The Place of Advanced Practice Nurses in the Community-based Health Care of Children with Complex Health Needs and their Families

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ABSTRACT

The problem that this qualitative study addressed was the lack of understanding of the place of advanced practice nurses (APNs) in the community-based health care of individuals and populations with complex health needs. The aims of the study were to access APNs’ understandings of their practice, the knowledge that informs it and the factors that influence it and to explicate the ways in which their understandings are shaped by the social context in which their practice is situated. Sixteen nurses who worked in advanced practice roles, organizing and providing community-based health care for children with complex health needs and their families, participated in in-depth interviews to elicit their understandings of their practice and the contextual factors that influence it. Data also included participants’ written responses to a transcript of the interview as well as field notes. Analysis of the data involved interpretation of APNs’ accounts, by focusing on the language they used, which provided access to their understandings of their practice and the larger social context in which their practice is located.

A central finding of this study is that while APNs’ accounts reveal that they do contribute to the health care of children with complex health needs and their families, both at the individual and population levels, their practice is constrained by a number of factors, which leads to their under-utilization as expert practitioners. The findings highlight the nature of their practice as relational rather than technical in that it involved education, support, advocacy, and co-ordination of care for children and families at the individual level and program development and educational outreach initiatives at the population level. A distinctive feature of the knowledge that informed APNs’ practice is that while they drew on empirical, theoretical, and sociopolitical knowledge, it was contextual knowledge that they saw as critical to the provision of quality health care. The factors identified as constraining their practice and their contributions to health care are system-wide and include: health care planners and policymakers who do not draw on APNs’ expert knowledge in the design and delivery of health services for children with complex health needs, organizational practices that structure their work around the demands of physicians and programs rather than the health needs of the children and families the programs serve, and APNs themselves who have difficulty articulating their practice because they do not have a language that accurately represents it.

Recommendations for nursing practice, administration, education, research, and policy are directed toward increasing APNs’ articulation of their practice and capitalizing on
care for those with complex health needs. A central recommendation is that APNs draw on the knowledge that informs their practice to provide them with a language for articulating their practice and their contributions to health care.
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In loving memory of my son,
William Evon Canam McCreery
February 10, 1979 – November 21, 1996
The continuing presence of your gentle spirit makes my path possible
CHAPTER ONE
INTRODUCTION AND BACKGROUND TO THE STUDY

The shift from institutional to community-based health care and home care during the past decade has placed increased demands on families who are now providing a level of care within their homes that previously existed only in hospitals or nursing homes (Patterson, Jernell, Leonard, & Titus, 1994). Although the stated mandate of advanced practice nurses (APNs) is to meet the increasingly complex health needs of society (CNA, 2002; Hamric, 1995), the findings from several research studies demonstrate that families report having great difficulty procuring health services to assist them in managing the complex health care of family members. Thus, there is a gap between APNs’ mandate to provide health care for individuals and populations with complex health needs and families’ reports of their experiences in procuring health services. This gap gives rise to the questions pursued in this research study.

Research on the impact of caregiving on the caregiver and family demonstrates that they are often overwhelmed by the unrelenting demands of caring for an ill family member (Canam, Bassingthwaighte, & Cunada, 1994; Knoll, 1992, 1996; McKeever, 1992; Steele, 1999). Singer (1996) points out that while caregiving has dramatically increased the workload of families, their capacity to meet these caregiving demands has actually decreased. Demographic changes such as smaller family size, more single parent families, lack of available extended family, and increased numbers of working mothers have resulted in diminished family resources (Bradley, 1992). Thus, at a time when the number of individuals requiring home care has increased, there are fewer family members and fewer hours available for caregiving. Singer refers to this phenomenon as “the collision of opposing trends” (p. 4) and the result is that “many families find themselves under considerable stress with few external resources available to assist them” (p. 7).
The shift to community-based health care has also impacted on nurses’ roles in the provision of health care. While traditionally nurses have been at the bedside providing direct patient care for individuals, they are increasingly practicing in a wide variety of health care settings, assuming a number of different roles, and working in conjunction with many other health professionals. Moreover, “as families themselves increasingly become caregivers to members in the home, nurses and other health professionals must more and more work with and through families to bring about effective care” (NAABC, 1988, p. 8). Both the national and provincial nurses associations emphasize the critical role that nurses have in the provision of health care as the shift to community-based care continues (CNA, 1999; RNABC, 1998). The provincial association describes the nurse’s role in the evolving health care system as including: coordination of health care, facilitation of continuity of care, and support of clients and their families particularly as it relates to enabling them to assume control of decisions that affect their health (RNABC, 1998, p. 3).

This expanded vision of nursing’s role in the delivery of health care has prompted nursing leaders to look to the advanced practice nursing role as a way to meet the increasingly complex health needs of society and to foster leadership in the profession (CNA, 2002; Davies & Hughes, 1995; Hamric, 1995). Advanced practice nurses (APNs) are those who have expertise in a specialized area of nursing (CNA) and who apply their expertise to meet the complex health needs of the population within a particular specialty (Davies & Hughes). The most commonly recognized advanced practice role in Canada to date has been the clinical nurse specialist (CNS). However, that is beginning to change as the nurse practitioner (NP) role is being targeted as a cost effective, efficient way of delivering primary health care to Canadians (CNA).

Although the stated mandate of APNs is to meet the complex health needs of individuals and populations across systems of care (Hickey, Ouimette, & Venegoni, 2000), findings from several studies, including those that I conducted with families of children with chronic health conditions (Canam, 1990; Canam et al., 1994), reveal that parents consistently
reported that the most stressful aspect of their caregiving role was trying to procure health services that were nonexistent, inconsistent or uncoordinated. The gap between APNs’ stated mandate in the provision of health care and families’ reports of their experiences in procuring health services was puzzling. What accounts for the gap? What is the nature of APNs’ involvement in the delivery of health care for individuals and populations with complex health needs? What factors influence their ability to provide health care for these individuals and populations?

**Background to the Problem**

In turning to the literature to answer the above questions, it becomes clear that despite the increasing focus on advanced practice nursing as a way of meeting the complex health needs of individuals and populations within the community setting, there is little understanding among policy-makers, the public, and health care professionals as to what advanced practice nursing is and how it contributes to the delivery of quality health care (Hamric, 2000). Hamric contends that the advanced practice nursing role is poorly understood in most health care settings and the public does not see advanced practice nurses as primary care providers. Even among advanced practice nurses who are functioning in a variety of roles and settings there is considerable misunderstanding as to what constitutes advanced nursing practice (Schreiber, et al., 2001).

There are a number of factors that have contributed to a lack of clarity regarding advanced practice nursing. A major factor is that the majority of research on advanced practice has employed quantitative methods and has focused on the roles, functions, and competencies of advanced practice nurses, which reflects an underlying assumption that clinical nursing practice can be defined and measured by behavioral indicators and functions (Buller & Butterworth, 2001). While these studies have contributed knowledge of the various components of the advanced practice role and the competencies APNs require to fulfill their role, this body of knowledge has not added to our understanding of the nature of APNs’ practice or how they contribute to the delivery of quality health care. Moreover, an
empiricist approach ignores context so the contextual factors that influence and shape APNs’ practice remain invisible (Styles & Lewis, 2000).

Another factor that has contributed to a lack of understanding of advanced practice is the absence of APNs’ voices in the health care arena. Nurses are being urged to speak up about the work they do because it remains “largely invisible to other providers, to administrators, and policy-makers...” (Rodney & Varcoe, 2001, p. 37). Baer (1999) claims that nurses’ work is also invisible to the public, most of whom do not know “what nursing is, what nurses know, do, and are capable of doing” (p. 79). Gordon (2000) concurs with this premise and suggests that if nurses want the public behind them they must inform them of what they do. One of the ways in which nurses can inform others of what they do is through research that incorporates APNs’ perspectives on their practice and their contributions to health care.

The Problem

The central problem that this study addressed was the lack of understanding of the nature of APNs’ involvement in the delivery of health care for individuals and populations with complex health needs and the contextual factors that facilitate or constrain their practice and their contributions to health care. Consequently, the place of APNs in the community-based health care of individuals and populations with complex health needs is largely unknown and unarticulated. Although the critical/acute care clinical background of most clinical nurse specialists is considered a strong asset in the current high-tech, critical care home environment (Roe-Prior, Watts, & Burke, 1994), the lack of clarity regarding APNs’ contributions to the health care of individuals with complex health needs can result in their under-utilization (Davies & Eng, 1995) as well as increasing the likelihood of the role being eliminated in the downsizing and cutbacks of current health care reforms (McAlpine, 1997), which could result in the loss of a critical component of the health care workforce, particularly in relation to the provision of quality, cost-effective, community-based health care to meet the increasingly complex health needs of society.
**Purpose of the Study**

This overall purpose of this study was to gain an understanding of the place of APNs in the organization and delivery of community-based health care for individuals and populations with complex health needs.

The specific aims of the study were:

1) to gain an understanding of APNs’ practice and the knowledge that informs it. In particular, I was interested in the knowledge that APNs draw on to inform their practice and how their knowledge contributes to the health care of children with chronic health conditions and their families. Chinn and Kramer (1999) point out that “the knowledge that [in]forms nursing practice provides a language for talking about the nature of nursing practice and for demonstrating its effectiveness” (p. 14). They contend that formally expressing this knowledge not only provides disciplinary identity but also is a means of informing others of what nursing’s contribution to health care is.

2) to explicate the ways in which the social context, in which APNs’ practice takes place, informs their understandings and their actions. Purkis (1994) contends “acting knowledgeably in the world, the nurse makes ‘inferences’ about the conditions constituting the work context. Alteration in work practices reflects these inferences” (p. 324).

3) to create a space for APNs’ voices so they can articulate their practice and their contributions to health care. Hamric (2000) emphasizes the importance of nurses in advanced practice roles communicating in an articulate and powerful way to other health care providers, the nursing profession, and society at large the contributions that advanced nursing practice makes to health care. Buresh and Gordon (2000) refer to this as the voice of agency and agree that nurses must illuminate the important contribution they make to health care.

To circumscribe the study population, I recruited APNs whose role involved organizing and/or providing health care for specialized populations of children with complex health needs and their families, across systems of care. I chose this population of
APNs because my research and clinical background is in the area of childhood chronic health conditions and family coping,

Assumptions

The assumptions underlying the current study were:

1. APNs contribute to the organization and delivery of community-based health care for individuals and populations with complex health needs but their practice is largely unarticulated and unacknowledged.

2. APNs’ contributions to community-based health care are constrained by a number of factors within the social context in which their practice is situated.

3. APNs will articulate their practice if they are given the opportunity to do so.

Research Questions

The overall research question driving this study was:

What is the place of APNs in the organization and delivery of community-based health care for individuals and populations with complex health needs?

To answer this question, I wanted to access APNs’ understandings of their practice, the knowledge that informs their practice, their contributions to the health care of individuals and populations, and the factors that influence their practice and contribution to health care.

Thus, subsumed under the overall question are three sub-questions:

1. What are APNs’ understandings of their practice, the knowledge that informs it, and their contributions to the community-based health care of children with complex health needs and their families?

2. What do APNs see as the factors that influence their practice and their contributions to the health care of children and their families?

3. How are APNs’ understandings shaped by the social context in which their practice is situated?
Issues of Language and Discussion of Key Terms

Advanced Practice Nurse (APN) - is one who has expertise in a specialized area of nursing (CNA, 2000) and who applies their expertise to meet the complex health needs of the population within a particular specialty (Davies & Hughes, 1995). In Canada, the term has most commonly been applied to clinical nurse specialists (CNA, 2000, Davies & Hughes, 1995). However, with the continuing development of the advanced practice role, the term is currently also being used to refer to nurse practitioners. Within this study the term is exclusively referring to the clinical nurse specialist role of advanced practice and not to the nurse practitioner role, as all of the participants are either clinical nurse specialists or working in a clinical nurse specialist role. My decision to refer to participants as APNs rather than CNSs was based on two factors. First, the majority of nurses who organize and provide community-based health care for children with chronic health conditions and their families are clinical nurse specialists. However, some of the nurses recruited for this study are not clinical nurse specialists but nurse clinicians who work in advanced practice roles. Although they have organized and provided community-based health care for specialized populations of children with chronic health conditions for many years, they do not have the educational qualifications required to be a clinical nurse specialist (that is, a masters degree in nursing or a related field). A second factor influencing my decision to use the term APN rather than CNS is that I wanted to include nurses within the community setting who organize and provide health care for specialized populations of children with chronic health conditions. Although these nurses work in advanced practice roles, they do not have a CNS title so it is more accurate to refer to them as APNs.

APNs' Practice - all of the actions performed by APNs that relate directly or indirectly to the health care of children with chronic health conditions and their families.

Community-based - refers to the community as setting and, unless otherwise indicated, is used within the context of this study to indicate care provided for individuals who are living within their communities (as opposed to being in an institutional setting such as a hospital).
**Chronic Health Condition** - is being used in this study to encompass a number of terms; chronic illness, disability, special needs, technology-dependent, medically complex. The population of children with chronic health conditions roughly falls into one of three subgroups; children with the more common childhood chronic conditions such as cystic fibrosis, cancer, or epilepsy (often referred to in the literature as chronically ill children); children with complex health conditions (often referred to as medically fragile or technology dependent); and children with extensive mental or physical disabilities (often referred to as children with special needs). While these are not distinct or all-inclusive categories of chronic conditions, they tend to be used to identify study populations in research studies on children with chronic conditions and to make decisions regarding health services. Since the focus of this study is nurses who provide community-based health care, their practice may encompass all three groups. Therefore, unless otherwise stated, when chronic health condition is used in this study it is inclusive of all three groups.

Much of the literature refers to children with long term health problems as chronically ill children rather than children with a chronic health condition. There are two things about this label that are problematic. One is that using chronic illness as an adjective rather than a noun denotes that the illness describes the whole child rather than a child who has an illness. Secondly, children with chronic health problems are not always, or even usually, ill. And parents do not refer to their child as chronically ill nor do they like it when health professionals use that term. The term chronic health condition is to me the most descriptive of children with long term health problems requiring periodic and/or ongoing health care and it is the one I use in communicating about and with these children and their families.

**Complex Health Needs** - this term is frequently used to delineate APNs’ domain of practice as being clients who have complex health care needs as opposed to clients with more acute, self-limiting health care needs. Calkin (1984) further specified the domain of APNs’ practice as addressing human responses to actual or potential health problems that
fall outside the usual or average responses. She conceptualized APNs’ domain of practice as being one standard deviation above and below the mean of responses on a bell curve. More recently, the domain of CNS practice has been described as patient populations experiencing unique and/or complex health problems (Hamric, 1995).

**Families of Children with Complex Health Needs** - This term reflects my bias as the researcher and requires an explanation. One of my earliest lessons in pediatric nursing was the realization that the best way to support sick children was to support their parents. I didn’t know it then but my conviction reflected the philosophy of family-centered care. It has been the guiding principle of my practice and research over the past twenty-five years. Although much of my research has focused on parents, and more specifically on mothers of children with chronic health conditions, I use the term family rather than parents or mothers because often there are other children in the family (as well as the child with the chronic condition) and by referring to parents of children with chronic conditions, this would exclude the child and his or her siblings. To my mind, these terms represent an important philosophical distinction and one that I needed to be careful not to place on the nurses who were the informants for the study. It could as easily be argued that children are agents in their own right and therefore they, rather than the parents, should be the focus of nursing care.

Another term that is used interchangeably with families of children with complex health needs in this study is **Caregiving Families**. The term family caregiver refers to one individual whereas caregiving families refer to all family members. I am aware of the criticism that use of the term family obscures the central role that women have in caregiving but all members are part of a caregiving family, regardless of the extent to which they participate in the caregiving. This distinction does mean that I need to pay attention to the terms that nurses use to describe the clients who are the focus of their practice and not make the assumption that they are using these terms in the same way that I am.
One final word about issues of language. Although both female and male nurses occupy the advanced practice role, the majority of nurses in advanced practice roles are female and those recruited for this study were all females. Because of this and to avoid the awkwardness of gender-inclusive language, I will use the feminine pronoun throughout this text to refer to advanced practice nurses.

**Significance of the Study**

As the shift from institutional to community-based health care and home care continues, governments and health care organizations are seeking innovative approaches to meet the increasingly complex health needs of individuals within the community setting. In articulating the place of APNs in the community-based health care of individuals with complex health needs and the factors that facilitate and constrain their practice and contributions to health care, my aim was to produce knowledge that will assist health care planners to more effectively capitalize on the advanced practice nursing role as a way of meeting the increasingly complex health needs of society. It was anticipated that such knowledge could lead to more effective health care for individuals with complex health needs and their families.

In addition, researching APNs’ practice and the knowledge that informs it, has the potential of developing the knowledge of the discipline. Chinn and Kramer (1999) suggest that formal expression of nursing knowledge “makes it possible to focus, shape, question, and influence what is collectively accepted as sound, useful and valued” (p. 2). Moreover, they contend that it creates a disciplinary community that reaches beyond the isolation of individual experiences and it provides a means of communicating what is known within the discipline as a whole.

**Summary of Chapter One**

The impetus for this study arose from the perceived gap between advanced practice nurses’ mandate to meet the complex health needs of individuals and populations across systems of care and research findings that demonstrate that families have great difficulty
procuring health services to assist them in the provision of complex health care for family members. In exploring the literature on advanced practice, it became clear that there is little understanding of the advanced practice nursing role or the ways in which APNs contribute to the delivery of quality health care. Thus, the primary purpose of this study was to gain an understanding of the place of APNs in the organization and delivery of community-based health care for individuals with complex health needs. The central research question is: what is the place of APNs in the organization and delivery of community-based health care for individuals with complex health needs and their families, and the sub-questions relate to APNs' perspectives on the nature of their practice and knowledge and the contextual factors that influence their practice and contributions to health care. It was anticipated that pursuing answers to these questions would produce knowledge that would lead to more effective utilization of nurses in advanced practice roles and ultimately lead to more effective health care for individuals with complex health needs and their families.

Having provided an introduction to the study in this first chapter, Chapter Two provides a detailed examination of the theoretical and research knowledge on advanced practice nursing and the factors that influence and shape it. In Chapter Three I discuss the philosophical and theoretical underpinnings of the study, the details of the research design and implementation, ethical considerations and considerations for ensuring scientific rigor. Chapters Four, Five, and Six represent the core of this report as I present my interpretations of the research data. Chapter Four provides a description of the nature of APNs’ practice and the knowledge that informs it. Chapter Five provides a discussion of the context of APNs’ practice in relation to their immediate practice environment and in Chapter Six I discuss the context of APNs’ practice in relation to the population level of health care. Chapter Seven provides a discussion of the research findings through a synthesis of key findings of the study, and an examination of these findings in light of the theoretical and research literature. In Chapter Eight, I conclude the thesis with a summary and key recommendations.
CHAPTER TWO
LITERATURE REVIEW

The research problem with which this study is concerned is the lack of understanding of the place of APNs in the organization and delivery of community-based health care for individuals with complex health needs. Although I am specifically focusing on the CNS role of advanced practice, I have explored the literature that encompasses the broader domain of advanced nursing practice, as well as the literature that focuses on clinical nurses specialists. Moreover, although the participants in this study worked with specialized populations of children with complex health needs and their families across systems of care, I approached the literature from the broader perspective of APNs who work with any specialized population of individuals with complex health needs. These specialized populations include, but are not restricted to, children with chronic health conditions.

I have organized the literature review within two major sections. In the first section, I examine the state of knowledge related to advanced nursing practice, including its development and how it has been conceptualized and studied. In exploring the research on advanced nursing practice, I directed my attention to research on the nature of APNs' practice and knowledge as well as research on the contributions of APNs' to the health care of individuals with complex health needs and their families. In the second section, I explore the context within which advanced nursing practice has emerged and is currently enacted and the factors within that context that shape advanced practice and APNs’ contributions to health care.

ADVANCED PRACTICE NURSING

Rose, Waterman, and Tullo (1997) assert that the advanced practice movement has been driven by the need to improve the delivery of health services to meet the changing needs of patients and to improve the professional status of nurses and nursing. The International Council of Nurses (ICN, 1992) identified several forces both within and
external to the nursing profession that are driving specialization in nursing. Forces external to the profession include: the changing health needs of society; increased complexity of health care; health policy decisions that change the way health care is delivered; delegation by the medical profession; consumer demand; and political interests driven by such events as the lobbying of interest groups. Forces internal to the profession include: development of nursing science; extension of the boundaries of nursing practice into areas such as primary health care as well as those specialties traditionally serviced by medicine; development of post-basic curricula for professional education for nurses; and the drive to more recognition of nursing through authority, status and financial rewards.

The rapid expansion of expert clinicians in both the inpatient and community settings in the USA has produced two models of nursing specialization: the consultative nursing model of clinical nurse specialists (CNSs) and the collaborative model of nurse practitioners (NPs), midwives, and nurse anesthetists (Bullough, 1992). These models share a commitment to research and utilization of knowledge from other disciplines but they differ in regard to practice settings, emphasis placed on nursing theory and medical content, and direct service activities (McGivern & Mezey, 1999). CNSs provide some direct care but the majority of their time is spent in consultation and education of those who provide direct care. NPs, on the other hand, spend the majority of their time on direct patient care with less time in consulting with and educating others (Kitzman as cited in Davies & Hughes, 1995).

Recently, some educational programs that prepare CNSs and NPs are evolving from separate programs to ones that prepare practitioners for a “blended” role with skills that transcend settings (McGivern & Mezey, 1999). However, not all nurse educators and practitioners agree with the blending of the two roles and instead advocate for continuing separate tracks for CNSs and NPs. Hickey, Ouimette, and Venegoni (2000) contend that regardless of whether the two roles are blended or remain separate, the advanced practice nurse (APN) is one who can provide comprehensive health care and illness management in a variety of settings as well as during transition points of illness. Moreover, they suggest
this APN will need to work in expanded collaborative relationships with physicians and other health professionals to meet the increasingly complex health needs of society. The overall goal of the advanced practice model of health care delivery is "to achieve access to quality, cost-effective care for all people, especially underserved and vulnerable populations that have ... been recipients of fragmented and poor quality care" (Hickey, et al., preface, p. v).

Advanced practice nursing is a relatively recent phenomenon within Canadian nursing. The Canadian Nurses Association (CNA) is currently promoting the advanced practice role as an avenue for nurses to contribute to the health care system in new ways and to foster leadership in the profession (CNA, 2000, 2002). The CNA recognized the importance of reaching a national consensus among key stakeholders as to the nature of advanced nursing practice in order to make decisions regarding its development, decisions such as determining the educational preparation needed, approaches to regulation, and the support required by nurses functioning within advanced practice roles (CNA, 2002, p. 3). To that end, they undertook an extensive national consultation process with CNA member associations and key stakeholders. From this consultation, the CNA developed a national framework to guide the ongoing development of advanced nursing practice in Canada. A coordinated approach nationally will ensure that the public has access to similar nursing services across the country (CNA). Another advantage of a national approach is that it provides strength for lobbying governments to implement this role in the design of health care delivery.

A team of researchers from British Columbia (policymakers from BC Ministries of Health Planning and Health Services, university researchers, RNABC, and Capital Health Region representatives) used the CNA document as a conceptual framework for a research study undertaken to further clarify the advanced practice role within this province. Findings from the 3-year study suggest, among other things, that there are considerable differences of
opinion among advanced practice nurses functioning in a variety of roles and settings as to what constitutes advanced nursing practice (Schreiber, et al., 2003).

The conceptual confusion surrounding advanced practice is not limited to B.C. or even to Canada. The United States has a much longer history of specialization and consequently has taken the lead in relation to the development of conceptual models for education, practice and research for the advanced practice role. Yet, it has been suggested that a great deal of conceptual confusion remains in the field. Styles and Lewis (2000) contend that this confusion is due in part to the terms “advanced practice nursing” and “advanced nursing practice” being used interchangeably. Advanced (practice) nursing is the whole field while advanced (nursing) practice is a vital function of the field of advanced practice nursing (Styles & Lewis, p. 35). This is a key distinction because when these terms are used interchangeably, Styles and Lewis warn there is a danger of narrowly focusing on a practice model while ignoring the social, economic and political factors that underlie and influence that practice, factors that become evident when the whole field of advanced nursing is conceptualized and addressed. Moreover, a narrow conceptualization can influence the education of advanced practice nurses, which in turn can result in nurses viewing their role in a restricted way. Also research that is directed by a practice model rather than a nursing model may be directed only at clinical practice while ignoring the larger contextual factors that shape the practice role. One of the criticisms of existing conceptual frameworks is that they focus on advanced nursing practice and the attributes and competencies that characterize the practice role while social, economic and political factors influencing the role are not addressed (Styles & Lewis).

Another factor that has created confusion in the advanced practice field is the lack of consistency in the terminology used to describe the basic elements of conceptual models within the advanced practice literature (Styles & Lewis, 2000). For example, domains, roles, competencies, functions, activities, and skills are variously used to describe the elements of an advanced practice conceptual model. Styles and Lewis maintain that the problem in
comparing, developing or refining these conceptual models is that there is no agreed-upon meaning or frame of reference. Although they refer to it as an issue of terminology, it signals the wider issue of language and the critical role that language plays in the discourses that arise around various conceptualizations of advanced practice.

The majority of the literature refers to the concept of advanced nursing practice rather than advanced practice nursing so this is the term that will be used in examining how advanced practice has been conceptualized. The literature is international in scope although much of it originates from the USA and to a lesser extent from Australia and Europe, including the UK. The literature has for the most part been dominated by debates over definition, title, role functions and competencies and the majority of articles are conceptual or comment papers.

**Conceptualizations of Advanced Nursing Practice**

Advanced nursing practice (ANP) encompasses a variety of nursing roles beyond the generalist role. For example, the American model includes four distinct roles under the advanced nursing practice term: nurse anesthetist; nurse midwife; clinical nurse specialist; and nurse practitioner; and a fifth role, case manager, is currently being developed. (Hamric, Spross, & Hanson, 2000). The most commonly recognized advanced practice role in Canada is the clinical nurse specialist (CNS), with that of nurse practitioner (NP) recently becoming more recognized in some parts of the country (CNA, 2002). The CNA (2003) position statements on the clinical nurse specialist and the nurse practitioner identify both roles as advanced practice but describe the educational requirements and the foci of their practice differently. A CNS is described as “a registered nurse who holds a master’s or doctoral degree in nursing with expertise in a clinical nursing specialty” (CNA, 2003, March, p. 1). A CNS “improves access to effective, integrated, and coordinated health care across the continuum of care ... [and] assists in providing solutions for complex health care issues at all levels – with patients, families, other disciplines, administrators and policy-makers”(p.1). The CNA position on NP education is more tentative. It states that, “the
completion of graduate education in nursing is the most effective means of acquiring NP competencies" (CNA, 2003, June, p. 1). A NP “provides services to manage the health needs of individuals, families, groups, and communities [and] diagnoses and treats health problems and prescribes drugs. NP work autonomously … and they work in collaboration with other health care professionals” (p. 1).

Within British Columbia, the CNS makes an important contribution to the evolving health care system by establishing and promoting quality health care for clients, often in new areas, and by developing programs that focus on emerging health issues (RNABC, 2001). In fulfilling the roles of expert clinician, consultant, educator, and researcher, the CNS promotes excellence in nursing practice and serves as a role model for nurses in the practice setting (RNABC). The NP role in British Columbia is currently being developed. Two universities have established NP programs at the graduate level and admitted students in September 2003. The first NPs in BC are expected to begin practicing in 2005.

Within the CNA framework, advanced nursing practice is defined as an umbrella term that describes “an advanced level of nursing practice that maximizes the use of in-depth nursing knowledge and skill in meeting the health needs of clients (individuals, families, groups, populations, or entire communities)” (CNA, 2002, p. 1). This definition, however, lacks clarity because of vague terms like “advanced level”, “maximizes”, and “in-depth knowledge and skill”, which give little direction to either the nurse or the public as to what an advanced practice nurse does and how that differs from what all registered nurses do. Hamric (2000) contends that a central and agreed upon definition of advanced nursing practice is critical to its continued development because there is little understanding of the role in most health care settings and the public does not see advanced practice nurses as primary care providers.

While I agree on the importance of “a Canadian approach to ANP” (CNA, 2000, p. 3), I find the American definition is more explanatory and provides clearer direction for nurses. It is defined as “the application of an expanded range of practical, theoretical, and
research-based therapeutics to phenomena experienced by patients within a specialized clinical area of the larger discipline of nursing” (Hamric 1996, as cited in Hamric 2000, p. 57). The term “therapeutics” refers to all the activities that are part of providing nursing care. This definition acknowledges the key role of theoretical, research-based, and practice knowledge in the advanced practice role, as well as the clinical component of the role. It also emphasizes the patient-focused and specialized nature of advanced practice while firmly placing it within the discipline of nursing (Hamric).

Hamric (2000) clearly makes the distinction that advanced nursing practice is “not the junior practice of medicine” (p. 57). She argues that while certain activities that APNs undertake may also be performed by physicians and other health care professionals, the nurse approaches these activities from a nursing perspective using theoretical, research-based, and experiential nursing knowledge. The CNA document on advanced nursing practice supports this position saying that, “it is the application of advanced nursing knowledge that determines whether nursing practice is advanced, not the addition of functions from other professions” (CNA, 2000, p. 4).

The advanced practice role has been conceptualized within the professional literature as consisting of certain characteristics and competencies which are variously referred to as domains, roles, functions, activities or skills. While it has been argued that it is necessary to delineate the role in this way to clearly distinguish what it is that these nurses do in relation to other, less expensive, nurses, Davies and Hughes (1995) contend that advanced practice is not fully explained by describing its components and that such description does not capture the essence of the role. Others have suggested that developing a checklist of competencies conflicts with the autonomous nature of advanced practice (Wilson-Barnett, Barriball, Reynolds, Jowett, & Ryrie, 2000). With this in mind the following discussion of characteristics and competencies feels a bit like “breaking the role into pieces without looking at the whole” (Davies & Hughes, p. 156). However, it is important to articulate how the role is being conceptualized, particularly within the Canadian nursing community,
because these conceptualizations can have a strong influence on the education of advanced practice nurses, the ways in which these nurse view and enact their practice, and the nature of the research under taken to clarify advanced practice (Styles & Lewis, 2000).

**Characteristics of Advanced Nursing Practice**

One central characteristic of advanced nursing practice is that it is specialized; that is, the nurse demonstrates expertise (expert knowledge and skills) in a specialized area of nursing (CNA, 2000). The nurse applies the expert knowledge and skills relevant to a particular specialty to meet the complex health needs of the population within this area (Davies & Hughes, 1995). This expertise also provides advanced practice nurses with a source of authority for making effective decisions (Atkins & Ersser, 2000). The specialized areas may be classified according to age of clients (e.g., pediatrics, gerontology), client’s clinical management (e.g., pain, incontinence, bereavement), medical diagnosis (e.g., diabetes, cystic fibrosis), practice setting (e.g., home care, acute care), and type of care (e.g., primary health care, palliative care) (CNA).

A second characteristic is that the nurse’s practice is grounded in in-depth knowledge that goes beyond particular clinical specialties. This knowledge is both theoretical and practical. Theoretical knowledge is drawn not only from nursing theory and research but also from a wide range of other disciplines (Kappeli, 1993; Manley, 1997; Smith, 1995). Practical knowledge develops from actual experience in a situation so it is both contextual and transactional (Brykczynski, 1999). Clinical judgment develops from theoretical concepts and practical know-how being refined and integrated through experience in clinical situations (Brykczynski). In Nursing’s Social Policy Statement, the ANA (1995) emphasizes the importance of research-based knowledge as well as theoretical and practical knowledge. Szaflarski (2000) emphasizes the importance of APNs having the ability to systematically organize their in-depth knowledge into meaningful patterns so it is easily accessed.
Advanced practice nurses also have the ability to critically appraise this knowledge for its application and limitations to inform clinical practice (Atkins & Ersser, 2000). Moreover the knowledge is applied in a “deliberate, purposeful, and integrated” way to provide health care for clients in highly complex practice environments (CNA, 2000, p. 5). Furthermore, the nurse has the ability to clearly articulate and justify a particular course of action in relation to this knowledge (Davies & Hughes, 1995; Sutton & Smith, 1995). The advanced practice nurse also contributes to the development of evidence-based nursing knowledge through participation in research and integration of research-based findings into her/his practice (Buchanan, 1994; Manley, 1997; Williams & Valdivieso, 1994).

Additional characteristics include: involvement in planning, implementing, evaluating and coordinating programs to meet clients’ needs using collaboration and partnership skills; the ability to critically analyze and influence health policy, and demonstration of a high level of responsibility and accountability (CNA, 2000, p. 5). Advanced practice nursing roles “require highly autonomous, independent, accountable, and ethical practice in complex, often ambiguous and rapidly changing environments” (CNA, p. 6). While some of these characteristics may be present in other nursing roles, it is their consistent presence in a particular role that defines it as advanced nursing practice (Hamric, 2000).

Competencies of Advanced Nursing Practice

Advanced nursing practice is further conceptualized as including a set of core competencies that are integral to the characteristics described above. Competencies are “the specific knowledge, skills, judgment, and personal attributes required for a registered nurse to practice safely and ethically in a designated role and setting” (CNA, 2000, p. 6). These competencies are demonstrated within five broad roles in the CNA document: clinical practice, research, leadership, collaboration, and change agent (CNA, p. 7-8). The American model also includes consultation and ethical decision-making skills among the core competencies of advanced nursing practice (Hamric, 2000). These core competencies are to
be acquired by all APNs who then apply them to their specific client populations and settings (Hamric).

**Clinical Practice**

The centrality of clinical practice to the advanced practice role is the one area within the advanced practice literature where there is consensus. According to Hamric (2000), direct clinical practice is the central competency, which interacts with and informs all the other competencies. The American Nurses Association maintains that it is critical that advanced practice nurses have direct clinical practice as their central focus to promote clarity of the role (ANA, 1995). This is not to say that direct clinical practice is the only component of the role nor is clinical expertise alone equated with advanced nursing practice. Those nurses who become clinical experts by experience alone are distinguished from advanced practice nurses by being referred to as experts-by-experience (Calkin, 1984). There is, however, less agreement about what clinical practice for the advanced practice nurse involves. Most theorists and researchers suggest that it is providing direct comprehensive care to patients (Sutton & Smith, 1995; Brown, 2000) but this has been interpreted as the provision of holistic person centered care by some and the enactment of technical skills by others (Mundinger, 1994; Wright, 1995). Sutton and Smith argue that focusing on the procedural and technical aspects of clinical practice reduces nursing to a series of tasks and undermines the art of nursing.

Brown (2000) has identified five characteristics of clinical practice that are associated with advanced nursing practice: a holistic approach to patients; forming partnerships with patients and other members of the health care team; expert clinical reasoning; practice guided by research evidence; and diverse approaches to management of health and illness. The CNA document on advanced practice (2000) is more specific regarding the skills that nurses demonstrate in clinical practice and therefore provides clearer direction for educational programs preparing advanced practice nurses. These skills include: the ability to analyze complex interactions between the various aspects of a client’s
situation and the client's lived experience; critical thinking and synthesizing skills; collaborative skills in engaging clients and other health team members in resolving ethical issues relevant to the client's care; skill in advocating for clients, nurses and other members of health team to improve health care; and organizational skills to coordinate client care to achieve integrated, comprehensive health care for clients. In addition, the nurse draws on her experience and a body of current knowledge regarding the client population to predict and explain a wide range of client responses to actual or potential health problems, implement a range of interventions to influence the client's health status and promote quality of life, and evaluate and document outcomes of decisions and interventions (CNA, p. 7). This last statement was drawn from a list of clinical competencies identified by the CNA and to me, it represents a much clearer definition of advanced nursing practice than does the one given in the CNA document quoted above.

Research

The CNA (2000) identifies evidence-based practice as central to the competencies of advanced nursing practice. Evidence-based practice is realized through the dissemination, facilitation, and application of relevant research findings to clinical practice and participation in research relevant to practice either as the primary investigator or as a collaborator (CNA). Hamric (2000) also identifies active involvement in research related to patient care as a critical component of advanced nursing practice. She emphasizes the importance of research on patient outcomes and cost-effectiveness in moving advanced practice nursing forward. She argues that the worth of any service is determined by its ability to meet the needs and priorities of society and its citizens. In health care, these needs are for appropriate services at an affordable cost. Hamric asserts that advanced practice nurses must recognize that they are a vital link in advancing both the profession's and health care system's knowledge about effective patient care practices. Likewise, she maintains that if researchers want their research to be relevant to nursing practice and health care delivery, they must involve the advanced practice nurse at some level. Hamric also emphasizes the importance of nurses in
advanced practice roles communicating in an articulate and powerful way to other health care providers, the nursing profession, and society at large the contributions that advanced nursing practice makes to health care.

**Leadership**

Competency in leadership involves nurses taking on leadership roles in the organizations in which they work (CNA, 2000, p. 7). This can occur at multiple levels from developing innovative solutions to complex practice issues to developing strategies to influence health policies. It can involve mentoring nursing colleagues to improve and support nursing practice or providing leadership in professional activities or on interdisciplinary committees related to the development of policies, education, or research in the clinical area (CNA). For example, one nurse in an advanced practice role in palliative care has taken a leadership role in the development of an interdisciplinary palliative care course that will bring together students from nursing, medicine, pharmacy, and social work to learn the knowledge and skills necessary to provide palliative care (P. Porterfield, personal communication).

Leadership also involves the nurse having a clear vision for the future of nursing and its place within the health care system (Atkins & Ersser, 2000). Atkins and Ersser point to the importance of vision in harnessing nursing’s unrealized potential for setting a positive direction for the provision of health services. In Britain, the term ‘advancing’ practice has recently emerged to capture the idea that “moving practice forward for public benefit in a rapidly changing health care environment is a continuous and ongoing process” (Wilson-Barnett, et al., 2000, p. 390-391). Although the American approach to competencies of advanced practice includes consultation as a separate competency, the CNA has included it under leadership. The advanced practice nurse provides consultation to other nurses who work directly with clients to enhance the quality of health care.


**Collaboration**

Collaboration involves the ability to establish effective working relationships with clients and their families, colleagues, and agencies for the purpose of enhancing the quality of health care delivery. This requires the nurse to have skills in communication and conflict resolution as well as knowledge of group dynamics and organizational and role theory. Equipped with such knowledge and skills the nurse communicates effectively, demonstrates respect for clients' and colleagues' knowledge and shares decision-making with them, and negotiates conflict successfully (CNA, 2000). Increasingly, collaborative skills are being employed by nurses in multi-professional as well as inter-professional situations to promote quality and cost effective health care (Atkins & Ersser, 2000).

**Change Agent**

The role of change agent exists not only at the clinical practice level but also at the systems level where the nurse takes an active role in influencing health policies (CNA, 2000). To be effective in the role of change agent the nurse must be able to anticipate and manage change competently. This requires knowledge of the change process and skill in coalition building, assertiveness, active listening, and conflict resolution (CNA). The nurse must also understand the social and political context of health care, which requires knowledge of health care organizations and how they function, the culture of health care, and issues of power and influence (Atkins & Ersser, 2000). In addition to being knowledgeable, the APN must be in a position to influence and change health policy to ensure quality of health services. This means being positioned on boards and so forth.

The previous discussion relates to the ways in which advanced practice nursing has been conceptualized within the literature. This review tells us what advanced practice should be and what advanced practice nurses can contribute to the delivery of health care. I will now turn to the research literature to determine what is known about the nature of advanced nursing practice. What does the practice of APNs actually involve? What is the nature of the
knowledge that APNs draw on to inform their practice? What contributions do APNs make to health care?

**Research on Advanced Nursing Practice**

In exploring the research on advanced nursing practice, I directed my attention to two main areas of the research literature – those studies that have as their focus the nature of APNs’ practice and knowledge and those studies that focused on the contributions of APNs’ to the health care of individuals with complex health needs and their families.

**Research on the Nature of APNs’ Practice and Knowledge**

The majority of the research on APNs’ practice has employed quantitative methods and has focused on the roles, functions/activities and competencies of advanced practice nurses. While these studies have contributed knowledge of the various components of the advanced practice role and the competencies APNs possess, this body of knowledge has not added to our understanding of the nature of APNs’ practice. Qualitative approaches have been more successful in producing knowledge that illuminates the nature of APNs’ practice and the knowledge that informs it. However, an interesting characteristic of both the quantitative and qualitative research is that the focus is almost exclusively on APNs’ practice with individual clients. This focus is puzzling given the conceptualization of APNs’ clients as “individuals, families, groups, populations, or entire communities” (CNA, 2002, p. 1) and the CNS as “providing solutions for complex health care issues at all levels” (CNA, 2003, p. 1).

**Quantitative Studies of APNs’ Practice and Knowledge**

The majority of quantitative studies of APNs’ practice have used survey designs to describe the various competencies and components of the role (Davies & Eng, 1995; McFadden & Miller, 1994; Scott, 1999; Smith & Waltman, 1994). For example, Scott (1999) employed a quantitative design to survey 724 CNSs regarding how often they performed specific activities within each of the five traditional CNS role components. Results were not particularly informative in that the participants “reported being involved in
clinical practice activities 29%-91% of the time (p. 185), with the remainder of their time spread across their educator, consultant, research, and clinical leadership roles. However, participants’ response to the statement, “List the advanced practice nursing skills that you perform in your role as clinical nurse specialist” did provide data on the nature of APNs’ practice. The nursing skills included twenty-three psychosocial activities and nineteen psychomotor skills, which highlights the technical and psychosocial dimensions of advanced nursing practice. An interesting side issue in this study is the researcher’s reference to the psychosocial dimensions as activities and the psychomotor dimensions as skills. Considering that included within the psychosocial dimension were such “activities” as family therapy, grief therapy, crisis intervention, and depression therapy, one would expect that those activities require as much skill as psychomotor activities do. This distinction between psychosocial and psychomotor suggests a devaluing of the psychosocial dimension of care.

Scott’s (1999) study illustrates the limitations of quantitative approaches to the study of APNs’ practice in that activities and skills do not give a sense of the nature of APNs’ practice nor do they address the context within which the roles are enacted and the factors that influence their practice. For example, in identifying an aspect of clinical practice as participation in interdisciplinary patient care conferences, there is no sense of what this involves. Davies and Eng (1995) employed a similar survey design to describe CNS practice. They found that although the participants clearly described the components of the CNS role and gave examples of activities under each, they concluded that one could not capture the essence of practice by describing the components of the role or producing a long list of competencies.

**Qualitative Studies of APNs’ Practice and Knowledge**

Qualitative studies suggest that APNs’ practice with individual clients consists of both technical and psychosocial dimensions of care (Brykczynski, 1989; Fisher, 1991; Johnson, 1993; Wong, Stewart, & Gillis, 2000) that are underpinned by a holistic approach
and a nursing perspective or framework (Fisher, 1991; Schreiber, et al., 2003; Wilson-Barnett, Barriball, Reynolds, Jowett, & Ryrie, 2000). The technical dimensions of care are associated with the medical aspects of the disease and medically related tasks and psychomotor skills. The psychosocial dimensions of care are associated with the client’s illness experiences and activities such as teaching, coordination of patient care and advocacy. It is apparent from these studies that the psychosocial dimension of care is not as clearly conceptualized as the technical dimension. The terms psychosocial, relational and interpersonal are used interchangeably in the various studies to refer to all dimensions of care that are “non-technical” in nature. Beyond the fact that these “non-technical” dimensions are not clearly and specifically articulated, there are indications within the various studies that the psychosocial dimension is not considered as important or as valued as the technical dimension of care. Only two of the studies discuss APNs’ practice as occurring beyond the level of the individual client to encompass a population or system level perspective (Schreiber, et al’s, 2003; Wilson-Barnett, et al., 2000).

All of the qualitative studies reviewed made a clear distinction between the technical and psychosocial dimensions of care and view APNs’ practice as encompassing both. Brykczynski’s (1989) study of experienced nurse practitioners described participants as addressing both biologic and psychosocial concerns of clients using a holistic approach. In describing the competency of detecting disease while attending to the illness experience of clients, an exemplar was used to illustrate the blending of a nursing and a medical perspective in NPs’ approach to their practice. One participant commented that “What can I do to facilitate the diagnosis and treatment of the disease and what can I do to help the patient psychologically deal with it in the brief time that the patient is with me? These things both have equal value in my practice” (p. 157). Fisher ‘s (1991) study of the negotiation of meaning between nurse practitioners, physicians and women patients had similar findings to those of Brykczynski. Fisher reported that NPs approached patient care holistically and relationally, integrating the medical and the social/biographical into their consultations.
Wong, et al. (2000) also identified the processes of care that APNs and other providers use in caring for clients in a primary care clinic, as being both technical and interpersonal. They defined the technical processes of care as technical competence in performing diagnostic and therapeutic procedures and the interpersonal processes of care as the psychosocial aspects of providing care— the interactions of health care providers and clients. These interpersonal processes were considered to include communication, explanation, and being sensitive to the patient’s needs. They use the term interpersonal rather than psychosocial to refer to the dimensions of care that involve interactions and communication, perhaps because the term more clearly reflects the process of care than does the term psychosocial. An interesting aspect of this study is the reference they draw upon to define the interpersonal process of care. The reference was an article written in 1991 and is oriented toward medical care as indicated by the following quote, “Interpersonal process is defined by Cleary and McNeil as the sociopsychological aspects of the patient-physician interaction” (p. 6). Given that nurses are traditionally the providers who address clients’ psychosocial needs, it is surprising that these nurse scholars did not draw on the nursing literature for a description of the interpersonal or psychosocial aspects of care.

Johnson (1993) approached the study of NPs’ practice from the premise that there are different ideologies or belief systems that guide nursing and medical practice. Medicine is disease-oriented and views the person as a biologic system whereas nursing is person-oriented and is focused on the individual’s response to disease and maintenance of health. Johnson was interested in how NPs actualized these two perspectives in their practice, given that their education involved a “blending” of a nursing and a medical perspective, with a particular focus on the medical management of patients’ health problems. Findings revealed that the NPs in the study viewed their over-arching approach to client care as nursing and the medical aspect of their practice was viewed as part of their nursing perspective. One participant commented, “we’re not mini-docs but teaching [medical] residents to be mini-NPs … we’re teaching them the psychosocial skills they didn’t learn in medical school; that
is the essence of nursing” (p. 155). The psychosocial dimensions of care were identified as nursing’s domain and they included such activities as coordination and continuity of client care, educating/teaching clients, and advocacy. NPs’ viewed these activities as their main contributions to the clinic practice. Advocacy was viewed primarily as the NP acting as translator between the patient and the doctor because they did not speak the same language. The NPs shared a common language with both physicians and clients so they took on the role of translating information between them. Johnson’s study was one of the few that actually reflected a valuing of the psychosocial dimensions of care over the technical aspects of care.

In her response to Johnson’s article, Brykczynski (1993) also emphasizes the significance of the psychosocial aspects of patient care in ambulatory clinics and contends that these “less quantifiable aspects of nursing care … have not lent themselves well to systematic study using quantitative designs” (p. 161). Consequently, Brykczynski notes, nursing knowledge related to such psychosocial aspects of care as “mobilizing hope, energizing active patient involvement, eliciting the support of significant others, and negotiating congruent goals” … have been “unacknowledged and trivialized” (p. 161).

Only two studies were found that described APNs’ practice as encompassing system level goals as well as individual client and family care. A study of nurses in advanced practice roles in Britain was conducted to explore the components of advanced practice from the perspective of experienced clinical practitioners (Wilson-Barnett, et al., 2000). Findings revealed that while the main focus of APNs’ practice was direct care of individuals, which involved comprehensive assessment of patients’ health needs, a second focus was to improve care delivery through continuity of care and better access to care. This goal was achieved by a variety of activities: developing new protocols to provide guidelines for practice and to standardize care, outreach health services, and inter-disciplinary and cross agency health care. Practice was “underpinned by a holistic rather than a technical focus” (p. 398).
A second study that described APNs’ practice as encompassing a systems-level perspective as well as an individual client perspective was Schreiber, et al.’s. (2003) study of nurses in advanced practice roles in British Columbia. The overall goal of the descriptive, exploratory study was to determine the contributions that nurses in advanced practice roles could make to health care delivery in BC. The researchers found “notable differences” (p. 38) in participants’ descriptions of advanced nursing practice that were related to their educational level. Participants with diploma or baccalaureate level education described advanced nursing practice as expert care of individual patients whereas participants with graduate level education described advanced nursing practice from a broader population health or systems-level perspective. The participants with graduate level education viewed advanced practice as encompassing a broad range of roles and responsibilities that were congruent with the CNA competencies of advanced nursing practice and, similar to the findings of Wilson-Barnett, et al. (2000), their approach to practice was holistic rather than technical. Participants made a point of emphasizing that taking on additional tasks was not the advanced practice piece. Rather they viewed advanced practice as “the decision-making, it’s the knowledge, it’s the theory base that makes a practice advanced, it’s not the tasks that are enacted as a result of that knowledge base” (p. 19) and if their practice included medical tasks these were incorporated within a nursing perspective or framework.

In summary, the majority of research on the nature of APNs’ practice and knowledge is quantitative and while a detailed description of the roles and competencies is an important step in achieving an understanding of APNs’ practice, a continuing focus on describing competencies keeps our understanding at a superficial level and ignores the important variable of context in the enactment of APNs’ practice. Qualitative research shows more promise of building a body of knowledge that will increase our understanding of APNs’ practice and knowledge but there remain a number of gaps in this area. For one, more research is needed to illuminate the specific characteristics of psychosocial care and to more clearly conceptualize and articulate this dimension of APNs’ practice. Another area
that requires more research is APNs’ knowledge, as the current research on APNs’ practice focuses on activities – what they do rather than on what they know and how this knowledge informs their practice. Finally, a limitation of both the quantitative and qualitative research on APNs’ practice is that the focus is almost exclusively at the level of the individual client so there is a paucity of research investigating APNs’ practice at the population or system level of health care.

**Research on APNs’ Contributions to Health Care**

To determine APNs’ contributions to health care delivery, I explored the research literature for studies on the outcomes of APNs’ interventions. There is a growing body of research that demonstrates the positive effects of care delivered by advanced practice nurses. Brooten and Naylor (1995) provide an overview of this research and identify a number of interventions by advanced practice nurses that are associated with improved patient outcomes. These interventions included patient teaching, individual counseling, home care, telephone contact, and comprehensive discharge planning. Patient outcome measures that were used in the various studies to determine the effectiveness of APNs’ interventions included patient knowledge, patient satisfaction, functional status, physical status and symptom distress, psychological distress and independence. Cost effectiveness measures included hospital admissions and re-admissions, length of hospital stay, use of acute care services, and return to work. In one of the studies reviewed, the use of a CNS in an emergency department that was frequented by children with poorly controlled asthma, resulted in a significant decrease in emergency room visits for the experimental group compared to the control group (Alexender, et al., as cited in Brooten and Naylor).

Brooten and Naylor (1995) suggest that determining the effectiveness of advanced practice nurses in the provision of quality, cost effective health care raises a number of key questions. What nurse interventions are critical to improved patient outcomes, for which patient group and in which health care environment? Which patient outcomes should be measured? One criterion that Brooten and colleagues insist is key to the effectiveness of
APNs is expert knowledge and skills in a specialty that matches the patient group being studied (Brooten, et al., 2002). They maintain that this expertise is most common in master’s-prepared APNs and it allows them to function more independently and to individualize patient care. Byers and Brunell (1998) agree, maintaining that APNs’ interventions are based on their clinical judgment and theoretical, practical, or scientific knowledge.

On the question of which patient outcomes should be measured to determine the effectiveness of nurse interventions, Brooten and Naylor (1995) reflect on whether studies that demonstrate differences in patient outcomes as a result of APN intervention, might not show greater effects if different outcomes were studied. The question might also be posed regarding studies that do not demonstrate differences in patient outcomes. In such studies is it possible that if different outcomes had been studied, significant differences in patient outcomes might have been demonstrated? As an example, a study by Lombness (1994) examined the relationships between the type of care manager (either clinical nurse specialists or physician assistants working with cardiac surgeons) and outcomes of length of hospital stay and complications for patients undergoing coronary artery bypass surgery. Findings demonstrated that although the patients in the CNS group had a statistically significant shorter hospital stay, the rates of complications among patients were similar for the two groups. The researcher concluded that the similar complication rates between the two groups may be explained by the constant rate of complications following cardiovascular surgery regardless of who manages the care. If that is the case, then selecting complication rates of patients may not have been the best choice. Choosing different outcome measures may have demonstrated more significant patient outcomes between the two groups. Brooten and Naylor say that the question of which outcome measure to use is an important one in the current health care environment where there is a trend to replace RNs with less prepared personnel.
Brooten and Naylor (1995), drawing on Lang and Marek's review of outcomes that reflect the contributions of nursing practice, suggest outcomes such as physiologic status, symptom control, psychological status, functional status, knowledge, quality of life, family strain including caregiver burden, and patient satisfaction with care. They maintain that these outcome measures are likely to provide more informative data for understanding the effects of nursing interventions than would the more global measures of patient mortality and morbidity. The cost of care is also identified as an important measure of nurse outcomes as it is "essential to understand both the benefits and the costs of nursing practices in order to make informed decisions" (Naylor, Munro, & Brooten, 1991, p. 214).

It has been noted that despite the growing body of research that demonstrates the positive effects of care delivered by APNs, data regarding the effects of nursing on patient and system outcomes are limited (Jones, Jennings, Moritz, & Moss, 1997). For example, Jones and colleagues point out that despite all the changes in health care delivery models, nursing has not yet produced the data needed to document the effects of minimal staffing and minimal lengths of hospital stay on patient outcomes. They argue that there is a compelling need to articulate the relationship of nursing interventions to client health outcomes "because what nurses do is unclear to many" (p. 266). It has also been noted that the majority of large health-related data sets contain no information that reflect nursing practice (Wong, Stewart, & Gilliss, 2000). Consequently, there is a lack of data to support the effectiveness of nursing practice and its contributions to patient outcomes.

Wong (1998) argues that nurse-sensitive outcomes must be developed by nurses to capture the knowledge that informs their practice and that makes a difference in the quality of patient care. She suggests that advanced practice nurses, and particularly CNSs, are in an ideal position to develop nurse-sensitive patient outcome measures. As an example, Smith and Waltman (1994) conducted a survey study of CNSs' perceptions of patient outcomes that they influenced through their practice. Findings demonstrated that CNSs perceived that their greatest influence was in the area of patient and family care. Outcomes that CNSs
perceived as positively influenced were patient and family knowledge levels, anxiety levels, satisfaction, coping and self-care abilities. CNSs also perceived that they positively influenced the interdisciplinary process, which included consultation with caregivers and physicians, referral of families to resources, advocacy and facilitation of cooperation among team members. In relation to their perceived influence on cost of care, CNSs identified decreased complications that would result in prolonged hospitalization, use of appropriate care products, and length of stay/timely discharge. An interesting finding was that comments that respondents wrote on the questionnaire indicated their concern with lack of accessibility to information about their impact on economic outcomes. These comments suggest that in addition to determining nurse-sensitive outcomes, the factors that influence these outcomes should also be identified. Wong maintains that qualitative studies may be more effective in determining nurse sensitive outcomes and the factors influencing them than the quantitative approaches that have dominated the area to date.

In summary, there is a growing body of research that demonstrates the positive effects of care delivered by advanced practice nurses. The majority of this research is quantitative and while it has demonstrated an association between patient outcomes and APN interventions, it has been argued that more nurse-sensitive outcomes are required if we are to uncover the nature of APNs’ contributions to patient outcomes. Many of these nurse-sensitive outcomes, such as comfort, do not lend themselves well to quantification and therefore will require qualitative approaches to the study of patient outcomes. Although the recent call for research on the impact of advanced practice nursing on the quality and cost of health care seems to be motivated by the escalation of health care costs (Munro, 2002), an equally important motivation for determining the outcomes of APNs’ interventions is to increase understanding of advanced practice nursing and what it is that APNs contribute to health care delivery.

This first section of the literature review has examined the state of knowledge related to the conceptualization of advanced nursing practice and the research on APNs’ practice
and knowledge and the contributions of APNs to client health care. The next section will explore the context of APNs’ practice and the factors that influence their practice and contributions to health care.

THE CONTEXT OF APNS’ PRACTICE

Advanced practice is enacted within multiple contexts that influence and shape APNs’ practice and contributions to health care. The contexts that I will explore in this section include historical, sociopolitical, and cultural contexts of advanced nursing practice and the factors within those various contexts that facilitate and constrain APNs’ practice and contributions to health care.

The Historical Context of APNs’ Practice

Hawkins and Thibodeau (1996) point out that advanced practice nursing is not unique to the later decades of the 20th century; it just acquired titles and more formal definitions. The early history of advanced practice reveals the roots of the independent nature of APNs’ practice and provides a glimpse of what advanced practice could look like if it were practiced in the ways that nursing leaders envisioned. There are two aspects of this early history that have implications for advanced practice nurses in today’s health care system. These pioneer nurses were practicing at both the individual and population levels of health care and physicians, who were strongly opposed to their independent practice, orchestrated their demise (Creasia & Parker, 2001). Thus, one of the most enduring of constraints on APNs’ practice, physician resistance, goes back to nursing’s beginnings.

Historically nurses in the community in the late 1800s and early 1900s were “developing what can be considered pioneer work in advanced nursing practice” (Hawkins & Thibodeau, 1996, p.18). This pioneer work includes that of Lillian Wald and the nurses at Henry Street Settlement House in New York who practiced independently to promote health and prevent illness for various populations. The early role of nurses in community-based health care was focused on the health needs of the public. Public health nurses identified health needs and set up demonstration projects to address these needs, keeping
records of patient and health statistics to evaluate the usefulness of the service (Creasia & Parker, 2001). An example of such a project was one initiated by Lillian Wald in which she volunteered the services of one of her nurses to the New York City school board in an experimental program to reduce children’s absenteeism from school due to illness. Within one month, the high absenteeism rates were so significantly reduced that the school board hired the nurse and the following year hired an additional twenty-seven nurses to work within the school system. Within two years school nurses were being hired across the country to provide essential health services for children (Creasia & Parker).

The role of public health nurses at the population level included industrial, tuberculosis, and infant welfare nursing. This work expanded the domain of nurses and, more importantly, brought essential health services to the public. According to Bullough (1987 as cited in Creasia & Parker, 2001) nurses’ pioneer activities in health promotion and disease prevention and their stand on welfare reforms were vital in shaping America’s public health system and the discipline of nursing. In 1912, the USA National Organization for Public Health Nursing was formed and became nursing’s first clinical specialty organization on a national level. This organization worked closely with the Children’s Bureau of the US federal government to implement studies to investigate the high infant/maternal mortality and morbidity rates within the nation. The outcomes of these studies drew attention to the need for infant and obstetrical services particularly for low-income rural families and resulted in the establishment of maternal and infant programs for at-risk mothers and children in forty-five states. By 1925, there were over 500 permanent child health and prenatal centres with public health nurses providing thousands of instructional home visits and ensuring that mothers and infants in need of medical care were connected to local physicians (Creasia & Parker). Thus, in their work at the population level these nurses addressed the health needs of specific populations by conducting research and using the outcomes of that research to develop programs. This early history provides a compelling exemplar of what advanced practice could look like if it were practiced in the
ways that nursing leaders envisioned. It also provides APNs with a model of health care that can create a much broader impact on the health of society than a focus at the level of the individual can.

The child health and prenatal centres established and run by public health nurses were terminated in 1929 mainly because of opposition from the American Medical Association. This strong opposition, in combination with the rise of modern hospitals and hospital-based nursing programs, led to the demise of public health nursing (Creasia & Parker, 2001). The theme of physician resistance to nurses’ independent practice runs through the history of advanced practice nursing and remains a strong undercurrent in APNs’ current efforts to establish themselves as independent practitioners.

**The Sociopolitical Context of APNs’ Practice**

The practice of nursing is embedded within the context of a health care system, which in turn is embedded within broader social, economic and political contexts that influence and shape it. Geertz (cited in Schwandt, 1994) argues that “culture is not a power, something to which social events, behaviors ... can be causally attributed; it is a context” (p. 123) and it is constituted by language and other symbols. Culture as a context includes broad societal forces, such as ideologies and discourses, that provide the backdrop for developing policy aimed at the delivery of health services (Singer, 1996). Canadian society is directed by liberal ideologies such as a free market economy and individualism (Browne, 2001) and although these ideologies are often invisible, they exert considerable influence over the delivery of health care and, in turn, over APNs’ role in the delivery of health care.

Market economics has become the dominant model of health care in the past decade and its use has led to a conceptualization of health care as a commodity to be purchased and sold like other commodities (Browne, 2001). Concepts such as consumer satisfaction, cost-effectiveness and competitiveness have turned health care into an industry rather than a human service and the exponential increase of technology in health care has further pushed it in the direction of “big business” (Browne). Kenny (2002) argues that technological
advances in health care have also increased the expectations of the public about the scope and power of medicine, to the point where there is "a kind of pathological pursuit of health and well-being" (p. 76) which has led to "the progressive medicalization of modern life" (p. 88). Kenny argues that medicalization is tied to market forces in which "the bottom line [is] ... profits from dependence on pills and machines" (p. 90).

Brooten and Naylor (1995) provide an example of how politics and economics dominate health care and constrain APNs’ ability to provide quality health care. Brooten and her colleagues’ developed and tested a model of nurse specialist (CNS) transitional care for very low birth weight infants and their families that demonstrated improved outcomes over current practices at lower costs. Hospital costs were 27% less and physician costs were 22% less. However, when CNSs attempted to implement this model nationwide to promote quality, cost effective care they were blocked from doing so by hospitals that were reimbursed by patient days. Consequently, while the CNS care model would reduce health care costs by discharging infants earlier, this could also reduce income to the hospital. Brooten and Naylor point out that in some areas of the country there was also resistance from public health nurses who were concerned that CNSs were infringing on their domain of practice.

The Organizational Context of APNs' Practice

The conceptualization of health care as a commodity impacts on APNs’ practice by creating practice environments in which the priorities are cost-effectiveness, efficiencies and competitiveness. Within such an environment APNs may find themselves in a position of having to justify their role within the organization by demonstrating their cost effectiveness and efficiency. Consequently, their focus becomes efficient use of resources rather than the provision of quality health care for clients and families. Cronin and Maklebust (1989) report on an model that they developed to preserve the CNS role within a hospital setting, by tailoring the role to meet the hospital’s changing needs (which translated to saving the hospital money). Within this model, CNSs were expected to deliver patient care within a
shorter time and to regulate the use of resources — both human and material. The authors report that this CNS model provided several economic benefits and saved the hospital thousands of dollars. There is no mention, however, of evaluating the quality of patient care either from the perspective of CNSs or clients. It is not difficult to see how quality patient care can be compromised in such a setting and the question arises as to the degree of satisfaction these CNSs experience in their work.

The particular organizations within which APNs work contain a number of factors that influence their practice and their contributions to health care. These factors include such variables as the philosophy of the organization, organizational structure, and administrative policies that influence working conditions. The philosophy of the organization is reflected in its priorities and in the model of health care that directs these priorities. A recent study found that management practices that focus on cost efficiency have a huge impact on nurses’ ability to deliver quality patient care (White, 1999). Practices such as classification of patient needs into levels so that standard care can be applied eliminates professional judgment and puts the focus on diagnoses rather than caring for the patient in a holistic way. White argues that these and other management practices such as workload measurement are oppressive in that they displace nursing judgment skills and knowledge of the patient and increase the amount of documentation that nurses must do as part of their job.

Another factor within organizations that impacts on APNs’ practice is the model of health care delivery that is used. Schreiber, et al. (2003) noted that APNs who worked in a program management structure found it challenging because this type of structure is “medically driven” and “not based on patients’ needs” which “obscured nursing’s contribution to patient care” (p. 27). Participants viewed meetings related to program management as taking them away from their practice. Moreover, they often faced heavy workloads, multiple demands on their time, and insufficient infrastructure support. The increased workloads resulted from cutbacks in staff which meant that they took on extra
responsibilities so their own work was done “off the side of their desks” or on their own time” (p. 27). This finding is similar to that of Wilson-Barnett, et al.’s (2000) study in which APNs identified a lack of human resources as a barrier to their practice because they had to spend their time engaged in service activities that could have been done by less experienced colleagues.

A third factor within organizations that has an impact on APNs’ practice is the extent to which APNs feel supported in their role. The most highly educated, expert nurse may not provide good nursing care if the organization does not supply the necessary resources to support nurses in their role. Luker and Kenrick (1995) contend that much of the nursing literature emphasizes that the individual practitioner is responsible for quality service provision when in reality the organization and policy context in which nurses work is a major factor in creating a climate for good practice. Gordon (2000) also comments that many administrators and policy-makers as well as the public do not understand that expert nursing care is a highly organized endeavor that not only requires individual attributes but also institutional ones. There are certain “organizational and social structures and resources that must be in place if good nurses are to provide good nursing” (p. 218).

Administrator or manager support is an important factor influencing APNs’ perception of their role and their satisfaction with their job. The participants in Schreiber, et al.’s (2003) study emphasized the importance of others understanding their role, including administrators, physicians, and other team members as a critical support for their practice. When these supports were missing the APNs perceived their absence as a challenge to their practice, particularly the lack of understanding of their practice and physician resistance (Schreiber et al.). Wilson-Barnett et al.’s (2000) study of nurses in advanced practice roles in Britain found that APNs considered support from nurse managers as essential for the development of their role.

The literature describes a number of ways in which administrative support for the advanced practice role can be demonstrated such as: clarification of the role, integration of
the advanced practice nurse into leadership of the organization at the executive level, economic justification of the role, commitment of resources to the role, and provision of peer support (Hamric, 2000). In Davies and Eng’s (1995) study of the CNS role, the majority of CNSs reported a number of similar indicators of administrative support for their role: clarification of the role throughout the agency by the chief administrative officer; integration of CNS into the leadership of the organization at the nursing executive level which provided the CNS with an opportunity to participate in decision-making regarding nursing issues; availability of the chief nursing executive to the CNSs; economic justification for the role, that is, a salary that is reflective of their clinical expertise and education; and commitment of resources to the role, for example secretarial support or money to attend conferences. The importance of infrastructure support was also identified by APNs in Schreiber, et al.’s (2003) study.

The Nursing Culture Context of APNs’ Practice

As discussed above, culture is a context that is constituted by language and other symbols and including broad societal forces, such as ideologies and discourses. The culture of nursing is a powerful context within which APNs’ are educated and practice. Dominant conceptualizations of advanced practice and advanced practice knowledge exert a strong influence on the education of advanced practice nurses, the ways in which these nurse view and enact their practice, and the nature of the research under taken to clarify advanced practice (Styles & Lewis, 2000). The first section of this chapter discussed the ways in which advanced nursing practice and knowledge have been conceptualized within the nursing literature. This section examines the impact those conceptualizations have on APNs’ views and enactment of their practice and the research undertaken to add to the knowledge base of advanced practice.

Conceptualizations of Advanced Nursing Practice

The Canadian Nurses Association’s Framework (2002) for advanced nursing practice is the dominant conceptualization of advanced nursing practice in Canada and
provides direction for education, practice, and research related to advanced nursing practice. Within this framework, advanced practice is viewed as a set of core competencies that are enacted within five broad domains: clinical practice, research, leadership, collaboration, and change agent. To give a sense of the breadth of the advanced practice role, there are 34 competencies identified within the five domains. It is noted within the framework that “it is the effective interaction, blending, and simultaneous execution [of the competencies] in highly complex practice environments and health care organizations that characterize ANP” (p. 6). The CNA position statement on the clinical nurse specialist (2003) includes the same competencies but identifies the five domains of CNS practice somewhat differently as practitioner, consultant, educator, research, and leader. While it is suggested that the balance among the five domains will vary depending on clients’ needs and the setting, the expectation is that the APN will do all of it.

The above conceptualization of advanced nursing practice exerts a major influence on APNs indirectly through influencing the research on advanced practice and directly in terms of the way they view their practice and their role. The majority of research done to clarify the advanced practice role is quantitative and has focused on the roles, activities and competencies of nurses in advanced practice roles. Most of these studies use the definitions established by professional associations such as the CNA (2002) and ANA (1995) as their conceptual framework. Consequently, the original conceptualizations of advanced practice put forth by professional nursing bodies are confirmed. There appears to be no recognition or acknowledgement within the literature that these conceptualizations may be problematic so they remain unchallenged. I would argue that the expectations placed on APNs through these conceptualizations are highly unrealistic and in insisting that they demonstrate all these competencies and enact all these roles, we are setting them up for failure.

In a recent study by Schreiber, et al. (2003), there is evidence that APNs see their practice as involving the multiple roles and competencies of the CNA framework (which was used as the conceptual framework for the study) and there are also indications that they
had difficulty fulfilling some aspects of these roles. Participants described their practice as involving “direct patient care, research, coordination of care, education, policy and program development, administration, leadership, and consultation” (p. 18) and they viewed advanced practice as including all (my emphasis) of these components. It is not surprising that these participants said they were “spread thin” and that research was not done at all or done “off the side of their desks” (p. 21). It is also likely that continuing to be spread thin and to not meet the expectations of their role creates the potential for burnout.

Qualitative research on APNs’ practice provides a different perspective, a more ‘up close and personal’ view of practice. What this research demonstrates is that APNs’ practice involves both technical and psychosocial /relational /interpersonal dimensions of care (Bryczynski, 1989, Fisher, 1991, Johnson, 1993, Wong, et al., 2000). These dimensions are underpinned by a holistic approach and a nursing perspective or framework (Fisher, 1991, Schreiber, et al., 2003, Wilson-Barnett, et al., 2000). This approach to practice creates difficulties for APNs who work within a health care system dominated by a biomedical/technical approach to health care. An ongoing tension between nurses and physicians has resulted from the lack of acknowledgement by physicians of the relational side of health care. In her study of the negotiation of meaning between nurse practitioners, physicians and women patients, Fisher (1991) urged nurses to take their private interactions public - to create public discourses about the nature of health care. However, within the current high-tech health care environment with its emphasis on cost-effectiveness and efficiency, it appears that the relational aspects of health care are not valued or seen as relevant. Relating to patients as persons and attending to their lived reality is not acknowledged in any formal way nor taken into account in the planning of health care (Bjornsdottir, 1998). Consequently, a large part of APNs practice is being ignored or discounted.
Conceptualizations of APNs’ Knowledge

What distinguishes advanced practice nurses from other nurses with less preparation and from physicians is the knowledge that underpins their practice and the way in which they use this knowledge to direct their practice (Hamric, 2000). As previously noted, the CNA document on advanced nursing practice is based on the assumption that “it is the application of advanced nursing knowledge that determines whether nursing practice is advanced, not the addition of functions from other professions” (CNA, 2002, p. 4). Therefore, nurses in advanced practice roles must acquire and apply this knowledge in their practice to fulfill their practice mandate. Moreover, since knowledge is the primary distinction of advanced practice nurses, articulation of this knowledge provides a means for increasing understanding of the contributions that APNs make to the delivery of health care. Consequently, understanding of the knowledge that APNs require in their advanced practice role is critical to the development of APN education and practice as well as to the progress of advanced practice.

The kinds of knowledge that APNs are said to possess are variously identified within the advanced practice literature as: theoretical, research-based, and experiential nursing knowledge (Hamric, 2000), theoretical, empirical, ethical, and experiential knowledge (CNA, 2002, p. 5), theoretical knowledge from theory and research from nursing and other disciplines (Kappeli, 1993; Manley, 1997; Smith, 1999), and theoretical, practical and research-based knowledge (ANA, 1995). Thus, APNs have theoretical, empirical, experiential / practical (these two are used interchangeably) and ethical knowledge, which are the kinds of knowledge that all nurses draw on to inform their practice (Chinn & Kramer, 1999). How then does the in-depth knowledge that APNs have differ from that of other nurses who are not in advanced practice roles? Turning to the research on APNs’ knowledge to answer that question was of little help as I found one study only that directly investigated APNs’ knowledge. Brykczynski (1989) studied NPs to uncover the knowledge embedded in their clinical practice, which she identified as practical knowledge.
Chinn and Kramer (1999) offer an explanation for the paucity of research on APNs’ knowledge. They contend that formal knowledge development in nursing has been dominated by empiric knowledge development. They describe the situation as “the empiric pattern of knowledge gone wild” (p. 14). Moreover, the authors maintain that knowledge has become associated with empirical knowledge to the exclusion of other forms of knowledge or ways of knowing. Brykczynski (1993) makes a similar observation saying that the psychosocial aspects of nursing care such as “mobilizing hope, energizing active patient involvement, eliciting the support of significant others, and negotiating congruent goals … has until recently been unacknowledged and trivialized” (p.161). This association of knowledge with empirical knowledge has not only dominated the research on knowledge development but it has also dominated the practice arena. In Bjornsdottr’s (1998) ethnographic study of nursing practice in acute care hospitals, she observed that technical knowledge dominated the health care arena while relational knowledge was driven underground by the dominant system’s rejection of it as subjective and therefore not knowledge. Given that the research on advanced nursing practice demonstrates that APNs’ practice involves both technical and relational dimensions of care, there is a pressing need for research beyond empirics.

Chinn and Kramer (1999) argue that one of the repercussions of an over-reliance on the development of empirical knowledge has been the view of knowledge development as separate from practice. Traditional methods of science have considered the practice arena unsuitable for the development of empiric knowledge, which Chinn and Kramer maintain makes the practice implications of empirical theory not obvious or readily applicable to the practice setting. They call for a shift in the development of knowledge to reflect other forms of knowledge or ways of knowing such as ethical, aesthetic, and personal knowledge, which they argue compels researchers to immerse themselves in practice. They suggest that in addition to developing knowledge on these other types of knowledge, the shift in focus will displace empirics as the center of the knowledge universe and it will become one way of
knowing. Moreover, they maintain that the use of methods beyond empirics can challenge many of the assumptions underlying empiric methods, "opening the way for creating empiric methods that better accommodate the contingencies of practice" (p. 14).

**Conceptualizations of the Relationship between APNs’ Knowledge and Practice**

Understanding how APNs’ knowledge informs their practice requires an understanding of how the interaction of knowledge and practice has been conceptualized. A discussion of the relationship between nursing knowledge and nursing practice has surfaced in the literature in the form of the theory-practice debate: that is, the debate regarding how theory and practice interact (Fealy, 1997). The relationship between knowledge and practice has been conceptualized in three main ways. A traditional view, which has remained dominant in contemporary nursing discourse, is that knowledge is derived from empirical research and it is applied to practice situations. A second view is that abstract knowledge interacts with knowledge drawn from the particularities of practice situations and, in the process, is transformed. A third view is that nurses draw knowledge from the social context of their practice and this knowledge informs their actions.

The traditional way in which the theory-practice relationship has been conceptualized in nursing is the applied science approach in which “theory as objective evidence derived from empirical investigation” guides and regulates practice (Fealy, p.1062). In this conceptualization, theory and practice are viewed as separate endeavors. Chinn and Kramer (1999) make reference to this view in their comments that the development of empiric knowledge has perpetuated the view that knowledge development is separate from practice.

A second view of the relationship between knowledge and practice is that they interact and in the process knowledge is transformed. This view was put forward by Benner (1984, 1994) who found that expert practitioners drew information from the particular clinical encounter they were engaged in, as well as from their bank of general theoretical and research knowledge. She argued that it is the coming together of general and particular
knowledge that provides the basis for nurses’ actions. And this knowledge of the particular comes out of nurses’ extensive experience in similar clinical encounters. Thus, rather than theory being applied, Benner sees it as being transformed in particular practice situations. This idea of abstract knowledge being transformed, rather than applied, is also supported by Chinn and Kramer (1999) who contend that while theories, principles and facts can be learned, “their meaning for the individual results from personal reflection and experience with the phenomena of the theory” (p. 6). They contend that formal knowledge is transformed into personal knowledge and communicated through the presence of a genuine, embodied self and through deliberate action.

One of the criticisms of the conceptualization of knowledge as being transformed by the particularities of a practice situation is that it does not account for the social context in which nurses practice. Purkis (1994) critiques Benner’s contention that expert nurses base their expertise on pattern recognition that influences future actions. She argues that this conceptualization ignores the context of interaction from which the pattern emerges. Purkis suggests that what nurses are responding to is a wider social knowledgeability and Benner’s conceptualization of experience does not account for this. In one case given by Benner as an example of expert practice, Purkis re-reads it as the nurse “propping up existing power relationships through discursive strategies” (p. 331). Purkis claims that the social context of practice influences nurses’ understandings of their practice and informs their actions. She contends that nurses draw on knowledge of the social and in particular on “readings of the social context in which nursing is practiced” (p. 116) and she sees practice as the production and reproduction of institutionalized practices.

In summary, to pursue an understanding of the knowledge that informs APNs’ practice, it is important to understand the ways in which the relationship between knowledge and practice has been conceptualized. These conceptualizations include: empirical knowledge is applied to practice situations, abstract knowledge is transformed through
interaction with practice knowledge, and the knowledge that informs nurses’ practice is drawn from the social context of their practice.

Summary of Chapter Two

In this chapter, I explored the current state of knowledge related to advanced practice nursing and the range of factors that influence it. The most commonly recognized advanced practice roles in Canada are the clinical nurse specialist (CNS), and more recently, the nurse practitioner. In examining the advanced practice literature, there is a sense of conceptual confusion surrounding the concept of advanced practice, which may be related in part to the variety of terms used to describe elements of the role, such as domains, roles, competencies, functions, activities, and skills. A common theme running through all of the characteristics and competencies of an advanced practice nurse, however, is the expert knowledge and skills required of these nurses to enact their role. While the knowledge and skills are explicitly identified within the literature, there is little understanding of the nature of this knowledge or how it actually informs APNs’ practice.

The majority of the research on advanced practice has been conducted from a quantitative perspective and has focused on describing the components of the role and APN competencies, which does not add to our understanding of the nature of APNs’ practice or the knowledge that informs it. Qualitative studies that have been done reflect the nature of APNs’ practice as both technical and relational and as guided by a holistic approach and a nursing framework or model. Research on APNs’ contributions to health care has focused on the association between APN interventions and patient outcomes. Again most of this research is quantitative so it is difficult to get a sense of the nature of APNs’ contributions to the health care of individuals or populations. There has been a call for more nurse-sensitive patient outcomes if we are to uncover the nature of APNs’ contributions to health care.

The factors that influence and shape advanced practice and APNs’ contributions to health care were discussed within the historical, sociopolitical, and cultural contexts in which
these nurses practice. An exploration of the historical context of APNs' practice demonstrates the roots of independent practice and the factors that have facilitated and restricted it. Discussion of the sociopolitical context of APNs' practice examines the impact of a free market economy on the delivery of health care and, in turn, on APNs' role in the delivery of health care. Another influence on APNs' practice within the sociopolitical context is the organizations in which APNs' work. Much of the literature on the factors that influence APNs' practice, either positively or negatively, address the organizational context of APNs' practice. Finally, the cultural context of APNs' practice is discussed from the perspective of the nursing culture and the conceptualization of advanced nursing practice and advanced practice nurses' knowledge as major factors within this culture that facilitate or constrain APNs’ practice.

This review was helpful in relation to selecting a theoretical perspective for examining APNs’ practice and knowledge and the contextual factors influencing their practice. First of all, it provided me with a conceptualizations of advanced nursing practice and nursing knowledge to use in approaching this study. The view of advanced nursing practice as a specialized body of knowledge that APNs draw on to inform their actions directed my focus to participants’ perceptions of their actions and the knowledge informing their actions. The view of knowledge as multiple ways of knowing led me to a consideration of the various kinds of knowledge that the participants talked about as informing their actions. And the views of how knowledge and practice interact directed me to look for the ways in which the participants talked about applying and/or transforming knowledge in the practice setting, as well as the ways in which their social context informed their actions. In addition, the various contextual factors identified within the literature as impacting on APNs’ practice provides a theoretical lens for investigating the context of APNs’ practice.
CHAPTER THREE
RESEARCH DESIGN AND IMPLEMENTATION

A review of the current state of knowledge regarding advanced nursing practice and the context of APNs’ practice provided direction for selecting a theoretical and methodological approach to the study of APNs’ place in the community-based health care of children with complex health needs and their families. First of all, APNs’ practice has been conceptualized and studied predominantly from an empiricist approach. This approach has produced knowledge of the competencies that APNs need to fulfill their role but not how they employ these competencies in the provision of health care. Consequently, we have little understanding of the nature of APNs’ practice or the knowledge that informs it. To move beyond knowledge of competencies, I wanted to elicit APNs’ understandings of their practice and the knowledge that informs it. This perspective is missing from the literature and I concur with Atkinson (1997) and others that researchers must begin their analysis of social situations with the “everyday understanding” of social actors because it is the means whereby they construct their reality (p. 332). Moreover, entering a research study from the standpoint of study participants provides them with a voice and this was an important consideration for me in studying the place of APNs’ in community-based health care.

A second consideration that provided direction for selecting a theoretical lens to guide this study is that although the literature suggests that there are various contextual factors that influence APNs’ practice, the context of their practice has received little research attention (Styles & Lewis 2000). To gain an understanding of the place of APNs in the organization and delivery of health care I needed to move beyond their understandings of their practice to the wider social context in which their practice is located. With these considerations in mind, I found that an interpretive perspective provided theoretical and methodological guidance for the conduct of this study.
This chapter is divided into two main sections: the first is a discussion of the philosophical and theoretical underpinnings of the study, including the perspective I brought to this inquiry. The second section is the application of these perspectives to the study of the place of APNs in the organization and delivery of community-based health care for children with complex health needs and their families. In this second section I provide details of the research design, including a rationale for the method of choice and a delineation of the processes involved in reaching the findings. I also discuss scientific rigor and ethical considerations.

**Philosophical and Theoretical Underpinnings of the Study**

The perspective that a researcher brings to an inquiry is the most important component of any study. The researcher's perspective is determined not only by her own values and beliefs but also by such factors as the philosophical and theoretical position in which she chooses to locate her study (Thorne, 1991). All researchers approach their research from a particular worldview, which includes a set of basic beliefs about the nature of reality and how it can be understood and studied (Guba & Lincoln, 1994). Although these beliefs are usually not articulated in research reports, they influence every step of the research process including the question, sample, method, data analysis and most importantly, the findings.

Other factors that determine the perspective a researcher brings to an inquiry include the traditions of the researcher's particular discipline (Thorne, 2001) and the historical context into which the study emerges (Thorne, Joachim, Paterson, & Canam, 2002). For example, a current frame of reference that defines acceptable forms of inquiry and acceptable knowledge is the critical perspective, which puts forth the view that social organizations and structures are appropriate starting points for social science inquiry (Clandinin & Connelly, 1994). Another frame of reference is that experience is the starting point for all social science inquiry since the social sciences are concerned with humans and their relations with themselves and their environment (Clandinin & Connelly).
Although Lincoln and Guba (2000) identify five major worldviews or paradigms that structure qualitative research, they acknowledge that “the various paradigms are beginning to ‘interbreed’” (p. 164) and that theorists who locate their work in different paradigms are beginning to inform one another’s arguments. I agree and while I locate my research as fitting within an interpretivist\(^1\) paradigm, this is not an exclusive affiliation as I also drew on ideas from the critical-emancipatory and feminist-poststructural paradigms to inform and expand my thinking in relation to my research. I will proceed by first discussing the disciplinary perspective I bring to this inquiry and then I will discuss the premises of the interpretivist paradigm that provided direction for the conduct of this study. Finally, I will discuss some of the ideas I drew on from narrative theory that also provided direction for this study.

**The Perspective I Bring To This Inquiry**

The perspective I bring to this inquiry is based on twenty-five years of experience as a nurse educator, clinician and researcher in pediatric nursing and family health care. It became evident to me early on in my practice that the most effective way to help children cope with a health problem was to help their parents cope. Thus, the main focus of my research has been parents of children with chronic illnesses or disabilities and their experiences in caring for and seeking health care for their child. My previous studies focused on parental coping with a child’s chronic health condition (Canam, 1986, 1987), and the development, implementation, and evaluation of a parent education program for parents of children with chronic health conditions (Canam, 1990, 1993, 2001). I have conducted both quantitative and qualitative research with interpretive description and phenomenology as the primary approaches for the qualitative studies. The overall purpose of my research has been to produce knowledge that would improve health care services for

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\(^1\) There is a difference among theorists regarding the naming of the various paradigms. For example Denzin and Lincoln (2000) refer to a constructivist-interpretive paradigm (p. 20). Lincoln and Guba (2000) refer to a constructivist paradigm (p. 164) and Schwandt (2000) refers to an interpretivist paradigm. I have chosen Schwandt’s label as his explanation of an interpretivist paradigm fits most closely with my epistemological beliefs.
families of children with chronic health conditions. The impetus for shifting the focus of my research from parents to nurses came out of the findings of my previous studies. Parents consistently reported the most stressful aspect of their caregiving role was trying to procure health services that were nonexistent, inconsistent or un-coordinated. As mentioned in chapter one, I found this puzzling given that nurses were supposedly coordinating health care, facilitating continuity of care, and supporting clients and their families to enable them to assume control of decisions affecting their health (RNABC, 1998).

My initial study of nurses who provide health care for children with chronic health conditions and their families was a qualitative study of nurses who provided in-home nursing care for children with complex health needs, many of whom were technology-dependent. The study also included in-depth interviews with parents about their experiences of having nurses caring for their child within the home setting (Canam, Bassingthwaighte, & Cunada, 1994). The findings from that study shed light on the factors influencing nurses’ ability to provide health care within the home setting. However, this population of children and families is relatively small compared with the general population of children with chronic conditions whose families manage the ongoing care of their child with periodic assistance from health care providers. I wanted to study nurses who provided health care for this broader population of children and families to gain their understandings of their practice and the ways in which they contribute to the health care of children and families.

**Interpretivist Paradigm**

The interpretivist worldview came about in large part as an alternative to the positivist view of the social sciences which purports that the study of social phenomena should be approached in the same way as the study of natural phenomena (Moss, 1996). The founders of interpretivism argued that the subject matter and the aims of the social sciences are fundamentally different from the subject matter of the natural sciences and require different methods (Moss). Interpretivists contend that the aim of human or social sciences is to
understand human action and the meaning of social phenomena whereas positivists argue that the purpose of any science is explanation (Schwandt, 2000).

The domain of social science is made up of subjects “who in the routine course of their every-day lives, are constantly involved in understanding themselves and others, and in interpreting the actions, utterances and events which take place around them (Thompson, 1990, as quoted in Moss, 1996). These subjects cannot be understood by simply observing them nor can they be understood “by simply eliciting and aggregating the perspectives of individual actors. The meanings are intersubjective and partially constitutive of the practices to which they refer” (Moss, p. 21). The object domain of social science consists “largely of symbolic constructions - texts, products, performances and actions - that reflect the meanings, intentions, and interpretations of the individuals who produce and receive them” (Moss, p. 21).

Two basic assumptions that underlie the interpretivist worldview are that human (social) action is inherently meaningful and to understand the world of meaning, one must interpret it (Schwandt, 2000). Moreover, humans are seen as situated in the world, historically and socially, so meanings are tied to context (Schwandt, 1994). Thus, interpretivists are primarily concerned with the situated meanings of everyday life, which can be studied through a variety of approaches. The focus of investigation for interpretivists is the meanings (understandings) that social actors construct about their actions and/or experiences, and more specifically, the processes by which these meanings are created within a specific context (Schwandt). The kind of meaning that interpretivists seek is “the intersubjective meanings and symbolizing activities that are constitutive of social life” (Schwandt, 1994, p. 120). This position holds that meaning or understanding is constructed by individuals, not as a solitary endeavor, but in interaction with others and drawing on a shared culture of language and other social processes. Thus, to understand the world of meaning, it must be interpreted through clarifying the meanings inherent in language and actions (Schwandt).
Approaches to Interpretive Understanding

Schwandt (2000) discusses three approaches to interpretive understanding that constitute the interpretive tradition. The first approach focuses on the meanings individuals give to their experiences and what that reflects about their interior life. A second approach focuses on how individuals interpret their own and others actions as meaningful through an analysis of conversation, “the sequential, utterance-by-utterance, socially structuring features of talk or talk-in-interaction” (Gubrium & Holstein, 2000, p. 422). The third approach focuses on human talk and action as meaningful by virtue of the system of meanings to which it belongs, including institutional and cultural norms; that is, “the collective generation of meaning as shaped by conventions of language and other social processes” (p. 127). I found the concept of systems of meaning useful, not in the linguistic sense, but in viewing APNs’ understandings as belonging to systems of meaning, including institutional and cultural norms, discourses, and ideologies. Viewing it in this way, provided direction for examining the social context of APNs’ practice, through the cultural norms, discourses, and so on that participants took up to make sense of their practice. Context is critical in this interpretive approach in that the individual’s representation of her or his ideas and experiences is viewed as being shaped by the context in which she or he is located (Kim, 1998).

A central epistemological issue for interpretivists is maintaining a balance between objectivity and subjectivity particularly as it relates to their position in the investigation of meaning. While on the one hand they privilege subjective experience, on the other hand “they seek to disengage from that experience and objectify it” (Schwandt, 1994, p. 119). Attempts to synthesize phenomenological subjectivity and scientific objectivity have been undertaken by interpretivists in various ways. One way is through the “judicious use of method” (p. 119). Other interpretivists have overcome the opposition of subjectivity and objectivity by refusing to see them as opposites. Rather they argue that “the activity of interpretation is not simply a methodological option open to the social scientist” (p.119) but
a basic condition of all human inquiry. However, this position does not acknowledge that there are various degrees of interpretation in the investigation of meaning. For example, in interpreting APNs’ understandings of their practice and the knowledge that informs it, I wanted to capture their understandings so I stayed close to their expressions and made extensive use of direct quotes to describe their perceptions. However, in examining the social context of their practice, I took a more objective stance and drew on theoretical and empirical knowledge to inscribe and fashion meaning from the language they used to describe their practice.

In summary, an interpretive perspective provided direction for this study in the following ways: First, it directed me to access APNs’ understandings of their practice through the situated meanings of everyday life and to access those meanings through language. I decided on qualitative, open-ended interviews in which participants could talk about and reflect on the everyday realities of their practice world. Second, in viewing meaning/understanding as drawing on a shared culture of language and other social processes, I sought to link participants’ everyday understandings to the larger social context in which their practice is enacted, through the language they used to describe their understandings. Third, I found the epistemological issue of maintaining a balance between objectivity and subjectivity provided the impetus for me to think through my position in relation to the process of interpretation.

Another perspective that I drew on to provide direction for this study was narrative theory. Although I had considered narrative inquiry as a methodology to guide the conduct of this study, in the end I did not do a narrative study. I did, however, find many of the ideas from narrative theory useful in guiding my thinking in various stages of the research process.

**Narrative Theory**

One area in particular in which narrative theory provided direction for this study was in accessing the social context of APNs’ practice through their language. The idea that
individual accounts of experience are grounded in social, cultural, and historical contexts and that these contexts are an essential aspect of the meaning-making process is widely accepted among narrative researchers (Chase, 1995; Mishler, 1986; Morgan, 1999; Riessman, 1993; Silverman, 2000). Morgan contends that: “all speakers are embedded in social contexts, making use of social resources to constitute their experiences, whether these are experiences of health, illness, or professional practice” (p. 69). Richardson (1990, as cited in Silverman, 2000) contends that to participate in a culture is to participate in the narratives of that culture; narratives that are told from the point of view of those in positions of power. And Chase contends that through analyzing narrative accounts one can “learn about the ways in which culture marks, shapes and/or constrains this narrative; and the ways in which this narrator makes use of cultural resources and struggles with cultural constraints (pp. 20, 22). This view of speakers as culturally embedded subjects who draw on shared cultural resources to make themselves understood, was useful in directing me to the language APNs’ used. Posing questions to the data, such as: what social, cultural, historical, or political discourses are APNs drawing on to understand and communicate about their practice was helpful.

I also found Atkinson’s (1997) perspective on narrative analysis helpful in directing me to link APNs’ understandings of their practice to the wider social context in which their practice is situated. Atkinson argues that although researchers must begin their analysis with the “everyday understanding” of social actors because it is the means whereby they construct their reality (p. 332), he cautions researchers not to privilege the person as an autonomous narrating subject. He maintains that it is the work of researchers to subject narratives to the same systematic social analysis as any other forms of data. Arguments put forth need to be grounded in a systematic analysis of the narratives rather than “unsubstantiated assertions, derived from a collection of personal convictions” (p. 339). He argues, “we will not produce good research on the social world by stripping out the social, replacing it with solitary voices or individualized versions of experience” (p. 343).
Atkinson emphasizes the importance of gaining a sense of how the narratives are constructed in interaction with others and how they are shaped by particular social contexts.

Finally, I found Bruner’s (1986, as cited in Richardson, 1997) conception of the two basic and universal human cognition modes as logico-scientific and narrative, particularly useful in understanding the nature of the difficulty APNs had in articulating their practice. Bruner contends that while both narrative and logico-scientific modes of thinking are “rational ways of making meaning” (p. 28) each provides a distinctive way of constructing reality. The logico-scientific mode looks for universal truths and is acontextual whereas the narrative mode is “contextually embedded” (p.28) and looks for specific connections between events. This “contextually embedded” way of thinking was evident in all of the participants’ accounts and was in sharp contrast to the logico-scientific mode of thinking that was evident within the dominant system of health care.

In summary, an interpretivist perspective and narrative theory informed this qualitative study by providing direction for the design and implementation, which will now be discussed.

The Research Design

The focus of this inquiry is understanding the place of APNs in the organization and delivery of community-based health care for children with complex health needs and their families, through an investigation of APNs’ understandings of their practice and the contextual factors that influence and shape it.

Research Questions

The overall research question driving this study is:

What is the place of APNs in the organization and delivery of community-based health care for individuals with complex health needs and their families?

Subsumed under this general question are three sub-questions:
1. What are APNs' understandings of their practice, the knowledge that informs it, and their contributions to the community-based health care of children with complex health needs and their families?

2. What do APNs see as the factors that influence their practice and their contributions to the health care of children and their families?

3. How are APNs’ understandings shaped by the social context in which their practice is situated?

**Method**

The most useful approach to accessing APNs’ understandings is to do in-depth interviews with nurses who can reflect on and discuss their practice. Thus, the primary method used in this inquiry was interviews with advanced practice nurses whose practice involved the organization and delivery of community-based health care for children with complex health needs and their families. Since the interview was the central means of understanding nurses’ perspectives of their practice, I gave a lot of thought to how these interviews would be approached. To begin, I considered and referred to the interview as a conversation with nurses about their practice, to convey the message that I wanted to talk with nurses not interview them. All conversations were audio taped and transcribed.

Following each conversation, participants were sent a copy of their transcript with a covering letter (Appendix E) to provide them with the opportunity to reflect on the account of our conversation and to add to or change it in any way that more clearly illustrated their practice. All but two of the participants wrote comments directly in the margins of the transcript and/or in an additional note. They clearly put a lot of thought into their written responses. All written comments were included as part of the data.

The other source of data was field notes. I began writing field notes on my first contact with participants, which was usually on the phone. I noted any questions or comments they had related to the study or their work, and the general tone of the conversation. Directly after each conversation I wrote field notes on my observations of the
process, our interactions, and anything that stood out for me. In most cases, I also sat and listened to the tape as soon as the participant left and made notes on anything that I remembered from the conversation that would not be picked up by the transcriptionist, such as body language or facial expression. I found this particularly useful later when I read the transcripts while listening to the tapes, as the notes I had initially made contained comments/questions that I would have forgotten without the prompting of the notes.

**Recruitment**

The participants for this study were recruited from a population of nurses whose positions involved the organization and/or delivery of community based health care for children with chronic health conditions and their families. Most of these nurses worked within ambulatory programs of a large tertiary care pediatric hospital and some were connected with specific programs within the inpatient area. A small number had positions within the community. Sampling was purposive with regard to recruiting nurses who worked in ambulatory programs, inpatient programs, and community health programs. Also, I sought nurses who had worked in their current role for a minimum of three years. I sent letters to nurses in pediatric advanced practice roles, describing the study and asking them to contact me if they were interested in participating (Appendix A). I wanted to convey to nurses that what they had to say is important and that I wanted to hear their perspective. Participants were also recruited through the snowball technique, in which those who participated told others about the study and they in turn volunteered to participate. For nurses who agreed to participate in the study, we established a time and place of convenience to them for the conversations to take place.

**Study Participants**

Sixteen nurses, who organized and provided community-based health care for children with chronic health conditions and their families, participated in the study. Ten of the sixteen participants are clinical nurse specialists and six are nurse clinicians. Eleven participants have a Master’s degree; nine have a Master’s in nursing, one a Master’s in
family studies and one an MBA in health administration. Five participants have a BSN and two of the five were enrolled in a Master’s in nursing program at the time of the study. The majority of the participants (12) have been practicing for more than 20 years. Of the four participants who have been practicing under twenty years two have practiced for nine years, one 14 years and the other 18 years. Nine of the nurses had been in their current position ten years or longer and the other six had been in their current positions for two to four years. Thus, these nurses have extensive experience in working with children with chronic health conditions and their families.

Participants were employed in sixteen different programs that shared one commonality. All of the programs offered diagnostic and/or treatment services for children with chronic health conditions and their families by a multidisciplinary health care team that included occupational therapists, physiotherapists, speech pathologists, social workers, psychologists, and physicians. Thirteen of the programs are located within a pediatric tertiary care institution and the other three are located within the community. Of the thirteen programs within the tertiary care institution, nine are ambulatory programs, which provide diagnostic and/or treatment and/or co-ordination of services within the community for various populations of children with complex health needs and their families. Of these nine programs, two are strictly diagnostic, providing no treatment or follow-up services, and seven provide diagnostic, treatment and co-ordination of services. The other four programs in tertiary care are located within inpatient settings of the institution and the APNs work with nurses who provide care for a specific population of children and families. Of the three programs located within the community, all three APNs work with nurses who work with specific populations of children and families. Whether working directly with children and families or with nurses, APNs articulated that their goal is the provision of quality health care for children and families.

As a reflection of the current health care environment, by the end of this study, seven participants had changed jobs and four were no longer employed. Of those who changed
positions, five participants cited their reasons for leaving their current positions as their increasing frustration with not being able to make the changes they saw as necessary to improve the delivery of health care. Of the four who were no longer employed, two had retired (only one of which was an official retirement), one was off on stress leave, and one had been “let go” because her position was being upgraded to a CNS position and she did not have the qualifications (a masters degree).

Data Collection

The Context

My goal was to create a context for the conversation in which nurses would feel comfortable reflecting on their practice and the factors influencing their practice. Participants were given a choice as to where they would like to meet for our conversation and all of them chose my home office, most likely because it is close to their place of work and most participants came after work. While they read and signed the consent form I made tea and snacks. I wanted to provide a transition from their workday and give their blood sugar a boost! The room in which the conversations took place had big stuffed chairs and a comfortable couch. Most of the participants sat on one side of the couch and I sat on the other with the tape recorder on the coffee table in front of us, but not in our line of vision. A few sat in one of the chairs across the coffee table from me because they had bad backs and the chairs provided more support. The seating arrangement provided an atmosphere more conducive to a conversation than an interview, which is what I wanted to create. Before I turned the tape recorder on we chatted about general things. Some were feeling harassed by a busy day with too many things to deal with. It was as if they needed to get the stresses of the day off their chest before they could relax and reflect on their practice. If there was anything discussed that I thought might be important to include I came back to it later during our taped conversation. Demographic data was collected on each participant at the beginning of the conversation before the tape recorder was turned on (see Appendix C). One thing that stood out for me was that many of the participants were concerned about
whether they would be able to contribute to the study; that is, rather than approaching the conversation with an attitude of ‘do I have something to say!’ they approached it more with an attitude of, ‘I don’t know that I can contribute anything’. At first I thought it was because I had not been clear enough in the participant letter but I came to realize that this worry of not having anything to say is reflective of a deeply entrenched attitude and is demonstrated in the difficulty that APNs have articulating their practice. Having said that, once they began to talk about their practice, it was like opening a faucet. All of the conversations were at least an hour and a half and some lasted over three hours. During the conversations there were many long stretches of talk by the participants without interruptions by me. These stretches of talk included descriptions of events of importance to the participant and stories. Most of my comments were short phrases asking for clarification, expansion or an example. I ended up with over 800 pages of transcript.

The Conversations

I started with an orienting statement (Appendix D) to direct participants’ attention to the focus of the study in which I told them that I was interested in their practice and the ways in which they contribute to the health care of children and families. I also told them that I was interested in understanding the knowledge they draw on in their practice as well as their perceptions of the factors that influence their practice. To enter the realm of their practice, I began the conversation by asking participants to tell me about the population of children and families with whom they worked and what the central health issues/problems of these children and families were and then I asked them to tell me about a particular child and family that illustrated these problem(s). This directed the focus to clients rather than to nurses’ practice and it was only in a later conversation with a colleague that I realized this approach reflected one of my biases. My colleague was doing a similar study (in another province) and was sharing thoughts on his preliminary analysis in which CNSs talked about their clinical practice. My preliminary analysis revealed that APNs were focused more on the big picture of the health services for the population and their role in providing these
services. In thinking about this difference I realized it was the way we approached participants. My colleague began by asking them about their practice whereas I began by asking them about the population with whom they worked. Since I was interested in their practice and the knowledge that informed it, asking them about their practice would have been an appropriate place to begin. However, my bias is that nurses’ practice is not an end in and of itself but exists to provide a health service for clients and families, so the focus should be on them. In hindsight, I think my approach was fortuitous because my colleague found that in asking CNSs directly about their practice they talked about the various roles they performed - clinical practice, research, consultation, and so forth. It was as if they were programmed to respond about their practice in terms of competencies, which is not surprising, given the literature on advanced practice nursing. I found, however, in asking APNs about the population of children and families they worked with, their responses revealed their extensive knowledge of the populations with whom they worked and this knowledge was instrumental in guiding their practice. In addition, the focus revealed many issues in the delivery of health care that may not have come to light if the focus had remained on their practice.

I had an interview guide (Appendix D) that I loosely followed, although in some of the conversations I didn’t end up using most of the questions. In discussing various aspects of their practice, I asked nurses to talk about specific situations so as to elicit what they did and why they chose to do that. Open-ended questions were posed and these were supplemented with probes, such as ‘what were you thinking?’ to extend their responses.

**Ethical Considerations**

The ethics of research relate to how the researcher approaches the participants of a research project; therefore ethical consideration begins with the recruitment of participants for a study. I needed to be particularly sensitive to the ethics of the recruitment process because I know many of the nurses that I was recruiting. It was important that they understood that participation was completely voluntary and that I approached them in such a
way that they felt no pressure to participate in the study. I addressed this by sending
potential participants an information letter (Appendix A), even those who had already
spoken to me about participating. In the letter, I explained the purpose of the study and their
rights as research participants. I included my phone number and asked them to phone me if
they were interested in participating in the study or wanted more information before
deciding. When they contacted me, I answered any questions they had and, if they agreed to
participate, set up a time and place for the conversations to take place. I sent letters to twenty
potential participants and I heard back from sixteen of them, all of whom agreed to
participate in the study.

Participants signed the consent form (Appendix B) at the beginning of the interview
(conversation) and I provided them with a copy. To ensure informed consent both the
participant information letter and the consent form clearly outlined the purpose of the study,
the method, the means of maintaining confidentiality of the data and anonymity of
participants, their right to withdraw from the study at any point, and the potential benefits of
participating in the study. There were no anticipated risks for the participants. I also
obtained ethical approval from the University of Victoria (Appendix F).

Confidentiality is an ethical issue in all qualitative research but it is of particular
importance when there are small numbers of participants within a fairly circumscribed
population. The pediatric advanced practice nurses’ group is a relatively small,
interconnected group. Therefore, I had an ethical obligation not only to remove any
identifying information from the transcripts but to also make sure that any quotes I used for
the dissertation had no data within them that would in any way identify the person or the
particular program within which they work. Also, in giving participants a copy of the
transcript of our conversations, they had the opportunity to remove anything with which
they were not comfortable. Only one participant of the sixteen asked to have statements
removed and they were related to derogatory comments about physicians.

In addition to removing identifying information, I gave each of the participants
a pseudonym which was the last name of famous women, selected from a book I had. I deliberately chose last names because of Buresh and Gordon's (2000) discussion of how physicians always use last names while nurses use their first names, which sends the message that they are not as important as physicians. They contend that the argument for not using last names as being a safety issue is a red herring as they point out that female physicians use their last names.

Interpretive researchers are particularly concerned with addressing the power differential between the researcher and the researched. I considered this research to be a joint undertaking between the nurses who volunteered to participate in the study and me. As mentioned previously, I knew many of these nurses and they are committed and passionate about the work they do. I think my genuine interest in their practice and respect for the work they do conveyed a sense of equality in the research conversations. However, I am responsible for analyzing the data and writing the dissertation so there does remain a power imbalance. To reduce this imbalance, I considered it an ethical obligation to represent participants' perspectives as accurately as possible. One way of doing this is to make liberal use of participants' narratives in the written report to balance my perspective as a researcher.

**Data Analysis**

The aim of the analysis was twofold: 1) to describe participants' understandings of their practice and knowledge and their perceptions of the factors influencing their practice and 2) to analyze the factors within the wider social context that influenced and shaped their practice and contributions to community-based health care. My intent was to represent nurses' understandings of their practice and the factors influencing it and at the same time, analyze the ways in which their understandings are shaped by the social context in which they practice. I did this through an analysis of the language they used to describe their understandings of their practice world. As Smith (1990) points out, an analysis of the links between everyday experiences or understandings and the larger social context, does not proceed by making "mystical connections" (p. 49) but rather through careful analysis.
This analysis is strengthened by the researcher’s theoretical and empirical knowledge of the context/culture that is being studied, as well as their theoretical stance. In taking up a sociocultural stance, I looked for the ways in which participants’ language indicated how they “[made] use of cultural resources and struggled with cultural constraints” (Chase, 1995, p. 22). I also looked for particular discourses that participants took up by asking questions of the data such as: what social, cultural, historical, or political discourses are APNs drawing on to understand and communicate about their practice and what contextual knowledge guides their actions?

In approaching the analysis from an interpretive and a sociocultural stance, I found Lieblich, Tuval-Mashiach, and Zilber’s (1998) approach useful. They suggest that the researcher needs to listen to three voices in working with participants’ accounts; the voice of the narrator as represented by the tape or text, the voice of the researcher as monitored through self-reflection, and the voice of theory as accessed through the study’s theoretical framework. In following this approach, I set up a file with three columns; the voice of the narrator, the voice of the researcher, and the voice of theory. I further divided the voice of the narrator into two columns, content (themes) and form (language). I will discuss how I approached the data analysis from each of these positions.

The Voice of the Narrator

The voice of the narrator is examined through what is said (content) as well as how it is said (form). Consequently, to hear participants’ voices, researchers must pay attention to both what they are saying and how they are saying it. Analysis of content can be approached by exploring themes and their relation to one another (Mishler, 1986). Analysis of form is approached by examining the language used by participants and how they use it. Anderson and Jack (1991) argue that: “a person’s self-reflection is not just a private subjective act. The categories and concepts we use for reflecting upon and evaluating ourselves comes from a cultural context” (p. 18). Thus, examining the language participants use to articulate their practice can lead to an awareness of the social and cultural forces
influencing their thinking and actions. To identify how participants use language to convey certain messages, Mishler (1986) suggests examining the language strategies employed, such as style of speech and affective characteristics (Lieblich, et al., 1998), digression from the question, response to question, and frequent use of a word or phrase (Mishler).

I began the analysis by listening to the audiotapes while reading the corresponding transcripts. I then read through the transcribed interviews several times to get a feel for the major themes running through participants' accounts as well as the way the accounts were formed through language. In examining content, I looked for recurring themes and their relation to one another. In examining form, I looked at the language and asked such questions as: are there certain discourses that participants draw upon in narrating their accounts? Are there core metaphors or frequent use of a word or phrase?

I selected and loosely grouped recurring themes and significant statements into categories related to similar meanings. I also made note of particular language or narrative devices that fit with these themes. I then studied similar phrases or quotes to make explicit the central meaning of each theme and selected appropriate quotes to exemplify this. This part of the analysis was tricky because I didn’t want to fracture participants' accounts into bits and pieces taken out of context. This required a moving back and forth between the whole account and the particular themes and narrative devices I was grouping together. The next step was to shift focus from individual transcripts to a consideration of the whole set of transcripts. At that point I focused on the pool of meanings rather than on the individual interviews. In scrutinizing the “pool of meanings” I looked for similarities and differences in meaning.

The Voice of the Researcher

In analyzing my own voice as researcher, I drew on Mishler (1986) conceptualization of the interview as a form of discourse that is constructed jointly by the researcher and the informant. Moreover, he contends that the researcher needs to examine the interview process itself as an important influence on the account that is constructed. He
maintains that interpersonal factors are an important element of the analysis and include those aspects of the interview that relate to the interviewer, informant, and setting, such as who the interviewer is, their personal as well as disciplinary qualities and the setting in which the interview takes place. Interpersonal data related to the context of the conversations were recorded in the field notes. In addition, the way in which I worded questions, picked up on certain statements or feeling tones from some informants and not others, the responses of the informants to my questions, as well as my own responses to their comments, provided data on the interpersonal context.

While the above factors provided data on the researcher's role in influencing data collection, I also drew on the concept of reflexivity to examine my influence on the interpretation of findings. To do this, I kept track of the decisions I made in analyzing participants' accounts by writing opposite the analysis, in 'the voice of researcher' column, what I based my decision on. This provided an audit trail as well as forced me to reflect on each step of the analysis, which was helpful in identifying the influence of my biases on the interpretation of the data. I also listened for what participants implied or suggested but didn't verbalize, as Anderson and Jack (1991) suggest that sometimes what is not said is more telling than what is said.

**The Voice of Theory**

The voice of theory provided me with theoretical direction for interpreting participants' accounts. For example, in interpreting APNs' descriptions of their practice as contributions to health care, I drew on the research literature that documents families' perspectives on what is helpful to them in managing their child's ongoing care. Among other things, information, support, and assistance in procuring health services for their child are perceived as important to families. Since APNs' descriptions of their practice included providing education, support, advocacy, and coordination of care, I interpreted these activities as contributing to the health care of children and families.
In taking a sociocultural stance, I drew on theoretical literature on the culture of nursing and health care to examine participants' accounts in light of the dominant discourses operating in these cultures. Being well grounded in this literature helped me to recognize the discourses that participants took up in describing their practice, knowledge and the factors influencing their practice.

In summary, my approach to the analysis was both descriptive and interpretive. I examined the content and form of each participant's narrative and then consider the whole set of transcripts together. In addition, I analyzed the influence of my role as researcher on the findings as well as interpreting the data in light of theoretical and empirical literature on nursing and health care cultures. Thus, the final analysis of participants' accounts represents my interpretation, which was informed by participants and the theoretical and research literature.

**Ensuring Scientific Rigor**

How do we know "good" science when we see it? What criteria can be used to determine the validity of the knowledge being claimed for nursing? As may be expected, there is not necessarily agreement on what constitutes good science. It depends to a large extent on the philosophical position the critiquer holds. Lincoln and Guba (2000) argue that validity, while not easily configured within the new qualitative paradigms, as opposed to the positivist paradigm, cannot be dismissed because the question of the authenticity of the findings must be addressed in some way if they are to be acted upon. They suggest that if the findings are considered authentic by participants and members of the community in which the research is conducted, they are more likely to act on them and to base policy and/or legislation on them. The issue is not one of presenting "the truth" but of presenting "local or context-grounded truths" (p. 178), that can be recognized by participants and members of the community in which the research is conducted.

Lincoln & Guba (2000) identify two forms of rigor that must be addressed in determining the validity of the findings of an interpretive inquiry: methodological rigor and
interpretive rigor. Although their focus is primarily on interpretive rigor, which relates to the trustworthiness of interpretive findings, they do insist that methodological rigor continues to be useful in ensuring the collection of credible data. I found the scholarly literature on narrative analysis was helpful regarding interpretive rigor. It is an accepted fact in narrative studies that very different accounts of the same event can be given by different people or by the same person at different times or to different listeners (Riessman, 1993). So how is it possible to evaluate narrative work? Riessman suggests four criteria that can be used to judge the trustworthiness of narrative data: persuasiveness, correspondence, coherence, and pragmatic use. These criteria can be summed up as evaluating the extent to which the findings (or interpretations) are plausible, correspond with informants’ accounts, are coherent, and provide the basis for others’ work (Riessman). I will draw on both the methodological and interpretive criteria to discuss the ways in which I ensured rigor in collecting and interpreting the data.

One criterion used to address methodological rigor is credibility or plausibility (Hills, 2000). The focus is directed to how methods can be employed in a way that increases the likelihood of the data being credible. To ensure credibility of the data that I was gathering, I paid attention to a number of factors. Throughout the conversations, I engaged in reflexivity regarding the biases that I brought to the inquiry so as to decrease the possibility of leading the conversation in a direction I wanted to take rather than following the informant’s lead. I listened critically to my own responses as well as to the questions I asked and the responses I received from participants. For example, because I approached the study with a conceptualization of APNs’ knowledge as embedded in particular situations, I initially asked them to expand on an issue or an idea they were discussing by relating it to a particular child and family. I found that while they could usually do this, the flow of their conversation seemed to halt and become somewhat forced and stilted. I wasn’t sure why this was happening but I changed my approach and rather than asking them to talk about a particular child and family, I simply asked them for an example, and they would
relate the issue to particular situations but not usually to particular children and families. It was during the analysis that I realized these nurses were thinking and discussing issues at the system level and, in asking them to talk about particular children and families, I was pulling them back to the individual level. Moreover, because they had little ongoing contact with individual children families, it was difficult for them to relate issues to particular families.

I also applied Anderson and Jack’s (1991) suggestions for decreasing researcher bias during an interview. They emphasize the importance of the researcher paying attention to the areas where they think they know what the person is saying. When this happens, they suggest that the researcher may already be appropriating what the person is saying to an existing schema and therefore no longer listening. To avoid this they suggest asking the participant what they mean by a certain word or term as well as paying attention to what is missing. There were a number of instances where I did pick up on words or comments that I assumed I knew what the participant was saying and these instances were always illuminating; for example, the word “soft” is often used to refer to nursing knowledge and in asking a participant “what do you mean by soft?”, she initially compared her support of a mom with the work a surgeon, suggesting that support was not as important as surgery. But on further reflection she came to the realization that the support she provided for the mother was as important as the work of the surgeon. There were also instances where I let a comment go by that I should have picked up. For example, in discussing her role on clinic days, one of the participants commented that they needed a “Wal Mart greeter” in the clinics and I let this slide by. In reflecting on this comment later, I realized I clearly missed an opportunity to have her talk about how she sees the value of her work.

To further increase credibility of the data, I sent each participant a copy of the transcript of our conversation with a covering letter (Appendix E) and a self-addressed, stamped envelope. I asked them to read through the transcript as a whole and think about whether it captured their practice, the knowledge that informed their practice and the
contributions they made to the community-based health care of children with chronic health conditions. I invited them to clarify, change, or comment on anything either of us said, and to write their comments directly on the transcript, in the margins. Also, I included questions/comments on post-it notes throughout the transcript in places where I was not clear on the meaning of what they were saying, or where I seemed to cut participants off and not explore what they were saying. I would write comments such as, “can you expand on this” or “I cut you off here, what were you going to say about .. ?”. I also invited them to add anything that they thought would further capture their practice and/or contributions to health care and to comment on the factors they thought most enhanced or limited their ability to practice as they would have liked.

I received fourteen of the sixteen transcripts back from participants. The two who did not return their transcripts had both moved on to new jobs and although I sent gentle reminders, I did not receive the transcripts. Most of the participants made several comments on their transcripts, clarifying and expanding upon their earlier comments. Also most of them wrote an extra page or two on their perceptions of their overall practice and the factors they saw as enhancing or limiting their practice. There was only one participant who asked to have some of her comments removed (disparaging comments about physicians), presumably because she was worried that they might somehow be identified with her. All of the written comments were included as part of the data. I think this method of increasing credibility of the findings is useful because it provides participants with the space to further reflect on their practice in their own time and it provides them with an additional opportunity to clarify and expand on their thinking about their practice.

A second criterion associated with methodological rigor but equally related to interpretive rigor, is consistency or dependability. Consistency relates to how dependable the research process is in generating the data and the findings (Hills, 2000). One of the ways that consistency is ensured is through an audit trail in which the researcher makes explicit how they came to their findings. Lieblich et al (1998) contend that it should be
possible to follow the researcher's line of reasoning in a trail of evidence originating in the
text. This line of reasoning applies not only to the way in which the method is employed but
also to the way in which the data is interpreted. Kvale (1996) argues that the most important
requirement of interpretive research, in which there can be a plurality of interpretations, is to
explicitly formulate "the evidence and the arguments that enter into an interpretation, so that
the interpretation can be tested by other readers" (p. 211). Reissman (1993) even goes so far
aa to say that researchers should make their primary data available to other researchers.

It is also important as researchers to ensure that our values are not imposed on the
data through subtle misinterpretations that confirm prior assumptions without actually
demonstrating them (Thomas, 1993). Foregrounding our assumptions and biases so that
other researchers have access to the influences on our thinking can also be a way to ensure
consistency of the findings (Reissman). To ensure consistency of the data, I clearly laid out
the steps that I took in both data collection and analysis, as well as my assumptions and
biases that I saw as potentially influencing the questions I asked and the way in which I
interpreted the data.

Neutrality refers to the objectivity of the findings (Hills, 2000) or what Guba and
Lincoln (1994) refer to as confirmability of the data. They contend that objectivity or
confirmability in qualitative inquiry is judged by inter-subjective agreement. If several
people share an experience, and presumably interpret the meaning of that experience in a
similar way, this is considered objective whereas, if only one person has an experience or
interprets the meaning in a unique way, this is considered subjective (not confirmable).
Going back to interpretivist epistemology, the creation of meaning is considered to be an
intersubjective process because of shared beliefs, values, norms and language. Therefore as
researchers we seek out intersubjective meanings (Schwandt, 1994), which will be common
because of a shared culture among those being interviewed.

I addressed confirmability of the findings in two primary ways. One way was
through polyvocality, that is, listening to the many voices of the research participants and
identifying the shared as well as the unique experiences. The second way was to give participants a copy of the findings chapter and ask them to read it and respond to the question “do these findings reflect your practice and the factors that influence it? If so, in what ways and if not, what do you see as the differences?” Because of time pressures, I asked only eight of the sixteen participants to participate and all agreed. Five were from ambulatory settings, two from inpatient settings, and one from the community. All of them wrote general comments regarding their overall response to the findings and they also wrote several comments throughout the chapter. Also as discussed below, I had an in-depth conversation with most of the participants when I picked up the chapter from them.

Seven participants commented that the findings did reflect their experiences of their practice and the factors that influenced it. One participant did not think the findings reflected her experiences in her current practice, but she said that reading it brought back memories of what it had been like when she worked at Y institution (which is where the majority of participants were employed). In other words, although it did not reflect her current practice, it did reflect her former practice and she commented that she felt sad for her colleagues because it was “a very doctor-driven system” so there were not the opportunities to engage in multidisciplinary practice, as was the case in her current position.

The overall comments from participants were surprising and gratifying. Many of them said they found it really interesting to read and two of them said they couldn’t put it down once they started reading it (one said she stayed up late to read it and was really tired the next day at work). Another said she found it very moving, and two or three others said they felt saddened by it. Many of them thanked me for doing this research. The following excerpt from one participant’s comments provides an example of the nature of the comments made about the findings.

My overall impression when reading this chapter was a feeling of recognition. Over and over again, I found myself thinking, “Right on!” I found it difficult to read about some of the examples of APNs struggling to articulate their practice and
allowing others, who we may view as more powerful, to dictate what work we will do. I’d like to think that we are stronger than these examples imply. However, it was also comforting for me to know that other APNs are struggling with similar issues, in a similar political climate, as myself. I’ve had many conversations with APNs about practice, but in my experience we have only ever “danced around” the issue of politics in the workplace and how we handle that. Reading this chapter helps me realize how pervasive these problems are and how important it is to address them in some kind of systematic way. Thank you for doing this work.

In addition to the overall comments that participants wrote, they also wrote frequent comments in the margins throughout the chapter. Common comments included, “so true”, “yes!”, “sad but true”, “happens all the time”, “absolutely”, “couldn’t agree more” and sometimes comments such as “excellent observation”. Occasionally, a participant would write beside a statement regarding a particular issue, “this has not been my experience”. These comments were helpful in assuring me that I had interpreted the data in a way that captured participants’ experiences. Although it is my interpretation of the data, if I had not had the response of participants recognizing these experiences, I would have seriously had to rethink the way I had analyzed the data. This brings me to the issue of member-checking which is currently a contentious issue in establishing interpretive rigor. Member checking involves researchers taking their interpretations of the data back to the individuals who participated in the study to check if they correspond with the intended meaning that participants gave to them. This is known as the criteria of correspondence and refers to whether interpretations correspond with participants’ meanings. Although member checking is considered by some researchers as an important way of increasing the validity of the researcher’s emerging conceptual structures (Hills, 2000), other researchers contend that those who insist that member-checking must be done for findings to be valid, are operating within the premise that they are not interpreting the data but presenting it in a way that fits for the individual (Schwandt, 2000). Thus, I chose not to do member checking in the
traditional sense of giving participants my interpretation of their individual data. I sent the overall interpretation of the data to some of the participants to get a sense of whether it fit with their experiences. Going back to Richardson’s (1997) discussion of the collective story, she maintains that the key to a well-told collective story is the individual response of “that’s my story; I am not alone” (Richardson, p. 33). Clearly, doing individual member checking would not get at the kind of response that Richardson is talking about nor the response I got by asking participants to respond to an interpretation of the whole.

In addition to the overall summary and the comments that participants wrote throughout the chapter, another source of data that confirmed my interpretation of the data was the conversations that took place when I went to pick up the chapter from participants. In most cases, we ended up talking for close to an hour about the findings and stories they had about the politics of health care and the issue of articulating their practice. It was as if reading the chapter had raised their awareness and they were beginning to think about some of these issues in a different way. In fact one participant (actually she was the first one I had a conversation with about the findings) commented that before she read the findings chapter she would have said the problem was medical dominance of health care and nursing, so it was hard to read about the nurses’ part in perpetuating the system and even more difficult to see her own part in it. She said the findings do reflect her experiences and it also validated that she was not alone. It was in conversation with her that I first verbalized the idea that the positive side of seeing the part that nurses have in perpetuating an oppressive system is that it then gives them power to do something about it. After another conversation in which a participant told me a couple of stories that related to power dynamics and nurses being silent, I wrote in my journal, “This conversation has just reinforced for me the importance of educating nurses to be politically astute - have the knowledge and skills to hold their own and the confidence to stand their ground and articulate their practice”.

Applicability or transferability relates to the potential of the findings from one study being applied to similar contexts (Hills, 2000). Guba and Lincoln (1994) refer to this as
“fittingness” and suggest that this criterion is met when the findings from a study are judged by those in other contexts to be relevant to their context. The findings should contribute to the field or to existing theories and previous research findings (Hammersley, 1992). I addressed the applicability of the findings by interpreting them in light of existing theory and demonstrated the ways in which they add to the existing theory base of the nature of APNs’ practice and knowledge and the factors that influence and shape their practice and knowledge.

Coherence of the account is determined by how the different parts of the interpretation fit together to create a meaningful picture (Lieblich, et al., 1998). As with the criterion of plausibility, coherence can be strengthened by the literary skills of the researcher (Reissman, 1993). Writing style and vividness of the account can add to the plausibility and coherence of the findings, which involves creativity on part of the researcher in the analysis and presentation of the findings. The importance of the literary skills of a researcher in determining the persuasiveness of a study’s findings is clearly illustrated by Hirschman (1987). He critiques two books on Latin American society that were originally written as doctoral dissertations by two North American scholars, with two very different styles of theorizing. One was written as a traditional research report in which several hypotheses were explained by a theory developed by the author. The second one was written as a narrative because, as the author comments in the preface:

the truth of the revolution ..... is in the feeling of it which I could not convey through defining its factors but only through telling of it. ... The analysis that I could do and that I thought pertinent I have tried to weave into the narrative, so that it would issue at the moment right for its understanding (Womack, as cited in Hirschman, 1987, p. 179).

Hirschman says that Womack succeeded brilliantly in conveying an understanding not only of the revolution but also of peasant revolutions everywhere, whereas the other book explained far too much and succeeded only in demonstrating the author’s biases. In
striving for coherence in the presentation and discussion of the findings of this study, I made liberal use of participants’ narratives to create a sense of APNs’ practice and the factors that influenced and shaped it.

In summary, scientific rigor of this study was attended to in a number of ways to ensure credibility of the data and the analysis. Ensuring credibility of the researcher’s interpretations is a critical step in the research endeavor because the findings are more likely to be acted upon by participants and members of the community in which the research is conducted if the findings make sense and fit with their understandings of their experiences.

**Potential Limitations of the Study**

One of the greatest limitations of this study to my mind is that in protecting the anonymity of participants, I could not discuss their specific contributions to population health care. Because the participants were drawn from specialty programs in which they were often the only APN and in some cases the only nurse, any reference to the program would immediately identify them. Yet it was not possible to discuss the innovative programs that two APNs in particular developed, without identifying the program and consequently the participants. I could only discuss the programs in global terms, which in no way gave a sense of the nature of the contribution or its magnitude in contributing to the health care of children and families. Given that the overall goal of the study was to increase understanding of advanced practice nursing and how APNs contribute to community-based health care, it was ironic that in protecting participants’ anonymity I had to hide their contributions, which would have added to our understanding of advanced practice.

Another potential limitation of the study is use of the term advanced practice nurse to identify the participants in the study. Although all of the participants fit the CNA (2000) definition of an advanced practice nurse, they were all either CNSs or functioning as CNSs, so using the term APN obscures that fact. Moreover, I want to make a distinction between CNSs and NPs because the current focus of government, educators, the nursing community and the public is on NPs – they are the new kid on the block and I am concerned that CNSs
are becoming the forgotten child. I want to draw attention back to the CNS as the other advanced practice nurse who has significant contributions to make to the delivery of quality health care that are distinct from the contributions of NPs.

A third potential limitation is the length of time that participants had been practicing nursing. The majority of the participants (12) have been practicing for more than 20 years and nine of the nurses had been in their current position ten years or longer. Moreover, many of the participants had been nurse clinicians in the program before becoming CNSs. Although I initially thought that experienced APNs would provide a broader description of advanced practice, I now think the findings may have been biased by this variable. This belief is reinforced by recent discussions I have had with two APNs who are relatively new to the role (within the last five years) and new to the program. There seems to be much more momentum on their part to get involved at a system level in developing programs, doing research, and community outreach. Although this is only an impression on my part, it does make me question whether the participants in my study were more entrenched in a paternalistic system and less able to climb out.

**Summary of Chapter Three**

This chapter provides a discussion of the philosophical and theoretical underpinnings of the study as well as a detailed account of the conduct of the study. An interpretivist perspective and narrative theory informed the study and provided direction for investigating participants’ understandings and the social context. I then provided a detailed discussion of data collection and analysis procedures, ethical considerations in the conduct of the study, the steps I took to ensure scientific rigor of the research findings and a consideration of the potential limitations of the study.
CHAPTER FOUR
INTERPRETATIONS OF THE DATA:
THE NATURE OF APNS’ PRACTICE AND KNOWLEDGE

Given that APNs are considered to have expertise in a specialized area of nursing (CNA, 2000) that they apply to meet the complex health needs of the population within a particular specialty (Davies & Hughes, 1995), it is surprising that we know so little about the nature of their practice or the ways in which they contribute to the health care of individuals and populations with complex health needs. To address this gap in knowledge, the current study sought APNs’ understandings of their practice, the knowledge that informs it, and the factors that influence it. In this chapter, I draw on APNs’ accounts to describe the nature of their practice and their knowledge in relation to organizing and providing community-based health care for children with complex health needs and their families. I also describe some of the factors that participants perceived as constraining their ability to provide quality health care for individual children and families. Contextual factors are, however, discussed in more depth in the following two chapters.

I began the conversations with participants with the statement, “tell me about the population of children and families with whom you work”. Thus, APNs began by talking about the children and families within their specialty and the issues and concerns they faced. What stood out for me in listening to their accounts is how knowledgeable these nurses are regarding the health conditions of the children, the common issues they face, their health needs, and the community resources necessary to assist families in caring for their child. Although the nurses rarely talked about their practice in terms of the contributions they make to health care, their narratives revealed a number of ways in which they contributed to the organization and delivery of community-based health care, both at the individual and population level.

The nature of APNs’ contact with children and families directed their focus to both individual children and families as well as to the population of children and families that the
programs serve. The following section will discuss APNs’ accounts of their practice with individual children and families and the knowledge that underpins their practice at this level. This will be followed by an examination of the nature of APNs’ practice at the population level, including their stated goals for health care, initiatives they undertook to meet these goals, as well as the knowledge they see as informing their practice at this level.

**APNs’ Practice with Individual Children and Families**

APNs saw their primary goal with individual children and families as assisting families to understand and manage the ongoing care of their child within their community. They described their practice as involving education, support, advocacy, and co-ordination of care for children and families within their specialty area. Since most of the children served by the tertiary care programs lived in widely dispersed areas throughout the province, APNs face to face contact with individual children and families was often brief and limited to the child’s visits to the clinic which may be only once (if diagnostic) or twice a year (if treatment). Consequently, APNs maintained that a significant aspect of their overall practice with individual children and families was by phone, and one participant referred to it as “clinical practice by phone”.

**Clinical Practice by Phone**

APNs said they spend many hours a week on the phone with parents. Some of this time was spent gathering information about the child and family for referral purposes but a majority of the time was responding to parents’ phone calls. The nature of the calls APNs received from parents included questions about the child’s health condition (if they were newly diagnosed), issues related to managing aspects of their child’s care, concerns about their ability to cope with the child’s care and situation, concerns about the child’s coping, or issues related to accessing resources within their community. Thus, APNs described the nature of their practice by phone as assisting parents in managing health problems, educating parents about the health condition and the child’s health needs, and providing support for parental and child concerns related to having a chronic health condition.
APNs identified parent education and emotional support as an important aspect of their clinical practice by phone. Addams explained that this is almost a mandated aspect of practice given the way the health care system is set up:

With a new diagnosis that's come from out of the blue, it’s really devastating for parents and yet we have a system that is a two or three day contact, give them the bad news, give them an hour to ask questions and then they go home. With those families I do a lot more follow up over the phone because chances are they won't have been able to take in a lot of that education part that I might be doing with them otherwise. So I'd have a lot of follow up to see what their understanding is of the information as well as how they're doing with it.

Addams’ comments point to the issue of time and its lack thereof within the fast paced health care environment. It also points to the important role of nurses in following up with families to provide ongoing support and education so they can begin to cope with and manage their child’s ongoing care.

The APNs suggest that clinical practice by phone is an effective way to assist families in managing their child’s care and to provide education and support for children and families across the province. Yet, they argue that it is an aspect of their practice that is not acknowledged or given sufficient resources. They contend that the majority of their time is taken up with organizing and coordinating the work of the program and other team members, so returning phone calls to parents is often tacked on to the end of their day after the work of the program is completed. Moreover, the hospital policy of record keeping sends a message to APNs that this aspect of their practice is not particularly important or valuable. APNs say that they and other team members use a ghost chart to document their phone conversations with families or other health professionals involved with the family. This chart is not part of the official record and, in fact, some of the APNs say the hospital is trying to get rid of ghost charts. The nurses, however, find this record of communication invaluable, as Frank explains:
We have a column, identifying the problem, and then the decision made and the action taken and then follow up. So this is how our chart has kind of evolved. Because it might not always be me that answers the phone, whoever does, has the information in front of them on the ghost chart. Or if someone else has talked to them yesterday but I happen to get the call today, I can see what action has been taken and what decisions were made so that I can make decisions for the next day or the next week. .... it's almost like a conversation as we go along. And they don't want that on the hospital chart.

Of all the professions, ours does the most outreach by phone, and if we didn’t have that documentation, I mean I talk to ten parents a day. I can remember what I said to each of them that day but I need something so that when they phone me back next week, I can go back and check what I have told them.

When I questioned her about what went on the permanent hospital chart she said it was more the medical aspects of the child’s care. This is an example of how the empirical, technical aspects of care [medical care] are privileged by remaining part of the child’s permanent record while the more narrative, contextual aspects of care [nursing care] are not considered important and are discarded.

The fact that the APNs see their communication with families and others involved in the child’s care as invaluable in providing quality health care, but the institution doesn’t, draws attention to the difference in the goals of care between the dominant system and APNs’ approach to health care. This was a recurring theme throughout participants’ narratives and one I will return to in chapter five on the discussion of contextual factors within the practice environment that influenced APNs’ practice.

**Advocating for Children and Families**

Advocating for children and families was considered an important aspect of practice for the participants in this study and it occurred mostly at the level of individual children and families. It was also an aspect of their practice that highlighted the differences between the
biomedical and the holistic approaches to providing health care for children and families. For example, one participant, Parks, tells the story of a discussion that she and another team member had with a physician concerning a particular family.

We had a family from a small community; the little girl is four years old. This is a mum who has three other children, she’s young, she has limited education and she’s just overwhelmed. One of the physicians said, well she was told last year she was supposed to do this, this, and this and she was suppose to get follow up and none of it happened. His attitude was, well, he even said, ‘well the child should be apprehended’ and (laughs) the speech path and I are saying, ‘well, you know, she just needs some help, calling people or knowing who to call or maybe we actually have to make that call for her’. Now some people have a problem with that and I guess a part of me thinks you’re right, theoretically people should take charge of their own health care but practically that’s not a reality for lots of people and so then whose job is that and I think nurses are the best people to do that.

Parks draws on her knowledge of the context of this mother’s situation in considering how to address the problem of no follow up, whereas the physician only considers that the follow-up was not done and determines what should happen on the basis of that. Parks’ narrative highlights the importance of drawing on contextual knowledge in making health care decisions that impact on children and families.

Another participant (Addams) also illustrates the difference between biomedical and holistic approaches to providing care for children and families in her story of advocating on behalf of parents who made a decision about their daughter’s treatment that went against physicians’ advice.

The family had a little girl who had a brain tumor and it was in a location that couldn’t be completely removed and it was also in a location that involved her optic nerve, so she was losing some degree of vision, although she did have quite a bit of vision left. She had a couple of surgeries to partially removed the tumor, to debulk it
and it was recommended, I guess by the oncologist and the neuro radiologist, that she have radiation and chemotherapy. The family had thought about it for quite a bit, had done a lot of investigation, talked to a lot of people and they didn't want her to have further treatment at that point; the reason being that they didn't want her to completely lose all of her sight because they were thinking about her quality of life and to them her quality of life would be better if she had sight. It also meant that she was running a higher risk of having the tumor kind of get way from it and, um, and her dying. And the physicians on our team had been contacted by the other physicians that had been recommending further treatment, basically with the message that you have to make them get treatment for her (laughs). So they were about to do this with the family; and I had met with the family and it seemed to me that, even though it might not have been a decision that I would have made for my own children, um, they had put a great deal of thought into it and it wasn't an uninformed decision and it wasn't, um, a decision that made them happy. It was so difficult for them but they had come to that end. I thought, for anybody to challenge that or to make them feel guilty for making that decision would not be in their best interests. So, um, I had quite a long discussion with the doctors that were going to see her, about what our role was and what we were really asked to do in terms of monitoring her vision for early signs of further deterioration, rather than, um, pressuring them to go for the other treatment. The physicians agreed and I saw myself as an advocate for the family’s right to make decisions [re their child’s care].

Addams justified her reasoning by drawing on her knowledge of the context of the situation, while physicians were initially focused on the medical condition and saw the parents as basically getting in the way of the child’s treatment. When Addams presented the family’s perspective and her judgment that this was a reasoned decision, physicians had another kind of knowledge to consider. And in considering the contextual knowledge, they changed their perspective.
The dominance of biomedicine was evident in other ways as well. Lange maintained that it was easier to advocate for services for children who were technology-dependent than it was for the population of children with neuro-behavioral problems. Her narrative reflects the philosophy of a health care system that is focused on the technical and the concrete and points out the difficulty of trying to advocate for services for children with invisible health problems in such a system.

When I was working with kids who had technology needs, they needed some kind of equipment and it's easy to rationalize. Okay, they need this piece of equipment, they need a certain bed and you're not going to have to turn them every two hours so that's going to save nursing care at night. You can easily fight for something like that, whereas some of the decisions that we're making right now, it's a little harder with the kids who need care in school or they need a structured environment and it's hard because you're advocating for services that aren't there and never have been and for a population that's sort of invisible.

The APNs contended that there is an expectation by administrators of the health care system and government agencies that families find their own way around these systems. Consequently, there is little effort extended to assist families with the maze of health services. Yet the APNs insisted that most families needed help navigating the system(s), particularly if English is not their first language.

Parents have to phone the ministry themselves to apply for the funding they are entitled to. It doesn't matter if they don't speak English; they've got to phone and make that connection and that's a ministry rule. They must apply for all of the services for which they are eligible, now that their child has this diagnosis. We found that wasn't happening so we [social worker and APN] were doing it for them. We would be playing telephone tag with the ministry for days because you leave a message, they call back and leave a message, you know what that's like. So now we're giving parents a letter, it's a form letter that we fill in and say he was assessed
at [tertiary care centre] by the team on this date, our assessment impression, final
diagnosis and we fill in those blanks in writing. We give it to the parents and they
can take it directly to government and we look up the name of the ministry and tell
them who they’re going to go see. We can at least do that for them so that they
don’t have to start with phone booking and stuff. They have it in writing and then
they’re eligible. We just say “reports to follow”. And we’re finding that is saving
us days of telephone time.

The importance of contextual knowledge in providing quality health services for
children and families is highlighted in the above stories. Given that nurses who are
interacting with the everyday realities of families’ lives have this knowledge, it becomes
nursing’s responsibility to translate and adapt policies to fit the realities of the lives the
policies affect.

**Coordinating Children’s Care within the Community**

Another aspect of the APNs’ practice with individual children and families is
coordinating the child’s care within their home communities. Being responsible for
coordinating children’s care meant that the APNs had to work across hospital -community
boundaries to connect the child and family to resources within their community. One
participant commented that this activity required that they “know the population, have
contacts in the community, and take each child as an individual”. This turned out to be one
of the most frustrating, and least rewarding, aspects of APNs’ practice because of
government cutbacks that resulted in a scarcity of community resources.

Well just lately, uh, we've kind of swung from closer to home to nothing at home
(laughing) and centralizing everything again. So I think the impact is that there are
fewer and fewer community resources to link families to, so that has for me,
implications for job satisfaction.

All of the APNs in this study talked about the lack of community resources and the
frustration of trying to find something for the child and family. One participant said that one
of the primary reasons for the phone calls she receives from parents; "and I get quite a number of them," has to do with changes in community services, "as things were moved, downsized, eliminated". These calls came not only from families whose child had been seen by their program but also from families who had been diagnosed elsewhere in the province. "These were families who were struggling along and didn't really know what to do or how to get help. They would call to have somebody who could hopefully link them up with services".

The lack of resources often required APNs to be creative and resourceful in coming up with community supports/services for the child and family. There were many examples in participants' narratives of their creativity in finding resources for families. One APN turned to family members and friends to act as resources in supporting families in their communities: "I have education sessions for grandparents, or an aunt, or even if it's not a relative, someone who is willing to come and learn what to do so they can take over the care of the child for awhile and give the parent a break". The other resource that APNs drew on in areas outside the metropolitan centre was community health nurses. APNs considered them invaluable in finding resources for families in the smaller communities throughout the province. APNs found that these nurses often played a big role in the community and had many contacts. As one participant commented:

Sometimes there isn't a hospital close by and in some of the smaller communities there isn't even a physician, there is a nurse. The physician is two towns away and the family can't always get there, but the nurse is there. If a parent is ill or has to go into hospital and doesn't know what to do, we can phone that community health nurse and say, 'do you know how we can get support, you know, how can we help this family?' and mostly they'll call back in a very short time. They'll find somebody.

Another resource that APNs turned to was home care nurses. A referral would be made to home care to provide teaching and support related to the child's care. The difficulty
is that most of the nurses in home care worked primarily with adults and had little or no experience in the care of children, so they were often not helpful in providing the practical support a family needed.

The regular home care nurses are not used to dealing with children and sometimes they’re not that much help, you know, because the parents know what should be done and a home care nurse comes in and doesn’t really know what should be done. So they can give great moral support and emotional support but practical support, then there’s a problem. I have, (laughs) a whole lot of home care nurses phoning up and, you know, well what do I do? So getting those community supports in place is not easy.

The APNs considered the lack of experience with children among home care nurses as a big gap in the provision of health care for children with special health care needs and their families within the community. Moreover, the APNs claimed that practicing beyond their area of expertise and competence was highly stressful for these home care nurses. A CNS in the community developed a model for delivering community-based health services to children with special health care needs (Bassingthwaighte, 2002). However, when the report was completed the CNS position was deleted, as part of cost cutting measures in community health, and the report was tabled. The tabling of this report was seen by the APNs in this study as a message that community health care for children with complex health care needs is not a priority of the government.

Despite their creativity, the APNs found that often there were no services to which they could link families, which created stress and dissonance for them. They saw their role as assisting families in the ongoing management of their child’s health care, and this often required community resources to assist families in their care-giving role. For example, one of the community APNs talked about the importance of respite care for families of children with complex health care needs. One of the local tertiary care institutions had a number of beds set aside for children living at home with extensive health care needs so the child could
be admitted for a week-end once in awhile to give parents a break from the unrelenting demands of the child’s care. Catt argued that respite was essential for these families so “parents could be spelled off for a bit so they could just refuel, recharge, recuperate, because they are just really exhausted”. However, she says this program is being phased out.

The APNs who provided care for children who were palliative, insisted that one of the critical pieces of organizing care in the community is the general practitioner (GP). In fact, they maintain that children who are palliative cannot be discharged unless there is a GP on board in the child’s community. One APN, Thatcher, said she is the one who often contacts the GP within the child’s community and “some doctors do not want to have anything to do with us”. Interestingly, she says the specialists from the tertiary care institution do not contact the physicians within the communities. According to Thatcher a GP is needed who can make house calls and that is not always easy to organize. In reflecting on the difficulty of finding GPs who are willing to care for the child, she comments:

P: I would like to figure out a way to make this tough situation easier.
R: because the doctors are key to you sending the kids home?
P: Oh, yeah. We’ve got to have a doctor there. On the other hand, the home care nurses manage in remarkable ways in these small communities.

She goes on to tell a story about a fifteen year old boy who was “going home to die” in a small community that had a fifteen bed hospital and all the home care nurses worked at the hospital as well as in the community. And because it was a small community, the nurses were all related to the family in some way.

The GP really couldn’t, had a hard time dealing with it because the GP’s best friend’s son had just died so here you have a community that is mourning the death of this one child, you know, and it was by suicide and, here’s this other child who is dying and the GP pretty much had opted out, he just couldn’t handle it. So we were
on the phone talking to the nurses and giving them advice about what to do which we don't really like to do because we're not there, we don't know. And they did such a good job, it was so hard but they just did it, you know, they just rolled with it. One time, he needed, uh, he lived about three minutes from the hospital and they were giving him Demerol, which seemed to be working for him. The director of nursing told me the home care nurse called her at midnight and she went in to relieve the nurse so she could go to the house and give the IM Demerol. Those nurses made the best of an awful situation, you know, it was inspiring. It was totally inspiring. They did whatever it took and the kid died peacefully in his own bed, pain free.

This story is illustrative of a comment made by another APN that “if situations come up that don’t fit with the system, then we change the system, not ignore families’ needs that are created by a faulty system”. The nurses in the above scenario were faced with a situation that did not fit the way the system is supposed to operate; a physician should be managing the child’s pain but he wasn’t available so the nurses took charge to meet the youth’s need for pain relief. The story points, once again, to the importance of contextual knowledge in making decisions about health care services and the importance of some degree of flexibility within the system.

Knowledge Directing APNs’ Practice with Individual Children and Families

“My role is really based on the family’s needs at the time and knowledge of the health condition, knowledge of chronicity, and children’s development”.

Participants’ narratives revealed that their practice with individual children and families is guided by a holistic approach to health care, contextual knowledge of individual children and families’ situations, theoretical knowledge of child development, families, and chronic illness, and empirical knowledge of a child’s chronic health condition. All of these types of knowledge were required for the provision of quality health care and they were often combined to determine health needs and provide individualized care for children and families.
A Holistic Approach to Health Care

One of the participants, Parks, illustrates a holistic approach to individual children and families in her discussion of the difference between inpatient and community-based health care.

When you work in an inpatient setting, your job is to do that piece of care from admission to discharge and you need to do that well. You don’t need to think about what happens when that family is at home. My current job is to think about what happens to that family when they’re at home, so while I need to know what went on during their hospital stay, I don’t actually have to worry too much about them there because they’re getting cared for. But I have to make sure that what we start here as an inpatient is sustainable for the family over the long term. It’s, how do you incorporate that child into your life in your community?

APNs who were currently practicing within the community setting reflected a similar perspective. One participant commented, “We have the child, we have the family, and we have the larger community; my interest is in building community around these families”. She saw her role in coordinating the child’s care as a holistic approach to the child and family and, like the other APNs from the community, she saw the nurse as the only one who was pulling it all together.

At the end of that day working with all the people on the team, the care was finally holistic. I was able to bring the members together so that they were able to communicate. It wasn’t so much something that I did hands on but had I not been on the scene, all the [health team members] would have continued to work in their own way without the cohesion and without the client perhaps as the focus, but more their part of the client.

The above quote is reflective of a theme that ran through participants’ narratives of the nurse being the one who pulls all the pieces together into a whole picture of the child and family.
Another APN from the community, Duncan, commented that at case conferences called by social workers to discuss a family labeled as high risk, she has observed that “it’s often the nurse in those case conferences who has the ability to pull it altogether, far more than the social worker”, even though it is not the nurse’s role to do so. Duncan says nurses do this all the time and it is a skill that is critical to organizing and providing health care for children and their families. Yet, it is not recognized or acknowledged by other members of the health care team.

APNs who had previously worked in community and had moved into tertiary care commented on how their community experience had broadened their perspective in relation to children and families. Lange suggested the advantage of having worked in the community is that it increased her awareness of the context of children’s lives and thus, made for a more realistic approach to planning the child’s care in the community.

Seeing kids in all of the variety of settings that they live, it’s not just about hospital. And I think people forget that all the time because I’m like, okay, so how is this going to work at school, you’ve got them giving meds every two hours (laughing). You know, like that’s not going to fly. So I think it just brings the context of real life to it and that’s, I mean that’s what we’re trying to get them to.

*Contextual Knowledge*

Participants considered contextual knowledge - knowledge of the practical, everyday realities of families’ lives with a child who has a chronic health condition(s), as critical to the provision of quality health care for individual children and families. They continually made reference to the contextual knowledge they draw upon in providing education, support, advocacy, and co-ordination of care for children and families and in making health care decisions. For example, consideration of contextual knowledge can be seen in Parks discussion of making an appointment for the child to be seen in the clinic.

This family has limited resources; they have to come for a number of surgeries over the next year. How can we get things organized for them so that while they not only
come to our program, they also do their cardiology consult and their orthopedic
consult and everything at once so they don’t come back five times; because I know
that dad only gets this much time off work and if he takes more time off work, he’ll
lose, you know, and mum’s also got a daycare that she runs and they need that
money for their mortgage.

The APNs perceived contextual knowledge as heavily influencing the goals of care
as well as the child’s outcomes. One participant talked about the importance of contextual
knowledge in doing child and family assessments. In discussing a child and family she had
recently seen, she maintained that the contextual knowledge of “new marriage, new child,
major health problems from birth, infant in hospital for two months, ESL family, working
parents, supportive grandparents” was critical to understanding the potential impact of the
child’s diagnosis on the family and in determining the goals of care for the child and
family.

The influence of contextual knowledge on child and family outcomes can be seen in
the previous section on advocating for children and families (p.81-83). In both of the
scenarios discussed, the APNs’ consideration of contextual knowledge led to a different
outcome (one that was in the best interests of the child and family) than would have
occurred if this knowledge had not been considered.

APNs said they gained contextual knowledge by starting with the family and
listening to their perspective and what their concerns were and what was important to them.
This approach was considered imperative to providing individualized care, as the following
quote illustrates:

What influenced me was the needs of the families, you know, what they identified
either through my studies or just by seeing them on a day to day basis, has really
influenced the way I evolved my practice. To begin with, people weren't listening to
the families. We were so busy telling them how it should be done and what you
should do and we're the experts and you do it my way and it will be alright. But
nobody was listening to them, nobody was thinking, ‘well, if you listen maybe they can't do it this way or maybe they don't even think the same’. I have learned to realize that everybody doesn't think like I do, you know, that they have different ways of observing things and accepting things and thinking. So I’ve changed how I do things. I have individualized my care and teaching to meet the family’s individual needs.

In listening to families and finding out how they see things, APNs said they gained knowledge of the context of families’ lives and what would be most useful for them in managing their child’s ongoing care. They also learned ways of managing the child’s care from families that they may not have thought of, which provided useful tips to pass on to other families whose child had a similar health condition. One APN, Frank, tells a story of learning a new approach to managing an adolescent’s care from one of the teenagers in the program.

Teenagers sleeping in is a big thing and at one time if you had [a particular chronic condition] you couldn't sleep in. You had to be up at the same time and, you know, your whole life was really regimented. Now we can teach them to take their [medication] Friday evening if they want to sleep in on a Saturday. This is something that I learned from teenagers because they’re smart and I had one come into the office one day and say, well you know what I do, I just take my Friday night [medication] later and its going to last later so I can sleep in. So I started telling other teenagers to try it and it works. So you can learn anything from the teenagers and now its part of our teaching. We’ve incorporated it, flexibility we call it, trying to work [the health condition] into your lifestyle instead of your lifestyle into [the health condition].

The day-to-day practical issues that parents encounter in managing their child’s ongoing care represent another facet of contextual knowledge that the APNs considered important in the provision of individualized care. The APNs frequently noted that even
while parents grappled with the meaning of the child’s diagnosis for themselves and their child, they wanted practical information on how they could help their child. However, this kind of information was often lacking. While there was information on the medical condition, there was little on how parents could help their child.

It quickly becomes clear to families that there is not a lot of support out there for them in terms of [a particular health condition]. There is not a lot written about how do you help your child? At most they find a paragraph about their child’s condition but it doesn’t give them any practical help of living with it.

The lack of practical information for families is a reflection of the dominant system of care, which is focused on the child’s medical care. Information available in texts and other written materials reflects this orientation. Although APNs said they often discuss the day to day practical issues of managing the child’s care with parents, this contextual knowledge is not captured anywhere except on the ghost charts, which are destroyed. The written materials that APNs do develop are often related to managing the child’s condition rather than more practical issues, such as balancing the child’s health care needs with developmental needs.

**Theoretical Knowledge**

Participants drew on theoretical knowledge to provide direction for their practice in two main ways. Inherent within the APNs’ goal of assisting families to understand and manage the ongoing care of their child within the community, are certain theoretical understandings of the meta-paradigm concepts of client, health, environment and nursing that influenced their thinking and actions. In addition, theoretical knowledge provided the backdrop for interpreting the contextual knowledge APNs gathered to understand the child and family’s situation.

The APNs viewed the client of health care as the child and family, which had implications for the way they thought about and enacted their practice as well as the goals of their care. For example, they saw the focus of their assessment as determining the needs of
the child and the family, and their interventions as directed toward addressing those needs. Comments such as “my role is really based on the family’s needs at the time” and “helping the family to cope or deal with grieving with a new diagnosis” reflect the APNs’ orientation to the family as client. This orientation is consistent with a family-centered care philosophy, which is a central theoretical approach in pediatric nursing.

Participants also drew on the theoretical concepts of empowerment and collaboration in conceptualizing their relationship with families. These concepts directed them to assist families in acquiring the knowledge, skills and support necessary to manage their child’s condition. Frank discussed the shift in philosophy of health care relationships from the “health professional as expert” model to a family-health professional collaborative model in which families are taught the knowledge and skills needed to manage their child’s health condition. This approach also reflects an empowerment model of care, which is frequently referred to in APNs’ narratives. It comes from awareness that parents are the ones responsible for the day-to-day management of their child’s care so assisting them in acquiring the knowledge and skills necessary for that care is the most effective way of ensuring quality health care. Frank discusses how the day program she developed for the population within her specialty reflects the change in philosophy of health care for children with chronic health condition and families

The teaching that I did when I first came into the program was nothing like the teaching that I do now. We would teach them the very basics and then, in many ways, the doctors were in charge of their [health condition] so the parents used to phone for [medication] and if they didn’t phone, then the children would end up in the hospital. But then I started teaching them how to manage [their child’s symptoms] and tell them that this doesn’t have to happen and explained to parents how to avoid hospitalization. In the last year, we haven’t had one child admitted in [an emergency situation]. Few children are ever re-admitted to hospital anymore and this is because of our phone calls, because of my teaching methods and by giving
families the abilities and the knowledge to take care of it because before the doctors or nurses kind of took care of it. You came to clinic and in-between, you did nothing, you relied on the doctor. Not anymore, we teach the parents how to do everything; their knowledge is as good as mine. If they follow it, they can do it.

Theoretical knowledge was often demonstrated indirectly in conjunction with contextual knowledge as participants talked about their assessment and interventions with children and families. There were many examples throughout the narratives of theoretical knowledge being used by APNs to guide the gathering of contextual knowledge needed to provide quality health care for children and families. For example, one participant’s statement, “If you are only measuring mom’s coping by the fact that she can change the [infant’s] dressing, then you’ve missed all of it, I think”, reflects knowledge of coping theory which is brought to bear on the particular situation of determining whether a mother is ready to care for her child at home. What is not said is that the ability to perform a dressing change using sterile technique is considered adequate criteria for discharge when drawing on biomedical knowledge but not when drawing on nursing knowledge. Knowledge of coping theory alerts the nurse to determine the stressors this particular family is facing and the resources they have available to assist them. APNs’ theoretical knowledge provides a topographical map over which contextual knowledge is placed; knowledge, which may include, for example, first child, extensive health care needs, father unemployed, supportive grandparents and so forth. By drawing on both theoretical and contextual knowledge, the nurse determines, in conjunction with the family, what they need in the way of assistance to manage their child’s ongoing care.

Another example of contextual knowledge being considered in light of theoretical knowledge was the participant who said she does follow-up phone calls to families who receive their child’s diagnosis and, within three or four hours, are on a plane or ferry back to their home town. Her decision to do follow-up phone calls to these families is based on her theoretical knowledge of family coping with a child’s diagnosis, which alerts her to the
probability that the family would be in shock when told and would later have many
questions that they did not think to ask at the time. In addition, her knowledge of learning
theory informed her decision to not present the family with educational materials at the time
of diagnosis because they would not take it in. Rather she provided information gradually,
taking her cues from the family as to what was important for them.

**Empirical Knowledge**

The APNs had in-depth knowledge of the health conditions of the children served
by the specialty programs in which the nurses worked. This knowledge included knowledge
of the disease process, physiology, therapeutics, pharmacology and knowledge of all the
subtle variations of the health condition. It also included knowledge of the latest technology
used to monitor and treat the particular health condition. The APNs gained this knowledge
not only from textbooks and other written materials but also from their contact over the
years with multiple children with the chronic condition. Also the processing of referrals to
the program provided them with the opportunity to obtain in-depth knowledge of the
particular manifestations of the chronic condition in individual children. They drew on this
knowledge in assisting families with the ongoing management of their child’s health care.

**Summary of APNs’ Practice with Individual Children and Families**

A distinctive feature of APNs’ practice with individual children and families in this
study is that the majority of it is conducted by telephone, as most of the children and
families served by the tertiary care programs were from other areas of the province. The
APNs’ stated goal of practice with these children and families is to assist families to
understand and manage the ongoing care of their child within their community, through the
provision of education, support, advocacy, and co-ordination of care. Thus, the nature of the
APNs’ practice is relational rather than technical. They approach the care of children and
families from a holistic perspective and they draw on contextual, theoretical, and empirical
knowledge to inform their practice.
The factor most commonly identified by participants as constraining their ability to provide quality health care for individual children and families was the lack of community resources to assist families in their care-giving role. Although the APNs were creative and resourceful in coming up with community supports/services for the child and family, they found that often there were no services to which they could link families, which created stress and dissonance for them. They maintained that community resources were critical to the provision of quality health care for children with complex health needs and their families.

**APNs’ Practice at the Population Level of Health Care**

The APNs’ focus on the population level of health care is related to the nature of the contact they have with children and families. As discussed above, although participants may have relatively brief face-to-face contact with individual children and families, the sheer numbers of children and families seen within the specialty programs for diagnosis and/or treatment mean that they have contact with literally hundreds of children and families over time. In asking one participant, “if you were to think about the impact you have had on the children and families, would it be related to following them over a long period?” she replied:

I don’t think the direct following them over time comes to mind first because I have spotty contact. There have been a few families that I was in contact with quite frequently, but for the most part the families I saw, I was a very small part of their lives. I think the impact I have had, is that even though I don’t see individual children and families over a long period of time, I see a lot of children and their families over a long period of time and in that way I get a sense of the population as a group.

**Knowledge Directing APNs’ Practice at the Population Level**

The nature of the contact that the APNs have with children and families has implications for the knowledge they acquire and the way in which this knowledge informs their practice. Their ongoing contact with multiple children and families provided them with
a broad understanding of the health needs of the population and the resources or health services required to address these needs. This knowledge is gained through the “intake” process, which involves gathering all the information available on a child from various community health professionals, parents, and other agency personnel involved with the child and family. One participant commented that by the time you finish the intake, “you know the child and family situation backwards and frontward and you are doing that for almost every child that comes through the door”. So the APNs became very familiar with the kinds of health issues these children and families are facing and the kind of services they require. They also gained knowledge of the health services available (or lacking) within various communities throughout the province, through co-ordination of the child’s care.

In addition to knowledge of the population of children and families within their specialty, the APNs also had first hand knowledge of system inefficiencies and ineffective health care practices that prevented quality health care for children and families. This knowledge was gained through their continuing encounters with situations in which health care practices were seen as protecting the interests of the system rather than the interests of children and families. I have labeled this knowledge as sociopolitical and I will discuss it in more detail in chapter six on the context of the APNs’ practice at the population level of health care. Although the APNs had reasoned ideas for how this knowledge could be employed to change ineffective health care practices and design more effective and efficient health services, they did not see themselves as having the power to use this knowledge to make changes to health care. However, the knowledge did serve the purpose of directing their focus to the system level of health care and to the health needs of the population. A common theme throughout participants’ narratives was “how can we help this population receive better health services?”

In focusing on the population, the APNs engaged in system level thinking in which, as one participant put it, “the thinking has to be way broader” than individual level thinking. Another participant commented:
Trying to think of the global picture and how do we best serve this population and coming at it from that advanced practice kind of view. How are we going to streamline this? How are we going to make sure the right kids are getting into our program? How do we organize it so that we're being most effective?

Thus, in focusing on the population's health needs, rather than generalized knowledge being applied to the particular situation (Benner, 1994) as it is in nursing practice with individuals, particular knowledge of individual children and families is transformed into general knowledge and used to develop health care services for a population. One of the community APNs, Edelman, commented "In the work I'm doing at the population level, I combine clinical knowledge with the ability to have a systems perspective to streamline services".

The APNs perceived that they were often the only members of the health care team who focused on the big picture in relation to the needs of the population of children and families and system issues. As one participant commented, "nursing sees the big picture and other disciplines see one small piece, theirs!"). The holistic approach adopted by the nurses is more congruent with systems thinking than is the biomedical/individualistic perspective adopted by other health care professionals. The biomedical perspective is reflective of the dominant system of care in which the focus is on the individual and particular aspects of the individual. Consequently, this difference in perspective between the APNs and other health care professionals led to different goals and different approaches to health care.

**APNs’ Initiatives to Address the Health Needs of Populations**

The APNs consistently emphasized three primary goals for providing quality health care for the population of children and families within their specialties: increasing accessibility of children and families to health care, establishing prevention/intervention programs, and increasing community resources. Although the majority of the APNs identified constraints that prevented them from achieving these goals, some of them did discuss initiatives they undertook to address the health needs of the population of children.
and families within their specialty area. These initiatives included program development, educational outreach to communities, and involvement in policy-making. I will examine these initiatives in some detail as they are representative of the ways in which APNs can contribute to the health care of populations with complex health needs.

**Population-Focused Programs**

Two participants discussed programs that were developed for the population within their specialty area. The two programs are for distinctively different populations and they illustrate the range of involvement that APNs can have in providing and/or organizing health care at the population level. The first program discussed involves lay personnel and is a good example of creative ways of meeting population health needs that do not necessarily involve APNs in the direct provision of care but more in the organization and development of the program. In the second program discussed, the APN was directly involved in the development of the program and in the provision of direct care of clients within the population.

Building Blocks is a program that one of the community APNs, Duncan, was involved in implementing. It is a program for vulnerable populations that involves paid lay workers who do ongoing visits with mothers and their infants within their homes and it is modeled after a program out of Hawaii called Healthy Start. The program focuses on first time mothers of Aboriginal, Vietnamese or Spanish descent and it continues from zero to five years. The purpose of the program is to provide one on one support for the mothers by a lay worker from the same culture as the families they visit. Moreover, another goal is to gradually encourage the mothers to go to a drop in where they can meet other mothers. There is a nurse attached to the program who meets weekly with the lay workers to provide consultation and discuss the families’ situations. Duncan says the program is implemented in the home because the nurses were finding that expecting the mothers to come out to a group and to be with a group was foreign to many of them. She said that even if they did
come, they would be reluctant to say anything and often they had no transportation to get to a group.

The program is funded by the health ministry (funding for nurses) and by a multicultural organization (funding for lay workers) within the community. Duncan maintains that the program has been highly successful as indicated by mothers staying in the program and showing initiative in taking a course in English or bettering their education in some way. Duncan insists that lay workers are more helpful than the nurses could be: "because they come from the country, they can speak the same language and I don't just mean the language itself but they can identify with similar kinds of cultural, religious kinds of issues that a professional just doesn't understand to the same extent".

Duncan suggests that another reason the lay workers are more helpful with these mothers is that the nurses don't have that kind of time to go in and spend with them. More to the point, it is not a particularly good use of the nurse’s expertise but it is an important intervention for the mothers. Duncan says that the biggest issue that nurses have in working with “high risk” populations is accessing them. And the Building Blocks program came about because they were looking for the best way to connect with this population. The concept of using lay workers to assist with meeting the health care needs of populations is becoming more common and another place in which the concept is being applied is for supervision of children with special health care needs within the home and school system.

Another example of a population-focused program is a Day Program for children newly diagnosed with a particular chronic condition. This program was developed by one of the participants, Frank, in conjunction with other members of the health care team. Frank identified the need for the program based on her research study of parents’ experiences of having a child diagnosed with a particular chronic condition. One of the findings that stood out for Frank was that parents said they felt overwhelmed by their child’s diagnosis and they could not take in all the teaching that was necessary to care for their child. One father made a comment related to going home at night and coming back to the hospital during the
day, and the seed was planted for a day program. Frank began to investigate programs in the States that were implementing a day program and she convinced the administration of the tertiary care hospital that such program would be better for the children and families and save the hospital money.

Frank maintains that the day program has changed the entire mode of management of children newly diagnosed with this condition, from an inpatient to an outpatient model of care. When children are diagnosed they immediately enter the program and spend the day at the clinic with their parents and go home at night and come back the next day and they do this for three to ten days, depending on how well parents are managing their child’s care. Their parents receive teaching every day and learn the knowledge and skills necessary to manage their child at home.

Frank claims that the benefits of this approach are that it is easier and quicker to get the child’s condition stabilized and easier to teach parents who are less exhausted. It is also less traumatic for the children and parents to not have the child admitted to hospital. In addition, the program has “saved the hospital millions of dollars because it’s a huge cost to admit a child to a tertiary care hospital bed and it’s less than a third of that to bring them into day care”. Frank does emphasize that a team approach is mandatory and says she would not have been able to develop or implement the program if she had not had the support of other nurses, physicians, dietitians, and social workers.

**Educational Outreach Initiatives**

Another initiative that the APNs suggested as useful in addressing the health needs of children and families at the population level is educational outreach to communities throughout the province. These initiatives involve APNs from specialty areas, along with other members of the health care team, going to other areas of the province to provide communities with educational resources. Addams, an APN from one of the ambulatory programs, discussed an educational outreach service that the health care team within her specialty undertook. The initiative involved a two-day workshop in five communities
throughout the province. They chose communities that “don’t normally get any kind of service like that” [referring to the service offered by the tertiary care program]. They teamed up with child development centres and infant development programs as all of the areas had those two services, as well as community health nurses. Addams found these groups were helpful in determining what the communities wanted to hear related to the chronic condition and a team was put together based on what the community wanted to talk about. Addams said it was interesting how the areas really differed in terms of what were issues for them and what they wanted to hear about. However, most of them did want to hear about sleep disorders as that seemed to be a problem for a lot of children in this population. One of the spin-offs of these workshops was that related community services had displays at the workshop so that families could become familiar with what was available in their communities. Addams saw this as a more effective and efficient way of helping families coordinate services then trying to do it over the phone from the tertiary care centre.

*Involvement in Policy Initiatives*

Given the APNs’ in-depth knowledge of the population within their specialty, it is surprising that only one APN discussed having a role in informing policy. Addams was part of a provincial committee to develop province-wide definitions for the health condition within her specialty. She found that her knowledge of the population helped her contribute to the committee.

I have a sense of the population as a group and how things seem to work in different areas of the province and the different issues in different areas and I think that helped me in the committee work. We came to something that was more practical and more immediately applicable than if I didn’t have that perspective.

The above initiatives by the APNs address health needs of specialized populations of children and families and they were able to articulate outcomes that benefited the health of children and families and, in one instance, saved the health care system money.
Summary of Chapter Four

The APNs described their practice as occurring at both the individual and population levels of health care, although they maintained that the majority of their practice was at the individual level. They saw the goal of their practice at the individual level as assisting families to understand and manage the ongoing care of their child within their community, through the provision of education, support, advocacy, and coordination of care. They are guided by a holistic approach to health care and they draw on contextual, theoretical and empirical knowledge to provide quality health care for individual children and families. Thus the nature of their practice is primarily relational rather than technical.

At the population level, the APNs’ stated goals were to increase accessibility of children and families to health care, establish prevention/intervention programs, and increase community resources through program development, educational outreach, and policy initiatives. They are directed by system level thinking and in-depth knowledge of the health needs of the population within their specialty and the resources or health services required to address these needs. All of the APNs’ had clear goals for the health care of the population of children and families within their specialty and reasoned strategies for addressing these goals. Yet the majority said that their practice at the population level was restricted by a number of factors within the dominant system, of health care. These factors will be discussed in chapters five and six. Chapter Five examines the contextual factors in the APNs’ practice environment at the individual level and Chapter Six examines the contextual factors influencing their practice at the population level.
CHAPTER FIVE

INTERPRETATIONS OF THE DATA

THE CONTEXT OF APNS' PRACTICE: THE PRACTICE ENVIRONMENT

Advanced practice nursing is enacted within multiple contexts that influence and shape APNs' practice and their contributions to the health care of children and families. The most immediate context is the practice environment in which they work. Participants' narratives revealed that their practice environments contained a number of contextual factors that influenced their practice and their ability to contribute to the health care of children and their families. A central factor is a health care system that is dominated by an individualistic focus and a corporate\(^1\) model of health care. An individualistic orientation is underpinned by a biomedical model of health care and physician dominance and a corporate model of health care is dominated by the goal of minimizing health care costs and protecting the interests of those in positions of power.

Participants described this orientation of the health care system as influencing their practice in a number of ways. They maintained that the dominance of physicians and a biomedical model in health care delivery resulted in their knowledge and expertise being ignored or discounted and a health care team that was not cohesive. Moreover, APNs perceived that a focus on minimizing costs and protecting corporate interests resulted in their work being structured to serve the interests of the programs and the organizations in which they worked rather than the health care of the children and families that the programs served. Consequently, APNs said that the majority of their

\(^1\) I am using the term corporate to refer to participants’ descriptions of the health care environments in which they worked. They described the primary goal of the organizations as minimizing costs and protecting the interests of physicians and others in positions of power.
time was spent organizing and coordinating the work of the program and other team members, while being excluded from decisions regarding the health care of children and families. APNs' also had difficulty articulating their practice, which further contributed to their exclusion. Finally, APNs perceived the nursing culture within this health care environment as influencing their ability to provide quality health care for children and families because of a lack of organizational supports for their practice.

I will begin with a discussion of the impact of an individualistic orientation of the health care system on APNs' practice, followed by a discussion of the impact of a corporate model of health care. I will then move to a discussion of APNs' perceptions of the nursing culture and its impact on their practice.

**Individualistic Orientation of the Health Care System**

Participants' narratives revealed that there are two distinctively different approaches to health care operating within the health care system, a biomedical model of care that is employed predominantly by physicians and other members of the health care team, and a holistic\(^2\) model of care that is employed by the APNs. Their narratives also revealed a tension within the health care team related to these differing models of health care and differing foci of care. Physicians, guided by the biomedical model, focus on disease and the physical aspects of care. Nurses, guided by a holistic model, focus on the person and their experiences, as well as the disease. This holistic focus includes the social and emotional (often referred to as the psychosocial) as well as the physical aspects of care. While these differing foci of care do not necessarily need to create problems, the APNs in this study maintained that they frequently experienced resistance to, or a

\(^2\) a concept that directs nurses to consider the physical, psychological and social needs of individuals and their environment.
discounting of, those aspects of their practice directed toward psychosocial or relational aspects of care. In fact, their narratives suggest that only the biomedical model of care is visible, while APNs’ holistic model of care for children and families is largely invisible.

The dominance of a biomedical approach to health care was evident in the primary focus of the specialty programs, in which only those aspects of the child that related to the specialty were addressed. This focus on a specific disease condition was problematic for all families whose children had chronic health conditions but it was particularly evident with families who had children with multiple disabilities, as the following narrative illustrates.

A number of the children we see in the program have multiple disabilities such as cerebral palsy, epilepsy and require all kinds of other treatments as well. So parents are always trying to coordinate and it pretty much becomes a full time job, just keeping things straight, let alone parenting their child. There isn’t always somebody coordinating everything and looking at the whole child. So that falls to the families most often and I think that becomes an issue for a number of families; the feeling that they have to do a lot of it themselves, that they now have to take on all these other roles that they never asked for and there wasn’t a lot of support for them.

Another participant commented that coordinating the child’s care does fall to the family because most of the APNs have such huge “caseloads”. She says that while this works for some families, for many it becomes overwhelming and the APNs end up doing crisis intervention, rather than providing quality health care.
Another indicator of an individualistic focus was the independent nature of the assessments done by various health care professionals who participated in the child's assessment. The outcome of functioning as independent health professionals rather than as a cohesive team was evident in the written reports that came out of the assessments.

Until about a year ago all the professionals who would see a child would prepare their own report and we'd end up with four or five reports saying the same thing for the first page with the background history, reason for referral, who was involved, da, da, da, and then, great long reports and people were expected to read twenty pages - the doctor, the parents, any community specialist that the parents agreed to have it sent to. It was time consuming and it wasn't very reader friendly. Plus, the recommendations were all over the place because you had five different reports and five different sets of recommendations. Sometimes they were repetitive, sometimes they were different and it was hard to pull it altogether.

Although, in this particular program they now have a joint report, the participant's narrative about the family/team conferences suggests that team members continue to operate as individual health professionals who come together as a team only to report the findings of their assessment. In fact many APNs' maintained that the members of the health care teams of which they were part did independent assessments and reported their results to the team. This approach reflects an individualistic orientation towards health care and points to the rhetoric of a multidisciplinary health care team; a rhetoric that serves to obscure the hierarchy and fragmentation within the system.
The Myth of Multidisciplinary Health Care Teams

A number of APNs discussed the lack of collaboration among the various health care professionals who made up the health care team within the ambulatory programs. This lack of collaboration was closely tied to the individualistic focus of the health care system as discussed above. In addition, while most health professionals work full time, their time is divided among three or four different programs which has implications for forming a cohesive team, as one APN explains:

Most [health professionals] work full time but they’ll have .2 FTE [full time equivalent] dedicated to this team, .2 FTE [1 day/wk] dedicated to this team, so they’re stretched out among about three or four assignments. I work .8 FTE [4 days/wk] so I have the biggest chunk of time so I’m the one that’s sort of corralling everybody in. We do meet once a week but everybody is on all different teams and if you have .2 FTE, that’s only one day a week. And you have two hours for this meeting, you have to see kids, so a lot of people will say ‘well my .4 (or whatever) is clinical time, I don’t have time to go to meetings.’ Our docs never come to the meetings. So how do you form a team? How do you become a team to take care of these kids if you can’t even get in the same room?

Given that health professionals are spread out over three or four teams, and the physician may only be there one or two half days a week, the APN is faced with trying to pull together a “phantom” team. While all of the participants talked about the importance of working collaboratively as a multidisciplinary team to provide quality health care for children and families, only two of them perceived the teams as working effectively together. One participant, Parks, perceived the multidisciplinary team of which she is part
as functioning in a collaborative, cohesive way to meet the needs of the population within the ambulatory program. She attributes the success of the team to three factors; “the very nature of the children’s conditions means that one person can’t do it all”, everyone’s role on the team is valued by the other team members, and there is not a sense of anyone being the “boss”.

When a surgeon who sees the patient in his office identifies that the child has significant social and teasing issues and needs to see the social worker, I think it’s pretty impressive that he picks up the phone and makes the phone call. Parks suggests that the lack of power differential amongst team members is quite unique when compared with most multidisciplinary teams. “I think in most places it’s still, you know, the [specialist] is the boss of the program and everybody else kind of falls in behind.”

Regardless of the team dynamics, APNs saw it as their responsibility to coordinate the team; “we have to know everybody’s role because we’re the one who quietly pulls things together and that’s often the invisible person”. This idea of nurses “quietly pulling things together” speaks not only to the coordinating role that nurses assumed as part of their role on a multidisciplinary team, but also to the invisibility of that role to others. One participant points out the central role of communication in coordinating the team.

When you’re on an inpatient unit, communication is very often nurse to nurse or nurse to charge nurse or nurse to patient. When you’re in this position, its nurse to nurse, nurse to physician, nurse to physio, nurse to community speech pathologist,
nurse to OT, nurse to child development center, nurse to school, nurse to parent, nurse to whoever.

There is a sense from the above comment that not only is communication a central aspect of coordinating a team but that the APNs serve as the “central switchboard” through which all communication related to the client’s care passes.

**Communication Difficulties within and among Health Care Teams**

APNs considered clear communication among various members of the health care team as central to the organization and delivery of health care for a population. Yet they often related stories that involved miscommunication or lack of communication among health care providers. Concern with effective communication was not limited to the health care teams within the various programs in which the APNs worked. APNs were also cognizant of the importance of effective communication between the tertiary care programs and the communities where children and families lived.

One of the community participants, Catt, relates a story that illustrates the lack of communication among health care professionals not only between hospital and community but also between various programs within the hospital. As the coordinator of a particular child’s care, Catt pulled together all the community professionals who would be involved with this child and they came up with a plan to promote the child’s health and development. A few weeks after this meeting Catt inadvertently heard about a meeting, regarding this same child that had been called by the staff of the ambulatory program, which the child attended for treatment. The meeting was supposedly called to organize care for the child in the community because they were unaware that anything had been organized. Catt called the staff to tell them about the existing community team
and they canceled their meeting. Moreover, Catt says the inpatient unit from which the child was initially discharged, had come up with the original discharge plan for community care for the child and they had not shared the plan with the ambulatory program to which the child would return for treatment. She argues that not only individuals but also departments work independently of one another; “each department runs like a silo ... there is no one looking at the whole picture”. Catt’s observations support the contention of APNs who worked in ambulatory care that there was no communication between inpatient units and ambulatory programs serving the same population of children.

APNs within tertiary care programs discussed a number of situations in which communicating with health professionals within the community was problematic, a problem they associated with issues of territoriality on the part of the community professionals. From their point of view, APNs within the tertiary care centre saw their role as working closely with community nurses to ensure the best care for the child after discharge. One participant commented, “I don’t feel that my job ends when the child leaves the hospital. I work very closely with the community nurses”. However, participants’ narratives indicated that community professionals sometimes saw APNs as interfering when they “didn’t know the community”. One participant said she ran into difficulty in her attempts to organize care for a child; “we were accused of not being able to let go and not knowing our place”. She said she was totally taken aback, “I thought we were all on the same wave length. I didn’t know we were not connecting”. Another participant, Sanger, had a similar experience in which a nursing colleague in the
community responded to her suggestion regarding a child’s care by going to her supervisor and saying that Sanger was interfering.

She went to her supervisor and I'm not sure what she said but the gist of it was that this hospital nurse was interfering with her role, and about the process, ‘really I had no business giving my opinion because after all this child was in the community’.

Another participant, Parks, emphasized that communicating across systems required a great deal of “diplomacy” on the part of tertiary care health professionals. Parks often had to communicate with hospital nurses in the smaller communities and she found that many of these nurses may have “worked in their tiny hospital for thirty years” and they were not necessarily up to date with the latest approaches to health care for children with certain chronic health conditions. Parks sees her role as supporting the family in a way that will sustain them but she also sees her role as supporting the nurses within the communities so that they can support the families. One of the ways in which she does this is by providing them with “information that is current and accurate”.

However, sometimes she found it difficult with older nurses, who are used to doing things in their own way, to get them to use current knowledge in their interventions with families. “I can remember saying to a nurse one time, you know, ‘are you taking this baby home?, because if you’re not then we need to help mum do something long term’”. Parks says she operates on the premise that “if you put the families’ interests first, I think that’s everybody’s goal, hopefully”.

Communication issues within health care teams were frequently associated with paternalistic attitudes on the part of physicians. One of the constraints APNs identified as
limiting their ability to communicate as a team was that physicians did not attend their multidisciplinary team meetings. As one APN commented; “Everyone comes except the physicians; it’s a waste of their time. The year 2002 and nothing has changed!”.

Physicians not only ignored team meetings but they often failed to communicate with other members of the health care team about what they were doing which not only constrained team collaboration but also impacted on children and families, as the following story by Thatcher illustrates.

We have kids going for major surgery and the communication around that, between the surgeon, the specialist, and the health professionals supporting the child (psychology, social work, physiotherapy, occupational therapy, child life specialists, and the nurses) is quite abysmal. The right hand doesn't know what the left hand is doing and so consequently the parents and the kid are left wondering what's happening. Now everybody thinks that they're communicating well but obviously not and this has been going on for a long time. One of the social workers came to me and said can you help us with this? So I said, ‘okay, why don't we have a meeting with all the stake holders and we'll just sit down and we'll figure what do people, what's going on here’. So I invited everybody, um, the docs didn't want to come and that was not unexpected. We figured out what currently happens and this was over a couple of meetings and then we met with the docs. We had an idea of what, how it should look and we tried to implement it but it wasn't done in a really formal sort of way. The social worker came back to me and said ‘look, it's still not working well’ and so I said, ‘okay, we need to meet again’.
Thatcher proceeded to solve the problem by getting everybody together to figure out “what’s going on here”. The difficulty she ran into is that the physicians wouldn’t come to the meeting. The team (without the physician) decided to develop a clinical pathway to spell out “what needs to be done when, whose going to communicate with whom, and not just leave it for the patient and family to figure it out”. Thatcher says there will be “patient and professional education around it and someone to be the gatekeeper to see that it is followed”. Given that physicians have not been communicating with the team or the family, it seems highly unlikely that they will follow a clinical pathway plan.

Sanger told a story regarding a decision being made by the medical staff to relocate the program in which she was working. The nurses in the program were not consulted for any input into the decision, although the relocation would greatly impact on them. They were basically told that it was going to happen.

There have been huge communication issues [around the decision]. Even after a decision was made, I was told a decision hadn’t been made. I said, ‘It’s interesting that a decision has not been made when we have architects coming in and drawing up plans and there have been meetings’. I said ‘we have to acknowledge that the nurses do not feel like they are hearing what is happening. We have to say a decision has been made and we are continuing to review it’. To try and say a decision was not made is quite annoying because that is really undermining and undervaluing what nurses have been going through.

The above narrative not only points to poor communication between medical and nursing staff but it also reflects the power dynamics of a system dominated by corporate interests.
Corporate Model of Health Care

APNs’ narratives revealed a health care environment dominated by corporate and economic interests, in which the primary motivation seemed to be minimizing health care costs and protecting the interests of those in positions of power, including physicians. Participants maintained that these corporate interests resulted in their practice being structured around program and organization demands rather than the health needs of the children and families the programs serve. Consequently, they did not perceive themselves as having control over their practice.

There were numerous examples in participants’ narratives of their practice being dictated by others - administrators, managers, and physicians - but the impact of this on their practice and their contributions to health care is probably best exemplified in their narratives about two activities that structured the majority of their time within ambulatory programs - organizing clinics and processing referrals for the team. Participants’ narratives of these activities provide a window into the power dynamics operating within the dominant system of health care and the ways in which APNs resisted or reinforced those dynamics. Narratives of organizing clinics reflect the dynamics of APNs’ exclusion from participating in decisions regarding the health care of children and families and narratives of processing referrals reflect the dynamics of APNs’ preoccupation with efficiency, which reinforced the central goals they saw as driving the dominant system.

Organizing Clinics: Narratives of Exclusion

In analyzing participants’ accounts about organizing clinics, the predominant theme that ran through the narratives was APNs’ exclusion from the main work of the program, that of diagnosing and managing children’s chronic health conditions. This
Exclusion took different forms and included: APNs not having a scheduled time to see the child and family when they came for their clinic appointment, not being asked for their input into health care decisions, being silenced by an objective/technical discourse, and being excluded from health care conversations. These various forms of exclusion will each be discussed in turn.

**Exclusion from Child and Family Assessments**

When children and families came to the clinic for their appointment, the APNs often did not have a scheduled time to see the child and family. Instead their time was taken up with organizing the clinic and making sure the children met with other health care professionals on the team, and in particular, the physician. APNs used such terms as “air traffic controller” and “traffic cop” to describe the hectic pace that ensued on clinic days. They maintained that this pace is created by the expectations of physicians that nurses co-ordinate the clinic in such a way that all the necessary information is on the front of the child’s chart and that the children see the right health professional at the right time. One of the participants, Brinker, commented on physicians’ expectations of her role in coordinating the clinic: “co-ordination to them meant that I was the person to make sure that all the patients got to see the professionals that they needed to see. Yet I was supposed to continue doing other things for them (my emphasis) such assisting with procedures”.

Physicians’ expectations that nurses not only organize the clinics, “gather charts, direct traffic”, but also do tasks associated with the child’s care such as “measure and weigh” was a common theme in participants’ narratives. APNs’ argued that these activities did not require a nurse but could easily be done by a clinic aide, which would
free up their time to do nursing assessments and/or teaching. However, when some of them approached their managers regarding the hiring of clerical staff, they were told that there was no money to hire more staff, which reinforced their belief that the primary goal of the system was minimizing costs and not providing quality health care for children and families. Because of the way their work was structured, some participants said they had to squeeze assessment and teaching around clinic activities while others said that they did not have the time for it.

Although APNs approached their managers about their under-utilization within the ambulatory programs, only one participant talked about confronting physicians regarding what they saw as unrealistic expectations of the APNs. Brinker commented that physicians’ attitudes toward her spending time with the child and family was; “do this nursing thing but don’t take any time to do it”. She responded by telling them; “everybody else on this team takes the amount of time with the parents that they feel they need and nobody says anything to them so I am going to do the same thing”. And she said to me “that’s what I’m doing!”. Brinker named what other APNs observed and remained silent about; that all the other team members had time scheduled with the child and family and no one told them how long they could spend. Yet APNs were running around “directing traffic” and fitting their work around others’ schedules.

**Exclusion of APNs from Health Care Decisions**

Not having time scheduled to see children and families, sent a message to APNs that their knowledge is not useful in contributing to the process of diagnosis, treatment, or ongoing management of the child’s health condition. Yet APNs argued that the knowledge gained from their assessments is key to the diagnosis, particularly in relation
to some of the neuro-behavioral conditions, and to the ongoing management of a child’s condition. Mead discusses how her assessment contributes knowledge of the child and family that other team members do not have.

During a family assessment I can observe the child with his parents, see how parents interact with their child in a relaxed, non-testing environment, and how parents react with each other. While I’m talking to the parents, I’m watching the child at free play and watching how the parents guide the child. The other team members don’t tend to see the interaction between the child and the parent. The parent may be in the room but the testing situation is very structured; they’ll have the child at a little table with some puzzles. They can’t ask leading questions like I can. I can ask ‘what is a typical day like for you?’ and you really learn a lot.

While Mead’s assessment provides knowledge of parent-child interaction and parental coping, knowledge that is not provided by other team members’ assessments, it appears that this knowledge is not seen as useful because Mead says her clinical time with families has been cut back during the past year (a decision made by the program director who is a physician). At the time of our conversation she was only seeing two families a month, yet there were clinics four times a week. Thus, in excluding her from child and family assessments, they are excluding a source of knowledge of children and families that could make an important contribution to the diagnosis and management of children’s health conditions.

A common perception among participants was that other health professionals do not really understand what they do or the knowledge they can contribute to the diagnosis and management of a child’s health condition. They base their perception on the
observation that health professionals often do not ask APNs for their input into decisions regarding the child’s care, which reinforces APNs’ perceptions that their knowledge is ignored or discounted. One of the participants, Addams, who did have scheduled time to see the child and family and did both a child and family assessment commented, “my observations were important and valued [by the health care team] in terms of making a diagnosis”. However, she also related a story that made her question just how much the team understood her nursing role and the knowledge that directs her practice. When she was on sick leave for three months she was not replaced.

In my absence, I guess in an effort to be helpful, there were other team members who would go and meet with the family in the community and try and implement some of the suggestions that came from the assessment. I guess trying to be helpful and trying to cover the gap, had offered to meet with families to provide them all the information and teaching that I would normally do with families. As well intentioned as that was, it wasn’t appropriate because it was different, the teaching was different, the background knowledge about the multiple disabilities and the associated diagnoses was different. Even though you can’t say, you know, ‘you’re infringing on the standards of professional practice’, essentially what these people were trying to do was be the nurse without the job description or the requisite education for that.

R: And how was that decision made that they would do that? Did they just take it upon themselves?

P: It was, yeah, they took it upon themselves and yet the other people on the team didn’t really see where the problem was with it because as they saw it, the gap
was being filled. I guess that comes down to maybe not a lot of knowledge about what the nursing role was but (laughing) uh, yeah, it surprised me that nobody questioned that.

Addams questions the teams’ understanding of her nursing role. However, her comment “you can’t say ‘you’re infringing on the standards of professional practice,’” (even through she saw their actions as inappropriate) indicates that she may not be explicitly communicating her role to others on the team. And if they do not observe what she does and do not know the knowledge she draws on to do it, then how do they come to an understanding of her role? (admittedly, not by doing it!) Could it be that others do not understand nursing’s role because nurses do not communicate about their practice and the knowledge that informs it? I would suggest that this may be a key reason that other health professionals do not know what APNs do and therefore do not ask for their input regarding health care decisions.

Another participant, Mead, also talked about the lack of understanding by other team members of what she does and the knowledge she has. She comments that the team see her role as “doing intakes” [processing referrals] and although she maintains that her role is much broader than that, she perpetuates the view that her work is task orientated in that she does not articulate the knowledge that she is contributing through the intake process.

They [health team] just say well, you’re going to do the intake workup and I say, yeah, I’ll do the intake work up. In my mind it’s a nursing assessment. I’m evaluating a child, a family, the community the family lives in. I’m summarizing it with the child’s needs and his problems and what intervention is likely to be.
Although she sees the intake as a nursing assessment in which she is contributing knowledge of the child, family and community, she does not say this to the team. In fact, her response to my question, “do you find that you’ve had to educate other team members about what your role is?” was, “no, no, I’ve never discussed it because my philosophy is, ‘I’m going to show them what a nurse can do’”. This idea of showing others what a nurse can do came up in a couple of the narratives and, to me, is indicative of nurses’ reluctance (or inability?) to articulate their practice. APNs’ not communicating about their practice and knowledge, for whatever reason, has two important effects. One is that their knowledge is not available to inform the health care of children and families and this knowledge is critical to the provision of quality health care, and secondly, other health professionals often do not have an accurate understanding of what the nurse’s role is on the team or the knowledge they can contribute to the child’s care.

While a case can be made for the importance of nurses’ articulating their practice and the knowledge that informs their practice, the reasons why they do not do so needs further exploration. The following discussion explores the exclusionary nature of an objective/technical discourse and how it can have the effect of silencing APNs.

**The Exclusionary Nature of an Objective/Technical Discourse**

APNs’ narratives reflect awareness that they practice within an environment where objective/technical knowledge is privileged and subjective/relational knowledge is discounted. Perhaps the reason that many of them took up the discourse of nursing as technical or task oriented, is the realization that objective/technical knowledge is the currency of the dominant system of health care and if they wanted to participate in health care conversations, they needed to speak the language, that is, use the language of the
technical. However, the perspective of nursing as technical did not fit with the realities of their practice, which involved education, support, and advocacy, and was therefore more relational than technical. Many participants had difficulty seeing these non-technical (relational) activities as nursing and they struggled with articulating those aspects of their practice that fall outside the technical, task oriented care. There was an underlying sense within their narratives of the legitimacy of nursing as a technical endeavor whereas the non-technical tasks were somehow less legitimate, or what some participants referred to as “soft”.

Give me a ventilated kid and I know exactly what to do because, from a nursing perspective, its like, okay, I can do this task and I can fix this stuff and I can set up their home care programs so they’ve got nurses and they’ve got everything organized. It’s much more concrete. This [her current practice] is very, you know, much more, sort of, soft kind of stuff. It’s sort of like the ICU nurse versus the psychiatric nurse, right, and I’ve always been that more technical kind of nurse. If I need to make a decision, I back up all the reasons why. So I’m good at that kind of thing but when it comes to this more, not wishy washy but sort of not, not as clear cut, it’s harder and you need to really think out why you’re making a certain decision.

This narrative reflects that Lange has taken up the dominant discourse of nursing as technical care with its emphasis on doing, and she sees herself as good at it. However, she struggles to articulate those aspects of care that fall outside the technical and she even questions whether those aspects of care are nursing:
I really feel like a lot of the stuff to do with the population isn’t sort of nursingish. When the child comes into the clinic, there’s a lot of co-ordination that needs to be done but the child doesn’t, in terms of their physical health, it’s sort of a different kind of nursing. But I think the role on this team is a lot of co-ordination and a lot of that figuring out what’s going on, a lot of program planning - where are we going, what are we going to do? Then the education piece is just huge; how do communities work with these kids?

Initially Lange is saying that a lot of what she does is not nursing in the sense of nursing being attending to the child’s physical health needs, but she then rephrases it as being a different kind of nursing, one that involves coordination, program planning, education, but she is still having difficulty articulating this “different kind of nursing”. Perhaps one of the reasons for her difficulty in articulating her practice is that the activities she identifies as nursing are not considered priorities by the program director or the nursing manager. In fact, she later says there was no time for education, and in terms of program planning she wanted to establish criteria for determining which referrals were accepted and she says she could not get the team together to have the discussion.

Taking up the discourse of objective/technical knowledge as privileged and ‘doing’ as valued, created dissonance for APNs in their encounters with the practicalities of everyday life for children and families. They witnessed children and families struggling to cope with a child’s diagnosis and ongoing care. And they understood that families needed more from them than technical competence. They needed education, support and advocacy,
They began to see the value of knowledge beyond the objective/technical, knowledge of the context of children and families’ lives. The narrative of one participant, Parks, illustrates the process of shifting from a valuing of objective/technical knowledge and ‘doing’ to a valuing of contextual/relational knowledge and ‘relating’. Her story begins with telling me about the difficulty she had in articulating her practice for a software developer who was designing a patient information system within the ambulatory programs.

Getting involved in trying to develop a patient system and, as a nurse, trying to define your practice; that little project did more for me in helping me figure out what I do with a family than anything else, because I had to actually tell the software developer what I did and it was hard. I remember saying to the speech pathologist, who has the most wonderful screens in her program, she’s very succinct, you know, ‘I can’t do this because I don’t know what I do, I just talk to people’. And it was her that helped me. She walked me through my whole assessment and the information I capture and then how to put it onto, um, a database. ... to actually have screens now that capture all of my information; both, you know, concrete height, weight, growth patterns, to social issues and feeding issues and all of that.

In analyzing the above narrative it is interesting to note how focused Parks is on what she does, “the doing”, as opposed to what she knows, “the knowing”. When the speech therapist helped her focus on the information (knowledge) she captures in her assessments, she could then articulate it. Parks’ comment, “I just talk to people” is indicative of her view that nursing is doing and if she is just talking then she is not “doing
nursing”. Yet earlier in the conversation she struggled to articulate her perception that “talking to people” is an important, even critical, aspect of health care.

You can teach anybody those task things. We now teach children to heparin lock their own central lines. We send nineteen year old mothers home with babies on IV antibiotics. What’s harder, and I think some of us are better at it than others, is the interpersonal stuff, the family stuff, the ‘how do I know that you’re not coping?’. I don’t even know how to say it; maybe that’s the thing they call the art, you know, the caring piece. It’s the stuff that’s harder to get at.

Reflecting further on this, she comments, “A lot of what we do is soft”. In asking her what she meant by ‘soft’ she replied:

I don’t go into the operating room and stitch it up but after, after I guess you do stitch it up because you provide the support for that mum, as she’s watching what’s going on for me with her baby, with care she’s getting, with feeding, with providing that little hand on the shoulder that says to mum, ‘go ahead, its okay’, or with listening … helping mom be heard.

Parks narrative illustrates the conflict that many of these APNs’ experienced between the view of nursing as technical and task oriented, yet realizing the importance of the non-technical aspects of care to the health of the child and family, while sensing that much of what they do is not seen as legitimate within the dominant system. Park later comments that her focus is really more education and support than tasks, which is congruent with what other APNs saw as the primary focus of their practice. She reflects on what a focus on education and support means in terms of the knowledge she requires to provide effective care.
Mum is doing all the tasks but is she coping? And if you’re only measuring her coping by the fact that she can swab the area, she can change the dressing, then you’ve missed all of it, I think.

Here she points out the two kinds of knowledge that foreground the clinical practice of most nurses; the technical knowledge of sterile technique and dressing changes, and the theoretical and contextual knowledge of coping with a child’s chronic illness. And there is an awareness that the contextual knowledge is as important, if not more important, as the technical knowledge to the health care of children and families.

The association of nursing with tasks and technical care was also evident in the narratives of APNs’ within the community setting, although it was viewed more negatively.

One of the participants, Catt, argued that defining nursing as tasks is a narrow and inaccurate reflection of nurses’ expertise that has serious repercussions for the provision of quality health care for children and families. She discusses a program within the community that provides in-home nursing respite care for children with complex health care needs. The eligibility criteria for a child to receive nursing services are determined by the tasks that need to be done.

The criteria for a nurse right now is if they [children] have to have oxygen adjusted, they have to have deep suctioning, you know, all these technical things. … it’s all based on tasks; nursing judgment they say, but nursing judgment is so much more than that. It is not tasks, it’s looking at the whole client.

Catt gives two examples of situations in which children and their families have restricted access to quality health care within the community because of the narrow
definition of nursing as tasks. The first example concerns infants from neonatal intensive care and the second example concerns children who require palliative care.

The possibility of getting these children home earlier and the only way they can go home earlier is to have a nurse care for them in the home for a short transition period while they become more stable. We bring them to our [NSS] admissions committee and they say 'no, they're not eligible for a nurse in the home because the tasks don't require a nurse; the oxygen doesn't need to be adjusted, there's no deep suctioning'. The task doesn't say nurse but the complexity, the whole picture, says nurse. And what the CNS [in neonatal ICU] is finding is that then the stay in the hospital is extended and these babies don't fare as well in the hospital, with the change over in caregivers. They do better with a consistent caregiver, they gain weight, and the risk of infections is much higher if they stay in the hospital.

Catt also describes the impact of defining nursing care as tasks on those families whose child requires palliative care. If the child does not require adjustment of pain medication or other related tasks for symptom management, they do not qualify for a nurse in the home and yet Catt emphasizes that "palliative care nursing is holistic, it's complex" and often having a nurse in the home means that families have a choice about where their child dies. If there is not a nurse within the home, families are often reluctant to take their child home or to remain at home. And while having their child die in hospital may be difficult for many families, it can be particularly so for those living in other areas of the province. "You take, not only the child, but the family out of their community and fly them down to another community and you take them out of their support, and it
medicalizes dying in a way that, that being at home doesn’t”. Catt believes that providing options for families is an important criterion of quality health care and she is lobbying the admissions committee to expand their definition of nursing care.

In summary, while several of the participants have taken up the perspective of nursing as technical and task oriented, there is a realization that this perspective does not adequately represent their current practice. Their practice primarily involves non-technical dimensions of care such as education, support, and advocacy, which is more aligned with a contextual/relational perspective than an objective/technical one. Although they recognize the importance of contextual knowledge in informing their practice, they have difficulty articulating this knowledge, perhaps because of their awareness that it is discounted by those who speak the language of the technical. Consequently, an objective/technical discourse has the effect of silencing them.

*Exclusion from Health Care Conversations*

The language of the technical dominates the health care system and since this language does not adequately represent APNs’ practice or the knowledge that informs it, APNs often found themselves excluded from health care conversations. Nowhere was this more evident than in the family/team conferences held at the end of a child’s assessment. Children come to the clinic appointment and have an assessment by several members of the health care team. Often the appointments are scheduled over a two day period so the complete assessment is done in one appointment since most of the children come from outlying areas of the province. At the end of the one or two day assessment there is a joint meeting/conference of every professional who has seen the child, and the
child’s parents, and sometimes professionals from the community who will be following the child.

Each professional who has assessed the child gives a report of their findings; which is usually in the form of concrete data - test scores, which one of the APNs, Mead, refers to as “their props”. “They say, ‘on this test he got this score which means that and on this test he got this score which means that’”. Mead contends that this way of reporting the findings is “almost unfair for the nurse and even the social worker because they all come in with their props and I don’t have anything like that”. Mead commented that all she had was “what the parents had disclosed to me and sometimes it shouldn’t be discussed at the conference, like they haven’t had sexual relations for a year”. Interestingly, she does not perceive this as important contextual knowledge of the impact of a child’s chronic condition on the family and the quality of their lives together. Perhaps she senses that it is not knowledge that would fit into the technical nature of the conversation and consequently she does not see a way of participating in the conversation.

It is not only nurses who feel excluded from the conversation. APNs contend that often in these conferences, the family is sitting there not understanding most of what is being communicated. Mead gives an example of this from a recent team conference. A family thought their child had a particular diagnosis because the community doctor had said he did. The interdisciplinary team was to confirm the diagnosis. After assessment was completed it was apparent that the child did not have that diagnosis so Mead thought it was going to be a wonderful conference, because the parents would find out that their son did not have this condition.
So we're all sitting around and the physician presented and the psychologist presented and then the OT presented, using words like physio preceptor and then it was my turn to speak. I said, 'well, I know you came here with the understanding that your child has [a particular condition] and you wanted to find out what level. Now you've heard everybody and he doesn't have [the condition] and they broke down and cried. That was the first moment they understood that and we had been talking for forty minutes. We were so far over their heads.

The health professionals’ approach of reporting their findings in technical language often leaves parents in the dark as to what is happening with their child. While it is logical to assume that the purpose of the conference is to inform the family of the child’s diagnosis and answer any questions they have, APNs suggest that this purpose is secondary to the opportunity for team members to “strut their stuff” for each other. One participant Walters, who had made reference to “disastrous” conferences, illustrated an example of this. When I asked her what a disastrous conference would look like, she replied:

where the team spent the whole time talking about what their findings were,
where they didn’t include people from the community in the discussion before the conference, where they didn’t ask questions, they just gave information, where they didn’t find out from the parents what questions they wanted answered, what were the questions the community [professionals] wanted to have answered, where certain individuals monopolized or went on and on and on about the testing. I mean, when people get that glazed look in their eyes, you know they’ve
had enough of that kind of information. People go away disgruntled because they haven’t gotten the information they wanted and they didn’t feel included.

In contrast, Walters gave an example of a team conference that went well because the primary purpose was to inform the family about their child’s diagnosis and what they could do to help their child. She asked the family before the conference what they expected from the conference and what did they want to have happen. She said they were very candid with her and told her that the last time they had a team assessment about five years before they came away from the conference very disappointed because they got a lot of information on what the child could and couldn’t do but very little information on what they could do to help their child reach his optimum development. So when Walters talked to the team before the conference she made a point of saying:

What we have to do in this conference is give these parents specifics, they don’t want to hear all the results of the assessments, other than the bottom line, so we need to give them the bottom line and then we need to spend all our time giving them specifics about what they can do.

Walters said she checked back with the parents at the end of the conference and they were very pleased with how it went. They’d been told their child had an intellectual deficit and qualified for extra services from the ministry but they were pleased because what was more important to them was not only having confirmed what they had been thinking but they had things that they could go home and do, they had strategies and they were listened to. And “they had a chance to clarify information; they had a chance to talk, and tell us what they thought about it, what their experiences were with their child”. The approach of answering parents’ questions, presenting information in a way that is clear to
them, and providing practical suggestions for helping their child can be empowering for parents.

Some APNs suggested that the only way they could include practical/contextual language within family/team conferences was to chair them. Mead suggested, “it’s much easier to advocate for the parents when you’re chairing, plus I have talked to the family and I know what they want out of the conference”. However, this did not happen often and when it didn’t, APNs took it upon themselves to clarify team members’ reports and recommendations to the family after the conference. As Addams notes:

- making sure that they understand the diagnoses and how to manage the recommendations. I guess playing a bit of an interpreter role for the other team members to explain to the families what the jargon means and what some of the recommendations are that maybe perhaps they haven’t felt comfortable to ask the other professionals if they haven’t understood.

It is interesting that APNs undertake the responsibility of making sure the family understands the information related to their child’s diagnosis and/or ongoing management. Yet, they do not confront team members with their “incoherent” communications in team conferences. Rather they would go along with it and then go to the family after the conference to “interpret”. In other words, through their silences, they perpetuated the dominant system, the exclusion of families and their own exclusion.

**Summary of Narratives of Exclusion**

Analysis of participants’ narratives about organizing clinics has provided a means of interpreting the dynamics of APNs’ exclusion from participating in decisions regarding the health care of children and families and the ways in which APNs resisted or
reinforced those dynamics. This exclusion took different forms and included: APNs not having a scheduled time to see the child and family when they came for their clinic appointment, not being asked for their input into health care decisions, being silenced by an objective/technical discourse, and being excluded from health care conversations. It is difficult to get a sense of the degree to which APNs’ perceptions of exclusion from health care decisions and conversations are the result of power dynamics on the part of other members of the health care team and how much of it is APNs own doing in relation to not communicating about their practice and their knowledge. A third possibility is that given that the objective/technical language of the dominant system does not fit with their practice and subjective knowledge is not accepted as legitimate knowledge within the dominant system, they do not have a language that accurately represents their practice which prevents them from participating in health care decisions.

I will now turn to an analysis of APNs’ narratives about processing referrals to demonstrate the dynamics of APNs’ preoccupation with efficiency, which contributed to the goals of the dominant system.

Processing Referrals: Narratives of Efficiency

APNs’ narratives about processing referrals to the program revealed a preoccupation with efficient use of team and system resources. While the stated goal of processing referrals is to determine which children referred for an assessment are appropriate referrals and who on the team they should see, it often seemed that a more pressing goal, from the perspective of APNs, was to make sure the team and system resources were used wisely.
It’s a fine line that you walk because you’ve got your monetary hat thinking ‘we don’t want to have services that are not needed and causing more dollars to go down the drain’ but are we making sure that when we do see this child that we’ve got everyone we need to get the result [to properly assess the child] and then in actual fact, its economically sound because then they can move on. You’re always wearing those two hats and trying to make sure that you are fiscally responsible.

This concern for efficient use of resources is ironic given that APNs saw their own expertise and time as being inefficiently used. Moreover, APNs were acutely aware of the impact of severe cutbacks in community professionals, which created greater demands on the tertiary care teams with no increase in their resources.

At [particular institution], our referrals have increased two hundred and forty percent in two years and that is a direct result of cutting back in communities in terms of services for kids, like OT’s, PT’s and its all that kind of stuff. If a child is school aged, because the psychology people are such a huge component of the diagnosis of [condition], we say “can the school do it first because we have limited resources?” Well a teacher wrote me back and said the school psychologist will not be in their school until May of 2003. [The request was in the fall of 2002.]

Resources in the community are drying up. In past years there were more services in the schools for a lot of these kids. Currently, a number of health professional positions have been deleted despite increases in numbers of children with [condition] as well as other diagnoses. We’re seeing more and more kids coming
in with two or three other diagnoses on top of [condition]. There are longer waitlists for assessments and more referrals to the tertiary care centres. Within the tertiary care setting, we’ve got the same number of people seeing this population of children but the demands are definitely greater in terms of increased acuity, number of diagnoses, and ESL families.

Given that government cutbacks in community resources, and in particular, community professionals, have created increased demands on ambulatory programs with no additional resources to meet the increased demands, APNs’ preoccupation with ensuring efficient use of resources at the program and team level is equivalent to putting their finger in the hole in the dike. Part of APNs motivation for ensuring that team members’ time was efficiently utilized is that they could be seconded by one of the other teams if they were not kept busy. One participant commented, “we’ve got to try and fit all the children in to keep everybody busy so we don’t have professionals sitting there not seeing kids. If that happens then they get pulled into other teams and used on other teams”.

APNs ensured efficient use of team and system resources by: a) determining that the referrals to the team were appropriate, b) making sure that the children saw the appropriate professionals on the team, and c) when possible, having parts of the assessments done by community health professionals (which was becoming more and more difficult with cutbacks in community resources). These decisions required expert decision-making skills, as illustrated in the following narrative.

I need to collect all the data from all of the different community players who are working with this child. I usually phone the parents first. I find out what school
they’re going to, whose involved, if they are involved with a child development center, if they’ve had psychological testing in school, figuring out who the players are. Then we send out forms for them to fill out and then I decide who of our team, of OT, PTs, speech language, psychology, nursing, recreation therapy and the docs, who all needs to see this kid and why. Are they having fine motor problems? Can the community OT handle it or do they need more of a tertiary assessment? You have to do that for all the disciplines. Then you say, okay, I think that they need to see OT because they’re having fine motor problems. They need psychological testing because they’re under five. If it’s over five the school has to do it. So it is all these kind of decisions that make it quite challenging.

Ensuring efficient use of team and system resources also required APNs to have extensive knowledge of the health condition of children served by the specialty program, so they could ensure that children are referred to the appropriate specialty program, which saves system resources that result from inappropriate referrals. For example, one participant, Mead, tells a story about a referral she received from a community physician. In the referral letter there was a word describing the child that jumped out at her because it was not a word that you would associate with children with this condition. She phoned the child’s preschool “to get a picture of what his day is like at preschool”. Then she phoned the parents to get more information and then made the decision to refer this child to another program because, "he wasn’t fitting enough of the criteria for [condition for which he was referred]”.

Mead maintains that the knowledge she has acquired over twenty years of working with this population, has allowed her to “pick up on those nuances of behavior
that straight black and white testing won’t pick up; it’s the experience of recognizing [condition] in interaction”. However, neither team members nor the program director acknowledge her in-depth knowledge of the health condition. In fact, Mead’s knowledge is discounted by the practice of team meetings to determine which team members should see the children referred. Although Mead says that in most cases the team rubber stamps her recommendations, in a later comment she suggests that the practice of team decision-making undermines the decisions she has made and that were part of her responsibilities as intake coordinator. “In a previous setting I had much more responsibility deciding who the child needed to see. Now I can only recommend and the team decides as a group who the child will see.” Mead comments that it is a very time consuming process of trying to get everybody together for bi-weekly meetings. The paradox of this is that Mead has to organize these meetings in which others second-guess the decisions she has made. If in fact the team does rubber stamp her recommendations, these meetings are one more example of an inefficient use of team resources and points to the irony of nurses taking on the responsibility of the efficient use of team and system resources.

Looking out for the system rather than for clients is an example of how nurses can, like physicians or other health professionals, get caught up in “caring for the system” rather than providing quality care for patients and families. APNs within the community setting also talked about the concern with conserving resources, but in this case, it was nursing resources. One of the resources within the community is a Nursing Support Services (NSS) program that provides nurses to care for children with complex health care needs within the home setting. There is a provincial committee of nurse coordinators
who determine the eligibility of referrals made to the program. One of the APNs (Catts) said that there was a concern, particularly among “the old guard” on this committee, that putting nurses in the home was not a good idea because, “you will never get these children off of nursing”. Catts argued that this attitude “makes nurses gatekeepers and we're not gatekeepers. They should be looking at the greatest good of the client, instead of the greatest good of the system.”

Saving the system money could often be seen as the operating goal overshadowing APNs’ concern for the effectiveness of health care for children and families. Another community APN, Edelman, was told by the nurse manager that the best way to keep the project she was working on going, was to “stress that it is going to be cost neutral or even save money if we can become more efficient in the way we deliver services, ... to try to make what we’re doing fit into their way of thinking”. Although the project was about designing more effective ways of delivering health care for children and families within the community, it was translated into “how will this save the system money?” Edelman realized she had to “play the game” and promote the project as saving the system money rather than increasing the effectiveness of health care for children and families; “otherwise, I’m afraid they’ll just say no to new projects, which is a distinct possibility anyway”. Framing the work they do in providing quality health care in terms of saving the system money is another way in which APNs take up the discourse of efficiency.

**Summary of Narratives of Efficiency**

This section has analyzed APNs’ narratives about processing referrals to their programs, as a means of examining the power dynamics of the dominant system and the
ways in which APNs resisted or reinforced those dynamics. APNs preoccupation with conserving system resources is puzzling given that it occurred within the context of severe cutbacks in community professionals which created greater demands on the tertiary care teams with no increase in their resources. APNs’ strategies to conserve team and system resources basically had the effect of reinforcing the dominant system of health care. Consequently, they contributed to the system goal of saving money rather than to the provision of quality health care for children and families. Moreover, their contributions to the diagnosis and treatment of children— that of bringing together all the information on the child and ensuring they see the appropriate health professionals—remains invisible to others. What the public and other health professionals see are nurses running around “directing traffic” while their contributions to a child’s diagnosis and treatment are carried out behind the scenes.

APNs’ narratives revealed that they perceived the nursing culture as contributing to their difficulty articulating their practice and to a lack of organizational supports for their practice.

The Culture of Nursing

The historical motto of nursing, “I see and I am silent” seemed, in many ways, applicable to the participants in this study. It is not so much that APNs bought into the dominant system. Rather they chose to be silent in the face of practices that were not in the best interests of children and families and their silence serves to perpetuate the system. One participant, Mead, illustrates the culture of silence in nursing in the following conversation. She had been talking about a difficult decision she had to make in regards to a team member (in her previous position when she was team leader).
R: In looking back was there any other way you could have handled it?

P: I could have just zipped my lip and not expected anything different; put up with it and role modeled more perhaps.

R: but it's kind of hard to do that when families are suffering.

P: yeah, I kind of wondered, would I have lived with it if other team members hadn't started speaking up too? I don't know. You know the nature of nursing sometimes is to never do anything or say anything that is difficult, to just absorb the shocks as they come along (laughter -hers).

Another participant, Sanger, comments on her observation of how easily nurses are swayed by others' opinions in talking about nursing practice, “especially if it is the opinion of a group of ‘high level’, ‘high power’ people”. In exploring what she thought was behind nurses’ reluctance to articulate their point of view, she initially replied, “I think not being listened to or the sense that we have not been listened to”. But she then went on to explore other aspects of the nursing culture that she thought contributed to nurses’ reluctance to articulate their point of view.

... being silent and yet when we try to speak, um, I think sometimes it gets overshadowed by others. We may speak with hesitancy because we're not sure. I think there is, okay this is a total generalization, a stereotyping, but I think in many ways, we feel that because our role is always serving others in nursing, and we want to please others, not please but serve others, meet other people's needs. Perhaps if we speak out, we feel that we [will be perceived as] against other people versus that this is just one additional opinion. We feel that it may be viewed as we're not being supportive. I think we're given subtle messages by
society too, that we're not as important as the physicians, we're not as important as some of the other groups of health professionals.

Sanger initially referred to the nurse's role in serving others as “pleasing others”. She corrected this by saying, “not please, but serve others, meet other people's needs”. However unintentional that slip may have been, she went on to say that nurses do not want to be seen as unsupportive, which relates back to pleasing others and not offending anyone. Sanger also referred to the messages that nurses get from society that “we’re not as important as physicians” which can lead to a lack of confidence in interactions with others, particularly when those others see themselves as important. It would seem that what is at issue here is nurses’ perception of themselves as not wanting to offend others or be seen as unsupportive and not feeling that they are as important as other health professionals. Although Sanger prefaces her comments by saying that she is stereotyping, her perspective could be a fruitful area to pursue in addressing nurses’ reluctance to articulate their perspectives on health care. As she later comments, “we’re not providing the best service to the children and families if we don’t articulate what we believe”.

Goodall made a similar observation to Sanger in regards to nurses “being swayed” by others who are seen as ‘high level’, ‘high power’. She notes that young charge nurses often have a difficult time defending their position with physicians in situations where they do not think the child should be discharged. “If they [physicians] pull that paternalistic, obnoxious approach, nurses just crumble rather than confront them or defend their position. It takes a really strong, clear, independent nurse to fence with them”. While this last comment would indicate that what is occurring is a power struggle between the nurse and the doctor, it is also feasible that nurses do not feel confident in
their knowledge so when their opinion is questioned, they cannot defend it. This interpretation relates to a conversation with Goodall when she was comparing nurses and physiotherapists talking with physicians.

If you hear the rehab staff in discussion with physicians, it’s a very clinical discussion. When the physician asks ‘how’s Johnnie?’ the OT and PT staff will give them a professional answer, use all the lingo, you know, some of us don’t even understand it, but they’ll use it because that’s their role. But when they ask nurses, ‘how’s Johnny?’, I hear, ‘okay.’ And sometimes the physician will have to pull, ‘well, how’s his temperature? Has he been up?’ You know, I’d like to run that nurse into the little room and say, ‘for god’s sake, don’t embarrass us; give a good clinical picture. You’ve been in with this child all day.’ But they say, ‘Oh, yeah, he’s doing better today; like, what does that mean? They can’t even describe what’s important.

The rehab staff is communicating in technical language, using “the lingo” of the dominant system and is seen as being “professional”. The nurses, on the other hand, are being vague and hesitant and, in Goodall’s opinion, unprofessional. She argues that they could participate in the conversation if they described “the clinical picture” but it seems as if they did not have the language to respond.

In addition to nurses’ reluctance to speak out and voice their point of view about patient care, participants’ narratives revealed that APNs also did not speak out about the increasing demands on their practice. Rather, to quote Mead, they “just absorb[ed] the shocks as they come along” but absorbing the shocks takes its toll, as Lange comments:
You get loaded on and I know, we have advanced practice meetings within [institution] where all of us kind of get together just to, 'how's it going', and everybody is like that. We’re all just getting piled on and some people have started, we’ve had one colleague go off on stress leave whose been amazing, you know, doing all kinds of stuff for a lot of years, but you just reach a point where ... (Voice trails off). I think a lot of people are kind of [burned out]. It’s just the shortage and the cutting back of services.

Lange’s last comment indicates that she, like many other nurses, has bought into the discourse that the current work overload on nurses (and many others within the system) is the result of government cutbacks and nursing shortages, rather than the way in which nurses’ work has been conceptualized and framed by those in positions of power (Ceci & McIntyre, 2001).

The above narratives suggest that nurses’ silence and reluctance to voice their perspectives are related to “not being listened to or the sense that we have not been listened to” as well as wanting to be seen as supportive and not offend others. It was also suggested that nurses internalize the societal message that they are not as important as other health professionals, particularly doctors. It would seem that administrators and/or managers also internalized this message as many participants argued that administrators supported physicians over them, even when the administrators were nurses.

A dominant theme that surfaced in the majority of participants’ narratives was the lack of support they received from managers in the organizations in which they worked. This next section will explore APNs’ perceptions of this lack of support and the effects it had on their practice. It is included within the section on nursing culture because in many
situations the managers who were not supportive were nurses and this idea that nurses are not supportive of nurses is another aspect of the culture of nursing.

**Lack of Support for APNs**

In examining APNs narratives for possible explanations as to why they saw themselves as powerless to change the system, lack of administrative support was a major reason given. The unwillingness of managers to lobby for them in relation to hiring clerical people to run the clinics created resentment among the APNs because they saw it as a message that their time is not valuable or that they do not have a valued role with the children and families. APNs also perceived managers as supporting physicians’ power within ambulatory programs, as the following narrative illustrates:

> Physicians in some of the clinics have complained that they don’t have a nurse working in the clinic, so they get nursing time assigned to their clinic. It seems that they are really looking for someone to gather charts, to direct traffic, to, you know, maybe measure and weigh, which isn’t a nursing role and a clinic aide could do the same thing, but they say ‘I need a nurse’ and they get a nurse.

Addams contends that administrative support for physicians is at the expense of nurses.

> It doesn’t mean that there are more nurses; it means that their time is divided up to more places. I don’t think that is terribly realistic because the nurses are already working flat out and there is no spare time in the day but now they are expected to do more and more and more with no more time.

Addams goes on to say that she thinks administrative support of physicians and increasing nurses’ workload reflect both the power of physicians to demand what they want and a lack of understanding on both the part of administrators and physicians
regarding what nurses can contribute to health care. Another, participant, Parks, reflects a similar sentiment:

One of the administrators [a nurse with a background in psychiatry] didn’t have a concept of what nurses in ambulatory programs did and she used to say all the time, you know, ‘these patients are coming to see the physician and the nurse is the helper in that program’. If you mentioned nursing caseload or case management she’d just like go around the bend, she didn’t want to hear it. Interestingly enough, Parks tells a story about this same administrator giving birth to a baby who had a chronic health condition that required a great deal of support and teaching from the APN in one of the ambulatory clinics.

over that two-week stint of her having her baby and engaging with [APN] and experiencing first hand what she needed, all of a sudden the shift in her thinking was absolutely incredible. And you could have told her all that stuff but until she experienced it, she had absolutely no idea. Was she appreciative? You bet.

In exploring the sense of resignation that Lange expresses, it is clear that the barriers she perceives go beyond physician dominance and include the nursing culture within the organization in which she works.

R: It sounds like you have some pretty clear ideas about how it could work differently and how, as an advanced practice nurse, you really could make a difference.

P: Absolutely and its frustrating to know that it’s probably not going to happen. The other thing is, you know, in a lot of other places where you work, you're kind of used to nursing having a fairly high profile because when you go to a hospital
ward, most people are nurses. In [institution where she works] there hasn't been a lot of really strong nursing leadership so its kind of, the nurses are the ones who change the bed pans. Lately we've had a few strong nursing leaders, um, but a lot of the old timers really don't think nursing has a lot to offer. There's a lot of that thinking, kind of engrained in nursing. When you talk about 'let's get a core group of the team members together, just to figure out how we're going to do this', and it's, 'oh, you can't do that, you have to have every single person' (even though they're extraneous, such as recreation therapy), 'they're just as important as everybody else'. Where I can see that's a good motto to have, it's troublesome when you're trying to get work done.

I've heard from [a colleague who moved from this environment], she's like 'when I want to make a decision I get three core people in the room, we make the decision and its done and all the people who that decision affects don't come into my office saying well, why wasn't I at the meeting?', which happens here. You know, it's all that culture stuff, you don't realize how much that all affects but it totally does.

Lange sees the nursing culture as also influencing her ability to impact change in the organization. Not only do physicians discount her knowledge and set up roadblocks but so do nursing leaders who view nursing as task oriented and use the rhetoric of “everybody on the team has to have input into any changes because they are all equally important” to block Lange from taking the initiative to make changes. Lange reached a point where she realized that “nothing is going to change” and that she had no power to effect change to the system to improve accessibility for children, so she handed in her
resignation and accepted a position somewhere else. “I hate giving up but, you know, you
sort of have to think, this is not working the way it is right now and nothing is going to
change”.

In general, there was a sense among participants that confronting physicians about
their dominant attitude would be professional suicide because of the support they had
from administration. This perception was, in fact, borne out in one participant’s case.
Brinker confronted physicians regarding their paternalistic, dominant attitude toward her.
She told them that she would not organize clinics and do the tasks they wanted done; they
had a choice; she would do one or the other. She also told them she would take as much
time as she needed with patients because everybody else on the team did and nobody said
anything to them. A short time after the conversation for this study took place, Brinker
lost her job, supposedly because they were upgrading the position to a CNS and she did
not have the qualifications. However, another participant in this study who is a CNS,
works as a nurse clinician because they would not upgrade her position; so it appears that
Brinker’s firing was politically motivated. And Brinker made it clear in our conversation
that the administrator sided with the physicians and told Brinker she needed to do what
the physicians requested.

One of the community APNs, Edelman, also talked about the lack of support
from nursing administration to carry out her advanced practice role within the
community. When Edelman began the position, she made a point of talking with the
nurses with whom she would be consulting. These nurses worked directly with children
with complex health needs and their families within the community and Edelman wanted
to find out what they needed in the way of support and education to practice effectively.
The nurses identified that meeting on a monthly basis to problem-solve around practice issues would be helpful to them. The nursing administrator who was responsible for the program in which they worked, told the nurses that there was no money for driving to a meeting so they couldn't do it. Edelman saw this as "blatantly undermining what I was trying to do" and she maintained that it was the result of the administrator's perception that "the position of CNS was not acknowledged as being important. What was important was front-line staff and she wanted the funding that went to pay my position for another front-line staff". In response to my question, "did she not see supporting those nurses as important?", Edelman replied, "I guess not".

This lack of valuing nurses who work directly with patients and their families was also evident in the narrative of another APN, Duncan, from the community. Duncan commented that there was no recognition or acknowledgement by administration of the impact of restructuring of community health on community health nurses (CHNs), even though it had a major impact on their work. She said that at the time the changes were being proposed, she voiced concern regarding the impact this would have on the nurses and was basically told, "that should not come into the consideration of what we were going to do; you should not be thinking about your needs as a professional", which was basically making it a personal issue which it wasn’t. When I asked where this came from she said it was the administration of the health board at that time.

Another indication of a lack of support for nurses within the community setting is that nurses are often required to practice outside their area of expertise and competence and there is no acknowledgment that this is not only stressful but also potentially dangerous. An example is that home care nurses who are expert in caring for adults and
older adults are expected to take on the care of children within the community because there is a shortage of home care nurses who have pediatric experience. Edelman is currently working on a project to decrease fragmentation of health services for children within the community and she comments on one of the outcomes she would like to see from the project.

I hope that the nurses who would be providing care for these kids are knowledgeable in pediatrics and are not pulled from some place else. I think what we’re doing now is really unfair to nurses who are excellent, excellent nurses in working with adults and problem solving with the elderly; they know hospice, they know the different supports that are out there, but when faced with a child, it is outside their area of expertise and they’re petrified. One nurse told me she just felt so awful when she left the home of this child, she thought she wasn’t competent and she sat in her car and cried before she could drive home. So I hope another change if this project works is that nurses won’t be subjected to being placed in situations where they don’t feel competent.

This sense of nurses’ work not being supported or valued by the system in which they worked was pervasive throughout APNs’ narratives. It is interesting how those APNs who worked directly with nurses rather than with children and families, all emphasized the key importance of supporting nurses so they could provide support for the children and families. Duncan argued, “I don’t believe in that original philosophy that the professional’s needs should not be considered, I think the professional’s needs must be considered”. She says her philosophy with nurses is the same philosophy she wants them to have in working with clients; “you want to help the client do for themselves, in
my role, I want the nurses to do for themselves, but to give them the freedom and the support to do that”. Sanger emphasized the importance of encouraging nurses to think beyond "the point of view of the majority. We need a system which encourages and listens to new ideas, new ways of practicing to improve the delivery of patient care". Another participant, Hooper, argued that by enhancing and supporting the quality of practice of nurses she was "building the capacity of the system”. It is also interesting that APNs did not sense this philosophy as being present among system administrators or managers.

**Summary of The Culture of Nursing**

The participants in this study described the culture of nursing as characterized by silence, by nurses “absorbing the shocks as they come along” rather than speaking out about injustices within the system or even voicing their opinions about patient care. Nurses’ silence was attributed to the need to be seen as supportive and not offend anyone, the sense of not being listened to, and not being supported by the managers and/or administrators within the organizations in which they worked. This lack of support created a sense of not being valued and feeling silenced. It is interesting that although APNs did not feel supported themselves, they emphasized the importance of supporting those nurses with whom they worked. The nature of that support involved listening to nurses, asking for their input into decisions that affected them, and encouraging new ideas and new ways of improving patient care.
Summary of Chapter Five

The APNs’ practice at the individual level of health care was structured by two central activities that occupied the majority of their time; organizing clinics and processing referrals to the program. Their narratives of these activities provide a window into the power dynamics operating within the dominant system of health care and how those dynamics played out in ways that discounted or suppressed APNs’ knowledge. Because APNs practice within an environment where objective/technical knowledge is privileged and subjective/contextual knowledge is discounted, they took up the dominant discourse of health care as technical care with its emphasis on doing. Consequently, they had difficulty articulating those aspects of their practice that fell outside the technical, which was most of it. Since the language of the objective/technical dominates the health care system, the APNs often found themselves excluded from health care conversations and unable to articulate their part in the delivery of health care to children and families. Moreover, they perceived the nursing culture as contributing to their difficulty in articulating their practice and to the lack of organizational supports for their practice. Thus, while the APNs can and do contribute to the community-based health care of children with complex health needs and their families, their practice is constrained by a number of factors that lead to their invisibility and their under-utilization as expert practitioners. The next chapter examines the constraints on APNs’ practice at the population level of health care.
CHAPTER SIX

INTERPRETATIONS OF THE DATA

THE CONTEXT OF APNS' PRACTICE: POPULATION HEALTH CARE

Although there was a strong message in participants' narratives about barriers that prevented them from providing quality health care for the population of children and families within their specialty, in re-reading the narratives it becomes possible to see something else, and that is the in-depth knowledge and skills that these APNs bring to situations in which they encounter barriers to the provision of quality health care. Consequently, the identified barriers are important sites where APNs have the potential for making a significant contribution to the health care of children and their families at the population level, if their expertise is capitalized upon.

In this chapter, I will discuss three areas that APNs identified as most problematic in relation to their goals of providing quality health care for the population of children and families within their specialty. These areas are accessibility of children to diagnosis and treatment, prevention programs, and resource allocation. Each of these areas represents broad issues related to the health care of children and families at the population level. I will examine these areas in light of the knowledge that APNs bring to them and how that knowledge could be drawn on to improve accessibility, prevention and resource allocation.

Accessibility of Children to Diagnosis and Treatment

Access to timely diagnosis and treatment is a major problem in the health care of children with chronic conditions as evidenced by the long waitlists in many of the
ambulatory programs that provide diagnosis and treatment for these children. Several of
the ambulatory programs have one to two year wait lists of children needing to be seen.
For instance, one APN says they have 250 children every month to see (based on
international guidelines of care for this population) and they can see 50 because of
limited funding to the program that restricts the number of clinics they can hold each
week. Thus, one of the goals that the APNs had was finding ways of reducing the
waitlists and increasing children and families’ accessibility to health care. On the surface,
the restricted clinic time for seeing children, appears to be an administrative/ funding
issue but, on closer examination, it is also an issue of physician dominance of health care,
as clearly illustrated in one participant’s narrative. Lange works in an ambulatory
program that diagnoses neuro-behavioral conditions in children and the focus is strictly
diagnosis, with no treatment or follow-up. There are two physicians who do all of the
diagnostic assessments of the children, and there is a two-year waitlist, which Lange
directly attributes to the physicians.

We have seventy to a hundred referrals a month and we see like three or four kids
a week, so it’s never going to get done. You've got these two doctors who
basically, they're superior and won't do anything about the way things are going
and they just put up roadblocks constantly. And they don't consider anybody to be
able to give them feedback, so it’s really very frustrating. This one doctor, to try
and get [doctor] to see more than one kid in a day, [doctor] freaks out, so its never
going to happen, and nobody can make [this doctor] see any more kids. So it’s
just, a lot of that stuff you have no control over.
Lange expresses frustration at participating in a system that is clearly inefficient but in which the doctors make it clear that they are in charge. Although Lange suggests she has no control over the situation, her narrative reveals that she takes advantage of physicians’ being late for clinics by doing the assessments.

I think she [doctor] lets us do stuff because she is so disorganized that if she didn’t have somebody tying up the loose ends it wouldn’t get done. I swear it just came out of necessity because she would be forty-five minutes late so we would start because you can’t leave them sitting there, right? Then she’d come in, ‘okay, where are we at? What are the things we need to work on here?’ and she just takes it from there. The other doctor I work with will do it all over again because she just doesn’t trust anybody. Her attitude is ‘a doctor is supposed to do this assessment so nobody else can do it’.

Lange argues that a nurse can easily do the assessment for the child and family within this particular population. She contends there is nothing in the assessment that requires a doctor’s knowledge (she goes through the various parts of the assessment to point out that she can, and does, all parts of it). While she acknowledges that nurses can’t “diagnose” she maintains they can provide all the data necessary for the physician to make the diagnosis.

Obviously I can’t diagnose, a doctor needs to do that, but the bulk of the work can be done by nurses. Right now, the physicians spend about two hours with the family taking the history and where mum is at and what’s going on. It’s quite a long time to take that history. A nurse can do that. And what we’re really tied up on now is the doctor time. That’s why our waiting list is so long. If we could just
get some more nurses who know this population really well and the doctors could just review the chart, interview the family quickly, half an hour or whatever, and be out of there. We (APNs) could really make a difference.

Lange points to a key ingredient of the APN being able to contribute to the diagnosis of children within this population and that is knowledge of the population. As mentioned previously, all of the APNs demonstrated in-depth knowledge of the chronic conditions of the children within their specialty, knowledge gained from their contact with multiple children with the condition over their years of practice.

Since Lange felt blocked in her attempts to get physicians to change their practice, she decided to tackle the problem of children’s access to a timely diagnosis in another way. She determined that, in addition to physicians being a factor influencing children’s accessibility to the program, the fact that the program had no clear criteria for determining which children they would see and which ones they would not also influenced the number of referrals to the program. She decided that having clear eligibility criteria could decrease the number of referrals to the program. Although she was not successful in getting these criteria established, her narrative reveals ways in which APNs could address issues of accessibility of children to the health care system. Moreover, Lange’s narrative reveals the knowledge and skills that she brings to bear on the problem. She not only has in-depth knowledge of the chronic condition for which the children are being assessed but she also demonstrates the problem-solving and organizational skills necessary to improve the effectiveness of the current program. Another participant in this study, who worked with a population of children with neuro-
behavioral problems, also maintained that APNs have the knowledge and could easily
and accurately do the assessments of these children.

Another issue in relation to increasing children's access to the health care system
is vulnerable populations. One of the participants, Lange, talked about the population she
works with as being in that position.

These families are (and I'm sort of putting them in boxes here) not highly
educated, have a lot of issues of their own, and they're not organized. I think if
this population could get together and just ... they need a voice and they don't
really have one.

Another participant, Parks, talked about a similar issue of children and families "waiting
in the wings" for their appointment because of a lack of funding to the program which
means fewer clinics and therefore fewer children can be seen in a timely manner.

A huge part of my job every month, it's the part I hate, is going through those two
hundred and fifty kids and picking out the fifty that will be seen. I started out very
altruistic; I said when I got my orientation, this is wrong, you can't do this, and
now I'm quite cynical (laughter). The really awful part is, if you've got people
calling you saying this is an issue, this is urgent, this is whatever, you most often
get seen. If you have a family that's waiting for you to call them and I don't know
them that well, they'll probably be three years.

Parks explains that selection of children to be seen is based on urgency, which
could be a surgeon requesting a pre-operative assessment for a surgery, that has to be
performed at a particular developmental stage or it could be (and according to Parks,
more often is) a parent, a school, a community health nurse, or a GP calling with
information about a child that needs immediate attention. Parks argues that if funding were adequate, the team could provide regular, appropriate assessments and treatment, which would avoid “crisis” situations and provide better outcomes for children and families. She feels so strongly about the need for funding to improve accessibility that she has written a proposal for government funding for the program. She told a story about writing this proposal and how abstract the questions were that she had to address. She was sure that the people who read it would not understand the problems of the children the program served so she sent the proposal off with pictures of the children before and after their treatment.

I took my proposal to my boss to go forward and I had all my photos. They were scanned, they were great, they were perfect and she said to me ‘oh, no, you can’t send photos’, she said nobody sends photos and I said ‘no, nobody has sent photos yet, but this is the page we’re sending on the top because, they’re not going to understand any of the stuff I’ve written here’, so it took a little convincing to get her to do that but she did. Anyway, we got a promise that we could have a hundred thousand dollars more, which we never got but that’s another story.

This story illustrates the creativity of the APN in addressing problems of accessibility to health care. It also illustrates the kind of knowledge that APNs see as critical to making decisions about health care resources for children and families and that is contextual knowledge. Parks sensed that providing answers to questions like, what are the determinants of health care for the population you serve? would not provide a clear picture of the kinds of health problems these children and families faced and the kind of health care they needed to address these problems. This is one of many examples of the
frequency with which APNs drew on contextual knowledge to address the health needs of children and families.

Children's access to timely diagnosis can also be impacted by generalized policies that are made without consideration of specific populations, as the following story by Addams illustrates:

I received a telephone call from a family whose child had been seen by our program before, and he was struggling in school. He had a significant [chronic condition] impairment. Our [program] philosophy has always been that psychologists who don't have experience with assessing children who have [chronic condition] should not be doing those assessments because the interpretation has to be quite different. So most of the time the psychologist from the tertiary care program team would assess the children. There was a policy change where I was working and they went to a more generalist model where they were really enforcing the tertiary aspects of the organization. So there was a blanket rule that anybody who was requesting a psychology assessment had to first get it in the community before they'd come into the centre. The community waiting list was at least two years long, the assessment was going to be considered inappropriate anyway, the results weren't going to be valid, and then the child couldn't be retested for a year following because of the training effect of the battery [of tests]. And I couldn't do anything to get [the child] in [to the tertiary care program].

R: So what prevented you from doing that was the policy?

P: The policy of the organization.
R: And who would be making those policies?

P: Uh, there was an initiative to deal with referrals and so it was the group that was trying to deal with referrals in a very generalized way through the entire centre. So it really came down to a collection of people all of whom are not in that position anymore but the children still have to live with these decisions that were made.

There is a high degree of awareness on the part of APNs as to the effects on children and families of policies and practices that result in lack of accessibility of children and families to health care, most likely related to nurses being in direct contact with children and families.

**Prevention Programs**

APNs' emphasis on prevention as an important dimension of the health care of children with chronic health conditions was based on their knowledge of the population within their specialties and evidence drawn from the research literature. Prevention for children with chronic health conditions was equated with early intervention, which meant early diagnosis. A frequently heard comment was, "we know that the earlier the intervention, the better the outcome". Yet, they continually encountered situations in which there were no preventive efforts or there were severe cutbacks to existing programs. The lack of funding for prevention was a huge source of frustration for APNs as they believed the government was being short sighted because the costs to the system are far greater in the long run than if early intervention has occurred; "it is expensive but they’re finding if you identify and treat a child early, in the long run you’ll pay fewer dollars to manage that child". However, one of the difficulties that nurses and others who
promote prevention programs have encountered is that governments are not willing to invest money in programs in which the outcomes are so far down the road.

APNs were concerned with prevention efforts on both the individual and population level of health care. On the individual level, APNs within the community were particularly aware of the preventive function of home care or in-home nursing respite care on families being able to keep their child out of the hospital. One of the community APNs, Edelman, told the following story of how one family’s multiple trips to the hospital might have been reduced had they had nursing support within the community.

There was an infant with a heart condition and virtually no lung tissue left and apparently he was in hospital most of his first year of life. He would frequently be discharged but he’d usually be back in hospital within twenty-four to forty-eight hours because, you know, his color changes or something like that and the parents get so scared, understandably, so they’ll take him into emerg. They’ll send him home again but the parents will bring him back again in the morning. I’m thinking if we had a pediatric home care nurse come and make daily visits or even twice daily visits to assess this baby and that might decrease the parent’s stress and therefore the number of trips to the hospital. I think if we are able to provide services at home, children wouldn’t need to be admitted into hospital.

APNs considered the provision of home care and in home nursing respite care as important preventive components of health care for children with complex health care needs and their families. Yet they say this component is chronically under funded and consequently children spent more time in hospital than they needed to if they had the
supports within the community. Again, this is an area in which documenting the effects on children and families (and costs to the health care system) of not having home care would be useful in making a case for increased funding.

Prevention was also high on the list of priorities of APNs who work with populations who have neuro-behavioral conditions or speech and hearing problems and they emphasized the importance of screening and early identification on the outcomes of children with these conditions. Some APNs saw lack of preventive efforts as being closely related to the referral process and the politics surrounding it. A common story is that APNs would see children in the ambulatory programs with speech or hearing problems that were downplayed by the family doctor so the child never got tested and therefore did not receive early intervention. Duncan talked about how speech delays in children are often not picked up because of the politics of the referral process.

We know the earlier you pick up speech delays, the better the child will adjust, you know, before behavior problems have resulted, rather than picking that up later. I cannot tell you how many times nurses will suggest that a child be seen by a speech pathologist, the client will go to their doctor and the doctor will say, ‘oh, that’s not necessary, boys especially, you know, they always speak later than girls’.

Duncan says part of the role of the community health nurse is working with parents (usually mothers) to help them decide for themselves what they want, based on the information. But sometimes the nurse is not successful because the mother will not question the doctor, particularly if the doctor has delivered her child; ‘well, I couldn’t, you know he’s saying I don’t need to do this’. Duncan maintains that all they can do is
state the facts based on the information they have and reinforce their recommendation that the child be assessed; “that’s one of the few things we can still try (laughing)”. So basically, while nurses can do screening and pick up on delays, they cannot make referrals. Rather, a physician who may have little knowledge or experience with children with speech delays can block the referral. The only option that the nurse has is to suggest to the mother that she insist on the referral, but as the above scenario reveals, the mother often accepts the doctor’s recommendation that nothing be done. Thus, physician dominance and lack of knowledge can undermine prevention efforts.

Another APN, Parks, had a similar story about the children with speech problems that she sees in the ambulatory program, a story that again illustrates the politics of prevention.

The population in our program, where we see kids with speech disorders, nine times out of ten by the time that child gets to us, that child is already six or seven and when you go back and take mum’s history, mum has known there’s something wrong and has been accessing different people who are saying to her, ‘you’re just worried, its your second child, they’re slower to talk, it’s a boy, um, if you didn’t harp on him he’d talk’.

Parks argues that the system is failing families because they are not listening to them and not trusting their instincts as parents. Furthermore, she argues that children’s accessibility to health care is limited by the politics of referral in regards to doctors being the only ones who can refer to specialists.

P: Families can’t access the people that probably could help them and listen to them. On the one hand we’re saying families should be empowered to take care of
their own health and on the other hand we’re saying but you must go to the physician to get a referral to do this. Your child has a speech problem and the speech pathologist has identified the speech problem but the speech pathologist cannot refer to the specialty program that can solve that problem. The speech pathologist must send you back to your family doctor who can say she’s wrong.

R: And that happens?

P: Oh it happens all the time. Why can’t I, as an “expert” in my field, refer directly to another specialist, whether it be a speech pathologist, a cardiologist, whoever. I have to go back through a physician to do it. Who thought that up?

The need to have a doctor make a referral for the child to see a specialist is another way in which nurses’ knowledge is discounted. Nurses see hundreds of children and they have reliable and valid screening tools for assessing these children. Yet they cannot make an informed decision that a child needs to be seen by a specialist. This system practice is one of many that reflect the knowledge dynamics that underlie the politics of prevention and referral. These practices are clearly not in the best interests of children and families.

Another participant, Lange, pinpoints early identification and early intervention as key aspects of prevention for the children with whom she works, which leads to them doing well and succeeding in school and life. She cities studies out of the University of Washington that show early intervention as a protective factor for children with neuro-behavioral disorders. Yet, “our kids don’t get identified early enough because there isn’t screening”. Lange points out the paradoxical effect that early intervention programs have had on the identification of children with neuro-behavioral disorders. One of the elements of early intervention is that a child does not have to have a diagnosis to get services. If
they have a "developmental problem", they can receive services from the Infant Development Program (IDP) without a diagnosis. Therefore, there is not the pressure to get the child diagnosed, whereas when they enter school, they don’t get funding unless they have a diagnosis, which explains the reason for the majority of children that Lange and her colleagues see in the clinic being school-aged. It also explains Lange’s frustration with a system that doesn’t identify these children early and offers them little when they are diagnosed later. The reason these children are picked up in the school system is that their behavior can become very disruptive and, basically, they become a problem for other people so they are referred to the team at [tertiary care institution]. However, the waitlist for being seen at [the tertiary care institution] is up to two years. Meanwhile, the child’s behavior problems can escalate.

Often you have to wait for the kid to really crash before they’ll get some help. Like if they get into [Youth Detention] they get a lot of service, they often get diagnosed there. But before that, you know, I had a kid the other day and mum said, ‘I’ve been told that we’re basically going to have to wait for him to break the law before we’ll get any help for him’.

Transitioning youth to adult care is another area that APNs perceived as an important focus for prevention. A youth transition program was initially developed by an APN to assist youth with chronic illnesses/disabilities in their transition to adult care. The impetus for this program came about because youth with chronic conditions were moving into adulthood with no preparation and in many cases no adult centres for them to go to or specialists to provide care. Interestingly, while APNs saw the need for the program and were keen to implement it with the youth in their areas, they got a lot of resistance from
physicians. Since the intent of the program is to get youth to take responsibility for their own health care, part of the process is for youth to meet with the specialist within the program to discuss their medical management and medications, and so forth. So if physicians don’t take part in it, it is difficult for youth to take charge of their health as they move into the adult world.

What is being recommended through the transition program is a different kind of relationship between the patient and the physician, one in which there is a collaborative partnership to address the youth’s health issues. One APN says that many physicians are not comfortable with this kind of a relationship because they are often “the old guard” who are used to being the expert. In fact, it is far more likely that this is the underlying reason that they are resistant of the program and not because it means that nurses won’t have time to do the blood pressures. One participant’s comments about the culture in ambulatory programs, supports this interpretation: “doctors don’t like [the youth assessment chart] covering up their notes, they want their notes on top. Basically the problems that have been uncovered is that there are bigger issues of clinical practice than this, because its not just the transition program, its any change of practice” [that physicians resist].

Other participants in the study discussed the difficulty they had in trying to implement the transition program within their ambulatory areas. For example, Addams promoted the transition program for youth based on her knowledge of the needs of the population with whom she worked and identifying a gap in the provision of services:

It’s almost predictable that come May and early June, we start getting a lot of panic phone calls from school staff and families, ‘my child is turning eighteen and
he is leaving school and all our services are going to drop away and we’ll have nothing. We need an assessment right now because we need everything set up before he leaves the school. Could you see him?”. At that point our usefulness is quite limited and there isn’t a lot we could do. I realized we should be starting a lot earlier.

Addams identified the youth within the population served by the program, as being “an underserved group [in regards to] becoming independent with managing their own health issues”. Her goal was to have the team take on the transition planning as part of the assessment but she did not think that would happen because “everybody would have to work even harder and take on even more and everyone seems so stretched as it is”. She did introduce the proposal to the team and for the time being, they will focus on one small part of the transition program, which Addams will do.

Although Addams attributes the lack of enthusiasm for the transition program by others on the team to the fact that everyone is so busy, other APNs suggest if physicians did not support it the team did not take it up as a priority. O’Keefe works within a specialty program in which the research shows that educating youth about their chronic condition and the treatments/medications they have received before they move on to adult care is important to their outcomes. Yet she maintains that of the seven physicians that work in this area, only one actually sends the youth a letter outlining the treatments they have received. O’Keefe says that presumably the other physicians do not see it as necessary or important.

Initially, I read APNs’ narratives about the issues around prevention for children and youth as an uphill battle in putting prevention programs in place in a system that
clearly does not value prevention. On re-reading their narratives I am once again struck by the knowledge these nurses have of the populations with whom they work – knowledge of the health needs, knowledge of the benefits of early diagnosis and intervention, including cost savings to the system, theoretical knowledge of the kinds of interventions needed to make prevention programs work, and contextual knowledge of the impact of that lack of prevention has on children and families' lives. This is a rich source of knowledge that is critical for designing health services for children with complex health needs and it is not being tapped. In fact, there is probably very little awareness within the general health care system of the breadth of knowledge APNs have in relation to providing health care at the population level.

The second thing that surfaces for me in re-reading these narratives is that, like their counterparts in the neuro-behavioral programs, these nurses are already engaged in prevention efforts. They are identifying children that need referral and even though they are blocked from actually making these referrals, they have the data to make a solid case for nurses to be able to make referrals. What they are coming up against are ideologies of medical dominance and physicians as gatekeepers to the health care system. As Street (1992) points out, the privileging of medical knowledge has been supported by the state through legislation which accords wide responsibilities and status to physicians, while subordinating the roles and responsibilities of other health professionals, including nurses, to them. Street argues that this apolitical view of medical knowledge disregards the ideological component in which medical knowledge “is exercised as social control to reproduce and support the class and gender interests of doctors” (p. 8). APNs are in a
position to challenge these ideologies in the interests of providing quality health care for children and families.

**Resource Allocation**

A consistent theme throughout participants' narratives is the lack of resources within the community for families that have children with chronic health conditions. These resources range from people, to programs, to financial and other material resources. Similar to prevention efforts, there was a wide discrepancy between APNs' emphasis on the importance of community resources in assisting families in the ongoing management of their child's care and government priorities. Again, it is likely that the priority given to the availability of community resources by the APNs is the result of their direct contact with children and families. They are the ones getting the phone calls from desperate parents who are having difficulty managing their child's care on their own and cannot find resources.

I earlier discussed the lack of nurse resources within communities, which include too few nurses to provide in-home and in-school support as well as home care nurses who do not have the expertise to provide care for children. While there is a demonstrated need for nursing support services for children with complex health needs within the community, it does not seem to be a priority for government or administrators. This is most clearly evidenced in the shelving of a report that developed a model for delivering health services for children with special health care needs within the community (Bassingthwaighte, 2002).

The availability of other health care professionals, such as school psychologists, speech pathologists, occupational therapists, physiotherapists, has also significantly
decreased, according to the APNs in ambulatory programs who often encountered scarce to nonexistent professional resources for children within their home community. Lange tells a story of what the lack of resources means for a child who is diagnosed with a neuro-behavioral disorder. Once the child is given a diagnosis they are “deferred back to the community team to arrange a structured program for the child in the classroom to help with learning and they need a teacher that understands their condition”. The school gets some extra funding from the government, supposedly to buy professional time to set up a structured program for the child. However, professional time in the schools is scarce and Lange makes the comment that “a community OT in the school will never get to a kid like ours” presumably because there are children with “more serious [read physical] problems” who need their help. Because these children have invisible health problems, they are not a high priority in the environment of diminishing professional resources.

In addition to a serious lack of community resources, the process of resource allocation can also result in a misuse of resources. For example, the “At Home” program is a community resource that provides financial support in the way of equipment, supplies, therapy and respite services for children with complex health needs who are eligible. However, one of the community APNs contends that a problem with this resource is that it has very extensive criteria for eligibility and once a child gets on it, there is no re-assessment later to see if they still require it. Therefore, many families remain on the service, when in fact, their child no longer qualifies for the benefits. Consequently, there is a long waitlist for families who desperately need the service but cannot access it until other families come off the program.
In exploring the reasons why community resources seem to be such a low priority for government funding, some APNs pointed to societal expectations on families to care for their own. What amazed the nurses was not only that families took on the challenge of providing very complex care for their child in the home setting but that they became such experts at it.

I'm constantly amazed at what we expect families to do. I can't believe it. I had one family whose kid was C1 ventilated and it was like running an intensive care unit in their living room. I sit there and think, 'you know what. I'm a nurse, I'm trained to do this. This mum has a grade ten education, and she's doing it and she's amazing. And I think, oh, my god, I couldn't do it for twenty-hours; I'd just pack it in but it's amazing what they're able to do and its amazing what we expect them to do. And when they say they can't, everybody freaks out and it drives me crazy. These parents are doing such amazing things for the system by taking care of these kids and we [society] take that for granted. I'm always really aware of that because, I mean, families have to quit their jobs and it's actually huge. I think there are a lot of people that really don't realize that and just take it for granted.

Catt’s perception of the responsibilities placed on families and the amazing job they do, raises the issue of societal expectations on parents to care for their own with little recognition of the toll this takes on families. Moreover, the lack of community resources to assist families is one more message that they should be doing it themselves.

While some families are able to take on this increased responsibility, the lack of resources is such that certain disadvantaged families are further disadvantaged. Lange draws attention to the families who are not able to care for their own, such as many of
those in the population with whom she works. When there is not “a parent in the court of that kid, you just feel like hey, this kid needs somebody to fight for them and they often don’t have anyone, so it’s hard”. Lange’s comment points to the important role of advocating for children and families who are vulnerable. Societal expectations of parents not only puts tremendous pressure on parents at the best of times but fails to recognize the high costs to families and the inability of vulnerable families to meet these expectations.

Another aspect of resource allocation that directly impacts on families of children with chronic health conditions is the availability and knowledgability of family physicians, in many areas outside the metropolitan area. APNs considered the child’s family physician to be a valuable resource for the child and family within the community, as they are often the family’s primary link with the health care system. There were, however, two issues that APNs identified in relation to family physicians being a resource for children and families. One issue is that the reality of today’s health care environment is that many families do not have a family physician.

In a lot of communities, physician support of families is poor and not poor from a skill set but poor because there aren’t many of them. We have more and more families now that don’t have family physicians, that use walk in clinics because there isn’t a physician in their community or there’s no pediatrician in the community or the pediatrician in the community has a caseload that’s ridiculous. So the family needs to take charge and organize their child’s care in the community.
Parks goes on to say that when families do not have a family physician they lose an important link with the health care system. Moreover, the family then has to take on the responsibility of organizing their child's care and Parks says while that works well for many families, others do not have the skills so they need assistance.

A second issue related to family physicians being a resource to the family is that many of the physicians outside of large metropolitan areas rarely see many of the chronic health conditions that children have. Often the APNs found themselves in a position where they were more knowledgeable about the child’s condition than the family physician because of their years of experience with children with the condition. It makes sense that APNs with their extensive knowledge could communicate this knowledge to physicians, particularly information on the condition itself as well as the child’s health needs. Yet this was not considered by the directors of the programs or the nurses themselves to be an appropriate role for APNs. It is another example where APNs’ knowledge is discounted, which could well be at the expense of providing quality health care for children and families.

Another area in which lack of resources impact on children with chronic health conditions is the school system. Children with chronic health conditions, like every other child, spend six to eight hours a day at school. Many of these children, such as those with diabetes or a seizure disorder, have potentially unstable conditions and therefore need someone in the system who is familiar with their health needs and can intervene if necessary. School nurses used to fulfill this role but within the last decade or so, they have essentially been eliminated. The community health nurses who are still connected with schools are for the most part responsible for immunizations, which require the
majority of their time. The absence of nurses in the school system means that teachers are now expected to add the child’s health care needs to their teaching role. The APNs recognized the difficulty for teachers of having to keep on top of children’s various health conditions, but also saw it as critical to the child’s health. One participant, Frank told a story that illustrates the negative effect on a child’s health if teachers are not informed about the child’s condition.

One child who I had to intervene with was a ten year old. She’d been diagnosed when she was four and she’d done quite well. At ten she got very involved in sports and her blood sugars tended to drop quite quickly after PE or games because she played very, very hard. In the classroom one day she had been playing sports and as a lot of ten year olds do, she hadn’t eaten quite enough snack to cover the sports and her blood sugar started going low. She put her hand up to ask the teacher if she could get juice out of her knapsack and the teacher said, ‘put your hand down and wait till I’m finished what I’m doing’. Now I teach children that you can’t do that, if the teacher says wait, you can’t wait, you have to eat. But this child thought she could wait and then, of course, as your brain lacks sugar, you get confused. So she got up to try to get to her knapsack at the front of the class and she was staggering between the desks and the teacher thought she was fooling around and told her that she had to go outside the class until she could behave better. The last phase of hypoglycemia if you don’t treat it is you become unconscious and in five minutes, the teacher sent somebody to bring the child back in and she was found slumped down in the corridor outside, unconscious. Now this really should never happen and the teacher was quite
devastated afterwards; she had forgotten this child had diabetes and she was very upset. But the parents were extremely angry because they had provided all the juice and the food and everything to treat this child for hypoglycemia if it happened and the one adult who was in charge of the child at that time did not provide the correct support for the child.

Considering the numbers of children within the school system who have chronic health problems, it seems unrealistic to expect teachers to take on the responsibility of monitoring and responding to the child’s health needs. Yet, without the presence of a school nurse, that is essentially what is happening. Although some APNs did educational sessions with teachers, it was a huge task considering the number of schools involved and most of the APNs said they had no time for this aspect of community education, even though they saw it as critical. Consequently, parents are left with the responsibility of educating their child’s teachers and, as Frank points out, parents are often reluctant to take this on for two reasons. Children often don’t want their parents to talk with teachers because they don’t want them to make a big issue of their health condition or to make them feel different. Also parents are concerned that teachers will think they are a nuisance and that this will jeopardize their child within the school system. Thus, there is a gap in the provision of health services for children with chronic health conditions within the school system. However, it is an area in which APNs have begun to make inroads and they do see educational outreach as part of their mandate, as health professionals with specialized knowledge of a population.
Summary of Chapter Six

The APNs discussed a number of barriers to the provision of community-based health care for children and families at the population level. However, what also surfaced in these discussions was the potential they have for making significant contributions to issues of accessibility, prevention, and resource allocation through the in-depth knowledge and skills they bring to these situations. APNs’ ability to think at the system level, combined with their in-depth knowledge of the population of children and families within their specialty, make them the logical health professional to address population health needs for those with complex health needs. Moreover, their continuing encounters with inefficient and ineffective health care practices have provided them with knowledge of the system that could be employed in the design of more effective and efficient health services.
CHAPTER SEVEN
DISCUSSION:
LOCATING THE INTERPRETATIONS WITHIN A THEORETICAL CONTEXT

The overall goal of this study was to gain an understanding of the place of APNs' in the organization and delivery of community-based health care for individuals with complex health needs. Given that there was little understanding of the nature of APNs' practice, the knowledge that informs it and the factors that influence it, I conducted a qualitative study that was informed by an interpretive perspective and narrative theory to provide direction for accessing nurses' understandings of their practice and the social context in which it is enacted.

A central finding of this study is that while APNs do contribute to the health care of children with complex health needs and their families, they often do so behind the scenes, as their designated role of organizing and coordinating the work of the program and other team members took priority. Their narratives reveal that two versions of health care are enacted within their settings of practice, the dominant one directed by a biomedical model of care, and APNs' version, which is directed by a holistic model of care and focused on both the individual and population level of health care. The tension between these two models of care is reflected in the power dynamics operating within the health care setting. Although APNs demonstrate in-depth knowledge of the population within their specialty program, they struggle to articulate this knowledge, which contributes to the invisibility of their practice. Moreover, while they are aware that others control their practice and that their expertise is not fully utilized, they do not challenge the system.

This chapter explores three central themes that arise from the interpretations of the data that have implications for both nursing's role in the delivery of health care and advanced practice nursing. First, I explore the nature of the power dynamics within the health care setting that the participants perceived as operating to control their practice.
Moreover, I will demonstrate how APNs’ difficulty with articulating their practice and the knowledge that informs it has contributed to the power dynamics they see as restricting their practice. I then discuss the nature of APNs’ practice knowledge and demonstrate how this knowledge provides them with a language for articulating their practice and taking their place at the health care table as equal partners of the health care team. Finally, I explore the nature of APNs’ practice and its fit with the goals of the emerging primary health care system.

**Accounting for Power Dynamics within Health Care**

While it is tempting to draw on theories that will explain the power dynamics in relation to medical dominance of health care and health care knowledge, this would be an over-simplification of a complex process. Moreover, to do so would provide an account of power dynamics that explains nurses’ subordination to physicians without providing an avenue for change. If physicians are seen as responsible for nurses’ subordination and limited independence, then they are the ones who must change. This of course leaves nurses feeling powerless because they cannot make physicians think and behave differently. However, if nurses see themselves as participating in maintaining the status quo and therefore contributing to their own subordination, this perspective places them in a position of power because they can change how they think, speak and act. Understanding power as inherent in our ways of thinking and speaking is associated with a postmodern perspective of power relations as embedded in various discursive positions (Street, 1995). Thus, the discourses that one takes up have within them a predetermined script for enacting power relations. This idea is reflected in Fisher’s (1991) argument that doctors and nurses are professionals “whose identities are produced by their location in a gendered profession” (p. 179) which prompts them to represent how the system works “in ways that re-inscribe or resist hegemonic discourse” (p. 180). Fisher points out that historically, nurses and doctors have been located differently, not only in the organizational structure of health care but also in the cultural structure of society. Physicians started out as independent
practitioners and gained their professional dominance from their association with powerful people in society through class, race and gender ties. This association gave them a state supported monopoly of medicine, which Fisher notes, was more of social and political victory than a medical one. Nurses, on the other hand, evolved in the context of physician dominance of medicine and as employees of institutions that reinforced their subordination to physicians.

If power is seen to reside in the various discourses that one takes up, then examining the power scripts inherent within discourses is a beginning step to changing these scripts or creating new discourses with different power scripts. For example, in taking up the discourse of nursing as technical or task-oriented care, the predetermined power script is that nurses are subordinate to doctors who do the important work of diagnosis and treatment and nurses assist them. Moreover, within a technical discourse, the other work that nurses do is not considered nursing and is therefore discounted by others, and even by nurses themselves. If instead of a technical discourse, nurses take up the discourse of nursing as a knowledge-driven enterprise in which nurses make valuable contributions to the health care of the public, the power script within this discourse is that nurses are equal members of the health care team who contribute valuable knowledge to client health care.

Although I will consider the impact that a biomedical/technical discourse has on nurses’ practice, I will also tease out some of the strands of the power dynamics in relation to nursing’s part in perpetuating a system that they see as controlling their practice. One strand, in particular, that I will focus upon is the nursing discourses available to nurses to understand and enact their practice. I will put forth the argument that these discourses often do not fit with the realities of the practice setting, which means that nurses do not have a language for articulating their actual practice. Consequently, they remain silent. Moreover, they somehow sense that the fault is with them, and their confidence in what they know is undermined. I will suggest that the discourses nurses take up to guide their practice need to
fit with the realities of their practice and the knowledge they draw on in particular practice situations. This knowledge can provide them with a language for articulating their practice.

**The Language of Power in Health Care**

Dorothy Smith's work (1987, 1990, 1999) explores how male-dominated institutions maintain power by ideological practices that discount subjective forms of knowledge and reify objectified forms of knowledge. These practices are maintained through language and Smith suggests that women end up with a split relationship to language. On one side of the split are the subjective forms of knowledge that come out of their lived experiences and on the other side are the objectified forms of knowledge which is the language of the relations of ruling. Smith contends that the language of those in positions of power is maintained by the ideological practices of converting people's perspectives of their own experience into objectified forms of knowledge. Thus, power is maintained and reproduced through knowledge, and since language is central to the production of knowledge (Morrow & Brown, 1994), it is also central to the maintenance and reproduction of power relations.

A major part of our socialization as human beings is to learn the language of our culture; the cultural meanings and their forms of transmission (signs, codes and sign systems). This language preserves the status quo by repressing alternative ways of perceiving, thinking and acting (Thomas, 1993). Thomas maintains that we often do not realize the extent to which our daily lives are shaped by institutions of power that lie behind cultural meanings. Although this power is symbolic in that it relies on shared beliefs (ideologies), it is difficult to change because it is embedded in the social practices and structures of everyday life (Smith, 1987).

In the current study, power is seen to be operating in the dominance of the biomedical model within the health care system, in which technical knowledge is privileged to the exclusion of other kinds of knowledge and a technical/rationalist discourse dominates health care conversations. Since the majority of participants' practice with children and
families is relational, not technical, a technical/rationalist discourse does not reflect their practice. Moreover, because they practiced in an environment where relational knowledge was considered subjective and therefore not knowledge, they were reluctant to use relational language to articulate their practice. Consequently, APNs felt excluded from many health care conversations, which had the effect of silencing them.

Smith (1990) suggests that in addition to exploring and disclosing the conceptual practices of the ruling relations, as women we also need to become aware of how our own ideological practices contribute to and maintain the power relations within dominant systems, and then work toward different social practices and different ways of thinking and knowing the society in which we live. Nursing's ideological practices can be examined through the discourses that have developed around various conceptualizations of nursing. Several authors have initiated exploration of the discourses that shape nursing practice. For example, Cheek and Rudge (1994) explore nursing from a poststructural perspective, in which they examine language with regard to the role it plays in both constructing and conveying understandings about nursing. They raise key questions about how nursing knowledge is produced and used and point to the potential of developing different discourses for nursing knowledge. I have conceptualized the various nursing discourses that influence and shape APNs' practice as part of the social context of nursing practice so I will include them as part of the analysis of the social context of nursing practice.

The Social Context of APNs' Practice and Knowledge

Liaschenko and Fisher (1999) are among the few theorists who emphasize the importance of connecting the knowledge that directs nurses' work to "the social reality in which nursing is situated" (p. 30). They maintain that the current literature on knowledge of practice, while moving nursing practice beyond a dependence on biomedical knowledge, has taken only a limited account of the influence of context on knowledge and action. Although they do not specify what they mean by the context of nurses' practice, within the current study I have identified three broad aspects of social context that I see as influencing APNs'
practice and knowledge: the setting of their practice, the population served by the programs within which they work, and the discourses that APNs take up to make sense of and guide their practice.

**Setting of Practice as Context**

Liaschenko and Fisher (1999) maintain that the way that health services are structured influences what nurses can know about and do for the patient. The setting of practice for the majority of APNs in the current study was specialized programs in ambulatory settings of a tertiary care hospital. The philosophical underpinnings of ambulatory care are based on a biomedical model of care in which health services are organized around physicians who deliver reimbursable services to ill individuals (Haas, Hackbarth, Kavanagh, & Vlasses, 1995). The structuring of health services around physicians influenced the nature of APNs’ practice and the knowledge that informed practice in a number of ways. To begin, the delivery of services is dependent on physicians’ availability to provide such services and because they had limited time to devote to ambulatory programs, clinics were often restricted to one or two half to full days per week. Moreover, the insistence that only physicians can diagnose and make referrals decreased accessibility of children to timely diagnosis and treatment and resulted in one to two year waitlists within most of the programs. APNs questioned this practice, maintaining that they were often in positions where they had the knowledge to make referrals or do the assessments required to make a diagnosis. Street (1992) argues that insisting only physicians can diagnose has left unchallenged the ideological component in which medical knowledge “is exercised as social control” (p. 8).

With physicians in charge of the programs, the APNs said there were explicit expectations that nurses were responsible for organizing and coordinating the work of the program and of other members of the health care team. Consequently, the majority of their time was structured by program demands while their practice with children and families was relegated to the background. While other team members met with children and families
during their clinic appointments, nurses often did not. Rather, they "directed traffic", while the majority of their contact with children and families occurred by phone after the work of the program was done. The result was that other members of the health care team associated nurses' work with tasks while their work with children and families remained invisible. APNs insisted that team members had little understanding of their practice. Thus, the structure of health services around physicians also had implications for collaborative practice among health care professionals.

The discourse of multi-disciplinary teams that work collaboratively to meet the health needs of the population they serve was not, with two exceptions, in evidence in this study. The two participants who maintained that the teams within their programs worked collaboratively, attributed this to: a) the fact that all team members had a common goal - to provide the best care for the patient, b) every member's contributions were valued, and c) there was a coordinator but no "boss". In the other programs, participants maintained that the physician was in charge and there was a sense of competition rather than collaboration among team members. This was particularly noted in family/team conferences in which team members seemed more intent on demonstrating their knowledge to other members of the team than in explaining the child's diagnosis to the parents. Also, physicians did not come to team meetings. The idea of the focus being on the client rather than the professionals seemed key in working collaboratively as a team. In contrast, in those situations in which the focus was on the professional rather than the client, participants described turf wars and professional jealousies.

Schroeder, Trehearne, and Ward (2000) contend that a major barrier to the effectiveness of the nursing role in ambulatory care is that "much of nursing work is hidden, unrecognized, and obscured" (p. 16). By hidden work, they are referring to aspects of the role such as facilitating the work of the bureaucracy, coordinating the work of others on the team, and educating colleagues and caregivers to ensure effective care, which were initially identified in research by McWilliam and Wong (1994). Those authors suggest that
nursing’s contribution to health care be documented beyond that of nurse-patient interaction so that it can be “recognized, valued, and appropriately supported by resources” (as cited in Schroeder, et al., p. 16). In the current study, it is the work with patients and families that is hidden and unrecognized and it is this work that needs to be documented and articulated. For instance, APNs “clinical practice by phone” which is a major aspect of their practice with children and families is hidden work. It occurs behind the scenes after program activities are completed and is documented on ghost charts that are destroyed. It is highly probable that most members of the health care team have no knowledge of this aspect of nurses’ work.

Arguing for documentation and articulation of nurses’ direct work with patients and families is not an argument against documenting the organizational activities that consume the majority of APNs time. However, rather than documenting organizational activities so they can be “recognized, valued and supported”, I would argue that the central reason for documenting these activities is to highlight the percentage of time APNs spend on organizational activities as compared to the percentage of time they spend in direct contact with children and families and relate these activities to child and family outcomes. Otherwise, APNs’ work will continue to be structured by activities that may have little to do with child and family outcomes while under-utilizing their knowledge and skills that could contribute much more effectively to outcomes.

Hackbarth, Haas, Kavanagh, and Vlasses (1995) identified additional barriers to effective nursing practice in ambulatory care as including lack of time, lack of support staff, administrative blocks to clinical practice and physician resistance. Similar barriers were identified by the APNs in the current study. One barrier that bears particular scrutiny is lack of time, as the underlying dynamics reveal subtle ways in which nurse’s practice and knowledge are controlled by being “too busy”. To begin, lack of time is associated with the way in which APNs’ practice was organized and viewed by others. For example, APNs said that organizing clinics is considered their responsibility but that it could easily be done by a
clinic aide or clerical person, which would free them up to do more direct work with children and families. However, they did not receive clerical support so much of their time was spent doing routine tasks that did not utilize their knowledge and skills. What is interesting is that many of them took up the discourse that the current work overload on nurses was the result of nursing shortages, rather than the way in which nurses’ work has been conceptualized and organized by those in positions of power (Ceci & McIntyre, 2001).

Another issue related to lack of time is the pace of the work. Participants reported that sometimes they felt as if they did not have time to think. One participant said she had a ritual of touching her nametag when she was really busy to remind herself to breathe. Given that one of the basic premises of praxis - the coming together of knowledge and practice - is reflection on practice, it would seem as if the current health care environment, specifically within ambulatory settings, is not compatible with reflective practice. Jones (1997) maintains that reflection on practice has the potential of increasing the possibility for change. Not having time to think/reflect decreases the likelihood of nurses changing their working conditions. Moreover, the pace of work was such that APNs did not have time to focus on system issues that were impacting on the provision of quality health care. Perhaps nurses’ preoccupation at the level of the individual is in the best interests of those in positions of power, as nurses will not change the system by remaining focused at the level of the individual.

Lack of administrative support was another barrier to effective practice identified by the participants of this study. Although the APNs who worked directly with nurses rather than with children and families emphasized the importance of enhancing and supporting the quality of nurses’ practice in order, “to build the capacity of the system”, they did not themselves experience support for their practice. Lack of support was evident in two primary ways. APNs were not provided with support staff to assist with the “busy work” that took up much of their time but did not require their knowledge and skills, and physicians’ priorities took precedence over nurses’ priorities for practice. Although there
was recognition that administration and, in particular, their immediate managers were restrained by fiscal concerns, participants sensed that administrators and managers did not understand their practice or their expertise with children and families. These findings do not correspond with those of Davies and Eng’s (1995) study of the CNS role in that the majority of CNSs reported a number of indicators of administrative support for their role including opportunities to participate in decision-making regarding nursing issues and commitment of economic resources to the role, for example secretarial support. However, the difference in findings related to administrative support could be accounted for by a gap of ten years in the two studies which was a time of massive health care reforms that changed the nature of nursing administration. It could also be that the lack of support experienced by the nurses in this study is related to the ambulatory care environment in which physician dominance is particularly noted. However, APNs within the community setting had little to do with physicians and they too reported that they did not receive administrative support for their practice, so there is clearly some other factor underlying the lack of administrative support that the APNs perceived in this study.

Population of Clients as Context

Nursing’s mandate is to provide a health service to the public, and effective nursing care requires an understanding of the health needs of the clients that nurses serve. In her discussion of where nursing knowledge comes from, Berragan (1998) contends that clients provide nurses with a wealth of knowledge that informs their practice. However, in our preoccupation with distinguishing ourselves from medicine and justifying that we are a profession, we have shifted our focus away from the health needs of clients (Reed & Ground, 1997). Yet clients are a rich and crucial source of the knowledge needed to provide effective health care. In the current study, the knowledge that APNs gained from the children and families within their specialty provided the basis for their nursing practice. I have identified this knowledge as contextual knowledge, which will be discussed in more detail below.
Two characteristics of the populations that APNs worked with were important influences on their practice and knowledge. First, the children had chronic health conditions, which often involved complex health care needs requiring ongoing management and second, these children were cared for at home, for the most part, by their parents. Thus, the APN within the ambulatory programs became the point person for these families, and they often phoned the APN with problems related to managing and/or coordinating the child's care. This was such a common aspect of APNs’ practice in ambulatory programs that it was referred to as “clinical practice by phone” and the central goal of APNs’ practice was to assist families in managing their child's ongoing care. Clearly, the health needs of the population were distinctively different from the health needs of children within an acute care setting and therefore required different kinds of knowledge to direct APNs’ practice. The most obvious difference is that there is virtually no hands-on, physical care; rather the practice of these APNs involved education, support, advocacy and co-ordination of the child's care within the community setting. Thus, the nature of APNs’ practice and knowledge was very much determined by the health needs of the population served by the programs.

**Nursing Discourses as Context**

Another aspect of the social context that impacts on APNs’ practice and knowledge is the conceptualization of nursing they take up to understand and enact their practice. Fraser (1997) contends that our social identities are shaped by the various discourses operating within a culture at a particular time in history. Which discourse becomes the common or shared one depends on the power of the various political interests that the discourses represent. Within health care, a technical/rationalist discourse continues to dominate the way in which health care is conceptualized and delivered, despite significant health care reforms during the past decade. Within this discourse, nursing practice is viewed as technical or task-oriented (Bjórnsdóttir, 1998) and this particular view of practice is one commonly held by nurses to serve as a model for their practice. In fact, it was the primary
discourse taken up by many of the participants in the current study. However, this discourse
did not fit with the reality of their practice, which involved education, support, advocacy and
co-ordination of care. Moreover, because the dominant discourse within the health care
setting is technical/rationalist, they did not have a language to articulate the actualities of
their practice. Although they also took up the discourse of holism, which did provide
direction for their practice, it did not provide them with a language for articulating their
practice. In the discussion that follows on holistic ideology, I will explore the reasons why it
does not provide a language for nurses to articulate their practice. Also of interest is that
none of the participants mentioned the nurse-patient relationship as being important to their
practice, even though it is considered a major concept in a holistic model. This is most likely
explained by the fact that APNs had very little prolonged contact with individual children
and families, as well as a particular understanding of relational practice.

Over the years various conceptualizations of nursing practice have been put forward
in the form of nursing models and theories in an attempt to define nursing and distinguish it
from medicine. Although, as Liaschenko and Fisher (1999) point out, nurses in practice
rarely use the language that composes these conceptual models, I would argue that their
practice is influenced by the discourses that develop around these various
conceptualizations, particularly as they take up certain discourses to make sense of their
practice. One discourse that has been most associated with nursing is the holistic model of
care. Boschma (1997) contends that a holistic ideology has been used to legitimize an
independent and unique role for nurses since the beginning of the twentieth century

Initially, notions of holism encompassed the physical, psychological, and social
needs of individuals as well as their environment. However, during the 1960s and 1970s the
language of holism began to shift from the concept of “total” patient care to “psycho-
social” care and “the nurse-patient relationship” which was considered central to resolving
the patient’s psychosocial problems (Boschma, 1997). In this re-incarnation of holism, the
physical aspects of patient care and the context in which care occurred faded into the
background. The concept of holistic care was replaced by the concept of psychosocial care and nursing distanced itself from the physical aspects of care, at least in the language of its discourse.

Boschma (1997) claims that the exclusive focus on psychosocial needs and the nurse-patient relationship as a way to meet those needs, served an ideological function by defining nursing's unique and independent role in the hospital setting. I would argue, however, that focusing on the psycho-social aspects of care as nursing's exclusive domain was misguided in two critical ways. First, constructing a discourse of psychosocial care that excluded the patient's physical needs did not reflect the realities of nurses' practice, which clearly involved physical care as well as psychosocial care. Ironically, in trying to establish a unique role for itself, nursing became as guilty of fragmenting the patient, in their exclusive focus on the psychosocial, as it accused medicine of doing in their exclusive focus on the physical aspects of care. Second, the creation of a psychosocial discourse to represent nursing practice set up an arbitrary dichotomy between nursing knowledge as subjective/relational and physician knowledge as objective/technical. This dichotomy led to binary thinking in which knowledge and practice were viewed as either technical or relational (Reed & Ground, 1997). While many nurses ignored the psychosocial and caring discourses and took up or continued with a biomedical/technical discourse to guide their practice, others were educated in the height of the psychosocial/caring movement, and entered the practice arena with a psychosocial discourse of practice firmly embedded in their psyches.

Bjornsdottir's (1998) study of nursing practice provides an example of the dilemma created for nurses in taking up a psychosocial discourse to inform their practice when the nature of their practice involves highly technical care. The nurses involved in the study worked on two general surgical units in an acute care hospital in which the primary purpose was treating disease through the application of medical science and technology. Bjornsdottir describes the nurses' work as task oriented, with wound care taking up much
of nurses' time. The volume of work was immense and the environment was characterized by uncertainty as patients' conditions could quickly change. Also, because both units were specialized, the nurses required advanced clinical skills. Given the pace and complexity of the setting, it is surprising that Bjornsdottir notes that “for many of the nurses, being able to develop a trusting relationship with patients was what made nursing work meaningful (p. 355)”.

Bjornsdottir maintains that while the relational aspects of nurses’ work were seen as “important to their personal understanding of themselves as nurses, it did not seem to be part of the nursing services as officially defined on the unit” (p. 356). This statement suggests that the nurses had taken up the discourse of the nurse-patient relationship and the relational aspects of care as central to nursing practice but the discourse did not fit with the clinical setting in which their practice was carried out. Picturing the clinical setting from the description, one can see why the relational aspects of practice were not part of the officially defined nursing services on the unit. Bjornsdottir notes that the official discourse on the units seemed to be objective and impersonal which, given the context of care, would seem appropriate, whereas the “private” discourse of the relational aspects of care does not seem to be a particular fit for the context of their practice. Moreover, it places nurses in a “no-win” situation. If their identity as nurses and the meaningfulness of their work is tied to developing a trusting relationship with patients, and they are in a setting where this is next to impossible, this sets them up to be frustrated and dissatisfied with their work. I would also argue that it decreases nurses’ credibility by not having a language that reflects the patient’s reality and the reality of the practice setting.

The discrepancy in the above study between what nurses see as important to their self-definition as nurses and what the health care institution sees as nurses’ work, suggests that theorists have not taken account of “the social reality in which nursing is situated” (Liaschenko and Fisher, 1999, p. 30) in their development of nursing practice knowledge. The point to be made from this discussion is not that technical or caring discourses are inappropriate in providing direction for nurses’ practice but that consideration must be
given to how they fit with the context of nurses’ practice in a variety of settings. When claims are made that caring is the essence of nursing, or the nurse-patient relationship is central to nursing practice, or that nursing is a technical or task-oriented practice, there is an underlying assumption that these theories or discourses are universal and do not require consideration of the context in which nurses’ practice. Yet, clearly, a high tech acute care setting where many of the patients may not be able to communicate requires different practice models than an ambulatory setting in which patients and families are, for the most part, managing their own care. I would argue that the failure of nurse theorists to attend to the context of practice in developing models for practice is associated with nurses taking up nursing models and discourses that do not fit the contexts in which their practice is situated and consequently do not provide them with the direction they need to enact their practice or with a language to articulate their practice.

**The Basis of APNs’ Difficulty Articulating their Practice**

When I began this study, my premise was that APNs have difficulty articulating their practice and their contributions to health care because they are expected to do so within a technical/rationalist discourse and that is not how they understand their practice. I posited that if APNs were given the opportunity to frame their practice and their contributions to health care in narrative rather than empirical language we would have a much clearer picture of the ways in which they contribute to community-based health care. The findings, however, do not support this premise. Participants did say they practice within a patriarchal system and are expected to communicate via a technical/rationalist discourse, which did not fit with their understanding of their practice. However, my premise that they would be able to articulate their practice and the knowledge that informs it in narrative form was not borne out. Although their narratives clearly illustrated the knowledge they draw on to inform their practice, they continued to have difficulty articulating their practice. Thus, I came to the realization that it is not simply a matter of APNs being given the opportunity to articulate
their practice but a matter of them making a connection between the knowledge that informs their practice as providing them with a language for articulating the nature of their practice.

In further exploring the reasons for APNs’ difficulty articulating their practice, I propose two explanations. The first one relates to the above premise that APNs are expected to articulate their practice within a technical/rationalist discourse, which does not fit with the way they understand their practice. Moreover, in their attempts to articulate their practice in the relational language of psychosocial care, APNs experienced a number of situations in which they felt that their knowledge was discounted or ignored, so they learned not to express their practice in this language. These experiences not only gave APNs the message that their knowledge is not valued but also undermined their confidence in their knowledge and resulted in their reluctance to offer their perspective. As one participant commented, “all I do is talk to people”, suggesting that this is not important and downplaying the contributions she makes to the health care of children and families by failing to articulate the role she plays in educating, supporting, advocating for, and coordinating care for children and their families.

Thus, one layer to APNs’ inability to articulate their practice is their perception that their knowledge does not fit within the dominant discourse and is not valued by others and consequently not valued by them. Brown (1999) notes, “ironically, as women and as nurses our first response is often to consider our own inadequacies” (p. 170). APNs seemed to sense that if others discounted their knowledge then it must not be important or relevant to the client’s care, so they tried to fit in by taking up the dominant discourse of technical knowledge. However, the technical language of the dominate discourse does not reflect their practice or the knowledge that informs it so they end up being silent which perpetuates the invisibility of their practice and their knowledge.

A second possible explanation for APNs’ silence regarding their practice is that they do not have an appropriate language for expressing it. Cheek and Rudge (1994) pose the question, “is the difficulty that nursing has in defining itself because it attempts to do so
in terms set by others?" (p. 18). Initially I saw the “terms set by others” as the technical rationalist discourse of the dominant system of care, and APNs indeed had difficulty defining their practice within those terms. However, I now perceive that the “terms set by others” could just as likely be the psychosocial and caring discourses which have provided the basis for a relational language of nursing practice. Although APNs maintained that their attempts to communicate their practice in relational language were ignored or discounted, it could well be that this language does not accurately reflect the nature of APNs’ practice.

This premise is supported by participants’ narratives, in which there are many examples of them struggling to find the words to articulate their practice, even though there was no pressure to fit their understandings of their practice into a technical rationalist discourse and ample opportunity to express their practice in relational language. Thus, I would suggest that a relational language also does not capture the realities of APNs’ practice. Because health care has been dichotomized as either instrumental/technical or subjective/relational (Reed & Ground, 1997), and the language of either does not capture APNs’ practice, they are without a language to articulate their practice.

Operating from the premise that APNs are silenced because they do not have a language for articulating their practice, offers another perspective on the power dynamics within the health care system and a different approach to addressing these dynamics. Rather than trying to change the system which is perceived as discounting nurses’ knowledge, the focus is on helping nurses develop a language that accurately reflects the nature of their practice, which places the power for change in their hands (and minds!). Moreover, having a language that accurately communicates their practice and their knowledge can enhance their confidence to participate in health care conversations as equal members of the health care team.

In light of the above explanation for nurses’ silence about their practice, I would argue that the interpretation of nurses’ silence as a reluctance on their part to talk about what they do has sent us in the wrong direction for addressing the issue. For instance, Buresh
and Gordon’s (2000) book “From Silence to Voice” is based on the premise that nurses
don’t have a public voice because they are reluctant to “tell the world what they do” and
their solution is to teach them the skills they need to communicate with the public and to
help them overcome their ambivalence to being more vocal. Conceptualizing the issue as
nurses’ reluctance to communicate what they do rather than their inability to communicate
what they know has put the focus on competencies and skills rather than on nurses’
knowledge. Consequently, we continue to perpetuate the idea that nursing is a task oriented,
rather than a knowledge driven, enterprise.

**A Language of Nursing Practice: Making the Implicit Explicit**

Chinn and Kramer (1999) suggest that encouraging nurses to focus on the
knowledge they draw on to inform their understandings and their actions will provide them
with a language for articulating their practice and informing others of their contribution to
health care. The key to developing a language of nursing practice is connecting it to the
social context in which nursing is situated. In other words, the language should come from
the knowledge nurses’ draw on in their actual practice rather than from theorists who are
removed from the practice situation. What this means is that the language is not fixed but
changes as social circumstances change, because nursing is a social practice that is

As discussed previously, the conceptualization of nursing knowledge as
subjective/relational and physician knowledge as objective/technical has created a tension
between nurses and doctors that is reflected in their attitudes toward each other’s
knowledge. Nurses criticize doctors for their exclusive focus on disease while ignoring the
person who has the disease and doctors criticize nurses for their preoccupation with
psychosocial care, which they see as having little to do with the individual’s health. I would suggest that one way to move beyond the binary thinking of technical knowledge as medicine’s domain and relational knowledge as nursing’s domain is for nurses to provide a knowledge-based rationale for relational care, which they can do by drawing on the knowledge that informs their actions.

A story told by Street (1995) provides an example for illustrating how nurses can provide a knowledge-based rationale for relational care and the potential impact this could have on dissolving the conceptual boundaries that currently pervade nurse-doctor communication. A nurse was working in a neonatal ICU and was calming a newborn who was crying and thrashing about while two doctors were trying to get an IV started on the infant. The nurse placed one hand under the infant and stroked his brow with the other, while speaking in soothing tones. The infant calmed quickly and his heart and respiratory rate dropped dramatically and he remained still while the doctor inserted the IV. When the doctor asked the nurse what she was doing she said, “I’m looking after the baby’s emotional needs” to which the doctor replied, “we need strapping”. The nurse called out for someone else to get the strapping and continued to hold the infant. Later she said that the doctor was irritated with her because she wouldn’t get the strapping and run the IV through. She interpreted this as him thinking she was there to assist him and seeing the technical tasks as more of a priority than caring for the baby’s emotional needs. There is however, another way of interpreting this story. Perhaps “looking after the baby’s emotional needs” didn’t have a lot of meaning for the doctor who was trying to get the IV stabilized and meanwhile his head was getting burned from the overhead heater (which he was leaning under because he was so tall). What if the nurse had responded to his question by saying, “I am calming the baby, which is making it easier to get the IV in. Research

1 As discussed in the literature chapter, the terms psychosocial, relational, and interpersonal are used interchangeably. I prefer the term relational care over psychosocial care because of what I perceive as the negative connotations associated with the latter term. However, the participants in my study used the term psychosocial, in particular when they were referring to their perceptions of physicians’ attitudes toward this aspect of their nursing care.
shows that talking in soothing tones and stroking the infant calms them”. Now it is possible that it might not have made any difference to the doctor’s response but it is a much more descriptive statement than “looking after the baby’s emotional needs” and it demonstrates knowledge-based practice. Furthermore, it demonstrates a collaborative approach in which the nurse is working with the doctor to provide care for the infant, which suggests a different tone than “assisting him”.

There were many examples in APNs’ narratives in this study where a similar articulation of a knowledge-based rationale for relational care could have been employed. One of the most common situations where APNs could articulate a knowledge-based rationale for their actions was in assisting families to cope with their child’s illness and ongoing care. Family coping was an important focus in APNs’ practice because they knew that the family’s ability to manage their child’s ongoing care in the community hinged on their ability to cope, not only with their child’s care, but also with the other aspects of their lives. Consequently, their theoretical knowledge of family coping, child development, empowerment, social determinants of health, and so forth provided direction for gathering and interpreting contextual knowledge of the family’s situation. For example, Parks told a story about her conversation with a physician regarding a mother who had not followed up on her child’s care as she had been requested to do. The physician’s response was that the child should be apprehended and Parks response was ‘well, you know, she just needs some help, calling people or knowing who to call or maybe we actually have to make that call for her’. What she did not relate to the physician was that the mum had three other children, she was young and she has limited education; all of which are important contextual data that led Parks to the conclusion that the mum was overwhelmed. And there is research-based knowledge, based on the social factors that decrease an individual’s coping skills, to support her conclusion. However, by not articulating either the contextual or the theoretical knowledge she had, Parks may have left the physician with the impression that she was
"enabling" this mother, as evidenced by her comment, "some people have a problem with that [referring to making phone calls for the mother]."

There was also an example from the data where an APN did articulate a knowledge-based rationale for relational care. Addams’ told a story of talking with physicians about respecting a family’s decision regarding not wanting their daughter to have further surgery, even though it could shorten her life not to have the surgery. Addams demonstrates how she justified her reasoning by drawing on both contextual and ethical knowledge in considering the family’s values and the family’s right to make the decision, and the health care provider’s role in that situation. When Addams articulated the knowledge behind her position, physicians changed their perspective and agreed with Addams that the family’s wishes should be respected.

As mentioned previously, the key to developing a language of nursing practice is that it should come from the knowledge that nurses’ draw on in their actual practice rather than from theorists who are removed from the practice situation. I will now turn to a discussion of the knowledge that informs APNs’ practice.

**The Nature of APNs’ Practice Knowledge**

The context of APNs’ practice influenced the knowledge they acquired and the way in which they applied this knowledge in their practice. The knowledge APNs drew on to enact their practice was directed by the goal of assisting families in managing their child’s ongoing care through the provision of education, support, advocacy and co-ordination of care. I have labeled the knowledge that informed APNs’ practice as: empirical, theoretical, contextual, relational, and sociopolitical knowledge. Although I will discuss each type separately, APNs’ narratives revealed that they often drew on all of these types simultaneously to determine health needs and to provide individualized care for children and families. For example, APNs began with the individual child and family. They drew on empirical facts related to the child’s health condition. They drew on contextual knowledge of the child and his or her environment. They drew on empirical (technical) knowledge
related to performing certain skills such as starting IV's or giving an injection. They drew on theoretical knowledge; for example, uncertainty and its impact on the family’s ability to cope with their child’s care, they drew on relational knowledge in their interactions with children and families, other health team members and those in the community who were involved in the provision of health services for children and families, and they drew on sociopolitical knowledge to coordinate the patient’s care and move them through the system. While all types of knowledge were necessary for the provision of quality health care, I will argue that contextual knowledge is the most critical source of knowledge and it is also distinctively nursing knowledge.

**Empirical Knowledge**

Empirical knowledge is one of the four ways of knowing identified by Carper (1978) in her now classic paper, based on her dissertation work, on the structure of nursing knowledge. It is factual, objective, descriptive, and generalizable knowledge (Carper). Within the current study, APNs’ empirical knowledge was biomedical and technical knowledge related to the chronic health conditions of the children served by the specialty programs in which the nurses worked. Although they were not, for the most part, involved in the physical care of children, it would be a mistake to say that their practice with children and families did not require empirical knowledge. As Kirk and Glendinning (2002) note from their study of nurses and families of children with complex health care needs in the community, although nurses mainly provided information and support (which included advocacy) they still needed technical knowledge so they could enhance the competence and confidence of parents who were providing the direct care.

In this study, the children served by the specialty programs in which the APNs worked have health problems that involve bodily and physical concerns and parents are continually dealing with the physical manifestations of their child’s condition, even in those conditions that are neuro-behavioral in origin. Thus, APNs require biomedical and technological knowledge, not only to assist families in the ongoing management of their
child’s care, but to also gain the parents’ confidence and trust. In an earlier study that I conducted on the nurse’s role in home care of children with complex health conditions (Canam, Bassingthwaughte, & Cunada, 1994), nurses who were perceived by parents as not having the biomedical or technological knowledge to safely care for their child were considered incompetent and parents did not trust the nurse with their child which, of course, defeated the whole purpose of in-home nursing respite care. Although the nurses within the current study were not providing direct care within the home setting, parents often called them for advice regarding their child’s physical care so it is reasonable to assume that parents would not have confidence in a nurse who did not have the necessary knowledge to assist parents in solving problems related to the child’s physical care.

The empirical knowledge of the APNs in this study is similar to case and patient knowledge identified by Liaschenko and Fisher (1999) as two types of knowledge that nurses use in the provision of direct patient care. Their research is based on nurses who provide direct patient care in acute care settings so they use the term case knowledge to refer to biomedical knowledge and patient knowledge to refer to knowledge of an individual’s response to a disease and treatment. The authors claim that biomedical knowledge is the primary knowledge that nurses use in their work in intensive care units and emergency services and it is the most generalized knowledge that nurses draw on, whereas they view patient knowledge as gained and applied through monitoring of individual patients; “the nurse monitors how a particular individual is responding to a therapeutic regimen using the established norms of biomedical knowledge” (p. 36). From this description, it would seem that monitoring the patient is technical or instrumental care that requires technical knowledge. This kind of knowledge is similar to the empirical knowledge that nurses who work with specialty populations have and apply, most often indirectly, in assisting individuals or family members in their ongoing management of a chronic health condition.

Within the current study, empirical knowledge was most frequently used in relation to particular children although APNs did use this knowledge in a generalized way in two
situations. Biomedical/technical knowledge was used in a more general way in consultation with other health professionals, agency personnel, and sometimes parents, from across the province. Participants maintained that they spent a great deal of time in phone consultation with a variety of people in regards to biomedical or technical aspects of the health condition. APNs suggested that because the programs in which they worked are specialized and are located within a provincial tertiary care institution, they seemed to be the one visible place that those who had questions related to the particular chronic condition could contact for information. Biomedical/technical knowledge was also used in a general way in the development of programs at the population level in which APNs drew on their knowledge of the health condition from many individual children to develop a health service that would address the health needs of children within the population. This application of knowledge at a population level will be discussed further on.

*Contextual Knowledge*

Contextual knowledge is knowledge of the particular context in which one is situated, and an understanding of what is salient in that context. It is about particularities rather than generalities. In this study, APNs emphasized that knowledge of the everyday realities of children and families’ lives when a child has a chronic health condition, is critical knowledge for them to have in assisting families with the ongoing management of their child’s health care. Questions such as, what are the health needs of this particular child, what are parental concerns in coping with and managing their child’s condition, what are the factors that facilitate and constrain parents’ ability to manage their child’s care, what resources, including strengths, do they have, what do they need in the way of services/resources to manage, - all of these questions require knowledge of the context of families’ lives; thus, I have labeled this knowledge as contextual. Contextual knowledge was gained and applied in every aspect of APNs’ practice with individual children and families, including assessments of the child and family, assisting families with the ongoing
management of their child’s health care, education, support, advocacy, and co-ordination of the child’s care.

Contextual knowledge is a critical source of APNs’ capacity for good practice because it allows them to provide individualized care based on the needs and concerns of the patient and family from their perspective rather than from the perspective of the nurse. In other words, contextual knowledge personalizes health care; it is an antidote for depersonalized health care, which is a criticism that is often leveled at physicians. There were many examples of APNs drawing on contextual knowledge in this study but one that most vividly illustrates the distinction between nurses’ contextual knowledge and physician’s acontextual knowledge of a situation is where the physician suggested a child should be apprehended because the mother had been told to take the child for a particular appointment and she had not done it. The nurse drawing on contextual knowledge of the mother’s situation, suggested that the mother needed support in making the appointment. Although this example may be extreme, it does demonstrate the critical nature of contextual knowledge in relation to providing health care that is relevant to the individual.

In many ways contextual knowledge is distinctively nursing knowledge because nurses are grounded in a holistic model of care, which encompasses the person and their illness experiences as well as their disease whereas other health professionals are grounded in the biomedical model of health care so they are directed toward the patient’s disease. Nurses’ holistic perspective directs them to the context of a person’s situation. Moreover, nurses have been grounded in the concepts of patient-centered care and family-centered care that direct them to begin with the patient’s perspective.

Although reference is frequently made in the literature to knowledge of the context of situations, contextual knowledge has not been identified as a separate type of nursing knowledge. The type of knowledge that most closely relates to the contextual knowledge I identified in this study, is Liaschenko and Fisher’s (1999) description of the social knowledge that links patient and person knowledge. They describe this knowledge as
knowledge of the context of individuals’ everyday lives including the social conditions in which the individual lives and the impact of the disease on their ability to function in different contexts. They argue that it is the nurse’s awareness of the impact of these factors on individuals’ lives that constitutes the knowledge that links patient and person knowledge. For the nurses within the current study, knowledge of the context of children and families’ everyday lives was critical knowledge to providing appropriate health care.

Another type of knowledge that is somewhat similar to contextual knowledge is aesthetic knowledge. I bring it up here because I suggest that contextual knowledge is a more accurate label for the kind of knowledge being conceptualized than is aesthetic which, I will show, is associated with artistic knowledge and is therefore often discounted within health care settings. Aesthetic knowledge is associated with the art of nursing and involves “a deep appreciation of the meaning of a situation” (Chinn & Kramer, 1999, p. 6) and an understanding of the experiences of individuals. This pattern is “focused on particulars rather than universals” (Fawcett, Watson, Neuman, Walker, & Fitzpatrick, 2001, p. 116) which is one of the characteristics associated with contextual knowledge. I would argue, however, that the word contextual more clearly represents the kind of knowledge being referred to than does the word aesthetic. The dictionary (Webster’s, 1991) defines context as “the whole situation, background, or environment relevant to a particular event, personality, creation” (originating from the Latin word “a joining together, to weave together”). Aesthetic is defined, as “of beauty, sensitive to art and beauty, showing good taste, artistic,” (originating from the Greek word “sensitive, to perceive) which explains why aesthetic knowing is associated with the art of nursing.

It is interesting to look at Carper’s original description of aesthetics in which she drew her ideas from Langer’s (1957) book called Problems of Art. In quoting Langer she says an aesthetic experience “resists projection into the discursive form of language” (p. 219) (my italics) which points to the difficulty of the concept of aesthetic knowledge as a type of nursing knowledge. How do we articulate aesthetic knowledge so that others
understand what it is that we know and how it informs our practice? Carper goes on to talk about the difference between recognition and perception, drawing on Dewey (1958). Recognition is related to identifying and labeling according to some predetermined classification scheme whereas perception includes “an active gathering together of details and scattered particulars into an experienced whole” (p. 216). Contextual knowledge consists of the details and particulars of a client’s situation that are gathered into a whole. And I would argue that it is less problematic as a type of nursing knowledge than aesthetic knowledge because it can be presented in a discursive form so that it can be articulated to others, including the clients of health care.

**Relational Knowledge**

A pattern of knowing identified by Carper (1978) that relates to contextual knowledge is personal knowledge. Both contextual and personal knowledge are subjective, specific to individuals, and interpersonal in nature. Carper describes personal knowing as knowing the self, and extending this personal knowing to other selves so that others are seen as persons; subjects, not objects. Personal knowing encompasses one’s belief about human beings, which impacts not only on how one views self but also how one views others. As Carper emphasizes, nursing is an interpersonal process, which “involves interactions, relationships, and transactions between the nurse and the patient-client” (p. 220). Carper connects personal knowing to the concept of therapeutic use of self and contends that without personal knowledge, therapeutic use of self would not be possible. She compares personal knowledge of humans with empirical knowledge to illuminate how the two ways of knowing humans would affect one’s approach to clients. Empirical knowledge provides abstract, generalized categories of basic biological, psychological, and social behaviors that groups have in common which, Carper notes, is essential knowledge for nurses to have. Personal knowledge, on the other hand, is subjective and “concerned with promoting wholeness and integrity in the personal encounter, the achievement of engagement rather than detachment” (p. 221). Of course, the interactions go far beyond
those with clients and include family members, other health care providers, administrators and so on but the point is still the same. Nursing is an interpersonal process and viewing others as individual selves, as persons rather than objects, is essential to effective interactions.

Within the current study, APNs were highly tuned to the interpersonal nature of their work, in that all aspects of their practice involved relating with others. I would suggest, however, that a more accurate label for the knowledge they drew on to enhance their interactions with others is relational knowledge rather than personal knowledge, as relational knowledge more clearly reflects the interpersonal component of the knowledge. Chinn and Kramer (1999) also suggest that the label personal knowing can be misleading in that it can imply that it is only knowledge that relates to the perceptions of the individual. While it does consist of this knowledge it also involves meaningful interactions with others. Thus, relational knowledge would capture both the individual and interpersonal aspects of this knowledge. Moreover, relational knowledge is frequently used in the literature, particularly in contrast to technical knowledge.

A type of knowledge that is similar to Carper’s personal knowledge is that identified by Liaschenko and Fisher (1999) as person knowledge, which they describe as “knowledge of the individual as a self with a personal biography” (p. 38) and a sense of agency. To access this knowledge, the authors claim that the nurse must directly interact with the individual over an extended period of time or through multiple encounters, which would suggest that it is the kind of knowledge needed to establish a nurse-patient relationship. The authors do point out that person knowledge is not always possible or desirable and although they do not specify in which situations this would be the case, they mention earlier that some of the nurses in their study worked in ICU and emergency psychiatry where patients “were often unconscious, paralyzed or mute” (p.37). Their point about the influence of the environment on the kind of knowledge used goes back to my earlier discussion on the importance of the discourse that nurses take up fitting with the reality of the clinical
situation. The authors maintain that person knowledge is used in situations in which there is a potential conflict between the individual and health care providers regarding a course of action. In those situations, drawing on knowledge of the person helps remind health care providers that it is the individual’s life they are discussing and individual agency should be supported. Knowledge of the person as an individual was not discussed by the participants in my study, perhaps because they did not have multiple encounters or contact over an extended period of time with children and families.

I would argue that in the emerging primary health care system, contextual knowledge and relational knowledge will be more useful in the delivery of health care than person knowledge which, Liaschenko and Fisher (1999) suggest, requires contact with an individual over an extended period of time or through multiple encounters. It seems to me that the idea of a nurse-patient relationship is a modernist concept that does not fit the reality of our contemporary health care system. For one thing, most nurses do not have extended contact with individuals. With those who work in acute care settings, the hospital stays are much shorter and individuals are often more acutely ill. Moreover, nurses who work with individuals within the community often do not have extended contact or multiple encounters, with the exception of those who work with individuals who require ongoing treatments such as dialysis. As discussed previously, the APNs in this study were highly tuned to the interpersonal nature of their work and relational knowledge could enhance their interactions with others.

A second reason that the idea of a nurse-patient relationship does not fit the reality of contemporary health care is that individuals do not necessarily want a relationship with the nurse. Reed and Ground (1997) make an interesting comment in their discussion of “new nursing” which they refer to as humanistic nursing. They maintain that the functional model of nursing (which they refer to as “old nursing”) is one largely constructed by patients whereas the humanistic model of nursing that stresses the nurse-patient relationship, is largely constructed by nurses and nursing theorists (p. 152). This
observation points to the importance of nurses considering the patient’s needs from their perspective, not from the nurses’ perspective. One of the criticisms I would make of nursing models that incorporate ideas from Eastern philosophy is that they are importing ideas that do not fit with Western society. I don’t know too many people, including my own family and friends, who would see themselves as growing toward higher levels of consciousness. This idea comes from a specific philosophy that I would argue is not shared by the majority of people in the Western world. While the developers of such theories subscribe to the ideas inherent within the theory, there does not seem to be recognition that this way of seeing the world may not be shared by others. Any nursing theory that does not begin with the realities of patient and families’ lives can be seen as serving the profession rather than the individuals who seek health care.

**Theoretical Knowledge**

Theoretical knowledge provided the backdrop for APNs’ interpretation of contextual knowledge and also provided direction for their interactions, assessments and interventions with children and families. They drew on a number of theories to inform their understanding of the realities of children and families’ lives in managing the ongoing care of a child with a chronic health condition, for example, theory of uncertainty and its impact on the family’s ability to cope with their child’s care. They also drew on theory to guide their interactions, with children and families, for example the theory of family centered care and empowerment theory.

Their narratives of nursing assessments and interventions reflect the integration of theoretical knowledge into their practice in that they did not refer directly to the theories they were drawing on but these theories were evident in their conversations. Kirkevold (2002) points out that in applying theoretical knowledge in particular situations we gain new knowledge that is different from either the theoretical knowledge we brought to the situation or the experiential knowledge coming from the situation. It is the interacting of these two kinds of knowledge that adds to our understanding, or as Thorne (1997) puts it, “refines
our theory”. Schultz and Meleis (1988) make a similar point in their discussion of how nurses “use knowledge from other disciplines but through reflection and imagination evolve perspectives on that knowledge which are unique to nursing” (p. 219). I would suggest that it is not only reflection and imagination on the part of nurses but also patient response to nursing practice that creates nursing knowledge from the application of knowledge from other disciplines.

Nursing theory was originally conceptualized as the product of empirical research (Carper, 1978) “for the purpose of describing, explaining and predicting phenomena of special concern to the discipline of nursing” (p. 14) and it was therefore subsumed under empirical knowledge in Carper’s explication of ways of knowing. More recently empirical knowledge and theoretical knowledge are referred to as two distinct types of knowledge in the nursing literature. However, the nature of theoretical knowledge as a distinct type of knowledge has received little attention. I think the association of empirical knowledge with theoretical knowledge (most evident in Carper’s ways of knowing) is problematic for a couple of reasons. I would argue that one of the reasons that there has been so much discussion/debate on the theory-practice gap (Fealy, 1997) is that we have associated theory with empiric knowledge and as Chinn and Kramer (1999) note, empiric knowledge often does not translate well into practice knowledge. Consequently, nurses in practice have not viewed theoretical knowledge as useful in guiding their practice. Yet many theories that have not been empirically tested have the potential of providing direction for nurses’ practice. Creating a separate category for theoretical knowledge can draw attention to these theories and legitimate their use in nursing practice. Moreover, by identifying and articulating such theory, we provide the impetus for practice-based research that can add to our evidence-based knowledge.

Sociopolitical Knowledge

The sociopolitical knowledge of the APNs’ in this study relates to their knowledge of the systems within which they practice and the workings of these systems. It also
includes knowledge of the interpersonal dynamics operating within these systems, including power dynamics. APNs drew on this knowledge to assist families in moving through the system, and to develop resources and programs to address system inefficiencies and ineffective health care practices. White (1995) identified sociopolitical knowledge as a type of nursing knowledge in her article on a critique and update of Carper's ways of knowing. White conceptualized sociopolitical knowing as including both the context of individuals (and particularly their cultural location) as well as the context of nursing which she saw as including knowledge of the social, political and economic structures that affect health.

Liaschenko and Fisher's (1999) description of patient knowledge is similar to the knowledge I have classified as sociopolitical. They view patient knowledge as knowledge of the health care system and the social actors within the system, knowledge that they insist is mandatory for nurses to have in helping patients through the system. They claim that knowledge of the interactions between social actors and institutional practices forms the basis of this complex, social knowledge that includes "knowledge of people's commitments, priorities, competencies, styles of working, vulnerabilities, emotions ... and the appropriate languages to use with these multiple others" (p. 36), as well as knowledge of how the institution works and who the key decision-makers are. While this type of knowledge was frequently drawn on by APNs within the current study in coordinating the care of children within the community setting, I would argue that the label of patient knowledge that Liaschenko and Fisher give it, does not reflect the nature of the knowledge as described. I think a more accurate label for this knowledge is sociopolitical rather than patient knowledge because of the power dynamics that tend to operate around the procuring of resources for individuals and their families. Certainly, within this study, APNs discussed power dynamics that surfaced around procuring and coordinating health care for children both within their health care team and between hospital and community health care professionals.
I would also argue that there is an advantage to labeling knowledge of the system and the social actors within the system as sociopolitical knowledge. It can assist nurses in becoming more politically astute and more skilled in dealing with the power dynamics that are present within health care settings. If we continue to skirt around the issue of power dynamics, nurses will not acquire the skills they need to address political issues within the system that lead to fragmented care and inappropriate or non-existent resources. Liaschenko and Fisher (1999) suggest that moving the patient through the system and the knowledge required to do so is a relational practice that, while essential to the patient and to the goals of the institution, is not visible, acknowledged or legitimated by the system as part of nursing work or knowledge. I would suggest that conceptualizing it as a relational practice rather than a political practice is a primary reason it is invisible and unacknowledged. The privileging of objective/technical knowledge within health care and the discounting of subjective/relational knowledge provides the impetus for the dominant system to ignore anything that is considered relational. Therefore, identifying this work as relational will ensure that it continues to be ignored. Identifying it as a political practice that requires political knowledge will make the practice much more difficult to ignore and therefore more likely to be given the attention and resources required.

Following on their conceptualization of moving the patient through the system as relational practice, Liaschenko and Fisher (1999) contend that acquiring appropriate resources for patients is part of nursing work that “requires a great deal of practical knowledge which is gathered largely through role-modeling, experience, and trial and error” (p. 36). While I agree that some of the knowledge they identify is practical, the majority of it has to do with the dynamics between people within organizations, which, I would again argue, is sociopolitical knowledge. And this knowledge can and should be gained through education and experience not trial and error. Sociopolitical knowledge consists of a body of knowledge, just as ethical knowledge consists of a body of knowledge, that can be taught and opportunities provided for students to practice the skills associated with the knowledge
such as negotiation and collaboration. Within the current study, APNs did not see themselves as having the skills to use their knowledge of the politics inherent within health care settings to improve health care delivery for the populations within their specialty. In fact, having the knowledge and not being able to use it to improve health care delivery was a source of great frustration for them and the main reason for giving up their positions and moving on. I would like to think that drawing out and naming this knowledge as sociopolitical and, teaching the knowledge and skills of which it consists, will go a long way to promoting a political intelligence in nurses. I suggest that nurses’ sociopolitical knowledge can ultimately benefit patients by being used to improve the delivery of health care and to increase nurses’ satisfaction with their practice and their contributions to health care. Moreover, within the emerging primary health care system, nurses will be working as part of collaborative health care teams and sociopolitical knowledge and skills will be critical to successful working relationships.

Summary of APNs’ Practice Knowledge

In summary, the types of knowledge that informed APNs’ practice at the individual and population levels of health care include: empirical, contextual, relational, theoretical, and sociopolitical knowledge. Empirical knowledge is in-depth knowledge of the chronic health condition of the children within the specialty program in which APNs worked, as well as knowledge of the latest technology for monitoring and/or treating the particular health condition. This knowledge includes knowledge of the disease process, physiology, therapeutics, and pharmacology. Contextual knowledge includes knowledge of the everyday realities of a child and family’s life and the factors within their particular situation that influence their ability to manage the child’s health care on an ongoing basis. Relational knowledge includes knowledge of the personal and interpersonal processes that influence interactions with others. Theoretical knowledge informed the contextual knowledge that APNs gathered, as well as providing direction for their interactions, assessments, and interventions with children and families. Sociopolitical knowledge is knowledge of the
systems within which APNs practice and the workings of these systems as well as knowledge of the interpersonal dynamics operating within systems. This knowledge provided direction for assisting families in moving through the system, and in developing resources and programs to address inefficiencies and ineffective health care practices. The conceptualization of APNs’ knowledge within this study differs from, and challenges, the most widely accepted “patterns of knowing” originally identified by Carper (1978) and expanded upon by Chinn and Kramer (1999) and has implications for the development of theory on nursing knowledge.

**APNs’ Contributions to Health Care at the Population Level**

In addition to their practice with individual children and families, APNs focused on the health needs of the population within their specialty. Their ongoing contact with multiple children and families and their work in processing referrals to the program provided them with a broad knowledge of the health needs of the population and the resources required to address those needs. APNs also had first hand knowledge of the inefficiencies and ineffective health care practices within the system that prevented quality health care because they were continually coming up against these inefficiencies in their practice and seeing the impact that they had on children and families.

In the shift from individual to population level health care, APNs engaged in system level thinking, focusing on the big picture rather than individual children and families and asking questions such as, how do we best serve this population? How do we organize the health service so that we’re being most effective? Thus, APNs’ knowledge application at the population level is the reverse of what it is at the individual level. Rather than generalized knowledge being applied to the particular situation as in nursing practice with individuals, particular knowledge of individual children and families is translated into general knowledge and applied to developing health care services for a population. One of the community APNs, Edelman, commented; “In the work I’m doing at the population level, I combine clinical knowledge with the ability to have a systems perspective to streamline services”.


APNs perceived that they were often the only members of the health care team who focused on the big picture in relation to the needs of the population of children and families. Perhaps this is related to the holistic approach they have employed which directs their focus to the individual, their family and the community, whereas they maintain that other health care professionals employ a biomedical perspective in which the focus is on the individual and particular aspects of the individual.

APNs’ goals for population level health care included developing resources to address identified health needs. The most common way of addressing health needs of populations was coordinating and/or developing programs to assist families in the ongoing management of their child’s health condition within their communities. However, APNs felt constrained in their efforts to provide population focused health care because the system in which they practice is dominated by a biomedical model, which keeps the focus of care at the level of the individual. Moreover, the demands on their time was another way in which their practice was controlled and contained at the individual level. Although APNs were acutely aware of system issues that constrained health care at the population level, they did not perceive themselves as having the power to address these issues. I would suggest that nursing’s focus on the individual and on the centrality of caring and nurse-patient relationships has served to keep us narrowly focused and has inadvertently played into the “hidden agenda” of those in positions of power to deflect the focus away from the system and it’s inefficiencies. As long as the focus remains on the individual, system change will not be addressed.

The Fit between APN Models of Care and Emerging Health Care Delivery

In the current context of primary health care reform, ambulatory programs, such as the ones in which the participants in this study worked, will be a priority across all regions of the province. The general consensus around a primary health care model is that community-based organizations will offer comprehensive services that focus on health promotion, disease prevention, and management of chronic illnesses, to specific populations
24 hours a day, 7 days a week, through interdisciplinary teams (with enhanced roles for nurses and other providers), with linkages to other community services (Romanow, 2002).

In response to the impending implementation of primary health care clinics throughout British Columbia, nursing leaders have lobbied for and achieved legislation for nurse practitioners to practice within BC. The first nurse practitioner educational programs in this province began in the fall of 2003. Within the Canadian health care system, advanced practice nursing has been defined as including both clinical nurse specialists and nurse practitioners. However, until recently, clinical nurse specialists were the only advanced practice nurses within BC. During the past year, there has been a noticeable shift in discussions regarding advanced practice nursing. These discussions are, for the most part, referring to nurse practitioners (NPs) rather than clinical nurse specialists (CNSs). The emphasis on NPs can be explained in part by the enthusiasm for a new category of nurses who will provide an entry point to the health care system. However, I would suggest that another explanation for this shift goes back to the argument made at the beginning of this study. There is little understanding among policy-makers, the public and health care professionals as to what advanced practice nursing is and how it contributes to the delivery of quality health care (Hamric, 2000). In particular, there has been little understanding of what CNSs do. With the push to nurse practitioner practice, there has been much greater visibility around NP practice than that of CNSs. Moreover, NPs are seen as an alternative to physicians as the entry point to the health care system and therefore present a cost saving mechanism for the government. Consequently, there is a tendency for policymakers to focus exclusively on the nurse practitioner role when considering options for the delivery of community-based health care while ignoring the contributions of clinical nurse specialists, particularly across systems of care.

I would argue, however, that CNSs have a unique contribution to make to the emerging health care system. What is unique about this group of nurses is their in-depth knowledge of chronically ill populations and their system level thinking. While it could be
argued that community health nurses who are engaged in population health and community development also think in this way, their focus has not been on populations with chronic illnesses nor do they have the in-depth knowledge of chronically ill populations. In fact, there are no other health professionals who are focused on population level health care for those with chronic illnesses. Nurse practitioners will be primarily focused at the level of the individual client so a CNS focus on populations will contribute to comprehensive health care for those with chronic illnesses.

**Summary of Chapter Seven**

In this chapter I have explored three themes that were central to the findings of the study and which have implications for the both nursing’s role in the delivery of health care and advanced practice nursing. These themes are the nature of the power dynamics within the health care setting that participants perceived as operating to control their practice, the nature of APNs’ practice knowledge, and the nature of APNs’ practice and its fit with the goals of the emerging primary health care system.

In my analysis of the power dynamics within health care, I took the position that power is inherent in our ways of thinking and speaking, which is associated with a postmodern perspective of power relations as inherent in various discursive positions. Thus, the discourses one takes up have within them a predetermined script for enacting power relations so exposing these power scripts provides a way of disengaging from the dynamics by changing these scripts or creating new discourses with different power scripts. I conceptualized the various nursing discourses that influence and shape APNs’ practice as part of the social context of nursing practice and discussed how these discourses influenced and shaped APNs’ practice and knowledge. I also explored the reasons for APNs’ difficulty articulating their practice which included their perception that their knowledge does not fit within the dominant discourse and is not valued by others and that they do not have an appropriate language for expressing it.
In discussing APNs' practice knowledge, I focused on the knowledge they draw on to inform their understandings and their actions and the ways in which this knowledge could provide them with a language for articulating their practice. I particularly focused on contextual knowledge because it is so foundational to APNs' practice and it is not identified within the nursing literature as a type of nursing knowledge. I also examined the ways in which they drew on theoretical knowledge to interpret contextual knowledge and provide direction for their actions. I compared contextual knowledge with current theories of nursing knowledge, and in particular Liaschenko and Fisher’s (1999) work. I also discussed sociopolitical knowledge, as it is also an important type of knowledge that APNs need to influence the provision of health care for children and families.

The nature of APNs' practice and its fit with the goals of the emerging primary health care system relate in particular to their ability to work at the population level of health care. The findings from this study point to APNs in-depth knowledge of the populations with whom they work, their ability to think at the system level, their experience in coordinating the health care of individuals and families, and their skill in communicating with a wide variety of health care providers and lay people. Their expert knowledge and skills position them as the most appropriate health professional to take a leadership role in the emerging primary health care system. In fact, they may be the best kept secret in the entire health human resource field. Unfortunately, the failure to recognize their potential for contributing to the health care of children and families is a loss to both families and the health care system.
CHAPTER EIGHT
CONCLUSIONS AND RECOMMENDATIONS

The impetus for this study arose from the perceived gap between advanced practice nurses’ mandate to meet the complex health needs of individuals and populations across systems of care and research findings that demonstrate that families have great difficulty procuring health services to assist them in managing the complex health care of family members. The purpose of the study was to gain an understanding of the place of APNs in the organization and delivery of community-based health care of children with complex health needs and their families in British Columbia. In this chapter, I discuss the conclusions I have drawn from this research and the implications and recommendations for nursing practice, administration, education, research, and policy.

The central conclusions from this study are:

1. APNs’ accounts reveal that they contribute to the community-based health care of children with complex health needs and their families, at the individual and population levels, drawing on their in-depth knowledge, their holistic approach to health care, and their ability to think at the system level.

2. APNs view their practice and contributions to health care as being constrained by a number of factors, which leads to their under-utilization as expert practitioners. Two primary factors are the structure of their work which does not capitalize on their expertise and contributes to the invisibility of their practice, and the difficulty that APNs have articulating their practice because they do not have a language that accurately represents its nature.

APNs Contributions to the Health Care of Children and Families

The APNs’ contributions to the community-based health care of children with complex health needs and their families occurred at both the individual and population levels. They saw their primary goal with individual children and families as assisting
families to understand and manage the ongoing care of the child within their community and their goals for the population as increasing accessibility of children and families to health care, establishing prevention/intervention programs, and increasing community resources. The findings highlight the nature of their practice as relational rather than technical in that APNs described providing education, support, advocacy, and co-ordination of care for individual children and families and program development, educational outreach, and contributing to policy initiatives at the population level. They approach the care of children and families from a holistic perspective and they draw on contextual, theoretical, sociopolitical, relational and empirical or biomedical knowledge to inform their practice. Thus the findings illustrate the complexity of the knowledge that informed the nurses’ practice.

Contextual knowledge - knowledge of the practical, everyday realities of families’ lives with a child who has complex health needs – was considered by the APNs as critical to the provision of quality health care for individual children and families. It was gathered and applied in every aspect of their practice, including assisting families with the ongoing management of their child’s health care, education, support, advocacy, and co-ordination of the child’s care. Contextual knowledge directed the APNs to provide individualized care based on the needs and concerns of the patient and family from their perspective rather than from the perspective of the nurse. Participants’ narratives revealed that their capacity to gain and act on contextual knowledge in the provision of quality health care was informed by theoretical, empirical, sociopolitical, and relational knowledge. APNs’ theoretical knowledge provided the backdrop for interpreting the contextual knowledge they gathered to understand the child and family’s situation, for example, how a particular family was coping with their child’s diagnosis. Empirical or biomedical knowledge was drawn on to assist families in managing their child’s complex health needs, particularly with regard to the technical aspects of care. Sociopolitical knowledge was drawn upon to assist families in accessing the resources they needed to manage their child’s health needs. Finally, relational
knowledge provided the basis for the APNs to connect with individuals and families on a personal level so they could access and act on contextual knowledge.

Contextual knowledge, informed by empirical, sociopolitical and relational knowledge, was also drawn on by the APNs to meet the health needs of the population of children and families within their specialty. For example, in contributing to policy initiatives, the APNs drew on knowledge of how various policies and practices impacted on the lives of individual children and families. In developing programs and educational outreach initiatives, the APNs drew on their knowledge of the multiple children and families they assessed to provide them with a broad understanding of the health needs of the population and the resources or health services required to address these needs. They also gained knowledge of the health services available (or lacking) within various communities throughout the province, through co-ordination of the child’s care. The APNs also had first-hand knowledge of system inefficiencies and ineffective health care practices that prevented quality health care for children and families, gained through their continuing encounters with particular situations. They drew on this knowledge to assist families in moving through the system, and to develop resources and programs to address system inefficiencies and ineffective health care practices.

Participants in this study discussed two models of health care delivery that they employed to meet the health needs of children and families within their specialty programs, clinical practice by phone and population focused programs. Although they emphasized the effectiveness of these models in meeting children and families health needs, they maintained that neither model was supported by the organization. Consequently, clinical practice by phone was often conducted after their regular workload was completed which usually meant at the end of the day. Many nurses said they often stay late to return phone calls because they know there are parents waiting on the other end of the phone who need assistance. Moreover, despite the inclusion of program development in their job descriptions, the APNs said that they are not given time or resources to develop programs. While most APNs
identified program goals for the population with whom they worked, few actually had the opportunity to develop the programs because of various constraints on their practice.

**Factors Constraining APNs’ Practice and Contributions to Health Care**

In this study, the APNs’ practice and contributions to health care were constrained by the way in which their practice was structured and their difficulty articulating their practice and their contributions to health care.

**The Structure of APNs’ Practice**

The APNs maintained that their practice was largely structured by the demands of the program in which they worked and that the majority of their time was taken up with program activities, including organizing the work of other members of the health care team. Their preferred practice of providing quality health care for children and families was relegated to the background and was not considered a priority by the dominant system, as evidenced by the minimal time allotted to direct client contact. Consequently, program activities took priority over their work with children and families, which was carried out behind the scenes after the work of the program was complete. Thus, the visible part of their practice was coordinating the work of others, while their work with children and families remained largely invisible.

The APNs reported that their specialized knowledge and skills were under-utilized and they were not practicing to their full potential. The under-utilization of their expertise created a sense of not being valued, which led to feelings of frustration and dissatisfaction with their work. The outcome of their dissatisfaction is reflected in the high turnover rate of participants in this study. Of the sixteen APNs who participated in the study, only five were in their same positions at the completion of the study. These findings have major implications not only for the way in which APNs’ practice is conceptualized and enacted within health care organizations but also for policy regarding human health resources.
APNs’ Difficulty Articulating their Practice

The research problem with which the study was concerned was the lack of understanding of APNs’ practice and contributions to health care by policy-makers, the public, other health professionals and even the APNs’ themselves. What became clear is that the APNs remained silent about their practice because they did not have a language for articulating it. In exploring reasons why they did not have a language for their practice, I turned my attention to the nursing discourses that APNs take up to understand and enact their practice. I came to the realization that it was the lack of fit between these discourses and the reality of the APNs’ practice that created dissonance for the nurses and left them without an alternative to a technical/rationalist discourse for articulating their practice. While a technical/rationalist discourse provides a language for nurses whose primary work is technical in nature, nurses whose primary work is relational in nature are left without a language through which to express their practice. Consequently, they remained silent.

Theorizing APNs’ difficulty articulating their practice as not having a language that reflects the reality of their practice, shifts the understanding of the power dynamics within health care that operate to silence nurses’ voices. Rather than viewing APNs’ articulation of their practice as being controlled by the language of the dominant system that does not fit the realities of their practice, they can take control of developing their own language. This understanding views the power for change as residing with nursing, whereas the previous understanding viewed the power for change as residing with the dominant players within the system, namely physicians and administrators. The latter perspective would require finding ways to persuade others to broaden their thinking and their language of health care.

In conceptualizing APNs’ contributions to health care, I proposed that it is the knowledge that they bring to health care situations that contributes to the health care of children and families. This conceptualization directed me to inquire about the knowledge that informed APNs’ practice. This turned out to be a critical conceptualization because it is APNs’ knowledge that can provide the basis of a language for articulating their practice.
Moreover, one of my observations in this study was that APNs lacked confidence in speaking out about their practice. I propose that developing a language based on their knowledge will provide them with the confidence to speak out and insist on having their voices heard at the health care table. Thus, a critical component of APNs articulation of their practice and contributions is confidence in their knowledge and the difference it makes to quality health care.

Drawing on the knowledge that informs APNs’ practice can provide the building blocks for developing a language that reflects the realities of their practice. Having access to a language that reflects their practice, can instill in APNs’ the confidence to take their place as equal members of a health care team devoted to providing quality health care within the emerging primary health care system. Moreover, in articulating their practice they will inform others of the contributions they make to the organization and delivery of community-based health care for children with chronic health conditions and their families.

In conclusion, the central findings of this study are that the APNs contributed to the community-based health care of children and families at the individual and population levels but the way in which their work is structured led to under-utilization of their expertise and contributed to the invisibility of their practice. Furthermore, the APNs had difficulty articulating their practice because they did not have a language that accurately represents its nature. The invisibility of APNs’ practice and their silence contributed to a lack of understanding of advanced practice and how it contributes to the health care of children and families within the community setting. These conclusions have implications for nursing practice, administration, education, research, theory, and policy.

Before beginning the discussion of implications and recommendations, it is useful to remind the reader that although the term advanced practice nurse (APN) has been used throughout the study, the participants were all CNSs or nurse clinicians who were functioning in advanced practice roles. Therefore, the recommendations are specifically directed toward the CNS role and I use the term CNS and APN interchangeably in the
following discussion. Moreover, it is also important to remind the reader that this study took place within a Canadian context so the findings and recommendations are specifically directed to Canadian advanced practice nurses.

**Recommendations for Nursing Practice**

Over fifteen years ago, the Nurse Administrators Association of British Columbia emphasized that if nurses were to be effective in the many settings in which they were beginning to practice they “must be able to convincingly interpret and defend to others nursing’s role in the delivery of health care … To do so they must possess a well-defined perspective of what nursing is, the knowledge and skills underlying what nursing does and the techniques to communicate these effectively” (NAABC, 1988, p. 5). This statement could just as easily apply to APNs in the current health care system. Why are nurses still faced with the need to interpret and defend their place in the delivery of health care? The current study answers that question in part by identifying that APNs’ have difficulty articulating their practice because they do not have a language that accurately represents it.

APNs need to be encouraged to draw upon the knowledge that informs their practice to provide them with a language for articulating their practice at both the individual and population level of health care. At the individual level APNs can begin to bring knowledge of the context of families lives to health care team discussions and show the relevance of this knowledge for the provision of effective and efficient health care. In the current environment, where the expectation is that families will provide the ongoing health care for their family member, it is imperative that health care professionals have knowledge of the context in which this health care will be carried out. APNs need to be able to clearly articulate this contextual knowledge and show its relationship to the provision of quality health care. APNs also need to articulate the empirical and/or theoretical knowledge they draw on in the decisions they make in the provision of health care to demonstrate evidence-based practice.
At the population level of health care, the APNs need to articulate their knowledge of the health care system, including ineffective and inefficient health care practices and policies that impact on the delivery of quality health care for children and families. Because APNs are continually situated within the clinical arena, their close proximity to children and families provides them with a perspective that is not available to other health professionals who come and go and may have one small piece of the health care picture. APNs also need to recognize that their knowledge of the system can make an important contribution to the design and delivery of quality, cost effective health care for children and families. They also need to develop the confidence to articulate this knowledge and lobby for changes in health care practices and policies that are not in the best interests of children and families.

Recommendations for Nursing Administration

The findings from this study that have implications for nurse administrators relate to the APNs dissatisfaction with their work environment and in particular with the way their work is structured and their lack of control over their practice. The first recommendation is to find ways to empower APNs by getting them involved in the decision-making level of the organization and by having a sense of control over their practice. One participant spoke favorably of nursing council as a place for nurses to be involved in practice decisions and to feel they had a voice and some sense of control over their practice. A second recommendation is that APNs' practice be structured around the needs of the children and families served by the program rather than the demands of the program. For example, clerical staff could be hired to organize clinic days and have reports on charts, etc. which would free up APNs time to devote to the health care of children and families, on an individual and a population level. A third recommendation is that funding be provided to protect APNs' time so they could devote it to developing and/or refining the two health care delivery models they employed to meet the health needs of children and families, clinical practice by phone and population focused programs. Given the potential of the clinical practice by phone model to meet the health needs of individual children and families
throughout the province and the population focused programs to reach far greater numbers of children and families than individually focused health delivery models, further development of these models could be an cost effective way of providing quality health care for children with complex health needs and their families throughout the province.

**Recommendations for Nursing Education**

The majority of participants in this study used a role and competency-based framework for conceptualizing their practice, which is understandable considering that this is currently the most widely accepted way of conceptualizing advanced practice. However, this approach has been criticized because of the narrow focus on practice and the inattention to the environments that surround and impact upon advanced practice (Styles & Lewis, 2000). These authors caution that advanced practice may fail in reaching its potential if surrounding environments are ignored. Over 15 years ago, Harrington (1988) argued that nursing needed to move beyond its heavy reliance on individualist frameworks and embrace theoretical frameworks that address health care systems, organizations, professionals and the society as a whole. She maintained that nursing would not become a serious player in the political arena until nurses gained an understanding of the larger issues drawn from the fields of sociology, political science, public policy, and economics.

The implications of the current conceptual approach for advanced practice for nursing education is that curriculums for APNs need to include conceptual frameworks for practice that move beyond the individualistic focus on roles and competencies and focus on health care systems, organizations, professionals and the wider culture. A framework that has potential for assisting APNs to gain a broad understanding of the factors influencing their practice and the wider health care system is a social ecological framework. Although the social ecology model was specifically developed to examine the contextual factors influencing a child’s development (Bronfenbrenner, 1979), it has successfully been applied to examining the influence of context on family caregivers, to illustrate the social environment that surrounds family caregiving and is critical to its success (Kazak &
A social ecological framework would direct APNs to a consideration not only of their immediate work setting and the clients but also to health care organizations and how they function, including the values and goals of the organization, administrative policies that influence working conditions, and the roles of other health professionals and institutions. The framework would also direct them to a consideration of the culture of health care as well as the wider culture and the impact of cultural ideologies on health care and their practice. Grounding students in a broad conceptual framework for their practice provides them with a conceptual tool for looking beyond their immediate practice environments to a consideration of the social and political context of health care, and issues of power and influence that shape their ability to provide quality health care. Developing an awareness of what these issues are is a beginning step toward addressing them.

Another implication from the findings of this study is the need to emphasize with students the kinds of knowledge that APNs draw on in their practice and demonstrate the pertinence of this knowledge to client care. Particular emphasis is needed on contextual and sociopolitical knowledge as these have received less focus in our education programs than has empirical, theoretical, and technical knowledge. The importance of educating nurses to be politically astute, to have the knowledge and skills to hold their own and the confidence to stand their ground and articulate their practice is of critical importance in the current health care environment. Sociopolitical knowledge consists of a body of knowledge, just as ethical knowledge consists of a body of knowledge, that can be taught and opportunities provided for students to practice the skills associated with the knowledge such as negotiation and collaboration. Drawing out and naming this knowledge as sociopolitical and, teaching the knowledge and skills of which it consists, can go a long way to promoting a political intelligence in nurses. APNs’ sociopolitical knowledge can ultimately benefit patients by being used to improve the delivery of health care and to increase nurses’ satisfaction with their practice and their contributions to health care. Moreover, within the emerging primary health care system, nurses will be working as part of collaborative health
care teams and sociopolitical knowledge and skills will be critical to successful working relationships.

Students need opportunities to practice articulating their practice to others. One of the participants in this study said that having to walk through what her practice involved for a software developer who was designing an electronic chart system did more in helping her articulate her practice than anything else had. This type of exercise could provide an excellent teaching tool for educators to use in teaching APNs how to articulate their practice and the knowledge that informs their practice. They could walk through their day and examine the knowledge required for the activities with which they are involved and the decisions they make. Class presentations could also provide students with opportunities to articulate their practice with one another. In addition, learning activities that connect students’ knowledge to client outcomes can assist them in developing confidence in what they know and the difference this knowledge can make to health care.

A third implication of study findings for nursing education is the critical need to include learning experiences in interdisciplinary collaboration as part of the curriculum. In this study APNs reported an almost complete absence of collaboration among health care providers, and in particular, those who were considered part of the same team. Although there were a number of factors influencing collaboration, one factor appeared to be APNs’ perception that other health care providers did not understand or value their contributions to clients’ health care. Opportunities to discuss client care within interdisciplinary groups could provide a way for health care professionals from different disciplines to gain an awareness and understanding of each other’s contributions to health care as well as the benefits to clients of having a health care team who are collaborative.

**Recommendations for Nursing Research**

The findings of this study suggest the need for further research in a few key areas. The current study is a beginning step in articulating the knowledge that informs APNs’ practice and more interpretive research is needed to continue developing the kinds of
knowledge that inform APNs’ practice. In particular studies are needed that build on the
knowledge that informs the relational dimensions of health care. Although the major focus
of APNs practice in this study was relational, they had difficulty articulating this aspect of
their practice. Understanding is needed of the knowledge that informs the current
interactions that occur between APNs and clients. What are the characteristics of the
knowledge needed to inform the relational dimensions of health care and how can this best be studied? Another potential methodology for developing APNs’ knowledge is
participatory action research. A major plus of this approach is that the APNs’ are involved
in designing and studying their practice and their knowledge. There are a number of
participants that were in my study who would be interested in pursuing this approach and I
think it has major potential not only for producing knowledge that is pertinent to practicing APNs’ but more importantly for empowering these nurses to articulate their practice and knowledge. The big disadvantage of this type of research is that it is very time consuming and adding it to APNs’ current workloads would be a detraction from participation.

Another area in which research is needed is identifying nurse-sensitive outcomes of
client and family care; that is determining the effects of nursing on child and family
outcomes. Keeping statistics that document the health needs of clients and outcomes of
APNs’ interventions is one way in which APNs could contribute to nurse-sensitive
outcomes. Technology should assist APNs to a great extent by having all client information in an electronic record so it can be easily documented and tracked. The data accumulated through documentation would still have to be analyzed but a statistician could be hired to analyze the data and the resulting research could provide useful information on which to base decisions regarding the design of health services and the development of policy that would be responsive to a population’s health needs. One of the building blocks of primary health care is “better information on needs and outcomes” (Romanow, 2002, p. 116). One of the ways of achieving better information on needs and outcomes is for APNs to
document client and health statistics to identify health needs and evaluate the usefulness of health services.

One of the findings from this study that would make an interesting qualitative study is the practice of keeping ghost charts on children and their families that contain most of the phone communication between health care providers and families. The data contained in these ghost charts could provide a contextual knowledge base to provide direction for APNs' practice with children and families. Families often complained that it was very difficult for them to find written materials on the practical aspects of managing their child's chronic health conditions and I would suggest that these ghost charts contain all kinds of rich data on the day-to-day management of a child's chronic condition. A qualitative study has the potential to contribute knowledge regarding the practical aspects of managing a child's chronic condition that would be useful to both parents and nurses.

Another study that would be useful is a study that documents the time that APNs spend on organizational activities and the percentage of time spent in direct contact with children and families and compare these two aspects of their practice to child and family outcomes. In the current environment of fiscal constraint, appropriate employment of human health resources is a priority and such studies could provide evidence for policymakers on which to make decisions regarding the appropriate utilization of APNs expertise.

**Recommendations for Policy Development**

A central recommendation from this study is for health care planners and policymakers to engage in consultation with APNs in determining the health needs and health services required for children with complex health needs and their families. The APNs' knowledge of the practical, everyday realities of families' lives with a child who has a chronic health condition(s) is the kind of knowledge that is critical for the planning of quality health services for children with chronic conditions and their families. “The individual client/provider level is where health care actually occurs, and decision-makers at other levels need to hear about problems to remain responsive to citizen’s needs” (CNA,
2000, p.10). Moreover, APNs’ continuing encounters with inefficient and ineffective health care practices has provided them with knowledge of the system that could be employed in the design of more effective and efficient health services. The APNs in this study identified gaps in the provision of health care services for children with complex health needs and their families. These gaps include lack of accessibility of children with chronic conditions to timely diagnosis and intervention, lack of prevention programs, and lack of health care resources within community settings, particularly in relation to chronic disease management. APNs have clear and reasoned ideas for how to implement changes to deliver more effective and efficient health care for children and their families. Yet, it is knowledge that, for the most part, has been untapped. The addition of APNs on policy committees and/or boards, would contribute a point of view that would be invaluable in determining health services for specialized populations.

A second recommendation is that APNs’ practice be broadened to encompass the health care of populations with complex health needs. The positive outcomes of some of APNs’ initiatives at the population level point to the inefficiency and shortsightedness of a system that keeps expert practitioners focused on program details at the individual level rather than also facilitating their practice at the population level where there is a much greater potential to impact on the health care of children and families. Moreover, a finding of this study is that the health care system is losing APNs because of organizational practices that structure their work in ways that do not draw on their expertise and do not allow them input into decisions that affect their practice. Not capitalizing on the expertise of these nurses is a real loss to the health care system, particularly at this time when we are moving forward with primary health care. APNs’ in-depth knowledge of populations of children and families with chronic health conditions, their holistic approach to health care, and their ability to think at the system level make them prime candidates for implementing population health care for populations with complex health needs.
Summary of Recommendations

Nursing Practice

- APNs need to articulate their practice by drawing upon the knowledge that informs it.
- APNs can bring knowledge of the context of families lives to health care team discussions and show the relevance of this contextual knowledge for the provision of quality health care.
- APNs need to articulate the empirical and theoretical knowledge behind decisions they make in the provision of health care to demonstrate evidence-based practice.
- APNs need to develop the confidence to articulate their knowledge of system inefficiencies and lobby for changes in health care practices and policies that are not in the best interests of children and families.

Nursing Administration

- Find ways to empower APNs by getting them involved in the decision-making level of the organization and by having a sense of control over their practice.
- Structure APNs’ practice around the needs of the children and families rather than around the demands of the program.
- Hire clerical staff to organize clinic days, place reports on charts etc. so APNs’ time can be devoted to the health care of children and families.
- Protect APNs’ time so they can develop and refine two practice models that they use to meet the health needs of children and families – clinical practice by phone and population-focused program models.

Nursing Education

- Curriculums for APNs need to include conceptual frameworks for practice that move beyond the individualistic focus on roles and competencies and focus on health care systems, organizations, professionals and the wider culture (e.g. a social ecological framework).
- Curriculums for APNs need to drawn from the fields of sociology, political science, public policy, and economics to provide an understanding of the larger issues that impact on practice and health care.
- An emphasis needs to be placed on the kinds of knowledge that APNs draw on in their practice and demonstrate the pertinence of this knowledge to client care. Particular emphasis is needed on contextual and sociopolitical knowledge as these have received less focus in education programs than has empirical, theoretical, and technical knowledge.
Include learning experiences in interdisciplinary collaboration as part of the curriculum. Opportunities to discuss client care within interdisciplinary groups could provide a way for health care professionals from different disciplines to gain an awareness and understanding of each other's contributions to health care as well learning the benefits of collaboration for the provision of quality health care.

Nursing Research

- More interpretive research is needed to continue developing the kinds of knowledge that inform APNs' practice. In particular studies are needed that build on the knowledge that informs the relational dimensions of health care.

- A potential methodology for developing APNs' knowledge is participatory action research in which APNs' are involved in designing and studying their own practice and their knowledge. It has potential not only for producing knowledge that is pertinent to practicing APNs' but also for empowering nurses to articulate their practice and knowledge.

- Research is needed to identify nurse-sensitive outcomes of client and family care. Keeping statistics that document the health needs of clients and the outcomes of health care is one way in which APNs could contribute to nurse-sensitive outcomes.

- A study to determine the appropriate utilization of APNs' expertise would be to document the time that APNs spend on organizational activities and the time spent in direct contact with children and families and compares these two aspects of their practice to child and family outcomes.

Policy Development

- Health care planners and policymakers ought to engage in consultation with APNs in determining the health needs and health services required for children with complex health needs and their families. Their in-depth knowledge of the health needs of specialized populations of children and the resources or health services required to meet those needs would provide valuable input in designing health services that are appropriate and useful.

- The addition of APNs on policy committees and/or boards, would contribute a point of view that would be invaluable in determining health services for specialized populations. Their contextual knowledge of the ways in which health care practices and policies impact on the lives of individual children and families is critical if those policies and practices are to be effective in meeting the health needs of children and families.

- Broaden the focus of APNs' practice to encompass the health care of populations with complex health needs. APNs' in-depth knowledge of specialty populations of children and families with complex health needs, their holistic approach to health care, and their ability to think at the system level make them prime candidates for designing and delivering health care for populations with complex health needs.
Summary of Chapter Eight

In this final chapter, I discussed two central conclusions of this study and the recommendations for nursing practice, administration, education, research, and policy that came out of the findings. The conclusions are that the APNs contributed to the community-based health care of children and families at the individual and populations levels but the structure of their work did not capitalize on their expertise and contributed to the invisibility of their practice. In addition, the APNs had difficulty articulating their practice because they did not have a language that accurately reflected the realities of their practice, so they remained silent. Thus, the APNs’ silence and the invisibility of their practice contribute to the lack of understanding of advanced practice and how it contributes to the health care of children and families within the community setting. The various recommendations are directed toward increasing APNs’ articulation of their practice and capitalizing on their expert knowledge and skills in the provision of individual and population level health care.
REFERENCES


Patterson, C., Pinelli, J., & Markham, B. (1997). Nurse Practitioners in Canadian health care: We're not out of the woods yet! In C. Patterson (Ed.), Visions and voices: The nurse practitioner today (pp. 1-27). Toronto: Lugus.


The Place of Advanced Practice Nurses in the Community-Based Health Care of Children with Complex Health Needs and Their Families

Researcher: Connie Canam, RN, MSN
Supervisors: Dr. Anita Molzahn, Dean, Faculty of Human and Social Development, UVIC and Dr. Colleen Varcoe, Associate Professor School of Nursing, UVIC

Letter of Information to Nurses

I am a nurse with a background in pediatric nursing and nursing education and I am currently a student in the PhD program in the School of Nursing at the University of Victoria. For my dissertation research project, I am conducting a study of nurses in advanced practice roles who organize and/or provide health care for children with complex health needs and their families within the community setting. The purpose of the study is to obtain a better understanding of advanced practice nurses' practice and contributions to the health care of these children and their families and the factors that influence their practice. I anticipate that the knowledge gained from this study will contribute to an increased understanding and facilitation of the role of the advanced practice nurse in the provision of community-based health care for individuals with complex health needs. It is anticipated that this knowledge will also contribute to an improvement in health care delivery for children with complex health needs and their families in the community setting.

You are being asked to participate in this study because your position involves organizing and/or providing health care for children with complex health needs and their families within the community setting. You have been selected because of my familiarity with your work through mutual professional interests or because you were recommended by one of your colleagues.

Your participation in this study would involve meeting with me for approximately one to two hours to discuss your practice and providing written feedback on the transcript I will send you of our conversation. If you are interested in participating or would like more information, please contact me at 604 733-1972 or my dissertation supervisors, Dr. Anita Molzahn at 250 721-8050 or Dr. Colleen Varcoe at 604 323-0637.

Sincerely

Connie Canam, RN, MSN
The Place of Advanced Practice Nurses in the Community-Based Health Care of Children with Complex Health Needs and Their Families

Researcher: Connie Canam, RN, MSN
Supervisors: Dr. Anita Molzahn, Dean, Faculty of Human and Social Development, UVIC and Dr. Colleen Varcoe, Associate Professor School of Nursing, UVIC

Nurses’ Consent Form

I have read the information letter regarding the above study and have had the opportunity to discuss it. I understand that Connie is interested in nurses’ practice as it relates to the provision of community-based health care for children with complex health needs and their families. She is recruiting nurses for the study who are in advanced practice roles and involved in organizing and/or providing health care for children with complex health needs and their families in the community setting.

I understand that by agreeing to participate in the study I will meet with Connie to talk about my practice and the factors that influence it. I further understand that Connie will provide me with a copy of the transcript of the interview so I have the opportunity to change or add to the interview transcript in any way that will accurately reflect my practice.

The interview will take approximately one to two hours and will be held at a time and place of convenience to me. I consent to having the interview taped and transcribed by a typist. I know that I can request that the tape recorder be turned off at any time during the interview and have the tape erased if I am uncomfortable with any of the information that is on the tape.

I understand that my identity will be protected throughout the study. My name or any other potential identifying information, such as the institution in which I practice or the names of people with whom I work, will not be mentioned in any oral or written materials. In addition, the names of those who participate in the study will not be revealed to one another. The tapes will be kept in a secure place and erased at the completion of the study. Connie and a typist will be the only ones to have access to the tapes. Transcripts of tapes with all identifiers removed will be retained for possible further analysis and will be destroyed when such analysis is completed or at the end of five years, which ever is sooner.

I understand that the findings from the study will be reported in Connie’s doctoral dissertation, in professional publications including on-line journals, at professional conferences and at local nursing interest groups. In addition, I understand that the findings may be used for teaching purposes as well as in written briefs to appropriate government ministries and health employers to provide research-based information for policy decisions. I understand that I will be offered a copy of the findings.
I understand that my participation in this study is completely voluntary and that I can withdraw from the study at any time or refuse to answer any questions. I understand that there are no known risks to participating in this study. I further understand that the potential benefits include the opportunity to reflect on the contributions I make to the delivery of community-based health care for children and families; the potential of furthering the role of nursing by providing data on the ways in which I contribute to the organization and delivery of community-based health care, and participating in research that can ultimately contribute to the improvement of community-based health services for children with complex health needs and their families.

I understand that if I have any concerns about my rights or treatment as a research participant. I may contact the associate vice-president of research at the University of Victoria at 250 472-4362.

My signature below indicates that I have agreed to be in the study and that I have received an information letter about the study and a copy of this consent.

Signature of Nurse Participant ___________________________ Date ______________

Signature of Researcher ___________________________ Connie Canam
Appendix C

Demographics of Nurses

Current position

Years employed in current position

Years employed as a nurse

Educational Preparation

Nature of chronic health conditions children have

Nature of setting

Frequency and nature of the contact with children and their families
Appendix D
Interview Guide

Orienting Statement
As you know I am interested in your practice and the ways in which you contribute to the health care of children with complex health needs and their families within the community. More specifically, I am interested in understanding the knowledge you draw on in your practice and how that knowledge directs your actions in the provision of health care. Also, I am interested in your perceptions of the factors that influence your practice and your ability to contribute to the health care of children and families. I will begin by asking you about the client group within your specialty. This will provide the context for the discussion of your practice and the knowledge you draw on to guide your decisions/actions.

Questions
1. Tell me about the client group within your specialty.

Probes:
- What are some of the problems or concerns that you see as unique to this population?
- Can you talk about a particular child and family that illustrates the impact of these problems?

2. Tell me about your practice.

- Think about a time within the last few months when you felt a sense of accomplishment in your practice because you were able to provide the health care you thought was needed. Tell me about that.
- Think about a time within the last few months when you felt a sense of frustration in your practice because you were not able to provide the health care you thought was needed. Tell me about that.
Probes
- What are some of the challenges you encounter in providing health care for children and their families?
  - Can you talk about a particular child and family that illustrates your response to a challenging situation?
  - Can you talk about a particular child and family where you feel you made a difference?
  - Tell me about a challenging decision that you recently had to make.

3. Describe a typical work day?

  Probes:
  - What activities occupy the greatest amount of your time?
  - How much of your practice is direct contact with families?
  - What do you see as the most significant aspect of your work?
  - What are the most rewarding aspects of your work?
  - What are the most frustrating aspects of your work?
  - What is the biggest challenge you are currently facing in your practice?

4. Tell me about working with other members of the health care team?

  - What is unique about your role as compared to other members of the health care team?
  - How does this differ from the contribution that other members make?
  - How would you describe your interactions with other members of the team?
  - What facilitates or constrains these interactions?
  - Can you tell me about a particular situation in which your contribution stood out as unique from that of other members of the health care team?

Is there anything else about your practice that we have not discussed that you think is important?
Appendix E

The Place of Advanced Practice Nurses in the Community-Based Health Care of Children with Complex Health Needs and Their Families

Researcher: Connie Canam, RN, MSN
Supervisors: Dr. Anita Molzahn, Dean, Faculty of Human and Social Development, UVIC and Dr. Colleen Varcoe, Associate Professor School of Nursing, UVIC

Information Letter for Nurses Responding to Transcripts

Enclosed is a copy of the transcript from our conversation. Please read through it as a whole and think about whether it captures a) your practice, b) the knowledge that informs your practice and c) the factors you see as influencing your practice.

If you would like to clarify, change, or comment on anything either of us said, feel free to write directly on the transcript.

In addition, if you would like to add something that you think would further capture your practice and/or your contributions to health care, please do so. You can write this on an additional piece of paper (attached to this letter).

Finally, I would like your comments on the factors you think most enhance or limit your ability to practice in the way you would like to.

Thank you for your willingness to participate in this process. I hope you enjoy reading your transcript and reflecting on your practice. My goal for this study is to clearly articulate to policymakers, health care professionals and the public what it is that advanced practice nurses do and the ways in which they contribute to the organization and delivery of community-based health care for children with complex health needs and their families. Your input is invaluable in capturing and articulating this.

Could you return this to me in the self-addressed, stamped envelope I have included.

If you have any questions about this process, you can reach me by phone or e-mail. Phone (604) 822-7494 or E-mail – canam@nursing.ubc.ca

Thanks again and I look forward to your comments.

Sincerely

Connie Canam, RN, MSN
University of Victoria - Human Research Ethics Committee

Certificate of Approval

Principal Investigator
Connie Canam
Graduate Student
Co-Investigator(s):

Department/School
HUMA

Supervisor
Dr. Anita Molzahn
Dr. Colleen Varcoe

Title: Advanced Practice Nurses' Experiences in the Provision of Community-based Health Care for Clients with Chronic Health Conditions

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Certification

This is to certify that the University of Victoria Ethics Review Committee on Research and other Activities Involving Human Subjects has examined the research proposal and concludes that, in all respects, the proposed research meets appropriate standards of ethics as outlined by the University of Victoria Research Regulations Involving Human Subjects.

J. Howard Brunt
Associate Vice-President, Research

This Certificate of Approval is valid for the above term provided there is no change in the procedures. Extensions/minor amendments may be granted upon receipt of "Request for Continuing Review or Amendment of an Approved Project" form.