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Exploring Perceptions of School-Age Children with Bleeding Disorders and Other Chronic Illnesses: Partnership Roles in Family Centred Care

by

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Abstract

My primary objective for this study was to explore how children between 7-11 years, who have a bleeding disorder or another chronic illness, understand their partnership role in family-centred care (FCC). I also examined the institutional context in which FCC occurs, and developed strategies with children to enhance their partnership role. I carried out this systematic ethnography in three phases: (phase I) unstructured interviews with children explored how they understand their partnership role in FCC; (phase II) document review provided legal and institutional context to appraise how this matched with children's perceptions; and, (phase III) validation interviews with children for member checking and creation of recommendations supporting children's partnership role. This study took place within the catchment area served by the Alberta Children's Hospital (ACH). Interviews took place at ACH or at the children's home based on family preference. In phase I, I used purposive sampling to recruit eight children who were living with a bleeding disorder (n=4) or another chronic illness (n=4), and were on the caseload at an outpatient specialty clinic at ACH. In phase II, I retrieved archives from public sources including institutional policies and legislation, and examined how these documents were aligned with children's understanding of their partnership role in FCC. In phase III, I recruited three children from phase I for validation interviews and generation of strategies to support their understanding of FCC. I carried out data analysis and collection using domain analysis (Spradley, 1979) and qualitative ethnographic content analysis (Altheide, 1987) while adhering to *trustworthiness* criteria (Lincoln & Guba, 1985). Phase I outcomes included seven key domains regarding how children understand their role as partners in family-centred care: *my best interests, virtues, talking* *and listening, being involved; knowing, making decisions, and being connected.* Phase II outcomes revealed how these seven domains were represented in legal and institutional contexts. Phase III outcomes included children's confirmation of domains and generation of key strategies to support their role as family-centred partners in bleeding disorder and chronic illness care: *graphic representation of FCC as a treasure map, interactive workshop, and online game.*

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List of Symbols, Abbreviations and Nomenclature

Abbreviation	Definition
ACH	Alberta Children's Hospital
CAYAC	Child and Youth Advisory Committee
CHR	Calgary Health Region
ECA	Ethnographic Content Analysis
FCC	Family-Centred Care
SACHYN	Southern Alberta Child and Youth Network
UofC	University of Calgary

CHAPTER 1: STUDY OVERVIEW

Introduction

While much has been written about partnerships in family-centred care for children with chronic illness, the literature appears to be parent-centred rather than family-centred with a focus on parent and provider experiences. Family-centred care (FCC) refers to an approach to healthcare that includes four key elements. First, people are treated with *dignity and respect.* Second, healthcare providers promote communication and *information sharing* with families in ways that are affirming and useful. Third, *participation* in experiences enhances families' strengths, control, and independence. Fourth, *collaboration* among patients, families and providers occurs in policy and program development, professional education, and the delivery of care (Institute for Family Centered Care, 2008; Johnson, 2000).

Given these key elements, it seems reasonable to assume that children have a part within FCC. However, it is also possible that children's role as collaborative partners is confounded by the dominance of parents, professional caregivers, and healthcare system processes. Partnership roles within FCC support "a relationship in which participants join together to ensure healthcare delivery is provided in a way that recognizes the critical roles and contributions of each partner in promoting health, preventing illness, and managing healthcare conditions" (Ball & Bindler, 2006, p. 13). In considering this research, I stared with an assumption that if children with chronic illness are to be partners in long-term self-care, they should develop some measure of awareness or participation as they grow up. When I looked at the literature I found that children's roles in self-care and FCC were poorly understood as little empirical work examined this from a child's perspective. This seemed to be an important consideration given that the determinants of health are based on personal care practices, beliefs, and experiences (Commers, 2002; World Health Organization, 2008). If we are to support children's health and partnership in FCC, we need a better understanding of what their practices, beliefs and experiences as healthcare partners means to children themselves. If we solely focus on the role of parent as decision-maker for their child, then we may miss out on the opportunity to facilitate children's emerging role as active partners in their healthcare. This is an important area of inquiry because if we promote children's health and self-care as a foundation for their future, we may also enhance their quality of life and reduce the related economic burden of chronic illness on our healthcare system (Canadian Nurses Association, 2002).

Professional Practice Considerations

In my work as a hemophilia nurse clinician, children often presented with symptoms of internal bleeding that were spontaneous (no related injury) and invisible (no outward signs). The practice standard was to listen to and believe the child; this approach was deemed safe and effective as not treating an internal bleed may result in life or limb threatening consequences (Association of Hemophilia Clinic Directors of Canada, 1999; Canadian Hemophilia Society, 2001; Sangostino, Gringeri & Mannucci, 2002). Believing the child's reports is understood as an important feature of hemophilia care as bleeding symptoms may be internal and therefore invisible to those assessing them. Thus, from an early age children have been treated as partners by hemophilia care professionals and taught how to recognize symptoms of bleeds, report related concerns to the caregivers, and assist with intravenous infusions of missing factor concentrates that will control their bleeding. However this did not necessarily extend to other aspects of children's care coordination and planning as outpatient clinic visits would quite often be dominated by parents and multidisciplinary providers who managed the child's healthcare plan. This overall approach to children's healthcare had glimmers of FCC partnering, but key elements of FCC were not fully recognized in practice. This experience made me wonder if the children from my hemophilia clinic shared similar experiences with children with other chronic illnesses. I wondered if children with various chronic illnesses faced similar challenges of being heard in care planning despite their emerging and important healthcare related responsibilities.

The current focus in youth self-care at the Alberta Children's Hospital (personal communication, Catherine Dunseith, December 20, 2007) is with adolescents whose unique developmental stage is characterized by challenges associated with minimizing health issues in an effort to develop their identity and fit in with typical peers (Ball & Bindler, 2006). Given challenges in this developmental stage, it seems reasonable to consider a more upstream approach by exploring how younger children understand their role in healthcare partnerships. Exploring partnerships with children at a younger age is beneficial so that their emerging chronic illness self-care roles may be understood and established at an earlier stage. School-age children may provide a valuable contribution to understanding pediatric partnership roles in FCC since they have the capacity to think logically, and their heightened sense of personal industry and initiative may be capitalized on (Ball & Bindler, 2006). This suggestion raised questions for me regarding the traditional role of parents and healthcare providers as responsible authorities over children. I wondered if children's partnership potential may be challenged by our societal beliefs on the role of the school-age child within the family and healthcare system, and if children's capacity to participate as partners is acknowledged, respected, and facilitated. I believe that the notion of principled adult jurisdiction does not fit with key elements of FCC and supporting children's developing self-care capacity. FCC requires that families and providers treat each other with mutual respect and dignity, share meaningful information, participate, and collaborate in healthcare (Institute for Family Centered Care, 2008). Assuming that children were included within the definition of family, I was surprised that I could not find evidence in the literature to support how FCC takes place with children as family-members in FCC self-care partnerships. Rather what I had read and observed in my own clinical practice did not reflect mutual respect, information sharing, participation, or collaboration as FCC was practiced by adults on behalf of children as passive recipients of care. Therefore a reasonable place to begin my doctoral work was to consider children's own perceptions of what FCC partnership means to them, what shape it takes, and how it is supported or not supported within the healthcare system.

Study Purpose

FCC is a prevailing vision in pediatric healthcare planning, yet this may not be lived out as an integrated practice. While the FCC concept has been well developed from an adult perspective and has been identified as a priority in healthcare delivery (Institute for Family Centered Care, 2008), there is no research-based evidence on children's understanding of their role in FCC available. If FCC is about mutually beneficial partnerships, then we need to know how to partner effectively with children in FCC. Children with chronic illness such as bleeding disorders must often learn to manage their own condition in order to develop effective health and coping skills as they mature. Given this gap in our knowledge, a systematic exploration of how children understand their role in FCC was required to develop evidence-based strategies that reflect and respect children as active partners in their chronic illness experience. Children's understanding of their partnership roles in FCC has not yet been reported; therefore this was the focus for my study.

Background

Children who have a medical condition that lasts longer than three months and is characterized by repeat assessment and treatment through home or school-based care, inpatient or outpatient hospital admissions and disruption to family life are defined as having a chronic illness (Ball & Bindler, 2006; Faux, 1998; Sartain, Clarke, & Heyman, 2000). Children are affected wholistically by chronic illness that may interfere with achieving developmental milestones ranging from physical to emotional, cognitive, social, and spiritual. This broad notion of how chronic illness interferes with children's development is considered for those with clotting disorders associated with poor clotting and continuous bleeding such as hemophilia, vonWillebrand disease, and other inherited platelet dysfunctions (National Hemophilia Foundation, 2005). Children with such life-long bleeding disorders must learn to manage their own condition in order to develop effective health and coping skills as they mature. This requirement is similar for children living with other long-term conditions, and thus it is important to extend this inquiry to different chronic illnesses to broaden our understanding of the topic. How children's partnership roles develop in bleeding disorder and other chronic illness care is an important area of inquiry as children with long-term conditions require support to develop progressive participation in their own self-care (Canadian Nurses Association, 2002).

My own clinical experience provided the context for thinking about this as a research problem. During my master's coursework, one of my clinical placements involved observing children's FCC experiences at the Alberta Children's Hospital. Since I had over 15 years of experience as a nurse at that institution, I was encouraged to take this placement as an opportunity to step back from my typical clinical practice, and learn about FCC through participant observation with a wider population of children, families, and health care professionals in the hospital and community setting. The bulk of my time was spent with inpatient children, families, and Child Life Specialists in the playroom at ACH. This was determined to be the best place to focus my learning as the Child Life team were experts in developmentally appropriate communication, collaboration, and coping through play with children. Furthermore, my mentor who was an administrative leader at ACH recognized that children and family's experiences with Child Life Specialists reflected fundamental FCC practice.

During this time, I had numerous conversations with children about their experiences with illness and health care. Many of these children had a chronic condition and received ongoing support through various inpatient, outpatient and community-based programs. I was surprised to hear from the children that they did not see themselves as central in their care as they described their parents and providers being "the most important." Nonetheless, children reflected on their remarkable illness experiences and relationships shared with parents and health care professionals. I felt that it was important to explore the children's view of their role in FCC, as I believed this would provide greater understanding regarding their own health beliefs and behaviours.

In reflecting on what the children told me, I used the literature to help me understand their experiences. However, the perspective of children regarding their care was only located in a few articles. As I did not locate any conceptual or research literature on children's perspectives of what FCC means to them, I realized it would be worthwhile to study children's views about their role in FCC. Furthermore, since children with chronic illness have long-term issues, I felt it was important to focus on this particular group given their ongoing illness experiences and FCC encounters. School-age children between 7-11 years of age were identified as a preferred study group as they have "logical thought processes and are learning about their bodies" (Ball & Bindler, 2006, p. 461). This suggested that this age group would have the capacity to engage in conversation about their chronic illness and how they understand FCC. The school-age child's developmental tasks include Erickson's psychosocial stage of industry, and Piaget's cognitive stage of concrete operational thinking (ability to solve problems and consider alternatives with constructive development of logical and moral thinking), self-concept, self-esteem, self-regulation, cooperative play and relationships (p. 160-163). School-age children are capable of logical thinking about their partnership roles and are typically interested in learning about their health experiences, yet no literature was located regarding how this group understood their partnership roles. Thus, I recognized that school-age informants would provide a fitting first glimpse into how children understand their partnership role in FCC.

Overview Summary

In Chapter 2, I provide a review of the literature starting with FCC theory and practice, and how this aligns with philosophical underpinnings regarding Dewey's pragmatism and children's autonomy including school-age children's cognitive and moral development; this review extends to FCC with children who have a chronic illness (including bleeding disorders) and alignment with systematic ethnography. In Chapter 3, I discuss all three phases of the research process including ethnographic method, participants, data collection, analysis, and ethical considerations including conducting research with children. In Chapter 4, I provide a detailed overview of findings from all three phases; this includes a reflexive examination of school-age informants, context, results, and development of subsequent research stages with a section specific to unique issues associated with interviewing children. In chapter 5, I discuss findings including study limitations and implications for practice, theory development, and future research related to FCC and children's partnership role in their chronic illness care. In chapter 6, I summarize my study and answer research questions. In chapter 7, I share my experiences on presenting study findings and how children's recommendations have been received.

CHAPTER 2: LITERATURE REVIEW

Search Background

I conducted this review of literature using a variety of online databases, including *Academic Search Premier, CINAHL, Medline, Philosopher's Index, PsycINFO,* and *Web of Science*. Search terms included both Medical Subject Headings (MeSH) and other key words related to the topic of interest. MeSH terms included *hemophilia* (bleeding disorder, vonWillebrand disease, platelet dysfunction, Glanzmann's thrombasthenia), *chronic illness* (condition, disease), *children* (childhood, school age, pediatric), *consent* (informed consent, assent), *autonomy* (personal autonomy, self-determination, decision making) and *children* (childhood, school age, pediatric). Searched key words included *family-centered care* (child-centred care, partnership, partner).

Although there were many conceptual and research articles on various aspects of pediatric FCC, I was not able to locate any studies that reported children's perspective of their own partnership role. In fact, I did not locate articles that considered children's partnership role in FCC from any perspective. I found this gap in the literature interesting since FCC was cited as a common approach in pediatric institutions. Given that children's partnership roles in FCC had not been addressed directly, I examined related literature to enable development of a framework for this study. In the forthcoming sections, I will start with a discussion of FCC theory and practice, followed by philosophical underpinnings (including pragmatism and autonomy) and pediatric chronic illness experiences (including perspective) in relation to children's partnership role in chronic illness. These three key areas will then be connected to the subsequent research problem, purpose and process.

FCC Theory

FCC is an "an innovative approach to planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families" (Institute for Family Centred Care, 2008, ¶1). As mentioned in chapter 1, the key elements of FCC include *dignity and respect*, *information sharing* that is affirming and useful, *participation* in care based on strengths, and *collaboration* among families and providers in care delivery, program development, and professional education (Johnson, 2000, p. 14). FCC developed from the assumption that the family is central and should be supported in promoting the health and well-being of the child (Ahmann, 1998; McKean, Thurston, & Scott, 2005; Nijhuis et al., 2007; Shields, Pratt, & Hunter 2006). Canadian research regarding family-centred services identified parents as experts with responsibility for their children's care in partnership with professionals (King, Rosenbaum, & King, 2004; Rosenbaum et al., 1998).

Attributes and Antecedents of FCC

Attributes of FCC include "respect, strengths, choice, information, support, flexibility, collaboration, and empowerment" (Institute for Family Centered Care, 2005, ¶ 4). These attributes were located in conceptual (Bradley, 1996; Johnson, 2000) and research literature (Dunst, Boyd, Trivette, & Hamby, 2002; Hutchfield, 1999; McKean, Thurston, & Scott, 2005). Antecedents of FCC include attitudes and institutional supports. Required attitudes for FCC include beliefs, family orientation to care delivery and collaborative practice, and institutional supports include adequate time and facilities for family learning and participation in care (Hutchfield, 1999).

Research regarding beliefs (King et al., 2003) and perceptions (Shields & Tanner, 2004) confirmed the above stated key elements of FCC and revealed how parents and providers understand attributes and antecedents of FCC. Parent perceptions of FCC may be quantified with the MPOC-20 (Measure of Processes of Care) (King, Rosenbaum, & King, 2004) for children's care covering all ages and diagnoses in five essential areas: "enabling and partnership, providing general information, providing specific information, coordinated and comprehensive care, and respectful and supportive care" (p. 41). Shields and Tanner (2004) developed and piloted a questionnaire that compared parent and provider perceptions of FCC in the inpatient and outpatient hospital setting. Authors found no statistically significant differences between parent and provider responses in key areas of respect, collaboration, and support. While parents and providers alike recognized parents as the "primary care giver" (p. 194), staff indicated that they had comparatively less confidence than parents in their collaborative practice as partners in children's care. This disconnect was associated with parents feeling more independent than what was recognized by providers, thus indicating a need for further inquiry regarding the complexities of family self-care in areas such as FCC of chronically ill children.

Families and Providers in FCC

Within a FCC approach, the family is understood as being "two or more persons who are related in any way – biologically, emotionally, or legally (....) with the family as a fundamental element of care (....)[and] the unit of intervention" (Institute for Family Centered Care, 2008, ¶ 6). This broad notion of family has been described as persons who are significant in the life of the child regarding "social roles.... and customs" (Shields, Pratt, Flenady, Davis, & Hunter, 2004, p. 6) such as foster parents, extended family, and close friends. Since the fourth key principle of FCC is collaboration, the relationship between family and health care professionals is also considered essential to the development of mutual dignity and respect between family and care providers (Institute of Family Centered Care, 2008).

Parent-provider collaborative partnerships in children's health delivery present challenging professional and ethical issues related to family participation in care and decision-making (O'Haire & Blackford, 2005; Callery & Smith, 1991). In order to support effective collaborative practice, provider preparation through interprofessional and patient-centred education was identified as a priority by Health Canada (Curran, 2004). A review of qualitative studies on FCC done by Shields, Pratt, and Hunter (2006) highlighted the tension between parents and providers regarding differences in beliefs, roles and subsequent children's care negotiations. Authors summarized that the tension around such differences had both emotional and financial costs for parents and providers alike. Eleven qualitative research studies were located ranging from phenomenology, grounded theory, thematic analysis, participant observation, and content analysis. Within this review, no research studies were located that invited the perspective of children in FCC. While the parent's role as the family representative was articulated in the literature, it was not evident how children's roles as family members factored in with FCC. This was an important consideration given that the underlying purpose of FCC is to facilitate children's health.

Situating FCC

Research indicated that FCC was evident in acute and community-based health care (Shields & Tanner, 2004). However, there was a broader question about how FCC was situated with regard to country and culture given that development of FCC concept and practices was primarily within high income developed countries such as Australia, Canada, United States and the United Kingdom. A rigorously developed questionnaire on FCC attitudes was developed and given out to 80 parents and 80 health care providers at four different sites with a response rate ranging from 83-100%. This questionnaire was completed by nurses, doctors, allied health professionals and parents from developed countries (United Kingdom and Australia) and developing countries (Thailand and Indonesia). Findings regarding attitudes on children's hospital care revealed that the "basic concepts of family-centred care [were] similar" (Shields & Nixon, 2004, p. 475); this related to effective communication and respecting the family as a whole. While this research indicated that FCC might be viewed as an international consideration for children's health care, current understanding of FCC is situated from a predominantly Western society perspective.

FCC Practice

From a *practice* perspective, FCC "requires a shift in the orientation of health services from a professionally-centred model to a collaborative model" (Shields et al., 2004, p. 3). In her conceptual article, FCC scholar Elizabeth Ahmann (1998) stated that a number of approaches, including professional-centered, child-centred, family-focused, and family-centred, have been used in describing how to practice in children's health care. According to Ahmann (1998) the "professional-centred" (p. 468) approach is akin to the traditional medical model whereby health professionals provide expert knowledge-based services that focus on illness management with little regard to family capacity or collaboration. In the "child-focused model" (p. 468) the child's wholistic needs are considered from a professional-centred approach with the expectation that families will follow through on directives. "Family-focused" (p. 468) care regards the family as important in care yet the family is not part of the decision-making process as care continues to be directed by professionals. In the mid 1990's there was an apparent shift to "family-centred care" (p. 468) whereby the focus was on family capacity, and professionals and families worked as collaborative partners in health care assessment, planning, and policy development.

Authors have begun to discuss family capacity in FCC through parent empowerment interventions (Ogden, Forgatch, Askeland, Patterson, & Bullock, 2005; Dunst, Trivette, Davis & Cornwell, 1988) and "relational participatory" (Dunst, Boyd, Trivette, & Hamby, 2002, p. 221) practices between parents and professionals that built on effective collaboration through communication skills, trust, and respect (Gottleib, Feeley, & Dalton, 2005; Blue-Banning, Summers, Frankland, Nelson, & Beegle, 2004). A series of six conceptual articles on family roles in FCC published in *Pediatric Nursing* between 2006-2007 focused on anecdotal reports by parents and their role in children's care (Dokken & Ahmann, 2006; Dokken, Moretz, Black, 2007; Dokken, Simms, & Cole, 2007; Landis, 2007; Siems, 2007; Williams, 2007). While FCC was founded on notions of collaborative practice between family and health care professionals, the emphasis of FCC in the literature revealed repeated examination of parent-provider relationships with the child as the passive recipient of care.

Rationale for FCC

The Institute for Family Centered Care (2005) claimed that FCC leads to "better health outcomes and wiser allocation of resources, and greater patient and family satisfaction" (¶ 3). Improved health outcomes for children reported in the research literature include enhanced therapeutic interventions through parent education and involvement (Prizant, Wetherby, Rubin, & Laurent, 2003). FCC has also been shown to be associated with decreased parent anxiety stemming from family-to-family peer support (Ireys, Chernoff, Stein, DeVet, & Silver, 2001). While parent satisfaction was related to FCC health care delivery in the acute care setting (Bruns & Klein, 2005), healthcare professionals' satisfaction also increased with the implementation of FCC practices given the related "culture of support" (Hemmelgarn & Dukes, 2001, p. 107). A Cochrane systematic review was completed to determine the wide scope of outcomes associated with FCC for children, parents, and providers as overall effectiveness of FCC has not been measured (Shields, Pratt, Davis, & Hunter, 2007). Of interest, these authors were unable to locate any studies that met their selection criteria for randomized or quasi-randomized control trials comparing professionally-centred care with FCC of hospitalized children up to 12-years of age. Their findings revealed an apparent lack of quantified data regarding FCC. Thus, while isolated studies point to the effectiveness of FCC, we do not have a systematic understanding of FCC related outcomes.

Who is Central in FCC?

FCC as presented in the literature appears to start with the assumption that parental involvement and presence are important, and the belief that parents "should have ultimate responsibility for the care of their children" (Rosenbaum, 1998, cited in Franck &

Callery, 2004, p. 267). The child is considered in context of the family, yet his or her role as an individual person appears not to be recognized. This is problematic given that parents and children do not necessarily have converging views regarding children's health experiences. Research with 92 school-age children revealed a negative correlation between children's ability to communicate their condition and parental rating of good health; those children with high emotional and communication skills rated their own health "better" while parents' reported their children's health as comparatively "worse" (Meade, Lumley, & Casey, 2001). This raises the question regarding the accuracy of parents' speaking on behalf of the child and representing the child's experience in healthcare. Furthermore, proponents of FCC assume that children's coping is enhanced by parent presence (Institute for Family Centred Care, 2008). However, some controversy exists in this claim since a recent extensive literature review on children having medical procedures with and without parent presence revealed that parent presence was helpful for parents, but did not make a difference regarding the distress experienced by the children themselves (Piira, Sugiura, Champion, Donnelly, & Cole, 2005).

Summary of FCC

While foundational elements of FCC were explicitly articulated in the literature (Institute for Family-Centered Care, 2008; Johnson, 2000), interpretations straying from this foundation created barriers to implementation. Non-congruence between tenets of FCC and application to practice was noted regarding parent participation as collaborative care partners (Bruce et al., 2002; Bruce & Ritchie, 1997). While there was an abundance of empirical work around parent and provider understanding and experiences with FCC (Galvin, Boyers, Schwartz, & Jones, 2000; McKean, Thurston, & Scott, 2005; Miceli &

Clark, 2005; Shields, Pratt, & Hunter, 2006; Shields & Tanner, 2004; Smith & Daughtrey, 2000; Swallow & Jacoby, 2001), there was a stunning absence of empirical literature regarding children's views about their own role in FCC. Most studies were qualitative and samples were representative of parents and providers. In a critical review of FCC theory, child health nursing scholars Franck and Callery (2004) suggested that children be involved in their health care planning and that this be considered in conjunction with parent views to better represent the perspective of all family members. Hence, I raised the question whether FCC was truly a reflection of the whole family, or if this instead represented an adult-in-charge perspective of family guardians and health professionals. This way of thinking required further inquiry regarding philosophical beliefs about children's roles in FCC.

Philosophical Underpinnings

In order for FCC to be applied, I reasoned that corresponding ways of *being* and *knowing* were required to support this approach in practice. While many philosophical views were fitting with the FCC key elements, I concluded that Dewey's pragmatism was closely aligned with this approach. Pragmatism assumes a contextual worldview whereby persons are continually interacting with the environment regarding their wholistic physical, mental, and social dimensions (Dewey, 1925a/1998; 1925b/1998); furthermore, this view is consistent with the World Health Organization (2008) definition of the determinants of health. The philosophy of classic American pragmatism was founded on the notion that meaning is formed by practical consequences from past experience or from those "experiences to be expected" (Peirce, 1902/1972, p. 300). Pragmatism thus provides a way of seeing the world from a dynamic view, knowing from learned experiences, and guiding future action based on reflection. These features are appealing given the promise of accord when applying FCC theory and pragmatic philosophy combined in practice. FCC and pragmatism both promote opportunity for children, families and providers to be regarded as collaborative, reflective partners who learn from experiences and each other in a responsive manner (Hartrick-Doane, 2003). Application of pragmatic philosophy to FCC is about the "possibilities, creativity and freedom" (p.29) to respect the dynamic view of all partners, share meaningful information, welcome participation of all members, and enhance collaboration in future healthcare planning. This is anchored in pragmatic ways of being and knowing and upholds key elements of FCC. Pragmatism also informs understanding of children's autonomy as a significant feature of children's partnership roles in FCC. I will review literature findings on these topics within this section on philosophical underpinnings.

Pragmatism and FCC

What are the Ways of Being in Pragmatism and FCC?

A dynamic *way of being* is supported by the pragmatist notion that beliefs are culturally situated, the value of beliefs is determined within a particular cultural group, and beliefs may change when challenged through practical consequences (Dewey, 1925c/1998). Pragmatist ontology may be summarized in Dewey's (1925a/1998) statement that "qualitative individuality and constant relations, contingency and need, movement and arrest are common traits of all existence. This fact [is] source both of values and of their precariousness" (p. 91). The pragmatist views the world as made up of experiences arising from the interaction of humans with the natural environment. "*Qualitative individuality*" refers to how experiences are "discriminated, (and) make sense" (Dewey, 1925c/1998, p. 139) as a real experience is continuous between an individual and the environment. Thus, reality exists within and beyond the mind in the natural world. As all parts of an experience dynamically connect through "*constant relations*", there is a rejection of mind/body dualism. This claim is supported by Dewey's (1896/1998, p. 4) argument that stimulus and response do not exist as a passive one-way "reflex arc", but rather as a continual "circuit" (p.6) that is responsive and interactive within the wholistic mind and body. Furthermore, the world is transitory as it is shaped by *"contingency and need"*; in other words, beliefs change when challenged through experiences and consequences indicating that such beliefs are no longer meeting our needs (Dewey, 1925c/1998, p.136). "*Movement and arrest*" suggest that interactions are modified to seek balance through a process of "active equilibrium" (p. 136). Finally, *"values and (...) precariousness"* indicate that our beliefs are not fixed, but instead contextually guided based on our experiences; hence, the truth is not a fixed principle to be adhered to, but rather is situated within a context. Thus, the pragmatist views humans as adaptable, active individuals who are continuous with nature, and exist within reality that is "multidimensional, context dependent, and relative" (Fawcett, 2005, p. 13).

The pragmatist *way of being* upholds the four key FCC elements (Institute for Family Centered Care, 2008) in practice given that pragmatism views truth as not fixed within a particular theory or person; rather, truth is recognized as fluid and understood from multiple perspectives. In this respect pragmatism invites collaborative partnerships so that truth may be understood in a particular way within a particular context. This gives possibilities for "dignity and respect" for all healthcare partners, as pragmatist truth recognizes all contributors within a context. This *way of being* supports "information sharing" because truth may be fully understood when critical appraisal of ideas is shared amongst persons. "Participation" would be thus enhanced since multiple perspectives are heard in this process of understanding contextual truth. Finally, "collaboration" may be supported because upholding key elements of FCC regarding "dignity and respect, information sharing and participation"(Institute for Family Centered Care, 2008) creates an opportunity for collective "forms of moral action that are creative and tailored to fit particular situations" (Hartrick-Doane, 2003, p. 29). This fluid notion of truth in pragmatism and FCC also provides opportunity to construct the flattened hierarchies that we strive for in collaborative partnerships and interdisciplinary healthcare (Orchard, Curran, & Kabene, 2005). Truth is recognized when a person looks at the practical aspects of a situation, and how this may inform our current and future practice (Hartrick-Doane, 2003). This *way of being* supports complementary *ways of knowing in* pragmatism and FCC.

What are the Ways of Knowing in Pragmatism and FCC?

From a constructivist approach, knowledge development begins when one faces a situation that confronts previously held beliefs, and then engages in a process of inquiry to reform beliefs (Dewey, 1925a/1998). Pragmatists believe that it is essential first to clearly understand and make distinctions about the object or experience. Thus, a shared understanding through respect for others, meaningful information sharing, and participation and collaboration (Institute for Family Centered Care, 2008) is required in a context that invites multiple perspectives. In pragmatist knowledge development, truth is not in the object itself, but rather is interpreted as a dynamic quality situated in context or experience actively understood through reflection of "relationships, conditions, and consequences" (Dewey, 1925a/1998, p. 88). Knowledge may be judged for its effectiveness in application (Dewey, 1925d/1998). From this view, there are two key facets within pragmatism that support *ways of knowing* in FCC through an active problem solving process of practical consequences: *symbols and reflective thinking*.

Symbols. Experiences are based on transactions between persons and the environment. The formation of meaning in these transactions may be understood through *symbols*, which form the basis of the language, that persons use to communicate. Interpretation of symbols allows persons to maintain connections and share information by creating and communicating meanings (Dewey 1927/1998, p. 296). Meanings are not recognized in the object itself, but rather, when an object is experienced it is identified and represented in the mind as a meaningful symbol (Dewey, 1925b/1998, p.50; Prus, 1996). Hence, the meaning of communication in FCC may be interpreted directly from the experience and "by the context of other symbols in which it occurs" (Dewey, 1931/1998, p. 207). Individual and shared experiences by all persons in FCC are based on continually mediated interactions and understanding.

Reflective thinking. Dewey believed that our understanding of causality was of great importance given that this awareness allows persons to modify their world (Dewey, 1925c/1998; p.140). He regarded systematic inquiry as an effective process to support pragmatist problem-solving that may be applied in everyday practice situations. While the emphasis was on actively learning through direct observation, persons may use *thought experiments* to test hypotheses through discussion (Dewey, 1925b/1998, p. 50). This is possible given that observations include those directly taken in by the senses and those recalled from past experiences (Dewey, 1933, p. 137). Dewey believed that knowing is realized through the *reflective thinking* process stages that include "*suggestions, problem identification, hypothesis, reasoning, hypothesis testing*, [and] *future reference*" (Dewey, 1933/1998, p. 137-143).

In making links between pragmatism and FCC, collaborative care partners may engage in the reflective thinking process by first reacting to the event or object with colliding ideas or *suggestions* to remedy the problem (p. 139). Then, preliminary *problem identification* begins through an examination of the purpose, abilities and limitations in connection with the conditions of the experience (p.139). While the first stage is reactive, the second stage of "intellectualization" (p. 140) promotes deliberate control of the problem solving process. Third, a person may generate a possible solution or *hypothesis* through problem exploration that gives deeper insight through information gathering (p. 140). In the fourth stage, a person focuses on *reasoning* with regard to connections between observations and ideas, and thinking about possible outcomes associated with the hypothesized solution (p. 141). In the fifth stage, the person uses *hypothesis testing* to evaluate the solution with regard to intended and unintended consequences of the action (p. 142). If a useless or ineffective consequence results, then further reflection is required to review this thinking process and explore what may need to change. In the sixth and final stage, the person reflects about the process as a *future reference* for thinking and action in a similar situation. While these stages are presented in sequential order, they are not consecutively fixed because knowing is regarded as an iterative process (Dewey, 1933, p. 132). This reflective way of knowing is a similar problem-solving process used by both school-age children (Calgary Board of Education, 2007; Center for the Study and

Prevention of Violence, 2006) and healthcare providers in evidence-based practice (Flemming, 1998).

Pragmatism and FCC in Practice

Pragmatist philosophy matches FCC in that the nature of our *being* is active, and that through our interactions we share a dynamic connection. We must first understand the qualities of our shared experience to ensure that our efforts are not misled; this understanding is supported by the key elements of FCC (Institute for Family Centered Care, 2008) given that the accuracy of our shared understanding requires mutual respect, meaningful information sharing, participation and collaboration with all partners. Through these connections, we may adapt and change our beliefs and knowledge when causality is understood through actions and practical consequences. While pragmatism and FCC are congruent, the notion of children as partners in care may not be so easily accepted given issues related to autonomy and informed consent. Hence, I will now explore these concepts.

Autonomy and Informed Consent

Current understandings of children's autonomy appear to be rooted in the same pragmatic philosophy that underpins FCC. I will first explore different ways that childhood is understood in the ethics literature. The current dominant view of children's autonomy was noted in bioethics principles (Beauchamp & Childress, 2001) based on Kantian philosophy. I suggest that pragmatist and feminist philosophical approaches provide a more fitting alternative regarding relational autonomy of the child in FCC. Furthermore, since notions of maturity and competency may serve as indicators for autonomy, these concepts are key to understanding how we view children's capacity to participate in FCC. This notion of maturity is recognized in Piaget's cognitive and moral development theories.

Cognitive and Moral Development

Jean Piaget (1897-1980) theorized that children's cognitive development progresses through successive stages regarding how they think about space, time and causality of experiences. These stages include *sensori-motor* (ages 0-2 years) which is primarily mediated by the senses, *pre-operational* (3-7 years) when language and symbolic thinking emerge, *concrete operations* (7-11 years) when reasoning develops, and *formal operations* (11 years and older) when abstract thinking begins (Slee & Shute, 2003). Piaget believed that such development is based on four factors including maturation, experience, social transmission and equilibrium through self-regulation (pp. 63-64). Children's ability to learn is enhanced through active experience (Smith, Cowie, & Blades, 2003). What remains to be established is if we invite them to participate as active learners in FCC.

Piaget also studied children's moral development and distinguished two groups of children: heteronomous and autonomous. The heteronomous group (typically under 9-years of age) made decisions based on "coercion or restraint", whereas the older autonomous group (typically over 9-years of age) made decisions based on "cooperation or reciprocity" (Smith, Cowie, & Blades, 2003, p. 258). This concept of autonomy is not based on individualism, but a "moral subjectivism" (p. 260) based on the child's ability to reciprocate with peers while assuming authority and responsibility in his or her own decision-making. These notions are important when considering the child's role in the family as it is assumed that with greater abstract thinking and moral awareness, the child becomes more autonomous corresponding with an ability to relate to others. Thus the child in FCC may learn maturity and competency as a family member, and autonomy develops through relationship with others and not in an individualistic manner.

Social and Cultural Views of Children

Piaget's theory suggests that it would be possible and necessary to measure children's maturity in order to assess whether they are capable of being competent knowers in their experiences. However, this is confounded by the notion that children's capacity is also socially and culturally situated. The social-cultural view of children based on Christensen's (1999) conceptual work on "*Childhood and the Cultural Constitution of Vulnerable Bodies*" informs thinking about this topic. In our Western society, children are commonly viewed as vulnerable persons in need of adult protection with a heightened appraisal of vulnerability when children experience illness. Such perceptions should be considered regarding how parents see children who are experiencing illness, as this lends to the view of adults as protectors of passive children in need of care. Christensen argued that this view of children as vulnerable persons is so deeply pervasive in our Western culture that we do not recognize this as a socially situated belief. Furthermore, this widespread conviction is problematic because focusing on children's vulnerability is not a function of promoting "the optimum growth and development of another human" (Pressler, 1990, as cited in Franck & Callery, 2004, p. 266), but rather "confirms adult power" (Holland, 1992, cited in Christensen, 1999, p. 42). This way of thinking raises awareness about culturally dominant beliefs regarding the parent as the ultimate family authority and responsible protector of the passive child. Again, it is important to consider how the child is situated in the *family in FCC* given our socially and culturally mediated understandings of parent and child roles, and the fundamental importance of collaboration in FCC.

The United Nation's (1989) *"Convention on the Rights of the Child*" statement implied that children should be recognized as partners in FCC in that "the best interest of the child shall be the primary consideration" (article 3), and "parties shall assure to the child who is capable of forming his or her own views the right to express those views in all matters affecting the child, the views of the child given due weight in accordance with the age and maturity of the child" (article 12). As "the child's right to self-determination is grounded in the principle of respect for autonomy" (Runeson et al., 2002, p. 585), how this basic right is upheld in policy and practice presents a fundamental concern for those caring for children with hemophilia and other chronic illnesses. The concept of children's autonomy is important to consider given that "the degree of family involvement in health care, [is] controlled by the patient, provided that he or she [is] developmentally mature and competent to do so" (Institute for Family Centered Care, n.d., ¶ 4).

Current Understanding of Children's Autonomy

I did not locate any research articles regarding children's understanding of their own autonomy, thus indicating a gap in our knowledge regarding how this may be upheld in FCC. The philosophical roots of autonomy are based in large part on Kant's notion of self-governance that refer to an individual's independent ability to consider and act on his or her own beliefs and wishes (Christman, 2004; Kant, 1883). This notion of autonomy and competence is consistent with Beauchamp and Childress' (1979/2001) seminal work on bioethics. Therefore, Kantianism and bioethical principles related to autonomy will be discussed in the following sections.

Kantian autonomy. The word *autonomy* is derived from Greek terms meaning *self* (auto)-*rule* (nomy) (Hoad, 2003, p. 29). From a Kantian perspective, the ability to self-govern is a fundamental aspect of our freedom as in being truly autonomous the individual (self) assumes and lives by universal rules (governance). These universal rules or principles refer to acts that are morally acceptable when conducted by all persons. Kant called these principles categorical imperatives (Brook, 2004; Kant, 1769/1969). Within these categorical imperatives, the value judgment from these universal rules is not in the context of the situation, but rather in the absolute principle that guides the act. Kantian philosophy assumes that our ability to act autonomously is equivalent to our ability to think rationally, meaning that autonomous actions are not influenced by external forces, but rather conduct is based on one's own individualistic rational thinking. Conversely, *heteronomy* meaning "*other-rule*" (Hoad, 2003, p. 215) infers that a person is not truly free when an external force influences a person's actions, as that person is not acting on his or her own rational thoughts and abiding by universal law. Therefore, autonomous persons are rational individuals not influenced by external forces. This interpretation presents an obvious challenge to somehow connect Kantian autonomy with our understanding of FCC as contextual and collaborative. Moreover, this also presents a challenge to appreciate the meaningful participation of children in FCC, as they are not self-governing, but rather subject to the external influences of their parents within the family.

Kantianism and autonomy as a principle of bioethics. Kantianism is foundational to our dominant understanding regarding the basic principle of "respect for autonomy" (Beauchamp & Childress, 2001, p. 12) as part of a "highly influential trend" (Clouser &

Gert, 1990, p. 220) in our theoretical interpretation of biomedical ethics. Beauchamp and Childress (2001) stated that "personal autonomy is, at a minimum, self-rule that is free from both controlling interference by others and from limitations, such as inadequate understanding, that prevent meaningful choice' (p.58). Respect for autonomy is defined in bioethics as a principle valuing that "ordinary persons...qualify as deserving respect for their autonomy, even when they have not reflected on their preferences at a higher level" (p. 59). In their view, autonomous choices require that the decision maker is intentional, has adequate knowledge to make the decision, and is not controlled by another person or outside influence. Beauchamp and Childress (2001) identified that children "may exhibit varying degrees of understanding and independence" (p. 59). However, *children's autonomy* was not recognized as children were regarded as objects of "discernment" (p.34), "conscientiousness (p. 37) of parent's decision-making and passive recipients of adult-directed practices for children's "best interests" (p. 102). The value of children's capacities and perspective was not evident in this widely used publication on bioethics. However, since "The Principles of Biomedical Ethics" (Beauchamp & Childress, 2001) has widespread acceptance in our healthcare system, it is important to consider how this Kantian interpretation of autonomy informs our understanding of children's roles in FCC.

Beauchamp and Childress' (2001) interpretation was congruent with Kant's notion of *children's autonomy* given that children do not possess the rational capacity for self-governance, and are thus heteronomous, since choice is for the most part under parental control. Such parental authority is aligned with the belief that parents are the ultimate expert on the child, and should therefore be responsible for all related decision-making to promote good in their child's care. However, from a whole family perspective of FCC that includes the child, Kantianism does not regard how children, who are growing towards adulthood, would *become* autonomous given that this is apparently an inherent rational capacity. This also begs the question regarding how parents would *become* empowered as it is inferred that in their role as parents they are inherently rational and self-governing.

What Philosophical Underpinnings are Consistent with FCC?

This discussion calls for further thinking about the philosophical underpinnings of FCC. As previously stated there are assumptions regarding *ways of being* and *knowing* that are congruent with FCC core concepts, practices, and children's autonomy. FCC concepts are defined by attributes such as "respect, strengths, choice, information, support, flexibility, collaboration, and empowerment" (Institute of Family Centered Care, 2005, ¶ 4), founded on the belief that families play a "vital role" (¶3) in children's health including "emotional, social, and developmental support" (¶3). From an ontological perspective, FCC concepts are consistent with ways of being that are wholistic, relational, adaptive, dynamic, and multidimensional (Fawcett, 2005, p. 13). From an epistemological perspective, FCC concepts are consistent with ways of knowing from experience as aligned with pragmatism. Given the assumption that the child is a respected person within FCC (Carnevale, 2004), we need to consider how to regard children's autonomy in light of the ontological and epistemological assumptions supporting FCC. While pragmatism is aligned with FCC, children's autonomy in FCC may be understood by combining pragmatism with feminism given that these viewpoints are philosophically congruent with each other and with FCC. Feminism adds a relational perspective (Baier,

1993) that is a key feature of collaborative partnerships in FCC. Both pragmatism and feminism share the notion that the nature of our being is contextualized, and that knowing is socially mediated through these experiences (Rooney, 1993). This combined viewpoint will be discussed further in the following section.

Pragmatism and children's autonomy. From a pragmatist perspective, children are knowers and therefore have an active role in their experiences such as in FCC. Pragmatism recognizes autonomy not as a principle in itself, but rather as a learned social value (Dewey, 1930/1998) that supports respect for persons. A person may learn to be autonomous, thus rejecting the Kantian view that the "freedom of the will has suddenly been inserted (….) [but rather,] there must be some practical participation from within to make the change that is effected significant in relation to choice and freedom" (Dewey, 1928/1998, p. 303). Through experiences with children in FCC, parents and providers may gain knowledge of children's capacity for self-awareness and responsibility. More importantly, children themselves are able to develop self-awareness and responsibility by learning through active involvement in valuing and evaluating situations (Dewey, 1925/1998). Thus, children are able to develop competency in autonomy in FCC by way of actively learning from practical consequences while maintaining their interdependency as a family member and partner in health care.

Feminism and relational autonomy for all. This way of thinking is congruent with feminist philosophy regarding *relational autonomy* whereby the ability or competency to be autonomous (Meyers, 2000) may be developed through interdependence shared by parents and children within families. This view challenges the assumption that autonomy is a constant and "fixed centre of one's principles" (Baier, 1993, p. 228). Rather, this perspective assumes that we all begin as "second persons" (Baier, 1985, cited in Sherwin, 1996, p. 53), and that autonomy emerges as we learn through social experiences. In other words, our ability to self-govern stems from how we are socialized. This is contrary to the Kantian notion of autonomy as individualist self-rationality. Moreover, relational autonomy is more aligned with Piagetian theory whereby the hallmark of children's autonomy is noted in their ability to evaluate their own judgments and actions from a collaborative stance. Hence, *children's autonomy* may be reconsidered as "meaningful self-direction within a context of interdependency" (MacDonald, 2002, p. 194).

Feminist philosophers such as Annette Baier (1993) challenged the idea of autonomy as an individualist feature of human beings. Baier suggested that the traditional view of autonomy fails to take into account our responsibilities to others in society, and treats autonomy as if it were a discrete entity that can be given to individuals. Instead, autonomy is considered as a dynamic, relational process requiring "relations of dependency on other persons" (Mackenzie & Stoljar, 2000, p.3). This view is important for how we regard children's partnership role in care, as this stance recognizes that all family members and health professionals have interdependent relationships, and that children's autonomy may develop within this relational context (McLeod & Sherwin, 2000). Some scholars assert that we ought to have respect for children's meaningful contributions as relational partners in their family-centered care (Lowes, 1996; Sartain et al., 2000). Children's relational partnership role may be considered as "meaningful self-direction within a context of interdependency" (MacDonald, 2002, p. 194). If children's partnership roles are regarded as a dynamic state, this further challenges the notion of autonomy as a constant and "fixed centre of one's principles" (Baier, 1993, p. 228).

Overall, this dynamic view supports the assumption that children are deserving of our respect, and that they have a role in developing a relational partnership role as FCC partners in their own illness care. Hence, the philosophical grounding of my study was informed by pragmatist and feminist approaches and invited multiple perspectives (Baier, 1993; McLeod & Sherwin, 2000).

Children's Informed Consent and Assent.

As alluded to above, the dominant view of individual autonomy has influenced and limited children's roles within the healthcare system with regard to meaningful involvement in their own care and informed consent processes (Kuther, 2003; Lind, Anderson, & Oberle, 2003; Miller, Drotar, & Kodish, 2004; Shields, Kristensson-Hallstrom, Kristjansdottir, & Hunter, 2003). In the context of healthcare, *informed consent* is basically understood as the autonomous and intentional "authorization...given knowingly, rationally (and) with volition" (Kuther, 2003, p. 344) for care given to an individual patient by a caregiver or group of caregivers (Lind et al., 2003). The process of informed consent thereby requires that the person giving consent have "legal entitlement and decisional capacity" (Kuther, 2003, p. 344). Given that children may have "limited capacity and decision-making abilities" (Lind et al., 2003, p. 506), *assent* has been understood as the child's agreement to care; this agreement is not legally binding, and is subsumed within the broader informed consent process. Traditional thinking supports the restriction of a child's role in the consent process when an adult guardian perceives that the child's choices may threaten the adult's obligation to do good for the child, and support what is in the child's best interest (Beauchamp, 2003). While the principled, individualistic understanding of autonomy is pervasive and influential in our health care system (Clouser & Gert, 1990), this approach seems lacking if the child's voice is not regarded within the dynamic and social context of the family. In order to assist children to develop their partnership role, we need first to respect their own developing abilities. It seems reasonable to think that, in respect of the child's voice, it would be an important first step to listen to them as they describe their perceptions of the nature of their developing role in the health care context.

The notion of children's autonomy in FCC is important to discuss given that "the degree of family involvement in health care, is controlled by the patient, provided that he or she is developmentally mature and competent to do so" (Institute of Family Centered Care, n.d., ¶ 4). This way of thinking is aligned with current understanding regarding informed consent and assent with children in health care delivery. The process of informed consent requires that the consenting person have corresponding legal rights and sufficient decision-making abilities (Kuther, 2003). This restriction of a child's partnership role in FCC is noted when the parent determines that the child's choices threaten the parent's obligation to protect the child's best interest (Beauchamp, 2003). Given this view, it was not clearly identified in the literature if there was a possibility of developing autonomy by participating in decision-making processes in FCC as the child grows up.

Summary of Philosophical Underpinnings

Philosophical underpinnings guide how FCC is interpreted and applied in the practice setting. Children's capacity for their partnership role in FCC may be reflected in *ways of being and knowing*; this includes how we understand truth, and how this truth is reconciled regarding symbols and reflective thinking. Furthermore, ways of being and knowing mediate our regard for children's autonomy and decision-making in FCC. Piagetian moral theory suggests that those under 9-years of age are heteronomous and make decisions based on "coercion or restraint" (p. 258), while older children are autonomous and are responsible in their decision making based on "cooperation or reciprocity." Autonomy is based on the child's relational ability to reciprocate with others while assuming authority and responsibility in his or her own decision making, thus deviating from the dominant Kantian notion of individualistic autonomy. This Piagetian concept is congruent with notions of pragmatist and feminist relational autonomy, and provides an important consideration in application within FCC as the child may develop autonomy competency within family and the health care community. Moreover, these concepts are philosophically consistent with FCC theory regarding collaborative partnerships in care.

Children's Chronic Illness Experiences

School-age Children Living with Chronic Illness

The developmental stage of school-age includes children who are between 6-12 years of age (Ball & Bindler, 2006). Those with chronic illness have a medical condition lasting longer than 3 months; the nature of this condition requires the child and family to undergo repeated involvement with the health care system, and is characterized by disruption in family life (Sartain, Clarke, & Heyman, 2000). In Canada, approximately 30.3% of school-age children have been reported to have a chronic health condition (McDougall, 2004). Despite the prevalence of chronic illness in school-age children, there is a remarkable lack of evidence in the literature regarding this age group and their health and illness experiences. Research done with 18 children from two outpatient diabetes clinics involved coding children's responses based on a scale of cognitive complexity to reflect their understanding; findings indicated that when compared with siblings or children without chronic illness, those living with a chronic illness had a more advanced understanding of illness experiences and social relations (Rubovits & Siegel, 1994).

Children with chronic illness face the challenge of coping with health issues while still meeting developmental needs including physical growth, academics, social skills and self-image (Ball & Bindler, 2006). Chronic health issues include disfigurement, functional limitations, dependency on medicine or technology, diet restrictions and frequent use of health services (Allen, 2004). Such challenges indicate that this may create barriers for children to attend school or socialize typically within their community thus interfering with their developing sense of industry and self-concept; this has been confirmed in the research literature in a survey of over 4,000 children as part of the National Health Interview Survey in the United States (Msall et al., 2003). Nonetheless, school-age children also have capacity for understanding about their illness given their logical thinking abilities (Ball & Bindler, 2006; Slee & Shute, 2003). School-age children have potential for increased ability to participate more fully in various aspects of their care including symptom monitoring, reporting and management (Ball & Bindler, 2006) thus suggesting a partnership role in their chronic illness care. School-age children have been reported to be typically supported by health care institutions that assume a FCC approach, whereby a collaborative partnership is shared between family and providers, the family is respected as central in the child's life, and the emphasis is on supporting family capacity in health care (Institute of Family Centered Care, 2005).

School-age Children with Bleeding Disorders

Children with chronic illnesses may become experts in disease presentation and management, and are generally thought to have a more advanced understanding of illness and health care than other children (Rubovits, 1994). This is no less true of children with bleeding disorders. 'Bleeding disorders' is an umbrella term for various congenital diagnoses associated with poor clotting and continuous bleeding; abnormalities of clotting factors or platelets include diagnoses such as hemophilia, vonWillebrand disease, and other inherited platelet dysfunctions (National Hemophilia Foundation, 2005). Children's knowledge of indicators regarding their bleeding symptoms must be taken seriously, as they become experts on their own disease manifestations (Canadian Hemophilia Society, 2001; Coyne & Lusher, 2000). Therefore health providers must consider not only the unique needs of children, but also their unique capacities. This can be accomplished in part by shifting from a professionally-centred to a FCC delivery approach (Ahmann, 1994; Lauver et al., 2002).

School-age children with bleeding disorders have a unique challenge in that they may experience symptoms of internal bleeding before this is visibly apparent to another person; thus, the child's ability to recognize bleeds and communicate with caregivers is of particular importance (Beeton, Neal, Watson, & Lee, 2007). While typical caregivers include family and healthcare providers, the role of peers and teachers must also be considered given that these children may spend significant time with such persons (Canadian Hemophilia Society, 2001). Bleeding episodes may be treated in hospital emergency, inpatient or outpatient setting; furthermore, some treatments (including clotting factor infusions) may be given as home infusion (Teitel et al., 2004), which may include the school or community setting. School-age children with bleeding disorders may be involved in self-care such as reporting symptoms, administering first aid, applying ice, taking medications, and preparing clotting factor infusions (Canadian Hemophilia Society, 2001; Khair, 2006). Furthermore, self-infusion under adult caregiver supervision was also cited as a consideration for children in this age group given their ability to initiate their own intravenous access with butterfly needles and infuse their clotting factor concentrate with a syringe (Khair, 2006). Children who are living with bleeding disorders have an important contribution as partners in their care.

Children's Perspective in Chronic Illness Care

A provider/parent-oriented view dominates the literature and does not readily include the child as a knower or active participant in his or her health related experiences. Woodgate (2001) identified that qualitative research is often used to explore children's health and illness experiences, yet the child's voice is often missing as parents and providers are the focus for such inquiry. This raises the question as to whether the scarcity of such research from the child's view is related to a perception that children may not be competent informants.

Only a few research articles were located that invited school-age children's perspectives regarding their healthcare. Sartain, Clarke, and Heyman (2000) conducted semistructured interviews with seven families (parents and children) and health professionals (ward managers, hospital and community nurses) on their experience with chronic illness. Children augmented their input with drawings. Data collection and analysis were guided by grounded theory. While findings revealed typical disruptions and transitions related to children's chronic illness when hospitalized, authors also identified that children experienced “familiarity and alienation” (p. 919) in how they were treated by parents and health professionals alike. However, children’s input revealed that they were “effective communicators of the ‘here and now’ ” (p. 919) in their chronic illness experiences. Furthermore, the authors recognized that children were “competent interpreters” (p. 913), of their health-related experiences and they have the capacity to be “active participants” (p. 919) in their health and illness care. The problem was identified that children’s voices were not sought out in their own care.

Carter (2002) described this problem as “professional ventriloquism and hidden voices” (p. 28). In this qualitative study, the author explored three families’ experiences with chronic pain, and invited children and parents to describe their encounters with the healthcare system. Children and parents kept journals to record their thoughts and experiences on living with chronic pain for six weeks prior to a semi-structured validation interview. Thematic analysis revealed that there was significant stress associated with “professional judgment and disbelief” (p. 33) when health providers would impose their own interpretation on the children’s and families’ explanations. Moreover, the child was not recognized as the centre of these encounters, but rather the focus was on the parent-provider dyad: “One mother realized that she was the main focus of observation rather than her child” (p. 33). Children stated that healthcare providers misrepresented their needs and “distorted, muted or ignored” (p.28) their perspectives. Carter recommended that health providers include the voice of the child to ensure accurate assessment in caring encounters with families.

How children’s values, opinions, and wishes were attended to in decision-making was reflected in a self-determination scale (Runeson, Elander, Hermeren, & Krisstensson-

Hallstrom, 2000). This 5-level scale was used to measure how actions of health care providers coincided with "opinions, wishes and valuations" (p. 456) of 26 children between ages 6-17 years of age and their parents regarding decision making in their health and illness care. Scale values ranged from level 1 (provider does not listen to the child's opinions, wishes, and values) to level 5 (provider acts in accordance with the child's opinions, wishes, and values). While this study identified relationships between children's preferences and provider's actions, findings did not fully explore how children themselves understand their role as partners in their care.

The importance of understanding children's illness and health experiences from children's perspective has been reflected in a conceptual framework to guide investigation of how children cope with chronic disease (Schmidt, Petersen, & Bullinger, 2003). Redman (2005) argued that seeking the voice of the child is important as there may be "significant harm and the undermining of a patient's ability to take advantage of life opportunities" (p. 360) when they were not actively involved and thereby unprepared to self-manage their chronic illness.

Summary of Children's Chronic Illness

Children living with chronic illness face many challenges in meeting their developmental needs (Ball & Bindler, 2006; Msall et al., 2003) while coping with a wide range of health and illness related issues in the home, school, community and hospital settings. Since a large number of children are diagnosed with a chronic condition (McDougall, 2002; 2004), it is important to consider their emerging capacity for self-care. However, few research articles were located that included school-age children's perspective of their chronic illness experience. I recognized this as a significant gap in our understanding given the assumption that children are "competent interpreters" (Sartain et al., 2000, p. 913) and should have some measure of participation in FCC to build their self-care capacity. Thus, the research problem was identified that we do not know *how school-age children who are living with a chronic illness understand their role in FCC*; this is important to explore given that such children need to develop skills as family and healthcare team members so that they can be part of managing their own chronic illness. Furthermore, I identified the challenge to explore this problem in a manner congruent with theoretical and philosophical underpinnings of FCC while placing the child's voice as primary in the research process. Given this challenge, it was concluded that *systematic ethnography* offered a methodology consistent with such elements associated with the research problem at hand.

Literature Review, Research Problem, and Process

Systematic Ethnography

I chose to explore this research problem through systematic ethnography given the congruence with FCC, pragmatism and relational autonomy while also placing the researcher's voice secondary to the children's perspective. Philosophic underpinnings of systematic ethnography stem from pragmatism and symbolic interactionism. How persons understand their culture is rooted in the philosophic underpinnings of systematic ethnography, with culture being the "acquired knowledge that people use to interpret experience and generate social behaviour .... as a system of meaningful symbols" (Spradley, 1979, pp. 5-6). The epistemological view underlying systematic ethnography assumes that related cultural meanings are primarily understood from the participant's perspective. Their "cognitive map" (p.7) of cultural themes is not simply a representation of culture, but rather provides guidelines that assist with understanding and navigating through the everyday lives of the cultural group.

These philosophical underpinnings support my inquiry in several ways. First, pragmatism is aligned with the notion that children with chronic illness are wholistic persons with dynamic experiences and connections that include family, providers, and hospital care. This worldview supports exploration of contextual factors that are part of children's health experiences and relationships in FCC. However, what stands out in this approach is that children are viewed as legitimate knowers of their experiences in FCC, and that their perspective is of primary concern. This assumption is of key importance, as I chose to use systematic ethnography inquiry so that I may understand and represent FCC from the viewpoint of the child. While the family is regarded as a whole in FCC, the view of the family from the parent's perspective has dominated the literature (Shields, Pratt, Flenady, Davis, & Hunter, 2004). Thus, the voices of children needed to be sought out to highlight how they understand their role in FCC. Systematic ethnography supports the exploration of children's "own understandings of how they want to be represented" (Denzin, 1997, p. xiii) as partners in FCC. This was recognized as a fundamental step in appreciating the broader dynamics of the family in FCC.

Literature Review Summary

How children understand their role as partners in FCC was not located in the literature. This is a critical gap to consider given that FCC is a foundational approach in children's healthcare. Nonetheless, this literature review indicated several key points that were relevant to this research problem. First, FCC key elements were confirmed through concept analysis and recognized as beneficial within the practice setting; however, there was a knowledge gap regarding how children understood FCC and regarded their role as partners in this approach. Second, FCC was consistent with philosophical underpinnings associated with pragmatism and relational autonomy; however, this awareness raised issues regarding FCC given that the dominant bioethics view of children's autonomy has Kantian philosophical underpinnings oriented to individualism instead of collaborative partnerships. Third, developmental theories suggest that school-age children living with chronic illness have the capacity to think logically and assume responsibility for their part in decision-making in a collaborative manner; however, FCC was presumed within children's healthcare without formally asking the children themselves how they understood this process. Hence, the purpose of my study was to explore how children understood their partnership role in the everyday context of their chronic illness; furthermore, I also needed to determine if children's understanding of FCC was supported by their healthcare context, and identify strategies that would uphold children's partnership role in FCC as generated by children themselves.

Research Questions

Primary Question

1. How do school-age children between 7-11 years of age with bleeding disorders or other chronic illnesses understand their partnership role in FCC?

Secondary Questions

2. What is important to children regarding their partnership role in FCC?
3. How do legislation and policy documents match with children's understanding of their partnership role?

4. What strategies do children identify that would support their partnership role in FCC, as they understand it?

5. What recommendations to support children's partnership role in FCC are congruent with the merging of legislation and policy documents and children's strategies?

CHAPTER 3: RESEARCH METHODS

RESEARCH METHODS

I used systematic ethnography as a method to explore the research problem and questions. In this chapter I first review the overall study design so that the key points of the research process are clearly outlined. Then I discuss ethnography basics from an introductory perspective. I follow this with a section specific to systematic ethnography as a research method including connections with philosophical and practical issues. In the final section I discuss how systematic ethnography was applied in this particular research study.

Study Design Overview

This study was grounded in practice. Further observation and review of the literature led me to question if FCC may be off target as only the adult perspective was located regarding partnerships that were limited to parents and providers. Given this background, the primary objective of the study was to find out children's views of FCC and their understanding of partnership roles in chronic illness. This study took place in three phases. During the first phase, I talked with children in unstructured interviews to explore how they understand FCC. Then I then examined legislation and institutional policies to see if and how these documents supported children's understanding of FCC. From this point I met with children to confirm their understanding and generate recommendations that would enhance their partnership role in FCC from their perspective. I chose to pursue this inquiry using systematic ethnography as a way to highlight children's expert perspective and report a cognitive map of their understanding of FCC since this was lacking in practice and the literature. This study took place within the catchment area served by the Alberta Children's Hospital. Interviews were conducted with children aged 7-11 years inclusive who were living with a bleeding disorder or chronic illness and who were on the caseload at an outpatient specialty clinic at the Alberta Children's Hospital. I used domain analysis (Spradley, 1979) and ethnographic content analysis (Altheide, 1987) while adhering to *trustworthiness* criteria (Lincoln & Guba, 1985) to ensure data quality.

Ethnography as a Research Approach

Ethnography Basics

Ethnography is "the work of describing a culture" (Spradley, 1979, p. 3) and is recognized as both an inquiry *process* and a written end-*product* (Boyle, 1994). Ethnography is a reflexive process (Altheide & Johnson, 1994) with a collaborative orientation whereby descriptions emerge by "learning from people" (Spradley, 1979, p.3). This was an important consideration to this study as my researcher role was that of the learner and the children's role was that of informant and teacher. Several key features characterize the ethnography process including context, informant's role, researcher's role, data collection and analysis, and the qualities of the written work (Altheide, 1996; Boyle, 1994; Speziale & Carpenter, 2003). I will describe these features below.

The process of ethnography is largely founded on a contextual worldview assuming that a person's beliefs and actions stem from meanings held individually and as members of their culture (Boyle, 1994). While this way of thinking invites qualitative inquiry, ethnography may also include complementary quantitative measures (Boyle, 1994). Although it is commonly understood that fieldwork (Boyle, 1994), direct participant observation, and intimate "cultural immersion" (Speziale & Carpenter, 2003, p. 158) are setting requirements, ethnography may also be conducted through review of documents, media, and Internet sources (Altheide, 1996). Ethnography is an iterative process. Through the collection and analysis of data, "differences and similarities lead to still other questions about the culture" (Speziale & Carpenter, 2003, p. 157). Ethnographic analysis involves interpreting cultural meanings as primarily conceptualized from the participant's perspective, with the researcher exploring, verifying, and making explicit the participants' tacit knowledge of the culture (Spradley, 1979). Data collection and analysis take on a "cyclic nature" (Speziale & Carpenter, 2003, p. 157) involving back and forth phases common to other social science research. These include "selecting a problem, formulating hypotheses, collecting data, analyzing data, and writing up the results" (Spradley, 1979, pp. 93-94).

Ethnographic Approaches and Method Selection

Ethnography is a broad term including classical, systematic, interpretive, and critical theory approaches. The choice of research method is dependent on the nature of the question. This study was a good fit with *systematic ethnography* (Muecke, 1994) because this method provided structure and process for describing children's own perceptions of how they understand FCC. By using this approach, I could then represent children's understanding of their FCC partnership roles in the ethnographic report as a "cognitive map" (Spradley, 1979, p.7). In comparison, classical ethnography would have provided "comprehensive descriptions of people's material constructions and perspectives" (Muecke, 1994, p. 191); this approach was not aligned with my research problem as attempting to uncover global cultural themes regarding FCC behaviour, actions and artefacts would be premature. Interpretive ethnography was not suitable as this method regarded inextricable connectedness of researcher, participant, and reader perspectives (Agar, 1986); this approach did not fit in with my research goal to represent children's understanding as the primary voice. Finally, critical ethnography was not appropriate as an emancipatory aim (Madison, 2005; Smith, 2005) was not well suited to explore children's roles given the emphasis of collaborative partnerships in FCC. Thus systematic ethnography was a fitting method to explore the research question as a first step in understanding how children see their role in family-centred care. I will discuss *systematic ethnography* further in the following section.

Systematic Ethnography

As previously stated, systematic ethnography is defined as "learning from people" (Spradley, 1979, p.3) and understanding how they comprehend their patterns of beliefs and practices. "In every society people make constant use of these complex meaning systems to organize their behaviour, to understand themselves and others, and to make sense of the world in which they live. These systems of meaning constitute their culture" (p. 5). My aim in applying systematic ethnography was to uncover cultural domains and themes that reflect how experiences (such as partnership roles in FCC) are understood. These domains and themes were viewed as elements of children's "cognitive map… [that provides a guide for interpreting, acting and reacting to] recurrent activities that make up everyday life" (p.7).

Philosophical Underpinnings of Systematic Ethnography

Systematic ethnography stems from pragmatism and symbolic interactionism. Pragmatism assumes a worldview that persons continually interacting with the environment also regard their holistic being to include physical, mental, and social dimensions (Dewey, 1925a/1998; 1925b/1998). This dynamic way of being supports the pragmatist notion that beliefs are culturally situated, the value of beliefs is determined within a particular cultural group, and that beliefs may change when challenged through practical consequences (Dewey, 1925c/1998). This way of looking at culture is based on the theory of symbolic interactionism in which there are three key assumptions: a person's action stems from meaning, meaning stems from social interactions, and meaning is personally interpreted (Blumer, 1969). The epistemological view underlying systematic ethnography assumes that cultural meanings are primarily understood from the participants' perspective. Their "cognitive map" (p.7) of cultural meanings assists with navigating everyday life within the cultural group.

Practical Implications of Systematic Ethnography

I implemented systematic ethnography as a "rapid ethnographic appraisal" (Muecke, 1994, p. 198) of a distinct problem within a specific cultural group, whereby time spent with the group was relatively shorter and more episodic than typical classical ethnography. I required identification of a distinct research purpose and problem in order to proceed with this kind of appraisal. This was fitting for the research problem at hand as the limited scope provided a timely "focused ethnography" (p. 198) through "selected episodes of participant observation, combined with unstructured and partially structured interviews" (p. 199). Another reason why I chose systematic ethnography was to create a report for a broad audience of readers given that children's roles in FCC are an important consideration for providers with various philosophical orientations. I was concerned that a strictly qualitative report might limit the audience to those already appraising and integrating naturalistic evidence (Lincoln & Guba, 1985). Analysis undertaken through systematic ethnography offered a balance between qualitative and quantitative data, and yielded information that reflected these complementary research methods (Smith, Sells, & Clevenger, 1994). I analyzed and reported children's words and phrases thematically and numerically as frequencies, percentages, and cross-tabulation. My approach was supported by pragmatism and symbolic interactionism given that both the numbers and words of qualitative and quantitative data (respectively) are symbols.

Emic and Etic Views

Emic: Informants and approach. I viewed children as expert informants regarding how they comprehended patterns of beliefs and practices as partners in FCC of their chronic illness. I used purposive sampling to ensure that those studied represented the culture of interest. My application of systematic ethnography positioned the children's voice as primary. I used a symbolic interactionist approach to guide the interpretation regarding how children go about and understand their everyday illness experiences. Several assumptions basic to symbolic interactionism were key to this study. First, children's experiences were intersubjective and understood within their cultural context. Their meanings developed as part of an intersubjective process within their cultural context. Moreover, children's meanings were rooted (and thus may be explored) in shared symbols such as language. Their actions were directed by meanings they interpreted within their context. Children's interpretation of their own meanings and actions were recognized as a changing and reflective process (Benzies & Allen, 2001; Mead, 1934; Prus, 1996).

Etic: Researcher and approach. As the researcher I was required to maintain children's voice as primary. This meant that I actively worked on accurately hearing children's views and reporting their intended meaning with as little interpretation as possible. I did this by openly acknowledging my possible biases as a nurse, mother and "grown-up" before, during and after the interviews. I reflected on each interview and questioned whether what I heard and summarized was based on their direct comments or if I had jumped to any conclusions stemming from my biases. I recognized children's experiences in FCC as intersubjective, and that interpretation of their own held meanings was a dynamic and reflective process (Benzies & Allen, 2001; Dewey, 1925a/1998; Prus, 1996). From a reflexive stance (Berg, 2001) I acknowledged my own biases and how this may have impacted my view of children living with a chronic illness. I assumed a reflexive account of participant observation and field notes in the interviews and ongoing iterative analysis. I used participant observation and field notes to supplement descriptions about the interview experience and provide context for the children's interview text. I observed, recorded and reflected on children's appearance, gestures, behaviours and interactions, then distinguished this from my own expectations and biases. I asked the children directly to verify their verbal and non-verbal communication so that my recording and manifest (direct) interpretation of children's perspective was supported by ongoing "corroboration [and] verification" (p. 139).

Application of Systematic Ethnography to this Study

I followed the method for systematic ethnography based on Spradley's (1979) developmental research sequence. Systematic ethnography was applied in the three phases of this study. In phase I, I conducted unstructured interviews with children to explore how they understood their partnership role in FCC. I performed a document review in phase II to provide legal and institutional context to see how this matched with the children's perceptions of their partnership role. In phase III, I carried out validation interviews with children for member checking and creation of recommendations regarding supporting children's partnership role. The following section will introduce the study by explaining the three study phases including informants, data collection and analysis.

Sample

Phase I

Recruitment and context. I used purposive sampling to support data quality regarding *transferability* or external truth value (Lincoln & Guba, 1985) as I selected variety of informants to provide a wide array of experiences. In the first step in the recruitment process I shared information about this study with key stakeholders through a presentation at a monthly routine meeting for outpatient nurse clinicians at Alberta Children's Hospital in November 2006. I was familiar with many of these nurses as I worked as an outpatient nurse clinician at the Alberta Children's Hospital from 1993-2005. I shared copies of my presentation by e-mail with all outpatient nurse clinicians. Subsequently, nurses from various clinics telephoned or e-mailed me and identified children and families for the study. From this initial contact, the clinic nurse and I determined if the child met the study inclusion criteria; if so, the nurse clinician telephoned the family to share basic information about the study and inquired if I could telephone them and screen them for participation. With permission, I collected demographic information regarding child's name, date of birth, diagnosis, date of diagnosis to enable screening; I also recorded a mailing address (see Appendix A).

During the next step in recruitment, I telephoned the children's parent(s). Two children's parents declined study participation citing time restrictions as a barrier to participation. Within three days after I made telephone contact with the child's parent, I mailed a study package to their home. Some parents opted to e-mail me and work out interview times. I provided a cover letter with details on the interviews (see Appendix B) and consent forms for the child (see Appendix C) and parent (see Appendix D).

At the scheduled interview, I reviewed the consent form, obtained consent and assent (discussed in detail later in this report) and conducted the interview. I mailed a letter to the child's family 2 weeks after the interview thanking the child for his or her participation (see Appendix E). I included a second copy of this letter with the intent that the parent and child were able to choose to send this letter to the child's school principal in recognition of the child's involvement in this research process. This latter approach was suggested by children with whom the study has been discussed informally from the outpatient hematology clinic, as they indicated that research participation was valued by the school as a community service. This was the choice of participants and their parents, as they might prefer to keep their participation confidential. Given that this type of qualitative research required saturation of themes, key informants were invited to participate in an optional second interview.

Informants. I recruited informants who were school-age children with a bleeding disorder and children with another chronic illness. School-age children were sought for this study given their emerging problem solving skills and ability to classify and categorize ideas in more than one way; the shift from egocentrism to relativism during this stage allowed the children to think from a variety of perspectives, and to consider more than one aspect of an issue (Ball & Bindler, 2006; Smith et al., 2003). Thus, the school-age group represented an appropriate sample given the study purpose to explore identifying features of children's partnership role. Children between the ages of 7-11 were of particular interest given that there was limited research about their involvement in healthcare processes and consent, while there has been research with the adolescent age group. Furthermore, participation was limited to those 11-years of age and under as the maturational changes associated with those older children who are approaching puberty are likely quite different and beyond the scope of this study.

I conducted unstructured interviews with eight children aged 7-11 years inclusive who were living with a bleeding disorder (n=4) or another chronic illness (n=4) and on the caseload at an outpatient specialty clinic at the Alberta Children's Hospital. While I estimated recruitment of 12 informants in the original study protocol, once I started recruiting it became apparent that time coordination was difficult for these families. This was discussed with my supervisor and we agreed to start with eight children and determine if more informants were required pending data analysis and saturation.

I recruited children for this study through initial information sharing with their parents on the telephone. Parents asked questions about the study on topics such as review of research purpose, child's role, parent participation (and rationale for not being present in the interview), time requirement, and relevance to their child's illness experience. All parents of recruited children conveyed that they would be "happy" to support their child's involvement for 2 key reasons; first that this would "help other children", and second that their child's participation in this study would 'be good for" their child's "leadership" development. All parents asked for my e-mail address to relay possible interview schedule times, as it was difficult to do this by telephone. Two parents asked if there was a study website with my picture so that their children would know what I looked like; these parents and children "looked me up" on my work website at Mount Royal College and one child e-mailed me to say "hello" prior to the interviews (I responded and included a copy to his mother).

Inclusion criteria. A purposive sampling technique was used to recruit children between ages 7 - 11 years of age (inclusive) who were:

- regularly cared for by an outpatient specialty care clinic at the Alberta Children's Hospital (with telephone or in-person care within 3 months); AND
- living with a bleeding disorder such as hemophilia, vonWillebrand disease, or platelet dysfunction (maximum of 6 children were estimated to be recruited from this group); OR
- living with a chronic illness for at least three months (maximum of 6 children were estimated to be recruited from this group).

Exclusion criteria. Children with developmental or communication disorders were excluded from this study.

Trust, Familiarity, and Unfamiliarity

I knew 2 children given my role as their Hemophilia Nurse Clinician and had not previously met the other 6 children. The parent(s) facilitated my re-introduction and interaction with familiar children as they explicitly identified me as a trusted person. My introduction and interaction with children who were not familiar was different, as I had to establish a trust relationship with both parent(s) and child. While I spoke with all parents and children at a developmentally appropriate level as part of the assent/informed consent process, I was required to spend more time reviewing my professional background and research purpose with unfamiliar parents. Unfamiliar children were eager to engage in the informed consent process, share their understanding and assent, and participate in the interview; one child exclaimed, "you are just like me – I am going to be a researcher too!." I established trust and rapport with all children and parents in our shared understanding of role clarity. My job was to record and share their story in confidence, their parent(s)' job was to be accessible to the child as required, and the child's job was to teach me what was important about FCC of their chronic illness and be in charge of ending the interview at anytime.

Face-to-face introductions and consent process. I greeted parents first, and then they presented me to their child prior to interviews held at home or the hospital. This was a comfortable way to engage the child since my contact with them was gradual and initiated with the support of the parents. In one instance, a child being interviewed at home was first to open the door for me; however his mother quickly came to the entrance and took over introducing their family and setting. In the home setting, the parent selected the location for the interview (either living room or kitchen). In both home and hospital settings, I reviewed the consent forms with the child and parent while seated; these forms were sent to the families in advance of the interview. While I sent the forms to the custodial parent, I did not send a study package to non-custodial parents; the non-custodial parents indicated that they wanted to be part of the information sharing process and were thus added to the contact list.

I provided 2 versions of consent forms: one for the child and another for the parent. With both the child and parent(s), I reviewed the child's version of the form aloud and pointed out how the child's form was different from the parents' form. Questions from the parent that came up during this process were typically around how the child and parent could access the final research report (knowing that this would be anonymous reporting). Questions from the children that came up during this process ranged widely and included topics around who was "the boss" of the interview, how their participation would "really help other kids", what my role was ("are you a scientist or something?" and "why are you still in school?"), and how I would keep their information "secret like a private detective." I found it interesting that all children were engaged by asking questions during the consent process. Moreover, this process gave me an opportunity to become familiar with children's priorities for the interview, how they expressed themselves, their attention level, and general sense of comfort. Again, this provided opportunity to establish trust with children and families as part of the research process.

Phase II

I conducted a document review from public archive sources and therefore did not recruit informants.

Phase III

Potential subjects in phase III were the same children recruited in phase I. I recruited from this same group so that I could verify findings generated in the initial unstructured interviews. I conducted two validation interview sessions. The first session was held with 3 children (n= 2 hemophilia; n=1 other chronic illness); the second interview session was held with one child (n=1 other chronic illness). I provided a cover letter with details on the interviews (see Appendix F) and consent forms for the child (see Appendix G) and parent (see Appendix H). At the scheduled interview, I reviewed the consent form, obtained consent and assent, and conducted the interview. I mailed a letter to the child's family 2 weeks after the interview thanking the child for his or her participation (see Appendix I). I included a second copy of this letter with the intent that the parent and child were able to choose to send this letter to the child's school principal in recognition of the child's involvement in this research process.

Setting

Phase I

This study took place within the catchment area served by the Alberta Children's Hospital. Unstructured interviews took place at the Alberta Children's Hospital (n=1 with hemophilia; n=2 with chronic illness) or at the children's home (n=3 with hemophilia; n=2 with chronic illness) based on child and family preference. I held two follow-up interviews with key informants at their home: one child with hemophilia and one child with another chronic illness. I scheduled hospital-based interviews in meeting rooms not typically used for outpatient care of these children. These rooms had a table, chairs, and telephone with promised easy access to parents as required. While I requested that interviews were scheduled when treatments were not taking place, one child requested that the interview be done while she received a routine prolonged intravenous treatment. She and her mother made this request as the child spent a considerable amount of time in outpatient care and preferred to maximize her time at home doing activities not related to her illness. This request was respected and the interview took place in the meeting room adjacent to the outpatient treatment unit nurses' desk. Of interest, this child was identified as a key informant given the rich details she shared in her life history and experiences with chronic illness at home, school and within the healthcare system. A follow-up interview was conducted in her home at her request. She told me that her participation in this follow-up interview was "important" as her role was to teach me and help other children living with chronic illness.

Phase II

I conducted a document review from public archive sources that were available online.

Phase III

Two validation interview sessions were held at the Alberta Children's Hospital. These interviews were held in rooms that were not typically used for outpatient care of these children. These rooms had a table, chairs, and telephone with promised easy access to parents as required.

Data Collection

Phase I

Welcoming parents and children. I offered food and refreshments for children and parents to enhance their comfort. While I included parents as part of the introductory process to review the research purpose and consent, I held the main interview exclusively with the child to ensure that the child's perspective was the central focus. Also, I kept the interview confidential so that the child's responses were freely given, and not influenced by potential concerns related to sharing such information directly with their parents. I made these details clear in the cover letter and consent form. I gave parents a copy of the interview schedule of questions before the interview so that they were aware of the discussion format. Furthermore, I had a follow-up discussion with parents after the interview completion which provided an opportunity to review any further questions that they had, while also permitting me to thank the family for their participation.

Interview warm-up. I began the interviews with an introductory activity to enhance a sense of comfort with the child. This activity required about 3-5 minutes and was a pen and paper (writing and drawing) exercise that the child completed with me (see Appendix J). I asked the children to explain each of their drawings to give them an opportunity to describe themselves to me. This exercise was a warm-up to hearing their voices as primary and allowed me to gain insight about their values, preferences, and dislikes; furthermore, this also served to reinforce that the interview was about the child and his or her expertise was valued. While I did not interpret the children's drawings directly, their comments around their own drawings were included. Furthermore, I gauged the child's typical language use around the illness experience through comments made by the child during this introductory activity. I then incorporated the child's use of language into my own questions throughout this process. One child used this exercise to readily express his anger associated with having his chronic illness; this allowed us to openly talk about his concerns and provided a relevant opening for our discussion based how he was feeling about his illness experience. Another child drew on this paper exercise for the duration of the interview as a way to supplement his verbal input; while this was distracting at times, his ability to doodle appeared to assist in his comfort while participating in the interview. This introductory activity was an effective way to engage and establish rapport with children in their informant role. I used a schedule of questions (see Appendix K) to explore relevant themes for qualitative analysis. From the inductively generated themes, I developed additional probing questions for the validation interviews (phase III).

The interview. Data collection and analysis were carried out simultaneously, and there was constant comparison of findings. I collected interview data as per Spradley's (1979) developmental research sequence and analyzed interviews in an iterative manner. I used *descriptive questions* (p. 78) to explore key themes from the participant's perspective, and semantic appraisal through *domain analysis* (p. 107) to ascribe names to these themes and spark inquiry to identify new domains. Then I asked *structural questions* (p. 120) to verify and explain the domains, and *taxonomic analysis* to interpret the internal structure of these confirmed domains (p. 145). I presented *contrast questions* (p. 155) to uncover the symbolic meaning of the domain and how this meaning related to other domains regarding similarities and differences; this was associated with *componential analysis* (p. 173) of the specific attributes that are in accordance with symbolic meanings. I then was able to understand broader *cultural themes* (p. 185) when a "number of symbols are linked into meaningful relationships" (p. 186). As previously mentioned, these cultural themes represented elements of the "cognitive map" (p. 7) of the children's implicit and explicit cultural knowledge. I regarded children as "guiding the mode of inquiry and orientation of the investigator" (Altheide, 1987, p. 66) by describing their held meanings about their role in the everyday context of their chronic illnesses in FCC. I verified and analyzed children's beliefs with consideration to open and prestructured categories based on key elements of the FCC concept (Institute of Family Centered Care, 2008).

Initially I developed a schedule of questions that were congruent with FCC theory and emerging domains identified by children that also followed the developmental research sequence (Spradley, 1979). This approach was used so that I could systematically explore how children understand their partnership role in FCC; also this provided a greater chance to gain deeper understanding of such domains regarding their taxonomy (parts or structure of domains), components (attributes of domains) and cultural themes (overall beliefs and principles). However, this schedule of questions was used as a guide only, and questions presented in the unstructured interviews were responsive and based on contributions from the children. I first asked descriptive questions to uncover domains; this included queries like "tell me what you know about your illness." I then asked structural questions to complement and extend descriptive questions to uncover taxonomy of domains; this included queries like "tell me what kind of information you get about how to take care of your illness." I asked contrast questions to gain further insight to the attributes of each domain and to establish similarities and differences between domains; this included queries like "tell me what's the same (or different) between knowing and making decisions." I also asked the children questions that would facilitate their story telling including past experiences, hypothetical situations, priority sorting and verification. While a schedule of questions was developed, I conducted these interviews in an unstructured format so that children's perspective and priorities could be revealed.

I held unstructured interviews so that children's contributions would guide the questioning format. I conducted interviews given my previous experience as a facilitator with interviews and focus groups. During the unstructured interviews I asked broad questions and probes. I sought children's views regarding question clarity as important considerations to ensure that the "child's frame of reference" (Bricher, 1999, p. 66) was reflected. Given that this type of qualitative research required saturation of themes, key informants were invited to participate in an optional second interview. All interviews were tape-recorded, transcribed, and supported by field notes; I analyzed transcripts using constant comparison. In each subsequent interview, I shared emerging domains with my thesis supervisor for manifest interpretation, and with children for verification and *credibility* to uphold trustworthiness criteria for data quality (Lincoln & Guba, 1985). While children agreed with input from previous interviews, they were comfortable to clarify, confirm and extend such ideas. I talked with children regarding how the iterative analysis process took place; children told me that because of this process they could trust me because I was "really listening" to them and other children too.

Closure and follow-up. I showed children how to turn on the tape-recorder to start the interview, and to turn off the tape-recorder when they wished to end the session. All of the children seemed quite intrigued by the tape recorder given their fascination with holding it and maintaining the controls. They ceremoniously pressed the big red button when they decided that the interview was over. Children conveyed that this was important because they “really knew” that they were “the boss.” On one occasion, a child indicated that he changed his mind and wanted to re-start the interview; thus his interview was restarted immediately and concluded again as per his decision.

Field notes. I recorded field notes in three parts; first as a review of demographics and context prior to the interview, second as an account of events during the interview, and third as a reflective writing that distinguished emic and etic perspectives. This approach was aligned with Dewey’s (1925b/1998; 1933/1998) pragmatist reflective way of knowing with a focus on what happened, what was significant and a future orientation to how this experience informed future analysis and interviews.

Post-interview. I told the children that I would send them a thank you letter in a few weeks time and to look for this in their home mailbox. I also told them that this thank you letter would include a photocopy that they could share with their school principal to acknowledge their participation. Children indicated that this letter for the school had special meaning as it formalized that “they were doing something really important.” Two children were key informants to this study; these children and their parents agreed to follow-up interview as part of phase I. I asked all children and parents if I could contact them again by telephone in a few months to see if they would be interested to take part in validation interviews (phase III).

Key informants. Two children were identified as key informants. I selected these children given their unique insights into children's partnership roles in FCC. I summarized findings from the eight interviews and showed a concept map of the seven identified domains of how children understand FCC. Then I invited their reflection and comment as a form of member checking. The purpose was to verify my interpretations of data and to ensure that I had presented it in a form that was understandable to children.

Phase II

My initial review identified documents relevant to school-age children's partnership role in FCC of their chronic illness. I selected documents that related to domains identified by children about their partnership role in the healthcare setting. This included decision-making processes, information sharing and communication, roles and responsibilities, accountability, ethical issues, and the law. My search of public archives included review of hard and soft copy sources from Calgary Health Region, Government of Alberta, and Government of Canada. I entered data on a computer using WORD™ in preparation for data analysis with Atlas.ti™ software.

Provincial legislation document review included:

- *Child, Youth and Family Enhancement Act* (Government of Alberta, 2007a), chosen because it specifies the nature of child protection and related guardian duties including provision of necessities, essential health care and adequate supervision while assuring the child's emotional and physical well-being.

- *Freedom of Information and Privacy Protection* (Government of Alberta, 2006) which outlines children's rights regarding accessing personal information records and privacy protection.

- *Health Information Act* (Government of Alberta, 2007b) which defines children's rights to access their personal information from "health record custodians" such as regional health authorities.

- *School Act* (Government of Alberta, 2007c), which outlines children's rights to education programs within public, separate, and francophone school districts.

- *Human Rights, Citizenship and Multiculturalism Act* (Government of Alberta, 2007d) outlines children's rights and responsibilities that are to be upheld irrespective of race, religion, gender, ability, socioeconomic or family status.

- *Family Law Act* (Government of Alberta, 2007e), which defines responsibilities of parent, guardian and child regarding the best interests of children and families.

National legislation document review included:

- *Charter of Rights and Freedoms, Part 1- Constitution Act, 1982* (Department of Justice Canada, 1982/n.d.) outlines children's civil liberties.

Calgary Health Region policy review included:

- *Consent for Treatment, Special Procedure and Intervivos Gifts for Transplant Policy #1414* (Calgary Health Region, 2002a) chosen because it summarizes the consent process for healthcare.

- *Protection and Privacy of Health and Personal Information #1471* (Calgary Health Region, 2002b) which indicates that children's health record information sharing is guided by the Freedom of Information and Privacy Protection Act (non-health related information) and Health Information Act (health related information).

Calgary Board of Education policy review included:

- *Health Services to Students #6002* (Calgary Board of Education, 2003a) specified that children who are deemed capable may have specific roles including taking medication at school. In fact, if capable the "student will be expected to assume as much responsibility as possible for the handling and administration of the medication"(p. 3). Parents and teachers also have clearly stated roles and responsibilities related to children's safety and health promotion including managing illness and emergencies.

- *Severe Allergies #6003* (Calgary Board of Education, 2003b) chosen because this outlines the processes in place in the school setting for children with severe allergies.

International policy review included:

- *United Nations Convention on the Rights of the Child (1989)* which outlines how children's rights are in accordance with the Universal Declaration of Human Rights,

Phase III

Two validation interview sessions were held. I facilitated the discussion while a recorder (who was a master's prepared pediatric nurse) took field notes and provided additional interview support as required. The first session had 3 children (2 with hemophilia, 1 with a chronic illness) ages 8, 10, and 11 years. Two of these children were also key informants. The session began at 10:00am in a spacious and well-lit conference room at the Alberta Children's Hospital. Children selected refreshments set out in an adjacent room and brought these into the interview room. Parents remained in the adjacent room with the refreshments. Children were seated at the table with a variety of colourful activities including paper, mystery bags, bubbles, multi-coloured markers, happy face ping pong balls, tactile shaping materials (FLOAM™), sticky backed foam letters and pictures.

The initial ice-breaker activity was to introduce ourselves by passing a happy-face ping pong ball to each other; this was followed by reviewing rules of conduct and personalizing their mystery bag. Activities were held as mini-breaks when a discussion theme was complete or when the children's focus began to wander; these activities included mystery bag decorating, bedsheet ping-pong, drawing, and sculpture making. The mystery bags were then given to me, and then and I put in a schedule of questions that I asked to clarify and confirm domains, taxonomy (roles) and components (attributes of the domains) previously noted in phase I. I gave children a piece of paper each with illustrations and text that represented domains identified in phase I; this paper was for them to review and edit through writing, drawing and discussion. Overall the children were very talkative amongst each other, took turns, shared jokes, praised each other's ideas and spoke respectfully when they disagreed. As the validation interview progressed, the children talked mostly amongst themselves with me guiding the conversation from the sidelines and the recorder primarily observing.

One of the participants had to leave the session after one hour given a previous commitment; she indicated she was happy to attend the interview and was reluctant to leave the session even though she was looking forward to attending a friend's birthday party. The session ended after one hour and fifteen minutes. At the end of the session, the two remaining children asked if they could bring in their parents to share ideas they had generated. Each child spent 10-15 minutes enthusiastically presenting to his or her parents including explaining the domains, interpreting how these domains were connected, and strategies regarding how to enhance children's partnership role in FCC; these ideas were consistent with what they had shared with the facilitator and recorder. Parents conveyed enthusiasm for their child's efforts, and the children left the session expressing that they were very "proud" and "happy" about the work they had done, and that they wanted to stay involved in this project.

Three children were recruited for the second validation interview session; however one child cancelled a few days before the interview and another child did not show up to the session despite confirmation. Thus the second validation interview session was held with one child (age 8) who had a chronic illness. This presented a unique challenge as I hoped to have the children converse with each other and collaboratively come up with strategies. Faced with this challenge, the recorder and I adapted our approach and we used play to enhance the child's self-expression as an expert informant. The recorder and I became the messengers for the first validation interview participants, and their ideas were communicated using similar language with this child. This child was asked to consider ideas generated in the first validation interview session and comment if the ideas made sense to him (or not), what strategies he agreed with (or not) and what new ideas he had. When the child's mother came to pick him up at the end of the session, this child spent 15 minutes excitedly sharing his ideas with his mother; these ideas were consistent with what he had shared with the recorder and me.

This child was seated at the table with a variety of colourful activities that he could select when thinking about his responses. These supplies included paper, mystery bags, bubble, multi-coloured markers, happy face ping pong balls, tactile shaping materials (FLOAM™), sticky backed foam letters, and pictures These activities were similar to those used in the first validation interview session, but the difference was that they were used more at the discretion and self-direction of the child. While the child seemed to be at ease with both adults in the room, he focused on shaping his FLOAM™ characters when working out his ideas and kept his eyes on these characters; then he eagerly made eye contact with the facilitator or recorder whenever he felt he had come up with a particular strategy. This was recognized to be similar to play used with puppets when children speak to the inanimate object in an effort to comfortably support their self-expression (Morgan, Gibbs, Maxwell, & Britten, 2002).

A third validation interview session was not held for several reasons. The two validation interview groups served the research purpose as strategies were generated and confirmed by informants. Thus a third interview session was not considered necessary. However since the other children were promised an opportunity to participate, this offer was made. Unfortunately, there were coordination difficulties for the remaining children and a suitable date could not be confirmed.

Analysis

Domain Analysis

I analyzed data as per Spradley's (1979) developmental research sequence and analyzed interviews in an iterative manner. Through constant comparison, *domain analysis* was used to ascribe names to key issues raised by the children while leaving open categories for new domains. When children provided greater detail on the structure of these domains this was further interpreted with a *taxonomic analysis* to interpret the internal structure. Symbolic meaning of domains and how meanings related to other domains regarding similarities and differences was interpreted through *componential analysis* of domain attributes. Broader *cultural themes* were recognized when domains were connected in a meaningful way, and this represented the children's "cognitive map" (p.7). I verified and analyzed children's beliefs with consideration to open and prestructured categories based on key elements of the FCC concept (Institute of Family Centered Care, 2008).

Domains are symbolic categories of meaning that share certain qualities. A domain includes three elements: cover term (key category heading), included term (different terms that represent the key cover term), and relationship term (unifying semantics that connect the cover and included terms) (Spradley, 1979). Through domain analysis, I regarded child informants as "guiding the mode of inquiry and orientation of the investigator" (Altheide, 1987, p. 66) by describing their held meanings about their role in the everyday context of their chronic illness in FCC. I directly interpreted and verified children's input to ensure that their voice was primary; I iteratively analyzed their input as a constant comparison with consideration to open and prestructured categories based on key elements of the FCC concept (Institute for Family Centered Care, 2005). I used open coding in the first interview to establish initial thematic groupings that had shared semantic relationships. I determined semantic relationships by examining how children's terms were related to other terms including common characteristics, and what these terms meant to children. Semantic relationships and shared meanings of terms included "strict inclusion, spatial, cause-effect, rationale, location for action, function, means-end, sequence and attribution" (Spradley, 1979, p. 111). Subsequent interviews were analyzed with a combination of open and established domain categories; these established domain categories were refined through constant comparison with each interview. I applied constant comparison technique to analyze data by manifest meanings of words and phrases by first developing category sets and criteria for sorting data. Once these basic sets were established, I then refined and related possible domain category sets and emerging sub-categories through analysis of each subsequent data set. Open coding in the first interview was used to establish initial thematic groupings that had shared semantic relationships. I verified key domains with children and generated initial identification of taxonomy (structure and organization) and components (attributes) of cultural themes (overall beliefs and behavioural rules) (Spradley, 1979). I named these domains based on children's words and phrases and established domain category definitions given their explanations (Altheide, 1987; Priest, Roberts, & Woods, 2002; Spradley, 1979).

Ethnographic Content Analysis

I sought further understanding of domains in all phases through ethnographic content analysis (Altheide, 1987; Priest et al., 2002). I used ECA along with domain analysis as the "reflexive analysis of documents" (Altheide, 1987, p. 65) that combined ethnography with content analysis (Smith, Sells, & Clevenger, 1994). I used ECA to provide further systematic verification of text, and "to document and understand the communication of meaning, as well as to verify theoretical relationships" (Altheide, 1987, p. 68). This included a triangulation of data collected from institutional documents relevant to children's partnership role. ECA differs from quantitative content analysis (QCA) in several ways. First, I reported the frequency of themes to reflect intensity rather than importance since discovery and verification of divergent and convergent themes were recognized to be valuable. This differs from QCA where the aim is to verify data reliability by counting words and phrases, and attributing significance to themes with greater frequency (Altheide, 1987). Second, I used ECA with prestructured and open categories for sorting themes that emerged from the data through "constant discovery and constant comparison" (Altheide, 1987, p. 68). By contrast, QCA is used with only predetermined categories to which words and phrases are inserted. ECA is also aligned with Spradley's (1979) ethnographic interview and analysis process outlined above. I applied ECA with a constant comparison technique similar to grounded theory. However, I noted that the difference between these methods is in the foundational research purpose, as systematic ethnography describes the everyday symbolic meanings held by a cultural group, whereas grounded theory researchers seek to develop a "substantive-level theory" (Creswell, 1998, p. 57) to be further scrutinized by empirical testing.

Phase I

Children identified the basic domains of their partnership role in FCC and I analyzed their comments as directly as manifest content; no latent interpretive analysis was used. I used ECA to further verify domains and quantify themes related to the structure (taxonomy) of domains. I did manual coding and qualitative data analysis software coding with Atlas.ti™. I supported this with a code book that had defined connected words and themes, and was used to quantify and qualify emerging patterns. I read and reread my field notes when reviewing interview transcripts to support my analysis.

Phase II

I located and verified the domains that children identified in phase I in the documents reviewed with open categories for new or emerging themes. I looked for the domain term used by children within each of the documents. I used WORD™ software "find" function to locate these exact terms; when an exact term was not located I then looked for synonyms and highlighted these words. Once these terms were located, I then read the whole document to understand the broader meaning of the policy or legislation. Then I went back to the document and looked for how these terms were used and if this was relevant to what the children had described. For example, the term 'respect' had different meanings in legal documents. Then I categorized how these documents reflected children's understanding of their partnership role in FCC by identifying elements from each document that were in accordance with domains identified by children. I interpreted institutional document data along with domains identified in phase I and III to provide a coherent structure for understanding how the healthcare context matched with children's understanding of their partnership role within FCC of their chronic illness.

Phase III

I verified phase I domains with children and sought their input on how to operationalize FCC domains to practice. I interpreted children's input directly as manifest content. I confirmed findings from phase I interviews, and compared with guidelines located in the phase II document review. I used institutional document data to match healthcare context with strategies generated by children in phase III to support their partnership roles. I recognized saturation of themes when no further insight was gained in the analysis of text around a particular category, thus conveying that the data was interpreted to the fullest extent (Creswell, 1998, p. 57).

Data Quality

I established data quality through application of the criteria for *trustworthiness* of qualitative research (Berg 2001; Lincoln & Guba, 1985). I established *credibility* or internal truth related to accuracy of data collected through ongoing verification with children, triangulation of data (correlation of interviews and document review), and triangulation of investigators (I did the interpretation with my advisor). I established *transferability* or external truth-value by providing detailed description of the children's views through coding based on a conceptual framework of FCC and through purposive sampling to ensure variability of participants that represented a wide array of experiences. I established *dependability* or consistency of measure by comparing data at different collection points, and consistent application of analytic framework throughout all three research phases. I supported *confirmability* through data rules for analysis as outlined in the code-book and clarity in reporting the audit trail of data collection. The audit trail included routine updates regarding research activities, preparation, and communication with doctoral committee members, as well as field notes from interviews. I also developed a schedule of questions aligned with children's views of FCC to guide institutional data collection (based on phase I findings) and phase III validation interview questions (based on phase I & II findings).

Ethical Considerations for Conducting Research with Children

As I recruited children to participate as informants in this study, I considered their status as potentially vulnerable subjects. I engaged children and parents in an informed consent process. First I established informed consent with the children's parent(s) given their "legal entitlement and decisional capacity" (Kuther, 2003, p. 343) as guardian to the child, and conducted through discussion and review of a detailed written consent form. Next I established assent with the children through discussion and review of a detailed consent form and I presented the research process in an appropriate language given their developmental capacity. Involvement of the children in the *assent* process was necessary to address "the need for a middle ground between autonomous consent and no involvement in the consent process" (Lind et al., 2003, p.506). Since I regarded and respected children as active partners in their care, if they chose not to participate in the study (regardless of their parent's consent) I did not accept their involvement. I set aside adequate time prior to interviews to ensure that the children understood their invited role in the research process. Furthermore, I was prepared on how to conduct interviews with children and included this approach in the research protocol (Bricher, 1999; Cameron, 2005; Morgan et al., 2002).

I upheld ethical standards of the Calgary Health Region, University of Calgary (2000), and Tri-Council (2003). Approval for this research study was obtained from the University of Calgary, Office of Medical Bioethics (see Appendix L). *Free and informed consent* was a priority in that children's capacity, comprehension, and voluntariness was protected through provision of cover letters explaining the purpose and process of the interview. I provided a consent form prior to and at the time of interview, and assessed the child's capacity to assent based on my years of clinical practice experience with children who have chronic illness. If the child indicated a desire to end the interview, I would remind the child to "push the red button" to turn off the tape recorder and we would stop the interview. I made strict efforts to maintain *privacy and confidentiality by removing* all identifying information from tapes and transcripts and using pseudonyms in the final research report. Personal demographics were limited to only those needed to permit description of the sample. I reviewed rules regarding respect and confidentiality with parents and children prior to starting the validation interview and did not share children's comments and transcripts with their parents. Data storage was in a locked cupboard within an office at Mount Royal College during data collection and analysis, and will go to the University of Calgary for long term storage, to be destroyed in seven years after study completion

During the consent process I clearly outlined *risks and benefits* by stating the potential *negative effects* related to anonymity that might be associated with knowing other participants in group discussion, and *positive effects* related to the collaborative effort to explore the unknown and create effective strategies to enhance partnership role for children who receive care in child health programs for their chronic illness. The methods did not present a known burden to children as unstructured interviews were held at the their preferred location (home or hospital), and validation interviews were held at a familiar location at the Alberta Children's Hospital. Also, interviews remained confidential so that children's responses were freely given, and not influenced by potential concerns related to sharing such information directly with their parents.

Engagement Considerations for Conducting Research with Children

I used ethical considerations when carrying out research with children as a foundation for engagement with children during the interview process. For example, treating children and parents consistently with respect and dignity created mutual honouring and trust prior to, during and after the interviews. While treating families with respect and dignity upheld my own nursing ethical standards (Canadian Nurses Association, 2002), this also enhanced a sense of trust with both children and parents. This was important for several reasons. I conducted interviews alone with children, thus parents and children alike needed to feel as though I could be trusted accordingly. Furthermore, since children's input was confidential and not shared with parents, I had to be trusted by parents and children that I would proceed according to ethical principles. The consent process served as a meaningful way to engage children in my study as together we were able to clarify their purpose, outline interview process, and detail how their input would be shared. Children thus knew what to expect and had trust in me as the researcher to carry out these promises.

To create an atmosphere of respect and valuing, I used introductory activities and messages that welcomed the child's perspective and reinforced that the child was indeed in charge of the interview and could stop at any time. During the interview itself, I used terminology similar to the child's and verified their messages through continual "probing and clarifying" (Morgan, Gibbs, Maxwell, & Britten, 2002, p. 11). One of the challenges of interviewing children was staying true to their voice without imposing an academic structure. Ongoing clarification served to verify responses from the children's perspective and validated that their contribution was legitimate and valued. This was important given that this age group is not typically given credit for what they have to say. Finally, I assured children that they would decide when the interview would end; they were in charge of the interview tape recorder and were shown how to turn it on and off. These approaches helped me to conduct interviews with children in a manner that was effective and consistent with my research purpose.

Research Methods Summary

I adhered to the process of systematic ethnography and ethical principles as reflected in recruitment, data collection and analysis. By exploring a variety of ethnographic approaches and related methods, I was able to appraise the best fit for investigating this problem and purpose with regard to philosophical, methodological, and practical issues. My application of systematic ethnography supported an inquiry that described children's cultural knowledge or "cognitive map" (Spradley, 1979, p.7) while linking and expanding existing FCC theory and further matching this understanding to the institutional context of the health care system. In phase I, I conducted unstructured interviews with children to identify the basic elements or domains of how they understood their partnership role in FCC. In phase II, I carried out a document review of legislation and institutional policies relevant to the research problem and domains identified in phase I. In phase III, I held validation interviews with children to confirm domains from phase I and to generate strategies regarding how their notion of FCC may be upheld in practice. I used results from each stage to inform data collection for the succeeding research process as each stage of the three phases of data collection incorporated emerging domains. I used domain analysis (Spradley, 1979) and ethnographic content analysis (Altheide, 1987) to interpret manifest content from interviews and document review. I facilitated trust with children and families throughout the research process by upholding ethical and engagement considerations for conducting research with children.

CHAPTER FOUR: RESEARCH FINDINGS

In this chapter, I discuss findings from domain and ethnographic content analysis of how children understand their partnership role in FCC. I share 3 phases of research findings including unstructured interviews that explored how children understand FCC, document review that determined how policies were aligned with children's views, and validation interviews that generated strategies on ways to support FCC. In this discussion I describe the study context so that my role, informants' role, and process may be located by a description of contextual factors (Altheide, 1987).

At this point, a word about the reporting of results is necessary. In many forms of qualitative research, the findings are generally illustrated by direct quotes. These are often lengthy and detailed, and serve to enrich understanding. While it is recognized that this is a useful strategy to making the results more interesting, readable and accessible, in this instance a deliberate decision was made to avoid such lengthy quotes. I made this decision given ethical considerations because such details may be easily linked to the small community of my informants. Furthermore, an important part of maintaining confidentiality with these children included not telling parents what their children had to say. Had I cited children's lengthy direct quotes, there was a high probability that parents could have identified their children, thus constituting a breach of confidentiality. Therefore it was decided to sacrifice some richness of description for the interests of confidentiality.

Timeline

I started this research process by sharing introductory study information with the manager for the Southern Alberta Child and Youth Network and outpatient nurses. This initial information sharing was followed by recruitment of informants from outpatient clinics in November 2006. I initiated data collection in January 2007 with completion by the end of May 2007. Phase I unstructured interviews were held in January and February, document review in March and April, and validation interviews in May 2007. While data collection was conducted over three sequential phases, I used iterative analysis and constant comparison of findings to guide ongoing development of domain coding categories and interview questions. In analysis of interviews, I made stringent efforts not to interpret beyond what they said, actively working on providing a straightforward analysis of their input.

Phase I

How Children Understand FCC

The first step in phase I analysis was to identify key domains (symbolic categories) or main issues that shared certain qualities about how children understand their partnership role in FCC. The key domains that emerged from unstructured interviews included: *me and my best interests, virtues, talking and listening, being involved, knowing, making decisions and being connected.* These seven domains (see Appendix M) included three elements: cover term (key category heading), included term (different terms that represent the key cover term), and relationship term (unifying semantics that connected the cover and included terms) (Spradley, 1979). Children's interpretation of each domain will be described in the following sections. These domains were identified from children's partnership stories thus making various persons' roles apparent and appropriate for initial taxonomic (structure) and componential (attributes) analysis within this domain; they also identified a cultural theme (relationship of meanings) that held the domains together (Spradley, 1979). Saturation of domains was noted after six interviews; however I carried out two additional interviews as these were pre-arranged and parents conveyed that the children were "looking forward to" participating in the study. Once domain analysis was conducted, I applied ethnographic content analysis (ECA) (Altheide, 1987) as a constant comparison of domains with subsequent refinement of category sets. Children described these domains as an interconnected whole represented by a "*treasure map*" with taxonomic roles identified related to persons and components (attributes) regarding *things I do, things we all do* and *things other do* (see Appendix N). These roles were coded and the number of comments related to each domain were noted as part of ECA. Children confirmed the domains and associated symbols in phase I as follows: *my best interests (*compass), *virtues (*shield for protection) and *being connected (*chain). At this point they identified a symbol for and provided a verbal description of what the domain should look like as a graphic representation. I confirmed their ideas through verbal discussion, and then one key informant developed graphic symbols that were verified and refined by a second key informant. The remaining domain symbols were identified and confirmed in phase III.

Domain Confirmation with Key Informants

Prior to conducting interviews with key informants, I completed the analysis from all 8 interviews and noted children's identified domains in a concept map (see Appendix O) regarding how they understood their partnership role in FCC. Both key informant interviews were held at the children's home as per their request. I reviewed findings from phase I with the first key informant who clarified and collapsed domain categories while I listened attentively to his rationale. In his explanation of how domains fit together, this key informant took up an ideas presented by other children and drew the domains with graphic symbols on a treasure map (see Appendix P). His criticism of my concept map was that it was not interesting and would not be an effective teaching tool; he also shared that the children's summary was reflected more accurately as a treasure map given that FCC was a team process that involved problem solving with a similar goal like "finding treasure." During the interview with the second key informant, she reviewed, clarified and confirmed the treasure map and domain symbols; she was enthusiastic about the treasure map and verified that this was an accurate representation of how children understand FCC. The two key informants also participated later on in dissemination of findings at a youth committee meeting held at the Alberta Children's Hospital, and this meeting will be discussed in an upcoming section.

How Children Understand the Seven Domains

1. My Best Interests. Children indicated that this domain was at the centre of their chronic illness experience in partnership with others. As one child put it, "the whole team thinks of my best interests while they are working together." One child described *my best* *interests* symbolically as a "compass" for providing direction when problem solving as part of a team; this representation was confirmed by subsequent children. Children identified initial taxonomies revealing that their best interests were met by various persons (self, mom, dad, sibling, grandparent, cousin, friend, teacher, and health care provider) in various places (home, neighbourhood, school, and hospital). All children shared stories about how their best interests were met, or not met, most often by mom, dad, and teacher or healthcare provider. ECA was used to verify the most significant person being mom as both advocate and "the boss of me"; mom was mentioned 102 times in all seven domains (see Appendix N). Components (attributes) associated with such roles will be further discussed in the following sections.

2. *Virtues.* This domain was first identified as 'being nice' in initial interviews; however children shared that this was a quality of intrinsic worth that could be seen in behaviours, and therefore was more than just an action. A child shared that "we all need to do our best work and be respectful and trustworthy. These are like virtues." Children emphasized that virtues represent a way of being from a personal and interpersonal stance. When describing virtues and the taxonomy of related roles, children identified a componential distinction of attributes regarding *things we all do* (being trustworthy, being respectful and nice, doing our best work, and trusting each other) and *things that others do* (protect me). ECA was used to reveal that the persons associated with the importance of *being nice* were children themselves (n=2), doctors (n=3) and nurses (n=5). One child expressed that "when the doctor speaks nicely to me I feel secure."

Moreover, another child described that when these virtues came together it felt like a "protection shield"; subsequent children confirmed this notion.

3. Talking and Listening. Children recognized *talking and listening* as distinct yet interconnected elements of communication. Children spoke about the value of having a turn to talk when working with adults in their care. They conveyed, "the most important person is the one doing the talking"*;* thus, they required a turn to talk in order to feel like valued partners in care. Children also acknowledged the need to balance talking with listening when working together. Several children echoed, "It's important that we listen to everybody."

They described a communication barrier in that children and adults did not take turns the same way. Children identified that their communication rules in the school setting reinforced the need to first *listen* then put up their hand to take turns *talking*, whereas they observed their parents and healthcare providers interrupting each other. Given this pattern, children identified that it was difficult at times to communicate with parents and healthcare providers as they felt it might be rude to interrupt an adult. Despite this underlying feeling, some children shared that they would nonetheless "speak up" when something was important. Once child described that he would also choose to talk "if it was really really really important to tell, but if it wasn't really important I probably wouldn't tell." All children described a difference in domain components (attributes) between pretending to listen and pretending not to listen. One girl remarked that "I just listen to what is important...sometimes I listen and sometimes I don't." When describing talking and listening as related to taxonomy (roles) within this domain, children distinguished between *things I do* and *things we all do*. This distinction was notable, as children did not identify *things others do* which would indicate that children were not part of the communication process at times; rather they described themselves as part of this process even when they were not being listened to, as they were aware that the outcome of such conversations may affect them. ECA revealed that when children spoke of "listening to what's important" that they felt this was exclusively a job for healthcare providers (n=9), whereas those persons who needed to "listen to me" were broader and included healthcare providers (n=4) and friends (n=6) alike.

4. Being involved. Children articulated that *being involved* made them feel significant. One child stated "when I get involved…in control I feel strong…ooh like I have power." They also indicated at times they wanted to have their parents do the health and illness related work for them so they could "just be a kid." This notion of being a kid was related to wanting "freedom" to focus on "normal kid things" like playing with friends, schoolwork, and "not worrying." They spoke about the tension between having the freedom to "just be a kid" and the benefits of taking on some responsibility in their healthcare. Children were able to resolve this tension when speaking about being involved but not being alone in the care of their chronic illness; they envisioned self-care as part of a collaborative team. However a barrier to this vision was noted once again when children talked about how they did not know how to be partners with adults in their healthcare. One child identified a concern that he was "never taught how to work with grown-ups so it's hard to know how to join the group." When describing *being involved* as related to roles, children distinguished between *things I do* (i.e. care of me by me;

n=22), *things we all do* (i.e. care of me with others; n=21) and *things others do* (i.e. care of me by others). *Things I do* included asking questions, taking medication at home and school (but not in hospital) and putting on splints. *Things we all do* included getting infusion supplies ready and going to appointments. *Things others do for me* included parents and healthcare providers coordinating care for the child and getting intravenous needles inserted.

5. Knowing. Children expressed a need for self-knowledge and key information that parents, teachers and healthcare providers required about their chronic illness. One child was quite pointed in his remark that "I need to know the important stuff" related to assessment, treatment and plans that will affect the child's ability to "just be a kid." Children spoke of wanting to know about their illness but within the context of what matters to them on a daily basis. While they talked about wanting to know about their disease and treatment, they specified that this should be limited to essential information that was useful and relevant to their ability to play, go to school and "do things with friends." Children also spoke of how they learned most often through experience and reflection on their own (n=28), with their friends (n=7) and with healthcare providers (n=3). Their two key information sources were mom (n=10) and the doctor (n=9).

They also spoke about the importance of knowledge that others had regarding their illness. While they felt that adult providers were expected and should be trusted to have their own adequate knowledge about the child's healthcare, children talked about their need to know about their illness and assume responsibility to teach school friends about their illness and what they require. Children stated that they would "teach" friends about their health and illness related needs (n=9) because they spent considerable time with their friends. They recognized the importance of having key information as part of a treatment plan if a health problem occurred while they were in the community or school setting. While the person who most often assisted them was their mom (n=17), children indicated that they might also need the assistance of others if a problem arose. In particular, several children described their experiences of going to the school office to call their mom, and how this went smoothly if the teacher and principal had knowledge about the child's illness and needs. "They [friends and teachers] need to know about me so I get help when I need it." Overall children recognized that *knowing* was key to *making decisions*.

6. Making decisions. Children identified that their role as decision makers was highly contextualized. While several children remarked that "I am the boss of me", this was often followed by "it depends on the situation." When describing *making decisions* as related to roles, children distinguished between "things I do" (i.e. put splints on, report to the school office if help is needed) "things we all do" (i.e. talk about treatment decisions). Children also recognized that "things others do for me" occurred when "grown-ups" ignored their contribution: one child expressed "and they just make the decision and I can't stop it." One child specified that "grown-ups" would take over decision-making when "things are really big." Children identified that they needed to have an active role so that their viewpoint and wishes could be part of the decision-making process. However, while children recognized that they had an active role to play in making decisions, all children expressed a fear related to making decisions on their own. One child shared that“ I do the right thing but I'm really scared of the right thing to do.” Children agreed that they could be in charge of decision-making when they were knowledgeable about the situation at hand. They also speculated that while their emerging independence with age would require them to make more decisions on their own, they recognized that working with their support persons would help them make more informed decisions. What stood out for me was when one child explained that “I would never ever make an important decision by myself even if I was a grown-up … why would I ever do this by myself no matter how old I get? It doesn't prove anything.”

7. Being connected. Children understood *being connected* as a requirement to work together as shared by all persons in their chronic illness care. While they recognized this connection, they also distinguished that care partnerships may be effective or ineffective: “just because you are on a team does not mean that you are good at it.” Children shared stories of working with parents, teachers and healthcare providers regarding effective and ineffective processes and the subsequent impact. They expressed that all persons had an important collaborative role in the child's care because “everyone is all connected just like a chain you know …and without all the parts connected everything shatters.” For example, parental advocacy during children's appointments was seen as supportive; conversely, when parents and healthcare providers were arguing and not getting along then children felt more vulnerable. Children expressed that it was important to “make sure everybody works together to keep me safe.” When describing *being connected* as related to roles, children distinguished between “things we all do” (i.e. different jobs that work together, knowing how to work together) and “things others do for me” (i.e. support me). “It’s like holding onto a chain. They have to make it even and they have to make the same weight go on the chain so that if they pull it… but if the chain breaks then they really can’t work together.”

Phase II

The documents reviewed were described briefly in Chapter Three. In this section I will give a general overview of the content of each document to show its overall nature and intent. In the subsequent section I will then follow with findings from each document as related to the domains in phase I (see Appendix Q).

Provincial Legislation document review included:

- *Child, Youth and Family Enhancement Act* (Government of Alberta, 2007a), specifies the nature of child protection and guardian duties pertaining to how the child’s well-being related to provision of necessities, essential health care and adequate supervision must be upheld.

- *Freedom of Information and Privacy Protection* (Government of Alberta, 2006) outlines children’s rights regarding privacy and accessing personal information. The act does not indicate a minimum age, therefore children may request access to their information. Guardians may also request information regarding the child in their care; this may be granted if the request does not present an unreasonable invasion of the child’s privacy. Protection of children’s personal information (i.e. report cards, specialist consults and class lists) in the school setting is regulated by this legislation, whereas hospital records are covered under the Health Information Act.

- *Health Information Act* (Government of Alberta, 2007b) defines children's rights to access their personal health information from regional health authorities. Children may request information provided that "they understand the nature of the right to consent to the release of health information and the consequences of consenting to the release of information" (Office of the Information and Privacy Commissioner of Alberta, 2002). Again, guardians may request information regarding the child in their care provided the request does not present an unreasonable invasion of the child's privacy.

- *School Act* (Government of Alberta, 2007c) outlines children's rights to education in a "safe and caring environment that fosters and maintains respectful and responsible behaviours" as per Section 45(1)8. This legislation includes children's rights to special education programs and resources given their unique "behavioural, communicational, intellectual, learning or physical characteristics" as per Section 47(1).

- *Human Rights, Citizenship and Multiculturalism Act* (Government of Alberta, 2007d) outlines rights and responsibilities for all children related to "race, religious beliefs, colour, gender, physical disability, mental disability, age, ancestry, place of origin, marital status, source of income or family status" as per Section 16(1). This legislation is considered primal and thus all other provincial acts are subject to this particular act. While children's rights are represented within this legislation, children are required to file complaints with a supervising adult (not necessarily a guardian) until they reach 16-years of age. Children may not use age as a basis of their complaint for tenancy or goods and services (including healthcare) (personal communication, Mike McQuade, Human Rights Officer, December 4, 2007).

- *Family Law Act* (Government of Alberta, 2007e) defines responsibilities of guardians regarding the child's best interests. The key feature of interest within this document is around how the best interests of the child are determined.

Federal Legislation document review included:

- *Charter of Rights and Freedoms, Part 1- Constitution Act, 1982* (Department of Justice Canada, 1982/n.d.) outlines children's civil liberties in that "everyone has the following fundamental freedoms: (*a*) freedom of conscience and religion. (*b*) freedom of thought, belief, opinion and expression, including freedom of the press and other means of communication. (*c*) freedom of peaceful assembly; and (*d*) freedom of association.." Children are recognized as having the right to "equal protection and equal benefit of the law"(Section 15) irrespective of age or disability. Furthermore, children's best interests are viewed as foundational and parental rights are protected given that parents will uphold their child's best interests (Zucker, Hammond & Flynn, 2005, p.91-95).

Calgary Health Region document review included:

- *Consent for Treatment, Special Procedure and Intervivos Gifts for Transplant Policy #1414* (Calgary Health Region, 2002a) summarizes that children (unless deemed to be a mature minor) are not recognized to have the capacity to give consent; no connecting policies were located that denoted the child's corresponding role in the assent process. Mature minors are children who have "satisfied the physician obtaining consent" (p. 5) that they fully understand the proposed benefits and risks of treatment/no treatment. The capacity of mature minors to give consent is recognized as an ability to ask relevant questions and provide clear, consistent answers with a demonstrated understanding of benefits and risks of treatment vs. no treatment. Obtaining consent is the responsibility of the physician unless another healthcare professional was primarily responsible for the procedure.

- *Protection and Privacy of Health and Personal Information #1471* (Calgary Health Region, 2002b) indicates that children's health record information sharing is guided by the Freedom of Information and Privacy Protection Act (non-health related information) and Health Information Act (health related information). Given this legislation, children may request their own records provided that such information is reviewed with a trusted healthcare provider who understands the information and is able deal with potential questions the child may have. Nonetheless, parental consent for children's access to health records is encouraged as common practice if they are under 18-years of age. All children's health record information is confidential and accessible by health service providers on a "need to know basis" (p. 2). Family members may be given general information regarding children's "presence, location, condition, diagnosis, progress and prognosis" for that day only. Information access is contextualized and parental review of information is limited if such information is deemed to be of a sensitive nature that may put the child at risk (personal communication, Janice Lamb, ACH Release of Information Specialist, December 5, 2007).

Calgary Board of Education document review included:

- *Health Services to Students #6002* (Calgary Board of Education, 2003a) specifies that children who are deemed capable may have specific roles including taking medication at school. In fact, if capable the "student will be expected to assume as much responsibility as possible for the handling and administration of the medication"(p. 3). Parents and teachers also have clearly stated roles and responsibilities related to children's safety and health promotion including managing illness and emergencies.

- *Severe Allergies #6003* (Calgary Board of Education, 2003b) indicates that exposure to allergens by children with severe allergies should be minimized while also facilitating typical interactions and reasonable restrictions for peers. Children, parents, lunchroom supervisors, teachers and principals have clearly defined roles. Children with severe allergies have responsibilities including "learning to recognize symptoms of a severe allergic reaction, promptly informing a teacher or adult as soon as…exposure…or symptoms of a severe allergic reaction appear, keep…medication handy at all times, and when age appropriate, know how to…take medication"(p.2-3). Administrative strategies assumed by the principal and teachers included educating the school community and raising awareness of emergency response protocols.

International policy document review included:

- *United Nations Convention on the Rights of the Child (1989)* outlines that in accordance with the Universal Declaration of Human Rights, children's rights should be respected regardless of "race, colour, sex, language, religion, political or other opinion, national, ethnic or social origin, property, disability, birth or other status" (p. 3). Furthermore, this convention recognizes that families are "the fundamental group of society and the natural environment for the growth and well-being of all its members and particularly children (p.1). Given children's potential vulnerability and emerging developmental abilities, protection of their rights is defined to ensure their well-being. Consistent with children's "evolving capacities" (p.4) for self-care, the best interests of the child are the primary consideration (Article 3). Family and cultural practices are to be respected (Article 5) and family unity is a priority (Article 9) unless contrary to the child's best interests. Those parties involved with children are deemed responsible to maximize the "survival and development of the child" (p. 4) through their best efforts as per Article 9 and 18. Children with disabilities should be supported such that they have full opportunities to be "self-reliant" (p. 11) and live according to

> their potential as per Article 23. All children have the right to freedom of thought (Article 14), association (Article 15), and may express themselves and access information (Article 17) provided that they are respecting the rights of others (Article 13). Children also have the right to education and vocational guidance in an atmosphere that treats children with dignity (Article 28). Education programs should develop children's abilities to their fullest potential while also teaching them to respect human rights for all and treat others with dignity. Authorities caring for children should be subject to routine review of their practices (Article 25).

I examined the seven key domains regarding how children understood their role as partners in FCC in a review of public archives from Calgary Health Region, Calgary Board of Education, Government of Alberta, and Government of Canada. Documents selected for review are all active documents that are in current use. These particular documents were selected given that content was relevant to the experiences of a school-age child living with a chronic illness. For example, when I conducted this review my initial assumption was to focus on health related documents. However analysis of the transcripts revealed that children made many mentions of the school setting (n=44) as compared with home (n=8) and hospital (n=10). Thus it became apparent that the hospital setting was a relatively smaller part of the children's experiences and that school related documents should also be considered. Furthermore, I recognized how the child was situated in society and as a family member to be important features; thus legislation related to children's rights and family law were deemed germane for the purpose of this review. In this search, I considered the roles of supporting persons in different settings given the initial taxonomic distinction of roles within domains. Finally, I also included the United Nations Convention on the Rights of the Child (1989) given that tenets mirrored the seven domains identified by children in phase I. The overall purpose of this review was to see how children's seven domains and their understanding of partnership roles in FCC were reflected in institutional policies and legislation.

1. My best interests. I located the domain term *best interests* as directly stated in several documents including:

- Government of Alberta (2007e) Family Law Act was the only document located that precisely indicates how the best interests of the child are determined. Discussion is limited, but it does name best interests as being related to "their physical, psychological and emotional well being as well as …history of care of the child, the child's views and preferences...the nature and strength of existing relationships, any history of family violence, any civil or criminal proceedings that may be relevant to the child's safety or well being." (Alberta Justice, 2007).
- Government of Alberta (2007a) Child, Youth and Family Enhancement Act outlines that the best interests of the child must be central in decision making regarding the child's safety and well-being. This act identifies that the "family is the basic unit of society and its well•being should be supported and preserved…the importance of stable, permanent and nurturing relationships for the child" (Part 5, item 2, a & b). Nonetheless, the child may be removed from the

family if the child's "survival, security or development" (Part 5, item 2, e) needs are not met.

- Calgary Health Region (2002b) policy on Protection of Privacy and Health Information refers to best interests only with respect to information and disclosure. It indicates that data may be disclosed to other individuals or agencies on behalf of the person who "lacks the capacity to give consent" provided that this is in the best interests of that person.
- United Nations (1989) Convention on the Rights of the Child indicates that the child's best interests are a "primary consideration"(p. 3) to protect the child's well-being. These best interests are considered regarding decisions either to maintain family connections or separate the child from family. Furthermore, it is assumed that the child's best interests are a paramount and "basic concern" (p. 9) when considering the rights and responsibilities of parents and guardians.

The term *best interests* was highly contextualized and based on the situation at hand. Common themes around this domain were located in other documents and referred to protecting children's safety and well-being (Calgary Board of Education, 2002a,b; Department of Justice Canada, 1982/n.d.; Government of Alberta, 2007,a,b,c,d). In summary, the child's *best interests* were identified as a key priority to uphold at home, school and our broader society with shared responsibility assumed by care providers.

2. Virtues. Children described four virtues including *respect, trust, trustworthiness,* and *doing our best work.* I located the domain term described by the children regarding *respect* (and distinguished from "in respect to") within the following documents:

- Government of Alberta (2007a) Child, Youth and Family Enhancement Act points to the need to respect children's "familial, cultural, social and religious heritage" (Section 2, item i). These elements are recognized as promoting the well-being of the child and family.

- United Nations (1989) Convention on the Rights of the Child indicates that children's education should be directed at developing respect for "the child's parents…[and] cultural identity" (p. 15). the environment, and human rights for all persons irrespective of age.

While not directly specified as "*virtues,*" common themes around this domain in reference to *respect* of children's rights were located within the Charter of Rights and Freedoms (Department of Justice Canada, 1982/n.d.) and Human Rights, Citizenship and Multiculturalism Act (Government of Alberta, 2007d). The concept was extended to children's unique needs given their developmental status in the School Act (Government of Alberta, 2007c), and the United Nations (1989) Convention on the Rights of the Child. In summary, the *virtue* of respect was upheld within children's education programs and recognized as a way for government social services to support health. The virtues of *trust, trustworthy* and *doing your best work* were not located in this initial document review; my curiosity was piqued when children were speaking of "virtues" as I wondered how this became a familiar term for 7-11 year olds. When reviewing the Calgary Board of Education curriculum (Alberta Learning, 2005) I then discovered that children were familiar with virtues since character and citizenship education was based on Popov's

(2000) virtues project. Virtues were described as "the qualities of our character" (The Virtues Project, 2001) with 52 specific virtues defined to inspire safety, caring, and excellence. Of interest, children identified 3 of their own 4 key virtue themes in this domain that were also part of the Alberta Learning curriculum:

- *respect:* "...speaking and acting with courtesy... treat others with dignity and honour the rules of our family, school and nation."
- *trust:* "...having faith in someone or something. It is a positive attitude about life"
- *trustworthiness:* "... being worthy of trust. People can count on you to do your best, to keep your word and to follow through on your commitments. You do what you say you will do" (The Virtues Project, 2001, ¶ 3).

The fourth virtue theme "*doing our best work*" was similar to a combination of items from the Virtues Project (2001) that highlighted the importance of 'best work" including "caring... commitment... diligence... (and) reliability...(and) service" (¶ 3).

3. Talking and listening. I did not directly locate this domain in the documents reviewed, but did find it referred to implicitly in discussions about communication processes within children's care that involved children, parents, and service providers in the Child, Youth and Family Enhancement Act (Government of Alberta, 2007a), Calgary Board of Education policies on Health Services to Students (2003a) and Allergic Reactions (2003b). For example, the Calgary Board of Education (2003b) policy on allergic reactions provides a clear outline of communication responsibilities held by school staff, parents and children. Furthermore, the Human Rights, Citizenship and

Multiculturalism Act (Government of Alberta, 2007d) and United Nations (1989) Convention on the Rights of the Child specifies that children have the right to freely "seek, receive and impart information" (p. 7). In summary, information sharing and communication processes amongst children, parents and providers were identified in both policy and legislation documents.

4. Being Involved. I located the domain term *"involved"* as directly stated in the Calgary Health Region (2002a) policy on Consent for Treatment. This policy indicates an underlying principal that children be involved in decision-making about their health care "as their capacity permits." The Calgary Board of Education (2003a) policy on Health Services to Students specifies an expectation that students assume "as much responsibility as possible" (p.3) in the administration of their own medications in the school setting. This is contrasted with the Calgary Health Region given that no policies were located that specified how children or parents were responsible for medication administration within the hospital setting. In summary, *being involved* is specified within the Calgary Board of Education policy given explicit roles and responsibilities.

5. Knowing. I located the domain term "*know*" as stated in the Calgary Board of Education (2003b) policy on Severe Allergies. This document specifies that children with this condition need to know how to give their own medications and adults must know emergency response protocols. Furthermore, while this domain term was not directly located, terms with similar meaning regarding information sharing about children's status and healthcare were found in the Child, Youth and Family Enhancement Act (Government of Alberta, 2007a), School Act (Government of Alberta, 2007d), and

Calgary Board of Education policies on Health Services to Students (2003a), the Freedom of Information and Privacy Protection Act (2007b) and Health Information Act (Government of Alberta, 2007c). These documents have outlined processes to support children's access to their personal information related to school and health care. Finally, the United Nations (1989) Convention on the Rights of the Child specifies that children should have access to information at their developmental level to support their whole health experience including physical, mental, emotional, social, moral, and spiritual well-being (p, 8). In summary, *knowing* was specified within the Calgary Board of Education policy specific to children's self-care knowledge; furthermore, legislation is in place to support children's access to their information.

6. Making decisions. I located the domain term "*making decisions*" or "*decision making*" directly stated in several documents including:

- Government of Alberta (2007e) Family Law Act regarding the role of parents or guardians in decision-making for the child including education, religion, residence, health care and information sharing. The role of the child in decision-making was not located.

- Government of Alberta (2007a) Child, Youth and Family Enhancement Act regarding the opportunity for children to take part in decision-making about guardianship. The act specifies that if the child's opinion should be considered in the decision-making process along with other contextual factors.

- Calgary Health Region (2002a) policy on Consent for Treatment indicated that individuals fully participate in making informed decisions about their healthcare. As mentioned in the section on "*being involved,*" the document further specifies that children have the right to be involved in such decision-making "as their capacity permits."

- United Nations (1989) Convention on the Rights of the Child indicates that parents and guardians provide "direction and guidance"(p. 4) for children when they are exercising their human rights including developing their views, expressing themselves and receiving information (p.7).

7. Being connected. I did not directly locate this domain term in the documents reviewed. Nonetheless, meaning associated with this domain was found regarding collaborative caring processes. These processes recognized the need for connection between children, family, and providers (health, social services or education) in the Child, Youth and Family Enhancement Act (Government of Alberta, 2007a), School Act (Government of Alberta, 2007c), Calgary Board of Education policies on Health Services to Students (2003a) and Allergic Reactions (2003b) and the United Nations (1989) Convention on the Rights of the Child. In summary, policies and legislation specified the connection shared between children, parents and providers in supporting children's care.

Phase III

Domain Validation

In support of *credibility* as part of *trustworthiness criteria* (Lincoln & Guba, 1985), children confirmed the seven key domains through validation interviews and editing work with the treasure map. Children confirmed these domains by their responses to questions that I asked them from the "mystery bags"(see Appendix R). They also reviewed and discussed the treasure map and confirmed that domain symbols represented how they understood their partnership role in FCC. After the interviews I reviewed transcripts and field notes to provide an added check to see how the discussion matched the observations and recordings. In the developmental research sequence, data collection and analysis progressed from domain analysis (key issues), taxonomic analysis (structure), componential analysis (attributes) and identification of cultural themes (Spradley, 1979). The insight shared by children led to the identification of seven key domains, with taxonomy of roles (persons) and components (things I do, things we all do, things others do for me) and *cultural themes* stemming from the interconnectedness of the seven domains. Cultural themes are any "cognitive principle, tacit or explicit, recurrent in a number of domains and serving as a relationship" (p. 186). Children identified that the seven domains were interconnected as representing their partnership role in FCC. The "key" or guiding rule for children that connected all domains was for all partners to put "my best interests" into action. While children described qualities of what their best interests looked like in their domain identification, they expressed that putting this concept into action connected all domains. This "rule" was confirmed with children as the main belief or cultural theme identified in this study. According to my informants, actions must reflect the best interests of children as a fundamental requirement for children and adults to work together as partners in FCC.

While one child from phase I initially developed the treasure map, children in phase III all agreed that this treasure map symbolically represented their thinking and that domains were represented wholly as interconnected themes. They defined that this map represented how they understood their partnership role in FCC, and that this was a problem-solving model: "everything is about figuring things out." While no new domains were added, children had further suggestions regarding how these domains could be symbolized on the treasure map. Children confirmed the following domains and associated symbols as follows: *my best interests* (compass), *virtues* (shield for protection) and *being connected* (chain). Children expanded their symbolic representation of domains. They came up with these symbolic representations primarily through discussion; this discussion was supported by presenting each child with a piece of paper and coloured pencil crayons and sculpting FLOAM™ to promote their expression and create their own symbols while they spoke.

My best interests were represented by a *"compass," "treasure chest," and a "key."* The compass represented how to "figure out" the child's best interests; the treasure chest represented the child and their best interests. The "key" was the symbol that represented "doing the right thing" and acting in the child's best interests; this was further described as the symbol that connected all domains. Since children interpreted FCC as a problem-solving process, they specified that all persons involved in their care needed to work through all the domains on the map to earn the key that would "unlock the treasure" that represented the child and their true best interests. *Virtues* were represented by a *"shield"* that symbolized the strength of a person's character and the protection of the child by others. Children drew and described the four virtues to be represented on the shield like a crest with the words *respect, trust, trustworthy,* and *best work. Talking and listening* was represented by a graphic of *verbal communication* that symbolized the importance of taking turns. Furthermore, while children described that all domains were connected, they understood that the three domains of *best interests, virtues* and *talking and listening* were required first, and were thus represented on the treasure map as starting point on an island. This island was bridged by a "key" to the mainland that held the other domains.

The remaining four domains included *being involved, knowing, making decisions, and being connected. Being involved* was represented by four different coloured hands joined at the wrists in an interconnected square formation; the children indicated that this symbolized everyone working together and "not letting go" to "support" each other. *Knowing* was represented by a graphic illustration of *putting heads together* with a *key* in the centre symbolizing how children and those involved in FCC care need to have their own knowledge while also sharing information and expertise: "I don't know everything but I know lots about me." *Making decisions* was represented by a *maze* that symbolized the many challenging paths that children and adults may explore when making decisions while knowing that they may "hit a brick wall" and "get nowhere", or keep trying to find their way out and "get the key." *Being connected* was represented by a *chain of people* that symbolized how everyone is connected whether they are working together or not;

children described that if someone is not good at being on a team they still impact the other members. They also described that when people work well together that the chain is strong and "does what it's supposed to."

Strategies for Supporting Children's Partnership Role in FCC

Children generated three main strategies to support the FCC domains; they identified that enacting such domains represented how to carry out their partnership role in FCC. The first strategy was to further refine and disseminate the treasure map visual representation of how they understood partnership roles in FCC as an active problem solving process. The treasure map then became the basis for the remaining two strategies: an interactive workshop and an online game. I will discuss children's generated strategies in further detail below.

First, children recommended that the *treasure map* be used as a communication tool with children and providers alike to show how children understand FCC and how we can all work together. This map may be shared in several different mediums including print form, online illustration, and enlarged as an interactive art wall. Children indicated that the treasure map should be shared as a widely accessible resource that functioned as a work in progress. Children expressed that this map should not be stagnant resource, but rather an ongoing collaborative project, as they believed that the "map" would only be made "better" if "more people" contributed their understanding. Thus, they requested that when I presented the treasure map that I would also ask for feedback on "how to make it better" and provide my e-mail address for related communication. Children emphasized the importance of sharing this resource in colour so that it would not be "boring like some adult stuff."

Using the treasure map as a basis for understanding, children recommended an interactive *activity-based workshop* with "no paperwork." This workshop would be for children and providers alike to learn how to team up in FCC. Children identified that this workshop be required of children and providers since "we've never been taught" how to work together and yet "it's something that we need to do." Workshop participants should be a mix of children with chronic illness, siblings, best friends, parents, providers, and teachers. Children did not limit workshop participants to their own experience; rather, these workshops should be open to everyone. They indicated that a mix of persons with different backgrounds would probably be "better" and "more fun." The workshop should have a leader who would help participants take turns, play games and "do some pretending" about how to work together to learn about the seven domains from the treasure map.

Finally, children recommended development of an *online game and community.* They anticipated that the treasure map would be the basis for an online problem-solving game. They suggested creating a menu of problems commonly encountered by all children with a chronic illness, and another menu of problems commonly encountered by children with a particular chronic illness. Children's characters would have to solve problems by moving through all seven domains in the treasure map and earning treasure chest keys when meeting related challenges. They would "move up levels" according to age or problem difficulty, and would "get the treasure" when they solved the problem. While the child player would be the main character, participants specified that players would have to interact and solve problems in different settings with other characters like parents, siblings, friends, teachers, and health care providers throughout the game. Children identified that it was important to personalize their character to look like them and have similar issues. Children also specified that they would like to create a safe online community where they can "play other players" and "meet other kids that have the same thing." In essence, children wanted to create avatars of themselves and learn about collaborative problem-solving that may be typical of their own particular illness within a virtual community. They indicated the importance of this virtual experience as a "safe" way to learn about being responsible for making decisions and related consequences. Finally, children expressed a strong desire to connect with other children who had similar illness experiences so that they would not feel like they were isolated or "the only one with this."

Research Findings Summary

The seven key domains (*my best interests, virtues, talking and listening, being involved, knowing, making decisions, and being connected*) represented how children understood their role in FCC. Subsequent interviews with key informants confirmed these domains as represented on a treasure map with interconnecting elements. Children identified role taxonomy regarding persons involved in their care and provided initial insight regarding attributes of each domain. Children also identified domain components related to "things I do", "things we all do," and "things other do for me." The main cultural theme identified was the interconnectedness of all domains by the goal of upholding the child's best interests. A document review was conducted in phase II to determine if and how these seven domains fit within with legislation and policy that was relevant to children's FCC. All seven domains were located either directly or indirectly in both the United Nations (1989) Convention on the Rights of the Child and the Alberta Child, Youth and Family Enhancement Act (2007a); these documents are similar in that their main purpose is to support the best interests of the child. In addition, the Calgary Board of Education (2002a,b) policies clearly outlined healthcare roles, responsibility and collaboration between the principal, teacher, parent, and child. Such role clarity was not explicitly located in a policy search within the Calgary Health Region. Children recruited in phase I were invited to participate in validation interviews to verify domains and create strategies to support children's partnership role in FCC. They confirmed that the treasure map and seven domains represented how they understood their role in FCC. Children generated three strategies to support their role in FCC: treasure map handout, interactive workshop with children and care providers, and development of an online game and community based on the treasure map.

CHAPTER FIVE: DISCUSSION

In this chapter, I reflect on the study process and findings related to research, practice and theory. I start off by discussing the research process and how findings may affect future inquiry. In turn, this provides a necessary foundation for understanding FCC practice implications from the children's perspective, subsequent theoretical development, and a proposed future research program.

Reflections on the Research Process

From a research methods perspective, systematic ethnography provided a good fit with this study purpose as children's ideas were analyzed from a literal and primary perspective. I explained this purpose to the children, and upheld this approach when asking questions and verifying their responses. They told me that they understood their role as informant and teacher, whereas my role was that of researcher and learner. I believe that it was important to explicitly tell children that their expertise was valued and how their input would be interpreted and used; from that esteemed standpoint, they were able to freely clarify concepts and disagree during the research process. I was particularly moved by these children as they expressed caring deeply about participating in this study and were committed to helping me comprehend how they viewed their partnership role in FCC. Children saw me as trusted but as an outsider who required some help in understanding their viewpoint: I was one of the "grown-ups" and needed to have things explained to me so that I could know what it was like to be "a kid."

While there were challenges in conducting interviews with children who did not elaborate on their comments, such brief responses were pointed and wonderfully incisive.

This initially presented a test for me to keep the conversation flowing. My reflection of children's direct commentary in field notes and transcripts provided rich insight to how children understand the scope and limits of their FCC partnership role. I learned to examine my own assumptions regarding engaging children during conversation, and to be genuinely open to receiving pointed remarks from children. This has presented an important consideration for conducting future research interviews with this school-age population.

I learned that it was important to consider the interview purpose and subsequent differences that may arise between unstructured versus validation interviews with children. I was surprised at the attention that most children offered in their individual interviews. After a short ice-breaker activity of drawing their personal story board, school-age children participated in unstructured interviews ranging from 15-60 minutes. An unstructured approach was important as this allowed children to direct the conversation based on their ideas, level of interest, and relevance to their chronic illness partnerships stories. However, a more structured approach in the validation interviews was required to effectively channel the children's eagerness in sharing their FCC related strategies. I used a variety of interspersed activities as a way to refocus and direct children's energy and facilitate their creative freedom to generate strategies. While I placed a time limit on the validation interviews, children extended this allotment in both sessions by their impromptu invitation for their parents to come to the room while they enthusiastically presented the treasure map and their FCC strategies. In short, unstructured interviews required an icebreaker activity to help develop a relaxed atmosphere that conducive to conversation; however, validation interviews called for interspersed activities to help children to initially connect and then subsequently refocus their abundant energy to the task at hand.

One challenge came up during the interview process regarding engagement with children. During the first few interviews, two of the children who appeared to be interested in the consent process suddenly appeared quite disinterested during the interview itself. These children had multiple responses of "I don't know" to questions while sighing and looking away. To my surprise, when I asked if they wanted to end the interview, both children indicated that they wished to continue. While I had years of experience as a pediatric nurse, this was my first experience conducting research interviews with children. Fortunately, I quickly learned that the embellishments I was accustomed to being offered by adults during interviews were greatly contrasted by the brief and pointed remarks shared by children. I recognized that I needed to learn how to listen to their blatant messages and respond to them in a similarly unabashed manner. Once I figured this out, my interviews flowed with greater ease and I was better able to appreciate and verify children's insight regarding how they understood their partnership role in FCC. My ability to problem-solve was supported by my ongoing reflection on my experience as a pediatric nurse and as the mother of two children.

I also recognized that there were differences between home versus hospital-based settings when interviewing children. In this research study, I held two individual unstructured interviews in the hospital setting, and the other six interviews at the child's home (kitchen or livingroom) as per their indicated preference; I held validation interviews at the hospital. I encountered fewer interruptions in the hospital setting, and the children's attention was highly focused compared to interviews conducted in the home setting. This seemed reasonable given distractions present in the home setting that ranged from doorbells, telephones ringing, pets, and family members entering and exiting the interview space. While there were obvious benefits to conducing interviews in a more quiet and controlled hospital setting, the advantage of interviewing at home was noted in the child's connection of their stories to their immediate environment: more stories about school and home were shared by children interviewed in their home setting.

In terms of process, children expressed interest and excitement that their interviews were "important enough" to be recorded and reported. I was somewhat surprised that children were actively engaged (sometimes more than their parents) and asked at least one question during the informed consent/assent process prior to starting the interviews. I wondered if this was related to my approach as I spoke to the child as the primary person, and then clarified issues with parents as required. Children also indicated feeling "like the boss" because they were able to start, restart, and end the interview at their discretion as they were in control of the tape recorder. Children were motivated to learn how to work the small voice recorder "just like a secret agent" and push the red stop button when they decided to end the interview. Thus, when given the opportunity to participate as a partner in research interviews, school-age children demonstrated their interest and ability to engage in this kind of inquiry as self-determining informants.

In phase I and phase III unstructured interviews, I recognized that there were limitations as data collection and analysis emphasized children's statements. While this was the intended research process, my field notes and reflective writings were used to provide greater context to these interviews. In phase III, I also recognized a limitation in that only one child attended the scheduled validation interview. While this child did not have peers present to share ideas with, he was nonetheless able to confirm domains and recommend strategies as presented by previous informants. Also, I could not rule out potential response bias cannot since I knew two of the children given my previous role as their outpatient hemophilia nurse clinician. My use of purposive sampling and small number of participants limits the generalizability of this study. Findings from the phase II document review were also limited in that policies and legislation relevant to the children's experience were selected and thereby primarily restricted to a regional and provincial perspective.

Practice Implications

In phase I, children identified seven domains that represented their understanding of FCC partnership roles in their chronic illness care. Children provided recommendations to support how they believe FCC should be practiced by children, parents, and providers alike. While their recommendations for practice may appear simplistic, these suggestions were nonetheless congruent with theories on collaborative partnerships and interdisciplinary teamwork. Moreover, it was striking that children's pointed recommendations were not observed by children as consistently practiced by adult care providers in their FCC healthcare experiences. I will first summarize their practice recommendations based on the seven domains. Then I will outline three key strategies that were put forth by children in phase III.

Practice Implications Related to Seven Domains

1. *My best interests.* Children indicated that the starting point for effective FCC partnerships in their chronic illness care was based on recognizing and upholding their best interests. This was seen as providing direction and foundation for good communication, trust, informed decision making and collaborative teamwork. While children agreed that their chronic illness care was "all about me", they articulated that caregivers such as parents, teachers and healthcare providers may have different views regarding what these best interests may be. From this standpoint, children expressed that an important consideration for practice was to clarify FCC partners' beliefs (including the child's perspective) and how this reflected the best interests of the child. Furthermore, children relied on parents to help them identify and uphold their best interests. Children also identified some inherent challenges as they were often taught to "listen" and "not disagree" with their parents. Therefore it was also recommended that children's *best interests* be supported by facilitating an opportunity for parent-child collaboration as an integral part of assessment, planning, and treatment.

2. *Virtues.* Children identified four main character qualities that were required in themselves and others in order to be regarded as effective partners in FCC*: respect, trust, trustworthiness,* and *doing our best work.* Children specified several ways that these virtues supported partnerships in FCC. *Respect* in action was recognized as "being nice" and "treating each other nicely;" this required all partners in FCC to treat each other as valued contributors so that children feel "safe." *Trust* in action was recognized as knowing that someone was "sticking up for" the best interests of the child; this required partners in FCC to "believe in you" and rely on each other. *Trustworthiness* in action was

recognized as "doing what you say you're going to do"; this required partners in FCC to practice actions congruent with their messages including "keeping promises." *Doing our best work* was recognized literally as such and required "doing your part...working hard...getting things done on time...doing the best work you can" so that you would be "proud."

3. Talking and listening. Children identified that all FCC partners required time to talk and listen to each other. Children saw themselves as having an important role in telling others about their health and illness experiences and self-assessment. However, they saw that adults had different communication rules than children in that adults interrupted each other during discussions; children were taught that this is "rude" to do with adults so they were not sure how to engage in these discussions. Furthermore, children identified that they may or may not be given the opportunity to talk by adult partners in FCC; while their participation was sometimes based on such opportunities (or lack thereof), children indicated that they also made active choices to talk, listen, pretend to listen, and pretend not to listen. Given their experience with talking and listening in FCC of their chronic illness, children recommended facilitating group processes so that everyone followed the same rules when talking and listening: "everyone should get a turn."

4. Being involved. Children recognized that all partners in FCC had roles that were context specific. They also understood that they had an active part in their self-care and their level of involvement increased as they got older. Children stated that if they did not choose to be involved that they subsequently relinquished their voice in decision-making; they also saw that their willingness to be involved required trust of themselves and their abilities, knowledge and support network. Children felt more "in control" when choosing to be involved. Nonetheless, they also expressed feeling "scared" and "afraid" of subsequently making mistakes and harming themselves. They welcomed the input of others and recognized when they work with other FCC partners that multiple perspectives and converging expertise function as a protective factor. Children also understood that there were times when they were passive recipients of care by FCC partners; this was context specific and children felt trust in this process provided that such actions were based on the child's best interests. Given their understanding of being involved, children recommended communicating explicit FCC partnership roles including clarity regarding the child's best interests, collaborative processes, responsibilities, and accountability.

5. Knowing. Children spoke of locating information, learning from experience and "figuring out what matters" in their chronic illness care. They recognized that knowledge held by themselves and care providers influenced all domains, with particular emphasis on *being involved* and *making decisions*. They indicated that *being involved* as FCC partners and participating in "good" decision-making required supporting knowledge held by themselves and caregivers. Given these insights, it was understood that *knowing* be supported by providing children with access to required information through preferred and valid resources including parents ("I just ask my mom"), written resources and the Internet. Children often shared their illness experiences by such reflective storytelling such as "one time there was this kid that I knew…" and "there was this one time that I…." Therefore, children should be guided to actively reflect on their experiences and integrate this knowledge to inform future behaviours and collaborative health care planning.

6. Making decisions. Children distinguished making decisions on their own, with others, and decisions that others made for them. While they expressed the importance of being aware of consequences related to making decisions with others and on their behalf, they recognized that this knowledge was of particular importance as part of their emerging skills to make their own decisions. Given these insights, children recommended that *making decisions* be supported by inviting children to actively participate in everyday decision-making regarding their chronic illness care instead of doing this for them: "sometimes they just make the decision and I can't stop it." Furthermore, they suggested that children and adult FCC partners be trained to make decisions together based on the best interests of the child.

7. Being connected. Children identified that collaborating as FCC partners may be challenging, as they were not sure how to work with adults. In particular, what stood out was that FCC and collaborative partnerships are a dominant way of thinking in healthcare, and yet these children were not consistently experiencing this in practice with parents, teachers, or healthcare providers. Given these insights, children recommended that *being connected* be supported by training children and adult FCC partners to work together as an effective team since "just because you are on a team does not mean that you are good at it."

Practice Implications Related to Children's Generated Strategies

Children also identified three encompassing strategies to support all domains as interconnected elements of their FCC partnership role. These strategies were identified as follows: *treasure map, all-ages interactive workshop,* and *online game.* Children's vision of these strategies and how to implement such ideas are outlined below.

1. Treasure map: Upon reviewing the seven key domains that represented how school-age children understand FCC partnership roles in their chronic illness, children expressed that this was best represented as a treasure map with interconnected elements. This recommendation was particularly intriguing given that the underlying purpose of systematic ethnography was to develop a "cognitive map" (Spradley, 1979) of how informants symbolized and understand their world. Moreover, children's map representation of FCC partnership roles further served to verify my interpretation of their expressed understanding. Their appreciation of FCC was easily communicated amongst each other in this pictorial format. Children indicated that the use of vibrant colours and explicit connections were of particular importance in sharing their understanding with others. They indicated that the way "grown-ups" see FCC was "boring" and "only for other grown-ups" and that they believed their interpretation to be a friendlier version that could be used by everyone. In keeping with *my best interests* as providing direction, this domain was symbolized as a compass; furthermore, the pursuit of meeting *my best interests* was symbolized as a key superimposed on remaining domains that represented a unifying purpose requiring all interconnected elements to be realized. Children recommended that this treasure map be used as a teaching tool that could be posted online, shared as handouts, and enlarged as an interactive art wall at the Alberta Children's Hospital. Children indicated that a visual map at the hospital would be important as they had doubts that their parents would access this resource online. I am currently exploring this recommendation with the Southern Alberta Child and Youth Health Network (SACHYN) and the ACH Foundation. Also, children who participated in phase III indicated that they would be interested to participate in development of this resource; their parents verbally agreed to this proposed idea.

2. All-ages interactive workshop. Children recognized their limitations as they indicated that they "don't know how" to work with adults as partners in FCC. Of interest, they also indicated that they are not entirely convinced that adults know how to partner with children either. In order to address this knowledge and practice gap for all those involved in caring for children with chronic illness, children suggested that an all-ages interactive workshop provides an opportunity to learn about FCC and how this may be lived out in practice. While children saw their "treasure map" as an accurate depiction of FCC partnerships, they also indicated that this is a work in progress and that input from workshop participants on how to improve their "treasure map" supported the domain of "*doing our best work.*" Children recommended that an all-ages interactive workshop (based on the seven "treasure map" domains) be developed for the purpose of teaching children and adult providers together about FCC and how to act as partners in children's chronic illness care. There are practical realities to consider regarding how to implement this recommendation ranging from time, resources, and participants' beliefs around partnering with children. While these practical realities may present potential barriers, this recommendation will be explored with the Alberta Children's Hospital Family Centered Care committee and SACHYN. Also, children who participated in phase III indicated that they would be interested to participate in development of this resource; their parents verbally agreed to this proposed idea.

3. Online game and community. Children envisioned an *online game and community* as an extension of treasure map domains that would be applied as a problem-solving game. The premise of this game would be to have the player's character (with physical features, illnesses, family members, friends and care providers selected from a menu to resemble the player) work through all levels (domains) of the problem that had to be solved in order to meet the child's best interests; players would earn "keys" or "key activators" at each domain that would be used to open a treasure chest; opening the chest and winning the treasure symbolized the player's successful problem solving around *my best interests*. The problem to be solved around the child's best interests would also be selected from a menu to draw parallels between the child's online and chronic illness experiences; it is suggested that the problems get harder ("higher levels") as the age of the player increases. Children also saw this game as an opportunity to create an online community where they could play with other children who have similar issues. Children envisioned this online game of problem-solving through all FCC domains as a collaborative effort given that working together with FCC partners would be part of the process. This recommendation is currently being explored with the Southern Alberta Child and Youth Network at the Alberta Children's Hospital. Children who participated in phase III indicated that they would be interested to participate in development of this resource; their parents verbally agreed to this proposed idea. Of interest, all suggestions presented by children may be implemented given the information reviewed in legislation and policy documents.

Theoretical Implications

Key elements of FCC from the Institute for Family Centered Care (2008) and the seven domains of FCC presented by school-age children have a reasonable theoretical fit.

The Institute for Family Centered Care (2008) outlines four key elements of FCC: *dignity and respect, information sharing, participation, and collaboration.* Three FCC elements including *dignity and respect, information sharing, and participation* are represented within the seven FCC domains presented by school-age children; the fourth element of *collaboration* is not recognized in children's understanding of FCC and this seems reasonable given that *collaboration* at an institutional level is not typically part of children's healthcare experiences. While their conceptual understanding may be reflected in three key elements, recommendations listed in each domain present worthwhile considerations for practice application to support FCC key elements. Dignity and respect are supported by *my best interests, virtues, and talking and listening.* Information sharing is supported by *talking and listening, knowing, and making decisions.* Participation is supported by *being involved, knowing, making decisions, and being connected.* Finally, collaboration is supported by *being involved, knowing, making decisions, and being connected.* Although key FCC elements are mirrored in how children understand FCC domains, children also question how these elements are put into action given their understanding of FCC partnership in practice.

While children's understanding of FCC has a reasonable theoretical fit with the key elements of FCC (Institute for Family Centered Care, 2008), an important criticism is that existing FCC theory lacks a coherent approach to regarding the mutuality of all partners. Children's understanding of FCC is not equated with the parent as expert. Rather, children identified that FCC requires all partners to be respected with shifting expertise based on the problem at hand; this understanding may be upheld and strengthened by integrating concepts from relational autonomy (Baier, 1993), interdisciplinary practice (Orchard, Curran, & Kabene, 2005), and supportive care (Oberle & Davies, 1993). This theoretical basis may extend our current understanding and inform how FCC may be reinterpreted as mutually beneficial partnerships focused on preserving integrity. In short, the Kantian interpretation of individualistic autonomy as "I am the boss of me" was challenged; instead, children suggested that all partners work together while upholding FCC through the seven key domains as primarily guided by the best interests of the children.

How do We Understand FCC and Relational Autonomy?

FCC and relational autonomy are recognized to be congruent in theory and practice possibilities given fundamental consistencies in ways of being (contextual) and ways of knowing (socially mediated). Relational autonomy (Baier, 1993; Christman, 2004; MacDonald, 2002) in practice supports that our decision-making and actions are not disengaged but rather guided and valued as interdependent social responses; this is fundamentally different from the predominant Kantian notion of individualistic self-governance that is a fixed imperative of adulthood. Relational autonomy is more aligned with self-direction in a social context, and fits with FCC partnerships in that assessment, problem-solving, decision-making, and actions may be shared amongst children, parents, and healthcare providers. Based on this research I have come to believe that it is important to consider autonomy as a socially learned value that guides our beliefs regarding the extent of participation exercised by children as members of the healthcare team. Thus self-direction may be taught and learned throughout the lifespan, actions may be evaluated from a relational stance, and interdependency becomes valued in FCC partnerships. This is quite different from the *parent is expert* way of thinking; relational autonomy regards all FCC partners as working together and shifting expertise based on the problem at hand.

Relational autonomy opens up possibilities for us to regard children in FCC as active participants in their families and in their healthcare. This view also welcomes the expertise of children, parents and providers as collaborative partners (Gottleib, Feeley, & Dalton, 2005) given that health care governance is contextual, and FCC concepts are supported for all participants. Such an outlook acknowledges adult caregivers' responsibility to facilitate children's active role in making decisions while also affording more respect to children. What I find intriguing about relational autonomy is that by challenging the adult dominated notions of family, there are new possibilities for parents and providers to learn from children. I believe this way of thinking indicates a hallmark for collaborative practice with whole families in FCC, as it invites the perspectives of all children as active participants in FCC, including the child with the illness and "forgotten" siblings (Pfouts, 1976).

How Do We Understand FCC and Interdisciplinary Practice?

Recent Canadian initiatives in interdisciplinary education and practice (Allison, 2007; Aronson, Leischner, Manahan, Randel, & Weir, 2008; Clark, Cott, & Drinkar, 2007 Herbert, 2005) are aligned with how children understand partnerships in FCC and relational autonomy. In particular, a conceptual model developed by Orchard, Curran, and Kabene (2005) presents a worthwhile consideration to guide healthcare professionals' participation in the interactive workshops recommended by children. This model is based on "participatory, collaborative and coordinated approach to shared decision-making around health issues" (p.1). Three barriers to interdisciplinary collaboration included organizational structuralism… power relationships …and role socialization" (p. 2). A transformational change process including "sensitization, exploration, intervention and evaluation" (p.3) is recommended in alignment with enabling elements such as "role clarification…role valuing…trusting relationships…and power sharing" (p. 4). Fundamental aspects of this model are similar to how children understood FCC barriers and facilitators.

The seven FCC partnership domains identified by children are recognized within this model of interdisciplinary care. In particular, the importance of "role clarification (and)…role valuing" (p.4) is mirrored in children's understanding of the role taxonomies in each domain given "*things I do, things we all do and things other do for me.*" Children's understandings of *virtues* and *being connected* are aligned with "trusting relationships" (p.4) whereas *communicating, being involved, knowing and making decisions* are recognized within the model's representation of "power sharing" (p. 4). Given this, I believe it is important to consider how information sharing and power sharing occurs with children and adults given various roles in all healthcare settings including home, hospital, school and community.

While Orchard, Curran, and Kabene (2005) identified their model as patient-centred, the core purpose of this model seemed to be collaborative practice rather than *my best interests* in FCC as understood by children. Furthermore, role clarity related to patient and family as partners was not explicitly outlined. Nonetheless, this approach seemed reasonable given that their model addresses how to remedy existing patterns, whereas children suggested a more upstream approach to initiate healthcare partnerships from the start. Therefore, insight provided by children from this study may orient interdisciplinary practice to a fuller partnership potential through the lifespan. More importantly, similarities between FCC and interdisciplinary collaborative practice suggest potential theoretical and application alignment and thus deserve further comparative inquiry. Since there are only a few studies located in this area (Herrick, Arbuckle, & Claes, 2002; Prelock, Beatson, Bitner, Broder, & Ducker, 2003) interdisciplinary collaborative practice in FCC is a worthwhile consideration for future inquiry.

The Supportive Care Model: Connecting FCC, Relational Autonomy and Interdisciplinary Practice

Similarities between FCC, relational autonomy, and interdisciplinary practice require a unifying view so that these ideas may be carried out together. The Supportive Care Model (Oberle & Davies, 1993) provides a conceptual framework that espouses these combined approaches through core dimensions of "*connecting, empowering, finding meaning and doing for*" with a central goal of "*preserving integrity,*" and "*valuing*" as the overall encompassing approach. Of interest, the seven domains that children identify regarding how they understand FCC may be upheld in the application six dimensions of the Supportive Care Model. First, *connecting* refers to the continuum of partnerships created in health and illness care; this dimension supports children's understanding of "*being connected*", "*being involved,*" and "*talking and listening.*" *Empowering* refers to the development of confidence and capacity to cope with health and illness experiences; this dimension supports children's understanding of "*being involved*", "*knowing*", and "*making decisions.*" *Finding meaning* refers to learning from experiences and creating beliefs from such reflection; this dimension supports children's understanding of "*knowing*." *Doing for* refers to interdependency in caring for self and others; this dimension supports children's understanding of "*being involved*," and "*being connected*." *Preserving integrity* refers to the core purpose of practice as a moral act in respect to the wholeness of each person's physical, emotional, psychological and spiritual being; this dimension supports children's understanding of "*my best interests*" and "*virtues*." Finally, *valuing* refers to the overall approach to practice in reverence of self and others; this dimension supports all of the domains identified by children in how they understand their partnership role in FCC of their chronic illness.

Furthermore, children's relational autonomy is reflected in the Supportive Care Model given that healthcare competency is rooted in connections and interdependence. This model is thereby recognized to provide a fitting approach to FCC by reflecting the interconnected care dimensions for children, families and healthcare providers alike. The Supportive Care Model also promotes respect and valuing in interdisciplinary practice as preserving integrity was a shared goal for all FCC partners. While this model is patient-centered, the role of family and healthcare providers is also valued and noted in partnership. Hence, this model may guide contextually responsive practice while supporting mutually beneficial partnerships in FCC.

Closing Thoughts

Many proponents of FCC are fond of the following quote used to depict a radical change in thinking:

> Copernicus came along and made a startling reversal – he put the sun in the center of the universe, rather than the earth…Let's pause to consider what would happen if we had a Copernican revolution (…). Visualize the concept: the family is the

> center of the universe, and the service delivery system is one of the many planets revolving around it. Do you see the difference? Do you recognize the revolutionary change in perspective? (Turnbull & Summers, 1987, as cited in Johnson, 2000, p. 5).

This quote is almost a paradox in that Copernicus did not put the sun in the centre of the universe (it was there already), nor have we included children in a meaningful way as the centre of our constellation of care. In fact, up to this point the child's voice has been effectively silenced. In this so-called revolutionary process of regarding the family as central in children's health care, we fixed our gaze on relational aspects between parents and providers and lost our focus on children themselves We shifted the centre of care from the professional to parent expert model with children as passive recipients of care. If indeed children are part of a family, and family promotes the health and well-being of children in FCC, then what is the child's role within that family to promote their own health? Since FCC is founded on collaboration, I sought the perspectives of children as partners in their chronic illness healthcare and related roles in FCC. Such refocusing on children's partnership roles did not minimize the important responsibility of parents or providers. To the contrary, this new way of appreciating FCC extended ways of thinking about children's developing relational autonomy as family members and partners in interdisciplinary healthcare. Children have articulated their role as collaborative partners in FCC. The next challenge is taking up their insightful recommendations in practice.

CHAPTER SIX: SUMMARY AND CONCLUSIONS

In this chapter, I make explicit how the research questions were answered in this research and summarize my study findings. I conclude with my plans for future research.

Research Questions Answered

Question #1. How do school-age children between 7-11 years of age with bleeding disorders or other chronic illnesses understand their partnership role in FCC?

Analysis of phase I unstructured interviews revealed seven key domains that represented children's understanding of their partnership role in FCC: *my best interests, virtues, talking and listening, being involved, knowing, making decisions, and being connected.* I clarified and confirmed these domains with key informants in phase I and validation interview discussions in phase III. While children's illness experiences and healthcare needs varied considerably, no differences were noted between children who were living with hemophilia or another chronic illness regarding how they understand their partnership role in FCC. Therefore, I was able to describe a unified interpretation of seven FCC domains given the children's viewpoint.

1. *My best interests.* Children indicated that the starting point for effective FCC partnerships in their chronic illness care was based on recognizing and upholding their best interests. This was seen as providing direction and foundation for good communication, trust, informed decision making, and collaborative teamwork.

2. *Virtues.* Children identified four main character qualities that were required in themselves and others in order to be regarded as effective partners in FCC*: respect, trust, trustworthiness,* and *doing our best work.*

3. Talking and listening. Children identified that all FCC partners required time to talk and listen to each other. Children saw themselves as having an important role in telling others about their health and illness experiences and self-assessment.

4. Being involved. Children recognized that all partners in FCC had roles that were context specific. They also understood that they had an active part in their self-care and their level of involvement increased as they got older.

5. Knowing. Children spoke of locating information, learning from experience, and "figuring out what matters" in their chronic illness care. They recognized that knowledge held by themselves and care providers influenced all domains, with particular emphasis on *being involved* and *making decisions*.

6. Making decisions. Children distinguished making decisions on their own, with others, and decisions that others made for them. While they expressed the importance of being aware of consequences related to making decisions with others and on their behalf, they recognized that this knowledge was of particular importance as part of their emerging skills to make their own decisions.

7. Being connected. Children identified that collaborating as FCC partners may be challenging, as they were not sure how to work with adults. In particular, what stood out was that FCC and collaborative partnerships are a dominant way of thinking in healthcare, and yet these children were not consistently experiencing this in practice with parents, teachers, or healthcare providers.

Question #2. What is important to children regarding their partnership role in FCC? Children expressed that all seven domains were important and significant to their way of understanding. Ethnographic content analysis was used to reveal the frequencies of what children literally described as "important" within taxonomies and components of each domain.

1. My best interests. Children expressed that recognition of their best interests was the most important element as this provided the starting point and direction to guide the other domains for all FCC partners. They also expressed that others had a role in representing my best interests much like having a "protector" (*mom* was most often noted) and caregivers who were aware of children's preferences and "what hurts me."

2. Virtues. Children felt that when upholding *virtues* that the following items were important: *respect* ("being nice"), *trusting* ("important to be believed"), *trustworthiness* ("tell the truth"), and *doing our best work* ("doing your part...working hard...getting things done on time...doing the best work you can").

3. Talking and listening. Children identified that it was important to take turns talking and listening. If they were not listened to, they felt to be at risk for not being understood or getting the care they required. They identified this lack of understanding to be linked to a threat to their personal safety as it might result in them not getting the care they require. Children felt that when *talking and listening* that the following items were important: "taking turns", "speaking up", "being listened to" as a means to getting safe care, and discriminating important information that should be told or listened to by "knowing what matters."

4. Being involved. Children voiced their fears related to being involved, and the tension between "being a kid" with no obligations and *being involved* and having some "control." In summary, children felt that when *being involved* that the following items were important including "feeling in control" and being part of self-care activities such as "taking my medicine."

5. Knowing. Children recognized that they themselves, along with parents, teachers, and health care providers held important knowledge as partners in FCC of their chronic illness. They also identified that the most important source of knowledge was their mom; this suggested that mom's knowledge base should be supported so that subsequently children may in turn have access to mom's meaningful information.

6. Making decisions. Children indicated that the role of "boss" was contextualized and interconnected with the other domains. They acknowledged that parents and other care providers may assume this role, and that they may be "the boss of me." Children felt that when *making decisions* that it was important to know who was the "boss" and that this role could be shared with other persons at the same time.

7. Being connected. Children felt that when *being connected* the following items were important: collaboration ("feel safe when everyone works together"..."like a chain"), presence of family members ("mom and dad being there for me), coordination of care ("grown-ups taking care of me work together because my time is important"), supporting self-care ("being reminded by my mom and dad if I forget to take my medicine") and recognition of each FCC partner ("everyone has an important job").

Question #3. How do legislation and policy documents match with children's understanding of their partnership role?

1. My best interests. The Alberta Family Law Act (2007e) explicitly outlines a definition of the *best interests* of the child. The United Nations (1989) Convention on the Rights of the Child and the Alberta Child, Youth and Family Enhancement Act (2007a) focuses on the best interests of the child yet does not have an explicit corresponding definition of what is meant by *best interests*. Nonetheless concepts presented in these documents corresponds with children's understanding of their best interests as wholistic and contextual while regarding the child as an active participant.

2. *Virtues.* Alberta Learning (2005) curriculum on character and citizenship is explicitly developed around Popov's Virtues Project (2001). The four virtues that children identify in FCC partnerships are mirrored in this curriculum. *Respect, trust*, and *trustworthiness* are found verbatim in this document whereas *doing our best work* is represented as a combination of other listed items from the Virtues Project (2001) including "caring... commitment... diligence... (and) reliability...(and) service." Furthermore, congruence with the virtue of *respect* for the child, parents, cultural identity, environment, and human rights for all persons irrespective of age is supported in other documents including the United Nations (1989) Convention on the Rights of the Child, Government of Alberta (2007a) Child, Youth and Family Enhancement Act, Charter of Rights and Freedoms (Department of Justice Canada, 1982/n.d.), and the Human Rights, Citizenship and Multiculturalism Act (Government of Alberta, 2007d).

3. *Talking and listening.* This domain is indirectly supported regarding communication processes involving children and caregivers in the Child, Youth and Family Enhancement Act (Government of Alberta, 2007a) and Calgary Board of Education policies on Health Services to Students (2003a) and Allergic Reactions (2003b). Children's right to seek and receive information is supported by the Human Rights, Citizenship and Multiculturalism Act (Government of Alberta, 2007d) and United Nations (1989) Convention on the Rights of the Child.

4. Being involved. This domain is congruent with the Calgary Health Region (2002a) policy on Consent for Treatment given the underlying principle that children be involved in decision-making about their health care based on their capacity. Also, the Calgary Board of Education (2003a) policy on Health Services to Students specifies that students should assume "as much responsibility as possible" (p.3) in administering their own medications in the school setting. Furthermore, the Calgary Board of Education policies have clearly identified roles and responsibilities for students, teachers and parents regarding health services for children. This is of particular interest when examining policies specific to the healthcare setting, as comparably defined role clarity is not located in the Calgary Health Region policies. This is important as the reviewed institutional healthcare policies do not reflect a family-centred collaborative approach and yet this is a foundational approach to institutional pediatric healthcare; thus, the practice implication to consider is to create healthcare institutional policies and procedures that also explicitly reflect the role of the child and family.

5. Knowing. This domain is congruent with policy specific to children's self-care knowledge as found within the Calgary Board of Education (2003b) policy on Severe Allergies. Furthermore, children's access to information in support of their *knowing* about personal school and health care information is supported by legislation such as the Freedom of Information and Privacy Protection Act (2007b) and Health Information Act (Government of Alberta, 2007c). Finally, children's unique capacity for *knowing* as health partners is reflected in the United Nations (1989) Convention on the Rights of the Child given the recommendation to share information at the child's developmental level to support their physical, mental, emotional, social, moral, and spiritual well-being" (p. 8).

6. Making decisions. Of all the domains, this area has the widest interpretation from a policy perspective. There was noted tension between how to respect a child's capacity as a decision maker while acknowledging the adult caregiver's responsibility in this process along with society's regard for the unique vulnerabilities of children. The child's voice in collaboration with adult caregivers in making decisions is noted in Government of Alberta (2007a) Child, Youth and Family Enhancement Act and the Calgary Health Region (2002a) policy on Consent for Treatment. However decision-making regarding the child's education, religion, residence, and health care is viewed as a responsibility held by the parent or guardian as per the Government of Alberta (2007e) Family Law Act. Nonetheless, the United Nations (1989) Convention on the Rights of the Child presents a more supportive picture whereby parents and guardians are responsible to provide "direction and guidance"(p. 4) for children. What remains to be made clear is how parents and guardians choose to provide such "direction and guidance" for children in decision-making processes. The child's scope in making decisions as FCC partners is subject to vast interpretation and adult discretion. Remaining questions relate to how a child's capacity is interpreted, who interprets this capacity, and what is a reasonable level of "direction and guidance" so that children may acquire skills in making decisions.

7. Being connected. The connection between children, family, and providers (health, social services or education) is noted in the Child, Youth and Family Enhancement Act (Government of Alberta, 2007a), School Act (Government of Alberta, 2007c), Calgary Board of Education policies on Health Services to Students (2003a) and Allergic

Reactions (2003b) and the United Nations (1989) Convention on the Rights of the Child. While such policies and legislation specify the connection shared between children and caregivers, it is also clearly noted that such connections require that the best interests of the child be upheld. This is consistent with how children understood *being connected.*

Question #4. What strategies do children identify that would support their partnership role in FCC, as they understand it?

While I discussed specific recommendations for each domain in sections on research questions #1 and #2, children also identified 3 encompassing strategies to support all domains as interconnected elements of their FCC partnership role. These strategies were identified as follows: *treasure map, all-ages interactive workshop* and *online game.* Children's vision of these strategies and how to implement such ideas are outlined below.

1. Treasure map: Upon reviewing the seven key domains that represented how school-age children understand FCC partnership roles in their chronic illness, children expressed that this was best represented as a treasure map with interconnected elements (see Appendix P).

2. All-ages interactive workshop. Children recommended that an all-ages interactive workshop (based on the seven "treasure map" domains) be developed for the purpose of teaching children and adult providers together about FCC and how to act as partners in children's chronic illness care.

3. Online game and community. Children envisioned an *online game and community* as an extension of treasure map domains that would be applied as a problem-solving game. The premise of this game would be to have the player's character (with physical features, illnesses, family members, friends, and care providers selected from a menu to resemble the player) work through all levels (domains) of the problem that had to be solved in order to meet the child's best interests.

Question #5. What recommendations to support children's partnership role in FCC are congruent with the merging of legislation and policy documents and children's strategies?

Of the recommendations outlined in research questions #1, #2, and #4, all suggestions presented by children may be implemented given the information reviewed in legislation and policy documents. However, the notion of children's recommendations as "congruent" with such documents is not accurate. Simply put, while we have no explicit policy or legal barriers to implementing children's suggested strategies, we do have policy content gaps as such guidelines do not fully recognize children as partners in FCC. Such gaps should be explicitly addressed so that our partnerships in FCC may be clarified and supported by written guidelines. For example, the United Nations (1989) Convention on the Rights of the Child provides an excellent guiding policy in support of the best interests of the child including the important role of families, caregivers, institutions and our broader society. While this UN policy recognizes the validity of children's contributions, the breadth of this standpoint is not consistently noted in other reviewed documents. In particular, the Alberta government provided qualified support of this UN policy and declared that parental authority would not be undermined by upholding children's rights (Pellatt, 1999). Locally, the Calgary Board of Education has clearly identified partnership roles in health service delivery policies involving students (children), parents and teachers, yet a similar policy within the Calgary Health Region is not available. Thus, consistencies and inconsistencies with children's understanding of their FCC partnership role are noted at all policy levels. The challenge exists to refocus these policies from the view of partnerships in FCC, and to rethink and reword such guiding documentation to reflect the best interests of children while also respecting their developing capacity as partners. Since children are not going to suddenly wake up on their 18th birthday and be self-determining, we need to facilitate this process in our practice and policies throughout the lifespan.

Children's participation in healthcare decision-making requires adult guidance until the age of majority. Since children from this study shared their belief in lifelong collaboration, the issue at hand is challenging individualistic decision-making and questioning how children could instead develop capacity for self-determination through relational autonomy in FCC. Children indicated that their perspective was required when applying all seven domains in practice and thus working with them as partners in FCC. Furthermore, since our healthcare practices are policy-based we require as a basic first step written guidelines to direct and support ways in which we can hear the voices of children as partners in FCC.

Further legislation supporting the voice of children is located in the *Canada Evidence Act* (1985/2007). This legislation specifies that evidence provided by children under 14-years of age must be substantiated by that child's demonstrated ability to communicate evidence and understand the nature of their oath to tell the truth. Children's capacity to communicate evidence is recognized as a combined ability to observe, recollect and communicate: "the issue of competence concerns only the capacity to perform these functions (Zucker, Hammond, & Flynn, 2005, pp. 64-65). While children's evidence is examined with the same scrutiny as adult's evidence, "credibility of children should not be assessed on the same basis as that of adults" (p. 81). The way that children interpret and express their experience is recognized in accordance with their developmental abilities. If this way of thinking were to be applied to policies that guide children's healthcare, then the voice of the child would be appraised accordingly and recognized as valid in FCC partnerships. This is a reasonable guide and first step towards promoting congruence between our policies and children's partnership role in FCC.

Research Summary: My Take Home Messages

1. Future research should shift from the dominant parent-provider view and extend inquiry to include perspectives from partners in FCC across the lifespan.
2. Children understood their partnership role in FCC as represented by seven domains: *my best interests, virtues, talking and listening, being involved, knowing, making decisions, and being connected.* Children saw themselves as potential partners in FCC, yet acknowledged this was not consistently recognized by other FCC partners including themselves, parents, teachers or healthcare providers.
3. Children identified important aspects of their partnership role in FCC to include:
    - *my best interests* – being treated age appropriately ("like a kid"), having a protector, being aware of needs and preferences;
    - *virtues*- respect, trusting, trustworthiness and doing our best work;
    - *talking and listening*- speaking up, taking turns;
    - *being involved*- feeling in control, being part of the process;

- *knowing-* being aware of what is important, acknowledging that awareness can be scary;
- *making decisions* – being one of the bosses in decision making, feeling afraid of making decisions, knowing who the boss is; and
- *being connected-* collaboration, presence of family members, coordination of care, supporting self-care, recognition and valuing each FCC partner.

4. Children's understanding of their partnership role match with legislation and policy documents; however two key issues are raised and subsequent recommendations put forward. First, articulation of partnership roles should be explored and explicitly noted. Second, children's partnership roles in FCC require that autonomy be regarded as relational and not individualistic.
5. Children identify 3 key strategies to support their partnership role in FCC: *treasure map, all-ages interactive workshop, and online game and community.* These strategies were enthusiastically received and are currently being explored with children and healthcare providers at the Alberta Children's Hospital including the Southern Alberta Child and Youth Health Network's *Child and Youth Advisory Committee.*
6. Strategies identified by children may be carried out given current legislation and policy documents; however, strategies are not entirely congruent with documentation in that clear articulation of partnership roles and a shift to relational autonomy is wanting.
7. Various theoretical foundations that inform and support children's understanding of FCC and practice recommendations include relational autonomy (Baier, 1993),

interdisciplinary practice (Orchard, Curran, & Kabene, 2005) and the Supportive Care Model (Oberle & Davies, 1993).

Ending and Beginning: My Future Program of Research

Feedback from children and adults alike on this study pointed to future research possibilities regarding partnerships in FCC. At present, there is an emphasis on promoting self-care with the adolescent population at the Alberta Children's Hospital (personal communication, Catherine Dunseith, December 20, 2007). My study informants recognized the importance of self-care, yet disputed the belief that self-care was equated with isolated independence; thus, these children raised the challenge to examine self-care as a collaborative practice within the context of FCC partnerships. Family and healthcare professional audience commentary during various presentations on my research have indicated that further study is required on the topic of meaningful partnerships in FCC throughout the lifespan. Suggestions have included hearing the unique voices of fathers and promoting FCC partnerships in preschool, gerontology, acute care and emergency care settings.

This study revealed initial evidence regarding how children with chronic illness understand their partnership role in FCC. Although my research questions were answered, I now have many more questions about FCC. While this list of questions may be endless, the process and outcomes of this study suggest several key areas for future research that I hope to undertake in my emerging role as a nurse in academia. I believe that children's voices should be a priority consideration in future FCC research to ensure that their perspective as partners is heard. I see my role as a proponent of this approach and will collaborate with interdisciplinary colleagues and families to identify priorities and implement research as indicated. My next step is to implement strategies generated by children and conduct formal evaluation regarding if and how this makes a difference. Furthermore, I would like to conduct similar research with Aboriginal school-age children. At present I work as a clinical nursing instructor with this population, and these children have a unique understanding of FCC and the determinants of health based on cultural beliefs and the medicine wheel. This would be a meaningful area of systematic inquiry given that these children represent a high risk population and are a priority for self-care and health promotion related initiatives (National Aboriginal Health Organization, 2008). Furthermore, I see my role as a researcher in FCC to develop theory including extensive lifespan experiences, as FCC is not exclusive to child health. Children with chronic illness are insightful teachers and envision FCC happening throughout their lives; thus, I believe it would be useful to open up a systematic inquiry that includes a broader age range inviting perspectives on FCC from children to seniors (Fitzpatrick et al., 2004). While future inquiry would inform FCC theory, I would ultimately take on these research priorities in order to inform and shape FCC practice. I am excited to develop this program of research as a way to bring children's meaningful contributions to FCC practice. I believe this will also further develop our awareness of how we all work as collaborative partners in interdisciplinary care. After all these years of graduate studies, I am delighted to think that my future learning and research will not be primarily guided by "boring grown-up" academics. Rather, my key teachers will be children and I am looking forward to see what I will learn from them.

CHAPTER SEVEN: EPILOGUE

One of the criticisms of qualitative research is that findings are not generalizable in the way that quantitative findings are generalizable. However, it is possible to consider the concept of theoretic generalizability, which for a study of this type means that the findings "work" with those who need to know, or who share the same experience. This is an important aspect of ethnography, and can be established through presentations and invited feedback. I had several opportunities to present my findings after this study was completed. This, in itself, testifies how timely and important the topic of children's partnership roles in FCC is perceived to be. Audiences included children, parents, and healthcare providers. My presentations took place between June 2007 to April 2008 while I was writing my dissertation. Feedback from my presentations confirmed that study findings resonated with those persons who are involved in children's FCC. This helped me to refine my thinking and articulation about this topic, and confirmed my passion to continue this work and carry out children's recommendations to the best of my ability. I shared my findings in formal presentations at the International Union for Health Promotion and Education conference, and at the Alberta Children's Hospital (ACH) Diabetes Family Conference, Youth in Transition Series Telehealth Session, and the Intensive Care Unit Lunch and Learn series. I have also been working with the ACH Southern Alberta Child and Youth Health Network to move the children's recommendations forward. I describe these presentations in the following sections.

My first presentation after study completion was in June 2007 with the ACH Child and Youth Advisory Committee (CAYAC). I was quite excited as I presented my research findings and recommendations with the two key informants. I discussed issues with these children and their parents regarding the fact that if they were part of this public presentation that their study participation would no longer be confidential; with this in mind, both children and parents agreed to participate. This was my first formal co-presentation with children, and I was delighted with the confidence they conveyed with our audience (with minimal guidance from me). I simply introduced the study and they took over from that point by describing the treasure map in great detail and outlining their recommendations. These children expertly answered questions posed by approximately 20 members of CAYAC. This group consisted of youth aged 12-19 years old from southern Alberta and southeastern British Columbia as part of the Southern Alberta Child and Youth Health Network (SACHYN); most members were patients or siblings of patients living with a chronic illness. CAYAC members indicated that it was meaningful to them to hear the perspective of younger children, and that they felt this was part of their own leadership agenda to assist school-age children. Meeting attendees enthusiastically agreed with how school-age children understood their partnership role in FCC and their recommended strategies on how to uphold such partnerships in chronic illness care. Such acceptance of research findings and recommendations were important as CAYAC promised assistance for ongoing development and application of children's strategies to support FCC. The two key informants were outstanding presenters and eagerly expressed their desire to continue to share findings and work on recommendations. I am excited about continuing my work with these amazing children.

In June 2007, I also shared study findings as a poster presentation at the International Union for Health Promotion and Education conference in Vancouver. This opportunity allowed me to create links and future research opportunities with other allied healthcare professionals who are interested in children's FCC. I shared some lively discussions with youth leaders and healthcare providers from around the world about children's interpretation of FCC. I found it interesting that there was still some tension around including children as partners in their own care. A few delegates who stopped by my poster shared an unfounded fear that recognizing children as partners may usurp parental authority; I was pleased to have the opportunity to highlight the treasure map and share children's perspectives that their partnership role actually was founded on collaboration and respect with their parents. Another point brought up was the notion of "parent as expert" in FCC. Again, this led to some lively discussions around shared expertise and collaborative practice that included children as legitimate contributors. My favourite exchange was with a nursing scholar from Australia who immediately entered into an animated discussion on children's rights and our duty to hear their voices. I left this conference with a growing sense of excitement that my research was meaningful and that I was on the right track.

I presented study findings in September 2007 as the opening speaker for the ACH Diabetes Family Conference for youth, parents, and healthcare providers. Audience feedback was mostly around how children's interpretation of FCC was long overdue and particularly helpful in this clinical area, as children are required to report their diabetes symptoms. What stood out for me was detailed written feedback provided by one of the fathers. He wrote that "the school doesn't get it –teachers don't follow instructions or listen to kids instructions." I had a chance to speak with him for about 15 minutes after my presentation. This was a great opportunity for me to extend my thinking about FCC partnerships with fathers, as this man claimed that FCC really was "mother-centered care." He expressed that "dads let the wife assume most of the responsibility and we fail to educate ourselves fully. We don't participate enough and think we know enough. We don't know how to handle the bad times." This father opened my eyes to the notion that not only are children's voices not heard in FCC, but that fathers' voices may also be underrepresented. I was pleased to hear this father suggest that the ideas presented in the children's treasure map and recommendations for partnership in FCC may address his concerns as well. Again, this helped me validate my findings that the ideas generated by children resonated with all partners in FCC, and believe that their suggestions may help guide FCC partners in all age groups and roles.

My presentation at the diabetes conference led to several other invitations including the ACH for the Youth in Transition nationally broadcast telehealth series. This was a particularly meaningful session for me as many of the attendees were colleagues whom I worked with since the late 1980s. The audience was comprised of interdisciplinary pediatric healthcare providers and their response to my study was overwhelmingly supportive. Attendees expressed that children's ideas were reasonable and that their view of FCC should be a priority for implementation. Furthermore, they shared greater awareness to develop policies that reflected the roles of all partners in FCC. After this presentation, representatives of the Calgary Health Region (CHR) Patient Experience Team, Wellness and Citizen Engagement Portfolio invited me to connect with them to promote FCC in the CHR and also participate in the upcoming Institute for Family Centered Care workshop in October 2008.

My very first job in pediatrics was at ACH in the intensive care unit in the late 1980s. I was honoured to be invited to presented my findings at the ACH Intensive Care Unit "Lunch and Learn" session in April 2008. A few of my dear old colleagues were in attendance, and I felt like I had come full circle. When the ICU educator asked me to present my research, I was initially concerned about how to make this relevant to this highly structured, stressful, acute care environment. While the notion of FCC partnerships in ICU may seem like challenging concept, I realized that many of these children may have lifelong chronic illnesses, and so establishing FCC partnerships at this point in their journey is an upstream approach to their long-term care. I was able to quickly establish relevance with participants at the start of the presentation by welcoming examples of their own FCC partnership stories that enhanced child, parent and provider capacities and collaboration in the ICU. The audience consisted of nurses, respiratory therapists, administrators, and a parent representative from the ACH FCC Committee. Their feedback indicated that children's partnership roles in FCC is an innovative and overdue concept that is worthy of further exploration and practice application for children, families and staff alike. Participants shared their realization that the way children envisioned FCC would help the healthcare team be more effective by upholding virtues around *respect, trust, doing our best work, and being nice*. One respiratory therapist commented "from the mouths of babes. We used to know all this stuff but we get busy and forget. We need to listen to the kids to remind us about what matters."

I am invited to present at upcoming ACH Family-Centred Care committee and Child Life continuing education meetings. I am also been working with the Southern Alberta Child and Youth Health Network to see how children's key strategies may be put in place. This has included meetings with representatives from the ACH Art Committee and ACH Foundation to see how the treasure map may become part of the hospital environment as an interactive wall and online game. Ideas around artistic representation, multimedia adaptations, and potential donors are currently being explored. I was completely overwhelmed and became teary eyed during one meeting, as I was surprised with how the children's ideas were eagerly accepted, creatively considered, and prioritized as action items. One member of the ACH Foundation shared that "you and your ideas are meant to be coming into our lives. This all feels right and fits with so many things we are doing." I now find myself reflecting on how lucky I am to be part of this process, and I am inspired to carry my work forward with persistence and passion.

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Appendix A: Phase I Demographics

This data will be collected as part of the recruitment process, but will not be reported.

Child's name: ______________________________

Family mailing address:

____

____

Child's date of birth: ___________________________

Approximate date of diagnosis: _____________________

Name of specialty clinic at the Alberta Children's Hospital:

____

This data will be collected as part of the recruitment process, and will be reported anonymously as an aggregate.

Child's age: ________________

Gender: *male* *female*

Diagnosis: __________________________

Community: *Calgary* *Rural* (beyond 30 minute commute to Calgary)

Research phase participation: *Interview* *Focus Group*

Appendix B: Phase I Cover Letter

UNIVERSITY OF
CALGARY
Celebrate 40 years
2006

FACULTY OF NURSING

November 3, 2006

Dear _______________,

As part of a university research project, we are talking with children about how they see their job as partners in their care. We are asking children to come up with ideas about how they are part of the team that takes care of their illness. One of the researchers (Andrea Pritchard) is doing this as a school project for university. You might know her since she has also been a nurse at the Alberta Children's Hospital for over 16 years.

We think that it is important that we listen to what you have to say about your job in your own care. We want to use your ideas to make changes at the Alberta Children's Hospital through the Southern Alberta Child and Youth Health Network (SACHYN).

Andrea will be having talks with children in their home, or at the Alberta Children's Hospital. You can decide what place you like best to have this talk. Since it is important to listen to what you have to say, this talk will be between you and Andrea. Your parents will know what we are going to talk about, and they will be close by if you need them. This talk should take around 30-45 minutes, and will finish sooner if you like.

Even though we will be using a tape recorder to keep track of your comments, everything you say in these talks will be kept private, and we will not use your real name when we write up our project.

How do you get to be part of this talk?
Andrea Pritchard will telephone your parents at home within the next few weeks to see if you will be able to join.

Thank you for thinking about helping with our project.

Sincerely,

Andrea Pritchard, RN, MN (PhD student) Doctoral program, Faculty of Nursing University of Calgary telephone 440-5073 ampritch@ucalgary.ca	**Dr. Kathleen Oberle**, RN, PhD Associate Professor, Faculty of Nursing, University of Calgary telephone 220-6268 oberle@ucalgary.ca

Appendix C: Phase I Child Consent

UNIVERSITY OF
CALGARY
Celebrate 40 years
2006

FACULTY OF NURSING

November 3rd, 2006

TITLE: Exploring the Perceptions of School-Age Children with Bleeding Disorders and Other Chronic Illnesses: Partnership Roles in Family-Centred Care

SPONSOR: Unrestricted grant from Bayer

INVESTIGATORS:

Dr. Kathleen Oberle, RN, PhD
University of Calgary, Faculty of Nursing
Associate Professor (403-220-6268)

Andrea Pritchard, RN, MN (PhD student),
University of Calgary, Faculty of Nursing
Doctoral program (403-440-5073)

Dr. Ian Mitchell, MB, ChB, MA, DCH, FCCP, FRCPC, MRCP
University of Calgary, Faculty of Medicine
Professor, Department of Pediatrics
Director, Office of Medical Bioethics (403-229-7818)

Dr. Nancy Moules, RN, PhD
University of Calgary, Faculty of Nursing
Associate Professor (403-220-4635)

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

BACKGROUND

We think that it is important that we listen to what you have to say about your job in your own illness care. We want to use your ideas to make changes at the Alberta Children's Hospital through the Southern Alberta Child and Youth Health Network (SACHYN).

WHAT IS THE PURPOSE OF THE STUDY?

As part of a university research project, we are listening to children about how they see their job in caring for their own illness. We are asking these children to come up with ideas about how they can be a part of making decisions about their care while they are growing up. One of the researchers (Andrea Pritchard) is doing this as a school project for university. You might know her since she has also been a nurse at the Alberta Children's Hospital for over 16 years.

WHAT WOULD I HAVE TO DO?

You can participate in this interview if you:

a) are between 7-11 years of age (inclusive); and
b) have been diagnosed with a bleeding disorder OR another chronic illness; and
c) are cared for by an outpatient (DAT) clinic at the Alberta Children's Hospital for your bleeding disorder or chronic illness.

Andrea will be having talks or *interviews* with children in their home, or at the Alberta Children's Hospital. You can decide what place you like best to have this talk. Since it is important to listen to what you have to say, this talk will be between you and Andrea. Your parents will know what we are going to talk about, and they will be close by if you need them. This talk should take around 30-45 minutes, and will finish sooner if you like.

WHAT ARE THE RISKS?

Participation in this interview has little risk as what you say will be kept private or *confidential.*

WILL I BENEFIT IF I TAKE PART?

We want to use your ideas to make changes at the Alberta Children's Hospital through the Southern Alberta Child and Youth Health Network (SACHYN). We hope this will help children who are living with a chronic illness to be partners in their care. Also, if it is okay with your parents, we will send a letter to your school principal as thanks for your help with this project.

If you agree to participate in this study there may or may not be a direct medical benefit. Their chronic illness may be improved during the study but there is no guarantee that this research will help. The information we get from this study may help us to provide better treatments in the future for patients with chronic illness.

DO I HAVE TO PARTICIPATE?

It is important to understand that this is a research study and you don't have to do it if you don't want to.

Participation in this study is voluntary and you may withdraw from it at any time without jeopardizing your health care. Also, the researcher can withdraw you from the study as required. If new information becomes available that might affect your willingness to participate in the study, you will be informed as soon as possible.

WILL I BE PAID FOR PARTICIPATING, OR DO I HAVE TO PAY FOR ANYTHING?

Food and refreshments for you and your family will be provided at the time of the interview.

If you choose to meet at the Alberta Children's Hospital, your parking for that day will be paid for. If you are traveling from out-of-town, reimbursement will be offered of $50.00 towards your gasoline expenses.

WILL MY RECORDS BE KEPT PRIVATE?

Even though we will be using a tape recorder to keep track of your comments, everything you say in these talks will be kept private, and we will not use your real name when we write up our project. Other kids will be interviewed too, and all the things that kids say will be put together in a report without naming anyone.

The interview is confidential, and your name will be removed from the record and substituted with a pseudonym (false name). Written and audio recording of interviews will be kept in a locked cupboard at the University of Calgary, and will be destroyed when the study is complete. Information will be accessed only by approved study investigators and the research assistant. Furthermore, the University of Calgary Conjoint Health Research Ethics Board will have access to the records.

SIGNATURES

Your signature on this form indicates that you have understood to your satisfaction the information regarding your participation in the research project and agree to participation as a subject. In no way does this waive your legal rights nor release the investigators, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time without jeopardizing your health care. If you have further questions concerning matters related to this research, please contact:

Dr. Kathleen Oberle (403) 220-6268

or

Andrea Pritchard (403) 440-5073

If you have any questions concerning your rights as a possible participant in this research, please contact Bonnie Scherrer, Research Services, University of Calgary, at 220-3782

Child's Name	**Signature and Date**
Investigator/Delegate's Name	**Signature and Date**
Witness' Name	**Signature and Date**

The University of Calgary Conjoint Health Research Ethics Board has approved this research study.

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

Appendix D: Phase I Parent Consent

UNIVERSITY OF
CALGARY
Celebrate 40 years
2006

FACULTY OF NURSING

November 3rd, 2006

TITLE: **Exploring the Perceptions of School-Age Children with Bleeding Disorders and Other Chronic Illnesses: Partnership Roles in Family Centered Care**

SPONSOR: Unrestricted grant from Bayer Inc

INVESTIGATORS:

Dr. Kathleen Oberle, RN, PhD
University of Calgary, Faculty of Nursing
Associate Professor (403-220-6268)

Andrea Pritchard, RN, MN (PhD student)
University of Calgary, Faculty of Nursing
Doctoral program (403-440-5073)

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

BACKGROUND

Even though many children who are living with a with chronic illness become involved in their own self-care as they grow up, we do not understand their partnership role. We need a better understanding of what this means to children themselves. Therefore, we would like to explore how children understand their developing role as partners in chronic illness. We would like to know more about what this partnership role means to them, how they describe it, and how it is supported or not supported within the health care system. Approximately six children with a bleeding disorder, and six children with another chronic illness who are cared for at one of the Alberta Children's Hospital DAT clinics (outpatient) will be asked to participate in these interviews.

WHAT IS THE PURPOSE OF THE STUDY?

This study will help us to understand how school-age children who are living with a chronic illness understand their partnership role in the management of their chronic illness. We will also explore the value children place on their role in their care, including who they work with to make decisions.
Interviews with children will help us to understand the child's role in their chronic illness care as they grow up. This interview will help to identify themes to explore at a future focus group of children regarding helpful strategies to use in their care at the Alberta Children's Hospital.

WHAT WOULD MY CHILD HAVE TO DO?

The interview will last approximately 30-45 minutes, based on your child's interest. The interview will be led by Andrea Pritchard, who has experience as a research investigator and child health nurse at the Alberta Children's Hospital. The interview will be held solely with the child (and not with parents or siblings) to make sure that the child's story is focused on. Also, what the child says in the interview will remain in private and will not be shared with parents to respect the child' s confidentiality. The interview will be audio taped with a tape recorder and then transcribed (typed into WORD™). Based on your preference, this interview may be done either in your home or at the Alberta Children's Hospital.

If your child participates in this interview, he or she may be invited to participate in another individual interview. Your child will also be invited to participate in a future focus group discussion with other children to create their own strategies regarding what they would like to see happen in their chronic illness care management at the Alberta Children's Hospital. This leadership role will be shared along with the children representing the Southern Alberta Child and Youth Network. Your child's participation in these discussions are optional.

Your child is eligible to participate in this interview if he or she:

a) is between 7-11 years of age inclusive; and
b) has been diagnosed with a bleeding disorder OR another chronic illness; and
c) is cared for by an outpatient (DAT) clinic at the Alberta Children's Hospital related to their bleeding disorder or chronic illness.

Children with a communicative or developmental disorder are not included in this particular study.

WHAT ARE THE RISKS?

Participation in this interview has minimal risk as your child's responses will remain confidential. The final report will include themes collected from all the children that will be reported anonymously; while your child's name will not be used, when parents review the final study report, there is a risk that parents may read something that they may disagree with or that may make them feel uncomfortable.

ARE THERE ANY BENEFITS FOR MY CHILD?

Benefits of participation include giving information that will guide the development of strategies to support the role of children as active partners in their care at the Alberta Children's Hospital.

A letter of thanks will be sent to the child, with an extra copy that may be forwarded by you to the child's school principal in recognition for their leadership role and participation in this process.

If you agree for your child to participate in this study there is unlikely to be any direct benefit to your child. The information we get from this study may help us to provide better treatments in the future for patients with chronic illness.

DOES MY CHILD HAVE TO PARTICIPATE?

Participation in this study is voluntary and your child may withdraw from it at any time without jeopardizing his or her health care. Also, the researcher can remove any participant from the study if it is felt that he or she is put at risk in some way, or is jeopardizing the participation of other children.

If new information becomes available that might affect your willingness to participate in the study, you will be informed as soon as possible.

WILL WE BE PAID FOR PARTICIPATING, OR DO WE HAVE TO PAY FOR ANYTHING?

Food and refreshments for your child and accompanying family will be provided at the time of the interview.
If you choose to meet at the Alberta Children's Hospital, your parking for that day will be paid for.
If you are traveling from out-of-town, reimbursement will be offered of $50.00 towards your gasoline expenses.

WILL MY CHILD'S RECORDS BE KEPT PRIVATE?

No health records will be used in this study, only interview data. The interview is confidential, and your child's name will be removed from the typed interview and substituted with a pseudonym (false name). The only exception is that if the child discloses any information about abuse, we are legally obligated to report this. Written and audio recording of interviews will be kept in a locked cupboard at the University of Calgary, and will be destroyed when the study is complete. Information will be accessed only by approved study investigators and the research assistant. Furthermore, the University of Calgary Conjoint Health Research Ethics Board will have access to the records.

SIGNATURES

Your signature on this form indicates that you have understood to your satisfaction the information regarding your child's participation in the research project and agree to their participation as a subject. In no way does this waive your legal rights nor release the investigators, or involved institutions from their legal and professional responsibilities. You are free to withdraw your child from the study at any time without jeopardizing their health care. If you have further questions concerning matters related to this research, please contact:

Dr. Kathleen Oberle (403) 220-6268

or

Andrea Pritchard (403) 440-5073

If you have any questions concerning your child's rights as a possible participant in this research, please contact Bonnie Scherrer, Research Services, University of Calgary, at 220-3782.

Parent/Guardian's Name	Signature and Date
Child's Name	Signature and Date
Investigator/Delegate's Name	Signature and Date

The investigator or a member of the research team will, as appropriate, explain to your child the research and his or her involvement. They will seek your child's ongoing cooperation throughout the study.

The University of Calgary Conjoint Health Research Ethics Board has approved this research study.

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

Appendix E: Phase I and III Thank You Letter

UNIVERSITY OF
CALGARY
Celebrate 40 years 2006

FACULTY OF NURSING

Dear Child & Family,

We would like to thank you very much for taking part in our research project. Your input will help us to make the Alberta Children's Hospital an even better place for kids and families.

We would like to recognize you for your leadership role in our research project. It is very important that we listen to children when we are thinking about how to provide the best care for kids and families. Your contribution is extremely valuable to our research.

If you would like, please share this acknowledgement with your school principal so that your school community also knows about the effort you have made for the Alberta Children's Hospital.

With sincere thanks,

Andrea Pritchard, RN, MN (PhD student) Doctoral program, Faculty of Nursing University of Calgary telephone 440-5073 ampritch@ucalgary.ca	**Dr. Kathleen Oberle**, RN, PhD Associate Professor, Faculty of Nursing, University of Calgary telephone 220-6268 oberle@ucalgary.ca

2500 University Drive N.W., Calgary, Alberta, Canada T2N 1N4 • www.ucalgary.ca/nu

Appendix F: Phase III Cover Letter

(date and letterhead)

Dear Child,

As part of a university research project, we are listening to children about how they see their job in caring for their own illness. We are asking children to come up with ideas about how they can be a part of the team that takes care of their illness. One of the researchers (Andrea Pritchard) is doing this as a school project for university. You might know her since she has also been a nurse at the Alberta Children's Hospital for over 16 years.

We think that it is important that we listen to what you have to say about how you can be part of the team in your own illness care. We want to use your ideas to make changes at the Alberta Children's Hospital through the Southern Alberta Child and Youth Health Network (SACHYN).

We will be having these talks with a small group of children in a meeting room at the Alberta Children's Hospital. There will be up to nine children in a group talking together. These talks are for children who are between 7-11 years of age who had been in another meeting on this topic with Andrea Pritchard; these talks are also for children who are members of the SACHYN Child and Youth Advisory Committee.

Everything you say will be kept private, and we will not use your real name when we write up our project. Also, before we start this talk with the group, we will go over important rules like respect for everyone.

If it is okay with your parents, we will send a letter to your school principal as thanks for your help with this project.

How do you get to be part of this focus group?
Andrea Pritchard will telephone your parents at home within the next few weeks to see if you will be able to join us.

Thank you for thinking about helping with our project.
Sincerely,

Andrea Pritchard, RN, MN (PhD student) Doctoral program, Faculty of Nursing University of Calgary telephone 440-5073 *ampritch@ucalgary.ca*	**Dr. Kathleen Oberle**, RN, PhD Associate Professor, Faculty of Nursing, University of Calgary telephone 220-6268 *oberle@ucalgary.ca*

Appendix G: Phase III Child Consent

UNIVERSITY OF
CALGARY
Celebrate 40 years
2006

FACULTY OF NURSING

TITLE: Exploring the Perceptions of School-Age Children with Bleeding Disorders and Other Chronic Illnesses: Partnership Roles in Family-Centred Care

SPONSOR: Unrestricted grant from Bayer

INVESTIGATORS:

Dr. Kathleen Oberle, RN, PhD
University of Calgary, Faculty of Nursing
Associate Professor (403-220-6268)

Andrea Pritchard, RN, MN (PhD student),
University of Calgary, Faculty of Nursing
Doctoral program (403-440-5073)

Dr. Ian Mitchell, MB, ChB, MA, DCH, FCCP, FRCPC, MRCP
University of Calgary, Faculty of Medicine
Professor, Department of Pediatrics
Director, Office of Medical Bioethics (403-229-7818)

Dr. Nancy Moules, RN, PhD
University of Calgary, Faculty of Nursing
Associate Professor (403-220-4635)

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

BACKGROUND

We think that it is important that we listen to what you have to say about your job in your own illness care. We want to use your ideas to make changes at the Alberta Children's Hospital through the Southern Alberta Child and Youth Health Network (SACHYN).

WHAT IS THE PURPOSE OF THE STUDY?

As part of a university research project, we are talking with children about how they see their job in caring for their own illness. We are asking these children to come up with ideas about how they can be a part of making decisions about their care while they are growing up. One of the researchers (Andrea Pritchard) is doing this as a school project for university. You might know her since she has also been a nurse at the Alberta Children's Hospital for over 16 years.

WHAT WOULD I HAVE TO DO?

We will be having these talks with a small group of children in a meeting room at the Alberta Children's Hospital. There will be up to nine children in a group talking together. These talks are for children who are between 7-11 years of age who had been in another meeting on this topic with Andrea Pritchard; these talks are also for children who are members of the SACHYN Child and Youth Advisory Committee.

WHAT ARE THE RISKS?

Participation in this interview has minimal risk as what you say will be kept private or *confidential.* Also, before we start this talk with the group, we will go over important rules like respect for everyone.

WILL I BENEFIT IF I TAKE PART?

We want to use your ideas to make changes at the Alberta Children's Hospital through the Southern Alberta Child and Youth Health Network (SACHYN). We hope this will help children who are living with a chronic illness to be partners in their care. Also, if it is okay with your parents, we will send a letter to your school principal as thanks for your help with this project.

If you agree to participate in this study there may or may not be a direct medical benefit. Their chronic illness may be improved during the study but there is no guarantee that this research will help. The information we get from this study may help us to provide better treatments in the future for patients with chronic illness.

DO I HAVE TO PARTICIPATE?

It is important to understand that this is a research study and you don't have to do it if you don't want to.

Participation in this study is voluntary and you may withdraw from it at any time without jeopardizing your health care. Also, the researcher can withdraw you from the study as required. If new information becomes available that might affect your willingness to participate in the study, you will be informed as soon as possible.

WILL I BE PAID FOR PARTICIPATING, OR DO I HAVE TO PAY FOR ANYTHING?

Food and refreshments for you and your family will be provided at the time of the interview.
If you choose to meet at the Alberta Children's Hospital, your parking for that day will be paid for. If you are traveling from out-of-town, reimbursement will be offered of $50.00 towards your gasoline expenses.

WILL MY RECORDS BE KEPT PRIVATE?

Even though we will be using a tape recorder to keep track of your comments, everything you say in these talks will be kept private, and we will not use your real name when we write up our project. Other kids will be interviewed too, and all the things that kids say will be put together in a report without naming anyone. Also, before we start this talk with the group, we will go over important rules like respect for everyone.

The interview is confidential, and your name will be removed from the record and substituted with a pseudonym (false name). Written and audio recording of interviews will be kept in a locked cupboard at the University of Calgary, and will be destroyed when the study is complete. Information will be accessed only by approved study investigators and the research assistant. Furthermore, the University of Calgary Conjoint Health Research Ethics Board will have access to the records.

SIGNATURES

Your signature on this form indicates that you have understood to your satisfaction the information regarding your participation in the research project and agree to participation as a subject. In no way does this waive your legal rights nor release the investigators, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time without jeopardizing your health care. If you have further questions concerning matters related to this research, please contact:

Dr. Kathleen Oberle (403) 220-6268

or

Andrea Pritchard (403) 440-5073

If you have any questions concerning your rights as a possible participant in this research, please contact Bonnie Scherrer, Research Services, University of Calgary, at 220-3782

Child's Name	Signature and Date
Investigator/Delegate's Name	Signature and Date
Witness' Name	Signature and Date

The University of Calgary Conjoint Health Research Ethics Board has approved this research study.

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

Appendix H: Phase III Parent Consent

UNIVERSITY OF
CALGARY
Celebrate 40 years 2006

FACULTY OF NURSING

TITLE: **Exploring the Perceptions of School –Age Children with Bleeding Disorders and Other Chronic Illnesses: Partnership Roles in Family Centered Care**

SPONSOR: Unrestricted grant from Bayer

INVESTIGATORS:

Dr. Kathleen Oberle, RN, PhD
University of Calgary, Faculty of Nursing
Associate Professor (403-220-6268)

Andrea Pritchard, RN, MN (PhD student),
University of Calgary, Faculty of Nursing
Doctoral program (403-440-5073)

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

BACKGROUND

Even though many children who are living with a with chronic illness become involved in their own self-care as they grow up, we do not understand their partnership role. We need a better understanding of what this means to children themselves. Therefore, we would like to explore how children understand their developing role as partners in chronic illness. We would like to know more about what this partnership role means to them, how they describe it, and how it is supported or not supported within the health care system. Up to 12 children with a chronic illness who participated in previous interviews on this topic, and 6 children from the Child and Youth Advisory Committee (Alberta Children's Hospital) will be recruited to participate in this focus group. There will be 2 focus groups, with a maximum of 9 children in each group.

WHAT IS THE PURPOSE OF THE STUDY?

This study will help us to understand how school-age children who are living with a chronic illness understand their role as partners in the management of their chronic illness. In particular, the focus group discussion will help will help us to develop strategies to support children as partners in the management of their chronic illness at the Alberta Children's Hospital.

WHAT WOULD MY CHILD HAVE TO DO?

The focus group discussion will last 60-90 minutes, and will be held in a meeting room at the Alberta Children's Hospital, with children sitting around a big table. The interview will be led by Andrea Pritchard, who has research experience and has been a child health nurse at the Alberta Children's Hospital for over 16 years. A research assistant will also be there to help out with the discussion. The focus group discussion will be held solely with the children (and not with parents or brothers and sisters?) to ensure that their perspective is focused on. The focus group discussion will be audio taped with a tape recorder and then transcribed (typed into WORD™).

WHAT ARE THE RISKS?

Participation in this interview has minimal risk as your child's responses will remain confidential. Your child may know some of the other participants in the focus group. Rules regarding respect and confidentiality will be reviewed before we start the discussion. The final report will include themes collected from all the children that will be reported anonymously; while your child's name will not be used, when parents review the final study report, there is a risk that parents may read something that they may disagree with or that may make them feel uncomfortable.

ARE THERE ANY BENEFITS FOR MY CHILD?

Benefits of participation include giving information that will help create strategies to support the role of children as active partners in their care at the Alberta Children's Hospital.

A letter of thanks will be sent to the child, with an extra copy that may be forwarded by you to the child's school principal in recognition for his or her leadership role and participation in this process.

If you agree for your child to participate in this study there is unlikely to be any direct benefit to your child. The information we get from this study may help us to provide better treatments in the future for patients with chronic illness.

DOES MY CHILD HAVE TO PARTICIPATE?

Participation in this study is voluntary and they may withdraw from it at any time without jeopardizing their health care. Also, the researcher can withdraw them from the study as required.

If new information becomes available that might affect your willingness to participate in the study, you will be informed as soon as possible.

WILL WE BE PAID FOR PARTICIPATING, OR DO WE HAVE TO PAY FOR ANYTHING?

Food and refreshments for your child and accompanying family will be provided at the time of the focus group discussion.

Your parking at the Alberta Children's Hospital for that day will be paid for.

If you are traveling from out-of-town, reimbursement will be offered of $50.00 towards your gasoline expenses.

WILL MY CHILD'S RECORDS BE KEPT PRIVATE?

The focus group discussion is confidential, and your child's name will be removed from the record and substituted with a pseudonym (false name). The only exception is that if the child discloses any information about abuse, we are legally obligated to report this. Written and audio recording of interviews will be kept in a locked cupboard at the University of Calgary, and will be destroyed when the study is complete. Information will be accessed only by approved study investigators and the research assistant. Furthermore, the University of Calgary Conjoint Health Research Ethics Board will have access to the records.

SIGNATURES

Your signature on this form indicates that you have understood to your satisfaction the information regarding your child's participation in the research project and agree to their participation as a subject. In no way does this waive your legal rights nor release the investigators, or involved institutions from their legal and professional responsibilities. You are free to withdraw your child from the study at any time without jeopardizing their health care. If you have further questions concerning matters related to this research, please contact:

Dr. Kathleen Oberle (403) 220-6268

or

Andrea Pritchard (403) 440-5073

If you have any questions concerning your rights as a possible participant in this research, please contact the Associate Director, Internal Awards, Research Services, University of Calgary, at 220-3782.

Parent/Guardian's Name	Signature and Date
Child's Name	Signature and Date
Investigator/Delegate's Name	Signature and Date
Witness' Name	Signature and Date

The investigator or a member of the research team will, as appropriate, explain to your child the research and his or her involvement. They will seek your child's ongoing cooperation throughout the study.

The University of Calgary Conjoint Health Research Ethics Board has approved this research study.

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

Appendix I: Phase I Warm-up Activity

All About Me

☺ Some of my favorite things are...	**☹ Some things I do not like are...**
My family is made up of these people.....	**Other people important to me include...**
Another thing you really need to know about me is.......	

(Hill, Laybourn & Borland, 1996)

Appendix J: Phase I Unstructured Interview Guiding Questions

1. Introduction:

- Introduction of facilitator and research assistant
- Review of research purpose, confidentiality, recording and reporting of interview, and destruction of data; and
- Overview and signature of consent form with parent and assent with child

Once this introduction is complete, the interview will proceed with the child.

2. Interview:

Warm up activity (see Appendix J)

The following questions serve only as a guide for the unstructured interview. Interview questions will seek to explore how the child understands their role in family-centred care through the use of ethnographic questions to elicit information that is:

- **Descriptive:** *Tell me about what usually happens when you come to the children's hospital for your bleeding disorder or chronic illness*; *Tell about how you usually get information about your illness?*
- **Example-based:** *Can you tell me what kinds of jobs you have in your illness care? Can you give me an example of being part of a team – is this what it is like when you get care at the hospital or at home? Can you give me an example of being on a team with adults? What kinds of decisions are you allowed to make…who allows you to make these decisions? What works for you?;*

- **Experience-related:** *Tell me about a time that you came for treatment at the children's hospital for your bleeding disorder or chronic illness;*
- **Hypothetical:** *How do you think that everyone should work together for your care...what does this look like...how should you fit in with this team...what kinds of things do you think should be done differently?;*
- **Verifying**: *Are there different ways that children and adults work together – can you tell me what some of them are? Are there different kinds of adults that you work with? Can you tell me about ways to work with adults in your healthcare team? What are the different steps?*
- **Priority sorting:** *What is most important to you when you are getting care for your illness? What is important to you about working with your parents and healthcare team to take care of your illness?* **and,**
- **Contrasting***: I'm interested in how you participate in your care – tell me how when you **** is different from when you ****?*

(Spradley, 1979).

3. Conclusion:

- *With the child- s*ummary and invitation to contact research team with further comments, questions, or study results; and
- Appreciation of contribution to research project.

Once the interview is concluded with the child, the parent will be invited to the room.

- *With the parents* - summary and invitation to contact research team with further comments, questions, or study results; and
- Appreciation of contribution to research project.

Appendix K: University of Calgary Ethics Approval Letter

FACULTY OF MEDICINE | UNIVERSITY OF CALGARY

OFFICE OF MEDICAL BIOETHICS
Room 93, Heritage Medical Research Bldg
3330 Hospital Drive NW
Calgary, AB, Canada T2N 4N1
Telephone: (403) 220-7990
Fax: (403) 283-8524
Email: omb@ucalgary.ca

October 4, 2006

Dr. Kathleen Oberle
Faculty of Nursing
University of Calgary
PF 2222
Calgary, Alberta

Dear Dr. Oberle:

RE: Exploring the Perceptions of School-Age Children with Bleeding Disorders and Other Chronic Illnesses: Partnership Roles in Family -Centered Care

Grant ID: 20238

Your request to modify the above-named protocol has been reviewed and approved:

I am pleased to advise you that it is permissible for you to use the revised protocol and the previously approved consent form, based on the information you have provided in your correspondence of September 26, 2006.

A progress report concerning this study is required annually, from the date of the original approval (2006-09-13). The report should contain information concerning:

(i) the number of subjects recruited;
(ii) a description of any protocol modification;
(iii) any unusual and/or severe complications, adverse events or unanticipated problems involving risks to subjects or others, withdrawal of subjects from the research, or complaints about the research;
(iv) a summary of any recent literature, finding, or other relevant information, especially information about risks associated with the research;
(v) a copy of the current informed consent form;
(vi) the expected date of termination of this project;

Thank you for the attention which I know you will bring to these matters.

Yours sincerely,

Glenys Godlovitch, BA(Hons), LLB. PhD
Chair, Conjoint Health Research Ethics Board

GG/mc

c.c. Child Health Research Committee
Ms. A. Pritchard (student)

Appendix L: Phase I Domain Analysis

Cover Term	Relationship Term	Included Terms
My Best Interests	Attribute←is a characteristic of←	What's good for me, what I need, best thing for me, it's all about me
	Means-end ←Is a way to do←	Look out for me
	Overall, the following 6 domains represented"means-end" or a way to support children's best interests	
Virtues	Means-end ←Is a way to do←	Being respectful and nice; trustworthy; trusting each other; doing our best work
	Cause and effect ←Is a result of←	Protect me
Talking and Listening	Means-end←Is a way to do←	Just ask, telling, teaching, saying what I think, interrupt, say excuse me, wait my turn, ask questions, hear me, hear them, I listen, I put my ear to the door,
	Means-end ←Is a way not to do←	pretend not to hear/listen
Being Involved	Means-end ←Is a way to do←	I take my...I put on my...
		I watch out for...
	Function Means-end ←Is used for←	With my mom...with my dad
	Means-end ←Is a way not to do←	Just let her
	Attribute←is a characteristic of←	Afraid, scared
Knowing	Means-end ←Is a way to do←	Figuring out, serious talking,
	Rationale ←Is a reason for←	Affects my life
	Means-end ←Is a way to do←	Learn, think about, because when,
		Other kids, this kid I know
	Function Means-end ←Is used for←	
Making Decisions	Function Means-end ←Is used for←	Boss of me, in charge
	Means-end ←Is a way to do←	Together, discuss, disagree, give me another option
	Rationale ←Is a reason for←	Affects me, about me, important stuff
	Attribute←is a characteristic of←	Feel funny, scared
Being Connected	Attribute←is a characteristic of←	Team, part of the team, all together
	Means-end ←Is a way to do←	Fit in, work together, helping, being there

Appendix M: Phase I Ethnographic Content Analysis Themes and Frequencies

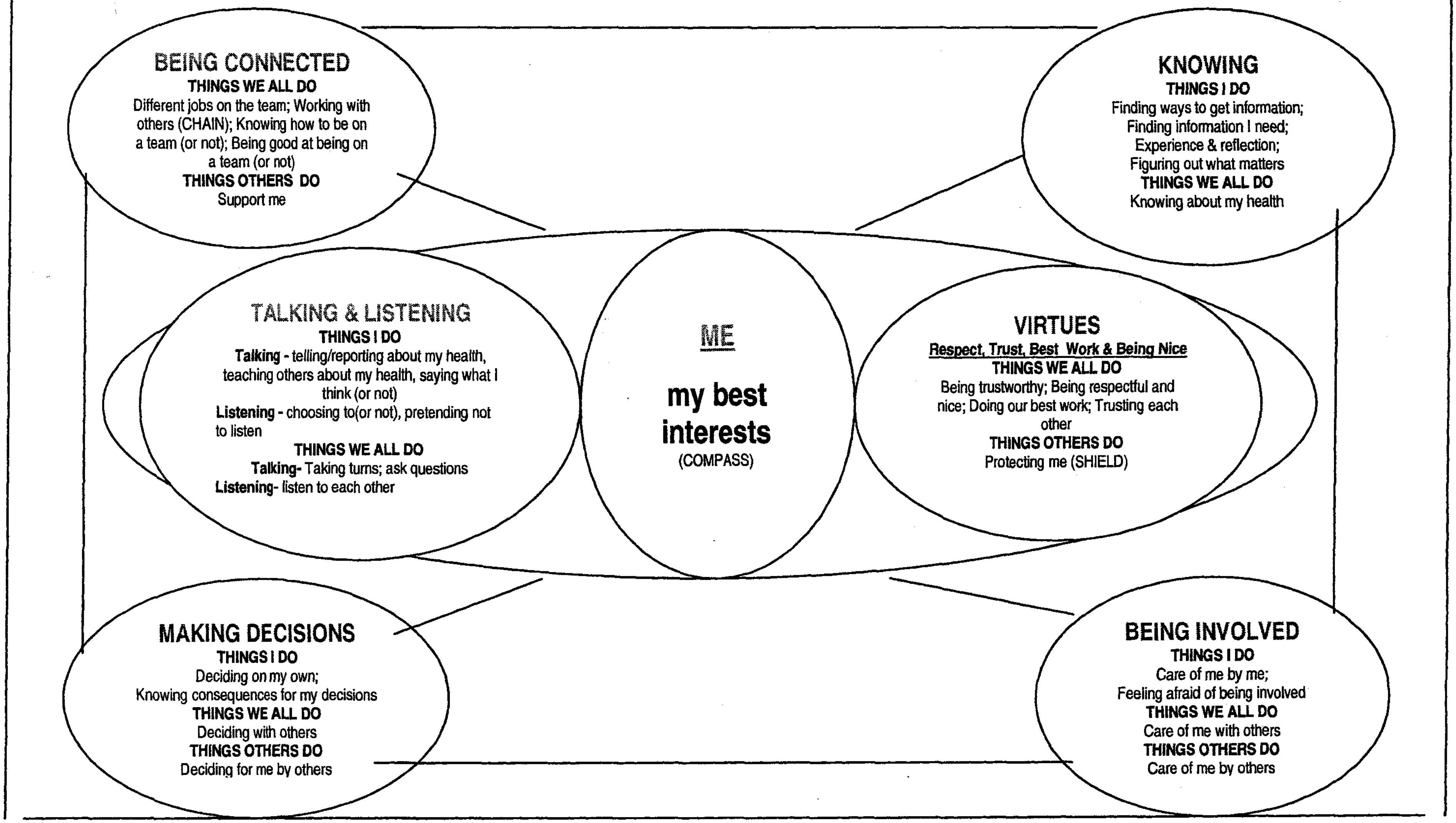
Phase I – Ethnographic Content Analysis

Domains/ taxonomy selected for analysis is based on: relative frequency of domains + *children indicating these taxonomies as important

DOMAIN	***taxonomy***														
Environment↓		Home 8									School 44 (office9)				Hospital 10
Being Involved	**Care of me by me (22)* *where it happens →*	13	*	*	*	*	*	*	*	*	13	*	*	*	0
Health	*where it happens →*	7	*	*	*	*	*	*	*	*	39	*	*	*	10
ROLES ↓		Me	Mom	Dad	Brother	Sister	Grandma	Grandpa	Cousin	Friend	Teacher	Doctor	Nurse	HCP	other
Supporting persons			102	37	8	3	5	3	1	32	6 +2 (principal)	32	24	8	*
My Best Interests	*Advocates (10)*	1	6	5	*	*	*	*	*	1	*	1	1	*	*
Choosing To or Not?		*	*	*	*	*	*	*	*	*	*	*	*	*	*
Communicating	**Important person talks(2)*	1	*	*	*	*	*	*	*	*	*	1	*	*	*
talking	**Being nice (9)*	2	*	*	*	*	*	*	*	*	*	3	3	1	*
	**Tell others about my health (21)*	*	8	*	*	*	*	*	*	3	9	*	*	*	Grown ups (2)
	**Teach others about my health (9)*	*	*	*	*	*	*	*	*	9	1	*	*	*	*
	**I speak up (4)*	*	*	*	*	*	*	*	*	*	*	2	1	*	Grown ups (1)
listening	**Listen to me (10)*	*	*	*	*	*	*	*	*	6	*	2	*	2	*
	**Listen to what's important (9)*	*	*	*	*	*	*	*	*	*	*	2	*	7	*
	**taking turns (3)*	*	*	*	*	*	*	*	*	1	*	2	*	1	*
Trusting	**Trustworthiness-others trusting & believing me (10)*	*	2	*	*	*	*	*	*	[2 -not believing]	2+ [2-not believing]	1	1	1	*
(shield)	**Trusting – me trusting others and feeling safe (15)*	*	7	6	1	*	*	*	*	3	3+[1 not]	2	1	6	*
Knowing	**figuring out what matters (12)*	6	3	3	*	*	*	*	*	*	*	*	*	6	*
	Info source (25)	*	10	3	*	*	*	*	*	*	*	9	*	1	conference (2); book/binder (3); computer(3)
	experience & reflection (41)	33	*	*	*	*	*	*	*	7	*	*	1	2	*
Being Involved	*Care of me with others (21)*	*	17	5	*	1	1	*	*	2	3	3	1	*	Family-1; Grown-ups 1
	Being afraid of being involved(8)	*	1	*	*	*	*	*	*	*	*	*	1	6	*
Making Decisions	**Consequences (10)*	X	X	X	X	X	X	X	X	X	X	X	X	X	X
	**Deciding on my own (25)*	X	X	X	X	X	X	X	X	X	X	X	X	X	X
	Deciding for me with others (24)	24	12	7	*	*	*	*	*	*	1	5	3	2	Family-1
	**Deciding for me by others (17)*	*	7	1	*	*	*	*	*	*	2	1	5	3	Grown-ups-1
Being Connected	**Support (11)*	*	4	3	*	*	*	*	*	6	*	*	1	1	*
	**Working together – enough time (2)*	*	*	*	*	*	*	*	*	*	*	2	*	*	*
	**Working together (chain) (49)*	*	11	2	*	*	*	*	*	*	3	11	7	7	*
	**Working together – different jobs (5)*	1	1	1	*	*	*	*	*	*	*	*	*	2	Grown-ups 1

Appendix N: Phase I My Concept Map of Seven Domains

ME – MY HEALTH – MY ENVIRONMENT – MY SUPPORTING PERSONS



BEING CONNECTED
THINGS WE ALL DO
Different jobs on the team; Working with others (CHAIN); Knowing how to be on a team (or not); Being good at being on a team (or not)
THINGS OTHERS DO
Support me

KNOWING
THINGS I DO
Finding ways to get information;
Finding information I need;
Experience & reflection;
Figuring out what matters
THINGS WE ALL DO
Knowing about my health

TALKING & LISTENING
THINGS I DO
Talking - telling/reporting about my health, teaching others about my health, saying what I think (or not)
Listening - choosing to(or not), pretending not to listen
THINGS WE ALL DO
Talking- Taking turns; ask questions
Listening- listen to each other

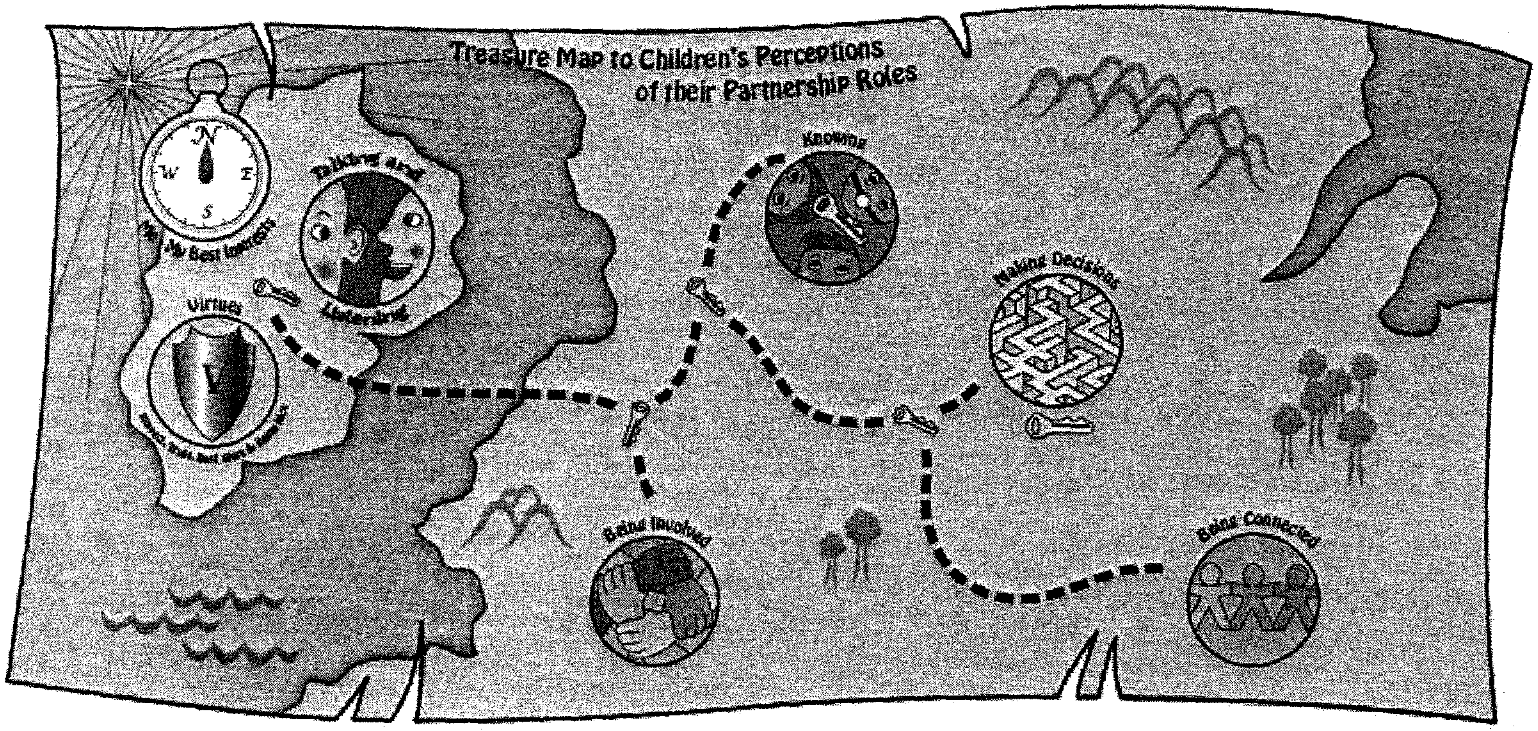
ME
my best interests
(COMPASS)

VIRTUES
Respect, Trust, Best Work & Being Nice
THINGS WE ALL DO
Being trustworthy; Being respectful and nice; Doing our best work; Trusting each other
THINGS OTHERS DO
Protecting me (SHIELD)

MAKING DECISIONS
THINGS I DO
Deciding on my own;
Knowing consequences for my decisions
THINGS WE ALL DO
Deciding with others
THINGS OTHERS DO
Deciding for me by others

BEING INVOLVED
THINGS I DO
Care of me by me;
Feeling afraid of being involved
THINGS WE ALL DO
Care of me with others
THINGS OTHERS DO
Care of me by others

Appendix O: Phase I Children's Concept Map of Seven Domains



Treasure Map to Children's Perceptions of their Partnership Roles

VIRTUES

Things We All Do
Being trustworthy; Being respectful and nice; Doing our best work; Trusting each other

Things Others Do
Protecting me

TALKING & LISTENING

Things I Do
Talking - telling/reporting about my health, teaching others about my health, saying what I think (or not)
Listening - choosing to(or not), pretending not to listen

Things We All Do
Talking- Taking turns; ask questions
Listening- listen to each other

BEING INVOLVED

Things I Do
Care of me by me;
Feeling afraid of being involved

Things We All Do
Care of me with others

Things Others Do
Care of me by others

KNOWING

Things I Do
Finding ways to get information;
Finding information I need;
Experience & reflection;
Figuring out what matters

Things We All Do
Knowing about my health

MAKING DECISIONS

Things I Do
Deciding on my own;
Knowing consequences for my decisions

Things We All Do
Deciding with others

Things Others Do
Deciding for me by others

BEING CONNECTED

Things We All Do
Different jobs on the team;
Working with others (CHAIN); Knowing how to be on a team (or not);
Being good at being on a team (or not)

Things Others Do
Support me

Appendix P: Phase III Document Review Overview

Phase II: Document Review

DOMAIN	***related issues***	**Legislation**	**CHR Policy**	**CBE Policy**	**UN** *(Other)*
Role of child and adults	Persons & roles (including role of the school-age child between 7-11 years)	Child, Youth & Family Enhancement Act (2007) School Act (2000)	Consent #1383; Consent for Treatment #1414; Protection and Privacy of Health and Personal Information # 1471	1004.6 – Duties and Responsibilities of Teachers 6001- School Discipline 6002 –Health Services to Students 6003 – Severe Allergies	Article 3 ; Article 9 Article 18 ; Article 25
My Best Interests	Children's care at hospital, home & school including processes for decision making; (consider advocacy)	Child, Youth & Family Enhancement Act (2007) Family Law Act (2007); School Act (2000)	Consent for Treatment #1414 Protection and Privacy of Health and Personal Information # 1471	6002 –Health Services to Students ; 6003 – Severe Allergies	Article 3 Inherent in all Articles of the convention that the child's best interests are central
Virtues	Respect *located Trust & trustworthiness Being Nice Doing best work	Child, Youth & Family Enhancement Act (2007); Charter of Rights and Freedoms (1982); Human Rights and Citizenship (2007); School Act (2007)		*The Virtues Project (2001)	Article 3; Article 16 Article 19
Talking & Listening	Formal processes for communication with children	Child, Youth & Family Enhancement Act (2006) Human Rights and Citizenship (2007);		6002 –Health Services to Students ; 6003 – Severe Allergies	Article 3 ; Article 12 Article 13
Being Involved	Medication administration by children; Reporting of health status by children to other children AND responsible adults	Age of Majority Act (1980)	Consent for Treatment #1414	6002 –Health Services to Students	Article 3; Article 12 Article 13; Article 14 Article 24
Knowing	Information sources for children Formal processes to facilitate learning from experience & reflection	Child, Youth & Family Enhancement Act (2006); School Act (2000), FOIP (2007);	Consent for Treatment #1414	6003 – Severe Allergies	Article 3; Article 17
Making Decisions	Consent & assent processes	Age of Majority Act (1980) Child, Youth & Family Enhancement Act (2007); Family Law Act (2007)	Consent for Treatment #1414		Article 3; Article 12 Article 13; Article 14
Being Connected	Working together – with child, as an interdisciplinary team	Child, Youth & Family Enhancement Act (2007); School Act (2000);		6002 –Health Services to Students ; 6003 – Severe Allergies	Article 3; Article 9 Article 12; Article 13 Article 14 ; Article 24 Article 25

Appendix Q: Mystery Bag Validation Interview Questions

Randomly drawn questions for verification of themes that were used as a warm-up (the use of "you" and "me" was interchanged).

A. Domains & Taxonomy

1. Best Interests

- How can your team…do what is BEST for you?

2. Virtues

- How can your team…be respectful?
- How can your team…protect you?

3. Talking and Listening

- How can people who take care of you…talk and listen better?
- How can your team… help you say what is important to you?
- How can my team…help me get information?

4. Being Involved

- How can your team…help you if you are afraid?
- How can my team…take care of me?

5. Knowing

- How can my team… help me figure out what matters?
- How can your team…be respectful?

6. Making Decisions

- How can your team…help you make decisions?

7. Being Connected

- How can people who take care of you…be good team players?
- If you were the boss of the hospital…what would you do?

B. Domains, Taxonomy and Components (the role of kids and grown-ups were interchanged)

1. Best Interests

- Are kids more about doing your best….or NOT doing your best?

2. Virtues

- Are kids more like nice….or respectful?
- Are kids more like trustworthy….or NOT trustworthy?

3. Talking and Listening

- Are kids more like a talker… or listener?
- Are kids more like someone who pretends to listen… or pretends NOT to listen?

4. Being Involved

- Are kids more about taking care of yourself…or having someone else take care of you?

6. Making Decisions

- Are kids more like a decision-maker …or NOT a decision-maker?