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Understanding Nursing Support for Parents Caring for a Child

with Cystic Fibrosis

by

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The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies for acceptance, a thesis entitled "Understanding Nursing Support for Parents Caring for a Child with Cystic Fibrosis" submitted by Sarah Malo in partial fulfilment of the requirements of the degree of Masters of Nursing.

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Abstract

The purpose of this study was to explore parents' perceptions of nursing support when caring for their child with Cystic Fibrosis. The study was conducted using the ethnoscience research method. Sources of data were three rounds of semi-structured interviews. Participants ranged from two to six participants, dependent on the round of interviews and all were receiving care from a large urban Cystic Fibrosis health care team. The findings of this study led to a description of nursing support involving four categories: (1) Tools or Skills, (2) Functions or Tasks, (3) Human Characteristics, and (4) Nice to Haves. Findings also revealed the importance of building a relationship with the family which develops into a partnership and could also continue to evolve whereby the parent(s) use control or power as a tool when working with members of the health care team.

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CHAPTER ONE

Introduction

Heather and Mike are parents of 7 year old, Molly, and 9 year old Megan. Molly was diagnosed with cystic fibrosis (CF) at the age of 1 year. Molly's overall health has been good and she has only been admitted to the hospital once since her diagnosis. Molly's symptoms have not greatly impacted her respiratory system, although a year ago, she tested positive on a throat swab for pseudomonas and responded well to treatment. Heather and Mike have been very involved in Molly's care since she was diagnosed and have demonstrated more independence in Molly's care and treatment regime over the last 3 years. Heather and Mike live in the suburbs of a city. Both work full-time outside the home and their other daughter does not have CF.

Since Molly's diagnosis, Heather and Mike have met and developed a relationship with Kate, the nurse on the CF team. They have had regular contact with Kate over the telephone, during routine clinic visits every 3 months, and during Molly's hospitalization. Heather and Mike feel that Kate has been very caring and compassionate and they often say that they don't know what they would do without her. Kate has noticed that their phone calls about Molly's health status have been less frequent over the last while and that they demonstrate an increased confidence and knowledge level during her interactions with them.

On a particular morning, Heather had left a message for Kate about Molly's cold symptoms which had begun with nasal congestion and had progressed to a wet cough this morning. Molly had a decreased appetite, but was sleeping well. Heather offered fluids and

TLC, but called Kate as she wondered if it would be appropriate to seek further treatment at this time.

Kate returned her call and asked a few more questions to expand on Molly's current health status, such as frequency of chest physiotherapy, nature of the cough, Molly's activity level, current antibiotic usage and color of sputum and nasal discharge. Heather explained that she was supposed to be working today but could bring Molly in to the clinic if she should be seen. Kate reaffirmed that Molly had not missed school and had been afebrile, but confirmed that Molly may be getting sick. Kate discussed options with Heather and asked Heather if she was comfortable pursuing adjustments to Molly's routine over the phone followed by an appointment later in the week if Molly's response was not satisfactory. Heather agreed that she would be comfortable with adjusting Molly's medications as Kate suggested. In order to determine the next step in Molly's care, Kate asked Heather about her comfort level, and level of confidence if the changes in medications were not satisfactory in improving her status. Heather told her that she would try a change in Molly's medications and would bring her in to the clinic if her condition continued to worsen.

This scenario depicts a typical interaction that a nurse might have with a parent with a child with CF. When reading this scenario, it might not be obvious that nursing support is being provided as there is no one specific "behavior" that the nurse is doing that might immediately be termed "supportive". In providing care for parents who are caring for a child with CF, the question then arises as to what really constitutes support. As an MN student I was exposed to this type of ambulatory nursing and I questioned how support was

being provided in this context. My preceptor found it difficult to differentiate her actions that were supportive in nature. As an observer, it was obvious to me that families were confident in their knowledge and abilities and I wondered if that was developed through the supportive nature of the relationship between the nurse and families. But how can you select certain behaviors or actions to define support in this context? After noticing the use of support in conversation between the clinical nurse specialist and families, I began a review of the literature on nursing support and found that little research has been done to explore how parents and families describe support in this context and there is a general lack of clarity in describing supportive nursing care. In order to begin to understand supportive behaviors, we must first allow families to describe their own definition of nursing support as they themselves are the recipients of supportive care.

The Context

Patterns of childhood mortality in chronic illness have altered considerably over the last two decades due to advances in medical technology, improved management, early recognition and implementation of preventative measures (Hockenberry, Wilson, Winkelstein & Kline, 2003). Due to the dramatic decline in mortality rates, there are increased numbers of children with health care needs who are requiring long-term health care services (Hockenberry et al.).

One such chronic illness is cystic fibrosis (CF), a common inherited childhood condition caused by a genetic mutation (Hockenberry et al., 2003). Clinical manifestations, when present, are related to the increased viscosity of mucous gland secretions including alterations in the respiratory system, gastrointestinal system and reproductive system

(Hockenberry et al.). There is no cure for the disease. Increased life expectancy is related to a complex regimen of treatment, mainly carried out at home. Mean survival is now over 35 years of age, and death in childhood is uncommon. Nonetheless, families are well aware of the possibility of early death. The daily regimen for a child with cystic fibrosis at home requires an enormous investment in physical and emotional work which impacts the entire family. Time and energy must be spent supervising enzyme replacement, monitoring the child's appetite and conducting the daily regimen of physiotherapy. This level of care may require that one parent limit hours of work outside the home or even resign from outside employment, which can have severe economic consequences. However, the child will appear well to others who may not appreciate the potential for deterioration.

Qualitative studies have been completed to explore the experience of caring for a child with CF (Carpenter & Narsavage, 2004; Hodgkinson & Lester, 2002; Wong & Heriot, 2008) and have identified that support from others, including nurses, enabled effective coping strategies. Parents caring for a child with CF require support from numerous individuals, including nurses, as well as knowledge and access to resources to care competently for their chronically ill child. Most of the time a child with CF is considered "healthy", so parents do not require formal assistance from health care professionals on a day-to-day basis. However, if the child develops symptoms, it may be vital that parents be able to access care from the health care team, specifically the nurse, in order to properly care for their child. The parent(s) may seek assistance through phone, email, clinic visit or Emergency, depending on the child's status.

Supportive nursing care is considered to be a basic characteristic of nursing practice (Gardner & Wheeler, 1987). It has been described as behaviors which aid patients to maintain or restore their ability to cope with their situation or experiences, but definitions have been vague (Gardner & Wheeler). Although many believe support is a fundamental role of the nurse, the concept of support has also been noted to be absent in the majority of nursing theories (Davies & Oberle, 1992).

The concept of nursing support has often been studied as a component of the broader concept of support and has not received focused attention (Hinds & Moyer, 1997; Steele & Fitch, 2008). Research in the area of supportive nursing care has been focused primarily in the hospital or acute care setting. Findings suggest that giving information is considered by patients as families as the most important aspect of nursing support, although there are variances in the type and degree of information that is required for supportive care (Hinds & Moyer, 1997; Hodnett, 1996; Turner et al., 2007; Waters, 1999). Patients described support as words and actions which were every day and ordinary in nature, but in the context of their situation were perceived as supportive (Hinds & Moyer, 1997).

Nursing support for families has only briefly been explored in parents with children who are hospitalized with an acute condition (Miles, Carlson, & Brunssen, 1999) as well as in parents with children with a chronic condition from a community perspective (Nuutila & Salantera, 2006). A few literature reviews have been done to explore the needs of parents and families in caring for a child with a chronic condition, including CF, which depicted the need for support, although descriptions of this support are vague (Coyne, 1997; Fisher, 2001; Lindblad, Rasmussen, & Sandman, 2005).

There are many differences in the nursing care, including support, required by a family with a child with a chronic condition compared with a child who is hospitalized with an acute condition, because the parents' level of knowledge varies considerably. Much of what has been developed to support families is based on caregivers' expectations of what families want and need. To date there has been little research on the perspectives of family members regarding their understanding of what would be most supportive. The nature of nursing support from the perspective of families caring for a child with cystic fibrosis has never been explored. In order to understand the role of the nurse in providing support to patients and/or families, further research is required.

<div align="center">Purpose and Rationale</div>

In order for nurses to provide optimal support to families caring for a child with cystic fibrosis, we must understand how parents define support in their own words based on their needs. At present, no study has been done to explore parents' perceptions, thoughts or ideas about nursing support in caring for their child with cystic fibrosis. The purpose of this study was to explore how parents of a child with cystic fibrosis describe or define nursing support. The central question guiding this study is:

How do parents of children with cystic fibrosis caring for their child at home describe nursing support?

CHAPTER TWO

Literature Review

The reason for this literature review is to articulate the significance of the current

study as well as provide background information regarding the topic. The purpose of a

literature review in qualitative research is to explore what is known about a topic,

determine gaps or inconsistencies in the research literature and gain insights for interpreting

study findings (Loiselle & Profetto-McGrath, 2007). Even though there is little research

done on the topic of nursing support related to parents caring for a child with CF, it is

important to explore the literature regarding nursing support in a variety of nursing areas.

The concept of nursing support in general has been insufficiently described conceptually

operationally. In this review I will first offer several definitions of support, then examine

the ways in which support has been addressed in the nursing literature, including how it is

used in theoretical frameworks or models, and how it is thought to be related to social

support. I will provide a summary of research on nursing support in caring for adult

patients in a variety of areas, as well support of parents of a child during a hospitalization

and in the community. Finally, I will explore the experience of caring for a child with CF,

including the need for nursing support.

Support in Nursing

Support is commonly used in nursing literature to describe a fundamental role of the

nurse in caring for patients and their families. There is no consensus on the best definition

of support (Grossman-Shultz & Feeley, 1984) although it has been conceptualized to

include behaviors of nurses to maintain, restore or increase patients' capacity to cope with

situations (Wheeler & Gardner, 1987). It is widely agreed to be instrumental in every interaction with a patient and his/her family (Davies & Oberle, 1992; Gardner & Wheeler, 1987).

Further to an exploration in dictionaries and encyclopedias, Stoltz, Pilhammar Anderson and Willman (2007) explored the concept of support in scientific database searches focusing on nursing support of family carers of older persons and found that there are "inconsistent and multiple readings of the term support" as well as a "great number of prefixes and suffixes to the term support" (p.1482). The authors found that only one fourth of the studies included in their literature review included an explicit definition of support; some of the researchers included their own definition while others used a reference. They stated that many prefixes used in the literature which in fact were actually adjectives for support: available, direct, emotional, financial, as well as nursing. They also mislabeled recipients as suffixes which included groups, persons, network/s, and organization. Two dimensions of support were noted in the literature. The first dimension is "very tangible, concrete but residing at a general impersonal level...support appears as goal-oriented mainly towards increasing the family carers' caregiving capacities or competence" (p. 1483). The second is "more intangible and abstract ... with a drive to be attuned to family carers' needs at an individual and highly personal level...support is what happens in meetings between human beings, co-created, as opposed to a service given and received" (p.1483). The authors concluded that, taking into account the various literature, support could be defined as:

... the provision of general tangibles such as information, education, economic aid, goods and external services. These are prerequisites for facilitating the family carers' competence and/or capacity in care. Moreover, it entails necessary qualities such as individualization, adaptability, lastingness, room for verbalizing emotions as well as an idea of reciprocal symmetrical exchange between involved parties. (p.1485)

Support can be interpreted to include many behaviors and/or actions dependent on the context in which it is used. In order to fully understand the concept of support in nursing, I will explore the theoretical models and frameworks to uncover how support is being put into practice.

Theoretical Models and Frameworks

Although the term support is used in many resources to describe the practice of nurses, there are few theoretical models or frameworks that incorporate a clear description of what nursing support "looks like". One exception is the Supportive Care Model (Davies & Oberle, 1990; Davies & Oberle, 1992; Davies & Oberle, 1993). The authors first developed their model based on a qualitative study of expert nursing care in an oncology outpatient setting (1990) and later revised it somewhat based on ongoing reflection and dialogue (1993). Dimensions of supportive care included "Connecting", "Empowering", "Doing For", and "Finding Meaning". The contextual foundation of nursing interventions was labeled as "Valuing" and the goal of nursing was "Preserving Integrity" (Davies & Oberle, 1993). The authors indicated that because the concept of support is complex it is difficult to separate its dimensions, as they are linked and interwoven. They highlighted

that characteristics of the nurse as a person are fundamental in providing support to a patient and all dimensions must be present in order for nursing care to truly be supportive. Another working model of support created by Grossman-Shultz & Feeley (1984), incorporated three phases of a relationship with a patient. Phase one included developing trust between the nurse and client in which a supportive relationship will develop. Phase two included establishing client-specific health goals which help to focus the relationship and phase three included the process of the client obtaining his [sic] goals and the nurse working with the client to help him achieve these goals and develop a sense of control over his problems. This model incorporated behaviors and actions for the nurse to apply in practice such as being available, helping in problem-solving, providing information and being friendly; however the authors stated that it would be helpful to further investigate this topic to develop and refine this model.

The term support can also be used as an adjective in the term supportive care; defined as a "benefit to patients and their families by encouraging individuals to live as well as possible" (Tebbit, 2001 as cited in Kerr, Harrison, Medvew, & Tranmer, 2004). The Supportive Care Framework for Cancer Care (SCNF) was developed by Fitch (1994) as a tool for cancer care professionals to provide a conceptual description of the help that cancer patients might need and how to plan for appropriate service delivery (as cited in Fitch, 2008). SCNF was developed based on a definition of supportive care as:

> the provision of necessary services as defined by those living with or affected by cancer to meet their physical, informational, psychosocial, emotional, practical, and spiritual needs during the prediagnostic, diagnostic, treatment, and follow-up

phases, while encompassing issues of survivorship, palliation, and bereavement (Fitch, p.11).

The model outlines a taxonomy of six categories of supportive care needs: practical, spiritual, psychosocial, informational, emotional, and physical, which can vary across the spectrum of experience (Fitch). According to Fitch, validation of this framework has occurred, since its development, through in-depth interviews with patients, cancer survivors, and cancer care providers. Further validation was identified by Fitch as the concepts incorporated in this framework are regularly described in the literature. The author suggested supportive care should be embedded in the practice of all health care professionals and that the framework could be useful to an individual practitioner in daily practice as well as program managers in designing, implementing and evaluating quality service delivery. Fitch explained that supportive care must be based on individual needs within the context of the situation and is aimed at helping the individual cope with the situation and maintain his or her quality of life.

Social Support

Nursing support has been inadequately defined within the literature and therefore has been inconsistently used as a concept (Vandall-Walker, Jensen, & Oberle, 2007). Some researchers have used the term social support when describing support provided by nurses (Hupcey, 1997; Langford, Bowsher, Maloney, & Lillis, 1997), while others have included their description of nursing interventions under the term professional social support (Ellerton, Stewart, Ritchie, & Hirth, 1996; Stewart, Ritchie, McGrath, Thompson, & Bruce, 1994; Waters, 1999). Hupcey and Morse (1997) stated that since the concept of social

support has been so poorly defined, anything associated with support or influential factors have been clustered under and identified as support in the literature. Hupcey and Morse (1997) argued that the support provided by professionals is not considered social support because social support is provided by someone who has a personal relationship with the individual, whereas support from a nurse involves a professional relationship. They explained that researchers must separate professional support and social support in order to fully investigate the aspects of the role of the professional that influence the outcome of support. Since there are many research studies that have subsumed professional nursing support under social support, one must include references to social support while exploring the concept of nursing support. A review of literature exploring nursing support as a component of social support is described in this section.

A conceptual analysis done by Langford et al. (1997) identified that the relationship between social support and health is positive in nature however the components of social support are inconsistent. They described four defining attributes of social support in their concept analysis: emotional (involves caring, empathy, love and trust), instrumental (tangible goods and services), informational (information given during stressful experiences) and appraisal (or affirmational refers to communication for self-evaluation). Antecedents of social support included social network, social embeddedness and social climate and consequences of social support were described as personal competence, health maintenance behaviors, perceived control, positive affect, sense of stability, recognition of self-worth, decreased anxiety and depression and psychological well-being. Langford et al. described three social support instruments that have adequate reliability and validity

estimates; however none of the instruments include all four defining attributes of social support. Therefore the authors suggested that until all four components of social support are included in an instrument, social support cannot be adequately measured in research and clinical practice.

The concept of social support in caring for a child with a chronic condition has been examined in two studies; one exploring perceptions of mothers (Stewart, et al., 1994) and the other, perceptions of children (Ellerton, et al., 1996). The definition of social support used in the studies included support from health care professionals and described how social support was used as a coping mechanism (Ellerton, et al.; Stewart et al.).

A Canadian qualitative research study was done with mothers of children with a chronic condition to explore the sources, types, and appraisal of social support that mothers received in relation to the demands of caring for their child (Stewart et al., 1994). The researchers defined social support as a "dynamic social process between people in relationships, and consisted of emotional, affirmational, instrumental, and information assistance provided by family, friends, neighbours, co-workers, indigenous lay helpers, volunteers, self-help mutual aid groups, and health professionals..."(p.62). Data were collected from semi-structured home interviews with 90 mothers of children who had spina bifida (n=30), diabetes (n=30), or cystic fibrosis (n=30). Mothers were chosen randomly with eligibility criteria including English speaking, children less than 17 years old and cared for at home and living within a two-hour radius of the city. With a sample size of 90, the authors described how comparisons of the descriptions of support between the three groups of mothers were possible. Similarities between the three groups of mothers were

found in relation to their description of burden and support. Mothers described a variety of demands in caring for their children, including the amount of time it takes out of their day to provide treatments. Supportive interactions were received from partners and health professionals, however stressful interactions were also most frequently with partners and health professionals. Mothers described their need for emotional, informational, affirmational, and instrumental support. Health care professionals were the most obvious resource to provide affirmational and instrumental support, but because they only provided informational support related to the child's condition, mothers indicated that support was needed from people with first-hand experience.

Ellerton et al. (1996) completed a descriptive exploratory study focusing on perceptions of social support in childrens' description of sources, types of social support and how it relates to coping with stress in their lives. The researchers included support from health care professionals, including nurses, when they defined social support as "interactions with family, friends, peers, and health professionals that communicate information, esteem, aid, or emotional help" (p.19). Sixty-two children were included in the sample (16 children with diabetes, 16 with cystic fibrosis, 15 with spina bifida and 15 who did not have a chronic condition). They were interviewed individually about supportive and nonsupportive interactions (based on the Children's Inventory of Social Support) and they also completed the Self-Report Coping Scale. According to the researchers "there was a significant between-group difference in the size of support networks" with the children without a chronic condition having the largest group of support networks (p.24). Children with a chronic condition described family members as the largest support when dealing

with a stressful situation. The children in the study explained that situations related to every-day life were more stressful than events connected with their condition.

From the literature it is clear that support from health care professionals is important, but research findings do not provide much guidance on which behaviors distinguish professional support from social support. Nursing support of adult patients can be quite different from nursing support of parents and/or families with a young child, because needs vary across populations (Kerr et al. 2004). Therefore it is important to explore the literature of nursing support of adult patients separately from nursing support of children and their families. Studies of nursing support with specific populations have included nursing support of adult patients including: oncology patients (Hinds & Moyer, 1997; Steele & Fitch, 2008; Turner, Clavarino, Yates, Hargraves, Connors, & Hausmann, 2007), women during the perinatal period (Bryanton, Fraser-Davey, Sullivan, 1994; Corbett &, Callister, 2000; Gale, Fothergill-Bourbonnais, & Chamberlain, 2001; Hodnett, 1996; Hong, Callister, & Schwarts, 2003;), and families of patients in the intensive care unit (Hupcey, 1998;; Vandall-Walker, et al., 2007; Waters, 1999).

Nursing Support of Adult Patients

Nursing support has been explored from the perspective of adult patients in order to gain an understanding of the patients' perceptions of supportive behaviors as well as nurses' perceptions. The findings seemed to indicate that the most common type of support required in nursing care is that of informational support; although there are variances in the type and degree of information that is required for supportive care (Hinds & Moyer, 1997; Hodnett, 1996; Turner et al., 2007; Waters, 1999). Also in exploring nurses' perceptions of

support, findings have revealed that there are many barriers that affect the outcome of providing appropriate nursing support (Gale, et al., 2001; Turner et al., 2007). Some of the initial findings of research in the area of nursing support will be explored in this section. Nursing support has often been studied as a component of the broader concept of support and has not received focused attention (Hinds & Moyer, 1997; Steele & Fitch, 2008). In these studies, the researchers often discussed the results of support of friends and family as separate from support from health care professionals, but it is difficult to identify specific supportive behaviors when described in the larger context of support. In exploring nursing support, supportive behaviors were also used to describe a person's actions in providing support.

Nurses' descriptions of support did not always relate specifically to supportive behaviors. This is further elaborated in a Canadian qualitative study that was conducted where 17 nurses were interviewed about their use of supportive behaviors in order to define and describe the effectiveness of these interventions (Grossman-Shultz, & Feeley, 1984). In addition, 42 nurses completed questionnaires where they were asked to describe examples of supportive nursing from their own practice, provide personal definitions of support and describe how they evaluate the effectiveness of an intervention. The authors' findings indicated a discrepancy between nurses' descriptions of supportive behaviors in their practice and their conceptualizations of support. Of the 42 examples of supportive care, 25 different supportive behaviors were identified as well as a wide range of words used to define support in nursing. In addition, the authors noted a significant discrepancy that existed between the nurses' descriptions of supportive behaviors and their definitions of the

concept of support. The authors explained that the behaviors that nurses used to define support were rarely applied in their nursing practice which expands on the notion that support is a vague and variable concept in the profession of nursing.

Oncology nursing. Support in the area of oncologic nursing has been explored through the patients' perspective through qualitative and quantitative research. In a qualitative study, Hinds and Moyer (1997) examined oncology patients' perspectives of support during their radiation treatment. The authors noted a perceived discrepancy between nurses' valuing support within the profession and the support provided to patients from health care professionals. The researchers defined support as "those behaviors aimed at helping patients to maintain, restore, or increase their strength in order to enhance their ability to interact and adapt" (Gardner & Wheeler, as cited in Hinds & Moyer, p.372). Since the focus was on the overall concept of support, not specific to support from health professionals, participants made little reference to professional support during their interviews until specified questions were asked. Results of the study indicated that support is based on a person's perception of social interactions that may be accepted as support based on their context. Patients described support as words and actions which were every day and ordinary in nature, but in the context of their situation were perceived as supportive. Patients perceived professional support as mainly informational, whereas the primary source of support was received from family and friends; patients may not even be expecting supportive behaviors from nurses. The authors posit the question "is it realistic that nurses could provide support beyond that which was informational and affirming?" (p.378).

Steele and Fitch (2008) completed a descriptive quantitative study in Ontario, Canada with the purpose of identifying supportive care needs of women with gynecologic cancer who attended an outpatient cancer center. They also explored whether patients wanted assistance in meeting their needs. The sample comprised 103 women attending a gynecologic clinic over a four month period. Data were collected through the use of a demographic form and the Supportive Care Needs Survey (SCNS); acceptable levels of construct validity, internal reliability, face and content validity were reported by the researchers. The SCNS included seven domains of supportive care: emotional, spiritual, psychological, physical symptoms, informational, social and practical and the findings of the study indicated that women were experiencing issues across all of the domains. The most frequently reported issues were from the emotional, physical, psychological and social domains, although the findings indicated that there were unmet needs across all seven domains. Also noteworthy were the results that women did not always want help with their identified needs. The authors stated that it is the health care professionals' role to further explore the needs of women as they may need to be approached by professionals about their need rather than independently articulating their need.

Supportive care has also been explored from the nurse's perspective in a qualitative research study aimed at better understanding attitudes towards the provision of psychosocial care, challenges and learning needs (Turner, et al., 2007). Supportive care was not defined by Turner et al. and little description of supportive care was provided in the background. Data were collected using focus groups as well as individual interviews for nurses in rural areas, until data saturation was achieved. The findings revealed the difficulty

that oncology nurses have in providing psychosocial support, which led to discussions about challenges, including knowledge deficit and lack of confidence in communication skills. The authors described how 'emotional presence' is a vital component of the caring role within oncology nursing, however the nurses in the study described the burden that they feel from this role which is manifested in avoidance of patients and/or families. In addition to the personal challenges, it was also identified that there are systemic challenges including the culture of the workplace, traditional nursing roles, and time pressures, to name a few. Nurses described challenges in working within the health care team in providing psychosocial support. The nurses in this study explained their professional development needs in providing support as well the need for exploration of team dynamics, the systems in which patients are being treated and attitudes towards psychosocial support.

Perinatal nursing. Support is also described in the perinatal nursing literature as labor support. Research done in this realm of nursing care described the barriers that impact nurses' ability to perform supportive care. In a meta-analysis of research trials exploring effects of support during childbirth, Hodnett (1996) stated labor support was care given to a woman during labor in order to help her achieve labor goals and meet emotional needs. Five categories of support have been reported: emotional, comfort measures, information, advocacy and support for the partner. One difference between support from a nurse and support from a partner included the lack of a social bond between the nurse and the woman. Hodnett described examples of nursing actions that can be performed at various stages of labor, such as deep breathing, to provide support. She noted barriers in providing labour

support such as lack of time and lack of educational preparation; however stated that support is a vital component of the role of the nurse within the labor setting.

In a descriptive exploratory study, Gale, et al. (2001) explored the amount of nursing support as well as factors influencing this support in relation to caring for women during childbirth. Data were gathered at a teaching hospital in Quebec, Canada. A total of 404 observations were made of twelve registered nurses during their shift on the labour and delivery unit. Observed activities were coded and categorized into "supportive care" or "other". A pilot study was completed following previous work sampling studies using the list of supportive nursing activities in order to determine if the activities in the tool were mutually exclusive and completely exhaustive. Following the observations, semi-structured interviews were used to understand the nurses' perceptions of supportive care as well as factors that may have influenced their care. Findings revealed that although the nurses in this study described supportive activities for laboring women, they were only spending 12.4% of their time performing supportive care. Nurses in the study indicated that "too many patients" or "not enough staff" were the prominent factors impacting their ability to provide supportive care, although these factors were seldom observed in the work sampling portion of the study. The authors described that further research is needed to help understand identifiable reasons why nurses are not able to provide the support that they identify as important in their own practice.

In exploring supportive behaviors of nurses from the patient's perspective, Corbett and Callister (2000) conducted a descriptive study in order to determine which supportive behaviors of nurses are perceived as most helpful for women in labor. The researchers used

Lazarus's (1983) cognitive theory of stress and coping as the theoretical framework guiding the study (as cited in Corbett & Callister) which includes social support as encompassing emotional, informational and tangible forms. Data were collected through the use of the Bryanton Adaptation of the Nursing Support in Labor Questionnaire (BANSILQ); the authors noted that this questionnaire had established content validity, and a high level of reliability. It is unclear how the women were invited to participate, although the researchers stated that eighty-eight women completed questionnaires with 100% return rate. Participants were also invited to share, in a narrative form, any additional behaviors they found to be helpful during labor and the results were categorized as emotional, informational or tangible support. Overall, findings indicated that emotional support was more helpful than informational or tangible support. The authors concluded that "the value of emotional support as a therapeutic nursing intervention needs to be emphasized to those who care for women during labor" (p.79).

Similar to the previous study, a retrospective study using quantitative as well as qualitative approaches was completed to explore nursing behaviors perceived by women as helpful in assisting them through their labor (Bryanton, Fraser-Davey & Sullivan, 1994). The Lazarus cognitive-phenomenological model of stress, appraisal, and coping (Lazarus & Folkman, 1984, as cited in Bryanton, et al., 1994) was used with the focus on the "environmental coping resource or perceived social support" (p.638). Eighty women (34 primaparae and 46 multiparae), who met the eligibility criteria, were approached to complete the questionnaires and the response rate was 96.6%. The questionnaires that were used included modified versions of the Nursing Support in Labor Questionnaire (NSILQ),

with an internal consistency rating of .93, and the BANSILQ, with an internal consistency rating of .99. Findings indicated that all of the 25 nursing support behaviors were considered helpful for the participants. The highest mean scores were the indicators "the nurse made me feel cared about as an individual" , "the nurse praised me", "the nurse appeared calm and confident in giving care" which were all included in the emotional support category. Bryanton et al. described limitations to their study, including a lack of generalizability of the findings as the socioeconomic status and ethnic background of the sample were not controlled. The researchers indicated that the results of their study had a high degree of consistency with studies done by Kintz (1987) and Field (1987) (as cited in Bryanton et al); their findings are also similar to those of Corbett and Callister (2000) as described above.

Critical care nursing. In exploring family members' perceptions and/or expectations of professional support from critical care nurses, the Professional Support Questionnaire for Critical Care Nurses Working with Family Members (PSQ) was used in a non-experimental between-group comparison study (Waters, 1999). The sample included participants who were visiting family members in the ICU and included equal representation from three cultural groups: African American, Hispanic, and White. Results were similar among the three groups: "calling me at home about major changes, answering questions honestly, assuring me that my family member is receiving the best care, explaining nursing procedures that are understandable, and giving information about my family member's condition in terms that I can understand at least once a shift" (p.113) were some of the most important items.

Further exploration of nursing support within the critical care environment was done by Vandall-Walker, Jensen, & Oberle (2007). The researchers conducted a grounded theory study focused on delineating the process of nursing support for families of critically ill adults from the perspectives of family members. A convenience sample of 20 family members from 14 families participated in face-to-face interviews. The core category of nursing support as described by the family members was "Lightening our Load". Informants described how when supported, a family members' energy is conserved, whereas nonsupportive actions create barriers that impact their ability to fulfill their responsibilities. The authors indicated that *Lightening our Load* consists of three interconnected, cyclical and recursive phases: Engaging With Us, Sustaining Us, and Disengaging From Us. Beginning with the family member's admission to critical care, the nurse must initiate the relationship with the family through acknowledging the family, getting acquainted, respecting, trusting and empathizing with the family members. Strengthening the relationship is described in the *Sustaining Us* category through Reassuring Us, Being There, Communicating with Us, Hearing, Informing Us, Helping Us Understand, Chatting with Us, and Being Accountable to Us. The final stage is *Disengaging From Us* which occurs when the patient is transferred or dies. Informants described supportive behaviors as Facilitating Our Moving On by Guiding Our Decisions and Helping Us Find Meaning. The findings of this study are unique as they provide family members' perspectives from admission to discharge or death. Participants in this study clearly emphasized that what got them through the situation of having a family member in critical care was support, not caring. The authors described that professional

support is different than social support as it refers to aspects of support provided by professionals when social intimates are not capable and nursing support is a form of professional support provided by nurses.

In summary from the above literature review regarding nursing support of adult patients, it is evident that support is fundamental to nursing practice no matter the area of patient care. It is also clear that professional nursing support is different than social support and must be explored separately in order to specifically identify supportive behaviors of nurses. Emotional and informational support seemed to be the most common types of nursing support, although the actions and behaviors of nurses were different in each situation. It is also important to note that nursing support of parents and/or families is an entirely different context that requires focused attention in research. An initial review of the literature will be discussed in the next section.

Nursing Support for Parents

The concept of support has been studied in the area of pediatric nursing, although no definitions or specific behaviors have been described in these studies (Hall, 1997; Lindblad, Rasmussen, & Sandman, 2005; McConachie, 1994; Nuutila & Salantera, 2006; Rowe & Jones, 2008; Sloper, 1999). Various kinds of support, including emotional, social, economic and practical have been reported as being important for families of children with a chronic illness (Nuutila & Salantera). Some research exploring parents' experiences of professional support, regardless of the child's diagnosis has displayed dissatisfaction of parents regarding information about available support (Hall). Some of the initial findings of

parents' experiences of support from health care professionals will be explored in this section.

Kerr, Harrison, Medves, & Tranmer (2004) did a literature review related to supportive care needs of parents of children with cancer from diagnosis to treatment. Kerr et al. used the Supportive Care Needs Framework (SCNF) to guide the review and found that all of the six categories of supportive care needs were articulated in the literature, where most of the studies cited three of more of the needs within the framework. The largest proportion of studies included in the review (88%) included informational needs in their findings with emotional needs the second most frequent category described. Kerr et al. described how the SCNF can be considered useful in working with adult populations, but there have been challenges in its use with pediatric populations as it did not specifically relate to the needs of families. The authors also identified that the term 'need' can have different meanings depending on the context which can lead to confusion and further research needs to be done to clarify the needs of parents to guide the planning and provision of quality care.

Support during hospitalizations. Miles, Carlson, & Brunssen (1999) described the development of the Nurse Parent Support Tool based on House's (1981) conceptual definitions of social support which encompasses professional support. Miles, et al. developed this tool to measure parents' perception of nursing support while their child was hospitalized. The tool included four overlapping aspects of support including: supportive communication and information giving, emotional support, parental esteem support, and instrumental support. Content validity of the tool was supported through interviews of

parents, nursing literature, and peer reviews done by 20 pediatric nurses across the country. A pilot study was also conducted with 115 parents of hospitalized children as well as a review done by 10 parents of infants in critical care in order to support the content validity. Miles, et al. indicated that the factor analysis provided "support for the underlying construct of the tool and significant correlations with other instruments provide support for the concurrent validity" (p.49) as well as a high internal consistency reliability. They also stated that further research is needed to evaluate the psychometric properties of the instrument, but it can be used in correlational, descriptive and experimental research studies.

Nursing support during stressful times is a component of the nurse's role, such as when a preterm infant is being transferred between neonatal nurseries. Rowe and Jones (2008) explored nurse's perceptions of their supportive practice during transfers of preterm infants within and between hospitals through the use of focus groups. The findings revealed three subheadings: the nurses' objectives in providing effective support, perceptions of organizational dynamics and how that impacted the support nurses provided, and strategies to enhance support. The findings also confirmed that emphasis should be placed on preparing parents to increase their participation in care as well empowering or enabling parents. The data from this study indicated that many significant factors affect support including the "organization's clinical focus, staffing levels and workload but also with the capacity of nursing roles" (p.788).

Support for parents with a child with a chronic condition in the community. Nuutila and Salantera (2006) explored parents' experiences with health care professionals while

learning how to care for their child with a chronic illness in a qualitative study. Data were collected through the use of interviews, although the specific method for data analysis was not described. The needs of the parents in the study changed as they evolved through the stages of coping with their child's chronic illness, from receiving information following diagnosis, to a two-way flow of information as their confidence level increased. Nuutila and Salantera stated that a fundamental characteristic of a positive working relationship between the parents and the health care professional was mutual trust. The groundwork for developing trust was described as the role of the health care professional and it was also emphasized that this could not occur without a permanent and consistent relationship.

In order to fully understand nursing support of parents with a chronic condition, one must also review the literature regarding parents of children with disabilities. Since much of the research of nursing support of parents as described above focuses on the acute care setting, nursing support of parents in the community often encompasses parents of children with disabilities.

Support for parents of a child with a disability in the community. Caring for a child with a disability is a stressful situation in which parents may require support from health care professionals, mainly nurses. Lindblad, et al. (2005) completed a phenomenological study in order to understand parents' experiences of being supported by health care professionals while caring for a child with a disability. Parents described an increased level of confidence in caring for their child when they were being supported. Parents' confidence level was increased through being acknowledged as a person, being acknowledged as the child's carer, and having one's worries eased in daily life. Parents in the study also

described how it was important for the nurse to acknowledge the child as valuable, including hope for the child's future as well as acknowledging the child as worthy of hope. Parents in the study described how they wanted to share in the mutual goal setting and strategies and work closely with health care professionals. The simple idea of spontaneous attention and genuine interest in the parent and child as persons was described as affirming trust and provided strength to the family.

Caring for a Child with Cystic Fibrosis

The experiences of families caring for a child with cystic fibrosis have been described in several qualitative studies (Carpenter & Narsavage, 2004; Gjengedal, Hanestad, Rustoen & Wahl, 2003; Hodgkinson & Lester, 2002; Wong & Heriot, 2008). Similar to the research findings in the areas of adult and childhood chronic illness, results have indicated that parents and/or families go through a variety of stages following the traumatic experience of diagnosis. Families described initial feelings of uncertainty and instability, which then led to a stage where they developed coping strategies which led to stability and acceptance (Carpenter & Narsavage; Gjengedal, et al.).

The experience of living with cystic fibrosis was explored in one study in which patients' and families' experiences in working with the health care system were revealed through focus group interviews (Gjengedal, et al. 2003). The researchers interviewed 14 adults with cystic fibrosis as well as eight parents of young children with cystic fibrosis. The precise method of analysis is unclear, but findings revealed three themes including *from uncertainty to certainty, a demanding but normal life,* and *a wish for continuity, stability, and respect* (Gjengedal, et al., p.152). The first theme included the experience of

parents and children in obtaining a diagnosis for their child and the daily struggles with this disease, including exacerbations. The second theme included a description of the complexity and time-consuming daily regime of caring for a child with cystic fibrosis. The third theme included the informants' experience in working with health care professionals and described the need for continuity, stability, trust and respect. According to the researchers, the main characteristic of people living with cystic fibrosis is a desire to have a normal life, which they also referred to as the normalization process. They suggested that normalization helps to promote hope with families and also helps them cope. The most common coping strategy identified by the authors in this study involved obtaining support from others, including nurses. Families often turned to nurses first when they had questions about information or concerns. This study is useful in describing some of the questions and concerns that families have, and some of their coping mechanisms, but there was no description of the support that the nurses provided to the families.

Similar themes emerged in a further qualitative study in which the researchers aimed to understand the life experiences of families caring for a child with cystic fibrosis (Carpenter & Narsavage, 2004). A purposive sample of families took part in interviews, focus groups and provided written narratives. Findings revealed parents' experience as captured in three main themes titled *falling apart, pulling together*, and *moving beyond*" (p.29). The theme of *falling apart* included the devastating change following diagnosis from what families had always considered their routine lifestyle. The next stage was *pulling together* where families were able to bring a sense of normalcy back to their life with the adjustments required (Carpenter & Narsavage). The third theme emerged as *moving beyond*

which included a sense of control and a positive attitude that came with newly developed ways of coping. The families in this study indicated that they needed information and emotional support in order to help them develop a sense of control.

Caring for a child with cystic fibrosis can also be stressful for parents due to the daily responsibilities required in managing the child's treatment regime. After the initial trauma of the diagnosis, many parents develop coping skills to manage the burden of care. A qualitative study was completed to explore stresses and coping strategies of mothers in order to help nurses understand how to support families of children with CF (Hodgkinson & Lester, 2002). The perceived causes of stress were captured by three themes: *the stress of feeling in the middle, the burden of responsibility* and *coping with a changed identity* (p.379). Coping strategies were categorized by the authors as "problem-focused, appraisal-focused, and emotion-focused" (p.379). Participants also indicated that they went to nurses for advice and support; nurses were seen as the link between the medical and non-medical worlds. This was identified as one of the problem-focused coping strategies and participants indicated that the continuity of nursing care provided stability in their care. The researchers indicated that implications for nurses must include instilling hope for the families, building bridges with medical and non-medical worlds, continuity of care and acknowledging the effort of the families which will provide support to the families.

Wong and Heriot (2008) completed a quantitative study aimed at examining coping strategies of parents with a child with CF and associations with child and parent adjustment. The researchers also investigated the effects of vicarious hope and vicarious despair on coping and parent and child adjustment using a 20-item self-report

questionnaire, reported by the researchers to be reliable and valid. The instrument was designed to measure the hope and despair that parents have for their child's future (the VFS). The sample was drawn from a support group (parents of children with CF), 35 parents, who were also involved in another study, agreed to participate. Self-blame by parents (42% of the participants) was more frequently associated with child and parent maladjustment than any other coping strategy. The use of emotional support (used by 69% of the sample) sought from family and friends, was found to be important in understanding positive adaptation to CF. The authors concluded that vicarious hope and vicarious despair are important variables in understanding adjustment to the diagnosis of CF whereby vicarious despair predicted parent anxiety and vicarious hope predicted parent emotional impact. Limitations were acknowledged by the researcher related to the sample, although the findings provide an initial exploration of vicarious hope and vicarious despair in this population.

A review of the literature examined how families caring for children with cystic fibrosis adjust to a diagnosis of cystic fibrosis in order to provide a guide for nursing practice and enhance support given to these families (Coyne, 1997). The author noted that parents have a large responsibility in caring for a child with cystic fibrosis and there is a lack of support from health care professionals to help parents cope with this burden. She stated that this deficit of support may be related to the health professionals' lack of knowledge of cystic fibrosis. Families go through a stage of adjustment following a diagnosis of cystic fibrosis which eventually leads to long-term adaptation to the illness (Coyne). The author described that symptoms of severe stress, depression, anxiety, anger

and communication problems within the families have been documented during this adjustment. Feelings of uncertainty and anxiety have been shown to be common in families while coping with the day-to-day management of their child's chronic condition (Coyne). Coping strategies that were identified in the literature included assigning meaning to the illness, sharing the burden, and organizing the care. Coyne stated that further research is needed to identify the parents' experiences as caregivers for their child as well as coping strategies so that they can develop a collaborative relationship that is sensitive to the families' needs. Suggestions were provided by the author in order to guide health care professionals in providing support to these families although these ideas were not obtained directly from the families and no specific guidelines were provided in the article.

As indicated in the studies explored in this literature review, nursing care is instrumental in the care of families caring for a child with cystic fibrosis. The need for nursing support is clear, although a description of how to provide appropriate support is not well described. In order to understand supportive behaviors, we must examine the literature regarding nursing support from the perspective of parents.

Families caring for a child with cystic fibrosis tend to work intimately with health care providers throughout their child's life trajectory in order to promote the health and well-being of their child. It has been noted in the literature that there are similar experiences of families who are caring for a child with cystic fibrosis due to the daily regime of physiotherapy, nutritional requirements and medication monitoring (Carpenter & Narsavage, 2004; Coyne, 1997; Gjengedal et al. 2003; Hodgkinson & Lester, 2002). The preventative and treatment regime of caring for a child with cystic fibrosis allows parents

and children to become experts in their care. In order to understand how to partner or collaborate effectively with these families, we must begin with an exploration of how families define nursing support within this specific population. Given the difficulties, it is evident that families might benefit from appropriate nursing support. However, the nature of such support is not clear, as there is a paucity of studies exploring the concept of nursing support with this population.

CHAPTER THREE

Method

The method used in this study was the developmental research sequence as defined

by Spradley (1979) which is an ethnoscientific approach to research. Spradley described

how ethnography is "learning from people" rather than "studying people" (p.3).

Ethnoscience is a type of ethnography that focuses on the meaning in language of a culture

and how behavior is influenced in a culture (Loiselle & Profetto-McGrath, 2007). In this

section, an introduction to ethnoscience is provided including an overview of the

Developmental Research Sequence (DRS) method and rationale for the chosen method.

The 3 round process for data collection and analysis which was used for this study is

described as well as sampling and ethical considerations.

Ethnoscience

The focus of ethnographic research is understanding a culture for the purpose of

describing and interpreting cultural behavior. There are a variety of types of ethnography

including classical ethnography, institutional ethnography and ethnoscience. Classical

ethnography typically involves the immersion of the researcher into the culture, with data

collection through participant observations and field notes whereas ethnoscience uses

interviews to focus on the use of language to describe one's culture. Ethnoscience is a

linguistic technique that focuses on discovering the "what" of a concept and the "why" of

behaviors within the culture in order to uncover the way in which the informants'

knowledge is organized (Evaneshko & Kay, 1982). It is a structuralist approach to

analyzing language in order to understand the rules of behavior and perceptions of

informants (Parfitt, 1996). There is an assumption that individuals of a culture organize

their knowledge in categories and are able to share this knowledge through language

(Evaneshko & Kay). Ethnoscience emphasizes the insider (or emic) perspective in order to

gain information about the implied understanding of a concept within a culture. A benefit to

the ethnoscientific approach is that it is a methodical, organized and rigorous approach to

data collection and analysis within the qualitative research paradigm (Parfitt, 1996).

A population such as that of families with a child with cystic fibrosis is thought to have a

particular culture that influences how its members interpret their experiences. In developing

an understanding about how these families experience support from health care providers it

is important to have a sense of the nature of that culture. The recognition of these families

as a culture allows the ethnographer to explore their experiences through the lens of culture;

thereby acknowledging their expertise and insight. Although each family may cope in

differing ways, one must acknowledge the similarities in experiences that families caring

for a child with a chronic illness may experience in order to apply an understanding to

nursing practice.

Evaneshko and Kay (1982) described how the value of ethnoscience for nursing lies

within the nature of the data generated as it allows the nurse researcher to "obtain insights

into the meaning of particular things and events as understood by participants of the

culture" (p.49). They also described how the use of the ethnoscientific technique allows

researchers to assist in enhancing cultural sensitivity in nursing research. Since I believe

that the informant is the one who best knows his/her thoughts, ideas, values, and behaviors,

an emic perspective for data collection was chosen. Since there is a lack of clarity about the

concept of support, an initial description or definition must be understood prior to exploring

the process of obtaining or providing support. Ethnoscience provides a structured approach

to identifying a definition of a concept or domain and therefore was an appropriate method

for the misunderstood topic of nursing support. I also see knowledge as something which is

acquired through understanding meanings of behavior as perceived by those experiencing

that behavior which made ethnoscience an ideal method for my research.

Research Techniques

In this study, I used the Developmental Research Sequence (DRS) approach that

Spradley (1979) developed to guide the researcher in doing ethnoscience. The DRS consists

of twelve major tasks designed to guide a researcher from locating an informant to writing

the ethnography. These will be described as part of the three round process that was used in

this study. Data collection and analysis occurred simultaneously therefore they will be

described sequentially as they occurred in the research study.

Overview of Data Collection and Analysis

In order to clearly describe the process of data collection and data analysis for this

study, an overview is provided for each of the three rounds. Round 1 data collection began

with semi-structured one-on-one interviews with each informant. In order to elicit a

description of nursing support, I began by asking the informants to describe experiences

where they received nursing support and based on their responses, asked descriptive

questions to further clarify the nature of support. Data analysis following round 1

interviews included reviewing the transcripts numerous times in order to obtain words and

phrases, or included terms, that were used by the informants to describe the domain of

nursing support (Spradley, 1979). The next step of data analysis included preparing a

domain analysis of nursing support where included terms were organized into hypothesized

categories. I gave each category a "label" or cover term based on the informants'

descriptions of the included terms. Cover terms were identified following a thorough

review of the transcripts and selecting a term that was used to describe many of the

included terms. In preparation for Round two interviews, the included terms (or words and

phrases) and cover terms were written on index cards for the card sort that was completed

in round 2 interviews. Structural questions were developed based on gaps of knowledge

regarding the domain analysis, or the included terms, cover terms and hypothesized

categories.

Round two included a one-one-one interview with the informants in which

structural questions and a card sort were used to aid in understanding the categories within

the domain of nursing support. The purpose of the card sort was to obtain structured

information in order to develop classifications of the explored concept (Harrison et al.,

2004). The card sort allowed participants to display their understanding of the relationships

between the selected words and phrases in order to identify a taxonomy that depicted the

hierarchical classification of nursing support (Harrison et al.). The basic unit of

ethnoscience is the category which is used as a component of a taxonomy as part of the

final "product" of the data analysis. Data analysis following round 2 interviews involved a

taxonomic analysis. A taxonomy is an organized system that describes a concept through

the use of categories as well as the relationships among the categories. A taxonomic

analysis was developed through an in-depth review of all of the transcripts from round 1

and round 2 interviews as well as the results of the card sort in order to hypothesize one overall organization of cover terms, included terms and relationships between them for the domain of nursing support. The final stage of data analysis included the description of cultural themes that emerged throughout the data collection and analysis which provided an overall generalization or assertion about nursing support. Spradley (1979) defined themes as "assertions that have a high degree of generality" (p.186).

The final stage of data collection was for the purpose of validation of the taxonomy and cultural themes. Round 3 interviews included structural questions as well as contrast questions in order to confirm the findings.

Sample

The sample was chosen using a non-probability purposive technique. It is important in an ethnographic study to ensure that the informants are currently involved in the cultural group under investigation. If they are not, their understanding of the concepts being explored may be more difficult to recall or the knowledge may be less accessible (Spradley, 1979). Volunteer informants who were receiving care from a CF clinic in a large urban hospital were recruited. As the data obtained from interviews is highly dependent on the participants' ability to describe their behaviors and knowledge of nursing support, it was important to include participants who spoke and understood English. Further inclusion criteria included: (1) at least one child who is diagnosed with cystic fibrosis, (2) diagnosis of cystic fibrosis has occurred at least one year prior, (3) receiving care from the Cystic Fibrosis Team in the large urban center, (4) able to reflect and share insight into their

experiences related to the chosen topic, and (5) able to commit to a minimum of 3 hours interviewing time which will occur during 3 rounds of interviews.

Purposive sampling can be used when it is beneficial for the researcher to choose subjects who are typical of the population or knowledgeable about the topic (Loiselle, & Profetto-McGrath, 2007). The Clinical Nurse Specialist (CNS) from the Cystic Fibrosis Team at the large urban hospital identified participants who met the inclusion criteria and were felt to have considerable knowledge of the topic of nursing support and be able to articulate this knowledge through the use of words. The CNS informed them of the study through the telephone or during a clinic visit. During this contact, she asked for their permission to release contact information to the investigator. Once they agreed, the investigator phoned them to provide further information about the study, after which they were able to decide whether or not they wished to participate.

The initial proposed sample size was 8 participants. However, similar concepts and ideas had emerged following 6 participant interviews. As three to six participants is the usual sample size in ethnoscientific research (Evaneshko & Kay, 1982; Parfitt, 1996) no further participants were recruited. One participant was unable to continue to participate following the Round 1 interview due to a lack of time.

All participants were mothers who were directly involved in the care of their child with cystic fibrosis. Age range of children with CF was 2 to 16 years. Some mothers had other children who were not diagnosed with CF and the majority of mothers were employed outside the home.

Data Collection Round 1

As described in the overview, data collection for round 1 began with one-on-one semi-structured interviews. I began by asking descriptive questions aimed at eliciting the terms that are used by participants to describe nursing support through descriptions of experiences in receiving nursing support. For example, I asked, "Could you tell me about a time when you experienced support from a nurse?" Questions became more detailed in relation to the informants' responses and were different for each interview, but an example of a descriptive question was "You said that it was important for the nurse to be knowledgeable; can you tell me more about the word knowledgeable?"

Data Analysis Round 1

Following Round 1 interviews, the process of data management and analysis began. Interviews were audiotaped, transcribed, and analyzed before proceeding to the next round of interviews. Working from the transcripts, the first step in analysis involved numerous reviews of the transcripts to underline specific words or phrases that might provide insights into the informants' understanding of the concept of nursing support. According to Evaneshko and Kay (1982) there are no rules or guidelines for this stage of data analysis; therefore I relied on my own knowledge of other aspects of the culture of caring for a child with CF to help select appropriate words and phrases. I reviewed all of the transcripts numerous times separately and together in order to select words and phrases (included terms) that were described as important regarding nursing support. The words and phrases that were chosen seemed to convey an important meaning to the informants when sharing experiences of nursing support. Some words or phrases that were selected were only used

by one informant but highlighted by the informant; many were used by more than one

informant. The 51 words and phrases that were selected from the transcripts of Round 1

interviews are listed in Table 1 in no particular order.

Table 1.   Words and phrases identified following Round 1 Interviews

Attitude (positive)	Easy to approach	Prepared	Acts as a facilitator
Confident	Caring	Provides clarity	Helps me achieve my goals
Knowledgeable	Understanding that the child matters	Compassionate	Warm
Provides information	Provides emotional support	Oversees the care	Works together with families
Available/Accessible	Provides individualized care	Qualified	Guaranteed support
Understands who the family is	Sets realistic expectations	Provides mental support	Familiar with the family
Prompt	Knowing you've been heard	Sensitive	Puts everything together
Respect	Goes beyond	Sympathetic	Wants to help
Makes the process more effective	Provides reassurance	Empathetic	Friendship
Listens well	Honest	Gives a full explanation	Develops a rapport
Steps into the patient's shoes	Trusting	Provides follow-up	Understanding
Goes the extra mile	Responds to calls	Support groups	Provides thorough information
Reliable	Knows exactly what to do	Adaptable	

Next, hypotheses were made about potential relationships between the included

terms to guide round 2 interviews and culturally appropriate labels, or cover terms, were

made for the hypothesized categories. Following numerous reviews of the transcripts, I

noticed that informants were using terms to describe nursing support, and were even

identifying categories in which terms could be included. For example, many informants

described characteristics of a person when providing nursing support, including warm, sensitive, and caring and some even used the word *characteristics* in their description. Using participants' categories and my own understandings I hypothesized labels the following labels: (1) Behaviors of the nurses, (2) Qualities or characteristics of nurses, (3) Health Care System; and (4) Relationship between the Nurse/Family.

Data Collection Round 2

In preparation for Round 2 interviews, the words or phrases (included terms) as listed in Table 1 were written on index cards and used during card sort. I explained that I would be handing them many cards with words and phrases that were used to describe nursing support and I wanted them to pull out the words and phrases that were not applicable for them and to organize the remaining cards in a way that made sense to them. I did not provide the hypothesized category labels to the participants as it seemed to generate confusion for the first participant, whose own labels did not fit the hypothesized labels. All of the participants began by organizing the cards on the table based on what they perceived to be similarities. I told the participants that blank cards were also available if they wished to create cards that they felt were missing. Each participant arranged the index cards slightly differently; some participants used every index card while other participants used only a few. The participants who used a smaller number of index cards provided descriptions of those chosen cards and described how the word or phrase was inclusive of other omitted words and phrases. One participant created two categories to describe nursing support while other participants created up to five categories. Since the cards were spread

in categories across a table, I was able to take a digital picture of each card sort in the case of an accident with the cards.

In addition to the card sort, I asked structural questions to verify, clarify and provide more insight into the cover terms, included terms and categories that they created in the card sort. For example, "You mentioned that a quality or characteristic of the nurse in providing support is sensitivity. Are there any other qualities or characteristics that a nurse needs to have to provide support?" In clarifying the organization of the cards, I often asked, "Since you have the cards organized in categories, would you say that the card at the top of the category is the most important with the card at the bottom as the least important?"

Data Analysis Round 2

Following Round 2 interviews, data management and analysis continued by applying the index cards to a poster board as they were arranged by each informant in order to provide a visual cue for each card sort. This helped me recognize similarities and differences between each informant's card sort and aided in the overall development of the taxonomy as I was able to identify the most important words/phrases and how they should be organized into categories.

The next stage in data analysis included the creation of a taxonomic analysis based on the card sorting activity and responses to the structural questions. The taxonomic analysis focused on the internal structure of domains, ie. relationship between the terms and categories (Spradley, 1979). The taxonomy that was created is identified in Chapter 4 in the description of the findings.

The last stage of data analysis as identified by Spradley (1979) included a description of cultural themes that emerged from the interviews. They may apply to numerous situations and can recur in more than one domain. Since the purpose of this study was to explore nursing support as the only domain, the themes are limited to a description of nursing support and do not relate to other areas of caring for a child with CF.

Data Collection Round 3

Round 3 interviews were completed with 2 participants and used as validation of the taxonomy and cultural themes. I initially left messages with 3 of the 6 participants and had difficulty arranging interviews due to their busy schedules. After a discussion with my faculty advisor, it was decided that a variety of options for validation would be presented to the participants and they could choose what best suited their availability. Suggestions included a one-on-one interview, a small focus group, a telephone call, and email. In order to accommodate their preference, one interview was completed in person and the other was conducted over the phone for convenience. Although two participants agreed to a small focus group, one participant withdrew a week prior due to a lack of time. The second participant agreed to a one-on-one interview. Since the participants were not adding new data as the purpose was to validate or confirm the taxonomy and themes, it was not necessary to audiotape the interviews. Instead descriptive notes were taken by the researcher. During the interview, I provided the participants with a summary of the findings and shared my notes with the participants to ensure I had all of their thoughts written down. The first participant shared thoughts to revise the themes although felt that the taxonomy reflected her perceptions of nursing support. Revisions were made to the themes upon

reflection of the first validation interview and a new summary of findings was shared with the second participant. During this interview, the participant felt that no revisions needed to be made to the taxonomy or themes and added a few thoughts to elaborate on each of the themes. Since no revisions were needed following the second validation interview, no further validation interviews were required.

Rigour

The overall goal of rigour in a qualitative research study is to accurately represent the informants' ideas and experiences (Streubert Speziale & Rinaldi Carpenter, 2003). Rigour in qualitative research involves a number of things and there is not one set of criteria that will "fit the bill" for every qualitative research study (Streubert Speziale & Rinaldi Carpenter). A variety of terms have been used to describe the processes but the most commonly used are those identified by Lincoln and Guba (1985): credibility, dependability, confirmability, and transferability (as cited in Streubert Speziale, & Rinaldi Carpenter, 2003). This section includes a description of methods used to enhance the rigour of this research study.

Credibility

Credibility involves activities that increase the probability that findings are believable. One of the best ways to enhance credibility is through prolonged engagement during data collection (Streubert Speziale & Rinaldi Carpenter, 2003) and since three rounds of interviews were completed, I had more than one opportunity to receive data from the participants.

Member checking is a process used to confirm the findings with the participants to ensure that they note the findings to be valid from their experiences (Beck & Polit, 2006; Loiselle & Profetto-McGrath, 2007). As the method of ethnoscience involves three interviews with the same participants, the process of member checking was also used throughout this research study in order to increase the credibility of the analysis (Beck & Polit). In addition, two validation interviews were completed in order to confirm the findings with the informants.

In qualitative research, it is also important to acknowledge preconceived beliefs or values prior to data collection and analysis to prevent them from impacting the interpretations or credibility of the researcher. In this study I had a preconceived understanding of what support was. My understandings were developed through my experiences in working with families caring for a child with cystic fibrosis and included interactions during hospitalizations on an acute adolescent medical unit in Manitoba. I was also recently involved in working closely with the Clinical Resource Nurse in the large urban hospital during a graduate clinical placement through a large urban University. Part of my role as a graduate student during this clinical rotation was to observe and participate in the care of families of children with cystic fibrosis and to reflect on the role of the advanced practice nurse, which included supportive nursing behaviors. Therefore I documented my personal beliefs and ideas in a journal throughout the research process and attempted to keep my own beliefs as much out of the analysis as possible.

Dependability

Dependability relates to the findings remaining true over time and can be enhanced through triangulation of method. Although I did not use method triangulation, I did incorporate data triangulation (transcripts and card sort) which may enhance the dependability since the data were provided in two forms which were analyzed simultaneously to enhance the findings. Although I was the sole researcher in the data collection, I used external checks such as peer debriefing by requesting a review from appropriate committee members at various stages of the data analysis to ensure I was clear in my analysis (Beck & Polit, 2006; Loiselle & Profetto-McGrath, 2007).

Confirmability

In order to address confirmability, I have been transparent when reporting the analysis and decisions made and created an audit and decision trail (Roberts et al., 2006). An audit trail incorporates a variety of documentation forms that demonstrates how the researcher came to conclusions about the data as well as decisions that were made (Loiselle & Profetto-McGrath, 2007). I used memos and notes throughout the study to provide a trail of the data collection and analysis of data and occasionally included my personal reflections following the interviews as well as explicit evidence to demonstrate the links that I made between the raw data and the analytic categories.

I also adhered to the assumptions and approaches of ethnoscience throughout the research process by allowing the informants to guide the interviews and by asking questions based on previous responses of the informants. I let the data guide my analysis, I was open to unexpected findings and I followed through with them. I was continually

collecting and analyzing the data, while continuing to acknowledge and limit (bracket) my own personal biases during this process.

Transferability

The transferability of the findings is identified by the reader of the research report and is affected by factors such as the sample that was used in the research study. It is important to note that all of the participants in this study were mothers, and therefore the findings may not relate to fathers' descriptions of nursing support.

In summary, many measures were used in the data collection and analysis of the research to enhance the trustworthiness of the study such as member checking, peer debriefing, and prolonged engagement. As generalizability is not the focus of qualitative research, further research is needed to validate the findings of this study.

Ethical Issues

Ethics approval was granted from the university's ethics board. I upheld the standards and policies held by both the Tri-Council Policy Statement (Government of Canada, 2005) and the university's policy on Ethics Review of Research Involving Human Subjects. The study was described in detail to the informants, who gave informed consent (see Appendix A). Prior to the first interview, I reviewed information about the study, the nature of the participants' involvement, and their time commitment. The informant's signature was obtained on a consent form. I also informed each of the participants that they had the right to withdraw from the study during the interview process; in fact, one participant withdrew following the round 1 interview and another participant withdrew

following the round 2 interview. The informants had the option to end the interview at any time and also had the right to choose not to answer any questions.

Privacy and confidentiality of data were maintained to the fullest extent possible; anonymity is impossible in an interview process as the interviews are personal one-to-one interactions where the researcher will inevitably know the source of the data (Streubert & Speziale, Rinaldi Carpenter, 2003). Actual names and initials were not used in the transcripts, my personal memos or in the reporting of the data. A number was assigned to identify each participant's data. As this is a small community, characteristics of the informants, for example, age and family structure, have not been included to safeguard participants' identities. Audiotapes, transcripts and memos were secured in a locked filing cabinet when not in the researcher's possession. Informed consents were kept separate from the transcripts in a locked cabinet. Transcripts were saved on a flash drive and were kept in the locked filing cabinet when not in use. The tapes will be kept for five years and then destroyed.

Participant burden was a potential concern in the study as the participants were involved in at least two rounds of data collection. I was conscious of this and tried to focus the discussion in the interviews and was able to keep them at a maximum length of an hour and a half. There were no costs or compensations for the participants to be a part of the study.

CHAPTER IV

Findings

The product of data analysis is a taxonomy and themes as described in Chapter 3. The taxonomy was validated during Round 3 interviews with two participants, and a description of each category is included in this section. Although participants began their description of nursing support during round 1 interviews they often expanded on their thoughts and ideas in round 2 so it is difficult to separate the results from round 1 and round 2. In exploring support, it was also important to ask the participants about experiences of non-support. Descriptions of the informants of non-support were used in developing the taxonomy to aid in identifying the description of nursing support. What follows is a description of the taxonomy of nursing support and then a summary of the themes that arose from the participants' descriptions of nursing support.

Nursing Support

At the beginning of the interviews, participants spoke about the difficulty they had in defining nursing support. One participant stated "that's a tough one, because it is, it's just there. It's nothing specific" (A.6.272). However, when asked to describe situations in which a nurse had been supportive, participants were able to give concrete examples of supportive behaviors.

The informants described four categories in relation to professional nursing support: (1) *tools or skills*, (2) *functions or tasks*, (3) *human characteristics*, and (4) *nice- to-haves* and identified specific roles, behaviors, or characteristics that were relevant to each

category. The taxonomy of participants' description of nursing support in caring for a child

with Cystic Fibrosis is presented in Table 2.

Table 2. Taxonomy of a description of nursing support in caring for a child with

Cystic Fibrosis

Tools or Skills	Functions or Tasks	Human Characteristics	Nice to Haves
Knowledgeable	Acts as a facilitator	Listens	Warm
Knows exactly what to do	Oversees the care	Understands who the family is	Sensitive
Confident	Works together with families	Adaptable	Easy to Approach
Prepared	Helps me achieve my goals	Honest	Goes beyond
Qualified	Available/Accessible	Caring	Goes the extra mile
	Prompt	Compassionate	Wants to help
	Responds to calls	Trusting	Sympathetic
	Provides clarity	Reliable	Providing a sense of knowing you've been heard to families
	Provides information	Positive attitude	Steps into the patient's shoes
	Facilitates support groups	Understands that the child matters	
	Puts everything together	Understanding	
	Provides reassurance	Provides individualized care	
	Provides follow-up	Respectful	

Tools or Skills

The category of *tools or skills* was identified by each participant when describing

nursing support. Some informants mentioned that it was difficult for them to describe these

attributes appropriately as they themselves are not nurses and therefore do not have a full

understanding of the professional role of nurses. In working with nurses regularly in caring for their child with CF, informants articulated that there are certain fundamental *tools or skills* that are important in supporting families which include qualities or characteristics that are related to nursing training and education.

> Knowledge, knowing what to do, confident, able to give an explanation, providing reassurance, facilitator, clarity that comes with tools of the trade. Trade being nursing. Okay, so that takes out personality and everything else, these are things to do the job, kind of tools to do the job and it's not personal. (B.1.478)

The most essential *tool or skill* that informants believed was a factor in providing nursing support was *knowledge*.

> I think the most important thing to me is um, that you're knowledgeable. I would hope that you would have the knowledge to do the job, that's the most important thing to me and that you're qualified. (B.3.155)

The term *knowledge* was used by all informants in describing nursing support, although there were conflicting ideas on the importance of knowledge, the definition of knowledge, and the characteristics of being *knowledgeable*. When asked to describe what *knowledge* meant in relation to nursing support, most participants stated that specific *knowledge* about the disease process of cystic fibrosis, although others felt that general *knowledge* was sufficient as they themselves had the specific *knowledge*.

> Well I think first, just knowledge about CF because I think there's a basic you know, nurse knowledge right, but there's specific things about CF that um, you

know I think uh, yeah are required um, so definitely knowledge about the disease. (A.2.282)

Most participants described how the level of *knowledge* that they required the nurse to have changed over time as their own comfort level of their child's condition evolved. Some informants did not articulate this change in the nurse's knowledge level. These parents were noted to have younger children therefore were still building their own confidence level and had expectations that the nurse would be the expert in the care of their child. Many informants had never heard of CF prior to diagnosis therefore they needed the nurse to be the expert on the disease at that time. As years went by and they became more familiar with the condition and their child's response to treatments, they themselves became the expert. The role of the nurse became 'supporting the parents in their *knowledge*' accomplished through encouragement of parents to share their expertise, positive reinforcement for acting or responding appropriately as well as sharing information regarding appropriate resources. When asked if *knowledge* was important, one participant stated:

> It probably would have applied at the very beginning but um, as time goes by I realize that I'm the one that has most of the knowledge and I'm looking to them to help me um, support me in my knowledge and direct me on what's available to meet that. (B.5.42)

This expertise can also be developed by the child; one parent described how her child has even become familiar with his needs over time:

[when speaking about the term 'knowledgeable'] It differs as he grows. So, right now, it's not a concern for me...as long as they know what he needs, then it doesn't matter to me how much you really know about it or don't...um, because of his age, but I wouldn't have answered that the same way 10 years ago. I would say that that's a very important thing when he's young and when he doesn't know what he needs. (A.5.568)

The term *knows exactly what to do* was used by informants to describe behaviors that are displayed based on the nurse's knowledge, confidence and experience. This is believed to be more than just being *knowledgeable* as the nurse needs to act appropriately based on his/her knowledge and experience, demonstrating confidence in his/her actions. The informants described how some nurses have a comfort level with their role that has developed from knowledge of CF, and experiences in working with children and their families. As two participants described the process "I think knowing what your job is to do, then you gain these skills of knowledge, qualifications, confidence and how to be prepared and then you know exactly what to do" (B.3.186). "She's got so much experience that um, yeah, she's, she's probably dealt with every sort of possible difference, that, yeah, she just, you know, she knows exactly what to do" (A.2.496).

A similar term that is linked to *knows exactly what to do* is confidence, as one participant stated "with knowledge comes confidence" (B.4.351). Informants believed that confidence was important for support to occur. Often, in times of acute exacerbations, children needed a change in treatment and when a nurse was confident in his/her role, parents were able to feel more at ease. "And being very confident of what they're doing.

Confidence level. Okay? Um, because then I know that she's in good hands. It makes me feel better" (A.1.397).

Preparation was another term used in the professional category of nursing support. Being *prepared* meant having information ready for parents which requires thought, planning and insight into understanding the unique needs of the family as well as intricate information about the disease process. Following preparation, the nurse was able to take the 'lead' and shared appropriate information with the family.

> She was at the lead a bit, she was the one coming in explaining, she's the one that's organizing um, you know specialists, you know, she's the one yeah, she's the one putting everything together so that you don't, you don't have to say, you didn't have to say, I didn't have to say like explain this to me. She was there ready like, with, with literature, with you know, like just prepared. (A.2.526)

Being knowledgeable was also linked to the term *qualified.* Informants explained that knowledge and qualifications are built through nursing education. Although they did not directly speak to the qualifications that are required of the nurse, they stated that qualifications came with training and experience. "Qualifications and knowledge I think fit into one category. To me that's like core skills to do the job, right?" (B.3.90).

One informant described how she would prefer for the nurse to have experience in performing certain skills rather than 'practicing' on her child. "So, the qualifications too, you know? Like if this is your first or second time, you know, I know you have to learn how to do it, but you know, not on mine" (A.5.451).

Overall, the *tools or skills* of the nurse provide the foundation for nursing support. They are obtained through education and training including the possibility of specialized education or training about CF. Although it is not an expectation of all nurses in all areas to be confident in their knowledge and skills related to CF, it is important for nurses who are more apt to come into contact with this population to have some confidence in their skills and abilities in this area.

Functions or Tasks

The category *functions or tasks* includes a variety of behaviors that informants felt supported their family in the day to day care of their child with CF. Descriptions in this category included *functions or tasks* of all nurses however most of the description involved the nurse in the CF team since this is the nurse with whom families have the most experience. The nurse in the CF clinic has a vital role in working with families as he or she is often the primary contact for the entire health care team. Many families described how the nurse is the one whom they phone first with any questions or concerns and then they believed it is the nurse's role to *oversee the care* or *act as a facilitator* to help them access appropriate resources.

> I think oversees the care, that's a core function, that's what you're there to do and responds to calls, that's what you're there to do and provide follow up. Those are, I think those are different because those, I expect those, those should be already there...those are the things that you're taught in your nursing studies. (B.3.171-176)

The role of *acting as a facilitator* was described as using information from the family in order to access resources for families. One informant stated "So as far as the

support system, [the nurse] is the one who takes all of what you have and facilitates that amongst whose there making the decisions and gets you what you want" (A.6.201). *Acting as a facilitator* also meant using one's 'access' to help families receive the best care and treatments for their child. Therefore, the nurse must be informed of the resources in order to act as that 'in between' person. One informant stated "she's the person who is that mother board with the connections to everyone else" (A.6.734).

Informants explained that they 'lean on' the nurse to facilitate resources for them as they themselves do not have access. This is conveyed in the following statement:

They're just a part of your family, they're a part of your CF family and uh, they're kind of the matriarch of it because as much as you can do things, you don't have medications, you don't have access, so you need that in between person. (A.6.463)

Many informants described how it is important for the nurse to provide individualized care and "come together" (A.6.436) with each family to figure out an appropriate plan. Informants believed that when the nurse acts as 'the expert' it is condescending to the parents and therefore difficult to establish a healthy working relationship. One informant described an interaction she had with a nurse when her child was having difficulty eating:

But they [the nurses] were very um, condescending in regards to, you know the mother, who, if I was feeling very insecure and inadequate, you did nothing to help me feel any better about that, you know, as opposed to saying oh, give him to me and I'll get him to eat, you know, why don't we come together and see if we can get him to eat. (A.6.431)

There were conflicting ideas about the phrase *helps me achieve my goals* as some informants did not see anything related to their child (or child's condition) as a 'goal' to be attained. Many informants discussed the nurse's role in receiving the best care for their child. For example:

> When I show up, I feel safe when I see [nurse], [nurse] is going to do what I want, she's going to help me achieve my goals every clinic, you know? She's going to do it in her own way, but she's going to, she understands my needs and she's going to help me facilitate, she's going to you know, get it done. (A.6.323)

The terms *accessible* and *available* were discussed by informants in three different contexts. The first applied to the set-up of the CF health care team as it was not assumed that every health care setting would have a similar organization of the health care team in caring for children with CF. Since informants were appreciative of this structure, they discussed the outcome of the nurse's *availability* and *accessibility* as supportive care. "Available, accessible...the nurses do the best they can, but they've got regulations that come way above them to do their job" (B.1.521).

Availability and *accessibility* was also described as a *function* in providing support. When asked about the importance of accessibility, one informant said it was 'huge' (A.3.234). One informant believed that it was the most important *function* of the nurse:

> Would say accessibility. I would, I would. For me to have a question answered, know that an antibiotic's been called in, to know that a doctor's been spoken to, you know to find out some information .That to me is going to be number one. (A.3.285)

Following diagnosis, families described how the *availability* and *accessibility* of the nurse were vital in order to answer their questions about the treatments or condition of their child.

> Initially just getting an understanding of what that meant, what the day to day care means and so um, you know really feeling like they were accessible, that questions were being answered. (A.3.159)

During the validation stage of the interviews, the participants felt that *availability* and *accessibility* fit in the *functions* or *tasks* category, however it was also described during a round 2 interview as linked to the *human characteristic* of being *easy to approach* as the third context.

Families described how they have a contact number where they can phone the nurse and know that during the nurse's office hours, their call would be returned as soon as possible with an answer or possible solution to their concern. "Everybody that I've always called has always returned my calls if I couldn't get ahold of them, they reply to my emails" (A.4.109).

Expectations of the phone call varied from informant to informant. One described how it was important just to know that the message had been received and that action was being taken.

> Well I often find it's the quick replies...it's the quick reply and it's not always with an answer, like it might be a quick reply to say got your message, want to get a bit more information from you and then I'm going to get back to you again. So

knowing that you've been heard...someone's got your message that they're on it, that they're going to get back to you before it's Saturday. (A.3.303)

When describing the nurse's *availability* and *accessibility*, the term *prompt* or *quick* was used. Some informants believed that not only was it important to get a call back, the timeliness of the reply was as important. Often, families were phoning the nurse about concerns with their child's health status and therefore they had a sense of urgency in receiving a call back.

What it primarily means is that someone's always there to answer a question. To, if I need you know, an antibiotic, I need an answer to something, you know, that I feel like I can ask that someone really quickly that I'm not waiting for a call back. (A.3.66)

Returning phone calls in a prompt manner helped parents feel that they 'matter' to someone and that their family is important.

It's just reassuring to know that you're not put on the side table until late in the afternoon when they get around to returning calls or whatever. That she is quite prompt at that, so it just makes you feel important you know, that your child's health matters to somebody. (A.4.207)

Communication is a vital function or role of the nurse in offering support to families. Communication skills are often used in *providing information* and in order for information to be considered supportive, it must be given in a way that is clear and informative. "I also think it's the nurse's job to give a full explanation so that the person

understands the parents or the patient understands what's happening or what's going to

happen" (B.3.182-184).

An informant described how the act of simplifying *information*, when describing

the child's condition, is supportive. One informant believed it was a conscious decision for

the nurse to direct the information to her family in a clear and concise tone and

acknowledged this as a supportive behavior.

> Her questions are so thorough and they're also, they're simple, right? She talks in a
>
> language that is, you know, if she wanted to, she could talk with the doctors, right?
>
> But she can also talk to, to the rest, you know, with obviously no medical
>
> background and make you or make it so that you understand, um, yeah, she's just,
>
> she's very thorough. (A.2.488)
>
> Sometimes when new things happen to a patient, we don't always know what
>
> questions to ask, um, for example [child] had a bronchoscopy in May and it came
>
> up with bacteria and fungus and I didn't even know what to ask, what fungus, what
>
> bacteria...I was just thinking whoa, fungus, bacteria and I kind of left that I didn't
>
> feel that the information was handed over like it should have been. This is what,
>
> exactly what she has, this is how serious it is, this is how you treat it. I ended up
>
> having to ask later on after some other people told me to ask and I didn't feel that
>
> the information side of it was really there. (B.4.49)

Participants believed that *information* needs to be factual, clear, accurate and

thorough so that the parents can get a clear picture of what is happening as well as what is

going to be happening. A few informants even described experiences when they knew that

a nurse did not know the answer to a question. The action of 'pretending to know' was seen as unsupportive and it would be preferred for the nurse to say he/she does not know rather than act as knowledgeable.

There were conflicting ideas from informants around the need for support groups. Some informants believed that a *function or task* of the nurse is to *facilitate support groups* in order to assist families in building connections with other families so that they don't feel alone.

> Then you can just see, you know what, there are other people that are going through this and this is how they deal with it. And sometimes it's little questions that the nurses can't answer, it's maybe more of a child care issue that you're wondering is this CF or is this normal? (B.4.191)

Other participants felt that support groups were not helpful in providing information or support to their families as they already felt that they had support from peers. The context of social support, meaning support from peers or other families with a child with CF, has changed in the last decade in relation to children with CF. There are now further concerns with the spread of bacteria when children with CF are near one another. This impacted a change in the set up of the CF clinics so that families do not mingle in a waiting room; there is now very little interaction with other families. One informant described how she almost avoids other children or families with CF because of her fear:

> Because you don't share with other families, I don't think a lot of people do, it's not that we don't...because you can't, because of the berkholderia cepacia, you don't, you no longer can have the group things with CF kids, right? So you don't come

across other parents and even when you do, you just kind of want to just stay away

cause you both have your kid with you. (A.6.509)

Human Characteristics

Several informants described the category of *human characteristics* as an important

component of nursing support. Within this category were nurse qualities that were

described as fundamental. Informants explained that nurses who work in the field of

pediatric nursing seem to portray numerous supportive qualities or characteristics. One

informant stated, "I don't know what it is with the CF nurses, they just seem to all have

this, this warmth that they truly need to have, yeah, it's phenomenal" (A.6.226).

The informants believed that these qualities or characteristics cannot be taught as

they are either inherent or lacking in the individual. One informant stated, "That's

something that I don't think is learned, these are things that are, that a person already has

developed" (B.4.94). Another said, "It's not something again that I think you can teach

people to be…this is either who you are as a person before you take nursing or you're not"

(A.5.118).

The patient's or family's perception was vital in determining whether someone has

these *characteristics*. For example, a nurse might believe that he/she is *listening*, however

unless the parent perceives the nurse to be listening, then it isn't supportive in nature. One

informant stated, "This becomes the individual as somebody perceives them to be"

(B.1.486); meaning one displays these characteristics in his/her actions.

Several informants described *listening* as the most important component of the

category *human characteristics* category. This is exemplified in the following statement: "I

don't know that you could learn these out of a textbook, I think these things come with the personality of the nurse...the most important thing to me is to listen" (B.3.240).

The organization of the health care team in providing care to children with cystic fibrosis and their families involves a lot of interaction over the telephone. Families often contacted the nurse with questions related to their child's status and the nurse would *listen* to their needs in order to help them manage the treatment regimen. Several informants described how the act of *listening* is different for the purpose of providing support as the nurse is *listening* to cues from the parent to understand the level of control or assistance that is required. Being "attentive" (A.5.575) allows the nurse to understand the family and its current needs.

Informants believed that the act of *listening* also allows someone to be attentive to *understanding who the family is* in order to provide individualized care or support to the family. The phrase *understanding who the family is* was also linked to the notion of 'being familiar with the family' in order to provide individualized care. These phrases are included in the *human characteristics* category because the ability to listen and respond with individualized care was described as part of who you are as a human. One participant talked about how providing individualized care is "an expectation" (B.2.258). Other participants stated that the *human characteristics* or personality of an individual enhanced the nurse's ability to *understanding who the family is*; which in turn effects the level of nursing support that is provided.

Because with CF and maybe other chronic illnesses, every individual is just a little bit unique...so they all got to be tweaked just a little bit different. So what works for

one doesn't necessarily work for another. So, there's that understanding from doctors and families that yes, so that listening and communicating is really important. (A.1.164)

Many informants believed that the concept of *understanding who the family is* was vital to the role of the nurse in the CF clinic. Many informants described the differences in family dynamics, family values and even the child's health status; therefore in order for the nurse to fully 'support' families, the nurse must take actions to address the need for individualized care.

Another *human characteristic* that is valued by families is *adaptability* which relates closely to the nurse's ability to *listen* and *provide individualized care*. Informants explained how the needs of families can vary from day to day or even hour based on the condition of their child therefore it is important for the nurse to be flexible. One informant stated that adaptability is "a real skill where you can adapt your interactions with people based on their personalities and their needs" (A.6.578).

So I think the next most important thing is being adaptable, that's because there may be times where, um, if I'm talking to a nurse or I need help, I don't want to know anything, I just, I just, can we just get some antibiotics and I'm good with that. But then sometimes like I need a shoulder, I need somebody to listen to me and like I'm having a really hard time with this, if you could just hear me out for a second and um, just listen because I just need you to listen. (B.3.263)

Another significant aspect of a person's qualities or characteristics is their ability or willingness to be *honest*. The informants believed that it was important to provide information in an *honest* way so that families are fully aware of the situation.

> If [child] took a big turn for the worse, I would need somebody's shoulder to lean on...because I would be looking for a complete understanding, complete honesty of what might be going on .(A.1.573)

The term *caring* was used by all of the informants to describe the nurse in providing support; however not a lot of detail was given as to what caring looked like to them. The closest that the informants came to describing *caring* was that it 'provided a sense of comfort' (A.1.220). Since the participants were more focused on the tasks or actions of the nurse in providing support, caring was not at the center of their discussion.

The term *compassion* was also identified within the *human characteristics* category of nursing support. One informant described how *compassion* can be achieved by performing a skill/task competently:

> Knowing that I'm having a tough time dealing with it, so if you can make it as easy as possible for me and not put my child in pain, like try and get a nurse that will get the IV the first time because I can't stand watching my kid screaming. (A.5.426)

Having a positive attitude appeared to enhance the nurse's ability to provide support. Informants discussed how some of the information that nurses need to share with the families about their child's health status is not always pleasant, but an optimistic approach helped participants to feel more supported in making difficult decisions or dealing with difficult circumstances.

It was his [the nurse] attitude and...he was really interested to know, was she going to spend another 3 or 4 days in there or was she going to be in there another week? How it made her feel because that attention was very positive to her. And that attention made her put up with that GI tube that she detested. It made her want to for him, be a real trooper, because he was counting on it, without him really saying it. Yeah, so his positive bubbly attitude reflected on her to do what she needed to do and be positive about it. (A.1.312)

Informants believed that *understanding the child matters* is important when providing support to families; one informant even described it as a "given" (B.2.220). It was described as understanding that the focus or attention needs to be on the child. When the nurse focused his/her time, and effort on the child, the parent felt supported.

Although there was not a lot of description of the term *trust* by the informants, it seemed to be embedded in the nurse/family relationship. One informant discussed how trust is earned based on "how you conduct yourself" (B.3.127). It is earned over time and is affected by a person's *human characteristics* or qualities.

Nice to Haves

The category *nice to haves* evolved as informants described characteristics that were not vital to providing nursing support; but when they are present, the level of support is enhanced. One informant described that this category was a bit broader than the category of *human characteristics* "This is kind of that part of the personal, but it's more maybe broader, how can I say it, just that little extra above and beyond....yeah, this is just a little bit more broader than this [speaking about human characteristics]"(B.1.585).

Another informant described this category as the 'warm and fuzzy' category compared to the *human characteristics* category that includes earned characteristics:

> What I see here are some categories that are like warm and fuzzy, so we have compassion, we have sympathy, we have sensitivity, we want to help, we're warm, understanding, easy to approach and we're caring. And I think these are really, really nice to have, but I think some of these other things like trust, respect, honesty, reliability, rapport, those are earned. (B.3.286-290)

One informant described how the *nice to haves* made the experience of receiving support a little more pleasurable or enjoyable, but they don't necessarily effect the level of support that's received.

> I think what we have here is um, emotional, fluffy, hug, warm fuzzy stuff here...yeah, those are sort of extras....those are nice to haves. If you have them, that's, those are excellent qualities to have in a nurse, but it doesn't always get the job done. (B.3.309-314)

The phrase *stepping into the patient's shoes* was used by some informants during the first round of interviews when describing nursing support.

> I think stepping into that patient's shoes at that patient's age level...try to think of what it would have been like if you could go back in your time and at the age of 6, 10, 16. How did you feel? How would you feel? I think then and only then you kind of get maybe an appreciation of what it must be like. (A.1.208)

When the second round of interviews was conducted, many informants described the potential difficulty performing this skill so many informants changed their minds on the importance of this behavior.

I think stepping into the patient's shoes, I don't know if you can do that, I mean,

you can be sympathetic and caring and compassionate, but boy, do we really

know...I don't think we really have any idea what that person is going through or

thinking and I think sometimes we think we might, but we really don't. (B.3.251)

The categories of *nursing support* were acknowledged and verified by the informants. The concept of nursing support includes a foundation provided by nursing education, *tools or skills*, qualities, or *human characteristics* that are unique to each individual. There are also *functions or tasks* that a nurse performs and there are extras, or *nice to haves*. Support can still exist without all of these characteristics or factors, but it will not be optimal or ideal.

Themes

The final section in the description of the findings, according to Spradley (1979) can include identification of major themes, although themes are not a necessary step in the ethnoscience research method. In describing the nature of support participants were describing a process. Their narrative descriptions could not be reduced to just simple terms, but instead implied a series of connected actions. The process is represented in three themes: (1) *building the relationship*, (2) *development of a partnership*, and (3) *the use of control/power as a tool* which evolved over time and changed as families became more experienced. The taxonomy and themes are interrelated as the taxonomy provides a

foundation or definition of nursing support and the themes include a description of the process of receiving support as perceived by the informants.

Building the Relationship

Informants described experiences where they had received support from a nurse and *building the relationship* was inherent in these descriptions. In describing their experiences of support, informants emphasized the importance of feeling valued. This involved a process that began with the nurse taking the time to learn about the family through attentive listening and openness. In turn the nurse must apply this information when caring for the child and/or family and adapt his or her personality to meet the needs of the family. Many words were used to describe this relationship that developed between the nurse and families; some called it 'developing a rapport', others described it as a 'friendship'. Characteristics that were used to describe the relationship included trust, respect and honesty.

Although families interacted with the entire health care team on a regular basis, including clinic visits, many informants described how the relationship that they develop with the nurse is 'different' from that of the other health care team members. One informant stated, "It's definitely closer. Um, moreso probably because there's more communication...so, that certainly helps develop um, a stronger relationship" (A.2.204). The informants described a need to connect or have a positive working relationship with the nurse in order for optimal support to occur. One informant described the importance of developing a connection or relationship with the nurse in order to make things 'easier'.

That's an amazing talent for people to have and to be able to do that and to be able to establish that relationship because like I said that, that then opens the door to getting everything else you want, whether it's trust or knowledge, so [nurse] is kind of that relationship guru where she knows if she can establish a bond and a relationship, her job's going to be much easier because people are going to look at her as a friend and not somebody they need to battle to get what they want, cause she's very good at, you know, setting that up with each one. So, the relationship is the, I don't know, to me it would be the priority and once that's established, everything becomes easier and more important. (A.6.789-798)

Development of a Partnership

Throughout the process of providing support to families of children with cystic fibrosis, a relationship between the nurse in the CF clinic and a family developed which could be considered a *partnership*. All informants described a unique relationship that developed between the nurse and families that is grounded from the regular and consistent interactions. "Well, I mean I think it goes beyond professional, I mean I think that they really understand our family and you know…and then knowing what we went through" (A.3.209).

Some informants described how the continuity or familiarity of nurses within the acute care setting can greatly impact the relationship as well as the support that they receive. When a child is hospitalized with exacerbations or infections related to CF, it can be onerous to describe repeatedly the child's health history as well as family dynamics.

Therefore, many informants described how having a nurse care for their child more than one day in a row allowed them to have some 'familiarity' with the nurse.

> Having familiarity rather than having another nurse again and saying, you know having to tell her what's wrong again and you know over and over again, you get tired of telling the story. (A.5.403)

A *partnership* developed when both parties were willing and able to share knowledge, resources and expertise with each other. This sharing of information is reciprocal and can vary from day to day or even hour to hour depending on the needs of the family. It takes time to develop properly as the process of getting to know the family as well as developing an understanding of the nurse's role is an important factor in developing an optimal *partnership*. All of the informants described the relationship with the nurse in the CF clinic as collaborative in nature, although the characteristics of the *partnership* look different with each family. One similarity of the description of the informants was the description of the *partnership* evolving over time.

Characteristics of the *partnership* included respect, trust, honesty and many of the characteristics that the informants described in the *human characteristics* category. Due to the reciprocal nature of this collaboration, it is important for the parents to have similar qualities and characteristics. What was inherent in the descriptions of the *partnership* between the parents and nurse were the feelings of confidence that the parents had in caring for their child; which could also be considered empowerment.

The Use of Control/Power as a 'Tool'

In order to develop the confidence to care for their child independently, a level of empowerment must be felt on the part of the parent. Feelings of empowerment were described as enhanced through positive reinforcement and encouraging words. Informants described the affirmative statements that were made by nurses and other health care professionals.

Some informants described a comfort level in their knowledge and confidence in their child's treatment regimen and other families still described how they require the nurse to have the confidence and knowledge. This change in comfort level seemed to be based on the amount of time that the informants' child was diagnosed with CF although no specific time frame was related to development of confidence; some families might take months or even years to develop this sense of independence.

Informants with more confidence described how they would try a variety of treatment options when their child became ill before they phoned the CF nurse or took their child to Emergency. One parent described how she now felt comfortable making decisions about her child's treatment without a discussion with the health care team, "I'll always try on my own before I bother them" (A.5.676). Parents often know more about their child than the health care professionals, including their response to treatments; and with this knowledge, comes confidence. One informant stated, "So...with that the whole CF thing, I find that we know more than they do. I know when [child's] sick, I know when something's going on just by his mood..." (A.6.191).

The development of the relationship over time was described by many informants; families began to lean on the nurse less and depended on their own knowledge and insight to care for their child.

It's a process. But it's a process more of knowledge...so if you were to throw that knowledge back in, probably everything would be different. But now I have that knowledge, so it, the whole focus changes. But at the beginning, no I didn't know anything and I was terrified and you, that's where you rely on the nurses to do whatever you want and whatever they say and you don't know. (B.5.92)

Through this process of gaining knowledge, independence and confidence, parents began to 'hand over' control to the nurse less readily and were more direct in their approach in identifying needs.

I think a lot of times in the situation and um, people can allow themselves to be overtaken or controlled or dictated to by the health system, whereas I, I choose to take the other approach, this is my son, this is my family and I will dictate what is best for him. (B.5.74)

The notion that parents use their control or feelings of empowerment as tools suggests that parents are the ones who 'take the reins' in the health of their child. It is understood that parents always have the final control on decision-making for their child's health concerns; however what was intrinsic in the descriptions of the nurse-parent relationship was the idea that a parent may decide when to 'hand over control'. When a parent does this, he or she is often inviting information and resources from the nurse. On the other hand, the same parent may decide that he or she has enough information and

resources to care for his or her child and may decide to independently (or with minimal guidance) make decisions regarding their child's health. It is also important for the nurse to assess the parents to ensure that parents are 'ready' to take back their control. Occasionally, the situation might be too overwhelming for parents. In these cases they might choose to hand control over to the nurse until they are able to feel confident in taking control back.

Nurses must have respect for the parents' confidence, knowledge and expertise in order for the parents to sustain their feelings of empowerment and/or control. One informant described the respect that she received from the nurse regarding the independence she had taken with her child's condition. Another stated, "I don't need them unless there's a problem and I think there's a respect for it" (A.1.589).

It is important to note that this theme emerged from informants who had more years of experience in caring for their child with CF and was not always the final outcome of families caring for a child with CF. Therefore the nurse must continually assess the family for their current needs in order to determine the level of collaboration that is needed by each family.

CHAPTER V

Discussion

This chapter is divided into four sections. The first includes an overview of

literature related to the nursing support in relation to the findings of this study; the second

contains recommendations and implications for nursing research and practice; and the third

includes a critique of the ethnoscientific research method. A summary and conclusion are

provided in the final section.

Discussion of the Findings

Four categories of nursing support within the context of caring for a child with CF

were described: (1) *tools or skills*, (2) *functions or tasks*, (3) *human characteristics* and (4)

nice to haves. In addition, three themes were identified: (1) *building the relationship*, (2)

development of a partnership, and (3) *the use of control/power as a tool*. The purpose of

this section is to discuss and critique these findings as they relate to current literature, and

the four themes of nursing support, offer implications for nursing practice and further

research and critique the method.

Nursing Support

As stated in the literature review, the term nursing support is consistently used in

nursing literature however there is little description of the concept from the perspective of

those receiving care. Findings of this study incorporate a variety of components, so I will

begin by relating the findings to overall descriptions of nursing support.

Stolz, et al. (2007) described two dimensions of support; the first is tangible and

concrete and the second is intangible and abstract. The findings of this study relate to the

second dimension of support as offered by Stolz et al. as the participants in this study described support as highly personal and individual based on the nurse's characteristics as well as the dynamics of their family. Stolz et al.'s definition of support included concepts such as individualization, adaptability and reciprocal symmetrical exchange which is very similar to the findings of this study. The authors also stated that it was a provision of tangibles in order to facilitate carers' competence and/or ability to care which also relates to the description of support from the participants in this study as they felt the role of the nurse was to *act as a facilitator* in order to assist them in caring for their child.

Descriptions of nursing support from the nurses in Grossman-Schultz and Feeley's study included behaviors such as listening, being available, acknowledging feelings and needs and providing information which were similar to the findings of this study. It is important to note that when support was explored through the nurse's perspective, the nurses' definitions of support were very different than the supportive actions that were observed (Grossman-Schultz & Feeley, 1984). Since the participants in the current study described nursing support through the lens of being a parent in caring for a child with CF, they were describing experiences where they received supportive care from nurses which may be different from the nurses' perspectives on supportive care.

The Family Support Model and family support program was developed and focuses on the aging population since many families are caring for their chronically ill and aging parents (Boise, Heagerty & Eskenazi, 1996). The authors stated that the ultimate goal of this model was to "build competency and self-reliance in families and patients so that they can effectively manage their own health and any illnesses that happen their way" (p.77).

This is similar to the findings of this study as the description of nursing support included the nurse's role as facilitator and overseeing the care while empowering the family to make decisions with guidance from the health care professionals. Boise et al. identified key support needs of families that are similar to the findings of this study, including: information, skills, respite and consistent or available support.

Support of Families

The concept of supporting parents of children with complex health care needs has previously been explored by Kirk and Glendinning (2002). They included a description of the difference in working with these parents as they, not the nurses, are the experts. Many findings emerging from Kirk and Glendinning's research matched findings of this study, such as valuing the expertise of parents. Kirk and Glendinning also explained that continuity enhanced the development of a supportive respectful relationship with professionals. Although the informants in the current study did not specifically use the term 'continuity', many described how it was helpful to have the same nurse so that they did not have to 're-tell' their story.

Kirk and Glendinning's (2002) overall description of support included three dimensions: emotional support, instrumental or practical help, and information. The theme of emotional support included concepts similar to those in the *human characteristics* category in this study, such as being familiar with the child and family, being approachable which enhanced the families' feelings of knowing 'someone was there for them', and *accessibility* or having the professional there when 'they needed it'. Other similar findings

were having someone that families could talk to about their fears and anxieties and promoting the self-confidence of parents.

Kirk and Glendinning (2002) described the theme of providing practical support as including the role of acting as an advocate for families, hands-on care and organizing services and equipment. Hands-on care was not directly described by the informants of the current study as it tends to occur within in the hospital setting and the majority of the descriptions of nursing support were related to the nurse in the CF clinic.

The final category identified by Kirk and Glendinning (2002), providing information, included similar roles and behaviors included in the category *functions or tasks* of the nurse. The authors described how providing information to parents helped enhance feelings of autonomy and control which are similar to the views of participants in the current study.

Many participants in Kirk and Glendinning's (2002) study indicated that obtaining information was an area of concern for them as they had to ask for information or it was insufficient or conflicting rather than having it readily provided. Informants in the current study discussed similar concerns related to clarity of information and *preparation* of the nurse. Kirk and Glendinning also stated that providing positive feedback or reassurance to families was important in order to recognize their knowledge and expertise and although these were not specifically stated by the informants in this study; it was evident that they valued receiving reassurance.

Tools or Skills

The category *tools or skills* was described by informants to the best of their ability as they did not feel they had a full understanding of the professional role of the nurse. They articulated that there are certain *tools or skills* that are important in 'supporting' families; more specifically related to nursing training and education.

The focus of the literature on nursing support included more discussion about the functions or roles of the nurse rather than the skills or abilities that a nurse gains in his or her education. When working with a child with a chronic illness, nurses must understand that parents develop formal knowledge as well as in-depth knowledge about their child and with that they are also able to assess the professionals' knowledge or comfort level (Kirk, 2001). Therefore it is vital for nurses to demonstrate competence, confidence, and preparation when caring for children with CF as it will largely affect the level of support that parents receive.

Functions or Tasks

One of the key *functions or tasks* of the nurse identified in this study was to provide thorough and clear information. This is echoed in numerous studies related to working with families of chronically ill children (Balling & McCubbin, 2001; Coyne, 1997; Fisher, 2001; Kirk & Glendinning, 2002; Nuutila & Salantera, 2006). Fisher (2001) described how parents gained knowledge and information as a way to increase feelings of empowerment and control of their situation in order to act within a partnership with health care professionals which is consistent with the informants in the current study. She also found in her literature review that parents are not generally satisfied with the information they

receive, which was unlike the informants in this study. Diehl, Moffit and Wade (1991) (as cited in Fisher) stated that parents would rather health care professionals admit that they do not know the answer rather than avoid their question which was also articulated by the informants in the current study.

The notion of the nurse being *available and accessible* was stated in the literature regarding nursing care of families with a chronically ill child (Lindblad, et al., 2005; Nuutila & Salantera, 2006). The *accessibility* of the nurse who was familiar with the family and who offered advice was a subtheme of the theme 'Gaining confidence as a parent' (Lindblad et al.). In order for the family to feel supported and develop confidence, the nurse must be available to provide resources and answer questions in a timely manner.

Coyne (1997) described how nurses need to complete a thorough assessment of the family's current resources and requirements to provide options or referrals based on their individualized needs; including facilitating support groups. However the informants in this study described how not all families may desire a support group; therefore providing a connection between families and their own social system may meet their needs.

Another theme that emerged from Coyne's (1997) literature review included the nurse's role in assisting families to develop an appropriate schedule to manage the treatment regime as well as some family leisure time which would promote the health and well-being of the parents and family. This was not directly stated by the informants of the present study; however one might infer that because the informants had already developed an appropriate schedule, this was not included in their description.

Human Characteristics

The informants of this study described the category of *human characteristics* as qualities of the nurse that enhanced the level of support but they recognized that these characteristics are innate in an individual and cannot be taught in nursing education. There was little literature that spoke specifically to the 'nature' of the nurse and how it impacted the care that families receive; however there were underlying discussions about the importance of certain qualities in enhancing nursing care.

One of the most important *human characteristics* was the skill of *listening*; which involved listening for the purpose of understanding who the family is in order to provide individualized care as well as to assess the level of control or assistance that is required. The act of listening was described in other literature regarding caring for children with chronic conditions (Lindblad et al., 2005; Nuutila & Salantera, 2006). Lindblad et al. found that the act of listening, responding without question, taking parents' assessments and ideas into consideration was important in providing support. They stated that the act of listening also acknowledged the carers and showed that they are being taken seriously.

Lindblad, et al. (2005) described parents' experiences of support by professionals which relieved burden and uncertainty in caring for their disabled child. Their findings indicated that parents need to be acknowledged as unique human beings with wants and dreams which related to the category of *human characteristics* in the present study. Some informants in the current study described how 'nice' it felt to have a conversation with the nurse about things other than their child's condition.

Lindblad et al. (2005) described the nurse's characteristic of placing value on the child and belief that the children are worthy of help which is the same as the phrase *understands that the child matters* as used by the informants in the present study. The authors continued to explain how acknowledging a child as having hope for the future and as worthy of assistance enhances the level of support received. Further to this, the concept of *understanding who the family is* expanded on the same idea of placing value on the unique characteristics of each and every family. Nuutila & Salantera (2006) articulated the importance of *understanding who the family is* and how the parents' participation in care was impacted by a lack of continuity and attitudes of the nurses. Their findings concurred with the findings of this study when it was described how the attitude of the nurse impacted the development of respect and trust in the nurse-family relationship.

It was noted that the *human characteristics* category of nursing support has not been identified specifically in previous literature however it is intrinsic in the descriptions of supportive nursing care. Focused attention might be required in future research to explore the qualities or characteristics of the nurse that are fundamental to supportive care.

Nice to Haves

The category *nice to haves* was described by informants as the 'warm and fuzzy' of nursing support. Many described how these characteristics were not required to provide nursing support, however the presence of these qualities enhanced the level of support received. The phrases *goes the extra mile* or *steps into the patient's shoes* were not specifically described in the literature. However, the characteristics of *warm* and *sensitive* were identified by Grossman-Shultz and Feeley (1984) when they described that supportive

interaction would not occur without a sense of warmth and genuineness. One might infer that although these terms were not directly identified in the literature, they are inherent in the descriptions of nursing support through the concepts of trust, mutual respect and caring.

Building the Relationship

As discussed in the findings section of this study, the process of *building the relationship* between the nurse and parents was foundational to providing nursing support. The responsibility of *building the relationship* began with the nurse taking time to listen to families in order to understand who they are. This was described by Davies and Oberle (1990) as the concept of 'valuing' in their supportive care model. They described two components of valuing: global and particular. Global Valuing involved a respect for the worth of others, while Particular Valuing involved valuing of an individual's particular characteristics or abilities. The importance of being respected and valued in receiving support was inherent in the descriptions of experiences in receiving support in the current study. Therefore, it can be assumed that both levels of 'valuing' were important to participants.

Feelings of being undervalued or incompetent while interacting with nurses within the hospital setting was identified by parents of children with CF (Coyne, 1997). Parents described increased levels of stress as nurses in hospital settings were questioning their competence level. Coyne reinforced the importance of providing positive feedback to parents about the efforts and role in the health of their child. One informant in this study described a feeling of being 'undervalued' or 'incompetent' while her child was admitted to hospital; however the majority of families did not have similar experiences.

Development of a Partnership

The theme of *partnership* is described in the findings of the study as the unique relationship that develops between the nurse in the CF clinic and families with a child diagnosed with CF. A *partnership* develops when both parties are willing and able to share knowledge, resources and expertise with each other and this seemed to be articulated in all of the informants' descriptions of nursing support, although a specific description of the partnership would have been different for each family. The concept of partnership has been explored or identified in numerous studies related to families of children with chronic conditions (Balling & McCubbin, 2001; Fisher, 2001; Lindblad et al., 2005; Nuutila & Salantera, 2006; Sloper, 1999). Fisher (2001) stated that parents had an "overwhelming desire" to be perceived as partners in caring for their child which was closely linked to control and lower levels of uncertainty. Sloper (1999) identified that the professional-parent relationship is central in providing effective care to families of children with disabilities. A *partnership* takes time to develop properly as the process of understanding *who the family is* as well as understanding the nurse's role within the partnership are important in developing an optimal partnership. It was difficult to determine what factors were involved in the development of the *partnership* between the informants and the nurse in the CF clinic however it may be inferred that the *human characteristics* category affected the development of the partnership.

Gallant, Beaulieu and Carnevale (2002) suggested that there are antecedents, attributes and outcomes of partnership. Similar to the findings in this study, they described how certain qualities or characteristics may actually be more favorable in a nurse being

involved in a *partnership*. Valuing the inherent worth of others and a commitment to share responsibility, risk, power and accountability were all important prior to developing a *partnership* (Gallant et al.).

Gallant et al (2002) suggested that *acting as a facilitator* occurred during the initiating phase of a partnership which is similar to the description of the *functions or tasks* category of nursing support in this study. As the *partnership* evolved, Gallant et al. described how the working phase involved a sharing of knowledge between the nurse and client which can be attributed in this study informants' description of their own role and the nurse's role evolving over time.

Similar to the findings of this study, McIntosh and Runciman (2007) stated that although *partnership* is cited frequently as important and being used effectively, there is little detail regarding its development and maintenance. They posed the question "is it sufficient to provide technical expertise and expert advice, or are there important features about the way in which a service is provided that are central to achieving high quality care?" (p.16). In their findings, they identified *partnership* attributes including respect of expertise, trust, negotiation, support and advocacy, to name a few. Parents in the study noted the knowledge, skills and experience that the nurses had in providing care to their child, however they also identified certain communication strategies that stimulated trust, respect and empathy for their child. Respect for parental routine was highly valued and enhanced the mothers' confidence and parents explained that the nurses' role was in the negotiation of services for families (McIntosh & Runciman). They also echoed the informants of this study in describing the length of time that it takes to develop a

partnership. There is a period of learning on the part of the professional: parental routines, knowledge of the child, trust of the family and understanding modes of adult learning such as the description of establishing a 'connection' by Davies and Oberle (1990). There is also the component of continuity that enhances the professionals' ability to provide this high-quality care.

Since the informants in this study included a description of nursing support from all nurses (including the hospital setting) it is important to explore both settings in this discussion. Based on their grounded theory study, Coyne and Cowley (2006) challenged the philosophy of *partnership* in the hospital setting. They indicated that, based on what is currently happening in the acute care setting, it is next to impossible for parents to be considered partners in the care of their child as the responsibility and establishing boundaries of care is the responsibility of the nurses. Mothers in this study described how they felt it was assumed that they would participate in the care of their child and their presence was seen as an indication of unconditional love for their child. It was identified that a key role of the nurse is to complete an accurate assessment of parents' wishes to be involved and confer about the plans for care.

For a *partnership* to be successful all parties involved must be clear about expectations and roles. Although the informants in this study did not speak directly about how to facilitate a *partnership* with a nurse, there is literature that describes how nurses' expectations of parental involvement can act as an obstacle in negotiating roles (Kirk, 2001). Kirk explained how 'negotiation' must occur before a partnership develops as well

as throughout the process of transferring responsibilities between parents and professionals (especially nurses).

One cannot explore the concept of *partnership* or *support* in pediatric nursing care without reviewing concepts related to family centered care as it seems to be a foundational concept (Hughes, 2007 & Hutchfield, 1999). Family-centered care has been explored in the area of acute care but limited research has been done in the area of community health or parents caring for their child in their own home. Family-centered care incorporates an individualized approach to care in which nurses are able to nurture skills and confidence of parents (Coyne, 1997).

Hutchfield (1999) described a hierarchy of family-centered care starting with parental involvement (nurse led) to parental participation (collaborative in nature) to partnership with parents (equal status) and family-centered care (parents are viewed as experts in all aspects of care of their child). Although mothers in the current study did not specifically use the terms *partnership*, 'participation' or 'family-centered' care, they described their active role within the health care team in caring for their child with CF. The informants in this study felt satisfied with the relationship they had with the nurse and the role that they played within this relationship.

Gallant et al. (2002) suggested that the overall outcome of a *partnership* is empowerment. It is important to note that the concept of empowerment may be interpreted differently when working with families who have a chronic illness rather than an acute illness due to confidence level of parents, knowledge and decision-making abilities (Gibson, 1995). Following feelings of 'empowerment', mothers were able to collaborate

with health care professionals, although they did not want to dictate what should be done (Gibson). Gibson expanded to say that it was not important for mothers to have control of the decisions; they just wanted to be heard by health care professionals. In order for the mothers to feel heard, it was also important to understand that the health care professionals needed to be receptive to what they were saying and recognize their expertise. This is similar to the feelings of some informants from this study who felt less confident in their ability to collaborate and required the nurse or other health care professional to provide information or solutions. Although the concept of acknowledging parental expertise did not specifically get discussed in the interviews during this study, it can be assumed that it was an important part of *acting as a facilitator* within the functions or tasks of the nurse category.

Increasing feelings of control for parents is an important component of 'empowerment'. Some families in this study described their confidence in this control, while other families were still building feelings of self-confidence. Coyne (1997) described how incorporating a schedule helped increase feelings of control and many of the informants in this study seemed to have a sense of 'order' or 'routine' in caring for their child. Coyne suggested that nurses need to provide reassurance and positive reinforcement in the contribution that parents are making.

The Use of Control/Power as a 'Tool'

Fisher (2001) also described how parents need control over their child's health management; lack of *control* was identified as a major stressor. She explained how *control* was attained through *partnership* with health care professionals and although partnership

has been included in the literature for numerous years, parents are still not being accepted as partners; this was described as being related to arrogance on the part of health care professionals. This demonstrates the superior level of care that the informants of this study have received from nurses as the majority of their interactions with nurses were described as partnerships.

Further to the development of a *partnership,* parents are able to develop skills in asserting themselves during negotiations of roles (Kirk, 2001). This level of assertion or *control* has been described as "greater" in the home than the hospital environment which may explain why some informants felt more *control* or *power* in making decisions about their child's health.

The findings of the current study provided a unique exploration of the concept of *control* within the nurse-family relationship as related to nursing support. Informants from this study described that by handing over *control* to the nurse, they were inviting information and resources from the nurse as they themselves were not able to access the resources independently. The idea of 'handing over control' has not been directly explored in the literature, so there is little understanding about how this type of partnership or relationship is developed and more specifically the role of the nurse. What was clear in the description of the informants of this study was that nurses need to have a respect for the knowledge and expertise of the parents and only then can this superior level of partnership develop.

It has been articulated in the literature that receiving support from nursing professionals allows parents to become invigorated as they are acknowledged as experts in

caring for their child (Lindblad et al., 2005). Although there is not full agreement in the literature regarding a specific definition of nursing support or the specific behaviors that will be perceived by patients and/or families, there are similarities between the findings of this study and supporting literature.

<div align="center">*Implications*</div>

Nursing Practice

The results of this study provide a description of nursing support from the perspective of mothers caring for a child with CF which had not previously been articulated in the literature. It is clear from this research that all families are unique and therefore the description of nursing support may in fact be different for each family, however similarities were found in the descriptions of the participants of this study which can be applied to nursing practice.

It is important to note that families develop confidence over time as they adjust and learn coping strategies for their child's condition. The nurse's role must evolve as the families change and require a different level of support. In the beginning, the nurse must *listen* to families in order to *understand who the family is* in order to provide individualized care to the family and build a relationship and/or partnership. There is a period of learning on the part of the professional involving parental routines, knowledge of the child, trust of the family and understanding modes of adult learning. Continuity of care also enhances the professionals' ability to provide high-quality care and should continually be strived for.

Supportive care includes components of *human characteristics* or *qualities*. Caring, trusting, and being adaptable were identified as key factors in the mothers' feelings of

support. Since these qualities can not necessarily be changed in an individual, it is important to acknowledge the nurses' work environment as affecting one's ability to demonstrate these *human characteristics*. A work environment that allows the nurse to be *available/accessible* as well take the time to *listen* can facilitate the level of support that is provided to parents.

What was unique in the findings of this study was the idea that parents may decide when to 'hand over control' to the nurse in caring for their child. This was not previously discussed in nursing literature which may be because the population of parents caring for a child with CF has never been explored in relation to nursing support. Since the level of control or the variation in the partnership was found to vary from informant to informant, it is important for the nurse to continually assess each parent during each interaction in order to understand their current needs.

The findings of this study provide an overall definition of nursing support including components such as *tools or skills, human characteristics, functions or tasks,* and *nice to haves* as well as offer a beginning understanding to the process of building the relationship between parent(s) and nurse within supportive nursing care. Nurses must understand that there are a variety of factors that impact a parent's perception of supportive care; some are internal and others are external. Although having all of these factors led to optimal support, it is important to note that not all of them are required to provide supportive nursing care. Support will look different with each and every nurse and each and every family, therefore it is important for the nurse to explore the relationship with the family in order to cultivate a healthy working relationship where support can be fostered.

Future Research

Several areas of future research can be identified following the findings of this study. The most obvious idea for future research is in relation to the sample of this study. Limitations of this study were related to the homogeneity of the participants. Fathers' perceptions of nursing support must be explored in order to fully enhance the description. It may also be appropriate to include a variety of participants from diverse socioeconomic backgrounds as well as participants from rural settings as their experiences of receiving support may be impacted by their distance from the urban health center.

It may also be beneficial to explore nurses' perceptions of nursing support as well as observing supportive care in practice in providing care to families of a child with CF. As the literature identified differences between nurses' and patients' perspectives as well as differences between nurses' descriptions and observations made of their practice, it is important to explore all populations that are involved in supportive care.

It is also important for the taxonomy of nursing support and themes identified in this study to be verified by further research. Further to validating the description of nursing support, further research is needed to explore the process of providing and/or obtaining nursing support through grounded theory.

Specific to the findings of this study, it might also be beneficial to further explore parents' use of control/power as a tool within the nurse-parent relationship. This could be explored within the environment of caring for a child with CF as well as in other settings where parents may develop a high level of knowledge and confidence in caring for their child.

Critique of the Method

Method

The purpose of this study was to explore parents' descriptions of professional

nursing support in caring for their child with CF. The ethnoscience method was chosen

because it is an inductive approach used to gain insight into how a concept is described

within a particular culture. Understanding how people describe something helps to

understand the meanings they attach to it. The DRS method (Spradley, 1979) offered a

structured, yet flexible, approach to data collection and analysis. However there were times

when participants struggled to explain or provide appropriate terms for their ideas or what

they wanted to say, including when they were trying to describe the nurse-parent

relationship. Researchers using the ethnoscience method must be aware that the taxonomic

structure may not be a precise replica of the informants' classifications as each informant

has a slightly different version of the structure. This is dependent on the informants' "life

experiences, innate intelligence, skill at logical ordering, and interest in doing so"

(Evaneshko & Kay, 1982, p.61). It can be stated that ethnoscience was a useful method for

eliciting interpretations that are meaningful for the group of informants as evidenced by the

informants' statements in the validation interviews (Evaneshko & Kay). This method

provided an appropriate means to elicit a description of nursing support from the

perspective of the informants as well as depth and richness to the findings.

Interviewing Technique

The use of interviews was an appropriate data collection method which provided

detailed and rich data regarding the informants' experiences in receiving nursing support.

Although the time that was required for the interviews was an hour to an hour and a half, the majority of participants opened their schedules in case the interviews went longer than expected. The majority of participants were filling numerous roles, including employment outside the home as well as primary caregiver to their child with CF, although only one participant was unable to find an appropriate time to schedule the round 2 interview and needed to withdraw from the study. No participant stated that they felt "rushed" or "hurried" and there were few problems in scheduling interviews at an appropriate time. The process of the card sort was a unique way to capture rich and thorough data and participants explained how it was a positive experience for them. Some participants felt that the technique of organizing cards as visual cues helped "capture" their ideas and clarified what is important to them. Some participants made statements or used phrases to describe nursing support in the first round of interviews, but in round 2 interviews, when they had the card with that phrase on it, they decided that, in fact, it wasn't important to them.

> I'm a little taken back by just, I've had to kind of go through it and it's like, it's not something that you can do quickly…it's like, wow, because then you start to look and then all of a sudden you see things that really maybe don't apply and some where you thought they applied in a certain way that really wasn't the way they worked anyway. (B.1.651)

Sample

A non-random, purposive sampling method was used in this study. It is important to note that although the Clinical Nurse Specialist within the CF health care team performed the screening of the families, there may have been unintentional or unknown bias in the

selection of participants. Data saturation was obtained following six round 1 interviews. Since the purpose of data collection in round 2 interviews was to work with the data from round 1 and not to obtain new information, it was not necessary to achieve data saturation.

The findings of this study focus on the definition of nursing support within the context of caring for a child with cystic fibrosis; however, it is important to note that this does not include the year following diagnosis as the description of support may look very different in that timeframe.

Although demographic data were not collected from the participants in the interests of protecting confidentiality in this small community of families, it was understood that all of the participants came from the same cultural group and similar socioeconomic status. In addition, although the invitation to participate in the study included all parents who played a direct role in caring for their child with CF, the sample ended up being all mothers of children with CF. These factors may have indirectly affected the findings and differing ideas or perceptions regarding nursing support may have been included had the sample been more diversified.

Summary

The purpose of this study was to explore parents' perceptions, thoughts or ideas about nursing support in caring for their child with cystic fibrosis. Although nursing support is a frequently cited behaviour or action in nursing literature, there was no consensus about the definition or description. As the literature suggested, there might be a variation in nurse's perceptions and parents' perceptions of nursing support, so the parents' perspective was chosen for the focus of this study through ethnoscience, as the research

method. Two to three rounds of interviews with 6 participants were the sources of data in this study.

Findings revealed four categories of nursing support were described by the participants: (1) *tools or skills,* (2) *functions or tasks,* (3) *human characteristics or qualities,* (4) *nice to haves.* The participants also described the process of building a relationship between the nurse and parent(s) as part of nursing support which is articulated in the following themes: (1) *building the relationship,* (2) *development of a partnership,* (3) *use of control/power as a tool.* Although the focus of this research study was not to describe the process of obtaining support, it was impossible for the participants to simply define support without providing a description of the process that is undertaken when receiving support. Each participant described their relationship with the nurse differently as they were at different stages in the development of their relationship however it was identified that there are similarities in the process that occurs for developing the relationship as described in the themes.

Once parents have adjusted to the diagnosis and have learned about the care that is required of their child, they become knowledgeable and confident in their abilities to provide the care, make decisions and even alter the care based on their child's condition. Parents feel a sense of control in caring for their child and are even able to use their control within the nurse-parent relationship. The focus of the nurse's role changes from acting as the source of knowledge and information to facilitating resources and acting as the "go between" between the parents and other health care professionals. The nurse is in a unique

position to aide in accessing appropriate resources to meet the family's needs as he/she is familiar with roles/responsibilities of other health care professionals.

This study suggests that there are a variety of factors that influence the perceptions of nursing support of parents beginning with qualities or characteristics of the nurse to the functions that the nurse performs. Although not all of the categories or components are required to provide nursing support, optimal support involves a balance between *tools or skills, functions or tasks, human characteristics* and *nice to haves* and an emphasis on *building the relationship* to foster a *partnership* between the nurse and parent(s).

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Appendix A

RESEARCH CONSENT FORM

TITLE: **Understanding Nursing Support of Families Caring for a Child With Cystic Fibrosis.**

INVESTIGATORS: Principal Investigator: Dr. Kathleen Oberle, PhD, RN

Co-Investigator: S.M. Malo, RN BN MN Student

This consent form is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, please ask. Take the time to read this carefully and to understand any accompanying information. You will receive a copy of this form.

BACKGROUND
Supportive nursing care is considered to be a basic characteristic of nursing practice. However, much of what has been developed to support families is based on caregivers' expectations of what families want and need. To date there has been little research on the perspectives of family members regarding their understanding of what would be most supportive. The nature of nursing support from the perspective of families caring for a child with cystic fibrosis has never been explored. In order for nurses to provide optimal support to families caring for a child with cystic fibrosis, we must understand how parents define support in their own words based on their needs.

WHAT IS THE PURPOSE OF THIS STUDY?
The purpose of this research is to describe nursing support within the population of parents caring for a child with cystic fibrosis in order to apply to nursing practice. This study is being undertaken as part of Sarah Malo's thesis research for her Master of Nursing degree.

WHAT WOULD I HAVE TO DO?
By signing this consent form, you will be agreeing to participate in three interviews. These interviews will include answering questions about support received from nursing professionals in relation to caring for your child with cystic fibrosis. Each interview will take about 1 to 1 1/2 hours maximum and will be conducted at a place of your choosing. It will be audio tape recorded and later transcribed (typed word for word) for analysis. The researcher will take notes during the interview that will also be used in the analysis. The researchers will read the transcripts carefully and pick out certain words and phrases that seem to have particular meaning, and will try to see how they can be organized to give a general picture of support. These words and phrases will be put on cards and you will be asked to sort the cards into categories based on the way you understand them.

WHAT ARE THE RISKS?
There are no known risks to your participating in this study.

WILL I BENEFIT IF I TAKE PART?
You will not receive any direct benefit from taking part in this research study. The information we get from this study may help us to provide better nursing care for families who have children with cystic fibrosis.

DO I HAVE TO PARTICIPATE?
Participation in this study is voluntary. You may refuse to answer any question or to withdraw from the study at any time during the interviews without jeopardizing the health care that you receive. However, once data analysis has begun we will not be able to take out your data, as it will be blended in with others' data in the analysis.

WILL I BE PAID FOR PARTICIPATING, OR DO I HAVE TO PAY FOR ANYTHING?
There will not be any costs involved in participating in the research and there will not be any compensation for participating in the study.

WILL MY RECORDS BE KEPT PRIVATE?
We will not be collecting any information from your health records. We will only use the results of the interviews and the card sorts. To be sure that your identity is kept confidential, we will change your name in our recorded data. Results of this study may be described in nursing and/or medical journals but your name will not be mentioned, and it will not be possible for others to identify you.
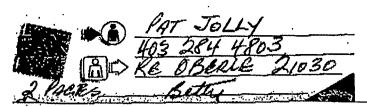
SIGNATURES
Your signature on this form indicates that you have understood to your satisfaction the information regarding your participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the investigators, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time without jeopardizing your health care.

If you have further questions concerning matters related to this research, please contact:
 (contact information of principal investigator and co-investigator provided)
Participant's Name_____
Signature and Date_____
Investigator/Delegate's Name_____
Signature and Date_____

A copy of this consent form has been given to you to keep for your records and reference

PAT JOLLY
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2 Pages   Betty

August 20/0/

CONJOINT HEALTH RESEARCH ETHICS BOARD

Form 7 CHREB COMPLETION/TERMINATION FORM Version JUNE 2008
Office of Medical Bioethics
Heritage Medical Research Building/Room 93
Email: omb@ucalgary.ca Telephone: (403) 220-7990 Fax: (403) 283-8524

Ethics I.D. 21030   **Submission Date: August 12, 2009**

Complete Study Title:
Understanding nursing support of families caring for a child with cystic fibrosis

Principal Investigator: **Signature:**
Kathleen Oberle

QuickTime™ and a
decompressor
are needed to see this picture.

1. Protocol Completion/Termination Date: ___August 12, 2009_____.

2. *Indicate:*   This study is: Complete x   Terminated

3. If protocol was terminated, please indicate the reason(s) for terminating the study.

4. Number of subjects accrued by age and gender:

Age	0-<1	1-<4	4-<12	12-<18	18-<65	>65
Number of Males						
Number of Females			6			

5. Number of subject withdrawals: _0_____

6. Were all adverse events reported?   o Yes   o No *(If no, contact Chair)* N/A
7. Were all modifications reported?   o Yes   o No *(If no, contact Chair)* N/A
8. Have results been published/presented?   o Yes   o No X

Thank you for advising the Conjoint Health Research Ethics Board that the above-noted research protocol ha now been **completed/terminated.**
Please note that according to University regulations, our files relating to this protocol will be retained for th following period as marked:
CLINICAL TRIALS: twenty five (25) years and will be destroyed on _____
OTHER STUDIES: twelve (12) years and will be destroyed on *August 12/2021*

Chair CHREB   Aug 12/09

Signature on previous page.

Glenys Godlovitch, BA (hons), LLB, Ph.D.,   date
Chair, Conjoint Health Research Ethics Board

cc: • Research Assistant/Coordinator • Adult/Child Health Research Committee
        • Department Head • Research Services • Financial Services