an important role to play as family advocates and

in policy development. It is of paramount importance that nurses remain committed to providing quality care to children and families, for the price for failing to support the nurse in her work with families may be to the potential detriment of the nurse, the family and most importantly to the detriment of the sick child.

Conclusion

This study has uncovered nurses' stories of their work with families that they perceive obstruct their care. The methodology of narrative inquiry was suitable for work of this nature and revealed nurses' stories about anticipating the worst, questioning-self, failing to connect, making sense of the hurt and avoidance. There remains much to discover about these experiences for nurses. As such, this study represents only a beginning understanding of what is clearly a crucial and buried issue for practicing nurses. I am left with little doubt that attention to the findings of this study is imperative if we are to support pediatric nurses in their work environment and also to promote best practice in nurses' work with families. I would suggest that many of the principles discussed in this thesis are also relevant to adult contexts. Undoubtedly, there are costs involved with the suggested strategies, both human resource and financial. However, I would suggest that the risks of failing to attend to the issues raised in this thesis are far greater in terms of nurses' professional well being and the quality of nurses' work with families.

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APPENDIX B: INFORMED CONSENT

Any information resulting from this study will be kept strictly confidential. The notes, audiotapes and interview transcripts will have all identifying information removed and your name will not be used in any research reports. Tapes and interviews will be identified only by a code number assigned to you and known only by myself. Only the researchers will have access to the tapes and transcriptions; the tapes and transcriptions will be stored in a locked filing cabinet. The findings of the research may be published but your name will not be associated with the study.

At the end of this study the audiotapes will be erased. However, the typed transcripts obtained in the study may be used for educational purposes and research that involves secondary analysis of interviews, with the understanding that any additional research projects that use the transcripts will be approved by the appropriate university research and ethics committees. The transcripts will be shredded in ten years time.

There are no known risks to the research. If you agree to participate, you will contribute information that may be beneficial to other nurses and to families whose child is hospitalised. You will receive a written summary of the results of the research upon its completion. Participation in the study is voluntary. You may withdraw from the study at any time or refuse permission for the use of your tapes or interview transcripts. If you do not wish to participate in the project, it will not affect your employment in any way.

There is no monetary compensation associated with participating in this study.

You may contact Dr. Richard Spratley, Director of the UBC Office of Research Services and Administration at 822-8598 if you have any questions or concerns about your rights or treatment in the research study at any time. If you have any questions at any time about the study, you may contact Dr B. Paterson, School of Nursing, UBC at 822-7505

Version #2: December 14th, 2000.

APPENDIX B: INFORMED CONSENT

Authorization:

I, _____, have read and decided to participate in the research study described above. My signature indicates that I have received a copy of the consent form.

Signature: _____ Date: _____

Witness: _____ Date: _____

Version #2: December 14th, 2000.

APPENDIX C: DEMOGRAPHIC DATA

Study: The Experiences of Nurses' working with Families who they perceive to be "obstructive" to the care offered to a sick child.

1) What is your current title at work (tick one)?

Staff Nurse Clinical Instructor

Clinical Nurse Specialist Other (Please specify)

2) On average, how many hours per week do you work as a nurse? _____

3) What is your educational background? (Check all that apply)

Nursing Diploma Basic Bachelor's Degree in nursing

Post RN Bachelor's Degree in nursing

Graduate Degree (Please specify) _____

Other (Please specify) _____

4) How many years have you worked as a nurse? _____ (Years)

5) During the time that you worked as a nurse, how many years have you worked in paediatrics? _____ (Years)

6) What areas of paediatrics have you worked in?

7) Are you _____ female _____ male?

8) What year were you born? 19 _____

9) Do you have children? _____ Yes _____ No

Thank you, for completing this form. The information will be kept confidential as part of this study.

APPENDIX D: INTERVIEW GUIDE

Study: The experience of Nurses' working with families that they perceive to be "obstructive" to the care that they offer to a sick child.

As you know I am interested in studying the stories that RN's have about working with families that they perceive obstruct the care that nurses' offer.

Questions

- 1) Can you think of a time that stands out for you when you worked with a family that you thought was obstructive? Start the story wherever you like.
- 2) How do you feel when you are working with a family who seems to obstruct your care? Can you think of a story that illustrates that feeling?
- 3) Have you found that working with a family who obstructs your care affects your working environment? Can you think of a story that best depicts that situation?

Prompts and extenders: What did that feel like to you?

What meaning does that have for you?

I'm interested in.....

What happened next?

Did this experience affect the way you worked with this family?

We have talked a lot today. Is there anything that we have not covered that you would like to talk about?

APPENDIX E: INTERVIEW SYNOPSSES

Synopsis of Karen's Interview

Karen is an RN with a great deal of experience in working with families. She tells a story of when she viewed a family with resentment because of the ways in which they made it difficult for her to care for their child. She recalled that they constantly questioned her practice and that such questioning added to her stress and got in the way of her regular assessments and care. After some time off work, Karen returned to find that the child had died suddenly and unexpectedly. The doubt in her mind was that she had missed something. If the parents had allowed her to provide direct care to the child, she felt she would have had a "better feel" for the child and been able to anticipate the impending deterioration. The impact that this experience had on Karen was to make her feel extremely guilty. She questioned whether she had been overtired and/or whether she had unfairly judged the parents. At some point Karen always tried to understand the family's perspective even if they seem to be obstructive. This experience has altered Karen's perspective on working with families.

Karen has also listened to other RNs stories of working with families so obstructive that the RNs didn't want to primary nurse again. The thought of working consistently and committing to a family for these RNs is at times overwhelming. This leaves Karen and other RNs with the challenge of facilitating consistency of care for families who are in need of primary nurses and who may be challenging.

Karen describes her experiences with families who obstruct care in the context of end of life issues. She recounts a time when a family wanted all life saving measures used even though the RN perceived the child's situation to be hopeless. The conflict that this situation caused for the RNs was that the family wanted the professionals to perform invasive procedures, which the latter found distressing. The RNs goal was for a peaceful death, which was incongruent with the family's wishes for maintenance of life at all costs. Karen felt RNs supported the family only with great difficulty, for they could not agree with the "unrealistic" treatment measures desired by family. She compares this situation with that of another family who wanted all life saving measures undertaken until the point of cardiac arrest; only then did the family join the RNs in their decision to call off the resuscitation. Karen describes the RNs experiencing a huge sense of relief as the family's goals became congruent with their own.

Karen also recalled an experience when the RNs struggled in their attempts to provide care; yet, as the parents attempted to advocate for their child, they obstructed care. The nurses expressed frustration and anger towards the mother; each of the nurses identified a need for space in which to work. Difficulty arose as the mother attempted to choose her RN for each shift. The mother absorbed a lot of the nurse's time, as she required much teaching from nurses for the reinforcement of concepts. All care of her child by the RN's had to be intensely negotiated. The primary nurses were drained but remained committed. However, after this experience none wanted to primary a child again for a long time.

Karen described feeling that working with families whom RNs generally resisted working with raised a conflict for her: she understood where nurses were coming from, but she also needed to promote a high standard of care and consistent care for the family. Karen feels RNs spend less time with obstructive families than with other families and offer obstructive families a different standard of care than they do other families.

Synopsis of Susan's Interview

Susan had looked after a critically ill child and found that the mother played the "good nurses against the bad nurses". The child and mother "bad-mouthing" the RNs, which caused resentment and was draining for the RNs. Susan feels this affected the RNs morale: she says that it was a constant struggle and that "everyone needed a break". Susan recollects RNs struggling both to provide consistent care for the child and to motivate RNs to "stick together and keep a level story". In looking after this family, Susan feels RNs were able to provide the physical care, but not the emotional care that was also needed, because the RN/family relationship was just too negative. Susan believes that the child probably suffered and that nurses dread this family being readmitted. She also believes their distrust of the mother caused RNs to protect themselves from potential accusations by working with the child in pairs; the RNs were on guard about what they said to the mother and found the effort exhausting. Susan suggests the problem is ongoing and will probably never be resolved.

Susan also tells of an unstable child whose mother refused to allow the necessary blood work because it upset the child—a situation which took a lot of time to work through: The nurses understood the parents had the right to refuse but believed the child needed the bloodwork to monitor the child's' status. Susan believes it was hard not to judge the parents even when she understood why the family was stressed. The nurses found support by talking to each other about the problem, and as RNs reported the family's behaviour to each other, Susan feels the family gained a negative label.

Susan also recalls a "highly abusive" family situation in which the family did not want the RNs to perform any physical care. She recalls thinking the parents non-compliant, for example, when giving the child things to eat and drink after a procedure (when contra-indicated) and allowing him to mobilize earlier than the standard protocols recommend for safety. Mum, she says, was very "verbally aggressive" and "yelled" at Susan. Susan can see the mother was trying to advocate for her child but also recognizes her actions were inappropriate. Susan recalls being so shocked by the mother's aggressive behaviour that she left the room immediately and cried as she told the story to her colleagues. She later returned to the child's room to complete her assessment of the child and was allowed to do vital signs on this occasion. She chose not to confront the mother about the earlier incident because she felt so uncomfortable. She reflects that talking to Mum was difficult because "she was so intimidating". Susan wonders whether she might have prevented the situation and the mother's hostility by talking more to the mother. The Mum was so angry that

Susan recalls feeling she had no choice but to step away. Susan believed that the best approach was to give the mother "her space". One of Susan's colleagues had suggested to Susan that she should have talked with Mum and confronted her about the "yelling" episode. The same RN worked with the child and mother the next day and had a similar experience, which she described to Susan as "scary"; she left Susan with no answers of her own. Susan recalls the situation was deemed by the RNs to be so unsafe and tense that the Human Rights Officer for the hospital was brought in to mediate.

Synopsis of Betty's Interview

Betty tells a story about a teenager with a chronic illness who was dying and highly unstable. The Mum and Dad did not do well with each other let alone with the nursing staff on the floor and were considered highly "volatile". They had been admitted to the floor because their usual unit was closed for the holidays and they did not want to be there. The problem escalated when the youth received the wrong type of drug as administered by a young RN. This led both to the parents refusing to let the RN nurse their child and to open criticism of the RN, with the mother yelling at staff at the nursing station. The other parents could hear her saying, "everyone needs to hear what kind of care my child's gotten." Betty recalls the nursing assignment had to be changed for the remaining two hours of the shift, which RNs felt was extremely disruptive and meant that the young man received inconsistent coverage; the father called the Chief of Nursing who came to the unit to investigate the situation. Betty adds that another complicating factor was that an outpatient appointment had been scheduled at that time for the teenager; yet, since the patient was too unstable to be taken off his intravenous feeding, the RNs believed they needed to cancel the appointment. Betty recalls that the father insisted that the boy be taken off the IV, contrary to nursing recommendations, and, after the father went directly to the department to insist on the appointment being kept, the boy attended his appointment. Betty recalls the Charge Nurse felt frustrated and disempowered because her time and efforts had been wasted. The situation made nursing staff feel the family not only ignored their concerns for the safety of the child but also personally attacked nurses.

Another story Betty tells concerns a mother whose toddler was very sick and who was physically intimidating to the staff. The mother was accusatory and created a lot of tension in the room. When needing to assess the vital signs for this child, the RNs would find the mother standing in between the child and the RN and verbally refusing to let the RNs do their work. The mother also yelled at the doctor; Betty adds that certain communications between mother and doctor were made in secret, only after Betty (or other RNs) had been ordered out of the room by the mother—such episodes made Betty angry and defensive. She describes this family as the worst she has ever had to work with. Betty says the staff were "just trying to give care to this child" and "we did everything we could". She concludes by saying it was such a demeaning and hostile environment that it disabled care-giving.

A story of a mother who physically barred the room door to prevent an RN getting in leaves an impression in Betty's mind: The RN involved could not provide

care and was extremely upset. This mother would act as an intermediary to her teenage daughter so that the nurses could never directly interact with the patient to make assessments. The mother told the patient and her younger sibling which RNs they should not talk to and these names were written on the communication board in the patient's room. An RN was later accused of hitting the daughter on the head with an object. As well, the mother threatened constantly to go to the media. After this incident the RN, Betty recalls staff would go in the room in twos in order they that each have a witness. When the time came for discharge, Betty says the mother stalled the discharge. Although the nursing staff had anticipated the discharge difficulties, it was none-the-less time consuming and distracting from the time the RN had for other families in her assignment. Ultimately the Human Rights Officer for the hospital had to draw up an agreement between the family and the hospital staff regarding such behaviour as shouting, swearing and preventing entrance to the room for future admissions. Betty recalls RN staff recommending the assignment ratio in future is one nurse to two patients; such a ratio would allow nurses to seek one another for assistance when extraordinary emotional support was needed by parents. Without such changes, Betty felt the nursing staff could not provide optimal care.

Synopsis of Barb's Interview

Barb tells a story about a mother whose teenager required intravenous therapy and who was verbally and physically abusive to staff such that staff felt unsafe without adequate support. To make sense of the confusing signals the mother was sending, the RNs needed to educate themselves about personality disorders. Barb recalls a particularly difficult scene at the time the teenager was discharged. Even though staff anticipated problems, the situation still felt chaotic: Barb was accused by the patient's mother of physically abusing her. In her anger, the mother contacted the in-hospital supervisor, who came to the unit to investigate the problem, and eventually the family left. Barb feels there was no hospital policy to back up her decisions. Barb says she involved the human rights officer for the hospital and the Ministry of Health officer to draw up a contract between the staff and the family which would support staff in the next admission and which outlined acceptable behaviour on the part of the family. Yet, Barb says the contract was only partially helpful because the mother did not adhere to it. Nurses then anticipated further admissions with trepidation and would go to great lengths to avoid working with this family, such as trading shifts or calling in sick.

Another story Barb tells is of a mother who did not want her child to receive a blood transfusion. When the mother was "threatened" with Ministry involvement she went along with the decision to transfuse. Barb recognized that the mother was not deliberately obstructing care but rather had different motivations behind her decision making. The situation leaves Barb feeling powerless as an advocate for the family and aware of a certain amount of friction amongst the health care professional team. The critical incident stress team was helpful and, as Barb says, "You know these situations will occur again and again". The situation was especially difficult because

the child died, leaving many ethical questions unanswered. Ultimately, Barb says she felt powerless in supporting this mother who was perceived by some colleagues as obstructing care.

Barb recalls of a time when she believed nursing care was affected, when the parents of a very sick child appeared to "pit staff one against the other"; these parents attempted to choose those staff members they "liked" to look after their child. Barb feels the parents had their own idea about how things should be done and had built strong relationships with some nursing staff on another unit. The staff from that unit would try to influence the provision of care on Barb's unit and this caused much friction between the two units as well as between Barb's unit and the parents themselves. This friction resulted in criticism from the RN's of the leadership on Barb's unit. There was a sense that the leaders on Barb's unit collaborated with the parents and did not support the staff. Overall, Barb recalls an emotionally stressful situation in which any member of the team of physicians would respond immediately to the parents' requests for information regardless of who was on call, and this was not the standard for other families. This family appeared to have raised expectations of what should be offered and when--including the ability to choose which unit their child would be nursed in. The nursing staff felt intimidated and nervous when working with or around this family. After one admission, a letter of complaint was sent by the parents to the Program Director. Yet, nursing staff had not been aware of the parents' concern during the admission; Barb feels staff had not been offered any opportunity to address the perceived problem with the parents. This example is one of many contributing to Barb's feeling "on edge" with the family, and she avoids them by restricting contact with them as far as possible when they are in the hospital.

Synopsis of Gail's Interview

Gail speaks of working with a family she and her colleagues found to be highly inappropriate. Because of this, people avoided going into the child's room when the parents were in there. Gail says she tried to avoid judging the couple and based this desire on her values, beliefs and morals--but this was hard. She recalls being concerned that, if the child was to deteriorate and if she had not done a thorough assessment, she might miss early warning signs. This made her feel guilty, as if she was not fulfilling her responsibilities. The situation was made worse in that the parents were taken to court to have the child removed from their care, and two of the Unit RNs had to testify against the parents. Gail believes the inappropriate behaviour was allowed to go on for "too long" before being addressed by someone in authority, saying that it was just "too hard to handle". She did not feel there was enough structure to address the problem in a supportive way. Gail's belief is that, when people are given the benefit of the doubt, often interventions are not commenced soon enough. This issue is ongoing with this family, and the staff does not know what to do next. If Gail passed the parents in the corridor, she would try to avoid contact with them by averting her eyes.

Gail looked after a “cardiac baby” who was prone to “blue spells” and whose father, during these times, would not let the RN staff near the baby. The father would both “play down” these episodes and become aggressive, swearing and “freak[ing] out”, when staff responded by conducting thorough assessments and calling the physician. As nurses answered the same questions over and over again, the constant questioning of nursing practice became draining. The father considered himself a medical expert and yet his approach was not acceptable to the nursing staff. He started to pick and choose staff and select RNs who perhaps did not assert themselves when he was demanding things be done a certain way. This was divisive of RN staff; Gail recalls each felt belittled, inadequate and judged by other parents, as delivering any kind of care to the baby caused a fight which then caused the RN staff to question their judgment. The father was not willing to listen, and he always had to have his way. For Gail, the experience of working with this family was hurtful; it felt personal.

Returning to her place of work after some time away, Gail recalls finding a mother of a child on the unit who had “stressed the staff”. Gail remembers the staff had divided into two “camps”: one believed the mother was appropriate, and the other believed her to be acting in a way that was not in the best interests of her child. The mother was controlling and shouted at the staff, which resulted in several crying episodes for individual staff members. She would also try to pick the RNs who cared for her and her child. Gail remembers that the child suffered and was later transferred to the family’s home community where the child eventually died. Gail speaks of the way staff in the two camps dealt with their different perspectives, recalling the ways they would discuss and respectfully acknowledge their colleagues’ different perspectives. Despite the tension surrounding this situation, Gail feels it a powerful illustration of staff supporting one another.

Gail offers a contrasting story of working with a family who, though it had been labeled as difficult, she found wonderful to work with. Since this experience, Gail is nervous about others labeling families; she finds the negative anticipation created by labeling a family—a “red flag” sent out by RNs to other RNs--makes working comfortably with the family difficult to accomplish.

Gail recalls a successful outcome of her work with one potentially obstructive mother. The mother was very nervous and would continually question the nursing staff about the child, but Gail built up a good lasting rapport with this mother. She felt the mother did not realize the impact that she was having on the RN staff, and she sensed the mother might listen to her. Gail and the Childlife specialist wrote out some guidelines for the mother that would support the child and nursing staff in providing care. Gail believes that, without this intervention, this mother would have gone on being labeled as obstructive.

Disturbing for Gail is the memory of a parent who lost composure after their child’s heart arrested. The baby had previously been in ICU and the parents’ behaviour had been difficult there too. In this instance the parent tipped the linen cart over and ripped telephone jacks from the wall. A nurse was assaulted. Once again, Gail believes that this behaviour, regardless of the stress for the parent, should have been addressed earlier and not “swept under the carpet” which she feels is the tendency when nobody wants to deal with those situations. Gail believes that perhaps someone in “higher authority” needs to deal with problem parents because it is so

difficult to deal with the family when you are involved in day-to-day care of their child. Gail has learned to address issues with families earlier rather than letting the situation go unaddressed.

Synopsis of Loretta's Interview

Loretta tells a story that is remarkable in that her entire narrative is about her work with just one family who left a lasting impression. The story starts with a family history revealing that a baby was brought to Emergency because of fever and lethargy. The family reluctantly agreed to blood cultures but then left the Emergency before the results were available and did not follow up for the results: the hospital could not contact the family, and the blood cultures were positive. The parents took the baby to their naturopath the next day and the baby, who had a seizure in the office, was eventually brought back to the hospital and admitted. Treatments were refused and the parents consistently blamed the hospital for the baby's deterioration with phrases such as "you are raping my family and killing my child". Loretta says she knew that the baby was going to be very sick and on the unit for a long time. Her policy was to introduce herself to every long-term family on admission, and she did this. She spent considerable time talking with the parents and immediately sensed their anger and hostility about their baby's state was directed at the hospital. The baby's father talked at length about naturopathy in terms and language Loretta knew nothing about but which she recognized and verbally acknowledged as important to the family. Despite very "family centered" nursing care, Loretta thinks staff felt unable to reach them: they were concerned about Mom's apparent passivity as she constantly hovered in the background; they saw no "connection" among the members of this family; and they worried the parents were giving non-hospital medications to the child without their permission. The staff was extremely affected by the father's behaviour: any nursing intervention required negotiation, which took up much time and energy. Because RNs felt personally and professionally assaulted by Dad, no RNs would voluntarily primary nurse this family, making the assignment extremely difficult to accommodate. The RN team participated in a Critical Incident Stress debriefing in which they discussed issues around family-centered care, in specific, the problem of reaching collaboration among family members and health care team. The needs of the child were being usurped by the father, and the RNs were unable to meet the family's needs because the family's requests were not reasonable. The Child Protection Team, consulted to assess the situation, deemed the father reasonable and allowed the baby remain in the parents' care; even so, the father was barred from the hospital for 36 hours. Mom did not relate to the nursing staff at all, preferring to talk to other moms who would pass information on to the RNs. Loretta feels nurses were being continuously undermined, mistrusted and discredited at every turn. Despite great patience and a family focus, Loretta got to a point where she did not want to go anywhere near the room; yet, she felt a strong sense of responsibility to Mom and Dad. Loretta believed that Dad did not intend to do the baby any harm but that he was "misguided". The staff "hated" the Dad and thought he was abusive and oppressive to

his wife. The relationship between the RNs and the family was described as "pathological and unreasonable"; for nurses, supporting the family's integrity conflicted with maintaining both their personal and professional honor and integrity. Loretta recalls that at no point did the RNs feel they were able to reach and care for the family in a positive way.

Synopsis of Donna's Interview

Donna speaks of working with a mother who took a while to trust any non-primary nurses, such as herself, responsible for her child's care. The mother would not give her information to allow Donna to assess or care for the child throughout the day. Donna recalls the mother reported chest drainage loss to a primary nurse caring for a different child that day, instead of to Donna. When the child's surgeon asked if there had been any drainage, Donna said, "No". Later she learned that the mother had been emptying the drainage device and reporting off to another nurse. Donna is hurt by such an event because she had enjoyed a reputation for working well with challenging families...she feel "set up". The mother's communication pattern split the RNs working on the unit and caused mistrust among them. Although Donna's experience as a nurse had taught her not to take the mother's actions personally, it was hard. Donna recognized that for this mother other issues such, as grieving for a sick child, also played a part in the dynamics, and she tried to give Mum the "benefit of the doubt". The issue has not been resolved even though the family is regularly in the hospital.

Donna recalls a mother making her feel as if the minute she walked into the room that her attention was drawn away from the child and towards the mother. The RNs felt uncomfortable with the situation and identified some concerns but tried to give Mum the benefit of the doubt. On occasion Mum would snap at Donna, and then be nice to her on her next visit to the room. For Donna a considerable amount of self-questioning took place in order to check her assumptions and to do the best job she could. As she tried to work out what was going on, Donna recalls avoiding the room. She felt deflated and unable to follow through on any plans with this mother. Other RNs experienced similar feelings to Donna but not all agreed; divisions occurred among the staff as all tried to make sense of their experiences. They had to work hard to coordinate efforts and avoid the mother splitting the staff into different camps. Several serious incidents occurred specifically when the primary nurses were not in the room. When the nursing staff started to work together as a team, each recognized the others had different experiences of the mother. The staff then met regularly to check out their assumptions and to respectfully acknowledge their colleague's perspectives. Yet, Donna recalls the list of RNs refusing to work with this family lengthened, and the situation became emotionally loaded because the RNs cared very much for the child whose care was being obstructed. The situation forced a formal review of the case, and the child was transferred closer to home in order for ongoing medical management and further assessment of social concerns. After the child left the unit disagreements still lingered amongst the RN's about the mother's care of her

child. Donna wonders whether the child may have been unnecessarily poked for bloodwork done mainly to satisfy the mother's requests and whether the mother was masterfully maintaining focus on herself. The situation was destructive for both the RN staff and the child.

Another story prominent in Donna's mind involves a family wherein two of the baby's siblings had died of Sudden Infant Death Syndrome. The new baby was being investigated for apnea, and nurses found the father to be very hostile and "very, very aggressive". Donna knows nurses suspected child abuse was involved in this case, and she recalls finding it very challenging to face the family. Donna recalls being challenged indirectly by the father: he watched her closely and commented that "some nurses are very aggressive with babies and other nurses are very gentle". Later that shift, he told her she was unusual in being able to quiet the baby by holding her. To Donna, the example illustrates the tension she felt in not knowing what to expect. She describes feeling as if she was "walking on eggshells" and trying to prove herself to the child's father.

Donna also worked with another father who was very aggressive and who would underplay his baby's need for oxygen and medical assessment, directly obstructing care. He would choose his favorite nurses, those not typically assertive. As well as being aggressive, he was also flirtatious, which was very confusing for the nursing staff. The father would distract the RNs from nursing the child by demanding a lot of attention. Perhaps because the situation felt personal (judgmental and flirtatious by turns), Donna states she was slow to trust her judgments.

Synopsis of Lori's Interview

Lori recalls a mother who was very obstructive to care. The mother would instruct the sick child's sibling to close the door to the room and prevent staff from entering. Unpleasant comments about the nursing staff appeared on the communication board in the child's room, making RNs feel uncomfortable. In many ways, Lori recalls family dynamics interfered with the child's care. While staff supported one another emotionally when one was caring for this family, none wanted the assignment and each dreaded the next shift. Though Lori had a reputation for being able to work with challenging families and hoped to be able to work something out with this family, she ended up in tears after her second day with them. Lori recalls feeling undermined and sensing from the family the sentiment, "I don't like you". Lori was completely at a loss for what to do to make a difference, and she questioned her responses to the situation in attempts to make sense of what was happening. Other RNs would look at "the hours" to anticipate whether they were going to have to work with this mother. With eventual involvement of the Ministry of Health and the Human Rights Officer for the hospital, a contract was drawn up to guide both the family and the RN staff. The RNs supported one another in a desire to avoid working with the family; yet, all "looked out for" those who were assigned to the family. Lori feels there has to be more support for the staff from higher authority in these situations.

Many years ago, Lori cared for a baby born with a severe Meningomyelocele and who quickly developed hydrocephalus. The baby was not wanted by the father but wanted by the mother. The medical orders were to not feed the baby, a plan Lori and the rest of the nursing staff felt was not acceptable; the staff refused to follow the orders. Eventually a compromise was reached to feed the baby if she cried but not otherwise. The family rarely visited which made the overall decision to withdraw feeds feel like a terrible burden on the shoulders of the nurses alone. It was difficult not to be resentful of the family's wishes even though Lori knew cultural factors influenced the decision to let this baby die. She knows she will *never* forget this story.

Lori recalls caring for a family who, transferred from another unit, continued to rely on the staff on that unit rather than to begin relying on the staff on Lori's unit. The parents would sometimes only convey information about the baby to staff on the other unit. When information thus flowed indirectly, the nurses on Lori's unit felt their ability to provide care and to feel respected as professionals by the family was compromised. The parents' reliance on the other unit caused much conflict between the RNs and the family; Lori feels it constantly undermined the nursing staff on her unit. Because Lori knew a member of staff from the other unit whom the parents liked, the parents approved of her. When the relationship between the parents and the staff member from the other unit deteriorated, conversation became awkward between Lori and this family. Lori thinks the parents were viewed as intimidating because they had a lot of knowledge about their child's condition and because they were not open to suggestions or advice from the RNs. There was a sense these parents were manipulating staff and "singling out" favoured RNs. Lori says she then cut down her contact with the family; she felt detached and guilty, but didn't want to get hooked into all the "personal stuff" again. A ward meeting was necessary for the staff to discuss the situation. Lori recalls that frustration was expressed in response to the sudden competitiveness that had built up between the two units. Lori feels the RNs were always on their guard at first but since have relaxed somewhat with the family as the child is less sick and the parents are more relaxed.