The Notion of Empowerment for Parent in Pediatric Health Care Delivery

by

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ABSTRACT

The delivery of pediatric health care has changed drastically, especially in the roles that families play in the care of their children. Many families are now faced with the challenges of living with a child's chronic condition at home, a situation that affects every aspect of their lives. The role of the nurse in supporting and facilitating the adjustments families have to make in these circumstances has long been recognized. Indeed, today's empowerment trend encourages health care professionals to enhance the competence of families to care for their children. However, further research is needed to gain a clear understanding of how parents obtain empowerment in pediatric nursing care and to answer questions like, What prerequisites are needed in a health care relationship to develop a positive, empowering parent-nurse relationship?

The purpose of this study was to gain insight into what kinds of parent-nurse relationships parents describe as empowering and how the relationship is empowering to parents; it was conducted by gathering parents’ descriptions of their experiences of empowerment in health care provider relationships with nurses. The main objective of the project was to describe and interpret what it was in the health care relationship that empowered them to develop an understanding of how the parent-nurse relationship is linked to empowerment. The method used in this study was interpretive description, which involves utilizing the existing knowledge as an analytic framework, to conceptualize the findings of the study. For the purpose of interpretive description a purposeful selection of research participants was conducted; eleven parents of children with diverse chronic conditions were interviewed for this study.
The findings of the study describe the conceptualization of empowerment as a developmental and interactive process. The parents described the nature of empowerment as being shaped by three main factors: that nurses had a role in creating the context for empowerment; that both situational and personal elements were involved in empowerment; and that the relationship between parent and nurse had distinguishable features. When the parents described the kinds of relationships with nurses that were empowering and why, some common themes emerged as the main components of an empowering relationship between parent and nurse. These five empowerment strategies or qualities of an empowering relationship with a nurse in a parent-nurse relationship are mutual trust, active listening, knowing the situation, teamwork, and support with decision making. The two main outcomes of the empowering relationship are that the parents competence in care management is increased by the relationship and that the parents confidence in decision making becomes stronger with the presence of such a relationship.

The findings also describe the parents’ own emphasis on the importance of the role of a nurse in creating the context for empowering nursing care to take place. The role of a nurse in empowerment is to be available, to be willing to work with the parents, to show genuine interest and concern as well as to be able to offer emotional support, to act as go-between who clarifies and interprets communications and information, and to take on an advocating role, offering a positive attitude and encouragement. From the findings of this study, suggested implications for nursing practice, education, and research are put forth.
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Chapter One: Introduction to the Study

In today’s pediatric nursing literature, great emphasis is placed on the importance of empowerment toward successful pediatric care. How best to provide empowerment, however, has not yet been well established in pediatric nursing care for families of children with chronic health conditions. Unfortunately, the current health care delivery for families who have children with chronic conditions does not sufficiently support the needs of parents, often the primary caregivers at home (Graves & Hayes, 1996). However, if empowerment is an effective way to address the necessary changes in the provision of health care for these families, we as nurses need to gain a clearer understanding of our role in empowerment of parents in nursing care.

The service policies toward the needs of families who have children with chronic health conditions have not kept pace with other changes in more acute settings of the health care system. Yet, changes that have occurred in the health care system have been geared toward de-institutionalization and home based care. This trend has increased caretaking responsibilities by families themselves as well as the public health care system. Because increased health care costs and the belief that hospitalization may be detrimental for children have contributed to the trend towards early discharge in the pediatric population, children are discharged by hospitals earlier than they used to be, and this trend increases the complexity of parents’ care-taking responsibilities. Thus, today, families are providing a level of care in their homes that previously existed only in hospitals or nursing homes (MacPhee, 1995; Patterson, Jernell, Leonard & Titus, 1994; Stinson & McKeever, 1995).
The current philosophy in pediatric nursing is *family-centered care*. While, family-centered care has been said to be the ideal in nursing practice, the lack of family preparedness to manage a chronic illness is a common situation. From my experience of clinical nursing and the relevant literature, I find families of children with a chronic condition are not discharged from hospital with sufficient information and support services to adapt to being home and managing adequately (Betz, 1990). Still, family-centered care has been said to be essential to provide quality care in pediatric nursing (Shelton & Stepanek, 1995).

Empowerment is a term very much en vogue; it stems from the self-care enhancing literature of health promotion and family-centered care. At present, “a small body of scholarly literature suggests that family empowerment is an intervention that nurses could use to help families of children with a chronic condition” (Hulme, 1999, p. 33). The literature on empowerment claims that families of chronically ill children have less power than they ought to have and therefore often feel too powerless to satisfy the health care needs of their children and to sustain family life (Hulme, 1999). Still, as nurses, it is our responsibility to ensure that families have the capacities to manage the responsibilities that are placed on them. Yet, until we have a better understanding of the influence that nurses have on a family’s feeling of power or powerlessness, we will have a difficult time putting this philosophical commitment into practice.

The confluence of themes found in the literature on health care relationships, family-centered care, and empowerment suggest we need to examine these bodies of literature together and to examine the relationship between them. Empowerment is discussed in nursing as a sender-receiver nursing intervention and the outcome of the
empowerment intervention is the response of the family. I question whether focusing only on the nursing intervention or the outcome of an intervention is sufficient for empowerment to take place? I would claim that the literature is starting to indicate a link exists between empowerment and health care relationships, a link that indicates the importance of the parent-nurse-relationship in facilitating empowerment. Such a philosophical approach to empowerment might bring a new dimension into the discussion on how to best support families charged with caring for a chronically ill child; it might provide nurses with new information on how health care relationships can be empowering; and it might stress the role of the nurse in empowerment. An understanding of what kind of parent-nurse relationships are empowering would assist nurses in working towards improving the provision of nursing care in families who have children with chronic conditions, because a relational approach to empowerment is not about power that is given or taken but is rather about power that emerges through interaction with others (VanderPlaat, 1999). The role of parent-nurse relationships in empowerment needs to be taken into consideration and made clearer. Behaviors of both nurses and clients should be examined in the context of the nurse-client relationship (Wright & Leahey, 2000).

This study addressed the gap in nursing knowledge relating to the needs of parents of chronically ill children, specifically what kinds of parent-nurse relationships are considered empowering and why. With focus on these relationships, the study tried to determine what it is in a parent-nurse relationship that makes the difference toward empowering families to use existing strengths and capabilities and helps them to develop new strengths and capabilities, to manage the challenges that they are faced with as they
care for children with chronic conditions. Gaining the views of parents regarding what kinds of parent-nurse relationships are empowering and why, will contribute to a better understanding of the phenomenon so that nurses can improve the provision of health care delivery for families of children with chronic conditions. In short, the problem toward which this study was addressed is the lack of knowledge, from the perspective of parents, of the relationship between parent empowerment and nurse-parent relationships.

**Purpose of the Study**

The purpose of this study was to gain insight into what kinds of parent-nurse relationships parents describe as empowering and how each relationship is empowering to parents. The study involved the gathering of parent descriptions of their experiences of empowerment in health care provider relationships with nurses. The main objective of the project was to try to describe and interpret what it was in the health care relationship that empowered them and to develop an understanding of how the parent-nurse relationship is linked to empowerment. Secondary objectives are to generate descriptive information that will inform pediatric nurses about the nature and meaning of empowerment in their relationships with parents of children with chronic conditions and to contribute to the literature an insider view on the concept of empowerment.

**Research Questions**

This study will be guided by two research questions:
1. What kinds of parent-nurse relationships do parents of chronically ill children find empowering and why?

2. What is it in the parent-nurse relationship that parents describe as having empowered them?

**Definition of Terms**

**Empowerment:** For the purpose of this study, empowerment was defined as anything that parents identify as helping them to feel confident and in control, so as to become more competent and able to manage the challenges that can accompany a child’s chronic condition.

**Parent-nurse relationship:** A developmental process that takes place in the context of a child’s chronic condition and which results in a therapeutic connection between parents and a nurse. A connection which is built on mutual trust, open communication and respect for each others’ expertise. May include various interactions, such as conversations, phone-calls, meetings in hospital, outpatient-clinic and home care visits, in addition to physical care.

**Family-centered care:** A philosophical approach in pediatric care which is based on certain fundamental values, including the following: the family is the constant in a child’s life. Families should be supported in their natural care-giving and decision making roles by building on strengths within the families. Patterns of living at home are to be promoted. Parents and professionals are considered equals in a care-giving partnership, working in collaboration at all levels: in the hospital, at home, and in the community. Family-centered care involves communication, collaboration, and
exchanging information with families as well as recognition of family diversity. All these elements of family-centered care are aimed at establishing the “best practice” in pediatric nursing (Shelton & Stepanek, 1995).

**Parent:** Whoever is and has been the main caretaker of the child in question, whether that individual be a biological parent, adoptive parent, foster parent, substitute parent, step-parent or care-giving grandparent.

**Assumptions**

For the purpose of this study, I assumed that

1) Parents would be able to identify and articulate experiences of empowering relationships with nurses and explain how interactions have empowered them.

2) Empowerment is a health enhancing strategy.

3) Therapeutic relationships between parents and nurses have the potential to be empowering.

**Limitations**

Two limitations of the study have been identified. The purposeful sampling method of asking an advanced practice nurse to contact families that were interested provided a sample of parents that are all more or less in good contact with nurse, which could have bias the findings by affecting the generalizability of the findings. The other limitation is that a homogenous sample of English speaking participants was used, so the effects of culture and language differences can not be valued. No two human beings are
the same; the experience of one parent cannot be taken and applied to everybody else.

The proposed study uses a small sample; yet, the study findings may provide information in the form of patterns or themes that ring true for pediatric nurses and parents of chronically ill children.

**Significance of the Study**

The practical significance of this study is clear when considering the increasing number of families of children with a chronic condition. The findings of this study contributed to the small body of research-based pediatric nursing knowledge relating parents' experience of empowerment in a parent-nurse relationship. The findings could increase nurses' understanding of empowering parent-nurse relationships by giving nurses insight into whether there are some common themes between parents and their situations or whether each and every family has its own opinion about what is empowering to them in a relationship with a nurse. An increased understanding of what kind of parent-nurse relationships are empowering will assist nurses in the future, in working towards improving the provision of nursing care in families who have children with chronic conditions. Therefore, this study can hopefully have implications for pediatric nursing practice, health policy development and nursing education, by providing grounds in support of the argument that there is a growing demand for a reform in health care delivery for children with chronic illnesses and their families.

**Summary**

There is a trend towards advocating empowerment strategies in nursing care for families who have children with chronic conditions. However, the provision of health
care delivery for families of children with chronic conditions has not kept pace with that trend. The question is, how can nurses provide more appropriate health care services for families who have children with chronic conditions. The purpose of this study was to gain insight into what it is in the parent-nurse health care relationship that parents interpret as making them feel empowered to meet the challenges of living with a child’s chronic health condition.
Chapter Two: Literature Review

In this chapter, a review of selected literature relevant to the issue of empowerment of parents in pediatric settings is introduced. Such a review situates this study within the current body of knowledge related to parents’ notion of empowerment in parent-nurse health care relationships. A search of existing literature in nursing, psychology, and related disciplines revealed only a few studies which specifically explored empowerment of parents of children with chronic conditions. In addition, no study specifically describes both parents’ experiences of empowerment in the context of a parent-nurse relationship. My focus on empowerment in these contexts led me to review the theoretical and research literature related to the parent-nurse relationship in the provision of health care for families of chronically ill children. I also reviewed the literature on parents’ perceptions of interactions with nurses and on parents’ perceptions of nursing interventions which make a difference for them. Furthermore, I will address the family centered-care and empowerment philosophies both to clarify the interrelationship between these concepts and notions to understand the health care relationships.

Review of the State of Knowledge and Background

Nursing history often maintains that the development of nursing has been sidetracked into providing illness-oriented services. And, yet the unique mission of nursing has always been health promotion, with efforts directed at improving health potential and maintaining health balance (Gibson, 1991). Too often people have found they are totally dependent on the services and relationships of health care provides.
Families often experience powerlessness in hospitals or in their interactions with health care professionals; that is, they are “overpowered” by the language, rules and complexity that can govern the interaction. Families are often told, rather than being asked, what their health care needs are, and decisions affecting them are often made without their participation (Registered Nurses Association of British Columbia, 1992). These feelings of being powerless and overpowered might be part of the reason why the philosophy of empowerment emerged. Gibson stated in 1991 that nurses would need to develop new skills and areas of specialization which would enable and empower people toward self-care, self-help and environmental improvement.

When I explored further the development and history of pediatric nursing, I found substantial overlap between the main philosophies of health promotion, family-centered care, and the newest trend of empowerment. The main philosophy in pediatric nursing care for the last decade has been family-centered care, a type of care that has its roots in health promotion philosophy but which adds emphasis to self-care. As well, out of the philosophy of family-centered care has emerged the notion (though not as yet the practice) of empowerment in pediatric nursing; the two philosophies enjoy many common elements.

Notions of empowerment extend both health promotion and family-centered care, emphasizing the beliefs, attitudes, and behaviors which should (and sometimes do) characterize nurses toward more effective practice and toward better outcomes of nursing care. Stemming from health promotion, empowerment is a process which enables people to increase control over and improve their own health (Clay, 1992). Within families who have children with a chronic condition, empowerment has been a useful philosophy that
strengthens the capacity to remain in control in decision making regarding family life and the management of care of their child.

**Family-Centered Care**

An exploration of assumptions which underly the provision of health care for families who have children with chronic conditions is essential to an understanding of pediatric nursing today. Pediatric literature reveals that family-centered care is the standard in care; key elements of family-centered care are well defined and supported with many research findings (Shelton & Stepanek, 1995). These well-documented principles of family-centered care are designed to help nurses understand the needs of families who have children with a chronic condition. In fact, its framework can be and is often used by pediatric nurses of every setting of care. Within this philosophy is the idea that families can and should be supported in their natural care-giving and decision making roles by building on strengths within the families. Patterns of living at home are to be promoted. Parents and professionals are considered equals in a care-giving partnership, working in collaboration at all levels: in the hospital, at home, and in the community.

Among the main elements of family-centered care is the idea that the family is the constant in a child's life. Family-centered care involves communication, collaboration, and exchanging information with families as well as recognition of family diversity. Also important are recognizing, respecting, and providing for the diverse strengths and needs within and across families through appropriate, flexible, and accessible services and support. Finally, partnership in care is essential to successful caring for all involved. All
these elements are aimed at establishing the "best practice" in pediatric nursing (Shelton & Stepanek, 1995, p. 364). The main elements in family-centered care in fact go very well with the characteristics of the direct care of advanced practice nurses as described by Hamric, Spross & Hanson (1996).

Although family-centered care is considered the standard in care and the best practice in pediatric nursing, recent discussion in the literature is starting to point out to us a discrepancy in the philosophy of family-centered care and its practice (Ahmann, 1998, 2000). In an exploratory descriptive study documenting pediatric nurses practices and nurses' perceptions of family-centered care, a questionnaire was used to reveal what activities nurses thought necessary for family-centered care and those currently a part of their practice. The findings highlighted the discrepancy between nurses' knowledge of the main elements of family-centered care and the ability of nurses to fulfill those elements in practice (Bruce & Ritchie, 1997). While nurses perceived most of the elements of family-centered care to be important to family-centered care practice, findings revealed that the nurses' everyday work did not match their perceptions of the activities necessary to provide family-centered care.

In the above study, nurses came closest to understanding the family's constancy in the child's life best among the elements of family-centered care. However, nurses reported they were least likely to participate in or facilitate parents' professional collaboration, also a main element of both the family-centered care and the empowerment philosophy. Since, as the authors of this study have stated, nurses who consider family-centered care as their philosophy in care find it difficult to incorporate into practice, it is
likely, in my view, that nurses also have difficulty incorporating some of the suggested elements of the empowerment philosophy into practice.

The Empowerment Philosophy

Empowerment is a very common term in the language of many disciplines today; yet, there is very little consensus regarding either the meaning or the elements of the concept of empowerment (Dunst, Trivette, & Deal, 1994; Vander-Henst, 1997). Empowerment has been used as an analytical tool in an attempt to inform the theoretical foundation of clinical nursing, however, there are many obstacles to its use in nursing practice. The main difficulties include lack of measurement, research, and a clear definition (Vander-Henst, 1997).

In a review and synthesis of the empowerment literature, authors Dunst, Trivette, and LaPointe (1992) concluded that the concept of empowerment is and has been used in six diverse but conceptually related ways: as a philosophy, as a paradigm, as a process, as a partnership, as performance and as a perception (p.111). A basic assumption in the empowerment philosophy is that everybody has the existing capacity, the strength, and capability to become more competent in managing and gaining control of the circumstances in their lives (Hulme, 1999; Dunst & Trivette, 1988; Dunst & Trivette, 1996).

Empowerment is thus defined by many disciplines in many different ways. The dictionary definition for empowerment is the “granting of power or delegation of authority to do” (Guralnik, 1982). The concept of empowerment has variously been defined in nursing as an intervention to empower others, as a process of becoming
empowered, and as an outcome of being empowered. In the nursing literature in general empowerment has most often been defined as an intervention (Hulme, 1999).

The bulk of the literature about empowerment of families comes from the authors Dunst and Trivette, neither of whom is a nurse. Their enabling and empowering model of helping relationships, first proposed in 1988, was designed to “increase parental participation in family-centered care” (Dunst, Trivette, Davis & Cornwell, 1988, p.71). They argued that help-givers need to consider helping relationships in specific ways for family-centered care to become a reality. According to their model, pre-helping attitudes and beliefs can and do influence help-giver behavior as the help-giver influences the response of the family (Dunst et al. 1988). My understanding from the discussion in the literature is that we are being led to further examine the interrelationships between parents and help-givers within the context of the empowering effects of family-centered care.

The most recent review and synthesis of the relevant literature about empowerment, to my knowledge, is the work of Hulme (1999). She has gathered together the theoretical and clinical literature on empowerment to design a theoretical model with suggested empowerment interventions for nursing care of families of children with chronic health conditions. The main interventions suggested in the literature are that nurses should: build a trusting relationship and collaborate and promote self-care through education of parents; be positive-oriented, an active listener who is empathetic and encouraging; provide accurate information regarding the child’s condition and treatment; guide families in assessing their own strengths, support system, and resources to mobilize their abilities to problem solve their own perceived needs; and, finally, assist families in
building skills in negotiating with other health care professionals by using role play (as cited in Hulme, 1999). With this model Hulme has drawn attention to the importance of integrating empowering intervention into nursing care for the population of families who have children with chronic conditions. She wants to “aid families through an empowerment process that consists of phases that correspond to the amount of trust and decision making a family shares with a health professional” (p. 33). In my view, Hulme’s statement refers to something shared in a relationship between parents and health professionals, something essential to empowerment—that is, trust.

Empowerment and Trust

Trust is a common theme in the nursing literature and, indeed, in the literature on empowerment for families of children with chronic conditions. However, the element of trust is not something that nurses or parents can or do take for granted. Hulme’s statement about the amount of trust shared between parents and nurses, in my view, points out that certain prerequisites are needed in relationships between parents and nurses to facilitate empowerment. Hulme suggests that, unless a trust in the parent-nurse relationship exists, empowering interventions or interactions will not be effective. Trust has been discussed by authors Thorne and Robinson (1988a, 1988b, 1989) who have conducted several studies about the health care relationship that develops between health care providers and families of chronically ill adults patients. They have found that health care relationships evolve through three stages: naive trust, disenchantment and guarded alliance. The findings revealed a core variable of reconstructed trust; this variable describes how the patients’ trust changes in their relationships with the health care
professionals in the chronic illness experience. In the beginning a relationship exists in which one trusts health care providers and assumes that they will act in their best interest. However when these expectations are unmet conflicts with healthcare providers occur, creating frustration and disenchantment, which results in a profound distrust in health care providers. Finally, the relationship evolves to the stage of highly selective reconstructed trust in health care relationships within which the patient can, in an informed way, negotiate with healthcare providers for care that is mutually satisfying (Thorne & Robinson, 1988). These study findings are of relevance to the proposed study because they provide insight into patients' perceptions of how the health care relationship evolves in clinical practice. And these findings confirm the importance of trust in health care relationships. It is expected in the proposed study that the parents who will participate will be at the stage of reconstructed trust in the health care relationship.

Similarities exist in the findings of both Thorne and Robinson (1988) and Gibson (1995) regarding the process of empowerment. The former describe the role of frustration in the ongoing development of a health care relationship which results in reconstructed trust in the guarded alliance stage -- the two main dimensions being trust in health care professionals and trust in the clients’ own competence. The latter describes the outcome of frustration within the empowerment process, which results in participatory competence when individuals, in this case mothers, developed and employed the necessary knowledge, competence, and confidence in themselves. Thus, both studies focus on ways a client’s informed confidence in his or her own abilities builds confidence to manage life in spite of the challenges that a chronic illness can represent.
Families’ Perceptions of what Nursing Interventions Make a Difference

Two recently conducted studies in pediatric nursing have addressed parents’ perceptions of helpful versus unhelpful interventions and supportive strategies to manage the care of chronically ill children. Garwich, Patterson, Bennett & Blume (1998) examined parents’ perceptions of helpful versus unhelpful types of support in managing the care of preadolescents with chronic conditions. This study involved a multi-method cohort study with 1-year follow-up. In-depth interviews and a questionnaire were used to collect data for analysis. Findings revealed that both mothers and fathers individually reported that another family member (i.e., each other or someone else) was the primary source of helpful emotional and tangible support. The main sources of support were grouped into the family cluster, the services provider cluster, and the community cluster, and these were rated on a social support questionnaire. Health care providers were reported to be the primary source of informational support.

Yet, reported incidents of non-supportive behaviors were most often related to health care providers. The most common problem was of communication with health care providers; respondents cited rudeness and disrespect as well as inadequate provision of information about the child’s condition or care as problematic. Last, parents were concerned about inadequate knowledge or experience that health care providers had in caring for children with chronic conditions. Garwich et al. conclude by stating “the result of the reported non-supportive types of behaviors indicated that there are gaps in services and problems that must be addressed to improve the care that children with chronic conditions and their families receive” (p. 665).
This study involved one-year follow up and the large sample of perspectives of both mothers and fathers who care for preadolescents with a variety of chronic conditions. However, the sample participants were all volunteers, families that defined themselves as functioning well, in short, those who might be more likely to volunteer for a study that requires a long time commitment; such a tendency could bias the findings.

The result of the study by Garwich et al. provides valuable insight into understanding what it is that parents value as most helpful when caring for a child with a chronic condition. Therefore, the findings are relevant to the proposed study. The study findings point out that both mothers and fathers receive helpful support from different sources, not only from health care providers. Still, further information is required that specifically examines the kinds of relationships that are most helpful to families; such information can offer direction to nurses caring for families of children with chronic conditions.

Robinson and Wright (1995) state that nursing interventions are not simple tactics or tools that nurses can learn and apply in care. They point out that to intervene effectively the relational context between the nurse and the family must fit, meaning that not each and every nursing intervention fits everybody, all the time. All of this rings true to me as I reflect on my clinical experience of working with families of chronically ill children. Robinson and Wright conducted a grounded theory methodology study to examine the experiences of families of chronically ill patients experiencing difficulties in management of the chronic condition. These authors set out to identify the nursing interventions that families described had made the difference in helping them to manage a family member’s chronic condition. A very important finding in this study is, in my
view, that the families emphasized the relationship between nurses and families, not the nursing interventions per se. Families mainly viewed nursing interventions as something that “promoted and enhanced particular kinds of relationships” between the family and the nurse (Robinson, 1996, p. 153).

The findings of the preceding study revealed that the interventions families considered had made the difference for them take place within two stages: creating the circumstances for change and moving beyond and overcoming problems. The interventions that the families identified were bringing the family together to approach their problems in a new way and lifting the sensation of isolation from the mother, the primary caregiver. This is similar to Gibson’s (1995) findings from her study about empowerment of mothers of chronically ill children, where she also describes the role of isolation of the mothers since they are the primary caregivers. Other interventions were development of comfort and trust in a therapeutic relationship; this involved showing respect, genuine interest, and attention in all family matters and encouraging the family to participate in meaningful conversation and focus on the family strengths, abilities, and resources by using positive feedback and commendations. A careful attention to concerns and problems was also highly valued. In addition, working in collaboration to face the challenges was essential to help families to gain control of the circumstances in their lives.

Other nursing behaviors that the families in this study reported helpful to them in their management of a family member’s chronic illness included: the ability of a nurse to be a curious listener and a compassionate stranger; a non-judgmental manner; a willingness to collaborate with the family; and the ability to be positive in attitude.
focusing on family strengths, resources, and possibilities (Robinson, 1996. p. 152). I find many of the elements of the empowerment philosophy are reflected in the findings of this study. These include building trust in the health care relationship, showing respect, collaborating, and focusing on strengths, abilities, resources, and encouragement.

Relevant to the proposed study, Robinson’s findings provide valuable insight into understanding families’ perceptions of how and what nursing interventions have helped them live with a child’s chronic condition. Furthermore, these findings suggest the importance of health care relationships for effective and appropriate provision of nursing care. That is, the families wanted to make it very clear that change does just not happen; rather, it happens in the context of particular relationships between family and nurses (Robinson & Wright, 1995). In my view, the study findings are indicating the families’ perception that some prerequisites in the parent-nurse relationship are an important contributor to a family's ability to manage a family members' chronic illness.

The sample in this study involved five families of chronically ill patients but only three of the families have children with a chronic condition. The other two families, were families of adult patients. All of those five families have defined themselves as having difficulties in managing a chronic condition. An important point is that the findings are similar among all the families, which might indicate that the nature of the chronic illness experience is comparable between families of chronically ill children and chronically ill adults.

The result of the preceding study gives grounds to the argument in this literature review. Thus, intervening more effectively and making empowerment strategies work may depend on certain prerequisites in the parent-nurse relationship. However, further
information is required from families of children with chronic conditions to gain a clearer understanding of what, in the parent-nurse relationship, makes the difference toward empowering these families.

**Barriers to Empowerment**

In my view, the empowerment philosophy is in fact saying that the health care providers should respect and feel comfortable about parents taking an active role, and that parents should be involved as much as they like in their children's treatment planning and care. However, the reality is not always this way. In fact I can say from personal experience that some of the health care workers are not oriented in this way. On the contrary, some health care workers believe parents should not be asked to make any decisions or take part in their child care; they believe that decision making is not a role of families and that only the health care professionals can know what is best for these families and their children. On the other hand, parental readiness and willingness to accept responsibility for the child's care have been said to be key factors in enabling and empowering families of chronically ill children (Nissim & Stern, 1991).

In her research work on women who have immigrated to Canada, Anderson (1996) discusses the issues in people's lives that affect if and how they can become empowered. She points out many factors that are missing in the discussion about empowerment for families who have children with chronic conditions and in the empowerment philosophy per se. Structural inequities in the system, like the context of the conditions in which people live and work, are barriers that need to be recognized. She asks the questions: how are class, culture, and power differentials to be addressed? How
can health care professionals empower people in a health care system that is organized primarily to provide services to people fluent in English, when adequate knowledge is the key to empowering people? Anderson warns of too much emphasis on the individual in the empowerment philosophy, deflecting attention from social issues and structural conditions in Canadian society.

Thorne, Nyhlin and Paterson (2000) recently conducted a secondary analysis of two databases generated to gain insight into adult patients’ chronic illness experience. These authors discuss in their paper the attitudes underlying health care relationships in chronic illness. Cross comparison of both databases showed that the patients explain their experience with illness in the context of interactions with health care professionals. The main conclusion of the findings was that “the general pattern of health care interactions described by all participants was characterized by a pervasive attitude of disbelief in their competence to make decisions on their own behalf” (Thorne et al., 2000, p.305). Patients’ reports included descriptions of how many health care professionals are not willing to respect the patients’ own expertise, abilities in self-care, and decision making concerning their medical treatment or own health maintenance. In fact, acts of not completely following medical recommendations were often met with resistance and suspicion from health care professionals. Other reported patterns were informational control, dismissal of questions, assumptions about biomedical superiority and interpreting physical symptoms as signs of a psychological problem.

Overall it can be maintained that these findings are not at all in the spirit of the empowerment philosophy and in fact give a very unfitting description of health care professionals’ attitudes, beliefs, and behaviors. In my view, these kinds of findings do
not support the idea that all health care professionals are oriented towards empowerment; the necessary foundation that should be underpinning the health care provision does not seem by these reports to be in place.

**Empowerment for the Adult Population**

In the literature on adult empowerment, most of the work is on empowerment of minority groups, including women, the elderly, and ethnic groups, and those involved in substance abuse, those dealing with immigration, those in poverty, and those within the HIV/AIDS patient population (Anderson, 1996; Beeker, Guenther-Grey & Raj, 1998). Of relevance to this proposed study is a practical action research which was conducted to evolve and test health promotion interventions in order to identify empowering strategies for old chronically ill Canadians. The study findings revealed five empowering strategies: building trust and meaning; connecting; caring; mutual knowing; and mutual creating (McWilliams, Stewart, Brown, McNair, Desai, Patterson, Maestro & Pittman, 1997). In the findings the authors discuss the participants’ apparent focus on relationships with health care professionals and their request for continuity in the health care relationship. In addition, they show how the participants emphasize a request for an understanding of their situation and active listening with an unconditional positive regard and a non-judgmental responsiveness. These authors’ conclusion is that professionals must really come to know and connect with their clients, that is, to use themselves therapeutically in building relationships with clients, if empowerment is to be achieved. The study results indicate that the professionals’ focus on relationships is a very important aspect in empowerment, as the authors suggest, perhaps professionals have the most to learn from
the process themes that emerged in the study. In my view, the findings also indicate that creating an experience of empowerment requires an ongoing relationship built on certain prerequisites, like trust, “understanding the individual’s situation and situatedness, active listening, unconditional positive regard, non-judgemental responsiveness and continuity of relationships” (p.118).

Because this study addressed older adults with chronic illness, the applicability of the findings to the situation of parents who have children with chronic illness is unknown. This study was conducted over the course of 12-16 home visits to the 13 participants of the study, each visit approximately one hour in length, which provided the opportunity for rich descriptions and for validating aspects of the data to ensure the rigor of the study.

The results of the preceding study give grounds to the argument that empowerment is indeed positively linked with health care relationships, and that further information is required on empowerment in the context of parent-nurse relationships. This is because the findings indicate how important it is for nurses to build a special kind of a relationship with clients in order for empowerment to work.

**Research Literature on Empowerment**

Few studies have yet been conducted directly about empowerment of parents of chronically ill children. A case study in psychology compared pattern matching from hypothesized patterns in an enabling model and empowerment model of helping (Dunst et al., 1988). The main idea was to obtain information about things professionals did that parents found either helpful or unhelpful toward creating a sense of control in their health
care for their children. The findings revealed that the descriptions of help-giver attitudes, beliefs and behaviors in the hypothesized model of empowerment were associated with the families’ sense of control or lack of control. Furthermore, the degree of control was related to different behavioral outcomes of the family as a result of help-giver versus help-seeker exchanges (Dunst et al., 1988). Only two families of children with special needs were interviewed for the purpose of this case study. However, the findings from this small study suggest that empowerment strategies might be something that nurses should be considering when trying to improve their practice and that further investigation is needed to show how empowerment is related to health care relationships.

In the same way as the literature questions the commitment in practice of family-centered care, evidence exists that empowerment is also starting to be questioned. This has happened because, although many health care facilities and health care professionals support concepts like empowerment, their vision is unknown to many parents (Darbyshire & Morrison, 1995). In England, the findings of Darbyshire and Morrison’s (1995) study about partnership and empowerment in care revealed that parents’ participation is occurring in practice—nurses are allowing parents to do certain things. Furthermore, the study findings also highlighted the reluctance of some nurses to encourage parental participation. The results of the preceding study provide valuable insight into understanding how nurses view their role in pediatric nursing. These findings might indicate that nurses have not in fact changed their roles as much from the traditional medical model as the philosophies of empowerment and family-centered care seem to suggest.
Darbyshire and Morrisson's study focus is on nursing care for children with special needs, not on families who have children with chronic conditions. Furthermore, there might be a difference in the delivery of health care between Canada and England, where this study was carried out, therefore, the applicability of the findings to the situation of parents in Vancouver who have children with chronic illness is unknown. However, the study is important to gain insight into what level nurses are engaged in partnership with parents, because partnership in care is a basic element of the family-centered care and empowerment philosophies. Therefore, further information that specifically explores partnership with parents as a part of empowerment to parents of children with chronic conditions in a health care relationship is required.

In order to refine the concept of empowerment in relation to mothers of chronically ill children, Gibson (1995) conducted a fieldwork study over a 12-month period, using both participant observation and in-depth interviews as the method of choice to describe the process of empowerment from an empirical perspective. By utilizing the hybrid model approach of concept development, Gibson selected a model case that best represented the process of empowerment. From the findings of her study she created a conceptual model of the process of empowerment for mothers of children with chronic conditions.

The data from Gibson's study (1995) reflected remarkably consistent patterns among mothers' experience of empowerment as a process. The main themes were mothers' ability to love, to bond, and to commit to acting in the child's best interest, giving mothers the motivation to go on with their lives, no matter what, and sustain the process of empowerment. Another main theme was frustration, a very powerful force
infusing the process of empowerment; frustration assisted the mothers to discover reality, and this was the first phase in the empowerment process. From there, mothers reflected critically, enabling them to take charge of the situation and finally to hold on to their sense of power no matter what. The outcome of the empowerment process was the mothers' participatory competence (Gibson, 1995).

I find the discussion about the role of frustration in the process of empowerment very convincing in view of my clinical experience with families of chronically ill children. These families so often have to walk way too far to get the information, support, and services they require. The findings of this study verified that frustration was a predominant theme in all interviews conducted: mothers felt frustration within the family; frustration occurred with the health care system and health care providers; and family caregivers felt frustrations with themselves.

When Gibson explains how the mothers became empowered and developed a sense of personal power, she describes how mothers examined their situations and realized that they knew their child best. From that standpoint, the mothers made decisions and established their priorities as they "became acutely aware of their values, goals, wants and needs" (p.1206). Furthermore, the findings revealed that all the mothers employed a positive style of thinking to see their own situation more favorably. Therefore, after critical reflection, the mothers were able to take charge of their situation.

Gibson's findings describe the taking charge phase as (a) advocating for the child; (b) learning the ropes to interact efficiently with the health care system; (c) learning how to persist to get the attention they needed for the child; (d) negotiating with health care
professionals so that opinions and requests were heard; and (e) establishing a partnership
with the health care team built on mutual respect and open communication between the
health care professionals and the mothers as well as commitment to a common goal.

Holding on was the last phase of the process of empowerment, and it resulted in the
mothers becoming aware of their strengths, their competencies, and their capabilities all
of which helped them both to maintain their sense of personal power and to take action
consistent with their values, beliefs, goals, and needs.

Gibson’s main conclusions were first that both positive and negative support
influenced the process of empowerment but that in order to become empowered first of
all mothers needed to be heard by health care professionals; second, that the process of
empowerment was largely intrapersonal; and, finally, that empowerment was a learning
process for the mothers, which was resolved in their mastery of their situation. My
interest in this study is focused on the discovery that the findings are in many ways not at
all in keeping with the conceptualization of empowerment in the theoretical literature I
have read so far. Many fascinating findings also arose from the data analysis of this
study. Looking more closely at Gibson’s statement that the factors that influence
empowerment are largely intrapersonal makes me wonder why the theoretical literature
on empowerment is mainly addressing interpersonal interventions. The study findings
revealed that none of these mothers had a nurse as a key contact to empower them along
the way. Nonetheless, Gibson recognizes that empowerment takes place in a context
which includes interactions with others, which I believe is fundamental for
empowerment. The results of this study provide a valuable insight into understanding
mothers’ notion of empowerment. In addition, these findings reveal a new dimension in
the empowerment discussion, the role of intrapersonal factors in empowerment. The findings indicate that there might be more to empowerment than interpersonal nursing interventions.

Gibson's study was conducted over a 12-month period, a length of time that provides opportunities for validating aspects of the data to ensure the rigor of the study. Therefore, the findings of the preceding study provide valuable insight into understanding what mothers' notion of empowerment is. However, the sample was limited only to mothers. Further investigation is required which specifically examines both parents' notion of empowerment and in different context, such as in the parent-nurse relationship and the parent-parent relationship.

**Health Care Relationships in Pediatric Nursing**

Nursing research has established that health care relationships are central to the quality of health care and to the experience of living with a chronic illness. In addition, an ongoing relationship with health care providers is especially important in chronic illness (Thorne, 1993). Health care relationships characterized as positive and family-centered have been associated with increased satisfaction with care, greater willingness to seek help from help providers, and higher levels of individual and family well-being. In contrast, when health care relationships are adversarial, as when a discrepancy exists between the family and the health care providers, these relationships can be both a resource and a constraint (Thorne, 1993; Van Riper, 1999).

In my view, the studies I include in this part of the literature review have shed light on what the consequences of empowering interactions between nurses and their
clients are, even though the main focus of these studies has not been to discuss empowerment. A study of the parent-professional relationship of families caring for medically fragile children at home revealed that factors contributing to a helpful parent-professional relationship included professional competence, genuine caring for the child, and respectful and supportive collaboration with the family. The negative aspects of the parent-professional relationship were also analyzed. The four main negative factors that were identified by parents were invasion of privacy; lack of respect for the family; unprofessional or inadequately trained staff; and staff turnover, cancellations, and scheduling hassles (Patterson et al., 1994). Other interesting findings revealed in this study included a difference in what mothers and fathers valued most in the relationship with a nurse. The mothers reported attitudinal and relationship factors as most important, followed by nurses’ competence and skills; the fathers reported the opposite (Patterson et al., 1994). A point of interest in the findings of this study is the reported struggle for control among parents and nurses. The authors maintain that they became sensitized “to the challenge that both parents and nurses experience in deciding who is in control and the aspects of the child’s care that require control” (p. 104). Findings revealed that if parents did not trust a nurse’s competence, they found it difficult to let the nurse take charge, and if the nurse did not trust or respect the parents, decision making was difficult and boundaries were unclear (Patterson et al., 1994).

The importance of the results of the preceding study to the proposed study is that the findings indicate that each participant in a health care relationship brings something to the interaction that affects the relationship between them. Thus, there are factors associated with both parents and nurses that make a difference in the efficacy and quality
of the relationship between them. However, because this study addressed families with medically fragile children the applicability of the findings to the situation of families who have children with chronic illness is unknown. This study involved a large sample of 48 families, including both mothers and fathers. What's more, the parents were surveyed by interviews and self-report questionnaires at two different times over a period of two years, which can increase the study rigor. Further studies are needed to gain insight into the nature of quality parent-nurse relationships to provide nurses with valuable information for nursing care of families who have children with chronic conditions.

When Robinson (1996) revisited beliefs about health care relationships, she conducted a grounded theory study to explore what it is that nurses can do to help in the health care relationship. Robinson's main conclusion from the findings of the study was that "health care relationships are not central to care, they are care" (p.153). She reached this conclusion because families emphasized the relationship between nurses and families, not the nursing intervention per se. Families mainly viewed nursing interventions as something that "promoted and enhanced particular kinds of relationships" between the family and the nurse (p.153). The nursing interventions that the families in this study reported were helpful to them in their management of a family member's chronic illness have already been discussed in this literature review. Within the findings from Robinson's (1996) study, I find substantial overlap with many of the elements of the empowerment philosophy.

Among the many points of interest in Robinson's revisiting of the discussion of health care relationships is her focus on the lack of clarity about what constitutes a context for change in nursing care. She also shows just how this lack of knowledge of
how to create the circumstances in which interventions act to influence change is inhibiting translation into nursing practice. I find this discussion relevant to the proposed study because the purpose is to gain insight into what kinds of relationships, that is, circumstances, are empowering and for what reason. In my view, Robinson’s findings confirm that there is a gap in nursing knowledge about what prerequisites are required in nursing care and about what kind of context will facilitate effective and appropriate provision of nursing care.

Robinson discusses the importance of the nurse’s relational stance and she states that, from the families’ perspectives, the nurse’s relational stance influences change. By the nurse’s relational stance, she means the nursing actions that enable change. Robinson’s discussion points out to us that the two facets, the context for change and the therapeutic change itself, have in fact been separated in the literature on nursing interventions. However, to make nursing interventions effective, nurses need to draw forth a context for change. With this discussion Robinson has drawn attention to the importance of the role of the nurse in the health care relationship, that is our role in creating the circumstances that make nursing interventions work.

**Relational Empowerment**

The discussion in the literature about relational empowerment comes from feminist psychological literature. Relational empowerment defines empowerment as the power that emerges between, through interactions in a relationship, not power that is given or taken. The main principle in relational empowerment is that no-one can be just an empowerer or a person in need of empowerment, because empowerment is always
mutual. And "the ability to be empowering or to support someone else’s capacity to be empowering grows out of mutual recognition that all of us can contribute to the construction of knowledge and social change but that, in that process, all of us have a lot to learn" (VanderPlaat, 1999, p. 777). Therefore, in an empowering process, everyone changes because "in the relational approach to empowerment, everyone involved, regardless of position of power and privilege, recognizes that he or she is both an agent of change and a subject in the empowerment process" (VanderPlaat, 1999, p. 777). It is my understanding that the relational empowerment discussion is pointing out to us our role in empowerment; everybody included in a relationship intended to be empowering becomes a focus of change and the emphasis is on the role of the relationship for empowerment.

Clearly no consensus can be found in the literature on the notion of whether empowerment is a sender-receiver type of intervention or more of a relationship type. Rapport (1985) has argued the sender-receiver standpoint saying that “empowerment is not something that can be given, it must be taken. What those who have it and want to share it can do is to provide the conditions and the language and beliefs that make it possible to be taken by those who are in need of it” (p. 18). To my knowledge, a discussion on empowerment as a type of health care relationship does not exist in the pediatric nursing literature. However, in my opinion, the recurrent theme of the importance of health care relationships in the research literature relevant to this proposed study, indicates that further research is required that can shed light on the role of health care relationships in empowerment.
Summary

A review of the relevant literature indicates the importance of the role of the parent-nurse relationship in facilitating empowerment of parents of chronically ill children. The intent of empowerment is to assist families to move forward and become competent by strengthening the capacity of families to remain in control of decision making regarding their family life and by enabling the family to manage the care of their child.

There are many different lenses in the literature on how to empower someone, both in nursing and among nursing and other disciplines. Empowerment is discussed in a range of different ways; as a sender-receiver intervention and as a process with interventions and outcomes; and within the concept of relational empowerment relationships, wherein all participants in an interactive relationship are agents of change. While, we can enjoy no certainty in the literature about what empowerment is, the literature, is in my view, is most recently starting to indicate that the most effective and important empowerment strategy is to develop a special kind of relationship between parents and nurses because that seems to be the key for empowerment to work.

Therefore, the role of the parent-nurse relationship in empowerment or the link between these concepts is not clear, and needs to be addressed directly by a study in pediatric nursing.

The common themes that arise in the literature clearly stress certain prerequisites that are required in order for the relationship to be effective. These recurrent themes are reflected in the empowerment philosophy, the most common of which is the importance of the health care relationship to making empowerment of parents work. What the
relationship affords, at best, is a building of trust in health care relationships, that is, parent-nurse relationship; a development of mutual trust and respect as well as the health care provider’s acknowledgement of parents’ expertise in collaboration with parents; encouragement and positive orientation with focus on family strengths; active listening or listening which is curious and empathetic and has no attitude of judgement; a feeling of being heard by health care professionals; and a sharing of goals, expectations, and good communications between parents and nurses.

In summary, a review of the most pertinent nursing literature indicates a very limited amount of research focusing specifically on the parents of children with a chronic condition’s notion of empowerment, and none in the context of a parent-nurse relationship. Therefore, further information is required to gain insight and understanding about what it is that parents believe has empowered them to manage a child’s chronic condition. Only by gaining a clear understanding of what parents report has been most helpful to them in the context of the health care delivery they have received can pediatric nurses provide more appropriate help and quality care to families of children with chronic conditions.
Chapter Three: Methodology

This study used the method of interpretive description. Where the purpose is to use a critical analysis of existing knowledge toward building an analytical framework to orient the inquiry, interpretive description is the method of choice (Thorne, Kirkham & MacDonald-Emes, 1997). Thorne et al. state “interpretive description ought to be located within the existing knowledge so that findings can be constructed on the basis of thoughtful linkages to the work of others in the field” (p. 173). In this study, the method involves utilizing as an analytical framework the existing knowledge about health care relationships in nursing and empowerment of families of children with a chronic health condition.

An interpretive description method appeared to be most suitable for this study for the following reasons: First, the purpose of the study was to explore phenomena of an ongoing nature in the chronic illness experience, a topic barely researched as yet. Second, an analytic framework based on existing knowledge provides an opportunity to lend theoretical support to explore the findings and use interpretive reasoning in interpreting meanings within the data. Third, the interpretive description method offers flexibility for maximal variation on the themes that could emerge from the inductive analysis, and diversity in participant experiences can therefore be accounted for (Thorne et al., 1997).

Sample Selection and Recruitment

For the purpose of interpretive description, Thorne et al., say that purposeful selection of research participants is recommended. This technique involved the selection of subjects for their ability and willingness to illuminate the phenomena of interest. The
continued selection of subjects was determined by the information obtained in the course of the study and the need for theoretical completeness (Sandelowski, Davis & Harris, 1989).

The selection criteria for participants included both parents of children between the ages one and eighteen years old with diverse chronic health conditions that have lasted for at least one year. The final sample size included eleven parents. Three of the families had a child who had been diagnosed with Diabetes and three of the families had a child that had been born with serious heart defects. One family had a child with severe cerebral palsy including a seizure disorder and the last family had a child that has a tracheostomy to be able to breath on its own. One of the families is a foster family and one of the families is a single parent family. Six of the families are living in the area near Vancouver and two families live inside Vancouver.

In order for the researcher to communicate effectively, a sample of fluent English-speaking participants was sought. Recruitment was accomplished by obtaining referrals from several advanced practice nurses who have contact with families in the community. These nurses phoned the families and ask them if they were interested; if so, the family was contacted by the researcher by phone and provided with further information about the study. Before each interview was conducted the parent receive the introduction letter for parents (Appendix A) that contained a description of the study and signed the consent form (Appendix B).
Data Gathering

Data was generated from face-to-face interviews with participants at times and locations convenient to the participants. Eight interviews were conducted with eleven participants. Three of the interviews were conjoint interview with couples, altogether four fathers and seven mothers participated in the study. All of the interviews except one were conducted in the participants, homes, the one remaining interview was conducted at the Registered Nurses of British Columbia office. Other data collection methods that were used were the taking of fieldnotes, and audio-taping a journal immediately after each interview, which documented the study process and included my thoughts about what the data was indicating, that is, the general feeling of the interview and reflection on emerging themes. Semi-structured open-ended interviews, were used (see Appendix C) guided by a set of questions, based on the recent literature and the author’s previous clinical experience. In conducting the interviews, an open-ended question was used to start the interview: What is it that nurses do that has enabled / helped you to manage well the care of your child and become the expert you are today, in your child’s care? (Refer to appendix C for examples of questions). Usually the interviews lasted about one hour, with three of the interviews lasting between one and one-half hour, to two hours. All of the conducted interviews were audio-taped and transcribed. I asked parents for a possible follow-up with a phone call to verify information from the interview, if needed, but further verification was not needed. All data was collected under the conditions of informed consent and confidentiality (see Appendix B).
Data Analysis

The data analysis method that was used is interpretive description. The data consisted of the interview transcripts and the researcher's field notes and journal that included descriptions of the interviews and reflection on emerging themes. Transcription of the tape-recorded interviews was provided for an accurate record of the conversational dialogue. A continuous immersion in the data after each interview directed the study analysis, and ongoing immersion during data analysis directed the researcher to conduct more focused interviews to test the developing conceptualizations in order to abstract the relevant common themes that emerged, as Thorne et al., suggest (1997). Data was repeatedly read through and examined to obtain a sense of the whole. The large margin on both sides of the transcripts allowed me to write down and identify the themes that I could see emerging from the data. The data analysis findings were discussed with the research supervisor. The closure of the analysis occurred when the data collected had been re-contextualized into more abstract concepts as a process, that provided suggestions for nursing practice. The themes that emerged from the findings were examined and compared with the existing nursing literature on empowerment and health care relationship.

Ensuring Study Rigor

Attention to the process of rigor is very critical to the interpretive-descriptive methodology (Thorne et al., 1997). The truth value of qualitative research is determined by its credibility. A study is credible when individuals recognize the descriptions of human experience as their own or when other researchers recognize the experience after
reading about it in a study (Sandelowski, 1995). The applicability of qualitative research is determined by examining the fittingness of the findings, as Sandelowski (1986) has stated, when “findings can fit into contexts outside the study situation and when its audience views its findings as meaningful and applicable in terms of their own experiences” (p. 32).

To ensure rigor in the study, I used the participant’s own words and perspective as much as possible to try to increase the truth-value in my interpretive descriptions. Furthermore, an effort was made to show both the commonalties and differences that were emerging in the data. By selecting settings and circumstances which are unfamiliar to the researcher, the credibility of the study was increased, since the closeness of the researcher-participant relationship did not influence the researcher in any way. A qualitative study is said to be credible when it can present a faithful description of human experience in a such a way that other individuals will recognize when they have experienced the same or similar phenomenon (Sandelowski, 1986). As suggested by Sandelowski (1995) the criteria for fittingness was met by using a sampling method that provided a sample of participants that could illuminate the phenomenon of interest in this study.

Sandelowski states “Auditability means that any reader or another researcher can follow the progression of events in the study and understand their logic” (1986, p. 34). In order to ensure that the criterion of consistency was met, I have tried to make my decision making in the study process as transparent and clear as possible through the use of audio-taped journalling and journalling. Likewise, I have tried to describe and explain what I did in the process of conducting this study as clearly as possible.
Confirmability is the criterion of neutrality in qualitative research. Confirmability is ensured when the other criteria of truth value, applicability and auditability have been established (Sandelowski, 1995). Confirmability was enhanced by linking quotes to the explanation of the properties in the description of findings. I identified my own biases through the use of a reflective journal to be aware of them when I was interpreting the data; to ensure that the findings were as objective as possible.

Ethical Considerations

The rights of the participants were ensured in several ways. This proposal was subject to review and approval by the University of British Columbia Behavioral Sciences Screening Committee for Research and other Studies Involving Human Subjects. All participants were provided with an information letter that explained the study procedures and purpose (see Appendix A). Furthermore, an informed consent form was individually obtained before each interview was conducted (Appendix B). I made it clear that no one was under any obligation to participate and everyone was free to withdraw from the study at any time. If any topic came up that the participant did not wish to discuss, I moved on to another topic. Confidentiality of names was maintained, because all data that could reveal the participants’ identity was removed. Transcripts were labeled by code numbers only, and the list of codes and the recorded tapes were destroyed upon completion of the study. Access to the raw data was limited to the researcher and her research supervisor. Data will be retained for possible secondary analysis. All files were kept in a locked filing cabinet.
Summary

The interpretive description method of inquiry was used in this study to examine parents' notion of empowerment in pediatric health care delivery. Procedures for theoretical sampling, data gathering and analysis that were utilized have also been described. Furthermore, actions that were taken to protect the human rights of participants have been put forth along with the methods that were intended to ensure the rigor of the study.
Chapter Four: Findings of the Study

In this chapter the findings of this study are presented. The purpose of this study was to gain insight into the kinds of parent-nurse relationships parents describe as empowering, to find the reasons it is empowering to parents, and to develop an understanding of how the parent-nurse relationship is linked to empowerment. The parents who participated in this study all had their individual story to tell; yet, common themes arose from the parents’ experiences: the challenges of a child’s chronic condition, the necessity of empowerment, the personal and situational elements in empowerment, the role of a relationship, the main components of an empowering relationship, and finally the outcomes of empowerment. Each theme represents both the experience of parents in interactions with nurses and the relationships between parents and nurses.

The Context for Empowerment

A child’s chronic condition brings forth certain challenges a parent and nurse must face together. These conditions force a necessity for empowerment if parents are going to meet the challenges which face them.

The Challenges of a Child’s Chronic Condition

Most often for the parents, what marked the beginning of their voyage through the empowerment process was the moment of receiving the shocking news that their child had a life-threatening disease or had been born with a serious birth defect. Nearly all of the parents explained they were not given a choice whether to deal with this--their lives had been changed forever; each was suddenly in a situation that demanded a lot of them. They felt powerless and overwhelmed in the situation and wondered whether they
would be able to handle it and whether they would ever gain control over their lives again. For that to happen the parents needed to take in a lot of new information, to learn health care-giving skills and to deal with making decisions about treatments and procedures, all for the well-being of their child. These demands not only affected all aspects of their lives greatly but called for a rearrangement of their lives. Their lack of confidence was evident as they attempted to handle the situation, meet demands, and find ways to cope with their new roles as primary health care providers to their child.

The Necessity for Empowerment

Right from the beginning of their story, each parent described how important it was for him or her to connect with a nurse who would give them the help they needed. This nurse was a “calm and caring nurse” who made sure the parent understood the information given, who tried his or her best to educate the parent, and who helped the parent learn the skills that were needed to master. These parents also needed a nurse to acknowledge the fact that they were grieving and to “really let you have your feelings,” a nurse who was “very loving about that fact that we had this little child”. Nurses were seen as comforting and caring, which in turn helped them cope with their situation.

Parents described how powerful it was to have a nurse who could tell them they were doing a good job and who could make them feel they were handling the situation; by giving positive feedback, nurses increased the parents confidence. However, all parents expressed they were not ready for discharge when it was time to go home; likewise, all of the families experienced problems finding their way through the system after discharge. Fortunately, the standardized program planning for the newly diagnosed families of children with Diabetes Mellitus (DM) is proving to lighten the burden of these
parents considerably. The findings show that the three families of children with DM that participated in this study benefited from having been involved with program planning from the beginning; the program is one that effectively helps parents of children with DM to learn to care for their children at home. In contrast, four of the five families having a child with another kind of a chronic health condition than DM experienced much more frustration and insecurity; they described how they had to “dig, scratch, talk to other parents and whatever to find out the information that they wanted”. Their struggles in caring for their child were accentuated because they required even more information and further resources.

Depending on the chronic condition their child was diagnosed with and correspondingly the effectiveness of the program planning offered to families with children with DM at Children’s hospital, families received a variety of health care services. The story of a family with a child having serious heart defects and living outside of Vancouver reveals how things can go wrong when discharge planning is not sufficient and when follow-up services do not responsibly take over evaluation of a child’s condition. The mother was told at discharge from the hospital to watch out for blue spells without understanding what blue spells were. After discharge the mother experienced many difficulties with the management of her child and had to be “forever back and forth to the family doctor who really never thought all this stuff was heart related, which was a big mistake”. Still today, five years later, this mom feels guilty that she missed the blue spells and other classic symptoms of congestive heart failure; she describes how she used to think she “was doing something wrong or [she] was not meant to be a mom”: “I just had this cranky little baby, I had no idea”. Finally at four months,
this child had a cardiology appointment, and it was discovered that the child was in very bad shape, needing urgent surgery that was done the next day. This mother said she had not been in any connection with a nurse; nor had she really had any interactions with nurses along the way. Looking back into the past, she said, “I do not know what nurses have helped me to do”, and added, “you need to have a contact, you need to have someone who knows what they are talking about”. This mother acknowledged that a connection with someone who knew her and understood her child’s condition would probably have been helpful; all parents in this study who had enjoyed empowering long term relationships with nurses emphasized their importance in helping parents manage the care of their child, especially at home after discharge. In summary, the families said they had not been ready for discharge when they went home; they emphasized their connection with a nurse as the biggest help in dealing with early discharge. Furthermore, the kind of health service families get seems to depend on the chronic condition their child is diagnosed with and whether there is a formal planning program offered for their child’s condition.

The Personal and Situational Elements in Empowerment

Elements that were identified as playing a role in the development of an empowering process for parents in charge of a child with a chronic condition were three: the intrapersonal elements, interpersonal elements, and situational elements.

The Intrapersonal Elements

All parents participating in this study shared the intrapersonal element of the motivation to act in their child’s best interest. The parents were willing and able to face
the situation because they wanted what was best for their child. A common attitude among the parents was to view the situation they could not change in a positive way and make the best of it.

The findings indicate that all of the parents found their own ways to deal with their situations; self-education, conducted mostly through the internet was a common element of all the participants. The reasons parents gave for example for needing more information focused on preparing themselves for conversations with medical people: one participant said, “I find the medical people say this stuff, and you do not know what it is about, so I usually bring it home and put it on the computer and look it up myself so I am prepared for the next conversation”. Describing his own lack of education and information, one parent said, “if you do not start asking the questions, the information is not going to be volunteered to you on anything”. These comments describe parents’ frustrations and struggles with finding their way through the health care system to find the information they need. These frustrations provided strong motivation to become empowered in handling their situation.

**The Situational Elements**

All parents experienced situations that they felt caused them frustration, for example, the frustration of not knowing where or to whom to turn with questions. One parent stated, “There is no real booklet that you are given at the beginning with names, numbers, whatever that would help when you have questions”. Likewise, parents described having experiences with the system when nobody seemed to know the answers they needed and/or when they were being referred to somebody else in the system who might or might not have the answers they needed. Thus, frustrations associated with lack
of clarity regarding who had the knowledge they needed and how they might access that
knowledge played an important role in creating the need to manage their circumstances
differently and regain some measure of control in relation to obtaining information.

Even after 10 years of struggling with the system, all parents still experienced
frustration at times as their need to negotiate for the rights of their child and for help with
caring for their child was still a driving force. A part of this problematic situation is, in
the parents’ opinion, that there are too many players in the system and too few
connections or communications among the health care professionals and agencies within
the system. Thus, the prevalence of communications difficulties between the various
professionals and services within the system further triggered the frustration that led to
the need for empowerment.

A situational barrier that surfaces for families who have children in the school
system is the issue of whose role it is to educate the school staff and even the classmates
about the child’s condition and needs; just who is ultimately responsible for such
education in these areas had not been answered. The parents would like the school nurse
to be in charge and to see to it the school gets the information it needs, but this is not the
case; a lack of school nurses and lack of clarity about their roles in the school system
seems to the more common situation. In the words of one of the parents:

Education is a huge part of it, education of the teachers, education of the other
children; a lot of it falls on the parents shoulders to go in and do this education,
but when you are first diagnosed and your child’s first going to school, that is
another huge stress that you have to deal with. It would be really nice for the
school nurses to take that pressure off parents and go in to staff and have a
presentation.

The role of a school nurse is not clear to the parents; all would like more support from the
school nurses in the system.
Clearly a number of situational factors contributed to the frustration level of these parents. Further, several individual situational factors played a role in heightening the frustration of certain families. For example, the families who lived a significant geographic distance from the Children’s Hospital found that this distance exacerbated the communications difficulties and the family’s general frustration level around information and support. Thus, various situational elements combined to motivate parents to become more empowered.

The Interpersonal Elements

One factor that all parents emphasized in explaining the process of becoming empowered was parent-to-parent support. From other parents, they learned a great deal about the experience of parenting a child with a chronic condition and about developing strategies with which to approach negotiating the health care system. The parents spoke warmly about the influence that other parents had had on their developing awareness and confidence. Many of them described the special advantages of being able to meet other parents while the child was hospitalized and after discharge from the hospital. A common remark was: we are all in the same boat.

In this way, all of the parents who participated in this study were in contact with other families “in the same boat”, and all describe such contacts in similar ways, as helpful and a comfort. Three of the mothers were involved in parent support group committees, indeed, the very kind of social work other parents were identifying they needed.

As has been mentioned other interpersonal elements that arose from the findings related to issues of boundaries and power struggles. All of the parents had experienced
interactions with nurses and other health care professionals where personal attitudes were
in the way of good communications, where the parents' wishes, expertise, and knowledge
of their child seemed to be undermined, and where parents felt they were getting the
message that health care workers were the only experts in the care of their children. One
parent said, "I am always, always hassled by nurses saying, 'So why do you want to do
that, that is not our policy?'" and, "every nurse, it is like a battle". These kinds of
comments show nurses and other health care professionals are having difficulties with
letting go of their responsibility as the experts and with handing over power to these
parents who have children with chronic health care conditions. In six of the eight
interviews conducted for this study, the parents described an attitude or behavior as a lack
of flexibility, a lack of individualized care, and as disrespect on behalf of the health care
professional towards the parent.

Parents mentioned that certain interpersonal factors among nurses facilitated the
empowerment process for them: these were a positive attitude, encouragement,
flexibility, and a willingness both to work together as a team and to establish a
connection with a parent. Effective nurses were those who acknowledged parents'
feelings and contribution to the welfare of their child; who were honest and told the truth;
who showed genuine concern, interest, and care for their child; who were willing to
answer questions, give information, and support parents' decisions and/or competence in
decision making. In addition, all of the parents put a huge emphasis on the ability of a
nurse to really listen and hear what parents have to say. About a nurse, one mother
reflected:

She listens really well, and she hears what our input is because we are always, as I
said, trying to figure out how to do this on our own and try to take control of this
by ourselves, without always being connected to the hospital and she is very supportive of that, and she made us feel OK about that, that we are doing our best. She validated my feeling and that is important.

All parents counted as a most helpful nursing action, creating the context for empowerment, the ability to really listen to all that parents were thinking through on their own.

In four of the eight interviews conducted for this study, parents gave examples of other parents they knew of or who they had come across who did not want to be empowered-who did not want to take control in a voyage into empowerment. Those not willing or not able to take on the management of a child with a chronic condition expected health care workers to take care of everything for them. In contrast, four of the interviews revealed examples of nurses who, in interactions with them, seemed not to be empowered themselves. These were nurses who could not provide the knowledge or information parents wanted or who did not have the skills to care for their child.

In the descriptions and examples from parents’ experiences above is indication that all of these elements, both the positive and negative aspects of the interpersonal, intrapersonal, and situational elements, affect the process of empowerment. In summary, parent-to-parent support is highly valued by all of the parents as a support to cope and to empower each other. Five of the eight families who have school age children expressed considerable difficulties in dealing with the school system, and frustration with the system is an ongoing force that infuses the process of empowerment. With a focus on nursing, intrapersonal skills -- such as being able to listen and connect with families -- are valued elements that served to facilitate parents’ empowerment in their interactions with nurses and with others.
The Role of Relationships

The role of a nurse in creating the context for empowerment to take place in a relationship with a parent was an outstanding theme in all of the interviews. All those parents who had been in connection with specific nurses (that is, nine out of eleven parents) described the role of the nurse and the relationship similarly: he or she is always available to care for them and their child, to comfort them, and to provide emotional support, education, and information. Likewise, these parents explained how these nurses were willing to establish a connection and committed to them by working together with them as a team, all of which has encouraged them through the steps of taking on the challenges of caring for a child with a chronic health condition.

The most important role of a nurse in the eyes of all of the parents, whether or not they had been in closer contact with the nurse, was to have or to have access to knowledge. Even though today all of these parents function within a stage of being experts in their child’s care, they were well aware of what had helped them most to get to that point, knowledge.

One of the parents describes his image: “my perfect nurse or perfect caregiver is someone who can either give me the knowledge or the resources, so if I need a specific readings or things and let me go back and read it or do whatever, and then makes sure that I understand it, and if they are unable to give that, direct me to where I can obtain that information”. In a similar way, all of the parents emphasized the importance of knowledge. A key element in receiving knowledge was the role of a nurse in helping the parents understand the information they received. Most of the parents described how
nurses helped them by interpreting and clarifying the information they had to understand, teaching them the skills they need to learn, and giving them positive feedback. This confirmed, complimented, and verified to the parents that they were doing a good job, all of which made them feel they could handle their family affairs. One parent explained,

The nurse becomes the real translator and interpreter then they (the nurses) can deal with the medical diagnosis that the doctor gives and have a discussion with the doctors as opposed to being just an order taken from the doctor. And instead of just passing it through, you know, doctor to patient, they can have discuss with the doctor and say well you know we have been following this for the last year and it shows this and have a discussion.

This same parent also said, “I think that the role of a nurse has to be probably elevated to a level where they can really get to know, I guess, as the more the psychologist or the relationship builders with the patients and the doctors are really just the analytical side of it”. Thus, almost all parents agreed the nursing role of go-between or a middleman is really helpful to them. It made a difference to parents that nurses knew them, knew the child’s condition, and knew their situation. Comments by parents describing their connection with a nurse were many. One parent said, “It was the nurses who made us feel that we had a connection and that we were not cut off and floundering on our own. We had resources and we had people to talk to and we had names. Yeah that was really helpful.” Another said, “when you have a child with a chronic disorder like ours then you want to have someone who, when you are calling or asking questions, that they have some familiarity with your particular case”. Another said, “I definitely think it is important to have a long term relationship with a nurse”. These parents felt the connection between a parent and a nurse created a context for nursing actions to have an empowering effect because the nurses were more approachable, they were on the parents’ team, so to speak, and they knew them and their situation.
All of the parents stated that part of the nursing role was to advocate for them.

One of the two mothers who had no connection with a nurse and who had experienced difficulties after discharge from BCCH described the delay in letting her and her husband know that something was wrong with their child: "The nurses should have had the doctor come in right away and say that they had some concerns and wanted to monitor the child for a while". For her, advocacy was lacking. Another mother spoke of how a nurse had been her advocate when she wanted to change her child’s treatment; she said the nurse "was able to use my knowledge and advocate for me. She was able to let me make that decision as well, and that was very helpful." The parents all agreed on the advocate role of a nurse and highlighted how important it was to have a nurse who could be an advocate whenever needed.

In summary, the parents emphasized the important elements of the role of a nurse in helping them both manage the care of their child and cope with their situation. Parents identified as helpful the continuity they experience when in a connection with a nurse who knows the family, knows their situation, knows education needs and areas of expertise, is able to offer emotional support, acts as go-between, and clarifies and interprets communications and information. Furthermore, they also appreciated the nurse’s availability and approachability as well as the role he or she played in advocating and encouraging parents toward a relationship that was based on empowerment. The parents who participated in this study were also articulate about their relationships with nurses and about what it was in these relationships that made an empowering difference to them. When they described their relationships with nurses, common themes emerged as main components of this empowering relationship between parent and nurse.
The Main Components of an Empowering Relationship

All of the parents in this study had some experience with being in relationships with nurses and other health care professionals that they considered empowering. Many had particularly positive stories to tell about their voyage towards empowerment. Among the most powerful of these stories were those from those parents fortunate enough to have had the opportunity to be in such relationships over an extended period of time due to the particular programs available for children with their particular chronic condition. While their stories were especially descriptive, the stories of all of the parents reflected the same general components of an empowering relationship.

There were five main components that were identified by these parents as important elements of empowering relationships: knowing the situation, mutual trust, active listening, support for decision making, and teamwork. Together, these components depicted the kinds of relationships from which parents gained empowerment.

Knowing the Situation

The parents stated in various ways that having a connection with a nurse who knows them, knows their child well, and knows their situation is very helpful to them. This nurse is a person they can always contact, a person who will follow-up on how they are doing, a person parents can “have a discussion with and bounce off ideas” with, and a person to help in decision making. A statement from a parent describes very well why it is important for the parents to have a connection with somebody that knows them well, “so to have that relationship where you know that they know, and they know that we
know, and we all know each other. That makes it so much easier to go again and again and again knowing they are all still there.” One of the nine parents who were able to sustain this kind of close contact with a nurse expressed, “I definitely think it is important to have a long time relationship with a nurse.” Similarly, one of the couples said:

She (the nurse) always takes time to know us, ask about us, she made that connection that you feel very comfortable with. Because when you have a child with a chronic disorder like ours, then you want to have someone who, when you are calling or asking questions, that has some familiarity with your particular case, so that you are not having to explain all over again how the child’s condition is and how she reacts to her treatment.

These same parents also used a contrary example to illustrate how it is important to them to have a connection with a nurse that knows them. Before they had established a connection with this one key nurse they were made to fax to the hospital weekly reports and then they got a call back with feedback about what they should do about the insulin levels. However, they soon discovered that the hospital staff evaluation and their own evaluation did not match and made them more unsure about whether what they were doing was right and therefore serving its purpose as well as it should have.

Thus, in order to explain why it made a difference that a nurse knew them and their situation, parents often articulated examples of contrasting situations, in which they had encountered situations that were contradictory to empowerment. Such illustrations often reflected situations in which health care professionals gave contradictory messages, leading to parental frustration and uncertainty. In offering dramatic examples of such negative instances, the parents were able to depict how particular knowledge of the situation helped nurses understand them better and provide them with better guidance and support.
Mutual Trust

Mutual trust seemed to be the most important theme within all of the descriptions of empowering relationships between parents and nurses. Being able to trust a nurse and feeling that that nurse trusted the parents was the foundation for cooperation, for open communication, and for ongoing constructive interactions with that nurse. One way in which such trust was apparent was when nurses verbalized respect for parents opinions and expertise. Similarly, when a parent trusted a nurse, the nurse seemed to be more approachable in relation to answers to questions and assistance with concerns. Parents revealed that gaining trust did take time for them; they and the nurse needed to get to know one another for trust to be established.

An example that one of the mothers shared, describes the effects of when mutual trust was not established, because of what she called, “lack of being upfront and straight from the start”. She claimed that she felt “betrayed” because she found out that “they had lied to her or were not completely honest with her” when all she wanted in her interactions with health care professionals was that they would tell her the truth no matter what it was, answer her questions, and give her the information she wanted. The way this mother handled the situation was to call the hospital after each and every admission for her child’s hospital records. This mother’s experience illustrates well the extra burden in parents’ lives when they feel that there is not mutual trust in their interactions with health care professionals and helps us appreciate how meaningful it can be to obtain that trust.

Establishing trust between a parent and a nurse was often described as a developmental process which made the parents feel comfortable in interactions with nurses and made them feel they had somebody to go to with their questions and concerns.
One way in which parents described the importance of trust was to report the satisfaction they experienced with the care their child was receiving. They often illustrated this linkage with examples of nursing actions that promoted trust. One of the fathers said, “I am very comfortable with the nurses, I know the level of care my child is getting and I have not ever had to question that care”. From his description, it seemed evident that he trusted the nurses to provide his child with the best care possible. One of the mothers explained the quality of her relationship with a nurse and why that connection worked well for her, saying,

I do trust her. I do respect her. If I come up with one of my hare-brained ideas, I can put it to her and she does not come back and say no. She explains why I cannot do it, or, yes, I can do it but we have to do it this way. For her to listen, see where I am coming from, and send it back to you to make you understand it better when the decision is on you.

Thus, for these parents of chronically ill children, mutual trust was the most important component of the empowerment process because it created the foundation for all other effective interactions in a parent-nurse relationship so that empowerment could take place.

Active Listening

The need to be heard by health care professionals emerged as a component of empowerment. All of the parents explained the importance of being really heard such that their concerns and questions were not ignored or dismissed as insignificant. As one of the parents phrased it, “a helpful nurse is a nurse that listens really well and hears what our input is”. Nearly all of the parents had experienced occasions during their voyage toward empowerment where they felt that their perspective was not understood or believed by health care professionals, they described this as feeling that their voices were not being
heard. Not being heard by health care professionals is, as parents described it, a very frustrating experience. One parent, who experienced many unnecessary difficulties due to the lack of follow-up service for her child and due to a lack of connection with somebody who knew their experience in relation to their child’s heart condition said, “the main frustration was that nobody was listening to me.” This parent described an instance that occurred at a later time, when she had learned to persist to get the attention she needed for her child and in which she had to take charge so that her voice could be heard. The child started having obstructive sleep apnea, and this mother believed that his adenoids and tonsils would need to be taken out. When she did not get anywhere with her family doctor, who dismissed this notion saying “Oh, it is such a mild case; we will not worry about it,” she decided to videotape the child when he was sleeping. Producing objective proof was enough to get a referral and, sure enough, the child needed surgery and has since then prospered. This particular mother was one of the two families participating in this study that had not had the advantage of an ongoing relationship with a nurse. Asked why she had not contacted the hospital nurses at a time in which she was having so many difficulties managing on her own, she answered, “because I think you would build that relationship right from the start. But if you were to follow up and just at least have that verbal connection, you are going to feel there is a little bit of a relationship there so that if you are having problems you would feel more comfortable to call”. Her perspective reflects similar statements from other parents who did have relationships with a nurse; that is, they all agreed that a nurse is more approachable and effective in fostering empowering interactions when a trusting relationship has already been established. Thus, one way in which the more ongoing relationships had a significant advantage was to
create the conditions under which parents could feel that they had been heard by health care professionals.

**Support for Decision Making**

In retrospect, parents were well aware of how their decision making process concerning their child's health care had evolved and changed. They observed how they as parents had moved from relying on health care professionals to make the decisions for them, to a situation in which they had become primary health care providers themselves, feeling that they could make most of the necessary decisions on their own. The parents were very clear about how important it was to them that nurses and other health care professionals were available to assist them with their decisions when needed, because they found it very helpful to have somebody to verify interpretations and reassure them that their decisions were in their child's best interest.

The discussion about decision making was also often connected with parent's wishes to be respected by health care professionals for their evolving expertise in their child's care. Thus, assisting parents in decision making seems to be an essential component of an empowering relationship from their perspective. This was especially apparent when parents would "bounce off" health care professionals their own concerns, ideas and decisions. In some such interactions, the parents and professionals did not reach a mutually agreeable decision, and in these instances it seemed especially important for the parents to have their views understood and respected. In fact, in many of the instances in which there was disagreement about the appropriate course of action, the willingness of the nurse or other health care professional to engage in a respectful discussion about
the issue was particularly empowering, whether or not the parents’ preference determined the final decision.

One of the couples described interactions with a nurse that were particularly empowering to them:

*When the nurse calls back, she will say “this is what the doctor suggests, but if you do not think that is right, by all means do what you would like to do”. So she does, with the doctor, give us that space to make our own decisions, so we do end up feeling like we have some control, which is a nice feeling.*

These parents were feeling empowered because they felt they had been given the support to make decisions concerning their child’s health care. This was important to them not only because they felt respected, but also because it made them feel that they were in control and able to manage on their own.

From her experience, another parent illustrated two contrasting examples about support with decision making. The first involved a battle with health care professionals when they wanted their child to get an insulin pump. “To convince the team was almost, it was brutal”. While their decision was eventually accepted, they resented the battle and the bothersome “constant reminders” for a long time afterward that “this was not a good idea and it was not a decision we should have made”. At a later point in their process, there was an occasion in which these parents were very concerned for their child because the child was in hospital and the wrong type of insulin had been put in the insulin pump. The mother described how the nurse in that instance had empowered her by coming to her and saying “can we give him something? Do you have something on hand that I can read quickly? ” Following this, the child went back on the same insulin as the mother suggested, and his levels came right down. This mother was pleased that the nurse was
able to use the mother’s knowledge and involve her in the decision making process. She explained how helpful that was, “because that way the nurse was able to advocate for me and believe in me and my knowledge”. These examples are illustrative of the contradictions that many parents described in their efforts to be involved with decision making. Although parents are expected to learn how to manage on their own, health care professionals are very quick to undermine their decisions and dismiss their opinions. Decision making is a context in which many patients become extremely frustrated with health care professionals. Throughout many of their accounts, there was evidence of frequent power struggles between parents and health care professionals wherein health care professionals were having difficulties with letting go of their power as the experts. One of the parents articulated the wishes of many in this statement of recommendation about how nurses could better support parents’ decision making as primary health care providers in their child treatment and care:

When nurses are looking to empower parents, offer and give the information. When the decision has been reached, whether you agree with it or not, review what that decision is based on and if it is based on stuff, research or things that are documented, whether or not you agree with it, then leave it alone. That parent has made the decision and do not argue with them. Cool it.

Thus, what the parents in general were emphasizing was; that they understand themselves to have been given the power to be their child’s primary health care providers, and to make decisions concerning their child’s treatment and care. They therefore wanted health care professionals to allow them to use that power and to assist them to use that power in their child’s best interest. In so doing, they expected to be evaluated in relation to the bases for their decisions. If those decisions were informed decisions that were based in evidence, then they expected to be supported and respected,
even when health care professionals may not have agreed with the decision. In essence, parents wanted to have nurses and other health care professionals available to assist with decision making and to support them with the decisions they had made.

**Teamwork**

Many parents agreed that caring for a child with a chronic condition required teamwork in the form of a working relationship between the parents and the health care professionals. Parents described a feeling of empowerment from being a part of the team; in that team, their input was respected, and they were made to feel their role was important toward the mutual goal of providing the best care for their child. Many aspects of managing life with their children did involve teamwork. Parents revealed that teamwork was a part of mutual decision making, of having a connection with somebody they could contact, of having someone who knew them and their situation and of being “able to bounce back ideas both ways.” One parent described teamwork as a form of partnership:

> It is intimidating enough dealing with what you are dealing with on a daily basis with chronically ill kids. Um but just knowing that they are partner with you, part of your team, um that they are not talking down at you, that they appreciate what you are saying as a parent. Um, because even in chronic illness you are still the mummy and you are still the daddy and that never goes away. So it is a two way street.

Parents said they knew that a connection between them and health care professionals was established when they felt a certain level of comfort. As one mother described it, “You look forward to it because you know you are going to see people you know and you know that they know everything about your child”. An important point that the parents seemed to be making was that, from their perspective, nurses cannot and do not treat everybody in the same way. One father said, “You know everybody’s got
their own needs, requirements. The nurses are the ones that really begin to understand the patient and individual patient’s needs and if there are any variables. Because not everybody is going to get treated the same.” Far from expecting nurses to treat everyone the same way, parents often expressed the wish that nurses could use an individualized approach. From their perspective, the same intervention cannot be appropriate for everybody because every person’s needs are different.

One of the parents told a story that depicted a typical example of the importance of teamwork by illustrating what could happen when it was absent. This mother is a foster parent and when she just had become the child’s foster mother, she was constantly told by the community nurse where they lived that something else (this and that) was wrong with her child in addition to the known chronic health condition. Because of this, she had to be phoning the hospital back and forth to ask if the “rumors about her child were true or not” and eventually concluded that none of them were true. The lack of a coordinated message from members of the health care team is obvious in this example, and it created a lot of extra strain on the parents which could have been avoided if the community nurse had behaved as a team member and followed up on the information or assisted the parents to find the answers that they needed.

The preceding sections have explored the parents’ description of their experience of empowerment in interactions and connections with nurses -- the thoughts parents offered on what kinds of parent-nurse relationship are empowering, and certain main components that were required in a connection order to build an empowering parent-nurse connection in the ongoing care of their child. These components contribute to empowerment as a part of the empowerment process, and describe the necessary qualities
of interactions between a parent and a nurse that will make the connection empowering.
From these accounts, it seems that these necessary qualities include knowing the
situation, mutual trust, active listening, support for decision making, and teamwork.
These components create and support an empowering connection because they help them
to manage their roles as primary health care providers for their children.

The Outcomes of Empowerment

What emerges from parents' description of these empowering relationships is two
main outcomes: that competence in care management is increased by the relationship and
that confidence in decision making becomes stronger with the presence of such a
relationship. On the whole, an empowering connection between a parent and a nurse
results in parents who are managing well in their roles as health care providers. They
demonstrate competence in care management, they are feeling confident because they
have either knowledge or the resources to gain knowledge, and they can advocate for
themselves and/or make decisions with or in spite of others. All of this enables parents
caring for children who have a chronic condition to cope with managing within their role
as primary health care provider for their children.

Competence in Care Management

Parents in this study knew themselves to have gained competence as they were
able to look back upon their own development. They remembered what it was like to feel
the novice, and now they were sometimes able to feel the expert at providing primary
health care for their children. The benefits that the parents described having gained from
empowerment were reflected in their development from novice to expert stages as
primary health care providers for their children. Their competence was facilitated both through interactions with nurses which lead to trusted relationships and through factors which were either personal and/or situational for the parents and/or the nurse. In spite of the changing challenges the child’s chronic condition could represent, parents felt they had the knowledge or at least the resources to gain knowledge required to manage on their own. This feeling was, they all agreed, a result of empowerment that enabled them to feel in control and to cope with their situation. Mastering their roles as primary health care providers meant for these parents not only having and using the resources and coping at home but also interacting effectively with health care professionals and negotiating elements of their child’s treatment and care. Their mastery was not a moment of achievement but a part of the process of their lives. One parent said, “doing it over again I think I would stand my ground more to tell [the nurse], ‘No, I do not want this’”. Another parent, who regretted not having taken a more active role earlier, said, “Today, I would not leave any stone unturned”. In looking back, one parent said,

I just felt empowered knowing what I knew from a chronic, a long term illness child to something simple as having tonsils out with my other child that I could just of sort do everything. And the nurses thought it was great.

She revealed that the range of her experiences had made her feel competent enough to take on anything. For her and for others, empowering relationships offered the ongoing support. Parents needed to be in touch with how well the ever changing situation matched the competence they each felt at the time. Through that relationship, they reviewed their need for knowledge or their grasp of it, their ability to make a decision or their need to seek help with one, their ability to control the situation or their need to ask assistance. This competent behavior required a continuing sense of empowerment.
Increased Confidence in Decision Making

Decision making, for parents, was most difficult and sometimes most significant when health care professionals did not support them with their choices. One of the couples explained it as an accomplishment with decision making when overcoming differences with the health care professionals resulted in mutual respect. Having researched a new treatment choice, they told their doctors about it, and they said, “No, we do not do it like this”. In spite of that, these parents went ahead with the treatment. One said,

We just decided on our own we were going to make that decision because we knew friends that were doing it, and it work well for their child. So we just told the hospital this is what we are doing, and they said fine. There was no criticism from the hospital, no criticism from the nurse that we had done something that they had not recommended, and then they just dealt with that. OK these parents have made a decision and on it went. But they gave us that right, and did not try to take it away from us, which was nice.

The confidence these parents experienced came out of an important combination of factors: they were coping well but were going through changes in their situation; the health care professionals knew their situation; the parents had done their own research, and their defiance of the doctors' wishes was thoughtful. Rather than losing confidence in the health care professionals, these parents gained confidence not only in themselves but in the health care professionals too. General fear of a new situation changed to general confidence. In order to accomplish this ongoing confidence, an ongoing empowering relationship proved instrumental.

Within empowering interactions with nurses, parents felt their voices are being heard and their expert opinions are being respectfully taken into consideration. Many
expressed the feeling that decision making should be respectful and interactive; it should be a discussion, even when or especially when disagreements emerge, and loss of respect for the other should never be a consequence of disagreement. Not surprisingly, such interactions foster even better confidence in meeting the complex health care needs of their child and even better trust among all involved. In short, an outcome of the empowerment process is that parents feel they have the capability (that is, the knowledge, skill, and competence) to experience continued mastery over their changing situation. The confidence which results from this continued strength and mastery allows them to feel that their lives are normalized and headed toward the best quality of life they can achieve.

Summary

In this chapter, an analysis of the common themes that emerged from the parents’ experience of empowerment are presented in a chronological order, that is, in the order parents generally experienced them. The conceptualization of empowerment is described as a developmental and interactive process. From the parents’ descriptions, it seems that the influence of the nurse upon the process of empowerment can be understood in relation to three main themes: the role of a nurse in creating the context for empowerment; the parents and the nurse situational and personal elements of empowerment; and the main components of an empowering relationship between a parent and a nurse. The important components and elements that facilitate the process of empowerment emerged from the findings as overlapping and intertwined. Exploration of these themes contributes to an increasing understanding of what kinds of parent-nurse
relationships are empowering to parents and in what ways some relationships are not empowering to parents.

The parents felt a good connection with nurses was one built on mutual trust and understanding of each other's role and situation. Effective interactions with health care professionals were ones in which they could openly discuss their child's treatment and care and experience the necessary space within the interaction to make decisions; as partners in care, they could normalize their lives and feel more comfortable with their ability to provide care for their child. These findings indicate that building this kind of a connection between a parent and a nurse can be an empowerment strategy in nursing care. Such a relationship can facilitate families who have children with chronic conditions as parents cope with and manage their roles as primary health care providers. Such a relationship would be characterized by mutual trust, active listening, teamwork, support for decision making, and the nurse knowing the family's situation. If nurses better comprehend just how it is parents do well in such situations, they can play a vital part in creating the context for empowerment. While both parties must be willing, and while attitudes, beliefs, values and situations will always be different components of individual relationships, the qualities of empowerment, and thus a parent's competence and confidence, will be achievable if understood as resting on simple and universal needs of trust, listening, genuine interest and concern, advocacy, and respect.
Chapter Five: Discussion of the Study Findings

The purpose of this discussion is to address selected key findings that emerged from the research findings described in chapter four. The existing literature was used to provide some theoretical support for the interpretations that might be made about the meaning of the findings. The present study was guided by two research questions: What kinds of parent-nurse relationships do parents of chronically ill children find empowering, and Why? What is it in the parent-nurse relationship that parents describe as having empowered them? The following discussion chapter compares and contrasts the relevant theoretical and research literature with the findings of this study. The highlights from the findings that I will be addressing are the essential qualities that constitute an empowering relationship between parents and nurses; the role of a nurse in creating the context for empowering change in nursing care; and the personal and situational factors that influence empowerment.

The Nature of Empowering Relationships Between Parents and Nurses

The findings of this study shed light on the influence of interactions between parents and nurses by providing a conceptualization of the way in which such relationships can develop over time. In general, parents reflected the views of a relatively satisfied group of parents who had established a positive working relationship with nurses involved in their child’s care.

The conceptualization of empowerment can be described as a developmental and interactive process. From parents’ own descriptions, the nature of empowerment appears to be shaped by three main themes: the role of a nurse in creating the context for empowerment; the situational and personal elements of empowerment; and the main
components of an empowering relationship between a parent and a nurse. That is, empowerment did not solely come from parents' own working relationships with nurses; rather, the data suggests there are factors from both the family and professionals which make a difference in the quality of the relationship between the two. These findings reflect the observations also made by Patterson et al. (1994), as to factors that contribute to the development of parent professional relationships.

The study findings show that a relationship between a parent and a nurse requires certain main elements in order for that relationship to contribute to the empowerment of parents. The three main elements that will be discussed here are mutual trust, teamwork, and support for decision making.

**Mutual Trust**

Forchuck (1998) defines factors that help the development of the nurse-client health care relationship. Her conclusion is that nurses can help clients to move onward by remaining available, by being consistent and by acting in a way that promotes trust. From the study data, mutual trust is described by the parents as the most fundamental prerequisite required to create and facilitate an empowering relationship between a parent and a nurse. Mutual trust is the component that lays the foundation for all other interactions between a parent and a nurse to be effective. Trust is not an intervention but rather a feature of the context that will facilitate empowerment. Trust develops in a relationship only over time; the parents point out that mutual trust is a condition that must always be reevaluated and newly felt for empowerment to continue. Relating the present findings to the current literature on health care relationships, parents' descriptions of their present trust in nurses and in other health professionals reflects the kind of trust that
occurs in the *guarded alliance stage*, which Thorne and Robinson (1988b, 1988b, 1989) reveal evolves over time within health care relationships. All the parents in the present study can be seen as having progressed through naïve trust that the professionals will know and act on their best interests, disenchantment that the system has failed them, and into a resolution phase of guarded alliance in their relationships with health care professionals, in which trust in specific professionals must be renegotiated and renewed on an ongoing basis.

The importance of the parent and nurse developing trust for a relationship to become empowering has also been described both in the Children’s Hospital of Philadelphia model of therapeutic relationships and in the Rainbow framework on therapeutic relations in decision making (McAliley, Lambert, Ashenberg & Dull, 1996; McKlindon & Barnsteiner, 1999;). Similar discussion can be also found in writings by authors Robinson and Wright (1995). Their study findings in relation to helpful interventions for families having a member with a chronic condition suggest that the relational context between a parent and a nurse must fit for that situation. Such a fit, as the findings of this study indicate, hinges on trust in a parent-nurse relationship, for only then can the relationship be an empowering one.

Thus, the importance of creating an effective relationship by developing trust has been clearly documented in the nursing literature and is supported by the findings of this study. The findings of this study strongly indicate that a parent-nurse relationship that is built on mutual trust is essential in making an empowering difference in the provision of nursing care.
Teamwork

Parent-nurse partnerships are considered in the literature to be collaborative efforts which enable and empower the family to share the caring role (Gill, 1993; Humle, 1999; Rushton, 1990). The teamwork theme emerged in this study as an empowering component of a relationship between a parent and a nurse. Parents emphasized the value of having connections with nurses and with significant others. The relationship of caregivers surrounding a child's chronic condition was said to characterize teamwork where everybody was working towards the same goal -- the optimal health of a child.

In her “rethinking empowerment” discussion, Anderson (1996) points out what she calls the need for fluidity in the relationship between a health care provider and a receiver; she says relationships can be conceptualized as moving back and forth along a continuum to accommodate the patient’s situation at any given point (p. 703). Her study findings have shown that the people want different things from health care providers during their illness careers and that people have different needs at different times depending on the stage of their illness. Evident in the findings of this study is the request from parents for an individualized approach to nursing care. In retrospective descriptions, parents offered views on how the empowerment relationship has evolved from the beginning of the process, from being a learner in the care of their child to being primary health care givers themselves and experts in their child’s health care. The findings of this study indicate that both of these factors --partnership and individualized care -- are important components of the process of empowerment. First, these findings illustrate that this process does not have a final end product, for it is a developmental interactive process (that only partly takes place between a parent and a nurse) which must constantly
restore trust. Second, they indicate that an individualized approach in care is what parents want; this aspect of the process needs to be more clearly understood as a goal for nurses, especially as the nature of the process would be different for every relationship between a parent and a nurse. These claims are supported in the empowerment literature by Wallerstein and Bernstein (1988) who explain that difficulties defining empowerment have been partly because empowerment takes on different forms in different people and within very different contexts. These authors help us understand why parents believe that a individualized approach is needed for each family toward empowering nursing care. Literature in both family-centered care and empowerment reflects the emphasis that parents in this study placed upon the notion that working with nurses as a part of a team is a basic element in nursing care (Ahmann, 2000; Humle, 1999).

The importance of pursuing continuity in a health care relationship has also been established in the literature on health care relationships (McAliley, Lambert, Ashenberg, & Dull, 1996; McKlindon & Barnsteiner, 1999; Thorne, 1993). Pursuing continuity in a relationship with a nurse was one of the factors parents in this study identified as helping to create an empowering relationship. While this study serves to support that continuity can be an important contributor to a relationship in which empowerment is facilitated, the notion of continuity is not prominent in the nursing literature on empowerment. However, they also indicate that, in order to facilitate empowerment, such continuity must be in the context of teamwork relationships. Parents clearly want to be part of the health care team caring for their child. They want an individualized approach in care and, when they find health care professionals who are open to such approaches, they want to maintain such relationships over time.
Support for Decision Making

Miller (1983) defined power as the ability to influence what happens to oneself, the ability to provide for and care for one’s self, the ability to direct others regarding care or self-care, and the ability to be the ultimate decision maker regarding care. Ferraro and Longo (1985) defined empowerment as opposite to helplessness; they stated the empowerment of a family is demonstrated in its ability to manage and cope with the situation. The parents in this study talked of how powerless and overwhelmed they felt in the beginning of their voyage. They described how they had evolved to become primary health care providers for their children and were now able to make decisions about their child’s health care, to manage and cope well, and to feel empowered. Basic elements in the family-centered care philosophy confirm that families require support in their natural care-giving and decision making roles (Shelton & Stepanek, 1995). The help-giving model of Dunst and Trivette (1996) includes three main components: technical quality, helpgiver traits and participatory involvement. Their participatory involvement component includes practices that provide help-receivers the opportunities to discuss options and different choices. That includes working in collaboration towards shared decision making in addition to other efforts to involve help receivers actively and meaningfully in helping relationship. In these and other ways, help-receivers are actively and meaningfully involved in the helping relationship. Their three components in many ways reflect the findings of this study in that parents emphasize the importance of support with decision making; when such support is experienced throughout the process of caring, parents seem to find it especially empowering.
A study by McWilliams et al., (1997) involved chronically ill individuals and focused on the creation of meaning that is itself empowering. These authors described the main components in their findings as empowerment strategies, including building trust and meaning; connecting; caring; mutual knowing; and mutual creating. The findings of their study relate well to those of this study, as parents identified similar components as helpful; the components of their study also describe the nature of an empowering process. The experience of what is helpful is thus close to the experience of what is empowering, and this holds true whether one is older and chronically ill or one is the parent of a child with a chronic condition.

The current study emphasizes the role of decision making in an empowering parent-nurse relationship. Indeed, parents in this study found it important to be in a relationship with a nurse who knew them and who could help them through the decision making process. Gibson (1995) described the mother’s confidence in making-decisions as an outcome of the process of empowerment; the findings of this study describe the decision making itself as a both a vital component of empowering relationships and an outcome of the empowerment process.

According to Cochran the feedback loops in the empowerment process reflect the fact that empowerment is a “regenerative process in which outcomes produced at one stage in the process in turn contribute energy to further participation in the process” (1992, p. 9). The findings of this study support the claim that decision making is also a dynamic component of the empowerment process. It seems that confidence around decision making is constantly challenged and sometimes wavers depending on the factors that sustain it. Because the chronic condition is ongoing and the situation is constantly
changing, the ability to make decisions also shifts with confidence and with circumstances.

One question raised by a comparison between the findings of this study and those of McWilliams et al. (1997) relates to the question of whether the empowerment process develops out of an interactive developmental process of the parent or may be a direct result of nursing interventions. McWilliam et al. (1997) were specifically testing a nursing intervention, derived from an adult theory of perspective transformation, which was aimed at helping, elderly, frail, chronically ill persons to manage better at home. Thus, their conclusion that empowering derives directly from the nursing intervention and not from a developmental process by the individual involved is consistent with their particular research question. However, in this study, the accounts of the parents strongly suggest that the developmental processes that the parents are undergoing in learning how best to care for their child and the interactions that parents have with nurses during that developmental phase interact to create the conditions under which empowerment may or may not emerge. From their perspective McWilliams et al (1997) offer useful implications for practice when they suggest that health care professionals really must come to know their clients and must use themselves therapeutically in building relationships if empowerment is to be achieved. They also support the findings of this study in that certain kinds of nursing care contexts may be more or less effective in facilitating empowerment. So, McWilliams et al. seem to be aware that relationship-building could be a strategy for empowerment; however, they remind their readers that none of the more prominent models for health promotion capture relationship-building as a significant component of health promotion/empowerment. Thus, from the findings of
This study, I would claim that the parents are identifying that the context for effective nursing care has to be created in order for empowerment to take place and that this context can only occur within a certain kind of a parent-nurse relationship.

In summary, the parents identified support in decision making as a very important component of empowerment in that it promotes negotiation of optimal care for their children and it helps them to feel they have control over their situation. The findings of this study indicate that building a parent-nurse relationship upon certain main components constitutes as an empowerment strategy in nursing care. All of these main components are reflected in the nursing literature, and their importance in facilitating empowerment is emphasized in the accounts of parents.

The Role of a Nurse in Facilitating Empowerment

Robinson’s (1996) study examined how the quality of family-nurse relationships affects patient satisfaction with care. In her findings, she discusses the importance of a “nurse relational stance”, the nursing action that enables change and that emphasizes the role of a nurse in the health care relationship (p.164). As was observed by Robinson in her study, the parents in this study did not emphasize nursing interventions; rather, they emphasized those elements of the nurse’s role which best affect their own confidence and expertise in caring for their child. Thus, similar to Robinson’s conclusions, the findings of this study indicate that the role of a nurse creates the circumstances which influence change, in this case, facilitate empowerment in a parent-nurse relationship. Other than Robinson’s work, little discussion exists in the nursing literature on how to create the
context for nursing care that can facilitate effective change in nursing practice and facilitate empowerment.

Knafl, Breitmayer, Gallo and Zoeller (1992) offer a study from which findings provide useful insights into the kinds of behaviors parents valued in health care providers that would create positive working relationships with nurses. Their participants, in accounts of outstanding health care interactions and advice to health care professionals emphasized a blend of technical and interactional competencies. The parents in my own study emphasized the role of a nurse in making the relationship a positive one; their views on the interpersonal skills and qualities of the nurse complement findings by Knafl et al. (1992). Thus, the parents valued and needed a connection with a nurse who knows the family, knows their situation, knows their educational needs and areas of expertise, is able to offer emotional support, acts as go-between, and clarifies and interprets communications and information. Parents also appreciated nurses when they were available and approachable to support parents, and foster in them developing confidence about being primary health care givers for their children. The nursing actions parents described are reflected in Humle’s (1999) empowerment model of interventions for families of children with chronic illnesses as well as in the family-centered care literature by Shelton and Stepanek (1995).

In summary, the role nurses can take on in creating the context for empowerment in relationships with parents of children with chronic illnesses is important. There seems to be a clear relationship between the role of the nurse in creating the circumstances that are conducive to empowerment and the parents’ ability to become empowered.
The Factors that Influence Empowering Relationships

Dunst and Trivette (1996) have stated that family-centered care is a special kind of effective helpgiving, and that effective helpgiving is a special case of an empowerment approach in care. Furthermore they claim certain kinds of beliefs, attitudes and behaviors will empower and optimize benefits of families functioning in helping relationships. The findings of this study indicate that certain elements -- attitudes, beliefs and behaviors -- influence the development of building and maintaining an empowering relationship. Within the literature on parents' perceptions of helpful versus unhelpful types of support in managing the care of preadolescents with a chronic condition, authors have stated that the positive effects of social support are well documented (Garwick et al., 1998). The influencing elements, as they emerge out of the findings, are divided into those that are personal and those that are situational.

Personal elements of both parents and nurses are of two kinds: interpersonal (these refer to the connections among individuals) and intrapersonal (these refer to an individual's abilities and characteristics). Parents' descriptions in this study revealed that the elements termed interpersonal contribute much to their own empowerment, especially parent-to-parent empowerment. The connections among parents were described by parents as extremely helpful to them. Gibson's (1995) findings about social support in the empowerment process support these findings, particularly her explanation that mothers value being understood especially in connection with another mother in a similar situation. Similarities exist also in the study findings of Garwich et al. (1998) regarding sources of helpful support in chronic illness. Their findings point out that parents receive and depend on helpful support from different sources, not just from nurses and other
health care professionals. Likewise, similarities exist in the Dunst and Trivette (1996) discussion of what they term “helpgiving conditions” (p. 336). They speak of relational aspects of helping, which include the helpgiver traits of active listening, empathy, compassion and caring, whereas helpgiver attributions include beliefs about the help receiver’s competencies and capacity to become capable of dealing effectively with life situations, concerns and desires.

Interpersonal elements emerging from this study among nurses, which parents describe as facilitating the process of building an empowering relationship between a parent and a nurse, are reflected in the current literature. They appear in Hulme’s (1999) synthesis on empowerment and in the study findings on nursing interventions by Wright and Robinson (1995). These include interpersonal elements, such as showing genuine interest, being concerned, and demonstrating respect; having a positive and encouraging attitude towards the parents; and showing willingness to work in partnership that is built on trust and active listening.

Other interpersonal elements which arose from the findings—power and boundary issues—have also been repeatedly reported in the nursing literature (Gibson, 1991, 1995; McAliley et al., 1996; McKlindon & Barnsteiner, 1999; Thorne, 1993). The findings of this study suggest that, between the letting go of power and the placing too much responsibility on the parents, a fine line exists. Continually, nurses and other health care professionals are experiencing difficulties figuring out just what is right for each parent who cares for a chronically ill child. Gibson (1995) discusses in her findings what she calls “the negative effect of empowerment”. She refers not only to unwillingness on the part of health care professionals to share their power but also to the placing of too much
responsibility being placed on the shoulders of a parent who appears fully competent; when this occurs, the competent parent can easily become too stressed. Gibson takes this discussion farther to say the mothers in her study judged to be empowered did not receive the support they required. Though the findings of my study did not clearly reflect her point, I agree with Gibson’s statement that health care professionals need to be sensitive to the possible negative effects of assuming someone is competent and finally empowered. Katz (1984) offers a statement that captures a claim fitting the findings of this study -- that both positive and negative aspects of the interpersonal, intrapersonal and situational elements can and do facilitate the process of empowerment. He says that, in the process of empowerment, conflict, tension and growth are inextricably intertwined. Anderson (1996) warns along the same lines, stating that nurses need to establish actions that are in the patient’s best interest, and that will not have the reverse effect of adding further hardship to illness management. Thus, certain prerequisites are required to establish the context in which empowerment can be facilitated. Since empowerment can be both positively and negatively influenced, a fine line may exist between empowering parents and overloading them.

The intrapersonal elements in this study are those which influence a parent’s condition of empowerment subjectively. These elements include a parent’s motivation, attitudes, beliefs and values—all that allows him or her personally to do the best possible for the child and to view the situation more favorably. Gibson’s study includes similar findings, asserting “both intrapersonal as well as interpersonal” factors influenced the process of empowerment (p.1209). Taking this notion one step further, I claim the parents are in fact empowering themselves; they are influenced not just from without but
from within, not just from what personal resources they already have but from the personal resources they are currently, and always, developing. Their quest to do the best they can for their child involves a steady dedication to inward changing with respect to education, to expectation, to values, to attitudes and to motivation.

From the literature on chronic illness, frustration has long been understood as having a negative role in people's experiences of health care. Why are parents still experiencing frustrations with health care professionals, with the health care system and, as in this study, with the school system? The findings of this study suggest that frustration is an ongoing force that sometimes positively infuses the process of empowerment. Other authors such as Thorne (1993) and Garwich (1998) have discussed the negative role of frustration in dealing with the impact of a chronic illness. It seems clear that, although our studies continue to document the frustration that individuals and families with chronic illness continue to experience in the health care system, it remains very difficult to determine what can be done to alleviate that frustration. Thus, empowerment will remain an important challenge for families of children with chronic conditions. In summary, both negative and positive personal and situational elements affected the process of empowerment of the parents who participated in this study. These findings indicate that parents are in fact empowering themselves and are being empowered by other people with whom they interact, such as their family, friends and other parents in similar situations. Therefore, the parent-nurse relationship on its own is not the only factor influencing parent empowerment, but it can become an important strategic focus for nurses who seek to facilitate the empowerment experiences of the families of the chronically ill children with whom they interact.
Summary

An interpretive discussion of key points which emerged from the findings of this study is presented in this chapter. While most of the findings are reflected in the current literature to some degree, what emerges in this study is a slightly more fine-tuned understanding of the nature of the process of empowerment for parents of children with chronic illness. These findings suggest that nurses can facilitate a certain part of the empowerment process by creating the context for effective care. Specifically, they reveal that building a particular kind of parent-nurse relationship can be an empowerment strategy in nursing care. Families with children who have a chronic condition can best assume new roles as primary health care givers for their children when the nature of the nurse-parent relationship is characterized by mutual trust, teamwork, and active support for parent decisionmaking. The nurse who is most successful in these will often be one who knows the family situation, can assess the educational needs of the family and identify its areas and levels of expertise. From such a foundation, the nurse can offer emotional support, act as go-between, and clarify and interpret communications and information. The nurse who is available and approachable may well be in the best position to advocating for parents and encourage them toward empowerment. These main elements and components of an empowering relationship between a parent and a nurse are reflected in the study findings; they represent the parents' notions of prerequisites necessary to create the context for an empowering change.

Both nurses and parents seem to play a role in creating the context for empowerment: both parties need to be willing to participate and make a connection that can become empowering. Although personal and situational elements will affect both the
nurse and the parent in a relationship differently—which is to say that the combination of attitudes, beliefs, values and situation among the two will always be different—commonalities within the parent-nurse relationship related within this chapter provide a framework for delivery of quality nursing care. Nurses working toward improving the provision of nursing care in families who have children with chronic health conditions should benefit from the contribution made by the findings of this study toward a better understanding of how parent-nurse relationships can be empowering.
Chapter Six: Summary, Conclusions and Implications

Advances in pediatric health care and the de-institutionalization trend have changed the role of families who have children with chronic health condition. Such advances have resulted in the expectation that parents will provide care at home for their children. Therefore, the context for nursing care has changed, leading to discussion in the literature as to how to approach the necessary changes in the provision of nursing care for these families. However, this discussion raises questions in my mind, such as, what is the role of the parent-nurse relationship in facilitating the parents’ transition into the role of primary health care providers for their child? The current literature suggests that empowerment of families of children with chronic conditions is the way to go, but there are gaps as to how to provide empowering nursing care in pediatric nursing practice. Therefore, this study was designed to gain insight into the parents’ notion of empowerment in pediatric health care delivery, because, until we have a better understanding of the influence that nurses have on a family’s feeling of power or powerlessness, we will have a difficult time putting this philosophical commitment into practice.

An interpretive description design was chosen for the purpose of this study because such a design allows for the necessary flexibility to explore phenomena within the current literature by lending theoretical support through which meanings within the data can be interpreted. Therefore, this method was well suited for providing insight into the two research questions that guided this study: What kinds of parent-nurse relationships do parents of chronically ill children find empowering and why? And, what is it in the parent-nurse relationship that parents describe as having empowered them?
Data collection occurred through eight interviews with a total of 11 parents. The sample included three couples and five individual parents (totally seven mothers and four fathers) of children with chronic health conditions. Two of the families lived in Vancouver and the rest living in neighbouring communities. Three of the families had children born with heart defects, one family had a child with severe cerebral palsy with a seizure disorder, one family had a child with a neurological disorder and three of the families had children with DM.

The findings reveal how the parents describe their voyage towards (or away from) empowerment, most often in a health care relationship with a nurse; they reveal parents’ stories of where their voyage had begun and/or of what has happened since then, to the point where they are today. In their descriptions of parent-nurse relationships, the parents emphasized both the importance of certain components in a relationship with a nurse and the role of a nurse in empowerment. Thus, when they successfully built strong relationships with nurses, parents felt they were enabled to take on new roles as primary health care providers for their children. The findings show that such relationships become empowering when both parties share the mutual elements of trust and understanding as well as when both experience knowing the situation in a working partnership. Many of the parents described how the continuity in a working relationship with a nurse had been helpful for them. Likewise, the parents felt that it was empowering if the relationship was built on the foundation of open communication, active listening, and honesty. Finally, it was very clear that the parents felt empowered if they were supported in their decision making concerning their child’s treatment and care.
In a parent-nurse relationship that is empowering, the role of a nurse in creating the context for empowerment includes the ability to be available and approachable, to know the child’s condition and the family situation, and to be able to act as a translator and/or interpreter: in short, one who can have a discussion, who can assist parents with decision making, who can navigate his or her way through the system, showing parents how to do so too, and who can encourage the parents and advocate for both them and their child when needed.

The conceptualization of empowerment was described by parents as a developmental interactive process, built on certain prerequisite components, in which a nurse can play a vital part in facilitating the empowerment process for these families. Empowerment, according to the findings, seems to be influenced by several factors, like the personal and situational elements which are both positive and negative forces that seem to infuse the process of empowerment.

Conclusions

A number of conclusions can be drawn from the findings of this study regarding the parents’ experience of empowerment in a parent-nurse relationship.

1. Parents experience considerable frustration in the process of learning how care for their chronically ill children, and they feel the need to become empowered in order to enact that role effectively.

2. The relationship that parents have with nurses can influence their process of empowerment.
3. Interpersonal, intrapersonal, and situational elements of each parent-nurse relationship can have a positive or negative effect on the parents' empowerment process.

4. Parents are able to articulate the aspects of nursing intervention they find helpful and empowering.

5. Parents describe certain prerequisites to an empowering relationship with a nurse. These include mutual trust, support from the nurses for their decision making competence, active listening on the part of the nurse, and the feeling that they are being understood, by nurses, as individuals.

6. Parents identify ongoing involvement with specific nurse advocates over time as particularly supportive to their empowerment process.

7. Other qualities for nurses that parents describe as helpful in the process of empowerment include a willingness to listen to what the parents have to say, an attitude that is positive and encouraging, flexibility, a willingness to establish a connection and work in a partnership, an acknowledgement of parents' feelings and contributions to their child's care, honesty, a willingness to provide information and support parents and a show of genuine concern for the family as its members develop caregiving skills.

8. Parents describe partnerships with nurses as ideal models for relationships that are conducive to their empowerment.

9. Parents recognize their own role in the empowerment process as including motivation to act in their child's best interest, willingness to work in partnership
with nurses and other health care professionals, and ability to make connections with those who can help in their empowerment process.

10. Parents believe that empowerment is an essential process in mastering competency in the role of caregiver of a chronically ill child, and they associate empowerment with a better way of living for their child and the family.

Implications

Several implications arise from the findings of this study for nursing practice, for education and for research. In my opinion, the claim is a reasonable one that the pediatric nursing literature in many senses already has the theoretical answers on how to empower parents and on how to improve pediatric nursing practice to accomplish this, but these theoretical answers are not as yet translated into practical approaches, and this is the challenge now facing pediatric nursing.

Implications for Nursing Research

A real limitation exists for this study in the smallness of its sample size; this must be realized when putting the study findings in the context of evolving knowledge for pediatric nursing. To begin with the sample did not tap the full range of chronic illnesses, and variations may very well exist within illnesses that specifically influence the empowerment experience of parents. The parents in this small sample may have been an assertive and vocal group; indeed, not all parents may have understood their goal as empowerment. Furthermore, the researcher did not have an opportunity to observe the dynamics of the empowerment process in action, as it occurred among parents and nurses; the researcher had very limited involvement with each family. As well as being
very small, the sample was limited to the greater Vancouver area. Therefore there may be many nuances that this study did not detect and which other studies might reveal by using a different methodology.

Furthermore, studies between different groups of families that have children with diverse chronic conditions would give insight into parent’s empowerment process over time, and it would provide opportunity for further comparison between diverse groups. There are many questions that still need to be investigated, such as: How are parents of chronically ill children empowered by nurses to develop their primary health care provider’s roles? What is the role of a nurse in facilitating parent’s empowerment? How effective are the existing programs for families of chronically ill children to facilitate empowerment? Is discharge planning for families of chronically ill children sufficient to facilitate and continue empowerment after discharge from hospital? Do these parents need to be empowered after their child has been discharged home? What effects have the different backgrounds of parents, such as their culture and language or language barriers, on the process of empowerment? Are pediatric nurses themselves empowered?

In addition, each of the intrapersonal, interpersonal and situational elements of empowerment needs to be researched in depth to determine the influence on the process of empowerment. Visible in the findings of this study are interpersonal factors for parents: what tools do parents have and use to empower themselves, and what are their values, goals, beliefs and coping styles that determine their ability to adjusted and cope with their situation? Also visible are external factors for parents, factors which empower them, such as parent support groups, parent to parent relationships and friends and families. Further research is needed to investigate the role of interpersonal, intrapersonal
and situational factors in parent’s lives that, for each, affect coping style and notion of empowerment.

The findings from this study indicated that parents find it empowering and helpful to be in a relationship with a nurse that is built on certain main components of the empowerment process. All main components need to be further explored as does the question of how to implement and facilitate this process in nursing practice: we need to know which strategies in this process are most effective toward providing empowering nursing care and why.

The findings from this study suggest a link between the process of empowerment and the parent-nurse relationship. When we can understand the relationship between these two concepts, we will have identified the most effective strategies for pediatric nurses interacting with families of children with chronic conditions.

**Implications for Nursing Practice**

The findings of this study suggest empowerment is a developmental process that partly evolves in relationships with nurses, enabling the parents to master the care of their child. What we can take from these findings is that a certain kind of a parent-nurse working relationship can facilitate empowerment. Drawn from the parents’ own experiences, the following are implications for nursing practice.

a) All families in which a child is diagnosed with a chronic condition should have the opportunity of a relationship with a key nurse who coordinates and oversees the care. Ideally, this nurse would establish a connection with the family from the beginning and maintain follow-up contact. That way the nurse knows the family and the situation, so that family members can contact the nurse with questions and concerns.
This ongoing contact would be especially helpful to assist families with major transitions, such as from hospital to home and from home to entering the school system.

b) When families are ready for discharge, the nurse should evaluate and predict the family’s needs. Increased nursing follow-up services, especially for those living at a distance from the urban care centre, will help with the effects of early discharge. Because of the complexity of the demands upon these families with children with a chronic illness, pediatric home care nurses would be ideally suited to providing follow-up service after discharge in order to facilitate empowerment.

c) The health care relationships that nurses form with families should include the main components and elements of an empowering process: mutual trust, teamwork, and support with decision making, mutual understanding and respect, active listening and good communication.

d) The role of a nurse in an empowering parent-nurse relationship should focus on being available to the family, having a positive and encouraging attitude, being flexible, and showing genuine interest and concern. It should also focus on being an interpreter who acts as go-between and clarifies communications and information, while making sure parents understand what they need to learn.

e) The education of parents should include various strategies to assist them in understanding complex concepts related to their child’s health. Parents in this study noted such strategies as repeat education, the use of visual pictures, handing out appropriate written information and the ability and willingness to explain until the
concept is understood. Nurses should respect parents' expertise, support their competence in decision making and advocate for the family when needed.

f). Nurses should recognize the value of parent-to-parent support and encourage parents of children with chronic illnesses to connect with other parents in a similar situation or with parent support groups.

The findings of this study suggest that one of the strongest resources pediatric nursing practice has to offer today is the nurse care manager or care coordinator who creates the conditions under which empowering interactions are more likely to occur, in order to improve the delivery of health care for children with chronic conditions by the families themselves.

**Implications for Nursing Education**

From the findings of this study, two main implications for nursing education can be drawn, and these contribute to nursing education the conditions under which empowerment is more likely to take place. First, it seems important that all nurses are educated in a way that enables them to gain an understanding of how the experience of caring for a family that has a child with a chronic condition can best be facilitated towards empowerment. Nurses and nursing educators need to re-evaluate their roles, attitudes, beliefs and values both in nursing education and in nursing practice towards empowerment because these factors directly affect the provision of nursing care. That way, nursing educators can enable pediatric nurses to understand how they can best approach these families and facilitate their voyage towards empowerment. We must discover what it takes to enable families to get from the novice stage to the expert stage of being the primary health caregiver of their child. Second, the first encounters a nurse
has with parents must be informed by the notions of empowerment; they should embody the attitudes, the beliefs and the skills parents themselves will need to provide empowered care. Hopefully, nursing education will be able to contribute to the conditions under which empowering interactions between a parent and a nurse are most likely to occur.

**In Summary**

The purpose of this study was to gain insight into the kinds of parent-nurse relationships parents describe as empowering and to understand how each relationship is empowering to parents. The study involved the gathering of parent descriptions of their experiences of empowerment in health care provider relationships with nurses. The objectives of the project were to describe and interpret what it was in the health care relationship that empowered families and to develop an understanding of how and if the parent-nurse relationship is linked to empowerment. In addition, the objective was to generate descriptive information that could contribute to pediatric nursing knowledge which informed the nature and meaning of parental notions of empowerment in their relationships with nurses.

In conclusion, the parent-nurse relationship seems to be a very significant component of empowerment for families faced with the situation of caring for children with a chronic condition. Parental notions of being empowered lend to the condition of being able to become their child’s primary health care provider and to manage mostly on their own. Confidence and competence enables parents to provide health care, to take charge and to make decisions in their child’s best interest. Mastering the shifting
challenges of a child’s chronic condition represents for parents a gained control within
the situation, all of which enables them to have a more normal life and a better quality of
life. Many of the qualities parents in this study identify as necessary to empowerment are
similar to those nurses might consider consistent with standards of excellence for nursing
practice.

The choice is yours!!!
REFERENCES


Appendix A: Information Letter for Parents

Title of study: The Notion of Empowerment for parent in Pediatric Health Care Delivery

Dear family member

My name is Bára Sigurjónsdóttir. I am a pediatric nurse from Iceland. I have worked for 10 years at the Childrens’ Hospital back home and for three years in nursing home care for children with chronic conditions. I am currently a student in the graduate program in nursing at the University of British Columbia. A part of my graduate work is to conduct this study which is my Master of Science in Nursing degree. I am studying the experiences of parents who are caring for a child with a chronic condition, which I hope will provide nurses with helpful information about how they can improve nursing care for families of chronically ill children.

I would like to invite you to share your experiences of what it is like to care for a child with a chronic condition. Through your participation, you can give nurses an insight into your experience of how it is to be a parent of a child with a chronic condition. An increased understanding of what parents say is important to them and most helpful in their circumstances will assist nurses in providing the most appropriate and relevant care to other parents in the future.
Appendix C: Research Questions

Parents’ Notion of Empowerment in Pediatric Health Care Delivery

Could you please help me understand how it has been to have a child with this ( ) kind of a condition. Maybe we could start our conversation with you telling me your child’s story?

Now when I have some understanding of what you have been going through and how you have been able to help your child, I am wanting to try to sort out what it is that nurses have done, that has help you to manage the care of your child and to go on with your lives?

1. What is it that nurses do that has enabled / helped you to manage well the care of your child and become the expert you are today in your child’s care? Like, how have nurses helped you in this process?

(Please use examples if you can)

a) For example what kinds of things have enable you to feel you have the strengths, skills and confidence to care for your child and make decisions in relation to your child’s condition / to feel in control of the situations? Know your limits when it comes to seeking outside help from a nurse?

b) Like, what was it that a nurse did or said that made the difference for you?

c) Can you please explain to me what has been most empowering for you in your relationships with nurses to go through this experience?

What is it in a relationship with a nurse that enables to cope with your situation?

Are there different kinds of relationships between nurses and parents?
2. Is there any relationship with a nurse that stands out in your mind and if so then why, or are there any past interactions in a relationship with a nurse that stand out in our mind? Positive or negative? (Please use examples if you can)

a) For example, how would you describe a helpful/unhelpful nurse?

4. In your mind, what factors does a positive working relationship with a nurse need to include?

a) What kind of a relationship would you like to have with a nurse? What kind of relationships with a nurse works best for you?

Finally, I would like to ask you for your advises for nurses that are providing nursing care to families like yours? How can a nurse best help a family like yours?

Trigger:

I am interested in

Can you tell me about

Tell me a little more about
APPENDIX D

ETHICAL APPROVAL