PARENTS' EXPERIENCES OF INTERACTING WITH NURSES REGARDING THE CARE OF THEIR CHILDREN WITH CHRONIC HEALTH CONDITIONS

by

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Abstract

An interpretive descriptive design was used to explore and describe parents' experiences of interacting with nurses regarding the care of their children with chronic health conditions, and to gain a better understanding of these experiences from the parents' perspectives. Eight parents, representing seven families, participated in audiotaped interviews. Data were analyzed concurrently with data collection, and the three themes of establishing rapport, meeting parental needs for information and support, and negotiating care, emerged.

Rapport was established more easily when the nurse demonstrated a degree of knowledge about the child's health condition and about the child as a person, when the nurse acknowledged having previous contact with the family, when information was reciprocally shared, and when the nurse conveyed friendliness, empathy, and optimism. Barriers to establishing rapport occurred when the nurse had a blunt approach, and when environmental factors not conducive to facilitating interaction were present.

Interactions with nurses were considered more positive when they served to meet parents' needs for information and support. Needs were more often met when nurses considered parents' readiness and ability to receive and process information, and when nurses cared for the parents and their children rather than for a single care recipient. Information needs were met more consistently than
were support needs.

Parents and nurses negotiated care on an individual basis, and several care responsibilities were often transferred from nurse to parent. Parents often changed their own approach when negotiating with nurses, which was thought to improve their children's nursing care. Nurses frequently mediated between parents and physicians, which parents also thought improved care outcomes.

The findings of this study engendered implications for clinical practice, nursing leadership, education, and research. Through reflection on individual practice, the development of formal interdisciplinary health care education initiatives, continued research in the area of collaborative practice, and with support from nursing leaders, nurses are better positioned to consistently provide holistic care to children and their families.
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CHAPTER 1: Introduction

Interactions between patient and nurse are considered cornerstones in the quality of nursing care. In the care of children, the interaction is usually between the child's parents and the nurse. Recognition of the importance of interactions with families has broadened to include other health care disciplines and health care administrations. In more recent decades, and in response to some influential trends affecting the pediatric population, there has been a growing movement toward recognition of families as expert in the care of their own children. Health care service delivery has been restructured to reflect this recognition. The espoused view places a partnership model at the center of the directions for clinical practice. The language of this model has become so ingrained in agency documents and value statements, that relatively little recent attention has been paid to whether or not the value of partnership has been enacted in clinical practice. Further, there is an absence of empirical evidence to support the assumption that families wish to participate in a partnership relationship, and despite continual efforts to improve health care delivery, dissatisfaction is growing among health care consumers. Therefore, the purpose of this study was to explore and describe the experiences of parents who interact with nurses.

Background

Patient-professional interactions are central considerations in nursing practice, and nurses are directed to involve the patient in all phases of care. In pediatrics, the clinician attempts to build what is often termed a working relationship with the family, as the family provides a link between the child and the health care system (Friedman, 1998). The desired relationship is often characterized as a partnership, but "collaboration", "participation", and "involvement" are often used synonymously to express this sentiment. These
Parent-Nurse Interactions

concepts are captured in the Family-Centered Care philosophy in which the professional recognizes the importance of the family and shifts control of care decisions to the family. The shift alters the nature of parent-professional interactions to one of a more equal partnership. Further, the philosophy of Family Centered Care has been embraced by most health care agencies in British Columbia (Children’s & Women’s Health Centre of British Columbia, 2000a). Interactions between parents and nurses are most often described in the context of inpatient hospital settings. However, nurses and other health professionals attempt to work in partnership with families in all service areas. Therefore, it is important to understand these interactions as they occur in other settings including outpatient and community areas.

**Influential trends**

Several health care trends have contributed to the value on, and efforts to achieve meaningful relationships with families. As these efforts continue to evolve, there is some discrepancy between their intended outcome and their current success. The most influential trends appear to be the increasing complexity of pediatric health conditions, the increasing responsibility that families assume for their children’s health care, and the implementation of a team approach to health care delivery.

Medical advances have dramatically increased the survival rates of critically ill children, and early diagnosis and treatment of chronic illness has led to growing numbers of children requiring care (Whaley & Wong, 1995). As such, families of these children will have several contacts with health professionals over the years. These contacts are likely to occur in several different settings such as inpatient units, outpatient clinics, and community environments. Because nurses represent the largest health discipline, and because of the
intimate nature of nursing care, the most frequent health care interactions are likely to be with nurses.

There has also been a shift in philosophical orientation regarding how health care should be delivered. Trnobraški (1994) attributes this shift to the emergence of consumerism in health care. She asserts that patients are viewed, and view themselves, as consumers of a service that is health care. As such, there is now an underlying belief that patients should be actively involved in their own care. For the most part, parents are the primary caregivers for children with chronic health conditions, and are expected to act as health care consumers on behalf of their children. Although this still involves contact with health professionals for support in managing the health concern, the family is now positioned in a role of central responsibility for coordination of care. Additionally, parents may also be required to acquire specialized skills that enable them to manage their children's care (Casey, 1995). Therefore, care roles have become somewhat blurred between family and professional. As families care for their children at home, often using higher level skills, relinquishing this role to nurses during hospitalization may be difficult for the families. Similarly, nurse acknowledgment of these parental care skills might not occur as nurses may feel threatened (Casey).

The idea of services delivered by multidisciplinary teams has evolved over the past 30 years. The current reality for families is that, over time, they may have many contacts with multiple teams comprised of several different disciplines. Parents are now considered to be team members within a multidisciplinary service (Children's & Women's Health Centre of British Columbia, 2000b). They are asked to fulfill their team member role by providing information which is vital to treatment planning for their children, and by
contributing to team summary discussions. However, for reasons including jargon used by health professionals, parents may not be able to fully participate in these discussions without assistance (Cottrell & Summers, 1990).

Collaboration, communication, and patient advocacy are specified as required skills for the practice of nursing (Registered Nurses' Association of British Columbia, 1998), and are often employed by nurses to assist families to more fully participate in team discussions.

Although team service delivery was intended to address the problems of conflicting specialist recommendations and poorly coordinated services (Jan & Robinson, 1989; Robinson & Clarke, 1980), some of these difficulties persist within multidisciplinary team work. Further complicating this issue is the lack of differentiation among terms used when referring to family participation. At present, there is no clear indication as to who in the family has what expectation of which professional. Therefore, parents may still face overwhelming and fragmented information regarding their children's diagnoses without the necessary access to ongoing supports (Cottrell & Summers, 1990).

As a result of these trends, there is a tremendous value on family involvement in care and on building parent-professional partnerships. As evidenced by initiatives such as the Partners in Care Committee and the Family-Centred Care Committee at B.C.'s Children's Hospital and Sunny Hill Health Centre for Children respectively, healthcare programs and services have been shaped in response to this value. However, family-centered initiatives may not always provide a meaningful forum for family involvement (Trnobranski, 1994). Further, the language of agency documents such as Mission Statements (Children's & Women's Health Centre of British Columbia, 2000a) reflects assumptions made by health professionals regarding what families want from
health care services. Despite values and efforts, consumer dissatisfaction with the current health care system continues to grow (Alspach, 1997). Relatively little effort has been made to elicit parental views about how they wish to interact with health professionals.

Over the past 13 years, I have worked as a pediatric nurse in many settings, at both British Columbia’s Children’s Hospital and Sunny Hill Health Centre for Children. Most of my work has been with children with chronic conditions and their families. I have directly experienced the effects of health care restructuring that promotes partnership-building with families. While I philosophically agree with the acknowledgment of family expertise and the need for meaningful parental involvement in pediatric care, I have also experienced the discrepancy between beliefs and success in effecting full partnerships with all families in all health care settings. I have become increasingly concerned about the zeal with which partnerships are promoted in absence of a consensus definition of the term. Of greatest concern for me is the general lack of understanding of parents’ current experiences when interacting with health professionals, and how this may be related to the generally persistent parental dissatisfaction with health services despite enthusiastic partnership initiatives. These initiatives appear to be based on the assumptions that parents and professionals define “partnership” and “relationship” similarly, and that all parents desire and are able to interact with professionals in this way. These terms connote certain attributes and a level of intimacy between participants. At present, these connotations are assumptions and may not be part of the families’ experiences. I believe that these basic assumptions may represent the root cause of the rift between enacting parent-professional partnerships and parental
satisfaction. Therefore, with the exception of the review of selected literature, I have used the term "interactions" in this study.

**Problem Statement**

Many questions remain regarding family perceptions of relationships with health professionals. Confusion regarding consensus definition of partnership, or one of its many synonyms, appears to intensify the fragmentation of this concept's development. As a result, it appears that the clinical and organizational changes based on the assumed definition are also fragmented.

Gaps still exist regarding our understanding of health care relationships from the family's perspective. This understanding is crucial in order to address the current discrepancy between the espoused view of interactions with parents and the current state of success with operationalizing the concept of partnership, and to design and implement meaningful services.

**Purpose**

The purpose of this study was to explore and describe the experiences of parents who interact with nurses, and to gain a better understanding of these experiences from the parents' perspective. A deeper understanding of this issue provides direction to nurses regarding how they approach interactions with families, and to organizational leaders regarding how agency philosophy is enacted with families.

**Research Question**

To obtain the parents' perceptions of their interactions with nurses, the following research question was posed:

What are parents' experiences of interacting with nurses regarding the care of their children with chronic health conditions?
Definitions of Terms

For the purposes of this study, the terms below were defined as follows:

PARENT: A child’s mother or father. (Foster parents were excluded as their experiences are believed to be different from experiences of birth or adoptive parents.)

NURSE: A health professional holding a current and practicing registration with the Registered Nurses Association of British Columbia, and who is currently employed as a Registered Nurse in a health care facility.

CHRONIC HEALTH CONDITION:
A diagnosed medical condition for which the child with the condition requires long-term or life-long monitoring, treatment, or care.

INTERACTIONS:
Contacts that parents have with nurses regarding the health care of their children.

Assumptions

The basic assumptions of this study were that:

1. parents’ interactions with nurses affect them in some way.
2. parents are willing and able to recall and describe these interactions.

Limitations

The depth and richness of the data could have been limited by several factors. The researcher’s time constraints restricted the number of participants interviewed. The data collected could have been limited due to the availability of the parents and their willingness to participate. In addition, most parents found...
recounting their experiences difficult due to the traumatic nature of the events. Therefore, their accounts may not have been as detailed as expected. The researcher is also a periodic recipient of health care. Thus, despite efforts to minimize researcher bias, the analysis of transcripts could have been affected by the researcher’s personal experiences with health professionals. The parents were invited to participate by members of the same health care services they utilize. Parents with whom the health care providers have a positive rapport may have been more likely to be selected. This may have skewed the parents’ responses to a more positive assessment. Finally, the researcher is also a nurse. Therefore, the parents’ responses and descriptions could have been influenced by this knowledge.

Significance of the Study.

This study partially addresses the current gap in nursing knowledge - that of parental perspective regarding parent-nurse interactions. Increased knowledge regarding parental experiences of such interactions will enhance nurses’ understanding of positive working relationships with families. It is hoped that this enhanced insight also suggests direction for organizational leaders regarding how agency philosophies are enacted with families.
CHAPTER 2: Review of selected literature

A broad-based literature review was undertaken to outline the existing current knowledge related to parents' experiences when interacting with health professionals. Various authors have asserted differing perspectives related to parent-professional interactions, although all seem to agree that these interactions greatly influence the quality of children's health care. Despite the varying views, four strong themes emerge from the literature and are: rapport, relevance, communication, and empowerment. The following is an exploration of each of these themes in which elements that authors deemed essential to parent-professional interactions are described. Articles, both opinion and research, most relevant to this study were selected for exploration.

Generally, several terms are used interchangeably to describe a positive parent-professional relationship. These terms include: partnership, participation, collaboration and involvement. Family-centered care is a phrase often used to capture the intent of the ideal relationship. As these terms are not differentiated in the literature, distinction among them will not be made in this review. Most articles included in this review are from the discipline of nursing. However, other health care disciplines' work is also represented. Therefore, for the purposes of this discussion, the term "professional" will be used. The term "family" will be used as it is consistent with most of the selected literature.

Underlying all authors' work in this content area is the presupposition that a relationship exists between the family and health professional (Cahill, 1996; Farrell, 1992). However, that is where absolute consensus ends as authors' opinions vary regarding defining attributes of positive relationships between parents and health professionals. Although there is very little research specifically concerning parent-professional interactions when compared to the
discussion literature on the same topic, some important analogous content has been explored through research. This work supports some of the assertions found in the discussion papers.

Themes

Rapport

Establishing rapport is considered important in positive parent-professional interactions. Collaboration can be enhanced by fostering trust, respect, and equality, when professionals view the families as capable of contributing to care, and when families are willing to participate in care. According to the popular opinion literature, the development of rapport begins with the first contact (McElheran & Harper-Jaques, 1994). “Trust” has been cited as a key element in the development of rapport (Kosper, Horn & Carpenter, 1994) and is fostered through honesty in how information is presented (Graham & Maze, 1997; MacPhee, 1995), and through maintaining confidentiality (MacPhee). Trust develops over time as the family and health professional come to know each other, and is more easily established if there is regular contact between partners (Wilson & Hobbs, 1995). A sense of trust is necessary to enable a family to meet the child’s health care needs and to minimize intervention from health professionals (Farrell, 1992).

Researchers appear to concur that trust is an essential element in developing rapport. Forchuk (1992) retrospectively collected data from records of 73 clients who had received health care services from community and mental health staff. The purpose of her study was to identify any demographic client characteristics or care delivery factors related to the client’s length of time spent in the orientation phase. This phase is said to begin with the first encounter between the nurse and the client. During this phase, the nurse and client come
to know each other as persons and the client tests the relationship's parameters to determine if the nurse is trustworthy. Once trust is established, and goals are identified, the client may then move on to the working phase. However, Forchuk found that 30 clients had reverted to the orientation phase after moving into the working phase. Thirteen of these clients reverted due to exacerbations of their psychiatric symptoms. More notably though, 17 of the 30 clients had experienced a change from staff with whom clients had built a rapport, and this was thought to precipitate their relapse.

Thorne and Robinson (1988) utilized a grounded theory approach to explore the concept of trust between health professionals and individuals with chronic conditions. The participants in this study described different levels of trust as their relationships evolved over time. This evolution took the participant from unquestioning trust in the professional to a trust that was based on more realistic expectations. Further, participants described an essential reciprocal quality of trust in their health care relationships. That is, due to the chronic nature of their conditions, patients came to demand acknowledgment of their competency to manage their diagnoses. Trust was meaningful, promoted patient self-esteem, and strengthened the health care relationship when affirmations of client competence were context-specific and individualized.

Mutual respect is at the foundation of a trusting relationship (Kosper et al., 1994; Wilson & Hobbs, 1995), and helps to maintain commitment to the relationship (Graham & Maze, 1997). Respect for, and trust in, each partner's competence is required for each to function within the relationship (MacPhee, 1995), and to make a valuable contribution to care (Gibson, 1995). All participants need a sense of commitment for rapport to develop. This commitment is to working collaboratively within the relationship (Kosper et al.,
1994), as well as to working for the benefit of the child (Rushton & Glover, 1990; Stower, 1992).

Balanced power within the relationship is a common thread through several articles included in this review (Coyne, 1996, Farrell, 1992; Rushton & Glover, 1990; Stower, 1992). To achieve a balance in power, each participant must have a degree of control in the relationship (Coyne). Building rapport is often viewed as a dynamic and reciprocal act, and is thought to be most effective when it is based on reciprocal interchange (Humphrey, Gonzalez, & Taylor, 1993; McElheran & Harper-Jaques, 1994; Stower). In this way, the participants are unified in their commitment to the relationship (Humphrey et al.) and two-way communication is enhanced (Rushton & Glover).

Attitudes will create a climate that can either support or impede the development of rapport (Rushton & Glover, 1990; Trnobranski, 1994). Health professionals are automatically positioned with greater power than the family holds as the professional can act as gatekeeper of the parental role (Knight, 1995). That is, professionals are in a position to regulate the amount of parents’ participation in their children’s care. Therefore, the professional’s attitudes are important factors in the ability to achieve shared power, decision-making (Knight) and a holistic approach to care (Stower, 1992).

While some authors contend that equality between family and professional is an important prerequisite to collaboration, some researchers have found that equality may not be part of this relationship. Biley (1992) used a modified grounded theory approach to identify the determinants affecting patient participation in decision-making about hospital nursing care. She found that participants described 3 categories, each of which contained a range of responses and shifts of control, which affected the degree of participation the
patient desired. The first category concerned the degree of illness. When patients were very ill, most preferred to be passive recipients of care. Whereas, when patients' conditions improved, they began to ask more questions and analyze the information before making decisions about participating in care. Secondly, patients were found to more likely be passive recipients if they did not have sufficient information on which to base a decision. The last category concerned organizational constraints. That is, if the hospital environment allowed, the patients would feel they could act on their decisions to participate. While equality in the relationship may be difficult to achieve, it is generally accepted that families can benefit from even a small degree of control over their own care. While Biley focused on control shift as related to the patient, Kelner and Bourgeault (1993) examined this notion from the perspective of physicians and nurses working with patients who were terminally ill. Through semi-structured interviews, subjects were asked about their own beliefs regarding who should have the final authority regarding end of life decisions. Some of these professionals stated that, although the socially acceptable answer to this question is the patient, the professionals could not always agree philosophically. The researchers discussed the possibility that patient control represents a challenge to the professionals' clinical judgment and identity. Patient control may also conflict with health care socialization to care for and heal the sick. Professional willingness to relinquish control over decision-making appears to be similar to the organizational constraints described in Biley's (1992) study. The success of shifting control may be largely dependent on professional attitudes, and family involvement remains difficult to promote in many settings.
Systematic family involvement has been shown to produce positive outcomes for patients, their families, and staff (Hoen Anderson, Hobson, Steiner, & Rodel, 1992). In their study, Hoen Anderson et al. found that patients with dementia could be managed on lower doses or fewer as-needed medications when their families were systematically involved in their care. Family comfort with the patients increased, which reinforced maintaining involvement, and staff job satisfaction increased. In Casey’s 1995 survey of 243 families of pediatric inpatients regarding parental involvement in care, nurses’ attitudes were found to be important determinants of family involvement. That is, if the nurse believes the family to be a positive and pivotal influence in the child’s life, she or he may be more willing to involve the family in care. Conversely, if the nurse feels threatened by the family’s knowledge, she or he is more likely to become controlling and limit parental involvement. Casey concluded that nurses may not fully be aware of their own attitudes and how these affect promoting family involvement.

Nurse attitudes and family involvement practices were evaluated before and after implementation of the Family Systems Nursing Medical-Surgical Project (Leahey, Harper-Jaques, Stout, & Levac, 1995). Prior to implementation of the project, nurse participants felt they valued family involvement and possessed adequate knowledge and skill for working with families. However, they were found to frequently make assumptions regarding patient needs rather than basing nursing action on a systematic assessment. From the project’s post-implementation questionnaire responses and semi-structured interviews, the nurses demonstrated a conceptual shift to a greater emphasis on the family in all aspects of the care they provided. The researchers linked this shift in
emphasis to a more quickly established rapport between nurse and family leading to a more mutual and supportive relationship.

Johnson and Lindschau (1996) sought to identify staff attitudes toward parent participation in the care of hospitalized children, and to assess personal and professional characteristics that could influence these attitudes. Using the Parent Participation Attitude Scale, they assessed the attitudes of 62 staff members who represented various disciplines in an urban pediatric hospital. Results revealed that, although nurses had the most accepting attitude of all professional groups studied, the majority of participants had a neutral attitude toward parent participation.

The use of parent-completed developmental questionnaires (PCDQ) in the assessment of young children was found to be linked to professional attitudes (McCaffrey Easley, Liptak, Bair, Campbell, Kaupang, & Strucker, 1996). In general, PCDQ’s are deemed important tools leading to more accurate diagnostic evaluations of children. Yet professionals do not routinely use these resources. McCaffrey Easley et al. found that the physicians and physical therapists in their study were more likely to use these assessment tools if they felt the parents’ information would make a contribution to care, and if they viewed parents as capable of giving accurate information and acting as equal partners during assessments.

Finally, but equally important to rapport-building, is family willingness to participate in a collaborative relationship (Coyne, 1996). Trnobrainski (1994) outlined the shift in health care from a medical model to a more consumer driven structure. As previously described, most health care models in North America embrace and actively promote holism and family participation in care. However,
some families may not wish to participate in this way (Stower, 1992; Trnobraški).

Most research related to collaboration and rapport focuses on developing a relationship that encourages family participation in care. However, some researchers have found that this approach may not be considered positive by all families. In fact, a conflicted relationship may result instead of a collaborative one. McLaughlin and Carey (1993) explored key issues which might help professionals to understand how they and families can better work together, and to provide support that is more likely to meet family needs. Their correlational study was conducted post discharge with families of patients who sustained brain injury. These authors concluded that family stress may result when the family members are not ready for the support being offered, or when the support provided encourages a degree of involvement that the family does not want. Waterworth and Luker (1990) echoed this caution through their qualitative research findings regarding the patients' perspective of involvement in decision-making concerning their own in-hospital nursing care. Rather than being eager to participate in decision-making, the participants of this study were preoccupied with displaying cooperative behavior to avoid punishment. As a part of this preoccupation, the researchers speculated that patients may engage in what seems like collaborative decision-making, even when they prefer not to. These authors further discussed the generalized value of participation with the comment "..., there is a tendency in nursing to consider that participation is good and that means good for everyone." (p. 975). They suggest that promoting individualized care does not necessarily equate to active patient involvement in care.
Rapport between families and professionals is essential to collaboration. Trust, respect, and equality are key components of establishing rapport. Professionals' attitudes, as well as family members' willingness to participate, greatly influence the degree to which families become involved in their loved ones' care.

**Relevance**

Ensuring relevance of the care plan is a worthwhile endeavor as families are more committed and motivated to strive for the common goal. Also, as families' health care experiences tend to be more positive when the plan of care is relevant to them, achieving the goals is more likely. Relevance is encouraged through a negotiation process which involves accurate needs identification and the development of a plan that the family views as acceptable.

Families are better able to engage in collaborative interaction with health professionals when there is a common goal in view (Gibson, 1995). The ability to develop mutually satisfying goals is considered to be a critical component of collaboration (Kosper et al., 1994; Wilson & Hobbs, 1995). The needs and resources that are identified prior to goal-setting must be relevant to the family in order to achieve the required commitment, to avoid family frustration (Gibson), and to achieve agreement on the plan (Rushton & Glover, 1990). Grandine (1995) suggests that the professional facilitates the collaborative process by presenting meaningful information which is based on the family's beliefs about the health concerns.

The process of negotiation is an assumed attribute of a collaborative relationship (Coyne, 1996; Trnobrański, 1994). Negotiation of terms is the vehicle by which equality and expectations for each participant are determined.
(Stower, 1992; Wilson & Hobbs, 1995). The optimal outcome of the negotiation process is mutual agreement (Knight, 1995).

Although equal participation in goal-setting is thought to be required before collaboration can begin, equal participation is not possible unless the professional believes that the family is competent to select meaningful goals. Humphrey et al. (1993) used questionnaires with 361 occupational therapists to examine the relationship between attitudes regarding families and several practice variables. Of significance were the findings that respondents who were not in direct service, those with degrees beyond baccalaureate, and those with more contact with families, tended to have more positive attitudes about working with families.

To establish relevant goals, family needs must be accurately identified. In Graves and Hayes’ 1996 comparative study, 38 parents and 13 nurses working with these parents completed the Family Needs Survey. The descriptive results showed that nurses identified more family needs than the families identified for themselves. There was some agreement between the two groups on themes of the needs identified on an open-ended item, but there was considerable disagreement on prioritization of parental needs. This raised concern for these authors that this pattern of interaction could undermine parental confidence and nurturant power. To avoid this consequence, they suggest collaboration between nurses and families at the assessment stage so that goals and priorities are mutually defined.

Through the course of another research study (Mathews, Everett, Binedell, & Steinberg, 1995), the importance of mutually setting and prioritizing goals, and collaboration in program development was highlighted. Mathews et
al. concluded that plans of care must be acceptable to the intended clients if commitment to the plans and their implementation is desired.

Hatcher and Barends (1996) agree that aspects such as rapport and relevance are generally important elements in building a positive relationship. However, they contend that commitment to the working plan may also be determined by the patient's perception that the professional-patient relationship is enhancing progress with treatment. Their study, which measured aspects of therapeutic alliance between patients with psychiatric diagnoses and their psychotherapists, revealed that a strong bond could still be formed based on patient perception of improvement, even in the absence of other partnership elements.

Therefore, relevance represents a positive force that helps to maintain momentum in the working phase of the relationship. Through the resultant enhanced commitment to the care plan, health goals are more likely to be achieved.

**Communication**

The way in which information is exchanged between families and professionals, and is understood by each, helps to shape the tone of the working relationship. Open sharing of information, terminology consistent with Family Centered Care principles, clarity, and regularity of discussions all contribute to a more positive experience. The professional's gender, willingness and ability to listen, as well as their attitudes toward family involvement in care, influence the communication patterns.

Open communication is cited as an integral component of positive family-professional relationships (Odle, 1988), as it serves to enhance family involvement in care (Rushton & Glover, 1990). When communicating in a
collaborative relationship, even the most basic of elements needs to be reconsidered. Terminology changes are indicated to better reflect the family-centered care philosophy (Bond, Phillips, & Rollins, 1994). Communication, however, requires more than a change in language. Complete sharing of information is required for the family to make informed decisions (Ahmann, 1994; Dunst, Trivette, Davis, & Cornwell, 1998; Gibson, 1995). Regularity of discussions is a required component in ensuring the maintenance of communication so that the identified needs are met (Wilson & Hobbs, 1995).

Authors of some of the previously described research studies also provide opinions regarding communication within a collaborative relationship. Following the orientation phase in which trust is established (Forchuk, 1992), the family and professional begin a dialogue as they commence the working phase of the relationship. The climate must be optimum to facilitate communication as time and opportunity must be created (Gibson, 1995). Much of the research found in the area of family-professional communication focuses on clarity. Clear communication is a precursor to partnership as it expedites accurate determination of care needs (Hoen Anderson et al., 1992) and maintains forward momentum in the relationship (Forchuk, 1992). Mutual goals are developed more easily (Opie, 1998), and misunderstandings leading to conflict are avoided (Casey, 1995) through clear articulation of expectations. Mathews et al. (1995) also determined that the consequences of vague dialogue are inaccurate assumptions leading to conflict. In turn, the work to be done in the relationship is stalled or halted.

Almost as prevalent as the topic of clarity in communication research is the notion of listening. Mathews et al. (1995) described listening in reciprocal terms, whereby both professionals and families must listen to each other in a
non-judgmental manner. Casey (1995) found that the ability to speak the same language significantly affected the extent of family involvement, as a lack of shared language decreased two-way communication. However, most authors' recommendations direct professionals to assume responsibility for actively listening. Gibson (1995) asserts that if families perceive that they have been heard by authority figures, empowerment is the likely result. Mathews et al. cautions that premature decisions resulting from insufficient listening leads to misunderstanding. Hatcher and Barends (1996) indicate that listening may not be sufficient to achieve a true dialogue. They suggest that the professional must probe for sufficient information so that the family has an opportunity to be understood. In this way, families feel that their own priorities are driving the interaction. On this note, Hatcher and Barends warn professionals "... that we cannot know what we do not ask..." (p. 1334).

Despite recognition of the link between open communication and a positive relationship, some researchers contend that this is not a consistent element during interactions between families and professionals. Clark, Gong, Schork, Maiman, Evans, Hurwitz, Roloff, and Mellins (1997) conducted a correlational study to examine the relationship between professional communication and partnering behavior and enhanced patient management of disease. To accomplish this, a Health Care Providers' Teaching and Communication Behavior (TCB) scale was developed and completed by physicians who treat children with asthma. This scale asks participants to self-report as to whether or not they utilize certain communication behaviors when providing treatment information to families. Families were then asked to confirm the physician's report. The authors acknowledged that the behaviors specified in the scale, such as giving nonverbal encouragement, are fairly subtle
and may not be noticed by family respondents. Nevertheless, statistical analysis revealed that a high score on the TCB scale was significantly associated with the physicians’ belief that the particular strategy would produce a useful result such as improved patient compliance.

Communication patterns also vary considerably depending on the professional’s gender. Roter, Lipkin, and Korsgaard (1991) used questionnaires and audiotapes to determine if there were interactional differences between patients and physicians based on gender. They found that there were indeed significant differences in that visits with female physicians were longer than those with male physicians, and, during the visits, female physicians engaged in more conversation with patients of either gender, especially during history taking. Patients of either gender tended to talk more with female physicians. The authors postulated that women may be more attuned to the tasks of identifying concerns and prioritizing mutual goals, and tend to use more patient-centered communication strategies.

Communication is a pervasive force in all contacts between families and health professionals. Good communication, then, appears to be a precondition to establishing rapport.

**Empowerment**

When rapport, relevance, and good communication are established, family empowerment may result. One of the purposes of partnership is empowerment (Wilson & Hobbs, 1995). Gibson (1995) describes empowerment as:

... a social process of recognizing, promoting, and enhancing peoples abilities to meet their own needs, solve their own problems, and mobilize the necessary resources in order to
feel in control of their own lives (p. 120).

The journey to empowerment appears to begin with a feeling of discomfort. That is, frustration from a number of sources can be a catalyst for families to seek change (Gibson). Several authors describe a process that builds on family needs, strengths, and resources as one which promotes empowerment (Ahmann, 1994; Bond et al., 1994; Gibson, 1995; Grandine, 1995; Hanson, 1987; McElheran & Harper-Jaques, 1994; MacPhee, 1995). To accomplish this, families need sufficient and accurate information to achieve the mutually determined goals (Rushton & Glover, 1990; Wilson & Hobbs, 1995), and to reinforce the family’s competence (Coyne, 1996). Through sharing knowledge, teaching skills (Farrell, 1992), and coaching families to navigate the health care system (Wilson & Hobbs), the knowledge - competence gap between family and professional is narrowed (Cahill, 1996). Promoting family competence, and creating environments in which the family can demonstrate competence, is crucial to a positive relationship (Stower, 1992). Empowerment may be hampered by an unwillingness to share information, parental feelings of inadequacy from lack of emotional and educational support (Odle, 1988), and professional concern regarding family ability to provide care (Knight, 1995).

Empowerment of family members requires that the knowledge and power differences between families and professionals be equalized, and control be shared. This power sharing appears to also involve mutual understanding of roles. Role clarification is an important aspect in operationalizing the plan of care (Stower, 1992), as the consequences of role uncertainty may be increased family anxiety and impaired family functioning (Knight, 1995). As partnerships are characterized by some form of contract, clear documentation of all parties’ expected actions helps to clarify roles (Stower). Generally, though, the area of
role clarification has received comparatively little attention (Knight), and successful role negotiation relies heavily on the involved parties' comfort with blended territories (Kosper et al., 1994). In short, role negotiation is a family-centered care philosophy that is accepted in theory but not consistently implemented in practice (Knight). Opie's (1998) study results support this opinion. She qualitatively studied multidisciplinary team practices used to empower patients, and found that team members still maintained processes that marginalized the patients despite a pervasive value on involving patients. These practices served to maintain the patient's role as one of passive recipient. Opie contends that the professional must be de-centralized in the process and practices, but acknowledges that this may continue to be problematic.

Gibson (1995) studied the concept of empowerment by conducting in-depth interviews with mothers of children with chronic neurological conditions. These mothers were identified by ward staff as having some degree of mastery over their situation. The purpose of her study was to understand the process of empowerment from an empirical perspective. The mothers described a process initially involving discovering the reality of their children's diagnoses, seeking information, and developing care skills. Catalyzed by frustration, the mothers were forced to critically examine their situation, become acutely aware of their own needs and abilities, and eventually develop confidence in their knowledge and abilities. At this stage, they no longer subordinated their own perspectives and they became more assertive. Here, the mothers wanted acknowledgment for their expertise. In fact, recognition was required if any partnership was to be established. Full empowerment was felt to have occurred when the mothers' core abilities endured despite changing circumstances. Although many positive results of empowerment were cited in this study, a few negative consequences
also surfaced. Among them was increased parental stress due to professionals who were unwilling to share power, or who placed too much responsibility on the mothers regarding care of their children.

Frequently prompted by frustration, empowerment involves a process which builds on strengths while narrowing the knowledge and competence gap that often exists between families and professionals. Some authors contend that, for many families, empowerment is a desired outcome of collaboration. Empowerment is also a concept of interest for professionals as family members who have a sense of control over their situations are thought to be better able to work in partnership.

In summary, the literature review reveals the 4 major themes of rapport, relevance, communication, and empowerment, and these concepts form the basis for collaboration. Barriers to building a collaborative relationship between professionals and families. Most center around professional attitudes, assumptions, and judgments regarding the family’s competence to participate, ability to make a significant contribution, and willingness to participate. Through review of these selected articles, the discrepancy between espoused organizational values and the operationalizing of family-centered care principles is made more explicit. The discussion papers on family involvement provide motivation to improve health care practices in a way families find meaningful. These discussions, largely led by health professionals, provide recommendations for how other health professionals should shape their own practice. Research endeavors in analogous areas provide important beginnings in understanding what forms of interactions with health professionals families find most desirable. Most research and discussion literature describes the issues as they occur in hospital settings in urban centers. Few authors describe how
families and professionals work together in community or outpatient settings. Even fewer authors have sought to understand the concept of collaboration from the family’s perspective. The literature review also reveals a variety of author perspectives regarding collaboration with families, and the utility of these views is not yet explicit. Therefore, the current knowledge base regarding interactions between family and professional requires further research.
CHAPTER 3: Method

In response to the stated research question, a qualitative research approach using the method of interpretive description, and informed by phenomenology, was employed for this study. Qualitative research is the most appropriate approach when very little research is available regarding the subject area, or when content analysis reveals that recommendations are based on assumptions (Morse & Field, 1995). In these instances, the nature of the experience must first be understood. As the nature of human experience cannot be evaluated using traditional quantitative measurements, qualitative methods must be used (Burns & Grove, 1997; Morse & Field).

However, traditional qualitative methods, such as phenomenology, are based upon other disciplines' principles (Thorne, Reimer Kirkham, MacDonald-Emes, 1997), and nursing's philosophical and theoretical foundations may not be adequately reflected in research which strictly employs one of these traditional methods. Therefore, adaptations, such as the use of interpretive description, are necessary to generate depictions of shared health experiences that represent nursing's unique perspective (Thorne et al.). For example, although phenomenological researchers seek to understand an experience from the perspective of those who live it, they seek to identify and describe the essence of an experience without placing the experience in any particular context. Therefore, such studies may limit the usefulness of findings in the practice of nursing, as nursing's work is highly context specific. The research question of this study indicates that a deeper understanding of parent-nurse interactions was sought as it applies specifically to pediatric care and enhancing nursing practice. For example, different qualitative approaches are aimed at the development of different types of knowledge (Johnson, 1997), and
phenomenological inquiry is a method used to gain understanding of the participants' experiences (Bergum, 1991; Morse & Field, 1995), and the meaning that these experiences hold for them (Bailey, 1997). As this form of study seeks the essence of a phenomenon (Morse & Field; van Manen, 1990), the explicated meanings are common to all. Thus, phenomenology does not provide insight into culture-specific meaning (van Manen). Although phenomenology provides the most appropriate method among the traditional philosophies, this understanding may not be fully illuminated if phenomenology is used in its purest sense. Thorne et al. suggest that adaptations to the traditional methods in the areas of sample selection, data sources, data analysis, and rigor, better ensure that the research provides more than theoretical knowledge to our practice discipline. However, in this study, phenomenological principles are useful when related to researcher attitude and role, and were applied in this specific context.

**Sampling Procedure**

The person living the experience is considered to be the only reliable source of information in this type of study (Burns & Grove, 1997). Random sampling is inappropriate in qualitative research (Strauss & Corbin, 1998). In interpretive description, a small number of participants are chosen based on their willingness and ability to describe their experiences (Burns & Grove, 1997; Thorne et al., 1997), and to illuminate the experience under study (Sandelowski, 1986). Therefore, a purposive sample of participants for this study was selected from among parents of children with chronic health conditions, who attend specific clinics at B.C.'s Children's Hospital. These children's conditions require monitoring and/or treatment by at least one team of health professionals, and these teams include nurses as part of a multidisciplinary approach. Parents who were able to verbally communicate in and read English, and who resided within
Parent-Nurse Interactions

the Greater Vancouver area, were approached to participate in describing their experiences and interactions with nurses. Interviews were conducted with the parent(s) considered to be primarily responsible for the child's care and, therefore, the primary contact with the nurses. Most of the children seen in the clinics involved have medical complications secondary to extreme prematurity or neonatal critical illness, and may have been hospitalized when they were newborn for lengthy periods of time. Their age is calculated based on their due date rather than their date of birth. In order to avoid complications that would be inevitable when dealing with a new diagnosis, I selected parents whose children were older than the corrected age of 18 months at the time of the interview. In this way, parents had gained the required knowledge and competencies regarding their children's diagnoses, and had some repeated experiences interacting with nurses. Eligible parents were initially contacted by one of the clinic nurses, either in person during a clinic visit or by telephone, to establish interest in and willingness to receive more information about the study. An invitation letter explaining the purpose of the study was provided to all interested, eligible parents (Appendix A). Purposive sampling was used as the data collection progressed to broaden the experiences described and, in turn, more specifically distinguish between unique and common aspects of the experience.

Data Collection

Demographic information was collected prior to further data collection (Appendix B). Primary data was gathered through in-depth audiotaped interviews with 8 parents representing 7 families. For each parent interviewed, permission for future telephone contact was obtained for the purposes of further data collection and for validation of emerging themes. One of the parent
participants was contacted to clarify a statement and to confirm some of the findings. Five of the interviews took place in the families' homes, one was arranged to take place at the parent's place of work, and one took place in the maternal grandparents' home. During these interviews, I posed broad, non-directive, trigger questions to encourage the participants to verbally describe their experiences of interacting with nurses (Appendix C). Field notes were completed following each interview to capture my general impressions and notes to augment the audiotapes, and to place the described experiences in the context of the individual interview.

**Researcher's Role**

The interplay between the researcher and the study process was considered from a phenomenological perspective. When using phenomenology, the researcher is directly involved in the research experience as reflexive thought is considered to be an integral component of the process (Burns & Grove, 1997). That is, the researcher remains cognizant of the dynamic interaction between self and the data. The phenomenological philosophy accepts that the researcher is part of the world under study (Bergum, 1991), and the two are inseparably connected (van Manen, 1990). In this study, I remained aware of the possible influences of the concurrent roles of health consumer and nurse on parental descriptions.

However, the researcher is also required to approach data collection and analysis without preconceived notions, expectations, or theoretical frameworks (Omery, 1983 as cited in Morse & Field, 1995). Therefore, my personal perspective was identified through the use of a reflective journal.
Analysis

In keeping with the interpretive description approach, analysis was conducted concurrently with data collection (Burns & Grove, 1997). Largely dictated by the interview scheduling, periods of immersion in the data collection were interspersed with periods of immersion in the data analysis. The process for analysis, involving several readings of each transcript, generally followed the approach as outlined in Cresswell (1998). The interview transcripts were first read to derive general impressions. From the second reading, significant statements about how parents experience interactions with nurses were sought and a list of distinct, nonrepetitive statements were generated in the form of margin notes. At this stage, each statement was treated as having equal worth. Next, the statements were grouped into meaning units, and verbatim examples from the interviews were extracted. Deeper analysis developed from the use of structural description as transcripts were compared. Here, the researcher sought possible alternate meanings and divergent perspectives associated with the meaning units. Common categories from the transcripts were collated into themes. The end result of this analytical phase was a description of common themes regarding how parents experienced interactions with nurses. From this, a composite description was written.

Procedures for Protecting Human Rights

Prior to commencing this research, approval was obtained from the University of British Columbia's Screening Committee, and from the British Columbia's Children's Hospital Research Review Committee. Rights of the participant were protected by:
• providing all participants with an information letter which included a full, written description of the study purpose, potential benefits, and expectations of participants,
• obtaining the participants’ written consent (Appendix D),
• assuring participants of their right to withdraw from participation in the study at any time without jeopardizing their children’s care or access to services,
• describing data management measures to ensure confidentiality and anonymity including:
  a) sharing audiotaped interviews and transcripts only with the chair of this thesis committee and a transcriptionist,
  b) erasing audiotapes immediately following study completion,
  c) storing transcribed interviews in a locked file cabinet,
  d) eliminating names, or any other identifiers, from the transcribed interviews, demographic sheets, or field notes,
  e) storing demographic data information separately from the transcribed interviews + field notes. Forms were tracked and linked using number codes.

Specific needs were raised during one of the interviews, and the researcher communicated these needs to the clinic staff for linkage to appropriate support resources.

Rigor

In qualitative research, specific procedures are used to ensure rigor. Just as the purpose, questions, and method of qualitative work differs from those of quantitative study, the procedures to ensure rigor must also differ. The terms
“auditability” and “confirmability” are used when referring to qualitative research, and replace the quantitative measures of “reliability” and “validity” respectively.

**Auditability**

This criterion of qualitative rigor refers to the consistency of the findings, rather than repeatability of the data (Sandelowski, 1986; Sandelowski, 1993). Auditability is achieved when another researcher is able to clearly follow the decision trail of the study in question, and reach the same or comparable conclusions (Bailey, 1997; Burns & Grove, 1997; Sandelowski, 1986).

For this research, the decision trail was made explicit through detailed record-keeping. These records included explanations of: how I became interested in the subject matter, how I viewed the study topic, the specific purpose of the study, how the participants and pieces of data came to be included in the study, how the data were collected, the nature of the settings in which data were collected, and how data were reduced and transformed for analysis (Sandelowski, 1986). The chairperson of the thesis committee for this study reviewed the decisions made as the project progressed. Auditability for this study is most evident in the final report that follows.

**Confirmability**

Confirmability refers to the criterion of neutrality in qualitative research, and is achieved when auditability, credibility, and fittingness are ensured (Sandelowski, 1986). Credibility is a measure of how well the data represents the experience, and how easily others experiencing the same phenomenon can recognize it from the data interpretation (Sandelowski). Therefore, credibility is determined by the participants rather than by the researcher. Fittingness is the measure of applicability in qualitative research, and compares the insights
formed from analysis to the data collected. This measure applies to the data rather than the participants of settings (Sandelowski).

To ensure confirmability in this study, several procedures were employed. Through the use of a reflective journal, the researcher's own biases were identified as they arose during the research process. Through attention to ethical considerations, and attempting to convey a non-judgmental interest, I strove to establish a trusting rapport with the participants to encourage open discussions. Data collection continued until no new themes were identified. Members of this thesis committee provided invaluable consultation regarding fit between data and emerging themes. Finally, as suggested by Sandelowski (1986) and Johnson (1997), credibility was enhanced in the final analysis which contains rich descriptions of the study's themes.
CHAPTER 4: Findings

Participants

Eight parents representing 7 families were interviewed for this study. The majority of parents were mothers with 1 father participating. All interviewed parents were caucasian, and their ages ranged from 28 years to 45 years. Seven of the 8 parents were married; one was a single parent. For all but one family, the mother was identified as having primary responsibility for the child’s medical management. The parents of the seventh family indicated that they share the responsibility equally. Parental education varied and ranged from high school diploma to university degree. Of the two-parent families, 4 had a dual income and 2 had one parent as a single earner. The single parent was employed. All parents described their own health as “good”. Four of the families had only 1 child. The remaining 3 families each had 2 other children in addition to the child with the chronic health condition. The siblings’ ages ranged from 18 months to 13 years, and parents described all of the siblings as being in good health.

The children with chronic health conditions ranged in chronological age from 19 months to 6 years with a mean age of 36.6 months. Most children’s (4) chronic conditions were diagnosed in the neonatal period. Two children were given their diagnoses at age 6 months, and 1 child was diagnosed at age 14 months. The etiology of the health conditions varied with 3 being the sequela of prematurity, 2 due to neurological syndromes, 1 due to a traumatic event shortly after birth, and 1 due to infection.

As necessitated by their children’s chronic health conditions, 2 families attended a single outpatient specialist service, 1 family attended 2 outpatient clinics, 3 families attended 3 clinics, and 1 family attended 5 specialist services.
However, not all of these outpatient clinics involved contact with nurses. Four families had contact with nurses in only 1 clinic attended, 2 families interacted with nurses in 2 of the outpatient services they utilized, and 1 family saw nurses in 3 of the outpatient clinics they attended.

The families also have had experiences interacting with nurses in the inpatient hospital areas. Three children had been born extremely prematurely and, consequently, were hospitalized for extended periods of time. One of the other children was critically ill in the newborn period and was hospitalized for this time, and another became ill in the newborn period and was hospitalized for 6 days. Two children were diagnosed on an outpatient basis, and were hospitalized at a later time. Most of the 7 children had been re-hospitalized at some point after their birth. Three children spent less than 24 hours in hospital as they had day care surgeries. One child spent 1 week in hospital due to a respiratory infection, and 2 children were unpredictably and frequently admitted to hospital due to seizure activity. Only 1 child has not been admitted to hospital since birth.

**General Comments**

In general, parent participants tended to characterize their interactions with nurses as being positive. Descriptors ranged from “fantastic” to “good”, with a few parents describing some nurses who were “not as good”. Examples from this range of responses are presented here.

One parent offered:

My experience was overwhelmingly positive... and they (the nurses) were one of the more positive things about being there.

Another parent concurred:

...it was really positive considering the circumstances.

One parent commented:
The nurses were all very good and, well, I just never had a problem.

Three others shared:

At no point...do I have the impression that we were sort of let down by the nurses.

...my experience with the people, no, there was nothing that I feel stands out as a huge negative.

...I can't really say we've had bad experiences.

Despite the decidedly positive tone of the parent-nurse interactions, most parents did describe at least one situation that they characterized as negative. However, for most parents, these were considered to be isolated events. As one parent summarized:

There are a few nurses whose style was sort of, they're not quite as good as most of them. But, you know, they're rare exceptions.

Parents found it to be difficult work to recall their experiences. Some struggled to remember due to the length of time that had elapsed between the events in question and the interview. However, most shared that their memories of the most significant times in their children's health care remained vivid and painful to recall. As one parent said:

It's hard to think about it again, you know. You really do try and forget about it because, human nature, you just don't want to think about the bad times."

In addition to the painful nature of the memories, was a desire to leave the negative events in the past. One parent noted:

...it's almost like it never happened. We sort of left everything behind when (our child) came home.

Another mother described the profound effect the experience had on her.
...being in the hospital really made me want to work there...because if I could give something back that would be great.

**Themes**

Three distinct themes regarding parent-nurse interactions emerged from the qualitative interviews, and are: establishing rapport, meeting parental needs for information and support, and negotiating care. Nurses were better able to meet parents' needs for information and support, and care was more easily shared, when they first established rapport with parents, and care was more easily shared. The focus of this chapter is a description of these themes with specific attention to the aspects that contribute to either a positive or negative parental assessment of interactions with nurses.

**Establishing rapport**

The intimate nature of nursing care necessitates personal interaction between parents and nurses. Not surprisingly, the parent participants in this study described numerous interactions related to establishing rapport. Parents maintained that the degree of rapport established between the parent and nurse is influenced by the nurse’s knowledge of the child, the nurse acknowledging prior contact with the family, reciprocal information sharing, having something in common with each other, the personal characteristics of the nurse, the parents' trust in the nurse, and the environmental factors within the health care setting. When rapport was established between parent and nurse, individualized care resulted.

**Knowledge of the child**

A key aspect of establishing rapport, from the parents' perspective, was the nurse’s demonstration of interest in learning about the child’s condition and in the child as a person. As one parent commented:
Some are more comfortable than others definitely. Some are, um, ask more questions, are more interested in, you know, like whether he sees or he doesn’t, what he likes or he doesn’t...

And another reasoned:

...they’re always looking at the child but not necessarily only at the lab reports.

Through the nurse’s knowledge of the child’s condition, parental confidence in care was enhanced and parents did not have to repeat information as often. As one parent commented:

That’s the worst - giving the entire history every time.

And another parent stated:

...Yes, they know (my child), they know what they have to do... Less questions are asked because they know...

The consequences of not knowing the child as a person was frustrating to parents and sometimes necessitated parental work to encourage nurses to recognize their children’s capabilities. This is highlighted through the words of one parent as she described how none of the inpatient staff had ever seen her child at his best.

...people at the (rehabilitation center) that have done physio or worked with (my child), they have. They’ve seen that other side, and I guess that’s the side that we see regularly that medical professionals don’t. I remember with one hospitalization having to bring in pictures to convince them that (my child) wasn’t vegetative, right?

Further, parents considered it important for nurses to learn about some of the child’s unique characteristics.

...he’s a child that hardly ever cries. He cries when he’s very, very sick...so to hear this kid scream for three hours, there’s something wrong.
When nurses demonstrated that they knew something about the children, parents felt more comfortable with the care their children received.

**acknowledging prior contact**

Parents appeared to find interactions with nurses more positive when the nurses demonstrated that they remember the child and family on subsequent meetings, and acknowledge having previous contact with them. One parent observed:

They’ll come and say ‘Hi’. And that little extra thing where it takes them three seconds or whatever, but that is definitely making the difference.

Parents seemed to particularly appreciate nurses who acknowledged previous contact with the family when they returned to visit an area where their children had been hospitalized for extended periods of time. One mother remembered:

There’s still always quite a few that come out and remember (my child), and it’s nice to see.

**reciprocal information sharing**

Establishing rapport involved a sharing of information between the parent and the nurse. Through this reciprocal exchange, parents came to know the nurses caring for their children. One parent described:

...and if there was a new person who I hadn’t met, they would tell me about themselves and that was good because we would communicate. And then they’d ask me about myself and about (my child)...

However, information is not immediately shared freely. Spending time together is important for each party to establish rapport, and to feel comfortable with each other. The amount of contact parents had with a nurse varied and depended on the setting and the type of contact. These factors influenced the degree to which they knew each other. In turn, the degree to which rapport could be developed
was also influenced. In general, more contact translated to a better rapport. Increased contact with the nursing staff took the forms of extended continuous contact and intense contact at significant times in the children's treatments. As two parents commented:

We were in there so long that I guess we were able to have good relationships with them and know them quite well.

...she sort of helped us along with all his steps, and when he came off the ventilator...she was the one that was sort of there when those things happened...so that's probably why we remember her so positively.

**having something in common**

Another pervasive comment from parents was that rapport was established more quickly, and that they felt more connected, with nurses with whom they had something in common. They explained the positive nature of the interaction in this way:

I guess there was more in common with the younger nurses...

...a lot of them had also been mothers and so they were able to pass on some advice...

probably because she handles things the same way I do...

Knowing the nurse on a more personal level appears to be more pertinent to developing a positive parent-nurse rapport than does parents' accuracy of understanding the nurse's professional role. Through their descriptions of events, some parents were not always able to differentiate between nurses and other health care workers such as unit clerks and psychologists. Further, parental understanding of the nurse's role, particularly in the outpatient clinic setting, was quite narrow. As a result, some parents did not access some services that they required as they did not realize that this assistance could be
provided by the nurse. For example, one parent required more detailed information about the child's condition and treatment. Her information needs were not met by the physician, and when asked if the nurse was able to provide some information and resources, she replied:

No, because it was really (the physician) that we were talking to, and I guess...I didn't really get into it with the nurses, and didn't know they would have that kind of information. That was something more that only the physicians could give us, I don't know...

Some of the issues parents would discuss with the nurses were the physicians' schedules, ward routines, and relaying messages to and from the physicians. They would also provide assessment information to the nurses as this was consistent with their parental perception of the nurse as information gatherer. Some of the parents did have a somewhat broader view of the nurses' role, citing information provision and assistance with accessing resources as primary functions within the role. Despite some inaccuracy in understanding the nurses' role, most parents reported having established a rapport with the nurses they encountered.

**nurse characteristics**

Nurse behaviors that were associated with rapport were being nice, friendly, empathetic, approachable, available, optimistic about the child, and providing care beyond the parents' expectations. A few parents commented that they "were very impressed with the level of (the nurses') professionalism". However, most parents described nurses as "good" and "not as good". Further, they described "good" nurses in relatively subtle ways, and generally did not immediately recall concrete examples of what made nurses good. Instead, they described a general but immediate impression.

...you know instantly that 'Oh good, I've got a good nurse for awhile.' It's almost instant.
It would take me ten minutes to know if I would want that person around my (child).

The nurses' personality characteristics seemed to lead to parental assessment of the nurse as "good" or "not as good", and of the encounters with nurses as either positive or negative. When asked for more details as to why a particular nurse stood out as "good", one parent replied:

...she just stands out in my mind as such a very nice individual."

And another parent responded:

It's just so nice to have someone who's nice.

Related to being nice is the attribute of friendliness. If a nurse provided care in a friendly way, she or he was deemed more likable.

"Good" nurses conveyed to parents that they understood that the circumstances were difficult for the families. Two parents commented:

I think they were all really nice, very empathetic, understand that you're going through something huge.

...she seemed to fully understand what I was experiencing, and I think when anyone has the ability to put themselves in your shoes, that's a real gift.

Specific nurse behaviors that indicated an empathetic attitude included taking time to talk to the parent, asking what the child and parent may need, and asking how the parent is feeling.

Most parents of children admitted to inpatient areas spoke about the times that they were not able to stay in the hospital overnight. These parents reported feeling comfortable telephoning the nurses to inquire about their children because of the nurses' open and approachable demeanor. In addition to being approachable, nurses that parents associated with positive experiences were also available to address parents' questions or concerns.
...we're very comfortable with her. If I have a question I can phone her and she'll phone me right back.

While describing an atypical situation during a labor dispute, one parent recounted difficulty getting her questions addressed.

That was, come to think of it, a frustrating time. That would be it because the nurse wasn't available. But you expect that they would be there. That was hard because it was a time when you're stressed out seeing your (child) sick and couldn't get help...you feel it then. 'Well, come on, you're a nurse. Help me.

The majority of parents positively discussed nurses who offered hope, even when that hope was faint.

I remember the nurse the first night..., because they didn't know if (my child) would make it through the first 24 hours. The nurse that was with him was very good, you know, very hopeful and very positive.

When their children were critically ill, parents retrospectively appreciated the nurses' open, optimistic approach tempered with protecting the family from alarming information.

Well I guess something that I appreciated was that they didn't let on when we didn't know what was wrong, they didn't let on negatives that it could have been...not letting on anything that would lead us to worry.

Another parent echoed this sentiment:

I guess they were just trying not to sound too scary. Because we were already scared after talking to the doctor.

Some parents elaborated on the nurses' optimism in contrast to what they perceived to be the physicians' negativity.

...you can talk to a doctor and you really feel bad and then the nurses would sort of have a good cop / bad cop kind of thing. So the nurses were a lot cheerier.

I mean they (the nurses) were very friendly and they, I don't know how to explain it, they were very cheerful all the time even when
(our child) was really sick in the intensive care area. They tried to focus on the positive things which was a nice sort of balance with the doctors. Because, I guess it's their job to, the doctors, to tell us what was wrong most of the time, and the nurses would sort of try and focus on what was better that day than the day before.

The interactions were regarded as highly positive when the nurse conveyed a realistically positive attitude regarding the child's prognosis. As one parent stated:

That's what I liked about them (the nurses), that they were always very positive. They would always say, you know, "Well this is common"...that's good. They would share with me their experiences that this is what happens. They would give me something that wasn't really that positive, but they would back it up with something that was a little bit more positive just to try and reassure me and make me feel better.

Parents hastened to add that these nurses did not offer false hope. Rather, their optimism was based on objective observations and assessment. As one parent described:

Yeah, but she was always reassuring, giving her own opinion...I mean she really thought it through. It wasn't just like she'd stand there and go 'No, no, I don't agree'. I mean she had reasons...

Another parent reported:

They would say things like 'Oh, he's going to be just fine', or 'look how well he's doing', I guess along those lines that were a little encouraging.

However, when the nurse did not offer any hope about the child, parents perceived the interaction as negative. One parent recalled:

We didn't leave the hospital with any positive, you know, it was totally negative...that's how we went home.

And another parent hypothesized:

I would have liked a little bit of hope for, you know, but then that's a hard one because a nurse doesn't want to give hope when maybe hope isn't possible. But, I guess, hope is always possible.
Parental perceptions of interactions with nurses were strongly shaped by the nurses' approach. That is, the way a nurse delivers care was just as influential on parents' perceptions as was the observable care the nurse provided. For many parents, the nurses' personality characteristics became explicit through their approach to providing care to the children. Specifically, parents found that interactions tended to be positive if the nurses demonstrated a willingness to "go the extra mile".

...they seem to offer a lot more, the good ones, than the ones that are just there for the bare minimum.

Nurses who made an effort to informally interact with the child and family, in addition to interacting for the purpose of providing clinical care, were remembered in a positive light. One parent recalled:

...one stopped and chatted for awhile and took time to be with (my child), and then talked a bit more with us. And I think we really liked that - the friendliness.

Less frequently, nurses displayed negative behaviors, which made rapport-building with the parents more difficult. One of the greatest challenges some parents faced was dealing with nurses who had a blunt approach, especially when these nurses were encountered during stressful times.

The personality that's more abrupt, doing the job and not really showing, you know, a more humane side or a nurturing side. It's more the business-like side, that's the type of personality in a nurse that I think is challenging. Because in my situation it was a very emotional, I guess a lot of people in hospitals are dealing with things that are hard, so you'd like to have a human touch. And when that's missing it makes it harder.

The nurses that failed to listen to parents and respect their priorities were mentioned as contributing to a negative experience. As one parent recalled:
...that was really the only time I've been mad at a nurse. They decided they had to get a catheter urine specimen and she tried shoving in a catheter that was too big. I asked for a smaller catheter...It was pretty tense.

Another parent commented:

...one nurse I remember very, she was very friendly but it's just, she was giving us, volunteering things that we probably weren't interested in, you know, and sort of didn't drop the matter.

Yet another parent recounted the time that the nurse caring for the child suggested invasive procedures to improve the child's appearance. However, the child had been gravely ill and had already undergone several invasive, life-saving procedures. The nurse's suggestions were "the last thing (they) wanted to do". This parent speculated:

...and one of them (nurses), she was very friendly but in an overbearing kind of way. It may have just been a generational thing with the different philosophies about how to deal with infants, I guess.

And, finally, one parent cautions:

...if you're pushing towards this parent participation, then you're going to have to show some respect for the parents involved...I mean parents live with their kids, they obviously see day in and day out and they have a lot of input.

Interestingly, nurses who did observe parental priorities and demonstrated respect for parental knowledge were not specifically mentioned for these positive characteristics. However, negative experiences were rare, so when they occurred, parents were surprised.

Of note is the observation that the nurses' approach changed as the child's prognosis changed. This point is significant as most parent participants provided examples of how this occurred for their families. When a diagnosis, and
therefore prognosis, was yet unknown, one parent described the nurses’ demeanor as “neutral”.

One parent described the nurses’ attitudes when the child was critically ill.

It just seemed like...they were very, the first week, very blunt. Which they probably, for their own protection too, but I don’t think they needed to be so direct and to the point.

Another parent described a change from a “cautious” and “more formal” nursing approach when the child’s survival was in question, to a more “casual” approach, creating an “almost homey” atmosphere when the child’s condition improved. Still another parent described the nurses’ approach change when the child’s condition deteriorated, and prognosis became bleak.

I definitely remember feeling a change when they knew how much damage had been done...then you could really tell the difference from everybody...their attitude and the way they acted, it wasn’t as warm...it was really a little bit cooler. When we left, they couldn’t even find anyone to talk to us or anything. And I had seen enough parents leave...that was night and day, too. I guess no one had anything to say.

Parents appeared to apply different evaluation criteria when determining whether or not a nurse was good compared to determining whether or not a physician was good. Nurses were acknowledged, and held to a higher standard than were physicians, for their interpersonal skills. As one parent compared:

The nurses are better. The doctors are sometimes gruff, no bedside manner. Very gruff as to what’s going to go on, and I think the nurses are better.

And another parent observed:

...nurses seem to have more people skills.

And still another parent specified:

They (the nurses) were really good. They were informative and they always answered all my questions and told me everything, or
most of them anyway. Probably more so than the doctors because the doctors just kind of speak in their language and you don't really know half of what they're saying. But the nurses will explain exactly what they were saying, which was nice.

Although nurses were deemed more highly skilled in interpersonal skills than were physicians, they were also evaluated by higher standards in this regard. This finding became more clear through parents' comments indicating that physicians are primarily evaluated on their clinical competence. As one parent articulated:

...I guess it's irrelevant what their bedside manner is. I mean, I guess what you're looking for is the best you can get... I mean, I found Dr. ( ) just horrendous but I said after the fact, in a crisis do you think that doctor will do the best for your child? I guess you just have to swallow whatever else comes along with it...

Some interactions with nurses that parents viewed negatively were related to the variability of nursing care. Parents described considerable variability in the delivery of nursing care. This variability seemed to depend more on the individual nurse's personality rather than on adherence to professional practice standards. Phrases such as "some are better than others", "it depends on the nurse", "it depends on the individual", and "sometimes good, sometimes not so good" were common in parents' accounts of their interactions with nurses. Although a frequent experience, it remained puzzling to the parents. As one mentioned:

...that time we had problems, the last time they were not bad, this time they were much better. I don't know why that changed.

And another commented:

You see a difference between nurses even on one day. You know, that other nurse that we had was nicer than this one, but not that any had done a bad job...Some are more clinical, others are more friendly.

Still another parent elaborated:
You don't know, right? Every shift change, I mean you don't know who you're going to get next. I don't know how it works, how the resources are spread out, but some just seem to have a lot more to give. And they're on the same ward. Like, how does that work? I guess I don't really understand how there's such a difference between one nurse and another. One acts like they don't have a minute to spare and the other one - there is an opportunity.

**trust**

Trust, a crucial aspect of rapport, was enhanced when parents deemed the nurses competent. Most parents described being able to sense that the nurses were competent to care for their children rather than being able to identify specific nurse behaviors indicating competence.

...I guess it's totally how you feel. Like the reaction you get from them, their attitude. I don't know, the way they go about it, I guess...So I don't know, you get that feeling. If they know what they're doing or if they're, you're not comfortable.

I just could tell that she had a lot of experience obviously and she knew, she seemed to know what she was doing really well...

Another parent expanded this sentiment by saying:

...it was always hard to leave at night, but it was easier knowing that (my child) was getting such good care from them...

And yet another parent echoed this idea:

They (the nurses) made it, they were a big difference, you know, because it was very comforting because they were there...It was hard just not being able to be there myself like twenty-four hours a day, but I knew that (my child) was getting really good care so that made it easier.

While knowing that a nurse was competent was more a feeling for most parents, others were slightly more specific about how they knew that a nurse was capable of providing good quality care. Specific features of a nurse which indicated competence were speed and certainty.
...and you know the time, they're quick, they're not humming and hawing.

Only one parent expanded beyond these features.

Well, for me it's how they handle (the infant), just how meticulous, how quickly and how they would hold him or soothe him. Or how he looked, how comfortable, how well wrapped and clothed and tubed. Also their composure, how they composed themselves...

Conflict was created when nurses became confrontational or defensive.

One parent described a situation during one of her child's hospitalizations. The child had become extremely lethargic, and the nurse was about to administer an increased dose of medication. One of the side-effects of this particular medication was lethargy. This parent expressed discomfort to the nurse and:

...the attitude is kind of like you're questioning, you know. 'I'm doing my job and I know what I'm doing and you're questioning my job.'

Consequently, a transcription error of the medication orders was discovered, and parental trust in the nurse's care of the child was compromised.

environmental factors

The physical environment of the inpatient areas, as well as the routines of the respective areas, influenced the parents' experiences as they interacted with nurses working in those settings. The environmental aspects created different climates in which the interactions took place. The atmosphere was affected by the size of the hospital, the focus of the hospital setting, the location of the hospital in relation to the family home, staff turnover, and the rules of the particular setting. Of note is that parental comments related to environment exclusively occurred in the inpatient areas.

The atmosphere of the hospital setting changed when the child was transferred to a less acute area within the hospital. The generally more optimistic atmosphere of the less acute areas helped parents develop a rapport with the
nurses. As a result, the possibility of positive interactions with nurses was higher. One parent recalls:

I can remember when he was moved to the less intensive nursery. There was a lot more joy in there because everyone was going to get out. You know when they got there they were going to survive.

Another parent recalls a similar impression:

It was just a different situation, I think. That room was basically all the babies who were going home in a few days...there weren't all the machines and alarms going off every few minutes. The lighting was different. So that probably added to my perception of it as well.

All of the parent participants' children had been patients of tertiary referral services at a large urban center, and the majority of interactions described took place in this setting. However, a few parents had also accessed services from smaller centers in their home communities. By contrast, the tertiary services were described as more “impersonal”. Adding to two parents’ perceptions of the area as impersonal was the observation of the nurses as being busy. This seemed to be linked to decreased contact with nurses.

I would say that they (the nurses) worked really hard, they were always doing something.

The other parent observed that “We didn't see the nurses too much”.

Another aspect related to decreased opportunity to interact with the nurses was the location of the hospital in relation to the families' homes.

...you're basically taking three hours. You get there and you stay for an hour and then you leave. So it's not very much of a visit. It's almost not worth it.

Consistency of staff was often mentioned as a positive aspect of care. Specifically, repeated contact with a smaller group of nurses was important in developing rapport with parents. When one mother was asked what made her feel that the nurses on the inpatient unit knew her child, she replied:
Well I would see the same nurse. She would have the same nurse for 2 to 3 days and then it would change to a different one, but it was always someone I knew.

The majority of parents commented on staff turnover. Most of these comments indicated that opportunities to interact with nurses were drastically decreased in areas with higher staff turnover.

Children's Hospital was more like a training hospital, so it was a high turnover of nurses. We didn't always know who the nurse was...

Another parent mentioned "There's a different nurse everyday", and another parent recalled:

Well we had bad luck with primary nurses. Every time we'd get a primary nurse, she would either be reassigned to another room or (our child) would be moved into another room where they didn't work.

Another parent described the negative consequences of limited contact with nurses due to a high staff turn-over.

...so we didn't always know who the nurse was...and then they don't know the baby. So you're coming in and they're saying 'What is (your child) like?'. So it's more like you're giving them the information, really.

A few parents seemed to be acutely aware of a shortage of nurses. As one parent stated:

That's what I find alarming. You become aware of it when you're a health care recipient...it's alarming that nursing shortage.

The shortage caused this parent to change her visiting schedule.

I just put a cot beside (the) bed for however long we were there. I stayed and I just would never have felt comfortable leaving (my child) there, just knowing that there's not somebody watching...
While the policy of the individual setting may have affected parent-nurse interaction in adverse ways, some parents found that ward rules were a positive aspect that helped them to care for themselves. With respect to parents being required to leave the inpatient setting during rounds, two parents had these comments:

...it was a good break because I would spend most of my day there. The only time I would go was when they would kick me out for an hour and a half or two hours. And that was fine because I had to eat.

I just couldn’t stay sane if I didn’t get some sleep.

A few families were required to observe strict isolation precautions. As a result, parents were not permitted to leave their children’s rooms without performing required, and time consuming, tasks. Consequently, these parents most often did not interact with many people while in hospital. The process was also complicated for the nurses caring for these children, leaving little, if any, time for informal interaction with parents. As one parent observed:

I mean there were red lines you couldn’t step over, you had to scrub within an inch of your life before you left the red line area. Their (the nurses’) pens and everything, they couldn’t bring in. So, I mean, it was a pain if they’d forgotten something.

One parent broadened this point through her belief that some nurses were more adaptable to isolation precautions as influenced by the nurses’ personalities.

There are people who are tolerant and who could stand being in there gowned and masked all the time while they worked, and the ones that just couldn’t...

Once rapport was established, nurses were able to individualize the care they provided. Parents certainly noticed when nurses delivered care in a personalized manner. When care was individualized, parents seemed to speak
of the interactions with these nurses as positive. They also provided more
specific examples of individualized care.

...just little things she did like put the formula that they put into the
breast milk...Every time she came on she’d get the packets and
she’d mix the milk. So not one package for fifty mils, but how much
milk he was getting for the day so it was all in his milk evenly...

And another parent shared this example:

We used to have boards, like we used to know the prime
information about (our child)...When (our child) had been moved
into one of the rooms, they left our board behind, and we got a
fresh board and we hadn’t really spent the time updating it...One of
the nurses that we knew quite well, she totally spruced up the
board...

This parent continued:

I mean the whole time, it’s not like we were a number or anything...

A nurse’s failure to individualize care also left an impression on parents.

One parent described her child’s frequent emergency room visits for treatment of
prolonged seizures. Typically, her child was given sedative medications to stop
the seizure, and then was admitted to the ward to “sleep it off”. Some nurses
performed regular vital sign assessments without consideration of the reason for
admission. This parent commented:

We get very bothered when these nurses are poking and poking
until she wakes up, and if they don’t have to. If they just left her
alone or did it later.

Another parent, whose child was in strict isolation, described what she
considered to be conflicted interactions with nurses due to a lack of
consideration for the individual situation.

...but a lot of these rules didn’t apply to us as well, like they have
the rule that you have report, well, where do we go? So these new
nurses would come in and go “You may have to leave now.” “No, I
don’t actually.” And she’s like “No, really you do. We’re having
report. I'm like "Actually no, really I don't have to leave." And, I mean, some of them really didn't like that room because their general rules didn't apply to us.

In summary, the degree of rapport that was established between parent and nurse was influenced by several factors. Nurses who demonstrated knowledge of the children's health conditions and unique characteristics, and who acknowledged when they had prior contact with the families, were able to develop better rapport with parents. Reciprocal information sharing helped to establish rapport, and was enhanced when nurses and parents had something in common with each other and spent time together. Certain nurse personality characteristics, such as being nice, friendly, empathetic, and optimistic, helped nurses and parents to connect. These personality characteristics were demonstrated through the nurses' approach. Parents noted a change in the nurses' approach which corresponded to changes in their children's acuity or prognosis. Parents' trust in the nurse was linked to parental perceptions of the nurses' competence. Environmental factors related to setting, consistency of staffing, and ward rules influenced the amount of contact that parents had with nurses. In turn, the ease with which nurses established rapport with parents was also affected. Once rapport was established, nursing care could be individualized.

**Meeting parental needs for information and support**

The positive or negative assessments that parents assigned to their interactions with nurses were partially influenced by how well nurses met their expressed parental needs related to information and support. Parents described how nurses often met their needs through thoughtful information provision which considered the parents individual learning style. Parents also described events
during which nurses provided practical and emotional support. When needs were not met, parents assumed this responsibility themselves.

**information needs**

Information was the most frequently discussed aspect of this theme. At certain times during their children’s care, parents could feel overwhelmed and unable to take in more information. As one parent described:

At that time I wasn’t ready for that information because I was having to go to way too many appointments and I was just stressed...

Several parents commented that most nurses were sensitive to their readiness to receive information, their need to receive it in manageable amounts, and the parents’ most comfortable way of understanding the information. One parent shared this event:

I mean it turns out one of the times where we thought a nurse was being, it seemed like she was being a little bit insensitive to (our child) because he was being quite fussy. She turned out to be right, you know, in terms of we couldn’t get him to sleep. And then after we sort of gave up, she came over and did it the way she said and it worked.

And another parent described assistance provided by the nurse with prioritizing the reams of printed material received from multiple professionals.

Because I still have so much information...that I still have to really go over. Because there’s a lot of information...It keeps coming...I think with (the nurse), there were a couple of things on top, she says “Make sure you familiarize with this, this is what you’re gonna need in the near future”...

And a mother described how the nurses were sensitive to her method of processing the information she received.

...I just needed to think about it more than anything. But generally they knew if I was sitting very quietly or thinking about something.
And they left me alone and it was just, I found, the easiest way to deal with it.

Relatively few comments were made about parent-nurse communication compared to comments made about the other themes in this study, and the comments that were made tended to be quite indirect. For example, one parent implied that communication was better with nurses that with other health care providers.

...we found it a lot easier to talk to nurses about what was happening with (our child).

Nurses also tended to avoid jargon when communicating with parents. One parent appreciated that "...they were always good to explain it to (me) in English".

All parents positively described at least one example of being taught by a nurse. These descriptions indicate that nurses were able to teach concrete tasks well, and the skills that the parents acquired as a result were deemed useful and necessary. Such tasks included routine infant care, comforting the child postoperatively, giving injections, and administering medications. Further, the pace of instruction was comfortable for the parents, and they felt confident to cope with these tasks at home.

Yeah, it was very smooth because it was very gradual. It wasn't like suddenly they started saying "Do his bath". They would show me how to do everything and it was, they were always there to help us at first until we knew how to do it.

Nurses generally demonstrated skill in preparing parents for a variety of experiences through the course of their children's medical management. The examples provided occurred exclusively in one inpatient area. These experiences included preparation for a milestone in the child's treatment such as discontinuing the ventilator,
...they were confident he would do O.K., but actually the first time they took him off he had to go back on, but then after that he was fine...she (the nurse) just sort of prepared us ahead of time saying he might have to go back on and to not get too excited.

and for the child’s surgery.

...helping us understand what was going on...what questions we should ask, they sort of helped us at that level as well. More of that early on but even later on when he went back into surgery, you know, they (the nurses) were all so good about making sure that we sort of were prepared for it.

One mother, however, found the nurse’s efforts to prepare her for the possibility of her child’s death intensified the negative experience.

I was talking to that nurse one day. "I wanted to slap you so bad!" She said even then “Well he could have died.” and I was like...”I know, but you don’t need to tell me that.” and she goes “Well, I didn’t want you to be unprepared...”.

Also, despite the nurses’ sensitivity to parental information needs, the information was not always provided in a way that parents found helpful. Three of the parents described events in which their information needs were not met. The first had a strong need for a deeper understanding of how her child’s crisis occurred, and how the medications affected her child. She felt that this understanding was important in managing care at home and preventing further crises.

...because when something like that happens, I mean we can predict what you’ve been exposed to. So I mean we can predict, we can see things that have happened...But when you’re exposed to something different then you’re basically saying “O.K., I didn’t know this could happen or how this happened”...I need to understand it better...

Yet, despite this strongly expressed information need, this parent did not feel that she had adequate knowledge. She continued:
...I still don't have a clear understanding of how those drugs work...Like I still don't get the concept and even, you know, the implications, right? So I still don't understand that...because you can't accept it if you don't understand it...

The second parent with unmet information needs recollected the early days during which her child was admitted to hospital. She retrospectively recounted this situation.

I have to say, I mean they could have relieved a lot of the beginning stress, I mean a lot of the things that I found out like how (the ward) worked and stuff, was not the nurses, who it probably should have been from. It was from other parents...that I knew what was going on and where things went...Not because it was the nurses. So probably if they were just a little more informative at the beginning.

Similar information needs remained unmet for the third parent. She stated that her biggest challenge when dealing with nurses was "...just knowing what the community can give me".

This parent also found herself in the position of providing information to the nurses as her child's diagnosis was quite rare.

...so I think the nurses, because it's a specific syndrome and not that common, the knowledge. Like they were coming to me more for the information than I would go to them for the information...

**support needs**

Parental support needs were less consistently met when compared to meeting parental information needs, although nurses were supportive to parents in both the emotional and practical aspects of their experiences. A few parents recounted in detail the events during which they received care and consideration from the nurses. Caring for the parent as well as for the child was viewed as something beyond the nurses' role expectations, and was appreciated. As one mother reported:
...when there was something that they had to do that was going to be hard for me, they just hustled me right out. So they were sort of motherly almost, and sort of taking charge and aware of things that would upset me...

Nurses also cared for parents in more direct ways. For example, one mother, whose infant had been taken to critical care shortly after birth, remembered one of the earliest times she went to visit her child.

...I had a huge hormonal swing and, the one nurse was...so compassionate and she even said "I know what's going on with you." And she gave me some information about me which was really nice...And something else I was impressed with, actually, was that it was reported how I was doing ...not only to the pediatrician but my doctor and he came to see me...I was impressed that I was not being totally ignored.

Another parent cited an example of how the nursing staff realized that more support was needed because of their observations of the parent's behavior change. One of the most memorable events for this parent was when her child's surgery was repeatedly postponed. As she became increasingly concerned that her child would deteriorate with further delays, her demeanor toward the nurses changed from calm and friendly to curt. The nurses noticed this as being out of character. As a result, the nurses advocated on behalf of the child to secure a surgical time in the operating room.

One parent recollected how difficult it was seeing some of the children, who had previously been patients in the same area as her child, coming back to visit. These children had multiple disabilities, and this parent then became alarmed about her own child's prognosis. The nursing staff observed that the situation was difficult for this parent, and took steps to minimize her exposure.

I guess they had it written down 'Please tell Mrs.( ) when it's safe to come out and when it's not', because there would be no one to take care of me.
Another parent described the difficulty she encountered with non-nurses in a community service. As her child would require long-term follow-up through that service, the nurse in the specialty area intervened to assist the parent to develop a more positive working relationship with the community service providers.

Another example described was of assistance with obtaining supplies prior to the child’s discharge.

When we were being discharged and we had to get the (medication) and we needed needles. I had nobody. Like the pharmacy said I could only have these needles if I had insulin, and she wasn’t on insulin...And this nurse, you know, looked around, went to each ward, took a couple of needles off each ward...she was wonderful...

Negative experiences in the area of meeting support needs that parents encountered were more related to times when nurses were not present,

Yeah, oh it was huge news...it was very devastating...Actually we did see nurses in the clinic to do the initial blood pressure, that kind of thing, but it was after hours...it was very late. or related to the nurses’ failure to provide support.

That did get missed in the sense that they could have connected me with the At Home Program, or just had somebody to talk to...

Comparatively few negative nurse behaviors were described. However, parents did report these infrequent events with vivid detail. The chief concerns were with nurses who were defensive, or who failed to convey a caring attitude.

One parent told this story:

It was a nurse we hadn’t had before and she just had a bit of a different way of speaking. It was like a big deal for me to hear that (my child) might be having another infection, and I was really worried about it. It was just the way she told me, just kind of emotionless...It was totally different than the other nurses that I’d been used to dealing with who, I’m sure, would have explained more about it and been more sympathetic...
Parents reported negative interactions with nurses when the care for them as parents was given at what they perceived to be the expense of their children's care.

...(my child) became very irritable one night and I was walking her around and one of the nurses approached me...so this totally shocked me and she said “Well, you need your rest. Why don’t we just, with these babies that are irritable and crying, we usually just put them in the back room and shut the door.”...what a horrible thing to say...

Parents did not always obtain support from nurses, and the support from other parents was often more helpful. Parents supported each other in negotiating care with the hospital staff as well as providing emotional support for each other.

One aspect of parent-nurse contacts that could have interfered with meeting parental needs for support was some parents' perception that they were a nuisance to the nurses. One parent commented about regular telephone calls from home to check on the child. The nurses freely provided the information in a manner that this parent perceived as approachable.

...and they (the nurses) didn't seem to mind. Which was good because I felt like I was pestering them...

Despite this feeling of being an annoyance, the interactions did not seem to be influenced by this aspect as the parents continued to contact the nurses, and did not report any specific perceived change in the interactions as a result.

When support needs were not met, some parents assumed the information gathering and coordination roles related to their children’s care, and adopted an attitude of having “to seek out the information (themselves)”, “to figure it out (themselves)”, and to “just do it (themselves) if you (the nurses) can’t do it”. One parent sought to meet information needs by directly contacting pharmacists familiar with the medications in question. Another parent, who
happened to have a nursing background, went to extreme lengths to coordinate her child’s care, both in the inpatient hospital setting and following her child’s discharge from hospital. When her child’s blood pressure became alarmingly high, and she was unable to have this concern addressed by the physicians or nurses, she resorted to arranging specialist consultations on her own.

I went to the desk, I looked up the nephrologist, and I paged him myself...from my room.

Following discharge from hospital, this same parent continued to access resources and coordinate care alone. However, she resented having to assume these roles.

...I was extremely overwhelmed when we first came back...community wise it wasn't really followed-through well. I had to do everything on my own. I had to find this blood pressure cuff and it would have cost, it was five hundred dollars or something for a blood pressure cuff...when I felt like the community should have access to a blood pressure cuff. So I ended up, you know, organizing it with the hospital and just went two, three times a day...but it was still very frustrating...

In summary, parents assessed their interactions with nurses partially based on how well their information and support needs were met. Parental information needs were the most frequently described components of this theme, and were also the most consistently met. Parents perceived their contacts with nurses as positive when their readiness for and ability to understand information were considered, and when nurses demonstrated their teaching skills. Parents also felt more positive about the interactions when they were prepared for probable events. Parental information needs were not always met when the information was not presented in a manner that the parents deemed useful, or when the parents felt that they were educating the nurse about their child. Support needs were less consistently met, but parents did describe how nurses
attempted to address both the practical and emotional aspects of parent support. Experiences were assessed as negative when nurses were not available to provide support, when nurses failed to provide support, or when nurses worked to meet parental needs at the expense of the children. Although some parents worried about becoming a nuisance to nurses, they continued to seek information and support from nurses. Parents' sources of support extended to include other parents in similar situations. When needs were not met, parents often assumed the responsibility for securing what they required.

**Negotiating care**

Parent-nurse interactions included a negotiation, similar to a contracted division of labor, of the child's care. This involved a continuum along which care responsibilities were gradually transferred from nurse to parent, and the interactions were influenced by the degree to which parents' input was valued. Parental approach also influenced how the care was negotiated. From the parents' perspective, nurses often improved health outcomes for the children by negotiating care with the physicians on behalf of the parents.

**continuum of care**

The work of sharing the care appeared to occur on a continuum from all care given by the nurse to a more equal division of labor, through to a greater proportion of work assumed by the parent. One example of a more equally shared responsibility revolved around a neonate's frequent feeding schedule.

I remember one of them (the nurses) said, she acknowledged how exhausted I was and what we'd been through. And she said "If you want to express, I'll do the middle of the night one for you"...And so that was such a relief for me...

For many parents, their children's lengthy hospitalizations entailed a transfer of care functions to the parents as discharge from hospital neared.
Generally, parents found the greater involvement to be positive. As one parent indicated:

I was quite happy to feel like I was doing something instead of standing there and watching them care for my kid...

And another parent shared:

There was a lot more hands-on. In that respect it was much nicer.

And another parent described the assumption of care as it coincided with the child’s improvement:

Once (my child) was getting better I was doing more of (the) care like (the) bath and changing diapers, and just holding (my child)...

And this parent described the give and take of the negotiation:

...they would ask me ‘What do you want me to do?’ It was like a partnership in that sense that they didn’t want me to feel I had to do everything, but the option was there if I wanted to do everything...

However, when parents felt that they were expected to provide the majority of their children’s care, the tenor of the experience became less positive. One parent with a nursing background noted the circumstances which forced her to provide direct care to her child.

I think some nurses kind of expected you to do a little more. Like I went in because there’s, you know, nursing shortage as it is. I did a lot of procedures with the doctors instead of a nurse coming in sometimes...I went in and kind of assisted because they didn’t have any nurses available...

And another parent commented:

...parents do a lot...because we’re here twenty-four hours a day. So we’re not really asking you (the nurses) to do that much...

Other parents described a more neutral situation in which their children did not require a great deal of nursing care, but required mostly routine child care. One parent described:
Being in the hospital is not usually a big thing, but the nurses are available and they do always check on her, but it's a matter of just sleeping it off...once we're on the ward, it's more calm and we just have to wait for her to wake up. Unusual things we call. Otherwise, I don't think we bother the nurses much. We don't need them, they really don't need us.

**valuing parental input**

Parents felt that they knew their children best and had information that was crucial to their children's care. Nurses enhanced parental comfort with nursing care by acknowledging parental knowledge and by addressing concerns.

Yeah and if I felt something was wrong, having the doctor come and look and just say "no, the baby is fine". But she'd (the nurse) actually continue to look. Generally, if I thought something was wrong, something generally wasn't totally right...She always took it to heart.

Nurses also contributed to a negative experience for parents when they disregarded the parents' contribution to care or failed to maintain consistency of care. One parent became concerned with the intensity with which the nurse performed physiotherapy on the child. The parent directly expressed her concern to the physiotherapist, who confirmed the parent had cause to be alarmed, and a conflict ensued.

So she came on that night, I said...'I asked, you need to go talk to somebody, you're not touching my child with your physio'. And she was a little angry with me, but I was a little angry with her too.

Another parent offered this opinion:

On the ward they talk about parents in partnership for health care. Yet when you try and take a strong role, they don't like it.
Parents encountered difficulties with nurses who were rigid about ward routines. One parent felt strongly about checking the child's medications prior to the nurse administering them. She observed:

I think that people were very resentful of that process.

Another parent speculated as to the reason some nurses enforce certain rules, such as not permitting parents to remain at the bedside during rounds, even though circumstances deviated from the norm. In this parent's case, the child was in strict isolation, and the nurse still insisted that the parent leave during rounds.

...there's the ones that like to stick by the rules, there's the ones that don't care (about the rules), and I think the ones who really cared (about the rules) are the ones that like to give the mental reports on the mum and don't feel comfortable doing it while the mum is right there...

One parent described a situation in which interactions were negative because the nurses' knowledge of the parent was inaccurate and was based on negative opinion. This parent described an adversarial relationship with the nurses in which she and the nurses on the ward regularly "smashed heads". As a result, this parent felt that the nurses had formed a specific opinion of her. Her perception of the nurses' opinion is summed up in her comment:

...because they must see me coming and 'Oh my God, here she comes again!'..

This same parent also described interactions with the nurses that indicate a lack of knowledge on the part of the nurses about the parent's intentions. She described a situation in which the nurses interpreted her wish to be aware of the medication dosages her child received as mistrust of the nurses' competence.
She said:

...sometimes it's just the way people interacted, and they see that as confrontational versus protective or me just being conscientious about the care for my child.

**parental approach**

Some parents made a conscious effort to adopt a certain demeanor when interacting with those caring for their children. Others were not so aware or calculated in their behavior. However, different aspects of the parents' approach seemed to be linked to either positive or negative interactions with nurses.

One parent felt that her own positive outlook made a difference in her child's progress and noted it was consistent with the nurses' view. She observed by contrast the nurses' attempts to change another parent's approach for the benefit of the child.

...she was just devastated, and she would sit over her son in the incubator and she would hold his hand and she would just be bawling. Well his monitor was constantly going off because he sensed she was so upset...The nurses even made her leave...But I knew I was positive, well I didn't feel like I had to be, I just was. I was because that's my nature...

One mother gave considerable thought to her own approach and its effect on her interactions with the nurses. Particularly regarding what seemed to be negative interactions with nurses, she considered the following:

Sometimes putting on the brakes and looking at it from their point of view. Like why they're saying what they're saying or why they're doing what they're doing before I would actually bite their heads off, you know.

She continued to discuss how she consciously shaped her approach to effect the best nursing care for her child:

If you're gonna make the nurses' lives miserable, I mean, they're not going to take it out on your (child) but they're going to try and
avoid (us) as much as they can. And if you’re nice then they’re better and more relaxed and take better care. Yeah, I’ve thought a lot about it. I wasn’t going to be making anybody’s life miserable because it just ends up affecting (my child).

Other parents were not concerned about the effect their own demeanor may have had on their children’s nursing care. As one parent voiced:

I didn’t even give that much thought at all. You know, you’re world is turned upside down. I knew I was going to get what I needed for (my child) regardless of who liked me or didn’t like me.

But this parent qualified the above statement with:

I’m a fairly easy going person, and I usually get what I need done without having to be aggressive. I mean I can be assertive and it just, it all seemed to flow. I didn’t have to put a lot of thought into it.

Still other parents were not cognizant of their effect on their children’s nursing care, but were self-aware about some of their own personality traits that may contribute to negative interactions. One parent, upset by the tone of a meeting, had a conflicted interaction with one of the nurses. This parent shared:

I couldn’t keep my mouth shut and, I mean, not if something bothers me.

This parent had also enlisted the advice of an advocate to help resolve issues related to the child’s school, and described their conversation.

I said to her ‘Maybe it’s me. Maybe I am hitting everybody wrong.’ And she basically came back and said ‘Yeah, you’re extremely aggressive. Probably they were intimidated by your approach’.

Although this situation occurred outside of a health care setting, one may infer that this parent may employ the same approach with nurses.

advocacy

Finally, a curious phenomenon arose by which nurses mediated in the relationship between parents and physicians. These acts usually resulted in more positive outcomes for the children and families. One parent described a
negative interaction with a physician whereby that physician felt that the parent was challenging professional authority. The parent took the following action:

I just talked to the nurse and we discussed it, and she felt the doctor didn’t really need to do that. (The doctor) just maybe had a bad morning or something like that.

The same parent also spoke with the nurse after an upsetting meeting with another physician:

...so I phoned her (the nurse) back and I said “It’s the doctor’s job to make sure that I as the parent understand what the instructions are.”...and I said “Well maybe you could mention it to her that, you know, I prefer she doesn’t do that.

One parent described that the nurses assisted the parents in communicating with the physician.

...and they were really good about making suggestions. You know, just guiding us in terms of what kind of questions we should ask the doctor, those kind of things...

In summary, care was negotiated between parent and nurse, and involved a continuum along which care was transferred to the parent. Parents felt positive about assuming more of their children’s care responsibilities when they could exercise the right to choose how much responsibility they assumed. However, when the transfer of responsibilities was expected or imposed, parents described these interactions with nurses as negative. The interactions were viewed more positively when parents felt that their knowledge and input about their own children was valued, and when nurses shared the care with parents more equally. Specific examples of negative interactions arose when nurses were rigid regarding ward routines, failed to maintain consistency of care, misinterpreted parents’ intentions, or based their knowledge of the parents on inaccurate or negative opinions. Parents altered their own approach to interacting with nurses, which led to what they perceived as good nursing care
for their children. Parents also believed that positive health outcomes resulted for their children when nurses mediated with physicians on the parents' behalf.

**Summary of Findings**

Parents were able to make connections with nurses that were deemed helpful in caring for their children. Positive characteristics of the nurse that led to a better rapport included spending the time to know the child and the parent, sharing personal information to enable the family to know the nurse, a friendly and caring manner, a willingness to share information, and an optimistic outlook regarding the child. Building rapport was more difficult when nurses based their care on incorrect assumptions about the parents' priorities, were more formal and rigid when delivering care, or when sufficient time to develop rapport was lacking. Environmental factors, such as the hospital's size and focus of care, staff turnover, and the rules, influenced parental assessment of the nurses working within these settings.

Parents described more positive interactions with nurses when their expressed needs for information and support were met, or when nurses treated the parents as well as the child as the recipients of care. Interactions became negative when nurses assumed that parents would provide more care than the parents felt comfortable taking on.

The nurses' approach when delivering care was one of the strongest influences on parental assessment of their interactions with nurses. More positive interactions were reported when nurses individualized care and when they enacted their positive characteristics. Regarding these nurses, parents were able to sense competence rather than describe specific behaviors that enhanced their trust in the nurses. Parents also strove to enhance their children's care by changing their own approach when interacting with nurses.
Negotiation of care was a component of parent-nurse interactions. The tone of negotiations was influenced by the degree to which parents' input was valued and how the care was shared. The interactions were more positive when parents felt that they were treated as making a valuable contribution to their children's care, and negotiations had a reciprocal quality. The degree to which care was shared formed a continuum which ranged from all care provided by the nurse to most of the care provided by the parent. The most positive point along this continuum, from the parents' perspective, was when they assumed some of their children's hands-on care without feeling pressured to assume more than made them comfortable. Nurses also negotiated with physicians on behalf of the parents, and this was generally regarded as leading to positive care outcomes.
CHAPTER 5: Discussion

This study has corroborated some of the assertions found in the research literature on collaboration and partnership, and has also revealed some unexpected findings. In this chapter, the more unexpected general findings will be discussed with reference to their most probable explanations, the level of congruency of the findings with the research literature will be examined, and the major points raised in the findings will be explored.

Parents in this study appeared hesitant to describe interactions with nurses negatively. This observation caused me to reflect on my concurrent roles as nurse, researcher, mother, and health care consumer, and to more carefully examine how my position may affect the findings of my study. As previously described as a limitation of this study, my role as a health care consumer may affect the data analysis. However, measures were taken to minimize this effect, and the consumer role does not explain the positive tone of the parents’ responses. I feel my role as a mother provided the common ground that parents often discussed in reference to the nurses caring for their children, and enabled me to develop a degree of rapport with the parent participants. Thus, this role served as an advantage in data collection, but does not explain the tenor of parents’ descriptions. In my view, the most influence on the tone of parental responses was my sometimes competing roles as nurse and researcher. All parent participants were aware that I was a nurse working within the same group of facilities as the nurses who had cared for their children. They were also aware that I had a working relationship with the nurses who had approached them about participating in this study. Therefore, I suspect that parents were less likely to directly comment about events they perceived as negative.
Parents' views of nursing care were often articulated in vague terms. Further, nursing care was frequently contrasted with that of physicians with respect to approachability and communication skills, both of which were strongly linked to establishing rapport. Thorne (1993) also reported that patients found nurses to be both more available and approachable than were physicians, and felt more comfortable sharing their information and concerns with the nurses. The parents, themselves, speculated that differences between physicians' and nurses' education and socialization were responsible for the differences in approachability between the two professional groups (Thorne). Yet, parents in this study were not always aware of the full scope of service they could expect from nurses, and often held narrow views of the nurse's role. These findings may be explained by considering the aspects of professional authority and hierarchies as they occur in the social context of health care. Despite progress in enhancing nursing's public image and encouraging a more accurate regard of nursing work, some authors suggest that, although education requirements for entry to practice are now more equal, nurses continue to employ elaborate strategies to secure quality medical care for their patients while maintaining the physicians' view that he or she directs the care decisions (Rachlis & Kushner, 1994). Consistent with the findings of this study, nurses seem to continue to advocate for children and their parents through mediation with physicians in such a way as to make invisible the unique focus of nursing work. Parents, then, do not usually have opportunities to witness examples of nursing care that more accurately reflect the distinct aspects of our profession.

The findings from this study were compared to the research literature concerning collaboration and partnership. While consistent with some aspects of the literature, many of this study's findings differed to some degree from others'
published works. The consistent aspects are now outlined and findings that differ from the current literature are discussed in more detail.

Consistent with the literature, rapport was more easily established when parents perceived there was something in common with the nurses. The body of literature regarding collaboration suggests that developing mutual goals is a critical component of collaboration (Mathews et al., 1995), and that goals must be relevant to the family to enhance commitment to the plan (Graves & Hayes, 1996). This study confirms that interactions were more positive when nurses respected the parents' priorities. Also, similar to Opie's (1998) findings, parents and professionals negotiate their roles when providing care, and the degree to which responsibilities are shared depends on the professionals' beliefs and environmental structures. This negotiation involves a transfer of responsibilities from the professional to the patient (Biley, 1992). Negotiation proceeds more smoothly when the nurse views the parents as capable of participating, and values the parents' knowledge (Humphrey et al., 1993). Similar to the patients in Waterworth's and Luker's study (1990), some parents in this study changed their own behavior to effect positive care outcomes. Findings from this study also support the conclusion that increased parental stress is created when nurses place too much responsibility on parents regarding the care of their children (Waterworth & Luker).

There is evidence from this study's descriptions that nurses are striving to meet the Family Centered Care mandate. However, although some agreement exists between these findings and the partnership literature, the majority of parental experiences described in this study do not closely reflect the literature recommendations regarding collaboration with families. The probable explanation is that, despite organizational mandates to build partnerships with
families, parents in this study did not characterize their interactions with nurses as collaborations or partnerships.

Another feature which may help to explain the discrepancy between this study's findings and the literature is the accepted fact that collaboration with families is simple to discuss, but is very difficult to enact in practice (Fenwick, Barclay, & Schmied, 1999; Liedtka & Whitten, 1997). This circumstance is further exemplified by Fenwick et al. who noted the multitude of Family Centered Care directives in the literature, but found in their study that nurses rarely engaged parents in relationship building.

Finally, there is a general acceptance in the literature that the parent-professional interaction affects how well parents learn to manage the chronic condition (Wuest & Stern, 1990). Organizational mandates, in the form of written documents, espouse the value of developing partnerships with parents. However, aside from satisfaction questionnaires, most descriptions specifically related to collaboration tend to be interprofessional and not between professional and parent. For example, Wells, Johnson & Salyer (1998) studied interprofessional collaboration between physicians and nurses and described the presence of many elements of partnership consistent with organizational mandates. However, professionals' success in enacting positive collaboration cannot be used as a benchmark when devising ways of providing Family Centered Care to families as the power base and level of investment differs.

**Establishing rapport**

Knowing each other was a notion consistently described by parents in this study. More specifically, parents' accounts emphasized the importance of the nurse coming to know the child and the parents, as well as the parents
developing a sense of knowing the nurse. Paavilainen and Astedt-Kurki's results (1997) confirmed that a reciprocal exchange, with contributions from both parties, is an element of a successful working relationship. Radwin (2000) furthered this point with the finding that the positive rapport resulting from mutual sharing helps parents to feel more comfortable. Nurses "knowing the child" was important to parents in that parents expressed a greater degree of comfort in the care provided once the nurse had learned about the child's health condition, capabilities, and unique characteristics. Further, parents were relieved of their educator role when the nurse knew the child and could proceed with providing care. In such instances, the parents were no longer required to provide the child's information with each encounter. Radwin's study of oncology patients' perceptions of the attributes of quality nursing care revealed that caring was evident when the nurse remembered the patient. Knowing the child appears to be a precondition of individualized care. Once the nurse knew the child, parents perceived that care was often tailored to the child's needs.

Fenwick et al. (1999) found that parent-nurse interactions were more egalitarian when they did not relate to specific actions. Rather, these were conversations about life outside of the hospital, and were directed by the parent and nurse equally. Parents in this study also reported more positive interactions leading to a better rapport when they felt they knew something about the nurse as a person. This allowed parents to connect with the nurse over things which they had in common. The interaction may then have been altered to a more equal level, allowing parents and nurses to more comfortably work together. Parents may have also felt more comfortable revealing their vulnerabilities to nurses with whom they connected in this way.
Parents and nurses were more easily able to build a rapport with each other when the interactions were characterized as more personal as opposed to professional. Therefore, it is not surprising that the nurses' attributes deemed most contributory to a positive rapport were related to their personalities rather than their professional behavior. Several of these personality traits were also mentioned in several authors' works and included: being nice, friendly (Kasch, Kasch, & Lisnek, 1998; Paavilainen & Astedt-Kurkl, 1997), caring (Radwin, 2000), empathetic (Wuest & Stern, 1990), optimistic (Radwin) open, approachable, and available. Conversely, attributes which detracted from rapport-building were: being blunt (Stewart et al., 1994), rigid (Latvala & Janhonen, 1998; Paavilainen & Astedt-Kurkl, 1997), confrontational, defensive, or neutral about the child's prognosis. These attributes were key to the immediacy of these parents' impressions of the nurses as "good" or "not as good".

Nurses' behaviors, and the manner in which nurses deliver care, were largely shaped by their personality attributes. Further, the manner in which children and their parents received care seemed to have profound effects on their parental perceptions of the encounters as positive or negative. For example, nurse behaviors such as taking time to spend with the family and making an effort to interact informally as well as clinically, conveyed a realistically positive attitude. Conversely, defensive and non-caring behaviors were remembered as negative experiences.

Although parents were not consciously aware of nursing actions which were consistent with the professional standards for nursing practice (Registered Nurses Association of British Columbia, 1998b), the examples of negative interactions with nurses they described could be narrowly interpreted as a lack
of adherence to these guidelines. For example, nurses who failed to take responsibility for their work and did not complete nursing care, or relied on following physicians' orders rather than employing nursing judgment, may be thought to have contravened standards respectively related to responsibility and accountability, and provision of service to the public (Registered Nurses Association of British Columbia, 1998a & 1998b). However, this may more likely indicate a lack of reflection on practice as it relates to expectations of professionals, rather than intentional disregard for practice standards.

Parents noted a transition in nurses' approach which paralleled their children's transition from critical care to less acute care. Specifically, when their children were the most ill, parents described the nurses’ approach as more "formal" and "cooler" than when their children's condition improved or they were given a more optimistic prognosis. During the times of highest acuity, nurses did not often converse with parents. When interaction did occur, it was more technologically-focused. The nursing care, under these circumstances, was also notably different, with parents describing a more task-oriented approach. Aside from the environmental and technological differences between care for a child whose survival is in question and a child who requires monitoring and more routine care, this difference in nursing approach may be due to nurses employing defense mechanisms against the stresses of caring for gravely ill children. This assertion is supported by Franks, Watts, and Fabricius (1994), who contended that nurses employ defense strategies against the anxiety created by close patient contact. To effectively assist families during times of high parental anxiety, nurses must actively work to ensure sensitivity in information presentation while encouraging open expression of emotions (Whaley & Wong, 1995). The consequences of this type of emotional caring
were outlined by Dr. Michael Whitfield, medical director of the Neonatal Follow-Up Clinic, in his presentation entitled "How to Give Bad News to Good People" (Into the Next Millennium conference, November 19, 1999. Surrey, B.C). Regarding physicians providing difficult information to parents he stated "...if you've done it right, you will feel like you have been run over by a steamroller". While physicians experience the stresses involved in providing such information, nurses contend with the longer-term stresses involved in assisting families to process this information. However, most nurses are not consciously aware of the level of personal involvement and energy required for this work. Consequently, the nurses’ approach may be less personal in the most severely stressful situations as a means of self-protection.

A few parents changed their own approach which led to perceived change in their children's nursing care. Only one parent invested time and thought into this behavior change; believing that the child would receive better nursing care as a result. However, several parents did comment about "not bothering the nurses". This seems to indicate that parents, themselves, wished to be regarded as likable, resulting in the nurses being more attentive to their children. In contrast to Thorne and Robinson's (1988) study, none of the parents in this study expressed fear that their children would be neglected or harmed if they did not appear cooperative. However, on some level, they did make an effort to enhance the quality of nursing care for their children.

Competence was a concept that was woven throughout descriptions involving nurses' approach. Parents were better able to sense competence rather than describe it from their observations. Most parents knew immediately if the nurse caring for their children would be "good". This immediate impression may be explained by exploring the concept of confidence. Paavilainen and
Astetd-Kurkl (1997) described how trust and confidence unfolded from friendly and confidential interactions with community health nurses, which, in turn, further enhanced the interactions as positive. Parents in this study expressed a similar sentiment in that conveying friendliness and being nice were two qualities they linked to a better rapport. For example, while parents described their feelings related to an inability to stay with their hospitalized children 24 hours a day, they also reported that their anxiety was somewhat alleviated by their confidence in the nursing care their children were receiving.

Aside from evidence of professional competence, parents did not seem to require an accurate view of the nurse's role for rapport to develop. This contrasts somewhat with Wuest and Stern's 1990 study in which parents who did not understand their physician's behaviors were more likely to be dissatisfied with the care received. This may indicate that interpreting professional role and interpreting the behavior of a professional as she or he enacts that role are distinct processes. Another possible explanation originates from Singleton's (2000) findings related to what she called a "conundrum of collaboration" for nurses. Initially, nurses in her study verbalized the accepted view of the setting in which they worked. However, as they regarded the institution's focus to be medical, they quietly incorporated family-centered principles into the care they provided. Therefore, while these nurses conformed to the official plan, they invisibly also focused on the clients' holistic needs. As such, nurses may be more fully enacting their family-centered role than is evident to parents who observe them care for their children.

Nurses' work was evaluated differently than was physicians' work. Parents in this study judged a physician as able to provide quality health care based on evidence of clinical competence alone. However, parents required
nurses to display positive personality traits and provide nursing care in a holistic and personal manner for the nurses to be assessed as “good”. Wuest and Stern’s (1990) findings support these observations as they found that parents became disillusioned with medical care when they were given cause to question the physicians’ competence, such as when a medication was prescribed to which the child was allergic. However, when nurses did not respond to the child’s distress they did not meet the parents’ expectations of providing comfort and care, and this became the greater cause for parental disillusionment.

Values differ across professions due to different education and socialization of each profession (Liedtka & Whitten, 1997). As such, nurses may more naturally value and display collaborative practices than do physicians. Therefore, parents seem to perceive collaborative behavior as possible with nurses, but limited with physicians. Parents may also perceive power to be more equal when interacting with nurses than with physicians. Through the process of knowing each other, parents entrust nurses with what Radwin (2000) calls “authentic” representations of themselves. The nurse’s failure to display a “human touch” when providing care may then cause the parents to feel vulnerable, and their favorable assessment of the nurse may then be diminished.

Environmental factors combined to limit opportunities for nurses and parents to develop a rapport. The first, and most frequently described, aspect which limited opportunity for building rapport was consistency of staffing. Parents often described confusion regarding who was caring for their children on any given day. As a result, the interactions with each nurse tended to be brief and focused on the physical care of the child. Little time was left for interactions on a more personal level. Trust and comfort in nursing care was not easily established under these circumstances. Participants in this study often
emphasized their desire for less staff turnover. Radwin (2000) also found that continuity of care, in the form of repeated encounters with one nurse, was important to patients, and Dobbins, Bohlig and Sutphen (1994) concluded that the desire for familiar and consistent caregivers was a priority to patients.

The setting in which the interactions took place was often a barrier to establishing rapport. As most interactions that parents described occurred in a tertiary center, they frequently commented on the impersonal nature of that environment. Although not specifically stated, these parents sounded surprised at this discovery. Wuest and Stern (1990) found that the parents in their study were also not prepared for the impersonal tone of the health care setting and were “appalled at the assembly line approach” (pg. 559). As well, Beverage, Bodnaryk and Ramachandran (2001), and Cottrell and Summers (1990) mentioned these setting aspects as barriers to parent participation in their children’s care. While lack of staff continuity contributed to an impersonal tone, other features such as the lighting, noise, location relative to the family home, and isolation precautions gave rise to a colder atmosphere. Consequently, personal interactions could not emerge until some of these barriers were removed. Establishing rapport became less elusive when children were transferred from critical care to a less acute area. This usually signified that the children were going to survive and, eventually, go home. This milestone was also concurrent with changes in the environment.

Parents were not directly aware of organizational barriers to establishing rapport, but did comment on the setting’s rules and on their observations of the working conditions. Several authors cite organizational support, or lack thereof, as a major barrier which prevents staff collaboration with parents. Coeling and Cukr (2000) pointed to a lack of professionals’ collaboration skills as an
explanation for a failure to collaborate with parents. Liedtka and Whitten (1997) provided an expanded view by contending that staff collaboration skills are not usually rewarded by health care organizations, and organizational leaders do not always model these skills. Organizational characteristics are thought to influence professional knowledge, continuity, attentiveness, and coordination (Radwin, 2000), and may provide barriers to nurses' ability to provide holistic care and to display collaborative behavior. Although the espoused view values collaboration practices (Coeling & Cukr), organizations still generally adhere to a task-oriented, hierarchical medical model (Singleton, 2000), which is not conducive to developing working relationships with parents on a more personal basis.

Most encounters with nurses that parents described were interactions, and were not considered to be relationships. Time may have been a factor in this finding as this element is often limited in a health care setting. Comments from parents in this study indicate that the element of time may not be required for positive interactions to occur, but is essential for any type of relationship to develop. This finding is consistent with Liedtka and Whitten's (1997) assertion that time is a resource investment which enables the development of the relationship. Paavilainen and Astedt-Kurki (1997) agreed that successful collaboration was dependent on time and continuity. These were also preconditions to individualization in Radwin's (2000) study.

Parents consistently mentioned that time was linked to knowing each other. However, recognizing that nurses were busy, the way in which time was utilized was sometimes more important to these parents than the amount of time the nurse had to spend with them. This was also a theme of Singleton's (2000)
study which explored, from the nurses' perspective, interventions to encourage clients in self-care.

Time is often viewed as an insurmountable barrier in health care, and interventions, such as those proposed by Tapp (2000), are usually shaped to accommodate seemingly unchangeable time limitations. While this approach serves to ameliorate difficulties posed by time limitations with establishing rapport, it does not eliminate the barrier. Curiously, some parents in this study indicated that some interactions with nurses were indicative of positive rapport-building despite the time constraints. These parents' interactions were also characterized by several other positive features of rapport including relevance. That is, the purposes of their interactions with the nurses were specific to their children's care needs, or to their own needs to enable them to care for their children. Liedtka and Whitten (1997) described this as a sense of "at-stakeness" wherein the parties commit to the relationship because it holds the promise of producing a desired outcome. The parents in this study may have deemed rapport with the nurses "positive" because enough of the positive aspects of rapport were present to compensate for the lack of time.

Parents appreciated nurses' acknowledgment of the impact the diagnosis had on the families, and nurses' demonstrations that they treated the parents as individuals. Individualized care has been positively linked to quality nursing care (Radwin, 2000). Parents were equally resentful of nurses who did not acknowledge the parents' contributions to their own children's care or their competence in managing their children's diagnoses. This seems to be a long-standing criticism from parents as several authors (Paavilainen & Astedt-Kurki, 1997; Robinson, 1985; Stewart, Ritchie, McGrath, Thompson, & Bruce, 1994; Wuest & Stern, 1990) have reported the same finding. It appears
that nurses frequently verbalize that parents know their children best, but are not often enacting this view.

**Meeting parental needs for information and support**

Parents described interactions with nurses in terms of how well these contacts met their expressed needs for information and support. The parents' information needs were best met when the nurses were sensitive to their readiness for information, provided the information in manageable quantities, and in a manner consistent with how the parents best process the information. Negative interactions were reported when the nurse failed to provide information, or relied on the parent for information. Stewart et al. (1994) highlighted these points as the parents in their study found interactions with health professionals stressful when information provided was insufficient or inappropriately presented. Sensitivity to the needs of the information recipients is crucial in ensuring accurate recall and appropriate information utilization (Ho, Miller & Armstrong, 1994).

Teaching and preparation were ways that nurses met parental needs when the focus of the information was relevant to the parents and related to a current or probable need. However, when nurses attempted to prepare parents for possible events, parents were more likely to find the interactions to be negative. Radwin (2000) also found that patients who knew what to expect were more optimistic and better able to withstand their illness symptoms and treatment side-effects than were patients who were not prepared for future events. It is important to note that patients in Radwin's study were given preparation for probable events.
Generally, nurses met parental needs for support less consistently than they met parental information needs. However, parents did report examples of nurses who supported them emotionally as well as with practical aspects of their children's care. The latter aspect was most evident during discharge planning or when parents had to interact with community services. There were also examples provided which left parents feeling unsupported by nurses. These were episodes during which nurses were either not present, such as after clinic hours, or when nurses failed to provide support because of oversights in care.

When parental needs were not met, parents took on additional work to meet the needs themselves, and it appears that this is not a new phenomenon. Wuest and Stern (1990) found that parents often learn to navigate a confusing health care system on their own. Only once parents had learned "the rules" (pg. 560) of the system could encounters with health care professionals improve.

A few parents in this study described how they obtained emotional and practical support from other parents. This lends support to several others' work (Beverage et al., 2001; Dobbins et al., 1994; Fenwick et al., 1999; Heiney, Ruffin, & Goon-Johnson, 1995; McGee & Burkett, 1998) that parents seek out peer support as some support aspects cannot be provided by nurses. Yet, parents in this study did not describe nurses who actively attempted to link them with other parents in similar situations.

Parents noticed, and deemed the associated interactions as positive, when nurses provided Family Centered Care (FCC). Although parents did not describe the nurses' actions in terms of FCC tenets, they did appreciate nursing care when it was provided to themselves as well as to their children. However, when the parents' needs were considered above those of their children, the
interactions with nurses became negative. In this situation, the nurses adopted a less family-centered view as they provided care to a single recipient.

**Negotiating Care**

Through parental descriptions, a continuum of negotiated care emerged. The encounters typically began with all of the children's care provided by the nurse. While parents regarded this as negative from the viewpoint of the ability to enact their parental role, they also recognized this as necessary due to the severity of their children's conditions. As the children stabilized, the caregiving responsibilities became more equally shared. Parents regarded this step as positive. However, the situation was regarded as negative when parents felt they had to assume most of their children's care. In this last circumstance, care was no longer negotiated. Rather, parents felt that nurses assumed they would provide the majority of the care. This contrasts with Singleton's (2000) descriptions of how nurses more positively encouraged patients to assume more of their own care. Although this also involved a gradual shift of responsibility, the nurses in Singleton's study did not force their clients to assume more care than they felt prepared to do. Radwin (2000) similarly concluded that individualized care entailed allowing the patient to assume as much control as the patient desired.

Conspicuous by their absence were the lack of direct descriptions related to empowerment. While some indirect aspects of empowerment were discussed within the context of themes such as rapport and negotiating care, the majority of interactions described in this study did not indicate that parents were empowered as a result. In this study, the parents' most vivid memories, and therefore most of their described interactions, took place at a time when their
children were gravely ill, were experiencing an exacerbation of their diagnosis symptoms, or when the family was in crisis. The roles of stress, anxiety, and crisis are major considerations in the area of teaching adult learners (Keane, 1993). Throughout their experiences with their children's health care, the parent participants in this study were also adult learners who experienced concurrent stresses and/or crises. As Whaley and Wong (1995) suggest, parents' capacity for understanding and providing information, and sharing in their children's care, was diminished. Therefore, equality in their interactions with nurses was impossible under these specific circumstances. Although all children of these parent participants had a chronic condition, the parent-nurse interactions did not concern daily management. Therefore, the situation gave rise to a power imbalance wherein parents were more dependent on nurses during these times.

The second frequently discussed feature of negotiating care is mediation between the parents and physicians. Nurses were frequently involved in assisting parents to interpret physicians' information and behavior, as well as interacting with the physicians on the parents' behalf. Perhaps this is indicative of the fact that parents reveal more concerns and queries to nurses than to physicians (Radwin, 2000). As such, parents may feel comfortable discussing physician-related issues with nurses while they may not feel as comfortable having the same discussions with the physicians themselves. However, Wuest and Stern (1990) found that parents in their study negotiated care with their children's physicians using manipulation, assertion, or confrontation, depending on the situation and the personalities of the parties involved. These parents did not use nurses as intermediaries. An important difference between this study and Wuest's and Stern's is that, in the latter, parents did not usually encounter nurses except for brief episodes in the emergency department or in day surgery.
Parents reported great variability in the delivery of nursing care, which was attributed to the differences among nurses’ personalities. However, this variability is not isolated to our own nation. Latvala and Janhonen (1998), two Finnish researchers, found that the most commonly used helping methods that nurses used with clients with psychiatric conditions were confirmatory in nature. That is, these methods were grounded in the traditional view with the nurses remaining dependent on the physicians’ authority. The traditional view apparently remains difficult to change and, as a result, consistency in adherence to professional standards above this view remains problematic. Nursing identity is contributory to upholding the traditional view. Nursing’s unique contribution to health care lies in the interpersonal domain (Kasch et al., 1998). Therefore, strict adherence to impersonal policies and procedures becomes more difficult, and nursing practice is subject to more variability by personality. Nurses’ professional identity remains strongly linked to tasks and technology in several health care areas (Fenwick et al., 1999). As a result, the nature of nurses’ work is in conflict with the atmosphere of some health care settings in which this work occurs.

Summary of Discussion

In summary, parents’ perceive that their experiences of interacting with nurses are generally positive, although their accounts are most often articulated in vague terms. Several of the findings from this study support conclusions from authors cited in the literature review. However, many of this study’s described experiences differ to some extent from the literature as the parents’ characterization of their experiences differ from those asserted by many health care professionals and organizational leaders.
Parents frequently contrast nursing care with the care their children receive from physicians. Physicians are evaluated on clinical competence alone while nurses are required to demonstrate an interpersonal element when providing care. Parents are not always accurate when describing the nurses’ role. Traditional views of professional authority and health care hierarchies, and nurses continuing to provide holistic care in subtle ways, perpetuate these inaccuracies. However, an accurate view of the nurses’ role is not necessary for interactions to be perceived as positive, as interpreting professional role and assessing the work associated with that role are distinct processes.

When nurses demonstrate knowledge of the children, and when parents also know something about the nurse, parents are relieved of their educator role, feel more comfortable with their children’s nursing care, and more often reveal their own concerns and vulnerabilities. In turn, rapport is more easily established. Parents’ assessment of their interactions with nurses is greatly influenced by the nurses’ approach, and the manner in which care is delivered is greatly influenced by the nurses’ personality characteristics. As such, nursing care can vary considerably from nurse to nurse. Nurses change their approach as the children’s acuity or prognosis changes. Nurses are more likely to be more formal and cooler when the children are more acutely ill, or when the children’s prognoses are less optimistic, as a defense against the heavy stresses created by intense patient contact. Some parents change their own approach when interacting with nurses to effect positive changes in nursing care. Environmental factors, such as limited time, are most often considered as barriers to establishing rapport. However, time, although necessary to building a relationship, is not required for developing rapport. Rather, rapport can still
evolve if the available time is utilized effectively, and when other elements of collaboration are sufficiently present to compensate.

Information needs are generally well met, especially when the information provided serves to prepare parents for actual or probable events. Information needs are more consistently met than are support needs. However, support needs are perceived as well met when nurses provide support for both the parent and the child. The experience is perceived as negative when nurses are seen as providing support to the parent at the expense of the child. When nurses fail to meet parents' needs, the parents assume the care responsibilities to meet their own needs.

Children's health care occurs on a continuum from all care provided by the nurse to most of the care provided by the parent. The most positive point on this continuum is a relatively equal sharing of care responsibilities. Experiences are perceived as negative, however, when parents feel pressured to assume more care than they desire. Nurses often engage in mediation between parents and physicians as the expectation of interpersonal skills from nurses facilitates parental disclosure of concerns and queries. Despite reports of generally positive interactions with nurses, parents are not empowered by these contacts as they occur at times of parental stress or family crisis.
CHAPTER 6: Conclusion and Recommendations

Summary of the Study

This interpretive descriptive study depicts the experiences of 8 parents of children with chronic health conditions, as they interacted with nurses regarding their children's care. Parents who communicated in English, resided within the Lower Mainland, and whose children were 18 months of age or older were invited to participate. Purposive sampling was used as the study progressed. Data were collected over a 3 month period using in-depth audiotaped interviews which were later transcribed. Interview data were analyzed using the principles associated with interpretive description, and 3 distinct themes emerged. These themes were: establishing rapport, meeting parental needs for information and support, and negotiating care.

The nature of the parent-nurse interactions gave rise to parental assessments of the contacts as either positive or negative. The first theme, that of establishing rapport, provided the foundation that enabled the other two themes of meeting parental information and support needs and negotiating care, to develop. The degree of rapport established between parent and nurse was positively influenced by the nurses' knowledge of the children's health conditions and unique characteristics, acknowledgment of prior contact with the family, and having something in common with the family which led to sharing information in a reciprocal manner. Parents' trust in the nurses was enhanced when they could sense the nurses' competence. The nurses' personality characteristics of friendliness, empathy, and optimism led parents to view their contacts with nurses positively. These characteristics were demonstrated through the nurses' approach. Conversely, parents found establishing rapport more difficult when
the nurse had a blunt approach. Environmental factors inherent within the health care setting, such as physical characteristics of the setting, consistency of staffing, and ward rules, also shaped parents' perceptions of their interactions with nurses.

The degree to which parents' needs for information and support were met partially shaped their perceptions of their interactions with nurses. Information needs were the most frequently discussed, and were more fully met when nurses considered parents' readiness for information as well as parents' ability to process the information. Nurses' teaching and preparation efforts, as well as their approach used while providing the information, also influenced parental assessment of the interactions. Parents derived practical and emotional support from nurses and also from other parents. Parents' perceptions of the interactions with nurses were shaped by the nurses' availability to provide support, and their ability to care for the child and parent rather than for a single recipient of care.

Child-specific nursing care was negotiated between the parents and nurses, and often involved a continuum along which care responsibilities were transferred to the parents. The negotiations were influenced by the degree to which parents' input was valued and the degree to which the care was shared. Parents viewed sharing their children's care with nurses as positive when they could control how much of the care responsibilities they assumed. Parents frequently changed their own approach when interacting with nurses, which was thought to improve their children's nursing care. Positive care outcomes were also thought to emanate from the nurses' mediating with physicians on the parents' behalf. Negative parental experiences resulted from the nurses' rigid approach, their failure to maintain consistency of care, and misinterpretation of parents' intentions.
The findings of this study gave rise to considerations in the areas of clinical practice, nursing leadership, education, and research. Although we, as nurses, are striving to meet Family-Centered Care mandates, we must continue to examine our own beliefs about parents' involvement in the care of their children, and more consistently apply holistic care principles in our substantive areas of practice. Enhanced support from nursing leaders in the areas of parent information regarding services, recognition of enacted Family-Centered Care, staffing, and employee health, make applying these holistic care principles more likely. The quality of care provided may be further improved if nurses and other health care professionals learn collaboration skills, beginning in their post-secondary preparation and continuing throughout their careers. Further research in the areas of parental perceptions of outcomes of their interactions with nurses, nurses' perceptions of interactions with parents, and the influences of gender and health care setting on the perceptions of these interactions would broaden our understanding of the health care experience of parents of children with chronic health conditions.

Conclusions

The major findings from this study indicate that parents perceive nurses to be striving to provide holistic care, and that their interactions regarding the care of their children with chronic conditions are generally positive. In most instances, parents felt that nurses are able to establish rapport with them, even in the absence of a partnership relationship. Established rapport leads to nurse behaviors consistent with individualized care, parents perceiving that their needs are more consistently met, and that their children's care is more successfully negotiated.
Parents reported that it was easier to establish rapport when nurses learned about the children's health conditions and unique characteristics, acknowledged when they have had prior contact with the families, found the common ground that they share with the parents, and reciprocally shared information with parents. Parents emphasized that factors beyond the nurses' control, such as high staff turnover, low staff availability, and the impersonal tone of tertiary care agencies, act as barriers to positive parent-nurse interactions.

Parents viewed interactions as more positive when nurses accurately identified parental needs and followed-through to meet these needs. Although nurses demonstrated skill in teaching and preparing parents, the experiences are more likely to be viewed as positive from the parents' perspective if nurses prepare parents for probable, rather than possible, events. Parents' needs may not always be met as their utilization of health care services can be limited by their often inaccurate views of the nurses' roles.

The trajectory of health care for children with chronic conditions often involves a transfer of care responsibilities from nurse to parent. Parents are more likely to regard this transfer as positive if they are able to choose the extent of the care that they assume. Parents indicated that nurses further improve health care for the children by negotiating with physicians on the parents' behalf. Parents viewed the nurses' approach as more open when the child's diagnosis or prognosis improves and as more formal when the child's condition is serious or deteriorates. Parents report that they will, at times, change their own approach when interacting with nurses in order to enhance their children's nursing care.
Implications

The findings from this study indicate that opportunities exist to improve and enhance parents' experiences as they interact with nurses regarding the care of their children. These opportunities present in the areas of clinical practice, nursing leadership, education, and research.

Clinical practice

Clinically, nurses must endeavor to more fully integrate the Family Centered Care philosophy into daily practice, and to ensure that the care they provide is consistent with the professional practice standards for nursing. The first step to closing the gap between Family Centered Care principles and their achievement in clinical practice appears to be the nurse's examination of her or his own philosophy related to collaboration with parents. Reflection and self-awareness in this regard would provide greater insight into how care is delivered and, in turn, perceived by parents. The most appropriate time to consider this is during the self-assessment component of the continuing competency requirements (Registered Nurses Association of British Columbia, 1998a), and could be incorporated into this annual process. The consistent application of care principles remains problematic in light of the finding of perceived variability of nursing care. Again, the self-assessment process, if utilized as intended, could be a useful tool in improving this situation. According to records of the Registered Nurses Association of British Columbia (RNABC), 97% of nurses renewing a practicing membership met the continuing competence requirements (Herman & Adlersberg, 2001). Some of the nurses who did not meet the requirements, misunderstood how knowledge gained in their workplaces could be applied to the professional practice standards.
RNABC, 1998b). Beginning September 2001, RNABC members will be randomly selected to complete an audit form for the purpose of ascertaining compliance with the continuing competence requirements for registration renewal (Herman & Adlersberg). In addition to enhancing compliance with the process, the addition of an audit may serve to enhance nurse understanding of how professional standards are linked to the individual nurse's own knowledge and practice. As a result, the variability of nursing care delivery, as experienced by parents, may decrease.

Nurses may more easily develop a collaborative rapport with parents if care is delivered using a Family Systems Nursing approach (Leahey et al., 1995), in which the family is viewed as the care recipient. This view would address the finding that parent-nurse interactions were perceived as negative when the nurse cared for a single family member. While this approach may not be appropriate to use in some instances, such as during trauma management, the philosophy of Family Systems Nursing is more in keeping with the espoused view of the Family Centered Care principles embraced by many organizations.

A more finely tuned assessment phase of the nursing process could enhance the nurses' ability to meet parental needs. Among others, parents need their knowledge about their children to be acknowledged. Nurses could take this positive aspect further by viewing parental knowledge as the base on which to plan care and by incorporating a parental knowledge component into their initial assessments. Also, by focusing on actual or probable situations, needs that are relevant to parents may more accurately be identified. Follow-through to meet these needs is also crucial. As parents identified support from other parents as a consistently undermet need, nurses working in any health care setting could focus on this aspect of support and increase their concerted efforts in this
regard. To some extent, nurses would need to collaborate with other nursing colleagues to link parents with each other on an individual basis, or to develop and facilitate more formal parent support groups.

Just as enhancing parental peer support involves collaboration among nurses, other aspects of nursing care heavily rely on good communication skills. Nurses, therefore, need to critically examine their own communication skills as well as the communication procedures in place within their work settings. Nurses are in the best position to assess these aspects and then make suggestions for positive change.

Although parents did not need to accurately understand the nurses' role to experience a positive rapport, the consequences of this poor understanding were evident in the degree to which their needs were met. Therefore, parental understanding of the nurse's role is an important aspect of quality nursing care. As such, nurses must encourage better understanding by promoting their own role and describing the services they provide. This information is similar to that provided with the intent of assisting families to better utilize resources as they navigate the health care system.

Finally, nurses must take time to recognize how the stresses of emotional caring impacts them. While the nature of nursing is to care for others, nurses cannot continue to disregard the effects of their work on their own physical and emotional health.

**Nursing leadership**

The gulf between the espoused view regarding collaboration with families and the enactment of this view in practice remains wide. This suggests that Family Centered Care is used as the ideal by which personal interactions and
organizational policy is examined, rather than as a description of how care is currently delivered. Yet, agency-approved parent information does not make this difference explicit. For example, Children's and Women's Health Centre of British Columbia (2000a) recognizes patients and families as the organizations' partners in the publicly accessible strategic directions document. Further, these partners are called to "work together to ensure access to the best care in the best setting" (p. 5). However, parents do not always know how they may function as equal partners with health care professionals, and the opportunities for working together may not always present in certain areas. Instead, the wording of parent information may create parental expectations that are based on the ideal of partnership rather than on the realities of the health care settings, and parental disappointment may result. To avoid parental confusion and, possibly, negative experiences for parents, organizational documents should be reviewed and revised to ensure that this information is congruent with the organizations' actual functioning. Additionally, nurses must participate in this review process.

One of the Family Centered Care principles involves building on family strengths (Beverage et al., 2001). While this tenet has great implications for nursing practice, it also presents an opportunity for nursing leaders to encourage Family Centered Care by example. Similar to parents, nurses also have many strengths on which to build. Aspects of nursing care that are consistent with the Family Centered Care philosophy could be formally recognized and their value demonstrated through the use of commendations (McElheran & Harper-Jaques, 1994). In this way, nurses may be made aware of the aspects of care they do well and should continue to incorporate into their practice. Further, it would allow them to focus more exclusively on areas in need of improvement. Parents in this study, as well as authors of articles in the literature, have recognized nurses as
having comparatively good collaboration skills. However, organizational structures do not easily lend themselves to the recognition or reward of these skills. Therefore, nursing leaders may need to capitalize on opportunities to recognize and reward those who strive to deliver holistic care.

Although interactions could be positive even if contacts with the nurses were brief, rapport developed more quickly when staffing was consistent over time. As such, primary nursing was considered to be a positive framework which facilitated rapport-building. Support for this framework, and implementing this in other areas, may enhance parent-nurse collaboration.

Parents in this study indicated that nurses are making a positive difference in their health care experiences, but aren’t always available where and when they are needed. For example, in some outpatient clinics, nursing is not represented on the multidisciplinary teams. In other clinics, nurses may not work the same hours as other team members and, therefore, may not be available to families to provide nursing care. In still other outpatient settings, nurses may not be replaced when ill or on vacation. Team composition, staffing, and relief are all issues to be considered to ensure that families have access to the full spectrum of health care services.

Caregiver burden and care for the caregiver are concepts that are typically applied to the patients’ family members. In light of the under-recognized stresses experienced by nurses, these ideas should be applied to nurses as well. More formal support regarding caregiver burden, as well as stress management workshops, must be offered to nurses to partially alleviate nurse burnout, and keep nurses working where they are needed most.
Education

The acquisition of collaborative skills, and therefore better parent-nurse collaboration, may begin in formal nursing education. Recognizing that nursing is a complex field, curricula has already moved beyond teaching a collection of tasks. Specific preparation is now needed for assuming a nurse role, and a professional identity that reflects the complexity of nursing.

Collaboration cannot be enacted by an individual, nor can nurses easily collaborate with parents when working relationships with other professionals are strained. This difficulty is partially addressed at the university level with the emergence of general interdisciplinary study programs (University of British Columbia, Faculty of Graduate Studies, January 28, 2000). Adding more health-care-specific interdisciplinary courses to existing curricula would help to lay the foundation for more positive collaborative functioning in practice. However, parents will continue to experience great variability of collaboration with professionals unless all health care disciplines participate in learning collaboration skills together.

Efforts to increase professional collaboration skills must continue in the workplace. The topic of collaboration, both with families and with other professionals, should be added to the repertoire for professional development and continuing education initiatives, and collaborative workshops should be developed to assist professionals in developing these skills. However, attendance of all disciplines would have to be ensured if the workshops were to be effective. Finally, support to develop or enhance time management skills specific to interacting with parents would assist nurses in using their limited time most effectively.
Research

While this study has outlined some findings which support the existing body of knowledge, and has generated suggestions for improvements to practice, many questions have also arisen. This study serves to describe parents' experiences when interacting with nurses regarding their children's care. However, parents' perceptions of the outcomes resulting from these interactions need to be explored. Parental descriptions of changes in nurses' approach and changes in their own approach prompt a need to investigate how the two affect each other. Although some authors have studied collaboration from the nurse's perspective, these studies tend to be focused on interprofessional collaboration. Therefore, nurses' perspective of parent-nurse interactions requires further study. As several findings in this study are setting-specific, parent-nurse interactions need to be studied in other settings in order to broaden the utility of these findings. Finally, only one father participated in this study and conclusions regarding the fathers' experiences cannot be derived from his remarks. However, his descriptions indicate that gender creates differences in the nature of the parent-nurse interactions and that the health care experience from the fathers' perspective should be examined.

Concluding Remarks

Although parents do not characterize their interactions with nurses as partnerships, it appears that a positive working relationship develops as a result of experiencing several positive interactions over repeated contacts. A strong foundation for positive parent-nurse interactions already exists. Therefore, great opportunities also exist to improve the quality of health care for children with chronic health conditions and their families.
References


Ode, K. (1988). In my opinion... Partnership for family-centered care: Reality or fantasy? *Children's Health Care,* 17(2), 85-86.


## Appendix B - Demographic Data

### Participant Code Number: 

### Family Constellation:

**Mother:**
- **Age:**
- **Education:**
- **Occupation:**
- **Marital Status:**
- **General Health:**
- **Lives in primary residence:**
- **Primary responsibility for medical management:**

**Father:**
- **Age:**
- **Education:**
- **Occupation:**
- **Marital Status:**
- **General Health:**
- **Lives in primary residence:**
- **Primary responsibility for medical management:**

**Siblings:**
- **Age:**
- **Gender:**
- **Place of residence:**
- **Health:**

**Child with health concern:**
- **Age at time of interview:**
- **Age when diagnosed:**

**Primary diagnosis:**
- 

**Additional diagnoses:**
- 

**Number of outpatient specialist services seen:**
- 

**Number of outpatient specialist services involving nurse contact:**
- 

**Frequency of outpatient specialist services:**
- 

**Number and length of hospital admissions:**
- 

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Appendix C - Sample Questions for Initial Interview

General questions will be asked to elicit parental experiences. More specific probe questions will be used if clarification or a more rich description is required.

1. Tell me about the time your child was (born, was in SCN, was diagnosed).

2. Who was with you at that time? What did they do or say that made a difference?

3. Tell me about your interactions with nurses.

4. Tell me about an interaction with a nurse that stands out the most for you. What do you feel made it positive? What would have made it negative? What would have made it more effective from your point of view?

5. What would you have liked to happen differently?

6. What do you think it was about that interaction that made it so memorable?

7. Is there a nurse that stands out for you? What is it about this nurse that you remember most?

8. Were there any situations you would have liked to happen differently in terms of how a nurse was with you?

9. Were the nurses different with you when ____ was extremely ill compared to when he improved?

10. Had you thought about your own approach with the nurses looking after your child?

11. In the clinic(s), what did you hope to find out / accomplish at the last visit? Were these concerns / questions dealt with?

12. What is your greatest challenge when interacting with nurses?

* during the interview, the child's name will be used
Participant consent:
I/we understand the nature of this study and give my/our consent to participate. I/we understand my/our rights when participating in this study, and that I/we may contact Hilary Espezel or Connie Canam if I/we have any questions. I/we understand that I/we may contact the Director of Research Services at the University of British Columbia, Dr. Richard Spratley at 822-8598, if I/we have any concerns about my/our rights as a research participant. I/we have received a copy of the participants' information letter and the consent form.

Signature(s) of participant(s): __________________________

Signature of witness : __________________________

Date : __________________________